

Research Symposium presentation on Thursday September 7th, 2017 at 11:05

Title: The lived experience of vulnerability amongst adults ageing with deafblindness

Presenter: Peter Simcock, King's College London, UK

Names and institutions of research collaborators, Principal Investigator or research mentor
PhD Supervisors: Prof. Jill Manthorpe and Prof. Anthea Tinker
King's College London.

Abstract:

Introduction: Deafblind people are described as one of society's most vulnerable groups, yet there is a dearth of research on the experience of this vulnerability amongst the deafblind population. As U.K. law and policy increasingly recognises that circumstances beyond inherent characteristics, such as wider environmental and situational factors, can render adults vulnerable, scholars have argued that the subjective, lived experience of 'being vulnerable' remains absent. This study explored such lived experience amongst a group of older people who have aged with deafblindness and considered the implications of the findings for safeguarding policy and practice.

Methods: This UK based study adopted a phenomenological approach and used qualitative methods, as these are best suited to the exploration of lived experience. 18 in-depth semi-structured interviews were undertaken, with 8 adults ageing with deafblindness (age range: 49 – 83); these focused on participants' understanding, views and experiences of vulnerability. Two participants had Usher Type I, three had Usher Type II, one had Usher Type III and two had congenital rubella syndrome.

Interviews were transcribed in full and analysed using Interpretative Phenomenological Analysis (IPA). **Results:** Participants did not experience vulnerability as a permanent state linked to their impairment, but rather described specific situations in which they felt vulnerable: rather than being a 'vulnerable group', deafblind participants are more accurately classified and declassified as vulnerable throughout their lives. The themes that emerged from participants' experiences included: 'An invisible and misunderstood impairment'; 'What will others think of me? Being perceived as incompetent'; 'Losing control'; 'ageing and deafblindness: inter-related'.

Conclusion: Failure to consider subjective experiences of vulnerability, may lead to health and social care interventions that disempower older deafblind people or override their wishes and feelings. This research develops our understanding of the complexity of vulnerability, and its contributing factors.

Research Symposium presentation on Thursday September 7th, 2017 at 11:10

Title: Problems identified by dual sensory impaired older adults

Presenter: Lieve Roets-Merken, Radboud university medical center, The Netherlands

Co-presenters: Maud Graff

Names and institutions of research collaborators, Principal Investigator or research mentor

1. Myrra J.F.J. Vernooij-Dassen, Radboud University Medical Center, Scientific Institute for Quality of Healthcare
2. Sytse U. Zuidema, University of Groningen, University Medical Center Groningen, Department of General Practice and Elderly Care Medicine
3. Gertrudis I.J.M. Kempen, Maastricht University, Department of Health Services Research, CAPHRI School for Public Health and Primary Care
4. Maud J. L. Graff, Radboud University Medical Center, Scientific Institute for Quality of Healthcare

Abstract: Problems identified by dual sensory impaired older adults. A qualitative study

Objective: To gain insights into the problems of dual sensory impaired older adults in long-term care. Insights in these problems are essential for developing adequate policies which address the needs of the increasing population of dual sensory impaired older adults in long-term care.

Methods: A qualitative study was conducted in parallel with a cluster randomised controlled trial. Dual sensory impaired older adults in the intervention group (n=47, age range 82-98) were invited by a familiar nurse to identify the problems they wanted to address. Data were taken from the semi-structured intervention diaries in which nurses noted the older adults' verbal responses during a five-month intervention period in 17 long-term care homes across the Netherlands. Data analysis was performed using qualitative content analysis based on the Grounded Theory. Findings: The 47 dual sensory impaired older adults identified a total of 122 problems. Qualitative content analysis showed that the older adults encountered participation problems and problems controlling what happens in their personal environment. Three categories of participation problems emerged: (1) existential concerns of not belonging or not being able to connect with other people, (2) lack of access to communication, information and mobility, and (3) the desire to be actively involved in care delivery. Two categories of control-in-personal-space problems emerged: (1) lack of control of their own physical belongings, and (2) lack of control regarding the behavior of nurses providing daily care in their personal environment.

Conclusions: The invasive problems identified indicate that dual sensory impaired older adults experience great existential pressures on their lives. Long-term care providers need to develop and implement policies that identify and address these problems, and be aware of adverse consequences of usual care, in order to improve dual sensory impaired residents' autonomy and quality of life.

