

Poster

**Title: Aspects of learning in deafblindness - opportunities and limitations for persons with Alström syndrome**

Presenter: Berit Rönnåsen, Specialpedagogiska skolmyndigheten, Sweden  
Co-presenters: Kerstin Möller<sup>1,2</sup>, Claes Möller<sup>1,2,3</sup>, Björn Lyxell<sup>3</sup> and Agneta Anderzen-Carlsson<sup>1,2</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/Both congenital and acquired deafblindness

Abstract: Purpose: The aim was to explore aspects of learning, from a lifelong perspective, in individuals with Alström syndrome (AS). AS is an autosomal recessive disorder causing early blindness, progressive sensorineural hearing loss, cardiomyopathy, endocrine disorders, metabolic dysfunction, and abbreviated lifespan.

Method: Eleven individuals with AS participated. The study had a qualitative explorative design, giving voice to the participants' perspectives on their situation. Data were collected using semi-structured interviews, which were subjected to conventional (inductive) qualitative content analysis.

Results: The analysis revealed in the participants a quest for independence and an image of themselves as capable people willing to learn, but in constant need of support to continue learning throughout their lives to be as independent as possible.

Conclusion: Based on the levels of functioning, i.e. personal resources, revealed in the interviews, supervisors, caregivers, and teachers are encouraged to allow people with AS to be their own advocates, as they know best how, what, and with whom they learn, and what type of sensory material – tactile, auditory, visual, or a combination – is most helpful.

Poster

**Title: Developing social connectedness through physical activities**

Presenter: Anders Martin Rundh, Centre for Deafblindness and Hearing Loss (CDH), Denmark

Co-presenters: Mads Kopperholdt (Center for Deafblindness and Hearingloss)  
Marijke Bolwerk (Royal Dutch Kentalis St. Michielsgestel)  
Lotte van de Weem (Royal Dutch Kentalis St. Michielsgestel)

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

Abstract: Subtitle: An international project between schools for children with deafblindness and multiple communicative impaired children.

In this presentation we want to inform you about an international project between Denmark and the Netherlands, concerning Adapted Physical Activities (APA). This project convinced us, and we hope it will convince you, of the importance and possibilities to focus on social interaction and communication between children with deafblindness during physical activities. In our project, we have seen that during those activities it is possible to create an ideal environment to work on social interaction and communication between children, which can be seen as an important base of social connectedness. You will go home inspired and with proved practical tools to take with you for using in your own practice.

**Summary**

In deafblind education interactions are often between a student and his or her adult communication partner. One of the reasons for this is that children with deafblindness need sensitive responsive communication partners to be able to develop. The focus on (the development of) social interaction and communication between the children with deafblindness is often limited. This is a shame, because, as all other children, children with deafblindness will surely benefit from contacts with their peers. It will have a positive effect not only their communicative development, but also their cognitive and social-emotional development.

Communication between children with deafblindness is not self-evident, they need help from their communication partners for this. In our APA project we help the children by creating a safe and inspiring environment with possibilities to meet and develop social interaction and communication with other children.

In this presentation we will share our experiences about the project. The first part of the APA-project started in 2011 and ended in 2013. It was a collaboration between Sweden, Denmark and the Netherlands to explore the possibilities of social development in physical activities. In 2016 Denmark and the Netherlands decided to start a follow up project to make our ideas about social connectedness in APA classes more evidence based. At this moment, both countries have weekly APA classes in which we create as



many social interaction situations as possible, embedded in the physical activities. The results of this project we will measure through dynamic assessment, in which we will focus on the development of the children and the effect of chosen partner strategies. At the time of the Conference we will be halfway our project and will share the first outcomes with you.

Poster

**Title: Early Steps for Speech Development in Congenital Multi Sensory Impairment**

Presenter: Eva Magdalena Oprea, „Cristal,, School Centre for Inclusive Education, Romania

Main focus: Mainly practice/Both congenital and acquired deafblindness

Abstract: Many children with multi sensory impairment have also brain injury. They have difficulties in moving their arms or legs, their tongue in the mouth or swallow their saliva. They can understand what people talk to them, but they can not answer because of their physical difficulties. Parents have difficulties to communicate with their children and ask support from specialists for improving their relation with the child.

