

Acquired Deafblindness: Rehabilitation Challenges with Older Adults

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

With the changing demographic profiles in many countries around the globe, low vision rehabilitation has seen an increase in more complex cases, whereby many working-age and older adults with visual impairment also present with comorbidities such as age-related or noise-induced hearing loss. The rehabilitation of these adult clients requires quite different approaches than the traditionally more established congenitally deafblind rehabilitation clientele. The upsurge in this population has increased research efforts, some of which will be presented by members of this international panel. Bernadette Gavouyère (Canada) will set the initial tone by presenting “How to develop best practices in rehabilitation: The birth of a community of practice in deafblindness”, a presentation that will introduce a new tool towards improved evidence-based practice. She will be followed by Karen Keyes (Canada)

who will provide a life-span perspective, examining “Intervenor services for adults with congenital deafblindness in Ontario, Canada - how far have we come?”. “The importance of combined visual and auditory functions for the visual rehabilitation of clients with dual sensory loss” will be discussed in a presentation by Ton Roelofs (Netherlands), which then leads into a presentation by Peter Simcock (UK) who will provide a global view of “The UN Principles on Aging - A perspective on Deafblind Seniors”, which will specifically examine aging with either congenital or acquired combined vision and hearing loss. Finally, Walter Wittich (Canada) will conclude the session with an overview of three studies that examine “The stigma of assistive devices as experienced by older adults with combined vision and hearing loss”. Overall, the purpose of the session is to give an overview of key current topics in the domain of deafblindness, as they relate to aging across the lifespan.

Acknowledgement: Partial Funding for this symposium was provided by Deafblind International to promote the DBI Research Network (<http://research.deafblindinternational.org/>)

Symposium Presenters & working titles:

1. Gavouyère, Bernadette (Canada): How to develop best practices in rehabilitation: The birth of a community of practice in deafblindness
2. Keyes, Karen (Canada): Intervenor services for adults with congenital deafblindness in Ontario, Canada - how far have we come?
3. Roelofs, Ton (Netherlands): The importance of combined visual and auditory functions for the visual rehabilitation of clients with dual sensory loss
4. Simcock, Peter (UK): The UN Principles on Aging - A perspective on Deafblind Seniors
5. Wittich, Walter (Canada): The stigma of assistive devices as experienced by older adults with combined vision and hearing loss

1. How to develop best practices in rehabilitation: the birth of a community of practice in deafblindness

Bernadette Gavouyère, MSc

École optométrie, Université de Montréal, Québec, Canada.

Installation INLB, CISSS Montérégie-Centre, Longueuil, Québec, Canada,

Introduction: How to maintain and develop clinical expertise for rehabilitation professionals in deafblindness? Rehabilitation of people with visual and hearing impairments requires a specialized approach. Often expertise is gained over the years empirically. This is in many cases a "know how" and a "skill" held by professionals working in interdisciplinary way. Nowadays, however, rehabilitation professionals are increasingly encouraged to rely on scientific evidence to consolidate and develop the best clinical practices. Access to texts, research, publications and dedicated clinical tools allows for the development of this expertise.

Method: The virtual platform of deafblindness community of practice, (<http://cdpsurdicecite.org/> on-line since spring 2016) by the Institut Nazareth et Louis Braille, offers clinicians a tool for the development of clinical expertise in rehabilitation. This platform allows the sharing of knowledge about deafblindness that comes from the stakeholders themselves but also from the scientific literature. Activities in presented face-to-face and on-line allow for interactions on the deposited materials and promote joint development of new clinical practices. The analysis of indicators coming from real-time custom reports of the platform and that of member surveys allow leaders to follow the evolution of the community of practice and guide its development.

Results/conclusion: Our results allow us to conclude that the platform makes the gained knowledge more accessible, which is specifically useful in large institutional environments with mobile and changing human resources. It also helps build a network of members that can interact to develop expertise in rehabilitation and thus encourage the emergence of best practice.

