PARTICIPATION OF PERSONS WITH DEAFBLINDNESS IN INDIA

by

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Abstract

Worldwide research on deafblindness is sparse, particularly in low and middle-income countries such as India. Persons with deafblindness often experience participation barriers. Yet little is known about their lived experience of participation, influencing factors, and ways to enhance it. To address this evidence gap, this phased study aimed to synthesize evidence on the participation experiences of persons with deafblindness (Phase 1); to understand what participation means to persons with deafblindness in India (Phase 2); and to describe the contextual factors that influence the participation of persons with deafblindness from the perspectives of those with deafblindness and their service providers (Phase 3). To fulfill the aims, I conducted scoping review in Phase 1, and qualitative interviews with 16 persons with deafblindness and two focus group discussions with 16 professionals in Phases 2 and 3. Interviews and group discussions were guided by the International Classification of Functioning, Disability and Health. The understanding of participation experiences and influencing contextual factors suggest ways to enhance the participation of persons with deafblindness. Findings indicate participation as a dynamic, individualized construct that is not just an end outcome. Rather, it is a means to achieve other goals important to the participants such as gaining respect, autonomy, independence, support and relationships, to fulfil aspirations and responsibilities, and to feel included and recognized in society. Life domains that persons with deafblindness value for participation were access to information, communication, mobility, relationships, education and productivity, and recreation and leisure. Resources, such as deafblind-specific rehabilitation services, alternative communication modes, and technology/aids (e.g., hearing aids, cochlear implants, refreshable braille displays, and magnifiers) were helpful in improving access to information, communication and social interactions, and thus important for enhancing participation. Results suggest that rehabilitation services and policies must be designed to focus on life domains that persons with deafblindness value. It is also important to address
environmental barriers such as lack of awareness about deafblindness among the public, negative societal attitudes, and limited resources to support the participation of those with deafblindness.
Co-Authorship

The manuscripts presented in this thesis are the work of Atul Jaiswal. For all manuscripts, Mr. Jaiswal was responsible for: conceptualization, developing the research questions and the study design; developing research tools including interview and focus group discussion guides; transcribing and analyzing data; and writing the manuscripts. The co-authors of the manuscripts are Dr. Heather M. Aldersey (Chapters 2-5), Dr. Marcia Finlayson (Chapters 2-5), Dr. Mansha Mirza (Chapter 2-5), and Dr. Walter Wittich (Chapter 2-5).

Chapter 2: Participation experiences of people with deafblindness or dual sensory loss: A scoping review of global deafblind literature. This manuscript has been published in PLOS ONE. Dr. Aldersey provided input regarding idea conceptualization, developing the research question, analyzing data and guidance in writing the manuscript. Dr Finlayson provided recommendations regarding conceptualization of research question, development of the manuscript, and editorial feedback on the manuscript. Dr. Mirza provided guidance in conceptualization of research question, development of the manuscript, interpretation of study results, and provided editorial feedback on the manuscript. Dr. Wittich provided input regarding conceptualization of research question, development of the manuscript, interpretation of the results, and provided editorial feedback on the manuscript.

Chapter 3: Meaning and experiences of participation: A phenomenological study with persons with deafblindness in India. This manuscript has been published in Disability and Rehabilitation. Dr. Aldersey provided input regarding development of the research question and interview guide, training regarding use of the interview guide, guidance in analyzing data and writing the manuscript, and provided editorial feedback on the manuscript. Dr Finlayson provided recommendations regarding conceptualization of research question, development of the
manuscript, and editorial feedback on the manuscript. Dr. Mirza provided guidance in conceptualization of research question, interpretation of study results, development of the manuscript, and provided editorial feedback on the manuscript. Dr. Wittich provided input regarding conceptualization of research question, interpretation of the results, development of the manuscript, and provided editorial feedback on the manuscript.

**Chapter 4: Using the ICF to examine contextual factors that influence participation of persons with deafblindness in India.** This manuscript is currently under review at *Archives of Physical Medicine and Rehabilitation*. Dr. Aldersey provided input regarding conceptualization of the research question and interview guide, training regarding use of the interview guide, guidance in data analysis and writing the manuscript, and provided editorial feedback on the manuscript. Dr Finlayson provided recommendations regarding conceptualization of research question, development of the manuscript, and editorial feedback on the manuscript. Dr. Mirza provided guidance in conceptualization of research question, interpretation of study results, development of the manuscript, and provided editorial feedback on the manuscript. Dr. Wittich provided input regarding conceptualization of research question, interpretation of the results, development of the manuscript, and provided editorial feedback on the manuscript.

**Chapter 5: Rehabilitation service providers’ perspectives on factors that influence participation of persons with deafblindness in India.** This manuscript is currently under review at *Disability and Rehabilitation*. Dr. Aldersey provided guidance in the conceptualization of research question, study design, and focus group discussion guide, provided input in analyzing data and writing the manuscript, and provided editorial feedback on the manuscript. Dr Finlayson provided recommendations regarding conceptualization of research question, development of the manuscript, and editorial feedback on the manuscript. Dr. Mirza provided guidance in
conceptualization of research question, interpretation of study results, development of the manuscript, and provided editorial feedback on the manuscript. Dr. Wittich provided input regarding conceptualization of research question, interpretation of the results, development of the manuscript, and provided editorial feedback on the manuscript.
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Dedication

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In the words of the great influential American Poet Robert Frost,

“Two roads diverged in a yellow wood, and sorry I could not travel both . . . and I—
took the one less traveled by, and that has made all the difference”
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List of Abbreviations

