

Abstract No. 1.1      Tuesday 5th September 2017 at 12:00-12:45

**Title: Deafblindness – Theory-of-mind, cognitive functioning and social network in Alström syndrome**

Presenter:                    Hans-Erik Frölander, The National Agency for Special Needs Education and Schools, Sweden

Co-presenters:            Claes Möller<sup>1,2,3</sup>, Björn Lyxell<sup>3</sup>.

1 School of Health and Medical Sciences, Örebro University, the Swedish Institute

for Disability Research, Linköping, Sweden

2 Audiological Research Centre, Örebro University Hospital

3 Department of Behavioural Science and Learning, Linköping University

Main focus: Both research and practice/Acquired deafblindness

Abstract: Purpose: The aim of this presented PhD-project has been to explore the emergence and expression of Theory-of-mind (ToM) in challenging conditions. ToM refers to the ability to understand thoughts and feelings of others. The challenge referred to is acquired deafblindness.

The presentation deals with young adults with Alström syndrome (AS). AS causes a severe progressive combined auditory and visual impairment, in addition to a multi-systemic pathology. To feature general consequences of dual sensory-loss and the impact of health, individuals with Usher syndrome type 2 (USH2) were included in one study. This deafblind-related group exhibits a slower rate of progression of visual loss than the AS group and the syndrome is not multi-systemic, enabling conclusions also about the impact of health. The main focus in this presentation is on the development of ToM, and how this relates to communicative prerequisites, development of some cognitive skills and social circumstances.

Methods: The design was quasi-experimental, with an exploratory focus. 12 individuals with AS, and 13 individuals with USH2 were matched to 24 nondisabled individuals on background variables as age, gender and educational level. Sensory functions were measured. Information about communicative skills and social behaviour was obtained from responses to a questionnaire. Advanced ToM was measured by a multiple task that taxes the ability to understand thoughts and feelings of story characters'. Verbal ability was assessed with a test of vocabulary. Executive functions (EFs) were measured by a test of inhibition and updating. Working memory (WM) was measured by a test of serial recall of non-words. Structured interviews were conducted with a social network inventory, to measure the size of the social network

Results; The group of individuals with AS was outperformed by both the nondisabled individuals and the individuals with USH2, in ToM-tasks. Individuals with AS further displayed a significantly higher degree of heterogeneity in performance in this respect. Some individuals with AS performed on equal level with nondisabled individuals. ToM performance was predicted by verbal ability and EFs, whereas WM proved to be an

indirect predictor. A later onset of visual loss further characterized AS individuals with better ToM. The size of the social network by individuals with AS was smaller relative to that of nondisabled individuals, and many of the acquaintances were professionals working with individuals with AS (mainly health professionals). Amount of friends correlated with ToM performance.

Conclusions: Variability in ToM in the AS group, seem to be highly dependent upon social prerequisites and communicative skills, in which EFs have a mediating role, Training of EFs could support ToM development in children with AS, by improving the prerequisites for social interaction. Implementation of assistive technology for optimal development of verbal ability and to enhance participation in childhood is further required. Assistive technology within different social environments is in addition required to maintain reciprocal social relationships in adulthood.

Abstract No. 1.2                      Tuesday 5th September 2017 at 12:00-12:45

**Title: Come on!  
Meaningful rehabilitation for people with acquired deafblindness.**

Presenter:                              Kirsten Washuus, CFD, Denmark  
Co-presenters:                        Else Marie Jensen

Main focus: Mainly practice/Acquired deafblindness

Abstract: CFD is the largest provider in Denmark of services for deaf, deafblind and hearing impaired people. From October 2015 and to March 2018 we are running a project for People with acquired deafblindness called "Come On!". We will have two courses for people between 25 – 65 years with acquired deafblindness. The first course will be with Danish as our language supported by loop, writing- or sign interpreter. The second course will be in Danish sign language. We have now finished the first course and in September 2017 we will have finished the second course.

The goal is to strengthen the participant's possibility to develop and strengthen own recognition in the life adjustment by ensuring:

- Improved knowledge about hearing and sight impairment and what acquired deafblindness could mean in life.
- Support in processing a demanding life adjustment
- Be part of finding the right assistive technology and support
- To acquire various coping strategies.

Method/approach:

The participants' will be visiting the following houses:

- AV – house

In this house you will find all about hearing, vision, assistive technology, and you'll begin working with you self. Take a look on your life and be aware of the situation you are in, and what it means for you and your family.

- Energy- house

In this house we will talk about how you can protect yourself, by recognize the lack of energy during a day, and how you can use ex mindfulness to get a balanced life, despite living with acquired deafblindness.

- Network –house

Here we will have a look at the communication in the family and other networks in the participants lives. We will talk about networking, how it can be one of the ways to cope with deafblindness.

We will together with the family, professionals in the acquired deafblindness area and a psychologist create- suitable houses for the rehabilitations program.

Abstract No. 1.3

Tuesday 5th September 2017 at 12:00-12:45

**Title: My Journey to Independence : From Isolation to participation**

Presenter: Linda Fistonich, , Australia (recorded presentation)

Co-presenters: Karen Wickham

Main focus: Mainly practice/Both congenital and acquired deafblindness

Abstract: My name is Linda Fistonich and I was born in Auckland NZ. My parents along with my two sisters and brother migrated to New Zealand a year or so before I was born. They came to make a new life for themselves from what was then known as Yugoslavia but is now known as Croatia.

I was born with the congenital condition known as Optic Atrophy and started to lose my sight at aged eight and my hearing at 11 years old.

The aim of my presentation will be to demonstrate my journey to independence, from being a negative, dependant and isolated person to one who is positive, happy and connected with others. It is my hope that you will gain a greater understanding of how to best support Deafblind people to achieve their goals through the development of close interpersonal, meaningful and positive relationships. I have strived to overcome obstacles in my life and build the life that I wanted for a very long time. My parents did what they thought was best for me especially as far as my educational aspirations were concerned, but failed to communicate how to cope with the many situations one comes across in the real world.

There have been many transitions in my life; the biggest transition that I will talk about in detail in my presentation is my journey from complete dependence, to moving into my own apartment in Parkland Villas and living an independent, fulfilling life. I had been happy to remain dependant as I saw no need to do otherwise and it was only when my mum went to a nursing home and I fully realised I could no longer rely on her that I took up the challenge and did a crash course in independence. I am relishing my new found independence and proving to others that for a deaf blind person anything is possible given the right support and attitude. Senses have been of marvellous assistance to me, both in my personal growth, building my social connectedness and closeness in all my relationships and encouraging me to become part of the Deafblind and local community. I have gained more confidence and am not so anxious of being left on my own, I have learnt I can be independent. Building a connectedness and closeness with all the communities I interact with and being met with respect and understanding has supported me to make these significant life changes. Touch is also been a part of my everyday life – and is integral to the Deafblind experience and to building closeness and connectedness in my relationships and my life. My experiences, family and supports have enabled me to embrace relationships, build communities, be a part of the wider world and enjoy all the benefits it has to offer. I look forward to sharing my experiences with the wider Deafblind community as an example of what a person can achieve given the right tools and as reassurance and guidance for Deafblind people, their parents, families and supports facing similar challenges.

Abstract No. 1.4

Tuesday 5th September 2017 at 12:00-12:45

**Title: Camp Abilities: educational sports camps for children with sensory impairments**

Presenter: Lauren Lieberman, The College at Brockport, State University of New York, USA

Co-presenters: Pam Haibach

Main focus: Mainly practice/Both congenital and acquired deafblindness

**Abstract: Camp Abilities: Educational Sports Camp for Children with Sensory Impairments**  
Camp Abilities an educational sports camp for children who are visually impaired or deafblind started in 1996 by Dr. Lauren J. Lieberman at The College at Brockport in Brockport, NY. The purpose is fourfold: 1) To empower children with sensory impairments to become active and involved in sports and recreation, 2) to train future teachers how to teach children who are visually impaired or deafblind, 3) to conduct much needed research in the area of physical activity and children with sensory impairments and their families, and lastly, 4) to educate the community about the high levels of skills and abilities children have in the area of sport and recreation.

Camp Abilities in Brockport started off as a single camp with 27 campers doing the sports of goalball, beep baseball, track and field, tandem biking, judo, swimming, and gymnastics. The recreational activities that were taught were rock climbing, canoeing, kayaking, fishing, basketball, soccer, kickball, horse back riding, rollerblading, and Showdown. The children were taught how to participate and excel in each sport with the necessary modifications. The counselors are taught systematically how to modify each sport and activity to meet the needs of each child.

The camp now hosts over 55 camper each year who leave with a sense of pride and empowerment. The counselors leave with the feeling that they are the experts when it comes to teaching children with sensory impairments. This program has been so successful that it has now been replicated in four places in NY state, in 19 other states and now in 7 countries.

In addition to the thousands of children that have learned sports and the thousands of counselors who have gone on to be successful teachers, Camp Abilities has been host to over 70 research projects with over 60 articles published to date. Articles span the area of physical activity, sport, recreation, physical education, motor skills, socialization, communication, and instructional strategies. Camp Abilities was also the impetus to more than five books on this topic from "Everybody Plays" through The American Printing House for the Blind (APH), to "Going PLACES" through APH, to "Physical Education and Sport for Individuals with Visual Impairments or Deafblindness" through The American Foundation for the Blind, and "The Gross Motor Development Curriculum" through APH, and "Possibilities: Recreation Experiences of Individuals who are Deafblind" through APH among many others.

Participants in this presentation will learn about the Camp Abilities model. They will also learn about how they can bring the model to their country and their town. The Camp Abilities model can be replicated in any country as long as there is a skilled and qualified



director and a safe and conducive host site. The book “The Camp Abilities Start-Up Manual” will be available for those who wish to start their own camps. For more information attendees will be directed to our web site [www.campabilities.org](http://www.campabilities.org) for videos, our mission, history, and accomplishments.

Abstract No. 1.5      Tuesday 5th September 2017 at 12:00-12:45

**Title: Never say never!  
Optimizing senses and functions releases new learning.**

Presenter:                      Line Hovland, Eikholt national center for the deafblind, Norway

Main focus: Mainly practice/Congenital deafblindness

Abstract: Overall theme:

Never say never – the story about a young woman with congenitally deafblindness who by the age of 29 finally learns to read through braille. A result of a well coordinated team around a motivated person?

Background:

Linda is born blind, with a severe hearingloss and cp, and has a delayed development. She has been followed up with special education at school through childhood and early adolescence, but was not able to learn to read and write.

As she got an iPhone, Linda used “Siri” to call her mother and her boyfriend. We thought the iPhone could give new motivation to try to learn to read and write, so she could reach her network through sms.

