Emancipatory Disability Research in the field of Deafblindness or Dual Sensory Impairment: Problems and Possibilities

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955, d'Assigny – door 139
Longueuil (Québec) J4K 5C3
Phone: 450 463-1710, ext. 346
Toll free: 1 800 361-7063, ext. 346
Fax: 450 670-0220
E-mail: braille.inlb@ssss.gouv.qc.ca

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# Emancipatory Disability Research in the field of Deafblindness or Dual Sensory Impairment: Problems and Possibilities

ATUL JAISWAL, Postdoctoral fellow, École d'optométrie, Université de Montréal

**20e Symposium scientifique sur l'incapacité visuelle et la réadaptation**

Symposium organisé par l'École d'optométrie de l'Université de Montréal, l'Institut Nazareth et Louis-Braille du CISSS de la Montérégie-Centre et le centre de réadaptation Lethbridge-Layton-Mckay du CIUSSS du Centre Ouest de l'Ile de Montréal, Montréal, 4 février 2020.

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	+ Sense International India
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## Background

* Year 1904
	+ {Illustration: Helen Keller}
* Year 2016
	+ {Illustration: Haben Girma}

{Comments}

People with deafblindness are one of the most under-represented populations in the field of health and disability research. Although we have world renowned people with deafblindness such as Helen Adams Keller (first deafblind graduate in 1904 in USA) and Haben Girma (Harvard Law School's 1st Ever Deaf & Blind Graduate in 2016 in USA), deafblindness remains an invisible condition and people with deafblindness remain an invisible population in the mainstream society. 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. This invisibility could be attributed to the following reasons: (a) researchers found it challenging to collect data from people with deafblindness with significant communication challenges; and (b) there exists no distinct methodology to conduct deafblind research owing to fact that there is heterogeneity in the deafblind population and variations exists in terminologies and definitions used to report this population worldwide (Ask Larsen & Damen, 2014; Dammeyer, 2015; Wittich et al, 2013).

There exists a lack of scientific research that directly voices the opinions and perceptions of people with deafblindness themselves. Majority of research conducted on deafblindness has very often not 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. In instances where the data is collected from persons with deafblindness, it is very often limited to people with dual sensory loss or acquired conditions where the speech or communication is not affected significantly due to deafblindness.

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## Deafblindness is a unique disability, causing extreme challenges…

95% of what we learn is through our eyes and ears.

Deafblindness combines varying degrees of both hearing and visual impairment.

"DUAL SENSORY IMPAIRMENT"

The varying combination of hearing and vision impairment results in **a unique condition** that is **more disabling than the sum of its impairments**

Source: Dammeyer, 2014; Moller, 2003

{Illustration not described}
Legend: Imagine what it is like to be a person with deafblindness

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Current estimates from Global report (2018) suggest it to be around **2% of the world population – approx. 150 million in the world**.

– In developed nations, number of older adults with dual sensory loss is rising and estimated to be 14.5 million in North America by 2036.

Source: Brennan & Bally, 2007

{Illustration}

Logo: World Federation of the Deafblind

**At risk of exclusion from CRPD and SDGs implementation: Inequality and Persons with Deafblindness**

Initial global report on situation and rights of persons with deafblindness
September 2018

Illustrations not described.

{/Illustration}

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## Different research paradigms used in the field of disability research

*Paradigms are "general philosophical orientation about the world and the nature of research that a researcher brings to a study"*

Source: Creswell, 2014, p. 6

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### Purpose of research

1. **Post-positivist:** Explanation, prediction and control of phenomena
2. **Constructivist:** Reconstruction of the constructions that people hold
3. **Participatory:** Transformation (improve the quality of life)
4. **Critical:** Confrontation of the oppressive structures

Source: Brown, 2001; Guba & Lincoln, 1994; Oliver, 2009; Swain & French, 2000.

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### Control of research

1. **Post-positivist:** Unequal power relationships; full control in the hands of researcher
2. **Constructivist:** Control and power is shared and researcher desire participants to take an increasingly active role
3. **Participatory:** Control is shared to varying degrees
4. **Critical:** Control and power resides in "transformative intellectual"

Source: Brown, 2001; Guba & Lincoln, 1994; Oliver, 2009; Swain & French, 2000.