ADL  Activities of daily living
AAC  Augmentative and Alternative Communication
BRTS Bus Rapid Transit System
Db   Deafblindness
DSI  Dual sensory impairment
DSL  Dual sensory loss
FGD  Focus group discussion
Grp  Group
HI   Hearing impairment
ICF  International Classification of Functioning, Disability and Health
INR  Indian National Rupees
JAWS Job Access-With Speech
LMICs Low and Middle-Income Countries
PRISMA Preferred Reporting Items for Systematic Reviews and Meta-analysis
RLC  Regional Learning Centers on Deafblindness
RP   Retinitis Pigmentosa
SII  Sense International India
SDGs Sustainable Development Goals
UNCRPD United Nations Convention on the Rights of Persons with Disabilities
Ush  Usher syndrome
VI   Visual Impairment
WHO  World Health Organization
Chapter 1

General Introduction: Setting the stage

“Blindness cuts us off from things, but deafness cuts us off from people”
-  Helen Keller, Gallaudet University Library

1.1 Overview: Why is participation important for persons with deafblindness?

People, regardless of whether they have a disability, generally like to participate in social and daily living activities and strive to lead meaningful lives (Cardol, Jong, & Ward, 2002). Participation is an important construct, measurement variable, and highly valued rehabilitation outcome (Hammel et al., 2008; Mallinson & Hammel, 2010). Moreover, it is also central to major models of disability (Magasi, Hammel, Heinemann, Whiteneck, & Bogner, 2009) and important human rights legislations such as United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (United Nations, 2006). However, despite its centrality in rehabilitation and human rights discourse, the meaning of “participation” is vague in the literature – warranting more research (Cornwall, 2008; Eversole, 2012; Mirza & Hammel, 2011; Mirza, Magasi, & Hammel, 2016).

Disability studies researchers such as Oliver (1996) stated that people with disabilities are deprived of their full participation in society and face isolation, discrimination, and exclusion at individual and collective levels (Oliver, 1996). The opportunities of participation for people with disabilities are restricted by social and economic inequalities and barriers such as conditions of poverty, education and employment disparities, discriminatory policies and practices, inadequate access to healthcare, and inaccessible transportation, housing, and information technologies (Mirza et al., 2016). Within the overall population of people with disabilities, people with deafblindness represent a unique population (Lagati, 1995; McInnes, 1999).
Deafblindness is a distinct disability with a combination of concurrent visual and hearing impairments affecting communication, mobility, and access to information from the outside world (Ask Larsen & Damen, 2014; Dammeyer, 2014, 2015; Sense International India, 2014; Wittich, Southall, Sikora, Watanabe, & Gagné, 2013). Persons with deafblindness often face significant challenges in their participation, frequently face social isolation, and do not get opportunities to contribute to the socio-economic-political world (Hersh, 2013a; Möller & Danermark, 2007; World Federation of the Deafblind, 2018).

Despite the push from international legislations such as UNCRPD, researchers in general rarely include people with communication disabilities such as deafblindness in research due to the complex nature of the disability and methodological challenges involved with participant recruitment and data collection (Dammeyer, 2015; Wittich, Jarry, Groulx, Southall, & Gagné, 2016; World Federation of the Deafblind, 2018). Hence, deafblindness is an understudied topic, and people with deafblindness remain one of the most under-represented populations in the disability and rehabilitation science fields globally (Dammeyer, 2014, 2015; Danermark & Möller, 2008; Murdoch, 2002) and even more so in India (Jaiswal, Kumar, & Paul, 2018).

A preliminary review reveals that the literature on people with deafblindness is dominated by studies conducted in Western countries and there are hardly any studies on the topic from low and middle-income countries (LMICs) in the Global South such as India (Jaiswal et al., 2018). Moreover, research in this area is dominated by quantitative cross-sectional studies that often rely on information from proxies (e.g., family members or professionals working with them). There exists a lack of evidence on participation experiences of people with deafblindness that could inform policy and programs. Yet, through qualitative research, there is a potential to gain insights into their lives to understand the lived experiences of participating in society. The process of grounding the research on “participation”, using both the perspectives of persons with deafblindness and rehabilitation service providers working with them may help in understanding
their participation experiences and identifying ways of enhancing their participation in society. This understanding could then inform the services designed for persons with deafblindness to improve support for their full participation in society. Furthermore, since the Government of India is a signatory to the UNCRPD and has officially recognized deafblindness as a distinct disability condition for the first time in the newly enacted, rights-based ‘The Rights of Persons with Disabilities Act, 2016’ (Government of India, 2016), it is timely to conduct a study and propose a set of recommendations for the government and non-profit sectors in India on how to enhance the participation of these individuals in society.

1.2 Objective of the doctoral thesis

The overall purpose of this doctoral thesis is to build an understanding of participation experiences of persons with deafblindness in India and to identify ways to enhance their participation in society. The aim is achieved by answering the following four research questions:

1.3 Research questions

1) What does the existing literature report about the experiences of participation for persons with deafblindness in society?

2) What does participation mean to persons with deafblindness in India?

3) What self-reported contextual factors influence the participation of persons with deafblindness in India?

4) What are the contextual factors identified by rehabilitation service providers that influence the participation of persons with deafblindness in society?