Goals: To strenghtening the independent way of connectedness with her social network through sms with her iPhone and brailledisplay.

Method/approach:

During the process several proffesionals are involved. The hearing is optimized and the cp-stricken hand is trained. There is focus on concept formation and orientation in space. The braille-teacher introduce and drill braille-letters on the brailledisplay wich gives maximized strong sensoryinput. The braille-teacher cooperate with the local teacher who use the letters in the reading-education. There is a close cooperation between all involved.

The result is that Linda today is reading, and now able to learn about the nuances in words and language through touch, which earlier was unattainable because of her hearingloss.

Conclusion:

To succeed in the work with people with congenital deafblindness an holistic approach is necessary. Maturation never stops, goals that was beyond reach can become achievable with time and the right contributions.

What can be learned from the presentation?

- 1) Never say never
- 2) The importance of a well coordinated team and an holistic approach
- 3) The maturation process is often delayed in children with congenitally deafblindness

Abstract No. 1.6      Tuesday 5th September 2017 at 12:00-12:45

**Title: Adapted Physical Activity: from idea to reality - Unlocking potentials**

Presenter:                    Mads Kopperholdt, Centre for Deafblindness and Hearing Loss (CDH), Denmark

Co-presenters:            Anders Martin Rundh, Center for Deafblindness and Hearingloss

Main focus: Mainly practice/Both congenital and acquired deafblindness

**Summary:**

Adapted physical activities (APA) is a practice - the key to all people with disabilities can play sports or be involved in movement with others. APA makes use of methods that make sport accessible to all, and to focus on opportunities rather than limitations. Adapted physical activity includes, but is not limited to, physical education, sport, recreation and rehabilitation.

We as teachers found strong relevance of APA within the field of deafblindness in 2008. We found the potential in adapting the idea to students with deafblindness in our school. According to the education act in Denmark we created a definition of APA within the field of deafblindness, in order to valid APA as a school subject. Our constructed definition equals social connectedness and closeness with the improvement of physical-, technical-, and tactical skills. In our classes, we create time, safe and innovative space with a known structure.

**Case study: Unlocking potentials**

When we started the APA group, one of the students was a shy boy of 12 with CHARGE syndrome who had a low self-esteem, found social relations difficult, did not benefit much from, nor found much pleasure in, Physical Education and was very dependent on his main teacher as his only route of communication and trusty adult. Through the sporting and social elements, which are the central principles of APA teaching, he developed slowly but surely. He started to expand his routes of communication, to interact with the other students, express the activities in words and signs. His self-esteem was increased through experiences of success and thus he gained the energy to help the other students in the group. He felt at ease with the exercises and himself. In the end he took a kind of leadership role in the group. This made us realize the potential of a positive role model. We found literature concerned the peer tutor concept. Through that we felt inspired to test the peer tutor concept on him. We focused on giving him the skills to structure and present a topic in the APA-class. This he now brings in to his everyday life. We have been working with him for two years now with great success. We see that he grows with the role and gains good competences in selecting information and preparing, presenting and carrying out the lessons - though still with the guidance and support by us as teacher. We evaluate each lesson with him and the result of the evaluation is used in the next lesson. We will through videos and theory show the remarkable development in order for you to get inspired.





Abstract No. 2.1                      Tuesday 5th September 2017 at 14:15-15:00

**Title: Threepart conversation - a multidisciplinary project from CDH**

Presenter:                              Camilla Lolk Rønshøj, Centre for Deafblindness and Hearing  
Loss (CDH), Denmark

Co-presenters:                        Tine Nørgaard Pedersen, Helle Buelund Selling

Main focus: Mainly practice/Both congenital and acquired deafblindness

Abstract: For one year, Rasmus (a young man with acquired deafblindness), Camilla (special educator for Rasmus in the daily activity center) and Tine (Rasmus' teacher of many years) met and talked about different topics and experiences from their daily life. The workshop will focus on some of the points we came across in our project on three part conversations. We will emphasize how the three part conversations can support the good stories and shared knowledge between the different communications partners relate to.

When Rasmus met Camilla, they both had a feeling that it was difficult to talk to each other. This despite the fact that both Rasmus and Camilla used tactile sign language. Inspired by Eija Lindqvist's master on three part conversations, we used three part conversations as a tool to create a more sustainable relationship between Rasmus and Camilla.

During the project we worked with two hypotheses:

- Tine, whom Rasmus knew well, could help them in the process of getting to know one another.
- Three part conversations could reassure Rasmus that less familiar persons can be good conversation partners.

Abstract No. 2.2

Tuesday 5th September 2017 at 14:15-15:00

**Title: To live with PHARC- a novel complex syndrome causing acquired deafblindness**

Presenter: Ane Marte Halkjelsvik, Statped, Norway

Co-presenters: Inger Marie Storaas

Main focus: Mainly practice/Acquired deafblindness

Abstract: PHARC is a newly discovered complex genetic neurological syndrome. PHARC is an acronym composed of the first letter of the five main symptoms involved in the syndrome (peripheral neuropathy, hearing loss, ataxia, retinal pigmentation, cataract) which defines it as a condition of acquired deafblindness. PHARC is very rare and there are about 50 individuals worldwide with this diagnose today. PHARC was identified as a gene mutation in 2010 by a research team at Haukeland University Hospital, Norway. Our experience is that providing information regarding consequences of PHARC to the patients and their network contributes to less social isolation and more participation for each individual with PHARC syndrome.

Our presentation will focus on the consequences of having PHARC syndrome. This will be highlighted by a personal story with a video interview with a man who has PHARC syndrome. The interview illustrates how a person with PHARC syndrome understands the initial diagnostic process and the issues regarding the physical and social consequences of living with PHARC.

PHARC is a newly discovered, complex syndrome. PHARC is very rare and there are about 50 individuals worldwide with this diagnose today. What chance do individuals with PHARC have to avoid isolation and stay socially connected?

The patients we have contact with are the first who have this diagnosis. They are the book we read, and we know little about the progression of PHARC and the future of our patients. How is it to live with such a diagnosis? What can we learn from their experiences?

Have you come across anyone with this diagnose or with similar symptoms?

If you know of a person with acquired deafblindness, showing similar symptoms, what are the possibilities for diagnosing and implementing adequate intervention procedures related to PHARC syndrome?

Abstract No. 2.3

Tuesday 5th September 2017 at 14:15-15:00

**Title: Friends from the wild: Developing relationships through ongoing outdoor activities.**

Presenter: Joseph Gibson, Deafblind Outdoors, Norway  
Co-presenters: Sofia Kristoffersen Nystuen, Norway  
Sunniva Joten Langsjøvd, Norway

Main focus: Mainly practice/Congenital deafblindness

Abstract: Friluftkurs is a week long course for young people held in Norway with the aim of creating an environment where young deafblind people can “be together” and develop their common interests in outdoor activities, learn from and with each other and have new experiences that strengthen their friendships. The course has been a great success especially in developing meaningful relationships among the participants, which have continued beyond the course.

The course has run for eight years and in that time there has been five participants with two who have attended all of the meetings. While all the various benefits that outdoor activities can offer have been noticed at different times this workshop will take a holistic look at the elements of social connectedness that have been observed over the eight years both with the group itself and externally. We will give an overview of the course describing the typical activities and other elements such as the support staff before focusing on the relationships, in particular the relationships between the participants.

Abstract No. 2.4

Tuesday 5th September 2017 at 14:15-15:00

**Title: CHARGE and working on social connectedness-  
a big challenge**

Presenter: Tanja Geck, Deutsches Taubblindenwerk, Germany  
Co-presenters: Sandra Runge-Fleischer, Deutsches Taubblindenwerk

Main focus: Mainly practice/Congenital deafblindness

Abstract: Based on our daily working experience with children and teenagers with CHARGE- syndrome we will consider the question why people with CHARGE regardless of their intellectual, cognitive and communicative skills come to limits in their social-emotional connectedness and get often in a social off because of going ballistic without transparent reasons. Examples are often change of school, dismiss of school, problems in finding a good job.

In this workshop we will discuss what this means for the qualification of the special assistance staff and the tutoring of the families, since there the basis for the `touch of closeness` and the `maintaining of social connectedness` is laid.

Besides teaching in the "Deutsches Taubblindenwerk" we care for early intervention. Since there is an increasing number of pupils with CHARGE we also advise teachers who work in regular schools. But we not only advise about the ordinary care for deaf-blind people but try to point out the special needs for CHARGE children. For two reasons this is not easy. First: for most colleagues the use of some technical gear ( e.g. FM, enlarging seeing aids) and supporting communication systems (e.g. gestures, symbol cards, reference objects) is uncommon. Dealing with these aids leads to insecurity and extra time and makes our colleagues feel that they have to climb on a high mountain of new tasks. Second: when entering school the pupils show no or only few behavioral disorder (stronger need for physical activities, necessary breaks, constant questioning) and this behavior is not a problem to deal with. In the consequence the way of special support of these pupils is seen in teaching basic reading, writing, calculating.

It is to say that even our profession regarded communication support as a guarantor to minimize behavioral disorder. The idée was: if my counterpart can talk to me about uprising problems, these problems can be solved with the help of speech on a cognitive level. Especially when we had to deal with older students we learnt how wrong this approach was. These students had to leave regular schools not because of cognitive problems but because of their massive behavioral disorder.

In this period Nafstad, Rodbroe, Janssen and Souriau published their scientific studies which led to establish the Co- Creating- Communication Model. "Successful Communication" was then newly defined.

From our point of view this brings a great chance for children with CHARGE. Their lack of social self-regulation can now be faced at an earlier state. Since these children normally can't judge their present emotional level and don't know how to come from one level to another, we do have to keep in mind not only to name things and circumstances. We as well have to regard enough the emotional status of these children and their counterparts and have to develop alternative strategies. This needs sensitiveness, empathy,



experience, competence and all the TIME it takes to deal with all aspects of our task to enable our pupils to live a content life in social connectedness.

Abstract No. 2.6

Tuesday 5th September 2017 at 14:15-15:00

**Title: Fun Chi: Adapting Tai Chi for Self-Regulation and Relaxation**

Presenter: Sharon Barrey Grassick, School of Special Educational Needs - Sensory, Australia

Main focus: Mainly practice/Both congenital and acquired deafblindness

Abstract: Tai Chi can be adapted effectively for individuals with deafblindness. As a Tai Chi practitioner for over 12 years, the benefits of Tai Chi for me personally have been enormous, including stress reduction, relaxation, increased energy and improved balance and posture. This overall sense of well-being encouraged me to train to become a Tai Chi Instructor about 9 years ago, which has enhanced my understanding of the benefits and possibilities of adapted Tai Chi.