In my presentation I would like to introduce a young boy who have all the difficulties I mentioned above. He can understand many words he hears, but he can not answer. He can not control his movements and he can not see very well, so he is like a prison in his body. The presentation is mainly focused on practice. I will present a touch based stimulation method who can help the child to swallow and move his tongue better. Improving tongue's movements will lead to a further speech development.

All these can lead to a better communication, a better social interaction and a better life.

Poster

**Title: Deafblindness connecting people on Facebook**

Presenter: Marcia Noronha de Mello, Instituto Benjamin Constant, Brazil  
Co-presenters: Bianca Della Líbera

Main focus: Mainly practice/Both congenital and acquired deafblindness

Abstract: Effective communication and professional development concerning deafblindness are still inconsistent in Brazil, and since people from different parts of the country are not closely connected, they have few opportunities to share experiences and practices. I am part of a group called Grupo Brasil (Brazil Group), which develops many initiatives in the field of deafblindness in our country. In order to raise public awareness about deafblindness, in 2016 the Group launched a campaign called “White and Red November”, and we agreed that a good way to boost the campaign was using social networks. We then signed up for Facebook, Twitter, Instagram and YouTube to cater for different kinds of social network users; however, Facebook is the network we have been working on the most, for it reached a greater number of people. The campaign took place throughout the month of November, and different groups from different parts of Brazil organized a series of activities. We used the social networks to advertise for these activities, which included in situ and online lectures, seminars and cultural activities, and to show what happened during the campaign. Because our Facebook fan page ([fb.com/surdocegueirabrasil](https://fb.com/surdocegueirabrasil)) got almost 200 likes in less than 24 hours and now, after three months of its launch, we got more than 500 likes, we decided to continue using it, along with the other social networks. In order to do so, we conducted a brief survey to have a more detailed profile of our fans and a better idea of what sort of information they expect to get from the page. Our public comprises people with both congenital and acquired deafblindness and their family members, different types of professionals who work with them, and people interested in the field. Followers are most interested in communication processes, language acquisition, professional development (many asked about specific courses for guides), and pedagogical and medical issues. There are also those who are interested in the research field, looking for study groups and research groups within our country. Considering these results, our aim now is to bring people together around deafblindness, making available to the public more accurate information about the condition itself, the life of people with deafblindness, professional development resources and academic research in the field.

Poster

**Title: Implementing Social Haptic Communication in the Netherlands. Partnership in development and training**

Presenter: Marga Martens, Royal Dutch Kentalis, The Netherlands

Main focus: Mainly practice/Acquired deafblindness, Both congenital and acquired deafblindness

Abstract: In the past few years Social Haptic Communication (R. Lahtinen, 2008) was introduced in the Netherlands by its developers Riitta Lahtinen and Russ Palmer. The participants who followed the workshops on Social Haptic Communication (SHC) were enthusiastic about the benefits of this holistic way of communication. But it is sad that Dutch potential users are still not acquainted with SHC and it is therefore not broadly used among them.

Striving to a more common use of SHC between people with deafblindness and their communication partners, professionals from four Dutch organizations started a shared project on SHC. The aim of the project was twofold, a) incorporating touch and environmental information during daily communication with people who are deafblind, for people with acquired deafblindness and for people with congenital deafblindness and b) using the expertise of people who are deafblind. To reach the project's aim, in a first phase a basic course in SHC was developed focusing on people with acquired deafblindness. The course includes the theoretical background and the training principles of SHC. Also a team of trainers was composed in which the trainers work in pairs including a person with deafblindness and a hearing-seeing partner. In a second phase of the project, the project group wants to investigate how people with congenital deafblindness may profit from (parts of) SHC.

In this presentation we will have a closer look at the shared project. We will

- illustrate the steps made during the process, in particular the cooperation between the experts with deafblindness and seeing-hearing professionals;
- share the issues discussed such as determining Dutch signs for the term SHC and the accessory terms Haptices and Haptemes;
- explaining concepts and principles for training;
- show the developed study material for lectures and participants.

We will invite participants to share tips and tops about working effectively and efficiently in own shared projects between people with deafblindness and seeing-hearing professionals. We are also curious if the principles of SHC are used with people with congenital deafblindness before. And if so, how? If not, why not?

Poster

**Title: Water Motion as a platform for Intensive Interaction**

Presenter: Nikolina Juric Tanfara, Special Education Teacher, Croatia

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Main focus: Both research and practice/Congenital deafblindness

**Abstract:** Following the child's interests and creating motivating settings are one of the main principals of Intensive Interaction. Our aim is to define influence of a therapeutic approach such as Water Motion on development of pre-intentional and intentional communication in students that are highly motivated to be in water. To our knowledge Water Motion, a practice that uses elements of WaterDance which is a dynamic movement therapy above and below water, hasn't been used with students with deafblindness.