Research Symposium presentation on Thursday September 7th, 2017 at 11:15

Title: Prevalence of older adults in Sweden with combined severe vision- and hearing loss.

Presenter: Elin Lundin, Örebro university and Audiological Research Center
Örebro University Hospital, Sweden

Names and institutions of research collaborators, Principal Investigator or research mentor
School of Health and Medical Sciences Örebro University
Audiological Research Center Örebro University Hospital Mentor
Stephen Widen Associate Professor, PhD in Psychology

Abstract:

The focus of the study is on older adults with severe vision- and hearing loss (dual sensory loss – DSL). DSL affects many older adults and in Sweden the prevalence of persons with DSL is not confirmed.

The aim of the study is to examine the prevalence of older adults who has DSL. It is a register study from two counties (Örebro and Värmland). Focus is on older adults (65+) with severe vision loss (≤ 0.3) and severe hearing loss (≥ 70 dB HL).

A statistical analysis will be done and the result will be generalized of the population in Sweden. This study will lay the groundwork for future studies about causality and rehabilitation for persons with DSL.

The study is financed from Örebro University and the research council of Uppsala – Örebro regions.

Research Symposium presentation on Thursday September 7th, 2017 at 11:20

Title: Working with Deafblind people to develop a good practice approach to consultation and research activities

Presenter: Alana Roy, Able Australia, Australia

Names and institutions of research collaborators, Principal Investigator or research mentor Professor Keith R MCVILLY Melbourne University Beth Crisp Deakin University

Abstract:

Background: Deafblindness includes those who are born with sensory impairments, and those who sense of sight and hearing deteriorate over time. Deafblindness can result in social isolation, communication deprivation, and difficulties participating in both economic and political activities in the wider community. People living with disabilities are now central to the development of social policy and services due to their lived experience and expertise. However, to date, there is a paucity of guidance on how to engage with those who are deafblind in the generation of knowledge on issues of importance, and solutions to the challenges they experience.

Aim: This study investigated good practice approaches to consultation and research activities involving deafblind people. **Method:** Working from the perspective of appreciative inquiry, a qualitative research methodology called The World Café which involves multiple rounds of questions and mixed group discussions was used to generate patterns of insight and collective discoveries from N=15 deafblind participants from Melbourne, Australia with mixed communication including Auslan, tactile sign language and spoken English. Data from The Deafblind World Café were analysed using inductive thematic analysis and the constant comparative method.

Results: The World Café methodology, with some minor adaptations, successfully generated data concerning issues of importance to people who were deafblind. 1) Being involved in research and policy consultation is a challenging journey into unfamiliar territory, but we want to go there, 2) Our story is best captured in conversation, not by means of rating scales or calculations, 3) We need to trust you before sharing our story, and this means we need time to develop relationships 4) We are deafblind, proud, and have a unique community 5) We can contribute if you include us.

Conclusion: The principles of appreciative inquiry and the practices of World Café methodology can be harnessed to enable deafblind people to participate in culturally sensitive, assessable and inclusive research on matters effecting their lives. Furthermore, reasonable adjustments to World Cafe methodology can be made, without compromising the fundamentals of the approach, to ensure good practice approaches to consultation and research activities involving deafblind people.

Research Symposium presentation on Thursday September 7th, 2017 at 11:30

Title: Work, health, social trust and financial situation in persons with Usher syndrome type 1

Presenter: Mattias Ehn, Audiological research center, Örebro, Deaf blind counselling and support team , Stockholm County, Sweden

Names and institutions of research collaborators, Principal Investigator or research mentor Claes Möller, Moa Wahlqvist, Berth Danermark, Örjan Dahlström, Audiological research center Örebro. Swedish institute for disability research , Örebro and Linköping

Abstract:

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

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 type1 (USH1), a group of persons with profound deafness and their health in relation to work activity.

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.

Research Symposium presentation on Thursday September 7th, 2017 at 11:35

Title: Employment participation of deafblind people

Presenter: Nadja Högner, Hanover, Germany, Germany

Names and institutions of research collaborators, Principal Investigator or research mentor Humboldt-Universität zu Berlin, Germany

Abstract:

People with acquired deafblindness are often excluded from participation in the labor market. Both entering the labor market and continuing to work are problematic. Persons often retire early without getting the option of vocational rehabilitation.