One day while planning for my students with deafblindness, in my 'real' job as a Deafblind Educator, it suddenly hit me – there are so many aspects of Tai Chi that could be adapted to benefit the children I was working with! Since that revelation I have explored ways that Tai Chi can be adapted for children who are deafblind or have balance issues, eg. CHARGE Syndrome. Self-regulation can be an issue with many children with deafblindness; there are many aspects of Tai Chi that can relate to and assist with self-regulation. Although targeted at children with sensory issues, Fun Chi techniques can be adapted and enjoyed with any child, regardless of abilities or disabilities. Part of Tai Chi's beauty is that it can be done just about anywhere, can be done alone or with the whole family and requires no special clothes, shoes or equipment. Fun Chi has incorporated elements to make it fun, e.g. Individualising names of moves to reflect personal likes and interests. Depending upon the individual, visualisation and imagination can also be enhanced. Some preliminary research has been done through Central Michigan University, with Tim Hartshorne's students. More research is required; however, in the meantime, just have FUN with Fun Chi!

Abstract No. 2.9

Tuesday 5th September 2017 at 14:15-15:00

**Title: Acquired Deafblindness in Ethiopia and its Coping strategy: The Case of Three Women with Acquired Deafblindness**

Presenter: Dr. Sewalem Tsega, Addis ababa University Disability center and SNE Department, Ethiopia

Main focus: Both research and practice/Acquired deafblindness

Abstract: Deafblindness in Ethiopia is the least understood and the most neglected disability. Women with Disability in developing countries are the most disadvantaged and the most neglected population with double jeopardy. This is the second ever study in the country studied next to the one presented in the World Deafblindness congress in Bucharest, Baseline survey in the situation of Deafblindness in Ethiopia. The main objective of this study is to investigate women with acquired Deafblindness who are struggling with triple jeopardy, Deafness, Blindness and being a woman in a patriarchal country like Ethiopia and their coping strategy. Snowball and purposive sampling techniques were employed in selecting the samples. Interview with a tactile sign language interpreter was the main instrument of the study. All of them reported that they cope by distancing them from the public and staying at home which is not good not only for the family but also for their futurity and other young Deafblind people who really need role models who became self dependent. This shows that they have less on no social connectedness with the neighbors and the community at large. From this, it could be recommended that the government, the association, professionals and other stakeholders should work hand in hand to let the women with acquired Deafblindness integrate in the society and enjoy their human rights in the country.

Abstract No. 3.1

Wednesday 6th September 2017 at 11:00-11:45

**Title: TMIC: a fine tool to create social connectedness.**

Presenter: Damie van Vianen, Kentalis Rafael, The Netherlands

Co-presenters: Amanda Buijs

Main focus: Mainly practice/Congenital deafblindness

**Abstract: Summary**

At the conference in Lille, august 2013, we first came across the topic of three-party communication by Eija Lundqvist. We could see the potential for the further development of our children with congenital deafblindness at Royal Dutch Kentalis Rafael school, and for giving them even more opportunities to participate in the world that surrounds them. We started working with conversations with multiple partners in the tactile modality and presented our findings during the World conference in Bucharest, May 2015.

Since then, we broadened our way of working with this fine tool. Seen in the light of the given workshop of May 2015, which was mainly focused on linguistic development, you'll find out that our approach in making Tactile Multi-Partner Interaction and Communication to good use, is much bigger these days.

**Workshop**

Our school, Kentalis Rafael, is a school for students with congenital deafblindness in the ages up till 20 years. A group of great cognitive diversity.

During our presentation we'll show the participants some striking examples from the practical field in which two competent partners making TMIC to good use, can set the stages for development regarding topics as building trust by listening in, sharing and naming emotions, bringing a person to a higher level of communication, making choices, leading by example, I-positions, joint attention, overcoming feelings of anxiety.

One of the main characteristics of multi-partner conversations is that when people are sharing experiences and/or information, a fellowship emerges; connectedness. A condition which induces a sense of safety, by itself of positive influence on learning and developing.

**Sharing by showing**

By showing these examples, we hope to illustrate the divers possibilities of the use of Tactile Multi-Partner Interaction and Communication for development. We profoundly believe our experiences in the practical field can be considered practice based evidence. We are keen on hearing comments and suggestions from our international colleagues about our efforts and hope to hear their experiences on this matter.

Abstract No. 3.2

Wednesday 6th September 2017 at 11:00-11:45

**Title: Arousal and interaction with people with deafblindness**

Presenter: Henrik Okbøl, Geelsgårdskolen, Denmark

Co-presenters: Tina Bendixen, Lone Rømer, Tanja Møller Christiansen, Denmark

Main focus: Mainly practice/Both congenital and acquired deafblindness

Abstract: The level of arousal is of crucial importance for a person's ability to communicate and to uphold and participate in social interaction on any level. If there is a problem with the level of arousal – i.e. too low, blurred or too high - interaction becomes difficult, or in extreme cases, impossible. Therefore it is of the utmost importance to assure that the person one is communicating with has the correct level of arousal, that is, either too low or too high.

Some people with deafblindness suffer from this type of problems due to their disability, especially people with other cognitive impairments. It is therefore important that the staff is aware of the challenges this group of the DB population represent and how to work with it.

Problems with arousal can disrupt interaction at different levels. At the most basic level it can prevent any interaction until the arousal is stabilized. This can be done in different ways, by application of relevant stimuli, like rubbing of arms or back, by a systematic presentation of different sounds or smells if the arousal is too low (hypoarousal), or by applying low arousal technique, like talking in a low, calm voice or turning the light down, combined with a very structured approach, if the arousal is too high (hyperarousal).

At the next level disruption can occur in the communication cycle, as described by Allan Shore, Ed Tronnick and Lene Lier. In the ordinary, healthy child, face-to-face interactions begin when the child is about two months of age, where the child leads and the mother follows. The interplay is fast, or to quote Shore: "In order to regulate the high positive activation (arousal) mother and child synchronize the intensity of their affective behavior within milli-seconds". This interaction is extremely important. To quote Shore again: "It seems that the ability to experience, communicate and regulate emotions might be the most important thing in the childhood."

In our work with some people with deafblindness, we see this process is easily disrupted, often with serious consequences for the development. Due to the nature of the disability ordinary face-to-face interaction between mother and child is not possible and the interaction must be replaced by tactile communication. There has always been focus on communication in DB pedagogy, but in order to maximize this it is also important to be aware of the basic cognitive processes, among them the level of arousal and its role, both as the foundation for communication and social interaction and on the more subtle level in the communication cycle with its turn taking and active/passive changes.

Abstract No. 3.4

Wednesday 6th September 2017 at 11:00-11:45

**Title: Tactile sign language in communication with people with Congenital deafblindness.**

Presenter: Bettina Kastrup Pedersen, Centre for Deafblindness and Hearing Loss, Denmark

Main focus: Mainly practice/Congenital deafblindness

Abstract: Tactile sign language in communication with CDB.

Throughout the last years there has been an expanded focus and interest on the fact that not all people with CDB are developing their language according to their potentials.

Knowing visual sign language help us to be able to see even small, weak or pro-gestures as potential signs. Idiosyncratic and “homemade” signs often emerge and have relevance to a specific context.

Gestures and bodily expressions are considered as signs from the body with intentional meaning and directedness towards someone. Maybe we can talk about “utterances”?

Tactile sign language might be the concept to expand in order to give people with CDB a more nuanced language because it is richer than signs only performed in hands and/or gestures and bodily expressions.

This workshop will point out the importance of a focus on tactile sign language and how to get started. Also raise a discussion about focus on “utterances”, and their importance in communication with people with CDB.

Partners who are in relation and communicate with people with CDB will be able to use this knowledge in their further work. The main idea of this is for the partner always to be a step ahead of their deafblind communication partner.

The workshop will have videos and exercises to emphasize the idea. And present a Danish concept used in staff training on CDH.

Abstract No. 3.5

Wednesday 6th September 2017 at 11:00-11:45

**Title: Conducting psychotherapy with individuals who have acquired deafblindness**

Presenter: Maj Volden, The Norwegian National Unit for Mental Health and Deafness, OUS-HF, Norway

Main focus: Mainly practice/Acquired deafblindness

Abstract: Individuals who have acquired deafblindness may develop mental disorders, e.g. depression and anxiety, in the same manner and for the same reasons as do individuals of the general population.

Challenges associated with deaf-blindness may impact on a variety of daily functions and psychological processes, such as communication and relating to others, mobility, feeling secure, and the individual's regulation of his/her inner world. These are topics that in different ways may appear central in psychotherapy with any patient, not exclusively those who have combined sensory loss.

In what ways may the content and meaning of these topics differ when a therapist meet with a deafblind person? If the therapist isn't familiar with the specific practical and psychological challenges that deaf-blind people meet, there is a risk of resulting either over- or under-shadowing in the psychological assessment process and during the therapeutic process.

Dr. Psychol. Jon Haug has developed a theory related to therapeutic work with individuals who have diabetes. His theory, called "The theory of specificity", pinpoints that different chronic diseases and disabilities may be accompanied by quite specific psychological challenges, experienced by all or most people within the same diagnostic group. The research is based on Dr. Haug's clinical experience during 30 years.

The lecturer will share thoughts of how "The theory of specificity" can be a useful tool when seeking to understand the psychological processes that deaf-blind people do present. Through 15 years' of therapeutic work with deafblind adults, the experience is that some issues arising in therapy seem to be common for all patients, while other issues are clearly related to the individual's specific and subjective life experiences. Each individual's psychological vulnerability and resilience may play a decisive role in how life-challenges are dealt with, and resilience may be found where you don't expect it to exist.