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### Role of researcher and participants

1. **Post-positivist:** Professional inquirer; Participants are "subjects" of research; and their voices missing
2. **Constructivist:** Facilitator of multivoice reconstruction; Voices of participants are included
3. **Participatory:** Researcher and participants acts as a "active collaborators"
4. **Critical:** Advocate and activist; researcher's voice as a "transforming intellectual"

Source: Brown, 2001; Guba & Lincoln, 1994; Oliver, 2009; Swain & French, 2000.

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### Emancipatory potential

1. **Post-positivist:** (have no emancipatory potential)
2. **Constructivist:** (may/may not have emancipatory potential)
3. **Participatory:** (may have emancipatory potential)
4. **Critical:** (Emancipatory)

Source: Brown, 2001; Swain & French, 2000.

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## Emancipatory research paradigm

**Principles of EDR**

* Plurality of methods
* Self-emancipation
* Reciprocity
* Devolution of control of research
* Raise consciousness
* Empowerment
* Shared gain and knowledge

{Comments}

* In 1992, Mike Oliver coined the term "emancipatory disability research" to refer to a new radical approach which was about the empowerment of people with disabilities through the transformation of material and social relations of research production in the field of disability; breaking down the traditional researcher-researched hierarchy (Barnes, 2003); and strengthening the links between research and policy initiatives (Barnes and Mercer, 1997).
* Oliver (1992) stressed that "emancipatory paradigm implies facilitating a politics of the possible by confronting social oppression at whatever level it occurs" (p. 110).
* Emancipatory research exposes the mechanisms for producing, maintaining and legitimising social inequities and oppression faced by the marginalized populations in the society (Vernon, 1997).
* Emancipatory paradigm implies shifting the control from the researcher to the researched (Oliver, 1997) which requires researchers to learn to put their knowledge and skills at the disposal of the researched to use (Barnes, 1992).

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## Strategies to be employed to achieve emancipatory goals

1. Operationalize the concept of disability based upon the notion that disability is a social creation (Oliver, 1996);
2. Involve participants from the beginning of the research to decide upon the research agenda, choice of topic, its objectives, method of data collection and analysis, its dissemination, and use for transformation (Vernon, 1997);
3. Locate causes of the problems faced by disabled people in the structures of an oppressive society rather than in the individual by using neutral but enabling language (Oliver, 1992);
4. Treat the participants as co-researchers in co-creation of the reality of their lived experience (Stone & Priestley, 1996);
5. Be creative in research design by using multiple innovative methods of engagement (Cameron, 2014); and
6. Be ready for scrutiny for idea, methods, and the generated knowledge from the research (Lunn and Munford, 2007).

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In the case of developing nations (such as India), there exists further marginalization of deafblind population from mainstream development and research due to either of three reasons: (a) a majority of deafblind population in developing nations belong to congenital group as more than 100,000 children continue to be born with Congenital Rubella Syndrome each year worldwide (Sense International, 2015; World Health Organization, 2017), (b) less deafblind specific interventions exists in these countries (Sense International, 2015), or (c) fewer research publications stems out from the programs that do exist (Eide, & Ingstad, 2013; Sense International India, 2014).

However, research can be used as a powerful tool to empower persons with deafblindness and help to mainstream their voices. The principles of emancipatory disability research as outlined by Oliver (1992, 1997); Barnes (2002); and Stone & Priestly (1996) may help the researchers to – (a) reach out to those individuals with deafblindness who very often fall into exclusion criteria of mainstream research, and (b) find solutions to overcome the challenges in conducting deafblind research.

This presentation is based on the fieldwork experiences of conducting Ph.D. research on participation for persons with deafblindness in India. Adhering to principles of emancipatory disability research, I used some key elements of emancipatory disability research to overcome the challenges associated with conducting interviews directly with adults with congenital and acquired deafblindness. This presentation tries to shed some light on the challenges in qualitative interviewing with 16 adults with deafblindness and how those challenges were addressed to ensure participants with deafblindness felt empowered and actively contributing to the research process.