In a qualitative study, both employed and unemployed deafblind people will be interviewed about work conditions and problems in the workplace caused by the deafblindness, about aids and support used in the workplace, the participation in vocational rehabilitation and its possibilities and limitations as well as the causes of their unemployment and the process of losing a job.

To date, nine deafblind people between 43 and 63 years who were no longer employed have been interviewed. Except for one person all of them had participated in vocational preparation and qualification measures such as retraining. In the case of four persons, the measures led to temporary employment and only in one person to a permanent employment on the labor market. Rehabilitation measures were often refused by the paying authorities. Instead of that early retirement was recommended. The main reason for the job loss was the inability to carry out work without any support or tools.

A proposal to improve occupational participation mentioned several times was the support through a job assistance. In view of the high functionality and importance of work in social life, for deafblind people measures for professional (re)integration have to be created. Suitable rehabilitation measures can lead to an increased rate of deafblind persons on the labor market.

Research Symposium presentation on Thursday September 7th, 2017 at 11:40

Title: ISTAT Research and future scenarios

Presenter: Patrizia Ceccarani, Lega del Filo d'Oro Onlus, Italy

Co-presenters: Ricci C. (1), Solipaca A. (2)1 Istituto Walden, Rome, Italy2 Istituto Nazionale di Statistica - ISTAT, Rome, Italy

Names and institutions of research collaborators, Principal Investigator or research mentor ISTAT - Italian National Statistics Institute

Abstract:

After than 50 years, the Lega del Filo d'Oro felt the responsibility to identify the number of people living with deafblindness in Italy, because experience showed us that the data we had from previous analysis couldn't be reliable. This research commissioned by the Lega del Filo d'Oro and conducted by ISTAT (Italian National Statistics Institute) also offered tools to analyze the difficulties these people face in their lives.

The analysis focused on key social inclusion dimensions given by the "ONU Convention on the Rights of Persons with Disabilities". To estimate the prevalence of people with deafblindness ISTAT made reference to two self-reported conditions declared by the recipients: presence of a disability - blindness or deafness - presence of a sensory deficit that limits the person on seeing and hearing. It has been estimated that, in Italy, there are 189 thousand people with sensory disabilities related to sight or hearing (0,3% of the Italian population). The 64,8% of deafblind people are women, while 97,9% are over 65 years.

About 108 thousand people rarely can go out of their house. 1 million 700 thousand people have sensory disabilities related to vision (sight) and hearing, 9.855 of them are children and young people enrolled in schools during 2014/2015 academic year. In most cases they are children and young people who live an extremely complex condition as they associate sensory deficit to other disabilities (intellectual, learning, motor, language development...). In fact, the deafblindness often leads to other forms of disability: 51,7% motor disability, 40,1% permanent damage as a result of intellectual disabilities, 32,5% behavioral disorders and intellectual illness.

The Research has shown a real emergency, which we should strongly respond to. The data clearly demonstrate that the living environment often influences social inclusion; this should push policies to intervene, eliminating barriers, providing support, aids and services.

Research Symposium presentation on Thursday September 7th, 2017 at 11:45

Title: **See and Listen to Me**

Presenter: Ann-Britt Johansson, Eikholt, Norway

Names and institutions of research collaborators, Principal Investigator or research mentor
Sahlgrenska Akademin, Göteborgs universitet

Abstract:

Introduction and objective: There are very few research studies about the experiences of living with deaf blindness. The objective of this dissertation is to capture the experiences of people with acquired deafblindness regarding their participation, rehabilitation and civic life in order to develop a deeper knowledge and understand how it is to live with deafblindness. The research questions relevant to this study are based on a life-world phenomenological research approach and builds on an openness towards phenomena to be studied: What does the concept of “participation” mean for people with acquired deafblindness? What are the conditions required for people with acquired deafblindness to experience participation in their lives? How do people with acquired deafblindness experience their own living conditions? How do they live with an acquired visual and hearing impairment, deafblindness? How do people with acquired deafblindness experience their rehabilitation? What ideas do they have about their experiences? What conditions are necessary for people with acquired deafblindness to exercise their citizenship and their civil privileges?

Method: Eight people with acquired deaf blindness have participated in this qualitative study, which has a life world phenomenological approach. The participants have been interviewed a number of times and were observed in a participant observation. The interviews have been transcribed, analysed and interpreted with a hermeneutic method.