In this research, we introduce the use of Water Motion as a frame and responsiveness in interaction with students in warm water pools. In our case, Water Motion is an interaction of teacher and a student. It is an activity that provides the opportunity for developing a trusting relationship through touch and closeness resulting from skin on skin contact. We describe two case studies with young adults with congenital deafblindness, and show the differences between baseline and final measurements in several key aspects of Intensive Interaction. Observed aspects are frequency of eye contact, physical contact and non-verbal communication for the first student, and shared attention, prolongation of directed attention and turn taking for the second student.

In this project 10 individual sessions will take place, each lasting 45 minutes, on a weekly basis. Teacher uses elements of Water Motion to provide pleasant experiences as a response to students' behavior respecting principals of Intensive Interactions. Measurements will be conducted by two blinded assessors from video analysis. We expect this project to show possible appliances of Water Motion as a novel therapy within an activity based curriculum.

Poster

**Title: Perceptions of social networks by adults who are deafblind**

Presenter: Katrina Arndt, St. John Fisher College, USA  
Co-presenters: Dr. Amy Parker

Main focus: Mainly research/Acquired deafblindness

Abstract: The presentation will include a discussion of study methods and three main findings. Theoretical frameworks that influenced the study are grounded theory and phenomenology, with additional influence from the constructivism paradigm. Grounded theory had significant influence on our decisions about coding the data after collection, and informed our decisions around using open and axial coding. A phenomenological perspective shaped the ways we considered what data sources were valid- were closest to participants' actual experiences- and this affected our interest in collecting traditional demographic data. Not least, a constructivist paradigm influenced all decisions throughout the study as we attempted to understand how the reality of being deafblind shaped participants' experiences.

Guerette and Smedema (2011) call for the collection of open-ended data to provide information about the quality of social support received by adults with visual impairments. In a study of the challenge of reestablishing social relationships after vision loss, Wang (2008) noted that in-depth qualitative inquiry is important "because quantitative methods aren't limited in their ability to reveal the richness and complexity of these experiences in people's lives" (p. 817). The methods we chose, 1:1 semistructured interviews, follow-up e-mails, and a closed discussion board, is one response to the need for rich, open-ended data.

In-person semistructured interviews, follow-up e-mails, and a closed discussion board were used to gather and triangulate data. After the retreat, participants were invited to continue the conversations on a closed discussion board; of the 10 participants who were interviewed, 2 responded. A final data source consisted of relevant e-mails from individual participants.

Ten attendees at Retreat were interviewed, and pseudonyms are used for all participants. The participants ranged in age from 26 to 62 years and included 5 men and 5 women, all deafblind. The participants were a bounded group: All went to Retreat, which indicated either the financial wherewithal to attend, support from a network to attend, or both.

Three themes were extracted from the data: (a) the importance of navigating adaptations; (b) the existence of significant gaps in support from family members, accommodations by employers, and access to resources; and (c) the necessity of resiliency and advocacy for managing gaps. Each theme affected many areas of daily life.



After a review of the methods and findings, a discussion will be facilitated by presenters about two major topics: 1) how touch functions as resilience and 2) the emergence of Pro-Tactile communication has emerged in the United States. The workshop will end with discussion of community led initiatives and how those initiatives support social connectedness.

Reference: Arndt, K. & Parker, A. (2016). Perceptions of social networks by adults who are deafblind. *American Annals of the Deaf*, 161(3), p. 369-383.

Poster

**Title: Health care consumption in infants with CHARGE syndrome - a case-study**

Presenter: Agneta Anderzén Carlsson, Audiological Research Centre, Örebro University Hospital and SIDR at Örebro University, Sweden

Main focus: Mainly research/Congenital deafblindness

Abstract: Purpose: To describe health care consumption during the first year, in a Swedish sample having CHARGE syndrome.

Background: CHARGE syndrome is characterized by impaired vision and hearing, as well as physical malformations. In Sweden, approximately 1 per 10,000 newborns is diagnosed with CHARGE syndrome. Previous studies have reported etiology and various malformations related to CHARGE syndrome and the treatment (hearing and vision aids, medication) provided. However, no study focusing on the healthcare consumption related to the identified malformations has been identified.