Abstract No. 3.6

Wednesday 6th September 2017 at 11:00-11:45

**Title: The formation of the communicative partner image for the deafblind students.**

Presenter: Svetlana Zarechnova, Children`s House for Deafblind, Russia

Main focus: Both research and practice/Both congenital and acquired deafblindness

Abstract: Children who have sensory impairments are limited in social experience and in interaction with the environment. They can't build the image of the world by imitation, observing the behavior of other people, by solving practical problems that appear in everyday life. Having a negative social experience (the child's home, medical manipulation) or not having it at all, deafblind children can not obtain information about their communication partner independently. Deafblind children have impaired the basic level of communication – tactile communication at a close distance. Often we teach children this contact. When children come to us, they have a negative experience. They come from children's homes, where social experience is limited, or from a family, where for this period of time it is in a state of shock from the birth of a disabled child. The parents of such a child do not receive a response from the child on the tactile level and begin to take the child on hands more rarely, to communicate more indifferently with the child. Such mother`s behavior worsens the child's condition. Often we teach children such contact. They don't know how to behave, if they are taken on the hands, hugged or snuggled. A lot of time should pass before the child allows an adult to come up closer to him. Tactile communication for deaf – blind people is the basic communication level, so you need to “give some extra hands” to the child. We see that children press to us with all their bodies and freeze, as if they are filling by the sense of merging, interaction with our body. Only when a child has "drunk enough" hands, he will step aside from the body contact and begin to look at the surroundings. This development stage is also passed by normally developing children ( but at an earlier age). In the communication of deaf-blind person with other people the process of the communication partner happens. Impressions which occur at the same time, play an important regulatory role in the communication process . Gestures, like facial expressions, voice, and the person poses can get into the image emerging in the deaf-blind person in the process of partner perception. At the initial stage of communication this component of the image of the partner is the most important for the deaf-blind, because it contains vivid detail, which the deaf-blind can thoroughly consider tactile. The constancy of the external parts in the appearance of the partner is important at the stage of contact formation. The formation of the image of the communication partner is a purposeful work, the leading role in it belongs to the teacher. That teacher defines the rules of behavior, preparing the people surrounding the deaf-blind to such contact. It is important to follow some rules to everyone who enters in tactile communication with deafblind child.

Abstract No. 3.7

Wednesday 6th September 2017 at 11:00-11:45

**Title: Positive Touch Access: Invitation to Touch Leads to Self-Actualization**

Presenter: Susanne Morrow, New York Deaf-Blind Collaborative, USA

Main focus: Both research and practice/Both congenital and acquired deafblindness

Abstract: This presentation will address two major issues related to touch and touch techniques:

1. Positive Touch Access. Over the past five years there has been a major shift in the way touch techniques are labeled and used in the USA, specifically with DeafBlind adults. The system of haptics, an influence from Scandinavia, has made great impact among some institutions and DeafBlind community members in North America. While Pro-Tactile, a USA DeafBlind adult community movement, has taken great lead and influence in the community at large and higher education institutions. And then a third term, Touch Signals, coined by a sub-committee of DeafBlind committee members associated with Helen Keller National Center, has entered the field. These similar yet differing approaches have all had positive influences; however, they have also caused confusion and conflict throughout the adult DeafBlind and interpreting communities. The presenter proposes a shift in approaching these often tension-laden ideas and suggests an overarching approach: Positive Touch Access.

2. Congenital vs. Late Onset. While these advances are happening in the adult DeafBlind community, this movement has gone on without much consideration for the way in which congenitally DeafBlind children have been educated. Research in the field of DeafBlind education has indicated for decades the critical aspect of touch in early cognitive and communication development (Nicholas, Jude. "From Active Touch to Tactile Communication: What's Tactile Cognition Got To Do With It?" DBI Review Number 45 (2010), Moss, Kate. "Some Things to Learn from Learning Through Touch" SEE/HEAR Newsletter (2005) and Miles, Barbara "Talking the Language of Hands to the Hands" DB-LINK (2003).) Technical assistance projects in the USA, funded by the US Department of Education, Office of Special Education Programs, have been in service as a result of the Congenital Rubella Syndrome epidemic in the late 1960s and early 1970s. These grant directors, coordinators and educational specialists have paved the way for exemplary practice for learners who are DeafBlind, with the main theme of constant, respectful touch.

This presentation will address these two critical aspects and show the natural marrying of the two that Positive Touch Access, thus providing an invitation to touch will lead to self-actualization in DeafBlind individuals.

Abstract No. 3.8

Wednesday 6th September 2017 at 11:00-11:45

**Title: 'Life in resonance', a personal exploration of communication through touch as a deafblind shiatsu therapist**

Presenter: Femke Krijger, own practice of shiatsu/Tao yoga therapy  
'levensvonk', The Netherlands

Main focus: Mainly practice/Both congenital and acquired deafblindness

Abstract: Being deafblind I have to find my way in life dealing with this chronic, progressive process of loss. This is a difficult and often painful process of adjustment. Long ago I realised I should not focus on adapting to the good sighted good hearing world alone. I should find my own ways of expressing myself by staying in contact with the surrounding world.

The sense of touch, I discovered, developed also without any conscious effort on my behalf. When I realised this I started to observe the sensory input of my sense of touch more closely and by doing so I trained it more rapidly. After a few years I decided to develop it further and started a four year training as a shiatsu (massage) therapist. During this training I learned so much about the powers of this sense of touch. I mention one here:

I observed a subtle interplay between the outer and inner dimension of senses. My outer sight is diminishing, while my inner sight is developing. I call it 'sight-feeling', because those two senses offer me sensory information I can no longer separate. It is a different way of seeing, and I know I am not the only one. But most people still find this a strange way of receiving information, they tend to think it's the delusional power of a deteriorating system. For quite a while I thought so myself. But in my shiatsu practice I found my sight-feeling observations true all too often and learned to trust it as I trust my other eyes, not completely, but still offering valuable information.

Also the inner hearing became a very useful instrument, lacking so much of visual body language input. A voice can tell so much, a word can sound different, like a stone in a river, it's this different resonance in a word that tells me something is going on. It's, like the stone in the river, an obstruction maybe but also a point of possible change.

With the deterioration of my sight and hearing I lost a lot, but I gained the power of focus. I see and hear what easily can be missed, because of my trained focus and concentration.

The benefit on the long term and short term of developing and exploring the sense of touch in the rehabilitation of db people:

-broadens range of communication

- strengthens self-esteem because it is something you can offer to others when in many situations you have to ask for help. In that sense it is an important help in keeping social relations healthy

- it can be applied in many ways, small (family/friends) or professional (working as massage therapist, volunteer in hospice, etc.). It's very valuable in every situation.

- it is bridging, because it is not only the deafblind person who is in need of being in touch with the surrounding world. Being touched is a general human need which for so many of



us is often neglected. I notice this in my practice. The enormous power of simple touch, in tune with what is going on (inside), is moving. This is 'life in resonance'. Therefore, let us not only focus on adjustments of db to the good sighted good hearing world, let us in turn develop a powerful instrument which will turn out to be a useful daily strength

I am in no way suggesting db is not a terribly difficult reality. I myself am often still devastated trying to deal with it. But this , which I try to share here today is also part of that reality.

It helps me to find my way, literally and metaphorically. It helps me to communicate with others in ways beyond my imagination and it gave me a sense of purpose again. In short, it helps me balancing loss.

Abstract No. 4.1      Wednesday 6th September 2017 at 12:00-12:45

**Title: Narrativity and embodiment**

Presenter:                      Myrra Smith, Centre for Deafblindness and Hearing Loss (CDH),  
Denmark  
Co-presenters:                Dorte Lindberg

Main focus: Both research and practice/Congenital deafblindness

Abstract: Mark Johnson talks about body in the mind and not body and mind. Our hypothesis is that every human being has the urge to share stories - this includes people with congenital deafblindness.

We want to combine how embodiment works in relation to narrativity, and show how important bodily experiences are in relation to how people with congenital deafblindness express their stories and feelings.

Based on an experience in the sea with a woman, we will show how both parties uses this experience in the relationship. Focus is how the experience is bodily traced, both on the woman with congenital deafblindness and on the communication partner. These traces are core elements in the shared communication and framed by the narrative structure. Using photos and video we will show different aspects of how to work with embodiment and narrativity based on the specific experience in the sea.

Our work is inspired by the theories by Mark Johnson, Shaun Gallagher and Jerome Bruner. We hope to inspire the participants of the workshop on how to implement these theories in practice.

Abstract No. 4.2

Wednesday 6th September 2017 at 12:00-12:45

**Title: Adventurous learning and declarative communication in a tactile multi-partner way**

Presenter: Amanda Buijs, Royal Dutch Kentalis, Rafaël school, The Netherlands

Co-presenters: Lieke van Buuren

Main focus: Mainly practice/Congenital deafblindness

**Abstract: Summary**

This presentation is a case description of a 19 year old young man with congenital deafblindness, a student at the Royal Dutch Kentalis Rafaël school. He learned to use declarative communication by experiencing different adventures in a bodily tactile manner, in a multi-partner setting. Through reconstruction of the adventure the two more-competent communication partners were able to scaffold the use of declarative communication for this young man.

**Main content**

Since 2013 we are using Tactile Multi-partner Interaction and Communication (TMIC) at Kentalis Rafaël, a school for children with congenital deafblindness in the age of 3 to 20. TMIC is based on three-party communication. We wanted to find out what impact tactile communication with multiple partners would have on our students. The young man in this case was one of the first to experience this new approach.

This young man is dependent on touch for the development of his active communication. He performs his gestures and signs in a subtle way, therefore one should know him well to understand him. Before starting the TMIC sessions he mostly used imperative communication while being at school. He tended to cease his communication initiatives when he was not fast enough understood.

At the beginning of a new school year this young man and two, more competent communicationpartners started engaging in new adventures, all in which gross motor skills play a role. During the adventures we engaged in, we needed to be close to each other and help each other. The first new adventure created an opportunity for the partners to add declarative tactile communication to the young man's concept of this activity. This was a turnaround. From that moment on he accepted reconstruction of the adventure by his partners. He even took an active part in the reconstruction of the adventure, having fun while doing this.

After that the number of adventures was expanded. We also started to capture the story of the adventures in a tactile manner. Later on an auditory component was added to the tactile story. Both components turned out to have their own added value.

It seems the TMIC adventure-sessions encouraged connection and created a bond in which trust and confidence were able to grow. After 1,5 years of TMIC adventure-sessions in school this young man uses more and more declarative communication, not only regarding the adventures, but also in general! He has become much more persistent



and creative in his communicative efforts when he is not directly understood. This is a beautiful development, which we are proud to present to you!