1.4 Reflexivity statement and personal motivation

Reflexivity is a process by which researchers are able to examine and question their own attitudes, beliefs, thoughts, values, positionality and ambitions that might shape the research interest and thus its focus (Clancy, 2013; Hopkins, Regehr, & Pratt, 2017; Moustakas, 1994).
This research relates to my own academic and personal journey since 2009 as an occupational therapist and a disability rehabilitation social worker trained in India. I worked as a disability rehabilitation professional in multiple settings like hospitals, clinics and non-governmental organizations for people with disabilities. Before coming to Canada, I worked with children and adults with deafblindness for three years in a national level deafblind organization – Sense International India, and I shared the joy of engaging with them and understanding their lives closely – their success stories and their failures. While working with them, there were times when I felt myself less equipped and felt the need to gain more knowledge and skills to better facilitate their participation in society. I wanted to explore the participation experiences of persons with deafblindness of navigating the world that is designed suiting the needs of a majority, non-disabled population, and understand the ways their participation could be enhanced in society. I believe in possibilities of conducting mainstream research including individuals with deafblindness, and feel it is my responsibility to mainstream the voices of persons with deafblindness using my research.

It is equally important to acknowledge my position as a non-disabled researcher with training in occupational therapy (clinical) and social work (social sciences), and how my own preconceptions and experiences might influence the research process, findings and its interpretation (Hopkins et al., 2017; Johnston, Wallis, Oprescu, & Gray, 2017). To ensure my research provided a venue for persons with deafblindness to be heard, I maintained epoché and employed bracketing and reflexivity throughout the research process (Clancy, 2013; Moustakas, 1994; Tufford & Newman, 2012). I tried to set aside all my preconceptions to take a fresh perspective to understand the lived experiences of persons with deafblindness from their point of view (Liamputtong, 2013).

In the next section, I present what is deafblindness in the global context, why it is a unique condition, and how it has been operationally defined in the context of this study.
1.5 Deafblindness

Worldwide, deafblindness is used as an umbrella term to describe individuals with dual sensory loss/impairment and ranges from mild loss in hearing and vision to total deafness and blindness depending upon its various combinations (Dammeyer, 2014; Wittich et al., 2013). A range of terminologies are used to refer to this impairment, such as deafblindness, dual sensory loss, or combined vision and hearing impairment (Ask Larsen & Damen, 2014; Dammeyer, 2014; Saunders & Echt, 2007; Wittich et al., 2013). Individuals with deafblindness are a heterogeneous population and can be classified into three categories. Group 1 consists of people with congenital/pre-lingual deafblindness (e.g., Congenital Rubella Syndrome). Group 2 consists of people with acquired/post-lingual deafblindness – people who have single sensory impairment (vision or hearing) by birth and then subsequently acquire another (vision or hearing) impairment (e.g., Usher Syndrome). Group 3 consists of older adults who were able to hear or see for most their lives but later develop dual sensory loss/impairment of vision and hearing due to age-related changes/diseases to senses (e.g., age-related macular degeneration, cataract, presbycusis) (Brennan & Bally, 2007; Dammeyer, 2014, 2015; Wittich, Watanabe, & Gagné, 2012).

There are an estimated 500,000 persons with deafblindness in India (Paul, Mathew, Kumar, Rizal, & Jaiswal, 2016); 390,000 people with deafblindness in United Kingdom (Sense UK, 2018); 150,000 in European Union (Hersh, 2013b); 10,000 in United States (Rönnberg & Borg, 2001); and 3306 in Canada (Watters, Owen, & Munroe, 2005). It must be noted here that since these estimates were done in different years using varying definition of deafblindness, these numbers may now be different.

Researchers from the National Health and Nutritional Examination Surveys in United States in 2013 revealed that a large number of individuals with deafblindness are being underreported and undiagnosed (Swenor, Ramulu, Willis, Friedman, & Lin, 2013). The reasons can be attributed to the use of inconsistent definitions; methodological challenges in conducting research with this population; inappropriate diagnosis; and ignorance among healthcare

Although deafblindness is considered a low-incidence disability (Dammeyer, 2015; Moller, 2003; Rönnberg & Borg, 2001), some researchers estimate that by 2030, there will be around 14 million older adults with dual sensory loss (Group 3) in the United States itself, and that similar scenario will emerge in other high-income countries where the ageing population is increasing rapidly (Brennan & Bally, 2007; Swenor et al., 2013). A recent global report by the World Federation of the Deafblind (2018) estimates that around 2% of the global population are those with deafblindness (around 150 million), and this condition is often underestimated and misunderstood by the society (World Federation of the Deafblind, 2018).

Deafblindness is defined in the Indian context in ‘The Rights of Persons with Disabilities Act, 2016’ as “a condition in which a person may have combination of hearing and visual impairments causing severe communication, developmental, and educational problems” (Government of India, 2016, p. 35). However, this definition is based on the premises of medical model of disability where focus is on the problems associated with impairments rather than on environmental factors that create a disabling situation. Hence, for the sake of this research, I used the Nordic definition of deafblindness that focuses on restriction of functioning and participation and calls for environmental alterations (The Deafblind Nordic Cooperation Committee, n.d.). This definition is influenced by the WHO’s International Classification of Functioning, Disability, and Health (ICF) framework (Signo Vivo, 2016). The Nordic definition describes deafblindness as “a combined vision and hearing disability which limits activities of a person and restricts full participation in society to such a degree that society is required to facilitate specific services, environmental alterations, and/or technology” (Danermark & Moller, 2008, p. S119).