Results: The study identifies three major areas of life that are strongly connected to participation. These are work, family and social life and efforts from society. All of the participants have experiences in their rehabilitation that relate to the theory of “the Lived body” and the concept of horizon and the intentional arc. The whole person in his life-world is not often the focus of interaction. The impairment tends to be the focus. To be able to live in society as full citizen requires special services to enable people with deaf blindness to participate and take advantage of their civil rights and citizenship.

Conclusion: The study provides evidence that special services from society to people with acquired deaf blindness enable them to participate more fully in daily life. These services are not always available and this can lead to frustration and social isolation. The participants emphasized also a lack of response towards people with deaf blindness, which also exists among professionals. This lack of response and bias towards emphasizing disability is often found in society. The study also uncovered a lack of

knowledge about the importance of addressing the special needs to people with acquired deaf blindness, and the need for changing attitudes towards people with deaf blindness.

Keywords: deafblind, adult, acquired, participation, rehabilitation, citizenship, lifeworld, phenomenological, hermeneutic, the lived body, horizon, intentional arc

Research Symposium presentation on Thursday September 7th, 2017 at 11:50

Title: Bringing Adults with Deafblindness from Margins to the Centre of Research

Presenter: Atul Jaiswal, School of Rehabilitation Therapy, Queen's University, Canada

Names and institutions of research collaborators, Principal Investigator or research mentor
Research Mentor/Supervisor: Dr. Heather Aldersey, Assistant Professor, School of Rehabilitation Therapy, Queen's University, Canada

Abstract:

Introduction. People with deafblindness are one of the most under-represented populations in the field of health and disability research. Although the history of this condition can be traced even before 1880, the development in terms of research and practice specific to this population is still in its infancy stage. Majority of research conducted on deafblindness have hardly collected data from persons with deafblindness directly, but rather used proxies (parents, caregivers, or professionals) to understand the experiences, needs and concerns of people with deafblindness. This use of proxies in deafblind research marginalizes persons with deafblindness and places them on the fringes of the mainstream research and development.

Methods. The paper is guided by the research question "What are the challenges associated with researching directly with adults with congenital and acquired deafblindness in India?". The paper is part of the Ph.D. research (qualitative in nature) exploring the experiences of participation for persons with deafblindness in India. The paper, based on the experiences of qualitative interviewing with 15 adults with deafblindness (using diverse communication modes), develops an understanding of the challenges associated in researching with this under-representation population. The paper also uses critical literature review to suggest the possible strategies for data collection while conducting a deafblind research.

Results/Anticipated Results. The preliminary findings from the interviews directly with adults with deafblindness conducted in March –April 2017 suggest that there are methodological challenges in conducting research with this population. Difficulties in data collection ranges from taking informed consent process to the member checking process at the end of qualitative interviews with them.

Conclusions/Significance. Persons with deafblindness are invisible from medical and rehabilitation science literature. Research directly with this population is much needed to ensure their human rights are met and their voices are heard in formulating policies and designing services for them.

Research Symposium presentation on Thursday September 7th, 2017 at 12:05

Title: Intersubjective communication development between students with deafblindness and their teachers.

Presenter: Kirsten Wolthuis, Groningen University, The Netherlands

Names and institutions of research collaborators, Principal Investigator or research mentor: University of Groningen; Prof. Marleen Janssen (promotor) Royal Kentalis; school Rafael, St. Michielsgestel (participants)

Abstract:

Based on Trevarthen's theory of innate intersubjectivity (Braten & Trevarthen, 2007), we developed a model that describes per layer of intersubjective communication development several characteristic communication behaviors. By using a coding scheme, we researched to what extent this model can be used to get insight in variances between communication levels of different students with deafblindness and their teachers.

Method: Four students with deafblindness and their teachers at a school in The Netherlands participated in this study. For each couple, four video-recordings of ten minutes were analysed. We used a coding scheme to score per ten-seconds whether or not the nine behaviours were intersubjectively shared. Subsequently, we scored if the student or teacher had the largest role in sharing the behaviour. During data analysis, couples were compared based on the amount of intervals that were intersubjectively shared regardless of the different coding behaviours. After that, we compared how often the behaviours separately were shared between the couples. Finally, the role of both interaction partners in the success or failure of intersubjectively shared behaviour was analysed.