Abstract No. 4.3

Wednesday 6th September 2017 at 12:00-12:45

**Title: Teaching Orientation and Mobility Skills to people with deafblindness who use tactile sign language**

Presenter: Meredith Prain, Senses Australia, Australia

Co-presenters: Bronwen Scott

Main focus: Mainly practice/Acquired deafblindness

Abstract: This workshop presents the outcomes of a twelve month collaboration between Able Australia and Independent Options for Mobility in Melbourne, Australia. The project involved an initial investigation of the specific orientation and mobility (O&M) needs of people with deafblindness, as well as those involved in providing O & M training. A series of workshops aimed at people with deafblindness, communication guides, interpreters, and O&M specialists was devised and conducted over a six month period. The workshops further highlighted the complex communication requirements necessary to undertake O & M training, and a DVD was developed to help address these issues. The DVD includes some specific tactile signs and haptics to use in O&M lessons with tactile Auslan users, and an accompanying booklet explaining some of the common O&M terms and techniques was developed to accompany the DVD. The project highlighted the importance of O&M specialists, interpreters, and communication guides working closely together with each other and in partnership with the person with deafblindness to ensure high quality, successful communication of new terms and concepts. This workshop will:

- outline the background to the project,
- outline what was covered in each of the workshops
- show the DVD and provide links to obtaining the accompanying booklet.
- provide participants with the opportunity to learn and practice the tactile O & M signs and haptics
- raise key points to consider when undertaking O&M training with a tactile sign language user
- raise points which require further work in research and practice in the future

Abstract No. 4.4                      Wednesday 6th September 2017 at 12:00-12:45

**Title: The art of sight**

Presenter:                              Sylvia van Doorn, Royal Dutch Kentalis, Unit Deafblindness, The Netherlands

Co-presenters:                        Ans van Gulick, Annet Eikelboom and NN

Main focus: Mainly practice/Both congenital and acquired deafblindness

Abstract: At first, the exhibition 'The art of sight' was intended to bring deafblindness to the attention of municipalities, health insurance companies and citizens in a creative way. Pictures of flowers, made by a colleague, inspired us to find a way of making these pictures tangible. Flowers are part of our lives and obvious in terms of shape, smell and colour. We see them everywhere and at specific occasions. For people with deafblindness this isn't as obvious as for us.

The works of art in this exhibition are the result of an action-oriented and experiential form of therapy. This way of working is a specialized form of guiding which aims to support processes of change, development and/or acceptance within people with deafblindness. The experiences create awareness and new insights into their own potential and the development of skills, which are practical applicable in everyday life.

Not only in the area of tactility do people with deafblindness experience difficulties. They often have insufficient understanding of their personal abilities and skills. And besides this, they often also experience energetic problems which put a heavy break on participation.

Reflecting this we started to look for a way how creative activities and resources could be used to develop a training which takes into account the energy problems and in which one learns to consciously use tactility to get insight into ones personal capabilities and limitations and wherein one learns skills to develop themselves.

An example of the outcome of this way of working is a travelling exhibition 'The art of sight'. 15 Works of art, in which 15 people, 10-65 years of age with congenital and acquired deafblindness tell their story. Each work of art was inspired by a floral photo and is complemented by fragrances, text and braille and video clips that can be activated by scanning a QR code. By using the glasses that go with the diptych, visitors can see how the artist perceives the world. Workshops accompany the exhibition in which creative therapy is explained and in which one can experience the world of deafblindness on a creative level.

6 Pieces of art out of 15 will be shown during the conference.

Abstract No. 4.5

Wednesday 6th September 2017 at 12:00-12:45

**Title: Deafblindness, Self-Stimulation, and Availability for Learning**

Presenter: David Brown, Self-employed, USA

Main focus: Both research and practice/Congenital deafblindness

Abstract: Most children with congenital deafblindness today have significant medical issues which result in other sensory systems, as well as vision and hearing, also not working properly, including perception of pain, smell, taste, touch, and balance. Because every one of our senses is designed to develop and work simultaneously with all the others, a problem with one sense may result in problems with the functioning of other, apparently unrelated and intact, senses. Two of these 'other' senses, the proprioceptive sense and the vestibular sense, are particularly important but often ignored. Knowing about these senses, how they work, what might happen if they are not working properly, and what to do about it, can make a surprising difference to the development of functional vision and hearing. A consideration of the functions of ALL our senses can help us to understand why we self-stimulate, and also understand what any child's self-stimulation behaviors tell about their difficulties and needs. As a result of this perspective many behaviors that are generally thought of as 'bad' begin to be seen as actually quite smart adaptive responses. Sometimes accepting, or re-channeling, or even encouraging these behaviors can be much more helpful than merely trying to stop them.

OBJECTIVES (What do you want the audience to learn?)

- 1.To develop a clearer focus on the identification & use of individualized motivators
- 2.To focus & organize their observations in a more effective way
- 3.To adopt and develop a broader idea of what constitutes 'self-stimulation'
- 4.To utilize a child's current expressive behaviors in determining the best way forwards
- 5.To adopt and develop a better insight into what certain behaviors mean
- 6.To develop an awareness of the very important proprioceptive and vestibular sensory systems

Abstract No. 4.6

Wednesday 6th September 2017 at 12:00-12:45

**Title: The support needs of family members of persons with Usher type 2**

Presenter: Ilse van Zadelhoff, Royal Dutch Kentalis, The Netherlands

Co-presenters: Saskia Damen

Main focus: Both research and practice/Acquired deafblindness

Abstract: When someone suffers from progressive deafblindness, this will not only influence the person with deafblindness, it will also have a great impact on his or her family members. However, there are no support programs for family members of people with acquired deafblindness in the Netherlands. This is a shortcoming, because family relationships are subject to change because of the impact of the progressive syndrome. For instance, people with Usher type 2 are known to have more stress (Högner, 2015), which has a negative influence upon the family dynamics.

There are currently several support programs available for people with Usher syndrome, but in order to have an optimal outcome of a certain treatment, involvement of direct family members is essential. Family members who receive support, are better able to provide more effective support and assistance themselves. Furthermore, it is an important aim of the government to shift the responsibility for increasing participation in society to the individual and his or her social network (Vreugdenhil, 2012).

The aim of this project, in which the target audience is involved in the design of the study, is to gain more insight into the support needs of families of persons with Usher type 2. By means of questionnaires and in-depth interviews information relating to, among other things, individual quality of life, the interpersonal aspects of the relationships of the participants and quality of family life will be gathered from the data. These findings will form the basis for an advice regarding the development of a support program for spouses and children of persons with acquired deafblindness .

During the workshop, information will be given about the results of the project so far.

Furthermore, the way in which a target group can be involved in the different stages of setting up and conducting qualitative research will be a central topic of the presentation.

After the presentation there will be time for discussion with the participants of the workshop on the question if and how support of family members is constituted in their home countries and what the role of family members is in the support of clients.

Participants will also be asked if they can give suggestions on the content of a support program for family members on the basis of their own experiences.

Abstract No. 4.7

Wednesday 6th September 2017 at 12:00-12:45

**Title: Enhancing learning for a child with deafblindness by putting on the ‘cognitive glasses’: Assessment of learning through working memory**

Presenter: Anne Schoone, Royal Dutch Kentalis, The Netherlands

Co-presenters: Monique Verberg

Main focus: Both research and practice/Congenital deafblindness

Abstract: In our daily practice as professionals of the Kentalis Diagnostic team in the Netherlands, we are often asked to assess the cognitive functions of people with congenital deafblindness. Questions regarding the person’s ‘learning potentials’ or ‘learning strategies’ often arise as part of the assessment.

Without reliable access to clear visual and auditory information, people with congenital deafblindness use their bodily-tactile sense to experience the world, gather information and guide learning. This means that we need to understand the features of the cognitive information processes in the bodily-tactile modality and the cognitive assessment should seek to identify the cognitive or learning or potentials rather than the deficits that the individual possesses.

Recently, we’ve been involved in developing and implementing an assessment scale for assessing working memory in the tactile modality. The scale is called the Tactile Working Memory Scale; TWMS (Nicholas, Johannessen & van Nunen, 2017). The TWMS has been developed for professionals to facilitate identification and promote effective interventions of bodily-tactile working memory in persons with deafblindness. The transactional model and the dynamic assessment model consist of the framework of the TWMS and these principles guide the assessment procedure when using the TWMS. In other words, providing scaffolding and active intervening are essential parts of the assessment process.

In this workshop we will share our experiences on how by using the TWMS and putting on the ‘cognitive glasses’ gave us some very useful new insights to support cognitive processes and enhance learning in a young boy with congenital deafblindness.

We’ll be using video sequences to illustrate how we applied parts of the TWMS, how we looked at the interaction process through the “cognitive glasses” and how this cognitive approach has offered opportunities to meet the child’s learning potentials. During this presentation we would like to invite the participants to put on their ‘cognitive glasses’ too. Additionally, we would like to discuss the possibilities and benefits of using a bodily-tactile cognitive assessment scale (TWMS) in understanding and fostering working memory in our daily practical work with people with congenital deafblindness.

Nicholas, J., Johannessen, A. & van Nunen, T. (2017). Assessing Working Memory in the Tactile Modality: The Tactile Working Memory Scale. *Manuscript in progress*.

Abstract No. 4.8

Wednesday 6th September 2017 at 12:00-12:45

**Title: Group training for communication of young adults with visual and hearing impairments**

Presenter: Alina Khokhlova, Yasenevo Center for Deafblind, Russia

Main focus: Mainly practice/Both congenital and acquired deafblindness

Abstract: Difficulties in communication of deafblind people happen also when it comes to the communication among the deafblind itself. Deafblind people among themselves are not homogenous. Ones have lost deaf or vision gradually, another borned deaf, but with vision, third – visually impaired but hearing. Therefore they prefer different tools of communication: verbal speech, dactylogy, sign language, tactile sign language. At the same time, there is a number of other difficulties that aggravate the communication. For example, the deafblind person not always knows who is in the room, he is not able to see or hear his statements, reaction. Communication often happens between two sides, the deafblind person not immediately understand who he is communicating with. Statements are often interposed as in all sorts of communication of people without disabilities.

The goal of training: creation of supportive environment for substantial dialogue and communication in the group of young deafblind adults, development of positive experience of interaction. This goal we propose to achieve by several means:

1. Overcoming of objective difficulties in communication
2. Deep informal acquaintance within the process of training.
3. Experience to express independently your our opinion in front of the group of people
4. Personal and creative potential fulfillment

Rules:

- Each of participants should have assistant-interpreter;
- All who is sitting in the circle should introduce themselves
- Everybody starts communication (in its turn), everybody starts communication with everybody;
- Thoughts should be formulated in short but utmost manner. Communication should not be interposed as in routine situation;
- Topics for discussion are aimed on strengthening of emotional contact.

Structure:

- Preparatory part: all the participants find out who is attending the training and where is he or she sitting. Everybody is prepared to work.
- Main part: carrying out exercises to boost the effective communication.
- Discussion: participants tell what have been their feelings like, what did they like, what was comfortable/uncomfortable, easy/hard.

Length: 8 meetings

Results:

- According to the comments of participants it is clear that they start to know each other much better, learn a lot of new things about each other;



- According to the observations of specialists many of participants, who used to communicate only with familiar close circle of people and with others – through the mediators, start to express their own opinion, maybe first time in their life;
- Training on communication allows to show the initiative and creates positive experience in communication with more wide circle of people. After training the participants continue gathering together.