The data collection of my research study involved in-depth qualitative interviews with 16 adults with congenital and acquired deafblindness at two locations – Delhi and Ahmedabad (Sense International India Regional Learning Centre on Deafblindness catering to deafblind population from Northern and Eastern, and Western and Southern regions of India, respectively). The period of data collection was for almost three months starting from March 28, 2017 to May 29, 2017. The population of participants for interview was heterogeneous in nature, in terms of their clinical presentation, mode of communication, and demographics (Male – 8; Female – 5; Congenital – 3; Acquired – 13)

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## A case study: Participation of persons with deafblindness in India

### Qualitative research study

* This case study is based on the fieldwork experiences of conducting Ph.D. research on participation for persons with deafblindness in India.
* The data collection involved in-depth qualitative interviews with 16 adults with congenital and acquired deafblindness.
* The principles of emancipatory disability research (EDR) as outlined by Oliver (1992, 1997); Barnes (2002); and Stone & Priestly (1996) may help the researchers to find solutions to overcome the challenges in conducting deafblind research.
* The population of participants for interview was heterogeneous in nature, in terms of their clinical presentation, mode of communication, and demographics (See Table 1)

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| **SN** | **Age / Gender** | **Type and Onset of disability** | **Mode of communication used during interviewing** |
| --- | --- | --- | --- |
| 1 | 18/F | Acquired; Progressive HI and VI at the age of 12 | Sign language, speech, lip reading, large print, and interpreter support  |
| 2 | 40/M | Acquired; HI (at 7 years) and low vision (by birth) | Speech, lip reading, writing on paper |
| 3 | 21/M | Acquired; HI(at 6 months) and VI (night-blindness at 3 years) | Sign language, large print, print on palm, and interpreter support |
| 4 | 45/M | Acquired; VI (by birth) and HI (at 13 years) | Speech, loud voice in left ear, Braille, and interpreter support (specific pitch) |
| 5 | 38/M | Acquired; HI (by birth) and VI (at 14 years) | Sign language (local), gestures, print on palm, and interpreter support |
| 6 | 25/F | Congenital; HI (by birth) and VI (at 2 months) | Braille, Refreshable braille display (in Tablet for questions), and interpreter support  |
| 7 | 42/M | Acquired; HI (by birth) and VI (at 9 years) | Print on Palm, Refreshable braille display in computer (via Facebook) |
| 8 | 35/M | Acquired; HI (by birth) and VI (at 24 years) | Braille, Print on Palm, Large prints, Tactile sign language, gestures, and interpreter support |
| 9 | 34/F | Acquired; HI (by birth) and VI (at 4 years) | Sign language (local), Gestures, and interpreter support |
| 10 | 24/F | Acquired; VI (at 5 years) and HI (at 9 years) | Speech, Large print using magnifier, Sign language, finger spelling, and interpreter support |
| 11 | 25/M | Congenital; HI (by birth) and VI (at 3 years) | Speech, Braille, Print on Palm, and interpreter support  |
| 12 | 26/M | Acquired; HI (at 8 years) and VI (at 10 years) | Speech, Large print using magnifier, and interpreter support |
| 13 | 34/M | Acquired; HI (at 10 years) and VI (at 29 years) | Large print using magnifier in computer (via Facebook) |
| 14 | 18/M | Acquired; VI (by birth) and HI (at 3 years) | Speech, Large print, and Braille |
| 15 | 23/F | Acquired; VI (at 5 years) and HI (at 9 years) | Skype with JAWS software |
| 16 | 21/M | Congenital; By birth (VI and HI) | Skype with Refreshable Braille Display device, and interpreter support for tactile sign language and typing in computer |

{Comments}

I interviewed participants (age 18-45 years; 5 female and 11 male; 3 congenital and 13 acquired) using a qualitative semistructured interview guide 39 at community partner's premises between March and May 2017. We started interviews with demographic questions and then used the interview guide with the probes to facilitate the discussion and obtain detailed information. We asked participants about their preference for the interview process (eg, face-to-face, online using communication technology, or with the help of sign language interpreter) to facilitate their independence. We used diverse communication modes and made interview questions accessible to participants with support of different technical aids such as computers with accessible features (JAWSa screen reader program, refreshable braille devices), magnifiers, large print, braille, print-on palm, lip reading. Certified interpreters helped with visual and tactile sign language (table 3). Of the 16 interviews, 12 were carried out face-to-face interviews and ranged from 1.5 to 2.5 hours in length. Another 4 interviews that were conducted using online platforms lasted for 2 to 5 hours depending on the typing speed of the participants.