Methods: Through the medical records of four males and one female, born in Sweden between 1978 and 2005, the health care consumption was calculated in terms of number of hospitalizations, diagnostic procedures, pharmacological treatments and multi-disciplinary contacts.

Results: The median age of the suspicion of a hearing impairment was 6 weeks. It was confirmed between the age of 6 weeks and 10.5 months (md= 5 months). The age at which the coloboma(s) were diagnosed varied. However, in all but one case it was identified within the first 4 weeks. The infants were hospitalized 26-230 days (md = 113), subjected to 10-34 (md = 20) different diagnostic procedures and prescribed 10-28 (md = 14) different medications during their first year. In addition to the primary pediatrician 8 to 11 (md = 9) medical specialties were involved in care. The findings highlight CHARGE syndrome as a highly complex medical condition, leading to a significant consumption of health care during the first year in life.

Conclusion and clinical suggestions: A cooperation of the infant and her/his parents is essential for successful healthcare interventions. From a parental perspective integration and coordination of care between specialists could improve daily life for these families. From a child perspective it is important to individually support the infants with CHARGE syndrome in their health care contacts, as their dual sensory loss makes it difficult for them to understand the world around them. Tactile stimuli such as the use of a pacifier, swaddling, rocking or skin-to-skin contact with a parent could be encouraged for the infant in order to decrease discomfort and pain during procedures. Likewise a small amount of oral sucrose could be worth trying for infants not affected by severe swallowing problems.

Poster

**Title: Towards common ground: supporting social connectedness through self-regulation**

Presenter: Gro-Anita Tunes, Statped, Norway  
Co-presenter: Evabritt Andreassen  
Main focus: Mainly practice/Congenital deafblindness

**Abstract:** This poster gives a case description of how a consultant team helped support the social connectedness of a person with congenital deafblindness through a self-regulation based intervention. Self-regulation may be defined as the capacity to manage one's own thoughts, actions, feelings and physiological states in adaptive and flexible ways across a range of contexts.

Ole is a 50-year-old deafblind man who has been living in residential homes almost all his life. However, during the past few years the staff reported difficulties related to psychosocial and behavioural issues, such as self-injurious behaviour, episodes of angry outbursts and aggression towards staff. Signs of decreased mood and social isolation were also reported. The staff felt unsafe around him and they started to interact and communicate lesser with him, thus a negative loop developed.

Together with the staff, the consultant team initiated a self-regulation based intervention. This intervention focused on understanding the reported behavioral challenges as self-regulation difficulties, especially Ole's emotional self-regulation. Hence, the reported behavioral challenges could be associated with his emotion dysregulation. Furthermore, his emotion dysregulation in turn may lead to increased social isolation, escalation of aggressive-disruptive behaviors and high levels of negative affect such as decreased mood. In this line of understanding, we used a behavioral assessment scale of self-regulation (KSF-DB; Nicholas, Andreassen, Broddstedt, Møller-Hermansen, Rieber-Mohn, Simonsen & Sjødell, 2015) to capture the Ole's self-regulation problems and subsequently implemented a self-regulation intervention involving both Ole and his staff.

The assessment helped us target the intervention in a specific manner. During the intervention, we supported the staff on how they could support Ole's communication development and how they could meet his emotion dysregulation. The main focus was to understand Ole's ability to respond to the ongoing demands during his daily life experience with the range of emotions in a manner that is socially tolerable. The base of the intervention was to guide the staff to identify Ole's emotional expression and his communication pattern through video analysis. We supervised the staff on how to best confirm his emotional state or expressions, primarily in the bodily-tactile modality, but also with visual signs.

During the intervention process, the staff reported a decrease in Ole's behavioural challenges. He appeared to be more socially close to his staff and his anger outbursts



had declined. In other words, Ole and his staff were now in a positive loop. He showed more initiatives to interact with the staff and his communication skills had improved. This poster will focus on the practical procedures, the applied assessment tool and on how the consultant team had supported the staff during the intervention. The poster will illustrate how a self-regulation based intervention had helped a man with congenital deafblindness to form relationships with others, while giving him a feeling of being in a close, interpersonal, meaningful and positive social relationship with others.