Abstract No. 5.1

Wednesday 6th September 2017 at 14:15-15:00

**Title: From Sensory to Symbolic**

Presenter: Basem AbdelGhaffar, University of Sharjah, United Arab Emirates

Main focus: Mainly practice/Congenital deafblindness

Abstract: Early intervention with the children with complex developmental needs can be very challenging for both families and professionals. The complexity of the needs makes it harder to detect, observe, engage, and support the unconventional communicative expressions i.e. support communication development.

This development leads the child from resonance, neonatal imitation to the development of reciprocation starting at 2 months of age. By two months infants already appear to transcend basic mirroring processes by manifesting first signs of reciprocation in face-to-face exchanges (primary intersubjectivity). They soon engage in triadic intentional communication with others about objects (secondary intersubjectivity, starting approximately 9 months) and eventually begin to negotiate with others about the values of things, including the self as shared representations (tertiary intersubjectivity, starting approximately 20 months). The notion of tertiary intersubjectivity was proposed by Trevarthen (2006). In Trevarthen's conception, the tertiary level is the first- and second-person reflective and recursive intersubjectivity, in the sense of communicative understanding mediated by meta-representations, and symbolic references to actual and fictional worlds of imagination or joint presence.

The role of Mirror Neurons is currently sets in the heart of the education/ habilitation process, especially because - as a neurological system - is not necessarily depends on the cognitive component, in the same context, mirror neurons system can be considered as the neurological base of social interaction, it is deeply rooted in the Limbic Brain –in terms of Paul MacLean's Triune Brain model- which makes it less vulnerable unlike the cortical functions including language, MacLean PD (1993). That should enable the caregivers to apply the mirror neurons inspired techniques on a wide range of children with various educational needs despite of the severity of disability.

Within the same context, there are three "natures" of communication models:

1. Sensory.
2. Emotional.
3. Symbolic.

The vast majority of the children with congenitally deafblindness tend to rely more at the first two communicative models before being able to reach cross the symbolic model. In this presentation, the author will review the pre-symbolic models of communication, highlighting the earliest steps of communication which are mainly "bodily-based" form of interaction that reflects the biological roots of communication development, and how near sensory modalities (touch - vestibular - proprioception) plays the principle role in establishing the very first glimpses of communication. The aim is also to highlight the connection between non-symbolic forms communication and symbolic communication despite their differences in qualitative nature, based on the dialectical law of transformation "small quantitative changes at a certain point give rise to a qualitative leap"



Within the presentation, there will be a new term to be used i.e. “Non-Cognitive Communication” which refers to the all forms of communication that doesn't actually need “Well-developed Cognition” to be successful i.e. bodily-based communication, and exchanging emotions as in early stages of social interaction, where no actual ideas or knowledge being shared, only affections and emotions.

Abstract No. 5.2

Wednesday 6th September 2017 at 14:15-15:00

**Title: Sailing Sense - Sailing for people with deafblindness and multi-sensory impairment**

Presenter: Miguel Olio, Sailing Sense, Brazil

Main focus: Mainly practice/Both congenital and acquired deafblindness

In 2002 deafblindness in Brazil was considered a category of disability. In that year, this disability was also named in an official document of the Education Ministry. After this change there were some studies about improving the quality of life of deafblind people. Within the área of sport there are many things to study. This project aims to enable deafblind people to learn to sail. With this purpose, we came up with some questions:

- Is it possible to teach deafblind people to sail?
- Can they sail with autonomy?
- What are the necessary adaptations for this to happen?
- Which are the specific techniques for teaching?

The project is collecting information through direct experiences with deafblind adults and children to answer these questions. Using this action research approach we are having good results and they showed that the methods we are using has been accepted by deafblind people. This workshop will outline the approach taken using photos and vídeo footage.

Abstract No. 5.3

Wednesday 6th September 2017 at 14:15-15:00

**Title: The important role that touch has played in my life**

Presenter: Vanessa Vlajkovic, University Student, Australia

Main focus: Mainly practice/Acquired deafblindness

Abstract: Sight and hearing are senses that most humans take for granted. So, given that their primary means of taking in information is through their eyes and ears, they are not usually required to rely on their sense of touch in daily life. However, as a deafblind person, I can vouch that touch is absolutely crucial for people who cannot obtain cues via the "normal" pathway. Of course, all deafblind individuals have different levels of vision and hearing, and not all of them will be dependent on touch. But whether they will readily admit it or not, most of them will certainly find it easier to sometimes receive something via touch than through their limited sight/hearing. I can explain, through personal experience, how Braille, sign language and social haptics have all combined to allow me to achieve my life goals in an effective and more involving way. I hope to educate others with my knowledge of these three particular methods of communication. I have no ground-breaking research; however, I do have my own life's challenges that I overcome, and these in turn are perhaps more valuable than any research could be. It allows an insight into the life of someone living with dual sensory loss whilst also helping people become more familiar with how particular communication methods work. Braille is a system of dots that can be felt with the fingertips in order to read print that is otherwise too small to be read. Technology such as the BrailleNote can open up countless opportunities making it feel as if literally anything is possible. A person can have all the freedom and independence they desire by learning how to access language and technology through Braille. It truly is revolutionary but unfortunately there is a shockingly low number of blind and deafblind people accessing Braille and Braille technology. Social haptics is fairly new to me, but it has given me so much joy since I was introduced to it. The feeling of being able to have someone convey information to me instantly by touch, by drawing facial expressions, room lay outs and more on my back or arms, is unlike any other I have known. It is highly effective and provides much more opportunity for involvement socially. Finally, sign language - most deafblind will be aware that this exists, but some may never have used it. Tactile signing in itself is an entirely separate method of communication, and can be relayed quickly and easily from one person to another. In short, these three means of communicating by touch are extremely powerful; they enable a deafblind person such as myself to enjoy life at the same level as an average individual with normal sight and hearing.

Abstract No. 5.4      Wednesday 6th September 2017 at 14:15-15:00

**Title: Affective sense of touch and movement in shaping closeness**

Presenter:                      Ivana Macokatic, Day-care Centre for Rehabilitation Mali dom-  
Zagreb, Croatia

Co-presenters:                Ana Katusic

Main focus: Both research and practice/Both congenital and acquired deafblindness

Abstract: There is growing neuroscience evidence that one of the modalities of somatosensory system – touch – offers, except well recognized discriminative input, also an affective input to the brain. The neurons in the skin responsible for detecting affective touch activates insular cortex, the area known to be responsible for processing emotions and related to social communication. This is why affective sense of touch plays an important role in many forms of social interaction and in the development of bonding. The aim of the workshop is to observe and to experience how different qualities of touch and movement can shape our interaction and mutual understanding. The focus will be on the awareness of various modes of touch and movement that we can apply to enhance relations and bonding in our social surrounding. By exploring different context in which we use touch in affective way, as the movement, the workshop will strike parallels for development of closeness and communication in people with deafblindness. Within applying Laban/Bartenieff Movement Analysis and Somatic Practice™, the participants will be engaged in defining three modes of movements (Shape Flow, Directional Movement and Shaping Movement) and their impact on social interaction for individuals with deafblindness. Through interactive and learning experience, the participants will explore their own body shape during relations with others and also discuss, within neuroscientific frame of affective touch, what is happening in central processing of this submodality, if someone is unable to use vision or hearing in social communication.

Abstract No. 5.5

Wednesday 6th September 2017 at 14:15-15:00

**Title: «What does language mean for me? »**

Presenter: Annika Maria Johannessen, Statped, Norway

Co-presenters: Olaug Grude Hobberstad, Klepp kommune, Norway

Main focus: Mainly practice/Congenital deafblindness

Abstract: Due to the difficulties of language acquisition in the population of people with congenital

deafblindness, only a few manage to develop language to their full potential. To be able to conduct a proper intervention towards language acquisition, we have experienced the importance of systematic intervention and good collaboration within the system, to facilitate the person with congenital deafblindness's language development.

This workshop will take the participants on a unique journey on how a man with congenital deafblindness and CHARGE syndrome learned language. At the age of 29 (in 2010), he had knowledge of approximately 400 visual signs (he could match sign and pictures), but did not use any of those signs in a communicative manner. He only communicated with emotions, vocalization, hand-guiding and bodily expressions. During the last six years, the staff have collaborated closely together with the competence system for deafblindness to introduce a bodily/tactile sign language. Today he can talk about how access to language changed his life primarily within the topics of accessing information, his mental health, reduction of social isolation and maintaining social relationships.

The workshop will emphasize how the intervention process towards a tactile language for the man with cdb and his partners progressed. We will highlight both the perspective of core intervention strategies (bodily-tactile togetherness, bodily-tactile language acquisition based on bodily/tactile experiences in context) and how the system managed to facilitate the intervention.

The main part of the workshop contains a video interview of a man with cdb, where he shares his personal story and tells about his own experiences of learning a tactual language and how this had an impact on his emotional life.

We want the participants to ask questions with a primary regard for the two perspectives we propose:

- a) What the intervention strategies were and how did the process develop?
- b) How the system facilitates such intervention?

We also want the participants to discuss with us some of the topics that the man with cdb raises himself (eg. Access to information, mental health, reduction of social isolation etc.).

Abstract No. 5.6

Wednesday 6th September 2017 at 14:15-15:00

**Title: Communicative engagement in multiparty conversations with persons with CDB**

Presenter: M. Worm, Bartiméus, The Netherlands

Main focus: Both research and practice/Congenital deafblindness

Abstract: Due to a lack of shareable communicative means, communication with persons with congenital deafblindness is at risk of being limited, while communication is seen as essential for development of cognition and the self. In the current study conversations of persons with congenital deafblindness have been enriched by the introduction of narrative and multiparty conversations. The aim was to enhance communicative engagement, which was operationalised in elements drawn from dialogical theory: positions (speaking, listening, thinking), endurance of tension, communicative projects and negotiations. The study was performed within the international master “Communication and Congenital Deafblindness” at Groningen University (NL). It was conducted at Bartiméus, a Dutch organisation for persons with visual disabilities. In two exemplary cases, narratives and multiparty conversations were introduced to the conversations of two adult women with congenital deafblindness who received residential care. These conversations were studied on the elements of communicative engagement with an idiographic procedure. The main tools for analysis were: ELAN, focus groups, conversation analysis, dialogical theory and the 6-space model from the Mental Space theory. In both cases, the duration of the conversations increased by the introduction of narratives and multiparty conversations. Furthermore, both participants endured negotiation processes in order to draw attention to the self and maintained extended and more coherent communicative projects. A following and listening attitude of the communication partner evoked more expressions of self. The introduction of multiparty conversations proved to be uncomplicated and natural. While conversations were prolonged and gained an higher level of complexity, the communicative engagement of the participants with deafblindness increased, bringing enhanced opportunities to develop cognition and self. Therefore, it is recommended to introduce narratives and multiparty conversations to many more persons with congenital deafblindness.