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### Challenges and strategies used

There are methodological challenges in conducting research that ranges from difficulties in taking informed consent process to the member checking process at the end of qualitative interviews with them.

| **S.N.** | **Challenges** | **Strategy used(based on EDR principles)** |
| --- | --- | --- |
| 1 | Challenges in engaging them in research | Reasonable accommodations (accessible formats, giving interview questions before hand to prepare, extra time to answer) |
| 2 | Difficulty in obtaining informed consent | Use of informed consent documents in accessible formats |
| 3 | Dependency on interpreter | Use or technology (Refreshable braille device, Facebook, Skype) |
| 4 | Difficulty in getting rich data in interviewing | Use of diverse communication methods (Speech, sign language, large print, print on palm, magnifier, braille) |
| 5 | Difficulties to get elaborated answer | Plurality of communication methods to probe |
| 6 | Difficulty in ensuring rigor | Member checking with the participants |

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{Comments}

The preliminary findings from the interviews directly with adults with deafblindness 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. Some of the challenges and strategies used are highlighted in the table.

Adhering to the principles of emancipatory research for provision of research materials in accessible formats, I asked participants how they would prefer to be interviewed and receive the interview questions so that they can read it and answer it independently. Diverse communication modes were used and questions were made accessible to participants with support of technology (computers with accessible features [software - Job Enabled Speech software (JAWS)], refreshable braille devices, and magnification features), large prints, Braille, speaking loudly in ear which had residual hearing, writing on palm, and interpreters for tactile sign language, gestures, and local language. I provided them with reasonable accommodations such as giving interview questions beforehand to prepare, ample time to understand and answer each question, probes of various types, allowing them to write answers on paper (if they found difficult to articulate it), conducting interviews at a place distraction-free and convenient for participants, and allowed presence of family members during interview. Probing was accomplished using diverse communication modes. It was more of hit and trial at the beginning, but gradually it went well.

For participants who would like to be interviewed using an online platform, Facebook and Skype were used to conduct interviews with them as it has reduced their dependency on interpreters and facilitated their independence and autonomy.

During data collection, providing the information in accessible formats, allowing the participants to discuss beyond the research focus, to give control and autonomy of the discussion, and allowing them to be critical of the researcher's position are some of the elements of EDR. Member checking at the end of interviews and with the transcripts ensured rigor and trustworthiness of the data collected.

{/Comments}

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### Key take away

* Persons with deafblindness are invisible from medical and rehabilitation science literature, but 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.
* Making them feel valued by warm welcome, treating them as knowledgeable, providing reasonable accommodations and ample time to build rapport, and showing sensitivity and empathetic understanding of their condition might break the barrier of communication.
* Alternative modes of communication and assistive technology can be a powerful tool to overcome challenges and facilitate to mainstream their voices.

{Illustration not described}

{Comments}

Persons with deafblindness are invisible from medical and rehabilitation science literature, but 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.

Our research helps to mainstream the voices of persons with deafblindness and reveals their feelings about themselves, others, and about the social systems with which they engage on regular basis.

Making them feel valued by warm welcome, treating them as knowledgeable, providing reasonable accommodations and ample time to build rapport, and showing sensitivity and empathetic understanding of their condition might break the barrier of communication. Technology can be a powerful tool to overcome challenges and facilitate research with this population.