2. DeafBlind Ontario Services, Canada: a holistic approach to providing Intervenor Services

Karen Keyes

DeafBlind Ontario Services, Ontario, Canada

Background: DeafBlind Ontario Services' holistic person-centered service model encompasses goal setting and resource allocation in alignment with persons' likes, strengths and abilities, choices, worries and fears and dreams that are supported by domains of living environment, recreation, community, social relationships, vocational, learning, activities of daily living, communication, health, orientation and mobility.

Aims: Guided by our Strategic priority of *Service Excellence – Sustain exceptional services for individuals who are deafblind*, we envisioned an evidence-based holistic service model to enrich the already successful intervenor services model. This holistic service model seeks collaboration of multi-

disciplinary service team consisting of Health Care Facilitator, Therapeutic Recreationist, Orientation and Mobility Specialist, and Sensory Exploration Arts Specialist with a central role of the Intervenor and the Client to enhance participation of clients in enriching his/her quality of life.

This presentation will illustrate how the holistic model was developed and give examples of the enhanced impact to a deafblind person daily life through the Sensory Exploration Arts Program and the Health Care Facilitator.

Sensory Exploration Arts (SEA™) promotes and fosters artistic expression of individuals with sensory impairments in a visual arts program. This stimulating and collaborative activity coordinated by Sensory Exploration Arts Specialist facilitates artistic expressions of individuals with deafblindness. Each individual can interact and express themselves according to their own needs. This program also includes the broader community through the inclusion of local artists who work with various art mediums.

Health care facilitation within the holistic service model focuses on the principle of care that focuses on wellness. A licensed practical nurse practitioner is an integral part on the holistic multi-disciplinary team and supports navigation amongst health care systems and ongoing consultation and support to Intervenors, clients and other allied service providers.

Funding: This presentation did not receive any funding

3. The importance of combined visual and auditory functions for the visual rehabilitation of clients with dual sensory loss

Roelofs, Antonius AJ, PhD¹ & Koopman, Jan, PhD²

¹ Royal Dutch Visio, Institute for visually impaired and blind people, Apeldoorn, The Netherlands; ²

Royal Dutch Visio, Institute for visually impaired and blind people, Amsterdam, The Netherlands

Background/aim: At Royal Dutch Visio, Institute for visually impaired and blind people, a significant number of clients have an auditory impairment, next to the visual impairment. However, for the visual rehabilitation, auditory compensation is one of the most important rehabilitation strategies. To assess the possibilities of auditory compensation, the auditory impairment and its implication for the visual rehabilitation must be assessed and the interaction of the impaired auditory functions with the impaired visual functions has to be investigated.

Content: Literature shows us that hearing can be subdivided into detecting sounds, distinguishing sounds, sound localisation, speech intelligibility in quiet, and speech intelligibility in noise. Therefore, a simple one-dimensional differentiation based on the pure tone-audiogram does not meet the actual needs. In order to assess the hearing impairments of our clients, we implemented a questionnaire in our client population, which was developed to differentiate between those different hearing functions. From approximately 400 clients of Visio Het Loo Erf (Centre for Intensive Visual Rehabilitation), data on the most relevant visual and auditory functions was collected. These clients also completed the above-mentioned questionnaire on auditory activities, as well as a questionnaire, on the experienced problems in activities of daily living. Through combining the auditory and the visual data, we obtained a better understanding of the interactions of these functions of both modalities, their influence and contribution on a number of activities in daily living.

Implications: For our visual rehabilitation programs, in particular the interaction between the visual field and auditory localisation is relevant. Also, visual acuity and contrast sensitivity related to speech perception capacities in quiet needs to be taken into account.

Funding: this work did not receive any funding.