Some medical conditions that were once prevalent but now rarely recorded in high-income countries are still very common in the LMICs (Barnes & Mercer, 2005; Barnes &
Sheldon, 2010). Deafblindness in India due to Rubella infection is a perfect example. It is worth noting that currently the major cause of deafblindness in LMICs is Congenital Rubella Syndrome, and more than 100,000 children are born with this syndrome each year worldwide (World Health Organization, 2013b). Out of total children born with Congenital Rubella, 30,000 are born every year in India (Dewan & Gupta, 2012; Sharma, 2018). In contrast, the deafblind population in high-income countries mostly belong to Group 3 (age-related deafblindness) and Group 2 (people with genetic conditions such as Usher syndrome) because Rubella has been eradicated in these countries with robust immunization programs (Blume & Tump, 2010; Dammeyer, 2010, 2014; Parkman, 1999; Peltola, Jokinen, Paunio, Hovi, & Davidkin, 2008; Wittich et al., 2012, 2016). In India, people in Group 3 (older adults with dual sensory impairments) are yet to be identified as the focus of interventions is currently on meeting the needs of estimated 500,000 persons with deafblindness – mostly individuals from Group 1 (congenital) and Group 2 (acquired conditions). The empirical data collected for this study in India, therefore, was collected with participants from Group 1 and Group 2.

In the next section, I provide the contextual background of the study, and discuss the policy environment on disability in India, particularly as they relate to deafblindness.

1.6 Context

According to the World Health Organization (WHO) estimates, approximately one billion people in the world live with a disability, a majority of whom are in LMICs (World Health Organization & World Bank, 2011). Further, the WHO estimates that 466 million people have hearing loss; 441.5 million people have mild to severe vision impairment, and around 190 million people experience significant difficulties in functioning (World Health Organization, 2018a, 2018b, 2018c). Persons with disabilities in developing nations such as India often experience discrimination, human rights violations, and remain one of the most vulnerable populations (Chopra, 2013; Mehrotra, 2011; World Health Organization & World Bank, 2011). Very often,
access to medical and rehabilitation services for people with disabilities is dependent on their ability to pay (Barnes & Mercer, 2005). Disability often poses social and financial barriers and inevitably, people with disabilities are not able to come out of this vicious circle of poverty and disability (Trani & Loeb, 2012; World Health Organization & World Bank, 2011). In the subsequent sections, I will map the disability landscape in India, highlighting the historical, social, and legal contexts for persons with disabilities.

1.7 Disability in India

India is home to 26.8 million persons with disabilities (2.21% of the total population of 1.2 billion) (Census of India, 2011). It is ranked 135 out of 187 countries on the Human Development Index (HDI), which implies that India is behind many other nations in providing essential services to its people (United Nations Development Programme, 2014). As per the Census of India (2011), 19 percent (5.0 million) of the population of persons with disabilities have visual impairments, another 19 percent (5.1 million) have hearing difficulties, and another eight percent (2.12 million) have multiple disabilities (Census of India, 2011). It is worth noting that the category of ‘multiple disability’ was included for the first time in the disability enumeration questionnaire in the 2011 Census of India to count people with multiple disabilities (such as deafblindness) in the country (Goldbart & Sen, 2013; Census of India, 2011).

India, a rapidly growing economy, has undergone a transition in understanding disability from a traditional religious/charity perspective to a human rights-based understanding of disability (Chopra, 2013; Mourdoukoutas, 2017, June 22). In contrast to the Western ideology of individual rights and autonomy, Indian society in general places emphasis on family/community ties and collective rights, and believes in mutual obligation to rehabilitate individuals with disabilities (Buckingham, 2011; Grech, 2011). For example, rehabilitation of a person with a disability is considered to be a responsibility of the family, and they “provide essential physical, emotional and economic support to its members with disabilities” (Dalal, 2002, p. 4).
The colonization of India by the British Empire in 18th century introduced the process of institutionalization by large scale missionary activities, and many disability institutions were set up in the country (Mehrotra, 2011; Miles, 1994 as in Dalal, 2002). People with disabilities were then segregated from mainstream society. The influence of Western ideology in colonization for two centuries first shifted rehabilitation practices towards charity-based model and then to biomedical model where emphasis was to cure, correct, or fix the disability (Dalal, 2002; Mehrotra, 2011; Mellory 1994). The shift from biomedical approach to human-rights based approach took place under the influence of global disability rights movement with the enactment of the ‘Persons with Disabilities Act, 1995’ in India (Chopra, 2013; Mehrotra, 2011). Although India had a disability law in place since 1995, implementation of this law to its best intention has remained a challenge (Chopra, 2013). Presently, the major problems of people with disabilities in the Indian society comprise societal attitudes towards disability, environmental barriers, and lack of accessible and adequate opportunities and services (Chopra, 2013; Groce 1999; World Bank, 2009).

Evidence suggests that a majority of individuals with disabilities in India are currently living in unjust conditions where access to basic medical services, rehabilitation and education is a daily challenge (Ghai, 2001). These challenges “may be further compounded by the intersection of disability with other forms of social division leading to further disadvantage for disabled people who experience oppression on the basis of their gender, life course position, class, caste, sexuality or race/ethnicity” (Barnes & Sheldon, 2010, p. 775).

In a scenario like this, civil society organizations play an important role in ensuring the rights of marginalized populations in society. Civil society organizations play a complementary role and “act as the third leg to development together with government and development partners (donors)” (Kaulem, 2007, p 2; Ramírez, 2016). Sometimes these civil society organizations develop a parallel system of support services for marginalized populations. For example, in case
of people with deafblindness in India (who had no legal recognition until December 2016 and almost no welfare services exist for them), *Sense International India* was established in 1997 to provide comprehensive rehabilitation for people with deafblindness in India (Sense International India, 2016).