{/Comments}

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{Web Screenshot}

**RESEARCH ARTICLE**

**Participation experiences of people with deafblindness or dual sensory loss: A scoping review of global deafblind literature**

Atul Jaiswal{n1, n±, n\*}, Heather Aldersey{n1}, Walter Wittich{n2, n3, n‡}, Mansha Mirza{n4, n‡}, Marcia Finlayson{n1, n‡}

{n1} School of Rehabilitation Therapy, Queen's University, Kingston, Ontario, Canada

{n2} School of Optometry, University of Montreal, Montreal, Quebec, Canada

{n3} School of Physical and Occupational Therapy, McGill University, Montreal, Quebec, Canada

{n4} Department of Occupational Therapy, University of Illinois at Chicago, Chicago, Illinois, United States of America

{n±} This authors contributed equally to this work.

{n‡} These authors also contributed equally to this work.

{n\*} atul.jaiswal@queensu.ca

**Abstract**

**Background:** Deafblindness, also known as dual sensory loss, is a varying combination of visual and hearing impairment in the same individual. Interest in this topic has increased recently due to evidence suggesting an increase in prevalence of this condition among older adults. Persons with deafblindness frequently experience participation barriers and social isolation. Developing an understanding of their experiences can inform the design of programs and policies to enhance participation of people with deafblindness in society.

**Objective:** To identify and summarize available research literature on participation experiences of people with deafblindness or dual sensory loss.

**Citation:** Jaiswal A, Aldersey H, Wittich W, Mirza M, Finlayson M (2018) Participation experiences of people with deafblindness or dual sensory loss: A scoping review of global deafblind literature. PLoS ONE 13(9): e0203772. <https://doi.org/10.1371/journal.pone.0203772>

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{/Web Screenshot}

{Slide 19}

{Web Screenshot}

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**Journal Disability and Rehabilitation**

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**Meaning and experiences of participation: a phenomenological study with persons with deafblindness in India**

Atul Jaiswal, Heather M. Aldersey, Walter Wittich, Mansha Mirza & Marcia Finlayson

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{/Web Screenshot}

{Slide 20}

{Web Screenshot}

Logo ACRM American Congress of Rehabilitation Medicine

**Archives of Physical Medicine and Rehabilitation**

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Archives or Physical Medicine and Rehabilitation 2019

**ORIGINAL RESEARCH**

**Using the ICF to Identify Contextual Factors That Influence Participation of Persons With Deafblindness**

Atul Jaiswal, PhD {nA} Heather M. Aldersey, PhD{nA} Walter Wittich, PhD, FAAO, CLVT{nB} Mansha Mirza, PhD, OTR/L{nC} Marcia Finlayson, PhD, OTR/L{nA}

{nA} School of Rehabilitation Therapy, Queen's Université, Kingston, Ontario, Canada;

{nB} School of Optometry, University of Montréal, Montreal, Quebec, Canada;

{nC} Department of Occupational Therapy, University of Illinois at Chicago, Chicago, Illinois.

**Abstract**

**Objective:** To identify and describe the contextual factors that influence the participation of people with deafblindness in India.

**Design:** Qualitative study, using directed content analysis approach and the International Classification of Functioning, Disability and Health (ICF) as a framework to analyze the data.

**Setting:** Community and social participation settings.

**Participants:** Community-dwelling individuals with deafblindness (N = 16). Age ranges from 18-45 years.

**Interventions:** Not applicable.

**Main Outcome Measures:** Personal and environmental factors that influence the participation of individuals with deafblindness using the ICF framework.

**Results:** Results indicate that the age of onset and nature of impairment (deafblindness) and willingness to explain the condition (functional consequences of deafblindness) emerged as important personal factors. Access to resources such as assistive technology, social support, and deafblind-specific services were found to be enablers of participation. Lack of services, systems, and policies specific to deafblindness along with negative societal attitude toward disability were highly perceived environmental barriers that influence participation of people with deafblindness in India.

{/Web Screenshot}

{Slide 21}

## Thank…

"The problem is not how to wipe out all differences, but how to unite with all differences intact"

– Rabindranath Tagore

## For Contact

**Atul Jaiswal, PhD**IRSC/CIHR Health System Impact Post-doctoral Fellow in Vision Science,
Wittich Vision Impairment Research Laboratory,

École d'optométrie,
Université de Montréal,
3744, rue Jean-Brillant, Bureau 6442, Montréal, H3T 1P1

Email: atul.jaiswal@umontreal.ca
Twitter: @atuljais111

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