Results: The higher the communication level of the couple, the more intervals are intersubjectively shared. All couples share behaviours at the first and second layer of intersubjectivity, but only one couple shares behaviours at the third level. The role of the teacher is most important in the couple with the lower communication level. The teacher mainly evokes behaviour to be shared and it is often the student that prevents the behaviour from being shared.

Discussion: The created communication model can be used to distinguish between the communication levels of different couples. It shows when moments are intersubjectively shared between the two and when not. And most importantly, it demonstrates who has the largest role in intersubjectively shared moments, which is useful information for teachers and other professionals.

Research Symposium presentation on Thursday September 7th, 2017 at 12:10

Title: Close correlation between staff education, competences, transfer and organizational learning.

Presenter: Anne Søbbye, Center for Døvblindhed og Høretab, Denmark

Co-presenters: Helle Buelund Selling

Names and institutions of research collaborators, Principal Investigator or research mentor
RUG, NL and AAU, DK

Abstract:

To have a sense of social connectedness, it is essential for people with deafblindness to have access to create social relations to other people. In a dialogical understanding learning, development and co-creation of meaning happens in interdependent relationships with others. In other words, one needs to be engaged in interdependent relationships with other people in order to develop, learn and co-create meaning. We are interested in how deafblind services can support the sense of social connectedness. This interest raises questions about what competencies staff need, in order to be able to act as trustworthy and competent communication partners in the encounter with the person with deafblindness.

Moreover, it raises questions on how management and staff development can support staff providing a service that values development and social connectedness. In our opinion, it is essential that there is a close correlation between the staff's sense of coherence between organizational management, development of staff competencies and the services itself. If you strive to conduct services in a dialogical manner, you have to conduct management and development of staff competencies in a dialogical manner. One could say a dialogical approach is important in order for staff to act dialogical.

Research Symposium presentation on Thursday September 7th, 2017 at 12:15

Title: Measuring social connectedness through adapted physical activities (APA)

Presenter: Marijke Bolwerk, Royal Dutch Kentalis, St. Michielsgestel, the Netherlands

Co-presenters: Lotte van de Ween (APA teacher, Royal Dutch Kentalis, St. Michielsgestel, the Netherlands). Mads Kopperholdt and Anders Rundh (APA teachers, Center for Deafblindness and Hearingloss (CDH), Aalborg, Denmark)

Names and institutions of research collaborators, Principal Investigator or research mentor ---

Abstract:

In this presentation you will be informed about a project, that is still in progress, in which we want to show that social interaction and communication between students can be developed through physical education. Although interaction and communication between children with deafblindness is not self-evident and often limited, we experienced in an earlier project on APA that they surely benefit from contacts with their peers. It has a positive effect not only on their communicative development, but also on their cognitive and social- emotional development.

This project, we will inform you about, takes place in two schools for deafblind and deaf multiple communicative impaired children; CDH in Aalborg, Denmark and Kentalis Rafaël in St. Michielsgestel, the Netherlands. During a period of several years (September 2016 – July 2019) we will follow 4 students. Each week these students attend APA lessons where, besides working on physical goals, a safe and inspiring environment is created with activities to meet and develop social interaction and communication with other students.

At the beginning of the project we described specific focus points for development for each individual student. As a study design, dynamic assessment is used. On 5 moments during the period the project is running we collect data by analyzing video fragments of the lessons. Focus of the data analysis will be the development of the students.

The effect of chosen APA-activities and teaching methods is subject of intervention. Outcomes of the project we expect to be: -awareness that APA-lessons are a good environment to work on the development of social interaction and communication between students. -ideas for guidelines to work on this development. During the presentation we want to share our experiences from the first period of this project.

Research Symposium presentation on Thursday September 7th, 2017 at 12:20

Title: Communicative Forms & Functions Used by Individuals with CHARGE Syndrome

Presenter: Susan M. Bashinski, Missouri Western State University, United States

Names and institutions of research collaborators, Principal Investigator or research mentor
Dr. Barbara Braddock, formerly of St. Louis University
Dr. Christopher A. Neal, University of Kansas Medical Center
Ms. Clarissa Huffman, graduate student, Missouri Western State University
Dr. Jennifer Heithaus, St. Louis University

Abstract:

Research AIMS

1. describe nonintentional and intentional prelinguistic communication forms and functions used by a sample of individuals with CHARGE syndrome with little / no conventional communication
2. collect information regarding augmentative communication experiences of these individuals
3. analyze these individuals' potential communicative acts (PCAs), according to communicative functions for which PCAs appeared to be used (term "potential communicative acts" used to describe verbal or nonverbal behaviors, interpreted by others as serving a communicative purpose).