### 1.8 Policy for persons with disabilities in India

Among LMICs, India has comparatively progressive disability-specific legislation in alignment with the international human rights standards. India is signatory to the ‘Declaration on the Full Participation and Equality of People with Disabilities in the Asia Pacific Region’ (2000); the ‘Biwako Millennium Framework’ (2002); and the ‘Biwako Plus Five’ (2007) towards an inclusive, barrier-free and rights-based society for persons with disabilities (Government of India, 2016). India ratified the United Nations Convention on Rights of Persons with Disabilities (UNCRPD) in 2007 and attempted to harmonize its laws and policies with the UNCRPD (Chopra, 2013; Government of India, 2016). One key step towards this harmonization was to replace the older law, The Persons with Disabilities Act 1995, with the newer, rights-based Rights of Persons with Disabilities Act 2016 (Chopra, 2013; Government of India, 2016). Table 1 highlights the disability-specific legislation enacted by the Government of India for persons with disabilities in the country.

#### Table 1. Disability specific legislation

<table>
<thead>
<tr>
<th>Name of the Act (in chronological order)</th>
<th>Key focus</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>The Mental Health Act, 1987</em></td>
<td>Treatment and care of mentally ill persons</td>
</tr>
<tr>
<td><em>The Rehabilitation Council of India Act, 1992</em></td>
<td>Regulates the standard of education, training, and examination of rehabilitation professionals</td>
</tr>
<tr>
<td><em>The Persons with Disabilities Act, 1995</em></td>
<td>Equal opportunities, protection of rights and full participation for persons with disabilities</td>
</tr>
<tr>
<td><em>The National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999</em></td>
<td>Establish a national-level body ‘The National Trust Board’ for welfare programmes of children and adults with severe disabilities (such as autism, cerebral palsy, mental retardation and multiple disabilities)</td>
</tr>
</tbody>
</table>
The Rights of Persons with Disabilities Act, 2016

Equal rights and entitlements, full participation, protection from discrimination, accessibility and mainstreaming, access to care and treatment, and strengthened enforcement mechanisms.

The Mental Healthcare Act (Rights of Persons with Mental Illness), 2017

Mental healthcare and services for persons with mental illness and protection of their rights

Among these statutes, the Government of India enacted the National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999. Under this Act, a national-level body The National Trust Board was established to provide a reliable arrangement for welfare of children and adults with severe disabilities (such as autism, cerebral palsy, mental retardation and multiple disabilities) with schemes such as legal guardianship, health insurance, scholarships, and residential centres for adults with severe disabilities (National Trust, 1999). It was this Act, that for the first time, recognized multiple disability and proposed support schemes to address the concerns of individuals with multiple disabilities and their families in India. Although deafblindness was not explicitly mentioned in this Act, persons with deafblindness received some support from the National Trust due to being eligible for benefits under the category of multiple disability (Rehabilitation Council of India, n.d.). This support, however, came from a welfare-based approach and was inadequate in comparison to the population with multiple disabilities in India (Chopra, 2013).

Currently, the most promising legislation for people with disabilities in India is the Rights of Persons with Disabilities Act 2016 that emphasizes accessibility, equality of opportunity, independence, autonomy, dignity, non-discrimination, participation and inclusion in society, and protection of rights of children, men and women with disabilities (Government of India, 2016). The definition of deafblindness used in this legislation continues to reflect the influence of the medical model, which emphasizes the impairment as the problem in greatest need of remediation. Nevertheless, the potential for rehabilitation in India seems promising with the enactment of the new, rights-based law, The Rights of Persons with Disabilities Act, 2016, which recognizes
deafblindness under the “multiple disability” category and puts emphasis on the protection and fulfillment of the rights of individuals with deafblindness (Government of India, 2016; Sense International India, 2016). Having provided the contextual overview for this dissertation, I will now provide an overview of the methods used in this study.

1.9 Methodology

1.9.1 Conceptual framework

The conceptual framework of this study is informed by the International Classification of Functioning, Disability, and Health (ICF) framework published by the World Health Organization (WHO) in 2001 (WHO, 2001). The ICF, also referred as a biopsychosocial model, provides a universal standard language for describing health and health-related states thereby improving communication between different users, such as health care workers, researchers, policy-makers and the public, including people with disabilities in 191 member countries (WHO, 2001).

Although the medical and social model of disability are valuable to the field of disability, scholars recommend use of the ICF because it moves beyond the two models and its limitations. While the social model ignores the realities of impairment and undertakes extreme position in defining disability as “socially caused” unilaterally (Riddle, 2013; Shakespeare 2006a & b), medical model situates disability inside the person and overlooks the role of environment in the creation of disability (McColl, 2019).

The ICF is the best-suited conceptual framework for this study for many reasons. First, the ICF is widely accepted, and integrates the two models of disability (medical and social model), focusing on the participation of persons with disabilities and contextual factors (personal and environmental) (WHO, 2001). The ICF can identify the extent to which various contextual factors (e.g., environmental factors such as products and technology; natural and human-made conditions).
environment; support and relationships; attitude, service systems and policies; and personal factors) act as barriers to or facilitators for participation. Also, the ICF focuses not only on identification of barriers, but also on facilitators, as any factor can act both as a facilitator and a barrier (WHO, 2013a). Lastly, the ICF is a “potentially powerful tool for evidence-based advocacy” (p. 84) by shifting the focus from the health condition to functioning, and documenting evidence of environmental barriers in life situations to make the argument for social change (WHO, 2013a).

The construct of participation is central to the ICF and has been defined as “involvement in a life situation” (WHO, 2002, p.10). In this study, the ICF informed the development of a research guide, guided the coding process for data analysis, and provided a theoretical foundation for writing thesis chapters. It is also important to note here that like any other model of disability, the ICF also has its own limitations. Scholars attempting to apply the ICF have found that distinction between activity and participation is not clear in the ICF and measuring the construct of participation is challenging (Dahl, 2002; Masala & Petretto, 2008; Perenboom & Chorus, 2003). However, strength of the ICF lies in its broad framework and flexibility (Dahl, 2002; Simeopnsson, Bjorck-Akesson & Lollar, 2012). Rather, it is being said that the ICF can only be improved when it is increasingly tested and used in research, policy and practice (Threats, 2003).