Poster

**Title: Applying Social Impact Assessment methodology at Lega del Filo d'Oro**

Presenter: Patrizia Ceccarani, Lega del Filo d'Oro Onlus, Italy  
Co-presenters: Vurro C. (1), Romito S. (1)  
(1) Department of Management & Technology, Università  
Commerciale "L. Bocconi", Milano, Italy

Main focus: Mainly research/Both congenital and acquired deafblindness

Abstract: Building on recent advancements in the field of measuring effectiveness in social sector organizations, our study applies social return on investment (SROI) approach to the intervention model of Lega del Filo d'Oro (Italy) with the aim of quantifying in monetary terms the value created for its direct beneficiaries, their families and the whole territorial community in which the organization is embedded.

Pressured by internal and external demand for evaluation tools to exercise accountability on how resources have been used and results achieved, third sector organizations are increasingly experimenting with impact evaluation of the service they deliver for the direct beneficiaries and all the other stakeholders involved.

It is in this context that there is a growing interest in social return on investment (SROI), conceived as the process aimed at translating into monetary value the ability of an organization to produce a tangible, durable change in the life of people benefiting from a certain action in a given field of intervention.

In accordance with the basic principles and typical steps in a SROI process, our project started with the identification of key stakeholder categories who are currently benefiting from and/or contributing to the realization of the social mission of Lega del Filo d'Oro, that is, to provide assistance, education and rehabilitation of the deaf-blind and multisensory impaired, as well as his/her integration into the family and society. Out of a more comprehensive list of categories, we decided to focus on direct beneficiaries and their families, employees, and local community as primary stakeholders to start with in this experimentation.

Then, causal relationships between activities and impacts were identified based on in-depth consultation with key internal and external informants (e.g., parent association representatives, medical doctors, staff and members of the management team). As a result, a questionnaire was developed and sent to families having benefited of the services by Lega del Filo d'Oro between 2014 and 2016. The questionnaire was meant to capture the differential impact of Lega del Filo d'Oro on the quality of life of families, by comparing their perceptions on multiple areas before and after starting their relationships with the organization. Secondary data were collected to quantify the impact of Lega del Filo d'Oro on employees and the local community. In this regards, impact areas were

related to the value of professional training received by employees, the increase in volunteering attitude at the community level, the incremental value of the knowledge transferred to local institutions and organizations related to the social inclusion of deaf-blind and multisensory impaired, and the increase in the volume of economic activities in the regional area.

The study offers insights into methodological and procedural aspects of quantifying the impact of interventions models for deaf-blind and multisensory impaired. Key issues explored include the quantification of benefits in areas where qualitative measures and storytelling still prevails. Beyond measuring results, this research project shows the feasibility of applying such a methodology even in multi-faceted, complex contexts.

Poster

**Title: Can work promote social connectedness and better health?**

Presenter: Mattias Ehn, Audiological research center Örebro University, Sweden

Main focus: Mainly research/Acquired deafblindness

**Abstract:**

Introduction: Research have demonstrated that persons with Usher syndrome have significantly poorer physical and psychological health compared to a reference group. There are however health differences within the Usher group where some persons showed better health than others. Recent reports reveal that work is an important factor associated with better health in persons with Usher syndrome type 2. In this study we have focused on persons with Usher syndrome type 1 (USH1), a group of persons with profound deafness and their health in relation to work activity.

Purpose: To explore the relation between health, social trust and financial situation in persons with USH1.

Material: The participants 67 (18-65 y) from the Swedish Usher database received a questionnaire and 47 persons were included in the study, 23 work active and 24 non-working (unemployed, on sick leave or disability pension).

Methods: The Swedish Health on Equal Terms questionnaire, covered health, living conditions, work, social relationships, financial situation among others. The questionnaire was translated to sign language and made accessible for braille readers.

Results: The USH1 work and non-work groups displayed significant differences with poorer physical and psychological health in the non-work group. The non-work group reported more problems with social trust, ontological insecurity and financial problems. Age, gender, hearing and vision impairment did not explain the differences.

Conclusions: Work can be crucial to reduce severe health problems in persons with USH1. Persons with USH1 have severe problems with physical and psychological health. These health problems as well as social trust, ontological insecurity and financial problems are increased in persons with USH1 who are not work active. Work is an important factor enhancing the social connectedness and perceived health in persons with deafblindness. This stresses the importance of early intervention of vocational training and work related rehabilitation.