METHOD

Families with a child with CHARGE syndrome ($n = 27$) participated in face-to-face interviews with researchers during the most recent International CHARGE Syndrome Conference (Chicago, Illinois). Children's ages: 17 months - 28 years; eligible children used fewer than 50 functional spoken words / manual signs. Families discussed their children's use of PCAs and the utility of these signals for conveying meaning. Primary data were collected through the administration of the Inventory of Potential Communicative Acts (IPCA).

RESULTS

All potential communicative acts reported were coded and categorized for each participant, according to both form and perceived function, across ten function categories. Twenty-four participants demonstrated nine or more functions; all 27 demonstrated PCAs in five function categories. Mean number of unique forms used by participants = 36.37. Family members' anecdotal comments regarding their child's communication abilities were analyzed using qualitative research procedures. History of experiences with AAC systems was compiled across the sample.

CONCLUSION

Results of this investigation inform families, teachers, and clinicians of the wide range of communicative functions fulfilled through the potential communication acts of learners with CHARGE syndrome. Further, these results serve as a possible treatment scaffold for clinicians for introducing conventional communication forms into the repertoires of individuals who have little functional, conventional communication. Finally, results highlight the need for appropriate unaided and aided augmentative communication instruction with individuals with CHARGE syndrome.

Research Symposium presentation on Thursday September 7th, 2017 at 12:30

Title: Evaluation of symbolization' level in children with visual and hearing impairments

Presenter: Alina Khokhlova, Resource center of support the deafblind people "Yaseneva polyana", Moscow, Russia, Russia

Names and institutions of research collaborators, Principal Investigator or research mentor Deaf-Blind Support Foundation 'Con-nection'

Abstract:

We propose method of evaluation of communicative tools of children with visual and hearing impairments. The goal of the method is to elaborate the evaluation of symbolization level which is available for examined child. This method is suitable for work with those children who do not use full-fledged verbal or sign speech.

We propose experimental procedure of evaluation of symbols' level, comprehensible for child. The experimental evaluation is needed to show not only the type of symbols which child uses in his daily routine (which can be revealed during the monitoring) but the ultimate level available for him. The results of such diagnostic might help in further education.

The age of children – starts from 5. Stimuli of method is assorted based on Symbolic model according to which the real object belongs to first level of symbolization whereas the meaning of language and word is the supreme one. Variant for the blind: 10 real objects, 10 representative objects, 10 – bas-reliefs and 10 tactile flat images, plates with Braille words. Variant for children with vision: 10 real objects, 10 representative objects, 10 accurate images, 10 pictograms, cards with printed words.

Procedure: children starts the selection of symbols of different level to real objects. The essential condition to commence testing is to ensure that the child recognize the subject. By such method the 15 children were examined.

The results can be summed up as following:

1. In the major cases we determined the level of symbols which is easy for child to carry on with, and also the level of symbols which is in the process of learning. And this is always the upcoming level according to the scheme of 'Symbolic stairs'.
2. Only two of 15 children have demonstrated the actual level but not the possibility for development of the next one.

Research Symposium presentation on Thursday September 7th, 2017 at 12:35

Title: Evidenced-based practices in communication, literacy, and social-emotional development

Presenter: Susan M. Bruce, Boston College, United States

Names and
institutions of
research
collaborators,
Principal Investigator
or research mentor

Abstract:

Communication is the most developed area of research in deafblindness (Ferrell, Bruce, & Luckner, 2013). New perspectives of literacy go beyond reading and writing to include communication and technologies to support interactions. Prelingual children who are deafblind often express themselves through behaviors, making research on socio-emotional interventions relevant to communication research.

A search of online data bases such as PsychINFO, ERIC, EBSCO host, and Google Scholar was conducted, along with reviews of meta-analyses and syntheses, and secondary searches to locate peer-reviewed articles about communication, literacy and socio-emotional studies that included children who are deafblind (0-22). A sample of the findings appear here. There is evidence of the efficacy of communication practices that fit within both child-guided approaches and systematic instructional approaches. There is moderate evidence of the efficacy of tactile approaches and strategies, including touch cues, to support communication (Chen & Downing, 2006; Chen & Haney, 2000 and others). Adult communication partners can improve their responsiveness, turn-taking, attunement and other communicative skills when provided with systematic demonstration and coaching (Chen et al., 2001; Janssen, Riksen-Walraven, van Dijk, Huisman, & Ruijsenaars, 2011; and others).