1.9.2 Research Design

The study uses a descriptive cross-sectional design. I chose qualitative research methodology to develop a conceptual understanding of participation phenomena as suggested by other rehabilitation researchers (Dijkers, 2010; Hammel et al., 2008; Whiteneck & Dijkers, 2009). Researchers trying to operationalize the concept of participation highlight that the “best judge of participation is the responder himself” (Perenboom & Chorus, 2003, p. 578). Individuals with disabilities are best positioned to describe their experience of living with disabilities (Eide & Ingstad, 2013). I adopted a constructivist paradigm to understand the socially constructed
meaning of participation from the perspectives of persons with deafblindness (Creswell, 2013). It is important to acknowledge the tensions that exist around the use of descriptive phenomenological method in constructivist paradigm (Seigfried, 1976). Following the argument proposed by Seigfried (1976), which states that the phenomena which phenomenology describes are, by their very nature, constructions of reality, my ontology is that the reality of participation experiences is socially constructed by persons with deafblindness. My research is a tool for the accurate description of those experiences in their own words without my influence. In this study, a descriptive phenomenological research method (Moustakas, 1994) was predominantly used to understand and describe “the meaning individuals’ make of their experiences” (Liamputtong, 2013, p.117) of participation. Consistent with this approach, I used in-depth interviews (Study 2 & 3) and focus groups (Study 4) that are ideal methods for collecting phenomenological data (Guest, Namey, & Mitchell, 2013).

1.10 Overview of the dissertation

This dissertation is divided into six chapters – introduction, four studies and a conclusion. The first chapter is the introductory chapter, where I introduce the research problem, its context and discuss the overall methodology. Chapter 2 is a scoping review which orients the readers to the breadth of the global literature on participation experiences of persons with deafblindness. Chapter 3 presents the findings of in-depth interviews conducted with 16 persons with deafblindness in India to explore the meaning and their lived experience of “participation” in society. Chapter 4 describes the self-reported contextual factors that persons with deafblindness believe influence their participation in society. Chapter 5 introduces readers to the findings of focus group discussions with 16 rehabilitation service providers (working with individuals with deafblindness) to understand the contextual factors identified by them while working to enhance the participation of persons with deafblindness in Indian society. Finally, the last chapter, Chapter
presents the summary of the key findings, conclusion, strengths and limitations of the work, its potential significance, and implications for policy, practice and research.

### 1.11 Significance of the research and its methodology

Persons with communication disabilities such as deafblindness are a small sub-population within the minority population of people with disabilities. As such, they may face further marginalization and are often not consulted in designing the services and policies that affect them (World Federation of the Deafblind, 2018). To date, no study has explored the experiences of participation of persons with deafblindness and suggested ways to enhance their participation in India. Hence, a qualitative study based on lived experiences is timely to fill the gap in the current evidence. This understanding would inform programs and policies to reduce social isolation and promote participation of people with deafblindness in Indian society.

Emancipatory paradigm promotes the use of qualitative research as a choice of method to capture lived experiences of persons with disabilities (Stone & Priestley, 1996). In this qualitative study, I tried to follow a set of principles commensurate with the emancipatory paradigm that includes reflexivity, transparency, participation, and accountability (Stone & Priestley, 1996; Zarb, 1992). In emancipatory research, reflexivity is a critical tool for researchers to examine the ways in which their own social identity and values affect the research data collection, analysis and reporting of its findings (Vernon, 1997). Barton (2005) mentions that it is crucial for the researcher to make his or her assumptions, values and beliefs increasingly transparent throughout the process. Persistent and thoughtful reflections by the researchers with regards to their position and roles in the research give a means of creation to the inclusive research (Barton, 2005). To ensure participation of participants, I used a range of different accessible modes of communication to interview persons with deafblindness. To implement the principle of accountability, I propose following knowledge translation activities to engage with my participants and share findings with them.
### 1.12 Knowledge translation

My knowledge translation partner in this study is *Sense International India (SII)*, which is a national level organization working exclusively to provide comprehensive services for individuals with deafblindness in India. An integrated knowledge translation approach began with collaboration with SII to frame the research problem and decide on methodology (Canadian Institutes of Health Research, 2012). SII also provided assistance throughout the study, particularly in data collection, participant recruitment, interpreter support for interviews, and in knowledge translation. The approaches outlined in Table 2 are planned to be used for knowledge translation with respective stakeholders in the subsequent years of the study.

#### Table 2. Knowledge translation plan

<table>
<thead>
<tr>
<th>Audience</th>
<th>Medium to be used</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adults with deafblindness</td>
<td>Capacity-building workshop with them to inform them about research findings in SII National Conclave of Networks (Dec 2019)</td>
</tr>
<tr>
<td>Parents of persons with deafblindness</td>
<td>Capacity-building workshop and provision of educational materials in SII National Conclave of Networks (Dec 2019)</td>
</tr>
<tr>
<td>Rehabilitation professionals</td>
<td>Capacity-building workshop and educational materials in SII National Conclave of Networks (Dec 2019)</td>
</tr>
<tr>
<td>Deafblind organisations</td>
<td>Capacity-building workshop and educational materials in SII Partners’ Meet (March 2020)</td>
</tr>
<tr>
<td>Researchers</td>
<td>Webinar, conference presentations (such as Deafblind International Conference) and peer-reviewed publications</td>
</tr>
<tr>
<td>General public</td>
<td>Online social media such as Twitter, Facebook, Blog, newspapers</td>
</tr>
<tr>
<td>Policy makers</td>
<td>Brief synopsis of research report with set of recommendations</td>
</tr>
</tbody>
</table>

### 1.13 References


Chapter 2

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

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. doi:10.1371/journal.pone.0203772

Funding Acknowledgment: Queen Elizabeth II Diamond Jubilee Scholarship provided funding to the first author (AJ) for his doctoral study.

