

Congenital Deafblindness: Current and Future Priorities

Chair: Walter Wittich, PhD

Co-Chair: to be named by conference organizers



Dr. Walter Wittich is an Assistant Professor at the School of Optometry at the University of Montreal, Canada, with a Junior Career Award from the *Fonds de recherche du Québec – Santé (chercheur boursier junior 1)*, with focus on the rehabilitation of older adults with combined vision and hearing loss. He is resident researcher at both the *CRIR/Centre de réadaptation MAB-Mackay du CIUSSS du Centre-Ouest-de-l'Île-de-Montréal* and the *CRIR/Institut Nazareth et Louis-Braille du CISSS de la Montérégie-Centre*. Coming from a background in age-related vision loss, he now conducts research in dual sensory impairment and acquired deaf-blindness. His research domains include basic sensory science, as well as medical, psychosocial, and rehabilitation approaches to sensory loss. He is a Fellow of the American Academy of Optometry, is Quebec's first Certified Low Vision Therapist and is the inaugural chair of the Deafblind International Research Network, leading a team of 5 researchers from 4 continents in their efforts to facilitate networking and knowledge translation in deafblindness research. He has published over 40 peer-reviewed journal articles and his research is funded by the Canadian Institutes of Health Research, the Alzheimer Society, the Canadian Consortium on Neurodegeneration in Aging, as well as several provincial agencies and industry collaborators.

Symposium abstract

Pediatric vision rehabilitation service delivery is often made complicated by the presence of comorbidities such as hearing loss. Given the low incidence of congenital deafblindness, the number of researchers in this subspecialty is extremely sparse and we are excited to have six specialists in this domain assembled to discuss current issues in congenital deafblindness research and its rehabilitation. This panel was made possible through partial funding by Deafblind International to promote the DBI Research Network (<http://research.deafblindinternational.org/>). Given the profound impact of early sensory loss on human development, the complexity of care and the challenge of communication are at the core

of the panel topics. The panel will be opened by Jude Nicholas (Norway), describing the difficulties encountered in “Understanding the complexity of congenital deafblindness”. Since service delivery with this vulnerable population should be based on evidence-based practice, Susan Bruce (USA) will then examine “Effective Instruction of Students who are Deafblind: What is the State of Our Evidence?”. One major preoccupation when working with deafblind children is communication. Therefore, Marleen Janssen (Netherlands) will present recent development on “Intersubjective communication: A model for guiding high quality communication interventions in people with deafblindness”, with specific implications on service delivery. Thereafter, Susan Bashinski (USA) will be “Identifying Effective Strategies for Teaching Communication, Language and Literacy Skills, with Learners with Congenital Deafblindness” which ties nicely into the continuing priority of communication research, leading to the presentation by Mijkje Worm (Netherlands), discussing “Communicative engagement of a person with congenital deafblindness in narrative and multiparty conversational practices”. The theme of communication is then concluding with the final presentation by Sakia Damen (Netherlands), who will present approaches of “Scaffolding Communication in People with Congenital Deafblindness: An Analysis of Sequential Interaction Patterns”.

Symposium Presenters & working titles:

1. Nicholas, Jude (Norway): Understanding the complexity of congenital deafblindness
2. Bruce, Susan (USA): Effective Instruction of Students who are Deafblind: What is the State of Our Evidence?
3. Janssen, Marleen (Netherlands): Intersubjective communication: A model for guiding high quality communication interventions in people with deafblindness
4. Bashinski, Susan (USA): Identifying Effective Strategies for Teaching Communication, Language and Literacy Skills, with Learners with Congenital Deafblindness
5. Worm, Mijkje (Netherlands): Communicative engagement of a person with congenital deafblindness in narrative and multiparty conversational practices
6. Damen, Saskia (Netherlands): Scaffolding Communication in People with Congenital Deafblindness: An Analysis of Sequential Interaction Patterns

1. Understanding the complexity of deafblindness

Jude Nicholas

National center for special needs education & Haukeland University Hospital, Bergen,
Norway

Aim: the aim of this presentation is to give an overview of some of the challenges related to congenital deafblindness. There are many causes of congenital deafblindness. However, the population of children who are deafblind has become more severely disabled over the past several decades. This may be due, in part, to advances in medical technology that have increased the survival rates for infants and children with very serious conditions, who are also deafblind.