There is a dire need for research on receptive communication, English Language Learners who are deafblind, reading and writing. There is a moderate level of evidence on the impact of etiology on behavior (Bernstein & Denno, 2000; Dammeyer, J., 2012; Graham, Rosner, Dykens, & Visootsak, 2000; Hartshorne, 2011; and others). There also is a moderate level of evidence for the efficacy of specific behavioral principles (such as praise, token economies, differential reinforcement of other behaviors) to reduce or eliminate stereotypies, self-injurious behaviors and aggression in children and youth who are deafblind.

There is a need for the field of deafblindness to conduct research on Functional Behavioral Analysis and Function Communication Training (FCT).

Research Symposium presentation on Thursday September 7th, 2017 at 12:40

Title: Connectedness by ongoing focus on the bodily- tactile modality

Presenter: Joanna Wisniewska, school Rafaël, Kentalis, The Netherlands

Names and institutions of research collaborators, Principal Investigator or research mentor
Eline van Rooij-Cooijmans

Abstract:

Hypothesis: intervention focused on tactility increased the use of it by the teachers during the day in their contact with their students. Even if teachers are familiar with importance of tactility by students with deafblindness they still do not use it optimal. Tactility is mainly used for students who are completely blind and for tactile communication.

Method: a small research intervention project during the school year 2016-2017 at Kentalis Rafaël with the use of the dynamic assessment model (Boers, 2015). First I established the baseline with the use of video: how many tactile utterances were made in 10 minutes of activity and how many more chances there were. I counted 3 ways of using tactility: tactile confirmation, tactile sharing of emotions and tactile experience of the events of the day. Then I started intervention, that consisted of 3 meetings of video analyze and coaching on the job with individual teachers. I finished the project by evaluating results.

Results: there was a significant grow in quantity and quality of tactile confirmation, tactile sharing of emotions and tactile experience of the events of the day by all of the teachers after intervention.

Conclusion: even by highly trained professionals there is a significant progress after using intervention focused on tactile approach. Focus on tactility increase conscious use of it. It makes teachers more aware of it and it is used more frequent and more efficient. My colleague's transformed from unconscious competent to conscious competent.

Research Symposium presentation on Thursday September 7th, 2017 at 12:45

Title: Overview of videofeedback interventions aimed at enhancing social interactions

Presenter: Saskia Damen, University of Groningen, The Netherlands

Co-presenters: Meredith Prain

Names and institutions of research collaborators, Principal Investigator or research mentor
dr. Saskia Damen works at the University of Groningen in the Netherlands and dr. Meredith Prain at Senses in Perth Australia

Abstract:

The aim of this study was to get an overview of video-feedback interventions for people with congenital deafblindness. We were particularly interested in how video-feedback is applied and which methodologies are used to measure the effect of such interventions. To answer our research questions, we carried out a systematic literature review.

The search resulted in 537 hits of which 523 were excluded on the basis of our criteria, and 14 papers were reviewed. The articles describe five types of video-feedback interventions: Contact, Intervention Model for Affective Involvement, High Quality Communication Intervention, CHANGE and Video-feedback for students.

These interventions were mostly aimed at enhancing the quality of social interactions and carried out by a trained coach. Both individual as well as groupwise video-feedback were used, often in combination with other intervention ingredients. The number and length of sessions varied and the actual techniques or structure used for the video-feedback itself was often not described. Lacking was also information about the way videos were selected and how the fidelity of the intervention was checked.

Effects of the intervention were mostly studied in single or multiple case experiments, using observations that were carried out by independent coders. The studies used small sample sizes, with 1-6 participants with deafblindness. Most interaction partners were professionals.

Overall, results show positive effects of video-feedback interventions and social partners report to be satisfied with the intervention. However, there are substantial differences between participants and effects only partly last. We recommend researchers to be more explicit about the content of video-feedback sessions and to provide numerical results to enable comparison between studies. More information is also needed on the amount of sessions needed to achieve positive changes and the impact on the daily lives of individuals with CDB.