Disclaimer: This manuscript chapter is mostly similar, but not entirely identical, to the published version.
2.1 The Fit of Manuscript 1 within the Dissertation

Manuscript 1, based on the scoping review study, contributes to the purpose of the dissertation by providing a synthesis of scientific evidence that exists on the topic of participation experiences of persons with deafblindness. This manuscript helps to understand the participation challenges for persons with deafblindness documented in the literature. This study also illuminates the knowledge gap in the sensory rehabilitation field that exists on the topic of participation experiences of persons with deafblindness from low- and middle-income countries such as India. This knowledge synthesis builds a strong foundation for the further exploration of participation experiences of person with deafblindness in India in the second, third and fourth manuscripts.
2.2 Abstract

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. The objective of the scoping review is to identify and summarize available research literature on participation experiences of people with deafblindness or dual sensory loss. A comprehensive literature search of eight databases (CINAHL/EBSCO, Embase, ERIC, Global Health, MEDLINE, ProQuest, PsycINFO, PubMed) was performed in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-analysis (PRISMA) during January 2017 and updated in June 2017. In addition, non-peer reviewed (grey) literature was also retrieved in the form of online published reports of research projects by 16 deafblind-specific organizations across the globe. To be included, sources had to be published after 1990, had persons with deafblindness as the focal population, and focused on their participation experiences. A total 1172 sources were identified of which 54 studies were included. The findings reveal that persons with deafblindness, regardless of origin of their impairment, experience difficulty in communication, mobility, daily living functioning, and social interactions. While these experiences may vary between individuals with congenital versus acquired conditions, they generally feel socially isolated, insecure and uncertain about their future. The participation experiences of persons with deafblindness are shaped by dynamic interactions between personal factors (such as onset and type of impairments) and environmental influences (such as attitude, technology, and supports). A better understanding of participation experiences may help professionals in placing emphasis on affected participation domains to design services to enhance participation of people with deafblindness.
2.3 Introduction

Deafblindness, often a lifelong disability, is a combination of visual and hearing impairment in the same individual (Ask Larsen & Damen, 2014; Wittich, Southall, Sikora, Watanabe, & Gagné, 2013). Deafblindness is also known as dual sensory loss and ranges from mild loss in hearing and vision to total deafness and blindness depending upon its various combinations (Dammeyer, 2014; Wittich et al., 2013). Since our abilities to see and hear are complementary and enhance each other, this particular combination of hearing and vision dysfunction results in a unique condition that is more disabling than the sum of its impairments (Dammeyer, 2014; Möller, 2003). The combined dysfunction “limits activities of a person and restricts full participation in society to such a degree that society is required to facilitate specific services, environmental alterations, and/or technology” (Danermark & Moller, 2008, p. S119). Consequently, people with deafblindness frequently experience social isolation in their lives (Dammeyer, 2014; Hersh, 2013a & b; Sense International, 2017; Wittich et al., 2013).

The deafblind population includes three distinct groups: Group 1 (people with congenital/pre-lingual deafblindness), Group 2 (people with acquired/post-lingual deafblindness – those who acquire both types of impairment during their lives or those with single sensory impairment [vision or hearing] by birth and then subsequently acquire another [vision or hearing] impairment), and Group 3 (dual sensory loss/impaired vision and hearing due to age related changes in older adults) (Dammeyer, 2014; Wittich et al., 2012; Simcock, 2016), each of which can vary in severity as well as order and time since onset.

The history of deafblindness can be traced back before the recognition of Helen Keller (1880-1968); yet, the development of research and practice specific to this population is still in its infancy (Dammeyer, 2015; Macdonald, 1994; Wittich, Jarry, Groulx, Southall, & Gagné, 2016). The interest in this population has increased recently due to emerging evidence suggesting a rise in the prevalence of this condition among older adults worldwide (Guthrie, Declercq, Finne-Soveri, Fries, & Hirdes, 2016; Wittich et al., 2016). With the increase in older population
globally, this rise in age-related deafblindness can be attributed to increased incidence of age-related sensorineural hearing loss, cataracts, glaucoma, and macular degeneration among older adults (Dammeyer, 2014, 2015; Guthrie et al., 2016; Wittich et al., 2016).

Participation is a highly valued goal in rehabilitation for persons with disabilities, including those with deafblindness (Mallinson & Hammel, 2010; Mirza, Magasi & Hammel, 2016; Perenboom & Chorus, 2003). Furthermore, international legislations such as the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) recognize the right of all persons with disabilities to fully participate in society and acknowledge the distinct needs of persons with deafblindness (United Nations, 2006). Therefore, it is vital to explore the participation experiences of people with deafblindness. A better understanding of deafblind individuals’ experiences can help rehabilitation professionals and policy makers design programs and policies to enhance participation of persons with deafblindness in society.

2.4 Methods

This scoping review was based on the methodological framework published by Arksey and O’Malley (2005) with the addition of recommendations from scoping review methodology scholars including Levac and colleagues (2010) and Peters and colleagues (2015). Scoping review is defined as a form of knowledge synthesis on a particular research area to identify key concepts, types of evidence, and gaps in the research literature by systematically searching and synthesizing existing knowledge to inform health care practice, policy, and research (Colquhoun et al., 2014; Daudt, Van Mossel & Scott, 2013). The purpose of this review was to map the literature on participation experiences of persons with deafblindness and summarize a range of evidence that could inform the programs and policies for rehabilitation of persons with deafblindness.