4. The UN Principles on Aging – A perspective on Deafblind Seniors

Simcock, Peter^{1,2} & *Wittich, Walter*^{3,4,5}

¹ King's College London, London, UK; ² Staffordshire University, Stoke on Trent, UK;

³ Université de Montréal, Montréal, Canada; ⁴ CRIR/Centre de réadaptation MAB-Mackay du CIUSSS du Centre-Ouest-de-l'Île-de-Montréal; ⁵ CRIR/Institut Nazareth et Louis-Braille du CISSS de la Montérégie-Centre

Background/aim: In 1991, the UN General Assembly adopted *The United Nations' Principles for Older Persons*. Their purpose is to guide and encourage governments to incorporate them whenever possible. Given their generality, it is not surprising that implementation and assessment has been difficult. In order to enable implementation in a specific context, they have previously been discussed from the viewpoint of older adults with visual impairment. The present paper aims to replicate this effort in order to facilitate the transition from rhetoric to action; however, this time from the perspective of older deafblind adults.

Content: The five major groupings of the UN Principles (independence; participation; care; self-fulfillment; and dignity) are used as a conceptual framework to explore existing research and public

policy relating to older deafblind populations. As a result of demographic changes in developed countries, and consequent increase in the older deafblind population, research into the needs of this group has increased and gained visibility; much of this literature focuses on the experiences of those with late life acquired deafblindness rather than those aging with the impairment. However, various research and knowledge gaps are identified across the five major groupings, reflecting the embryonic nature of research in this field. The existing literature suggests that the UN Principles are yet to be fully realised for the growing number of deafblind seniors.

Implications: Exploring research through the lens of the *UN Principles for Older Persons* may provide a useful framework for future researchers engaged in the field, and can offer those in the policy community a structure within which rhetoric can be translated into action, thereby supporting the older deafblind population.

Disclosure: WW holds a Junior 1 Career Salary Award from the *Fonds de recherche en santé du Québec*

5. Stigma and Age-related Dual Sensory Impairment: perspectives of the media, clinicians and clients

Wittich, Walter^{1, 2, 3}, Fraser, Sarah⁴ & Southall, Kenneth^{5, 6}

¹ School of Optometry, Université de Montréal, Montréal, Canada; ² CRIR/Centre de réadaptation MAB-Mackay du CIUSSS du Centre-Ouest-de-l'Île-de-Montréal, Canada;

³ CRIR/Institut Nazareth et Louis-Braille du CISSS de la Montérégie-Centre, Longueuil, Canada; ⁴ Interdisciplinary School of Health Sciences, University of Ottawa, Ottawa, Canada; ⁵ Centre de recherche de l'Institut universitaire de gériatrie de Montréal, Canada;

⁶ School of Social Work, McGill University

Introduction: With an ageing population, there is an increase in the prevalence of multiple chronic health conditions, such as combined vision and hearing loss. Traditionally, explorations into the health care stigma have focused on one impairment. This approach does not account for the possibility of experiencing multiple stereotype threats, as is the case in dual sensory impairment (i.e., vision and hearing). Three studies were conducted to better understand and describe the stigmatization associated with dual sensory impairment.

Methods: In Study 1, we examined the presence and promotion of stereotypical information in Canadian print media through a discourse analysis of articles in the *Globe&Mail* newspaper. In Study 2, we employed in-depth interviews to better understand the attitudes and perceived roles of health professionals who work with this population. In Study 3, we solicited the perspective of older adults with dual sensory impairment through in-depth interviews to give them a voice on the topic of stereotyping and depict their lived experiences.

Results: While Study 1 provided numerous examples of stereotypes that are being perpetuated in the media, the perspectives of clinicians in Study 2 did not reflect these same issues. Instead, health professionals identified their responsibilities in a very positive light, while at the same time stating that their roles often extended beyond their specific professional scope. In Study 3 we found that most participants had not experienced stereotyping, or denied that stereotyping was important to them. Other participants described powerful examples of borderline mistreatment.

Conclusion: These studies were the first to examine stigma and stereotyping in the context of older adults with dual sensory impairment and provide some clarity on the importance of stigma to the rehabilitation process. In addition, these studies highlight the significance of context and individual factors that can strongly affect the perception and impact of the stigma associated with multiple impairments.

Funding: Funded by the Quebec Ministry for Aging and Family.