One major challenge is related to the identification of deafblindness. Many of the children who are deaf-blind have one or more additional disabilities or health problems and may be identified as having multiple disabilities rather than deafblindness. In these cases, the impact of combined hearing and vision loss may not be recognized or addressed.

The second challenge is related to the impact of the genetic causations (genotype/phenotype) or the neurological impairment (combination of cerebral visual/auditory processing problems) on the functioning of the child with deafblindness. In these cases, one should not only emphasize on individualized approaches based on the functional use of residual vision and hearing, but also on the bodily-tactile, neurological or genetic profiles of each individual child.

The third challenge is related to the issue of challenging behaviors in children with deafblindness as being diagnosed as a behavioral disorder. In these cases, it is important to consider that the behavioral and emotional difficulties that accompany deafblindness are often the natural outcomes of the child or adult's inability to understand and communicate.

Conclusion: Although there are several complexities surrounding congenital deafblindness, supporting early social interaction and providing communication or other developmental and educational needs are essential for every child with congenital deafblindness.

Funding: this work did not receive any funding

2. Effective Instruction of Students who are Deafblind: what is the State of Our Evidence?

Bruce, Susan

Boston College, Chestnut Hill, Massachusetts, U. S.

Introduction/aim: The focus of this presentation is on the state of research evidence in deafblindness as identified through an analysis conducted for the CEEDAR Center, University of Florida. Essential instructional practices and their level of evidence were determined across these 12 topical areas: administration, assessment, early identification and early intervention, assistive technology, communication, literacy, social-emotional, mathematics, science, life skills (including orientation and mobility), placement/inclusion, and transition.

Methods: The research team reviewed peer-reviewed articles that were published in English (between 1967 and 2013). Only high quality studies with positive effects were considered. The identified essential practices emerged from the review of the studies and the CEEDAR Center's standards of evidence were applied, with the following possible ratings: strong, moderate, limited, and emerging. For example, a practice was considered to have *strong evidence* if it met any of these four criteria: (a) two or more experimental or quasi-experimental designs with random assignment or a control group conducted by two independent research teams, (b) five or more single-subject design studies (with a total of 20 or more participants) conducted by at least three independent research teams, or (c) five correlational studies with correlation $<.30$ conducted by three independent research teams. The presenter later updated the review of the communication research through 2016.

Results: Two of the identified 45 practices are: (1) apply child-guided approaches to support communication development and different types of dialogues (limited evidence) and (2) improve daily living skills through systematic instruction that includes task analysis and the application of behavioral principles, such as graduated guidance (strong evidence).

Conclusion/Implication: The analysis revealed relatively stronger evidence in the area of communication. The field of deafblindness is in dire need of research in mathematics, science, and transition. We also need more studies on reading and writing, Orientation and Mobility instruction, and assistive technologies.

Funding: CEEDAR CENTER, University of Florida.

3. Intersubjective Communication: a Model for guiding High-quality Communication Interventions in People with Deafblindness

Marleen J. Janssen

Professor Congenital and Early Acquired Deafblindness, Special Needs Education and Youth Care, University of Groningen, Netherlands

Introduction: This paper describes a conceptual model based on the theory of intersubjective development according Trevarthen (Trevarthen & Aitken, 2001). The aim of this model is twofold: 1) to understand underlying processes of intersubjective development in relation to communication and language acquisition; 2) to guide High Quality Communication interventions in learners with congenital deafblindness. The purpose of this study is to investigate to what extent aspects of this model are applied in intervention studies on congenital deafblindness.

Method: A systematic review is performed with help of the electronic databases of Ebsco Host Complete. An advanced search is performed with the key words intersubjectivity combined with deaf, blind, deafblind; and Trevarthen combined with deaf, blind, deafblind. Studies were selected on relevance for intervention principles, intervention models, intervention studies.

Results: The model presented notes that affective interpersonal communicative support influences the growth of communication and language, represented in three layers of intersubjectivity. Intersubjectivity is described as “active self and other awareness”. The first layer is characterized by mutual interaction and affect attunement, the second layer by meaning making and the third layer by symbolic and virtual communication. Twelve intervention studies were found.

Conclusion: Results indicate that studies in deafblindness focused mainly on the lower levels of intersubjectivity, but all three layers were measured. Intersubjectivity theory offers good possibilities to develop interventions. Higher layers of intersubjective communication should be emphasized and supported in future interventions in research and in practice (Damen, 2015; Wolthuis, 2016).