Abstract No. 5.7

Wednesday 6th September 2017 at 14:15-15:00

**Title: Teaching Concepts to Children Using the BEST Elements of Dance**

Presenter: Kristen Paul, University of Utah, USA  
Co-presenters: Brooke Barnhill  
Catherine Nelson  
Pamela Geber Handman

Main focus: Mainly practice/Congenital deafblindness

Abstract: Available research on the impact of the arts on learning and education demonstrates a significant correlation between quality arts instruction and academic learning and cognition (e.g., Deasy, 2002; Ingram & Riedel, 2003). In addition, there is a growing body of research demonstrating the positive impact of integration of the arts including rhythmic and movement-based activities on learning for students with disabilities (e.g., Deasy, 2002; Corbett, Wilson, and Morse, 2004; Mason, Thormann, & Steedly, 2004; Kern, Wolrey & Aldridge, 2006; Srinivasan & Bhat, 2013). While creative dance and movement-based arts integration activities have been shown to improve student outcomes, teachers may be reluctant to use them as a context for learning in special education classes (Nelson, Paul, Johnston, Kidder, & Hyte, 2014, Nelson, Paul, Johnston, & Kidder, In Press). Although, the research base on using dance activities with students who are deafblind is limited, interactive movement activities are congruent with evidence-based practices in the field of deafblindness that include child-guided learning, active and coactive movement, and responsive, harmonious interactions.

A multidisciplinary university course taught by the presenters increased pre-service teachers' capacity to use creative dance as a context for learning in special education settings. A primary focus of the course involved using the elements of dance known as Body, Energy, Space, and Time (BEST) (Green-Gilbert, 1992). The pre-service teachers used BEST to develop instructional programs for teaching creative dance/active movement activities to students with disabilities including students with visual impairments and deafblindness. The elements of dance known as BEST and their corresponding concepts proved to be a useful tools for developing creative dance lessons designed to teach academic, adaptive, and social skills. In particular, social connectedness among students and adults was fostered during the creative dancing. In addition, BEST can be incorporated in instructional programs for teaching skills across academic and community settings.

The purpose of this workshop is to introduce the BEST elements of dance that include; Body (e.g., body parts, balance, and inner self), Energy (e.g., adult led flow, child led flow, balanced turn-taking, biobehavioral states, self-regulation, and motivation), Space (place, size, inward and outward focus, orientation and mobility,) and Time (e.g., rhythm, anticipation, patterns, and timing) as a context for teaching academic, adaptive, and social skills during creative dance lessons to students with sensory impairments. First, workshop participants will learn the specific concepts associated with each dance element and strategies for using the concepts to support functional skill development for students who are deafblind. Next, case studies with video will be presented to exemplify ways in



which BEST can be used to teach concept development and social skills during creative dance classes. Finally, participants will practice using BEST as a context for teaching academic and social skills through creative dance lessons for students who are deafblind.

Abstract No. 5.8

Wednesday 6th September 2017 at 14:15-15:00

**Title: Research programme Communication and Deafblindness: Overview and new research**

Presenter: Marleen Janssen, University of Groningen, The Netherlands  
Co-presenters: Saskia Damen

Main focus: Both research and practice/Congenital deafblindness

Abstract: Three ongoing PhD projects focused on communication and language in people with congenital deafblindness (CDB). A short overview will be given: Bodily Emotional Traces in intervention (Bloeming-Wolbrink, in progress); Follow-up Model for Communication (Wolthuis, in progress) and Fostering Influence in Communication and Language.

In earlier studies we found that few people with CDB were able to communicate at an advanced level, using symbolic communication to share thoughts and ideas and communicate about past events. Furthermore, we found that support partners often communicated at levels lower than that of the person with CDB (Damen et al., 2015). Our new research focuses on advanced levels of communication and on agency in tactile bodily communication and tactile sign language (Janssen & Damen, proposal 2016).

The main questions in this new project are:

- Is use of the intervention associated with an increased agency in communication by people with CDB?
- Is use of the intervention associated with enhanced communication and language use between people with CDB on the one hand and support partners on the other?
- How do communication coaches implement core components of the program with regard to fidelity and how well are they able to apply different coaching forms live and on-line?

Because we are at the start of the project, we want to show some video recordings and discuss with the audience the following points:

1. Are the chosen categories for agency in communication the right ones: initiative in directing attention, making choices, initiating topics of conversation, aspects of negotiation?
2. Can the intervention be improved with regard to competences of the people with CDB, partner competences and dyadic aspects?
3. Do you have experience with on-line coaching, and can you advise us?

Abstract No. 6.1

Thursday 7th September 2017 at 14:15-15:00

**Title: From thoughts to language to reality - getting closer to social connectivity**

Presenter: Sabine Brink and Ole Wøssner, CFD - Døvblindehuset, Denmark  
Co-presenters: Tanja Nyons  
Litte Frehr

Main focus: Both research and practice/Both congenital and acquired deafblindness

Abstract: About a year and a half ago, a young woman came to our facility; she moved into her own flat in a single dwelling, as for years she has been unable to socialize with others. She has acquired deafblindness due to Usher Syndrome, type 1, and since she was about seven years old she has displayed a high degree of psychotic and hallucinatory behaviour. To a considerable degree, this behaviour has locked her into a rigid pattern that has also caused her to be mentally and socially stuck and isolated. We soon realized that she has a considerable potential for developing her sign language, which in our assessment has been insufficiently stimulated during the past two to three years. When she interacts with deaf members of staff, we see a very communicative and interested young woman, who is keen to engage in conversation, but who is also very rigid and repetitive in her topics of conversation.

In October 2016, we launched a project aimed at assessing, developing and expanding her sign language capacity in order to have the opportunity to speak with her about the situations and periods when she is psychotic and hallucinating as a way of enabling a cooperative effort to build a more nuanced and stable linguistic platform capable of externalizing her mental disorder.

We wish to acknowledge what she experiences while also holding on to reality by communicating that we do not see what she sees, that it is not real – and, if possible, offer tactile stimulation to help her distinguish between real and not-real.

With regard to her sign language, we will also be working on externalization by synchronizing our communication and assigning specific signs to her psychosis to enable it to be expressed. We aim to facilitate her ability to engage socially and express her thoughts, feelings and concerns. This would allow her to work with her partner to develop a closer grasp on reality and lessen her psychosis – facilitating social connectedness. We will involve sign language interpreters in the assessment of her sign language skills; specifically, we will look up to the experiences from the pilot project on congenital deafblindness and sign language interpreters under the Danish National Board of Health and Welfare. Moreover, psychologist Litte Frehr of the CFD will provide supervision throughout and coordinate the communicative intervention strategies.

In a sense, thus, the project has two – complimentary – tracks; 1) as we aim to assess and develop her language in order to equip her with new words and concepts, 2) so that she can describe and share her psychotic experiences, which in turn would allow her to develop a higher degree of closeness with the real world and her partners – ideally, eventually, also with other residents in our facility.

The project runs until June 2017, so at the workshop we will be able to present our results – including video recordings documenting the process and the assessment and



development of communication as well as a brief report on the project in whole, including the project hypothesis, objectives, evaluation and conclusion.

Abstract No. 6.2

Thursday 7th September 2017 at 14:15-15:00

**Title: Adult children of parents living with Usher syndrome: Experiences across the life span**

Presenter: Karen Wickham, Senses Australia, Australia

Main focus: Both research and practice/Acquired deafblindness

Abstract: In this presentation I will share the experiences, challenges and reflections of children being raised by parents living with Usher syndrome and dual sensory loss, across the life span. Participants will share stories from different stages of their lives: childhood, adolescence and adulthood. Through this research we hope to identify particular themes and issues that are commonly faced by children of parents with dual sensory loss, with a view of comparing and sharing experiences and helping to raise awareness about the challenges and the triumphs experienced on this unique journey. Along with aiding organisations to provide superior, inclusive support long term to families and advocacy for more relevant support services for the Deafblind community. This study builds on the presenter's previous research on parenting and Usher syndrome.

Being the child of a parent or parents living with Usher syndrome presents some unique challenges and opportunities. Some studies have indicated that children of parents with a disability can develop positive skills and qualities that are absent in other children. However, research also clearly indicates that when inadequately supported, carers' physical, mental health and wellbeing can be jeopardized. Young carers can worry about the health of the person they care for, their own health and who will look after them in the future. Many teenager carers express a sense of isolation and alienation from their peers because the caring role varies considerably from more typical adolescent experience. Caring responsibilities can interrupt education and make the transition from home to independent living difficult. High numbers of adult carers reported on the negative effects on physical, mental and emotional health; and many said that caring work had taken a toll on personal relationships and limited their life choices including restrictions in their ability to take part in paid work, education or other career opportunities. The hearing children of Deaf parents have a unique experience as bicultural and bilingual members of the Deaf community, they are the critical link (interpreters and cultural mediators) to the hearing world, regardless of their age. They are a source of information, a spokesperson for the family and consequently some can grow up feeling that they have been deprived of a childhood.

This study uses qualitative analysis of 13 semi-structured interviews and has been approved by the Edith Cowan University Human Research Ethics Committee. Through this research we are interested to learn the participants' perspective of taking on the carer role, in whatever context that appears within individual families, and how this experience impacts on aspects of their lives, their relationships, and their mental, emotional and physical wellbeing across the lifespan. Drawing on this new research, specific to the



Deafblind community, we will also examine what are the implications for practice and future research in this area.

Abstract No. 6.3

Thursday 7th September 2017 at 14:15-15:00

**Title: Autonomy support for students with congenital and acquired deafblindness: how can it be assessed and addressed?**

Presenter: Ineke Haakma, University of Groningen, The Netherlands

Main focus: Mainly research/Both congenital and acquired deafblindness

Abstract: In this workshop, I will discuss the key role autonomy plays in the education of students with congenital and acquired deafblindness. Autonomy refers to having the opportunity to make your own choices and to express your own ideas. Autonomy is often linked to a host of positive outcomes, including higher quality of learning.

I have conducted five studies on the interactions students with congenital or acquired deafblindness have with their teachers. These studies examined the ways in which teachers foster students' psychological needs to feel autonomous, competent and related to others. These three needs determine the extent to which people flourish, are satisfied and experience personal well-being.

In the classroom, these three psychological needs determine a students' motivation to learn. Teachers of students with congenital and acquired deafblindness find it less difficult in making students feel competent and related to others. However, they often find it more difficult to support autonomy. Therefore, in this workshop I will highlight how to support autonomy in the classroom with students with deafblindness.