Poster

**Title: The Power of Volunteers**

Presenter: Anya Rakoczi, Sense, United Kingdom  
Co-presenters: Sian Stamper

Main focus: Mainly practice/Congenital deafblindness

Abstract: As an organisation Sense is committed to delivering high quality services, and exploring creative and new ways to meet individual's needs. Volunteers – without their professional knowledge - provide a powerful way to achieve outcomes for individuals. Their fresh perspectives and creativity offers opportunities for disabled people to form relationships as equals – and outcomes of independence, increased social circles and reduction in isolation, increased confidence, and wellbeing are achieved.

This session will outline a new Sense befriending service for children & young people in east London. Volunteers are supported to develop positive and strong relationships with a child or young person, and together, through weekly sessions, pursue interests and participate in the local community. Underpinned by a culture of positive risk taking, this service is about creating a safe environment where young people and volunteers both build new relationships, explore new situations and interests, and step outside of their comfort zone. Using case studies and evaluation techniques we will demonstrate the added value volunteers can bring.

Discussions will take place on the merits and pitfalls of a volunteer led service model, the challenges and solutions of starting new services, and, once successful, how these projects can be scaled to other areas and or countries.

Poster

**Title: Identified Needs in Deaf-Blindness: Recommendations for Orientation & Mobility Training**

Presenter: Tara Brown-Ogilvie, National Leadership Consortium in Sensory Disabilities (NLCSD) Fellow-University of Northern Colorado, USA

Co-presenters: Silvia M. Correa-Torres  
Associate Professor, University of Northern Colorado, USA

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

Introduction: Historically, orientation and mobility preparation programs, have been found to be insufficient in providing graduates with in-depth knowledge of how to work specifically with clients who are deaf-blind. Often an overview is provided, yet many orientation and mobility specialist express a need for additional training to best serve the unique needs of travelers who are deaf-blind. As a result, this qualitative survey seeks to identify the key areas of need for pre-service orientation and mobility specialists and thusly provide insight to modifications that could be beneficial towards improving current practices of orientation and mobility preparation programs.

Objective: To identify necessary supports for orientation and mobility specialist working with individuals who are deaf-blind in order to improve personal preparation.

Methods: Qualitative research design was used in this study, specifically interviews. Participants were recruited through professional listservs and were asked to identify their needs when working with students/clients who are deaf-blind. The interview protocol included a set of open-ended interview questions, with follow-up/probe questions asked throughout the interview as needed. Data were analyzed to determine systematic categories through coding. The method used to create these categories was the constant comparison method. Categories drawn from meaning units across all participants and/or in more than one interview question were retained. Categories that did not appear as meaning units of all participants or across several questions were discarded for lack of support. Finally, categories were clustered together into themes based on similarity of content.

Results Similar to current literature in the field, in this study it was found that communication is often the greatest barrier in providing high quality orientation and mobility services to individuals who are deaf-blind. Participants also identified modified techniques, assistive technology, and the use of interpreters as challenges when working with this population.

Conclusions: Findings from this study indicate that orientation and mobility preparation programs should provide more training on working with individuals who are deaf-blind including communication and strategies on how to better serve this population. Further



professional development and resources to in-service professionals are also needed. This could potentially mitigate the noted needs and challenges expressed by the participants of this study. Additionally, further research is warranted to enhance strategies for best serving individuals who are deaf-blind.

Poster

**Title: Zika virus: a new challenge for social inclusion**

Presenter: Shirley Rodrigues Maia, Grupo Brasil and Ahimsa, Brazil

Co-presenters: Vula Maria Ikonomidis

Main focus: Both research and practice/Congenital deafblindness

Abstract: School inclusion in Brazil began in 2008, in these nine years of mainstream schools open for the access and participation of students with disabilities it was possible to expand and bring more opportunities to people with deafblindness access and participate in different kinds of educational settings: from early childhood educational services, preschool, elementary and secondary school, and even university levels, with the support services of Specialized Educational Services, teacher training and multifunction classrooms, including education at home settings when needed.

In this scenario it was possible to achieve and pass laws that organize and support the educational services for deafblind people, for example, the creation of a new job in Brazil of guide-interpreters and intervenors that help deafblind students access the information, have an active participation and stay in school. These services have expanded the opportunities of social interaction and access to different settings and environments.

Nowadays, in Brazil, we can say there is inclusion of many deafblind students and students with multiple sensory disabilities. According to general data of the school census recorded in 2015 by the agency INEP National Institution of Educational Studies and Research, there is an estimated number of students with disabilities out of which about 1,5% may present deafblindness and some 10% may present multiple disabilities.