Funding: Intervention studies were funded by Royal Dutch Kentalis, Bartimeus, Royal Visio and ZonMW-InZicht

4. Identifying Effective Strategies for Teaching Communication, Language and Literacy Skills, with Learners with Congenital Deafblindness

Susan M. Bashinski, Ed.D.¹, Susan M. Bruce, Ph.D.², H. J. Marleen Janssen, Ph.D.³

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Introduction: Many learners with congenital deafblindness will not develop language and may not understand abstract representations. This reality impacts the way education professionals view what constitutes “literacy” for these learners. In contrast to traditional definitions (i.e., literacy as the fluent use of written / spoken symbols), more inclusive views of literacy expand this notion to include the skills of making meaning and sharing information through multiple, varied forms. The researchers’ goal was to hear, in practitioners’ own words, how they interpret and deliver communication / language / literacy instruction with learners with congenital deafblindness.

Methods: This interview study represents one of a series of investigations conducted across three sites: (1) Northeastern USA (2) Midwestern USA and (3) The Netherlands. (Other data sources included videotaped observations and field notes.) Adult participants included 23 fully licensed teachers and SLPs, who reported their experiences with 22 learners with congenital deafblindness, who used < 40 conventional words / signs. Data analysis procedures included grounded theory, constant comparative analysis and in vivo coding. Researchers conducted individual interviews with teachers / SLPs; audio recordings were collected and transcribed. Two raters performed open coding, followed by consensus coding, merging results in one document.

Results: Researchers identified the top five strategies reported at each site; ten unique strategies emerged. Two strategies: individualizing instruction and increasing communication partners’ sensitivity / responsiveness to learners’ signals, ranked among the top five at all three sites. Two strategies: implementing multimodal communication and utilizing predictable routines emerged at two sites. Six strategies placed among the top five at only one site: sharing experiences, creating meaning / conversation, keeping the next step in mind (Netherlands); facilitating joint attention, getting to know learner (Northeast); and using object cues (Midwest).

Conclusion: Quotes derived from interview recordings will support the observed cultural and regional differences reported above.

Funding: The researchers are grateful for the research funding provided by: Royal Dutch Kentalis and the Michael and Susan Argyelan Education Research Fund

5. Communicative engagement of a person with congenital deafblindness in narrative and multiparty conversational practices.

M. Worm, MSc

Bartiméus, Doorn, The Netherlands

Introduction: 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.

Method: The study was conducted at Bartiméus, a Dutch organisation for persons with visual disabilities. In two exemplary cases, narratives and multiparty conversations are 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.

Results: 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.

Conclusion: Therefore, it is recommended to introduce narratives and multiparty conversations to many more persons with congenital deafblindness.

Funding: this work did not receive any funding

6. Scaffolding Communication in People with Congenital Deafblindness: an Analysis of Sequential Interaction Patterns

Damen, Saskia

University of Groningen, Groningen & Royal Dutch Kentalis, Sint-Michielsgestel, The Netherlands

Introduction: The High Quality Communication (HQC) intervention aims to stimulate communication between individuals with congenital deafblindness (CDB) and their partners and was found effective in multiple case-experiments. The aim of this study was to test one of the presumed working principles of the intervention: that social partners can “scaffold” communication behaviors in individuals with CDB, by displaying these behaviors themselves.

Methods: Interaction patterns were analyzed in nine dyads involving a child or adult with CDB and a social partner (parent, teacher or caregiver). In total, 36 observations were used for the analysis of two-event sequences of partner behavior and the subsequent behavior of the individual with CDB. The correspondence between communicative behaviors in these patterns was determined. Furthermore, differences were calculated between the occurrence of behavior of the individual with CDB that were preceded by the same behavior or other behavior of the partner.

Results: The overall correspondence between communicative behaviors of the individuals with CDB and their partners was strong. The display of a specific type of communicative behavior by an individual with CDB was significantly more often preceded by the same communicative behavior of the social partner. As expected, this association was not seen for behaviors that were already managed by the individual with CDB during the baseline phase.

Conclusion: Our findings support the idea that social partner can stimulate the emergence of complex communication behaviors in individuals who are still developing these behaviors. This is a powerful argument for supporting social partners of individuals with congenital deafblindness. Measuring the use of communicative behaviors before and during interventions may be useful to determine how much intervention and what focus in intervention is necessary.

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