I will start this workshop by explaining the concept of autonomy as described in the theoretical framework of Self-Determination Theory. Thereafter, I will explain how an observation scheme was developed and used to assess teachers' autonomy support and students' motivation. Furthermore, I will briefly present the coding procedure, interpretation of the coded data, results and the implications of the findings. Additionally, I will focus on two essential questions: What makes it so difficult for teachers to provide autonomy support?; What are the possible ways to make it easier for teachers to provide autonomy support in order to make students with deafblindness feel more autonomous in the classroom?

Abstract No. 6.4

Thursday 7th September 2017 at 14:15-15:00

**Title: My isolation makes me fear that I'll forget how to communicate**

Presenter: Rikke Norup Christiansen, CFD Rådgivning, Denmark  
Co-presenters: Karin Moreau Andersen and Malene Kure Strandkvist

Main focus: Mainly practice/Acquired deafblindness

Abstract: "My isolation makes me fear that I'll forget how to communicate"

The number of elderly people increases and more and more people are living longer. Therefore the number of elderly people who have both vision impairment and hearing loss are increasing. We can see how welfare systems around Europe are under a lot of pressure. How do we ensure, that the general perception of people suffering from both vision impairment and hearing loss is different from people "just" getting old. Working professionally with this particular group of (elderly) people, it's important for us to describe their special needs.

Elderly with acquired deaf-blindness can only benefit from the same activities as other elderly if their deafblindness is taken in consideration and necessary initiatives are taken. In order to achieve better circumstances for the elderly with acquired deafblindness the deafblind consultants in Denmark are offering advice and education to their family as well as their official caregivers in care homes and home care. Knowledge of the consequences of acquired deafblindness as well as knowledge of how to interact on behalf of this knowledge can lead to a more meaningful life not only for the person with acquired deafblindness but also the surroundings.

For this workshop you will meet two elderly deafblind citizens describing some of the challenges of their everyday life. "My isolation makes me fear that I'll forget how to communicate" – says one of them; the 85 year old man, staying at a nursing home. The workshop will also give you an insight into what kind of advice and education we provide to professionals working with our deaf-blind citizens.

For caregivers, it may be difficult to assess how much citizens can see and hear. The consequences of sensory loss may vary from each situation or from day to day.

Questions occur: How do you interact and communicate with a person who is functionally deafblind - to secure participation and avoiding misunderstanding?

Why don't they participate in activities or why do they withdraw (resign) from activities after a while? Is it possible to change this situation? Isolation is a consequence of lack of touch of closeness and maintaining social connectedness. What are the consequences of isolation?

The aim of the education for caregivers is to supply the caregivers with knowledge of acquired deafblindness and an understanding of the impact the acquired deafblindness can have on daily life. Focusing on how consideration can enable touch of closeness and maintaining social connectedness.

To simulate the impact acquired deafblindness can have on people the participants are blindfolded and hearing-impaired at the beginning of the sessions and during some educational exercises.



The sessions vary in length and content according to the wishes of the participants but mostly include presentation referring to (if any) known people with acquired deafblindness, exercises and discussion.

Relating the topic to people known to the caregivers makes the topic recognizable, crucial and meaningful.

Abstract No. 6.5

Thursday 7th September 2017 at 14:15-15:00

**Title: Come to shared knowledge in 1 day!**

Presenter: Sonja van de Molengraft, CRESAM, France  
Co-presenters: Guillaume Ferron  
Séverine Clément

Main focus: Mainly practice/Congenital deafblindness

Abstract: CRESAM, national resource centre of deafblindness in France, provides advice, support and training to individuals and their families and friends, and to professionals, on all issues regarding deafblindness.

With this workshop we would like to explain our observation programme. The main aim of this programme is to find (new) skills and abilities of the individual with a multi-sensory impairment.

Each individual, each situation has his/its own specific needs and in some very complex cases we advise to do an observation at CRESAM. A specialist staff, consisting of different disciplines (orthoptist, eye-specialist, psychologist, practitioner of Feldenkrais, other specialists) will be put together.

We offer an observation programme in a neutral setting, a normal house in a normal residential neighborhood. This area has nothing to do with institutions or hospitals and therefore visitors feel comfortable pretty fast and so we create different conditions:

1. A new environment can already evoke different emotions and actions of the individual. The individual will have to adapt to a different situation, and (new) skills can be observed.
2. The family has already a great knowledge and experience with the individual. They have developed a routine together and because of that sometimes the potentials of the individual are not recognized. By inviting the family to a neutral setting they lose the routine and so they are obliged to invest in the relationship.
3. By inviting professionals to a neutral setting we experience that they are more engaged. They don't get distracted by other work-related issues, and so there is a greater focus on the individual.

We experience that a neutral setting creates a dialogical platform in which all partners are equal. They are all challenged to adapt to a new situation, the routine is broken. They are all willing to learn to see the potentials of the individual. Parents share their knowledge with the professionals, and vice versa. From here on we co-construct knowledge and we will come to shared knowledge.

In general, the programme lasts 1 day, it is adapted to each individual and his partners. There will be several tests during the day with the individual. Family and professionals are present also and can witness and participate the different activities of the specialist staff. At the end of the day there will be a moment where all participants exchange their experiences of the day, connections will be made with the past and new skills are discovered, new skills that were maybe already there but never seen or shared before. We experience that in general the results of an observation programme offer shared meaning between the families and professionals which contributes to the wellbeing of the individual!



Touch of closeness  
maintaining social connectedness

Abstract No. 6.6

Thursday 7th September 2017 at 14:15-15:00

**Title: Trapped In Deafblindness – The Story of A Man with Acquired Deafblindness**

Presenter: Anette Kjær, CFD Councelling, Denmark

Co-presenters: Jette Mistegård Jørgensen

Main focus: Mainly practice/Acquired deafblindness

Abstract:

“I wish I could communicate with my surroundings and that my surroundings know how to communicate with me.”

We would like to tell you a story of a man who was born with Usher type 1. He was born profoundly deaf and he lost his sight when he was in his fifties. Now at 79 years of age, he is both deaf and blind and with a longing for interactive communication and social engagement.

His isolation is almost complete as people around him do not know how to communicate with him. His caretakers do not know how to sign and his lack of information of what is going on in the world, makes it difficult for him to understand, should somebody know how to communicate with him.

He experiences multiple psycho social consequences of living, such as frustration, depression and powerlessness.

In Denmark people are considered equal and are to be offered equal opportunities to realize their full potential.

This is proclaimed in the United Nations Convention on Rights of People with Disabilities and is also an important aspect of the social legislation and the overall healthcare system in Denmark.

That is what we like to think, but is it the truth?

It is both in the interest of society and the individual to live up to these values and it is expected that we all do our best to search for and use these possibilities.

Communication is a key word regarding individual welfare and identity. Persons, with severe progressive loss of sight and hearing who wish to be active citizens on equal term with every other citizen may not be able to be so due to serious communicational barriers. Dependence on others limits any chance of spontaneity and decreases the opportunity of living an ordinary life. We all want to control our own lives regardless of deaf blindness or other disabilities.

With a loss of sight and hearing it is not unusual for a person to feel isolated and alone.

Therefore it is of vital importance to be able to communicate with your surroundings.

However this is often difficult for people with severe progressive loss of sight and hearing because of lack of able communicators in their lives.

We want to discuss how we can give information to the environment in order for others to want to and to be able to communicate with a person with acquired deaf blindness.

Abstract No. 6.8

Thursday 7th September 2017 at 14:15-15:00

**Title: Health and people with Usher syndrome, need for biopsychosocial approach**

Presenter: Moa Wahlqvist, Audiological research centre, University hospital of Örebro, Sweden

Main focus: Mainly research/Both congenital and acquired deafblindness

Abstract: To live with deafblindness can be challenging for several reasons and its implications for interaction with others and with the surrounding environment can be vast. People with Usher syndrome constitute the largest group of individuals under the umbrella term of deafblindness. People with Usher syndrome have a congenital hearing loss to varying degrees and a progressive eye disease, balance is also affected in some persons. Three clinical groups of Usher syndrome have been identified named 1, 2 and 3, and 13 genes have been disclosed. The progression of Usher syndrome means that over the life course there is a need to adjust to new everyday life situations. Clinical knowledge and limited research that exists have shown that people with deafblindness experience difficulties in everyday living, including problems with anxiety, depression, social withdrawal and communication breakdowns. The aim of the presentation is to discuss the importance of a biopsychosocial approach when describing health for people with deafblindness, here with the example of health for people with Usher syndrome.

The empirical material employed was based on an extensive survey in which people with Usher syndrome, all three types included, answered two questionnaires concerning health, anxiety, depression, social trust, work, health-care, financial situation, and alcohol and drug use. The focus was on general health, physical health and psychological health, social trust and financial situation.

The results revealed poor physical and psychological health, a lack of social trust and a strained financial situation regardless of clinical diagnosis and in comparison with a reference, a cross-section of the Swedish population. People with Usher syndrome reported high frequencies of fatigue, headache, different kinds of pain in back, neck and shoulders, suicide thoughts and suicide attempts. Furthermore social problems in terms of being afraid to go out alone, lack of general trust in others, having no one to share innermost feelings and confide in and having no one to ask for help when needed was revealed.

At the workshop different theoretical perspectives of health will be addressed and the discussion will stress the importance of taking a biopsychosocial approach when describing the health of people with USH, in which previous research is lacking. If a biopsychosocial approach is not considered there is a risk of reducing the complexity of living with a progressive condition such as Usher syndrome.

Abstract No. 6.9

Thursday 7th September 2017 at 14:15-15:00

**Title: A guide for supporting people living with deafblindness through their palliative journey**

Presenter: Lorraine Simpson, DeafBlind Ontario Services, Canada

Main focus: Mainly practice/Both congenital and acquired deafblindness

Abstract: The purpose of the guide is to educate, support and inspire intervenors/support teams who may be supporting a person living with deafblindness on their palliative journey. The need to understand what is happening at different stages will assist those to provide the best possible care. It will also help the people who are living with congenital deafblindness to better understand what is occurring at these stages on their journey. This presentation will also include discussion on using a Palliative Performance Scale (PPS), which assists the person and the intervenor/support teams to make choices and decisions in four areas: activity, intake, self-care and ambulation. Also included are examples of basic options to allow the client to actively participate in relaying information about their current state in the PPS scale.

We will demonstrate how the guide speaks to inclusion, support, end of life decisions, and the close relationship between the intervenor/support teams and the person living with deafblindness. In addition, familiar terminology with terms and working as a team and what to expect during and after a life limiting illness.