The actual figures will be presented during the workshop, for instance, regarding the children from birth to 5 years old enrolled in day care centers and kindergarten there is an estimate number of 675 deafblind children and 2250 children with multiple disabilities.

But since 2015 a new challenge has been put before Education in Brazil to maintain and give opportunity to expand inclusion and social interaction of students with deafblindness and multiple sensory disabilities: the children who suffer disabilities and frail health from the Zika virus Syndrome.

Specially the Northeast Region where the states of Pernambuco, Bahia and Alagoas are the most affected, there is today an average of 4000 cases identified and the challenge now lays on train professionals who work in the day care centers and kindergartens to understand how to best educate this great number of children, there is much still to learn and research is taking place as we write this abstract, many of which have described different associations of health problems besides visual and hearing impairments in many of the children.

This population will need more resources and new governmental actions, researches in the health and educational fields in order to ensure their full inclusion.

Poster

**Title: Simulator a communication model for people with cognitive and communicative difficulties and who are unable to express themselves, verbal or with sign.**

Presenter: Anne Nina Buss and Frank Hedegård, Blindecenter Bredegaard, Denmark

Co-presenters: Ann Christin Hed Pedersen

Main focus: Both research and practice/Congenital deafblindness

Abstract: The Simulator

A model or method for communication.

Imagining you are unable to express yourself not verbally or with signs about what you want to eat, happy or not happy, to do things, in your daily life and social activities?

We are a group of Pædagoger /Teachers who are working with people who are Deafblind with cognitive and communicative difficulties, we have discussed and developed a model for better understanding in the relation in the daily pedagogic praxis.

In our work, we have developed different communication tools like KOMMUNIKATION PAS, which is a description of individual sounds, mimic and things that represent special issue or approach regarding the individual person.

This model is not enough we needed a model or method to prevent an only normative approach, with a further theoretical discussion about etic and power, in trying to understand the individual person. One of our topic is the discussion of participate in decision-making in own life.

To be understood is essential for “all life”, “wellbeing”, “emotions” and “mental” health and just be a human being. In the workshop the focus is both research and practice and the topic is concerning participation in own life, social activities and society, to prevent isolation and deprivation.

The Simulator.

The Simulator is a process where one person is trying to “imagining/ simulating” the person who is unable to communicate. In the process the participants in the model can be, the person itself if possible, or a professional, relative, friends or other who is related to the person. In our daily work, we professionals are making decisions for the Deafblind every day. But how to do that and to put ourselves aside – and our normative approach. Yes, we can do it better?

Keywords in our discussions is:

Etic

Power (Foucault)



Participation in decision making.

Empowerment

Social responsivity (Per Lorentzen)

Recognition

Responsibility

Other important issues and perspectives are important, but our focus is as described.

How to take another person's perspective?

To take another person's perspective a difficult must be evaluated and discussed in reflexive team and sometimes again and again. If you are "imagining or simulate" another person, you have put you own person aside and be loyal with humanity and respect in the Simulator. You will always be under influence by own life story, therefore it is important to have a reflective team as observants in the process, but one must have, the courage to take the other person's perspective!

Poster

**Title: Three Countries Connect**

Presenter: Tracey Veldhuis, DeafBlind Ontario Services, Canada  
Co-presenters: Michael Karlsson  
Melaine Gauthier  
Mireya Cisne  
Francis Gutierrez

Main focus: Mainly practice/Both congenital and acquired deafblindness

Abstract: Despite more than 10000 km separating them, organizations from 3 different countries began a partnership in November 2015 which has brought them together and created a solid social connectedness.

This presentation will speak about the partnership that has taken place between MoGard, (Sweden) Asociacion de Sordociegos, ( Nicaragua) DeafBlind Ontario Services (Canada) and Canadian Helen Keller Centre (Canada). We will highlight the successes and challenges of collaborating and how, despite distance, cultural and language barriers we have been able to work together, learning from each other and sharing experiences and knowledge for the benefit of all organizations.

The presentation will include a brief overview of each participating organization, how we became involved in the partnership. We will also share tips on how others could start partnerships like this.

During the workshop, we will highlight successes from participating organizations, and the benefits we have had from the collaboration, as well as some of the challenges we encountered. We will highlight the recent training program, which took place in Masaya, Nicaragua with educators and deafblind consumers, as well as feedback from the facilitators and participants.