The Arksey & O’Malley framework includes five stages: identifying the research question, identifying relevant studies, selecting studies, charting the data, and then collating,
summarizing, and reporting the results. I enhanced rigor in methods by creating a linkage between the purpose and research question; ensuring breadth and comprehensiveness of the scoping process; using an iterative approach in study selection and extraction; including a descriptive numerical summary and qualitative thematic analysis while reporting results, and discussing the implications for future policy, practice, or research (Levac, Colquhoun & O’Brien, 2010). I also incorporated recommendations of Peters and colleagues (2015) by reporting the operational definitions of ‘population’, ‘concept’, and ‘context’ of the review; search strategy; research database searched; details of the criteria used for inclusion and exclusion of studies; and how the data will be extracted and mapped (Peters et al., 2015).

**Stage 1: Identifying the research question.** The review was guided by the research question, ‘What does the existing literature report about the experiences of participation for persons with deafblindness in society?’ For the purpose of this study, the population ‘persons with deafblindness’ are individuals with a varying combination of visual and hearing impairment (Dammeyer, 2014; 2015). The concept of ‘participation’ was defined as involvement in any life situations (World Health Organization, 2001). The spatial context for this study was societies around the world where persons with deafblindness live, whereas the temporal context was post 1990 as a unanimous resolution was passed in the 1990 Conference of the International Association for the Education of Deafblind People (currently known as Deafblind International) to create the unified term “deafblind” recognizing the unique nature of this disability (Lagati, 1995; McInnes, 1999; Wittich et al., 2013).

**Stage 2: Identifying relevant studies.** A database search strategy was developed by the research team in consultation with a senior health science librarian from Queen’s University. A comprehensive literature search of eight databases (CINAHL/EBSCO, Embase, ERIC, Global Health, MEDLINE, ProQuest, PsycINFO, and PubMed) was performed in January 2017 and last
updated in June 2017 in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-analysis (PRISMA) (Moher et al., 2009) (Table 3).

Table 3. Sources and search terms.

<table>
<thead>
<tr>
<th>Research databases searched</th>
<th>Search terms</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Cumulative Index to Nursing and Allied Health Literature (CINAHL)</td>
<td>(deafblind* OR deaf-blind* OR (“deaf and blind”) OR &quot;dual sensory loss&quot; OR &quot;dual sensory impairment&quot; OR (&quot;combined hearing and visual impairment&quot;) OR (&quot;combined hearing and visual loss&quot;) AND (experience* OR engage* OR participat* OR involve*) AND (society OR community)</td>
</tr>
<tr>
<td>• Education Resources Information Centre (ERIC)</td>
<td>(deafblind* OR deaf-blind* OR (“deaf and blind”) OR &quot;dual sensory loss&quot; OR &quot;dual sensory impairment&quot; OR (&quot;combined hearing and visual impairment&quot;) OR (&quot;combined hearing and visual loss&quot;) AND (experience* OR engage* OR participat* OR involve*) AND (society OR community)</td>
</tr>
<tr>
<td>• Embase</td>
<td>(deafblind* OR deaf-blind* OR (“deaf and blind”) OR &quot;dual sensory loss&quot; OR &quot;dual sensory impairment&quot; OR (&quot;combined hearing and visual impairment&quot;) OR (&quot;combined hearing and visual loss&quot;) AND (experience* OR engage* OR participat* OR involve*) AND (society OR community)</td>
</tr>
<tr>
<td>• Global Health</td>
<td>(deafblind* OR deaf-blind* OR (“deaf and blind”) OR &quot;dual sensory loss&quot; OR &quot;dual sensory impairment&quot; OR (&quot;combined hearing and visual impairment&quot;) OR (&quot;combined hearing and visual loss&quot;) AND (experience* OR engage* OR participat* OR involve*) AND (society OR community)</td>
</tr>
<tr>
<td>• MEDLINE</td>
<td>(deafblind* OR deaf-blind* OR (“deaf and blind”) OR &quot;dual sensory loss&quot; OR &quot;dual sensory impairment&quot; OR (&quot;combined hearing and visual impairment&quot;) OR (&quot;combined hearing and visual loss&quot;) AND (experience* OR engage* OR participat* OR involve*) AND (society OR community)</td>
</tr>
<tr>
<td>• ProQuest</td>
<td>(deafblind* OR deaf-blind* OR (“deaf and blind”) OR &quot;dual sensory loss&quot; OR &quot;dual sensory impairment&quot; OR (&quot;combined hearing and visual impairment&quot;) OR (&quot;combined hearing and visual loss&quot;) AND (experience* OR engage* OR participat* OR involve*) AND (society OR community)</td>
</tr>
<tr>
<td>• PsycINFO</td>
<td>(deafblind* OR deaf-blind* OR (“deaf and blind”) OR &quot;dual sensory loss&quot; OR &quot;dual sensory impairment&quot; OR (&quot;combined hearing and visual impairment&quot;) OR (&quot;combined hearing and visual loss&quot;) AND (experience* OR engage* OR participat* OR involve*) AND (society OR community)</td>
</tr>
<tr>
<td>• PubMed</td>
<td>(deafblind* OR deaf-blind* OR (“deaf and blind”) OR &quot;dual sensory loss&quot; OR &quot;dual sensory impairment&quot; OR (&quot;combined hearing and visual impairment&quot;) OR (&quot;combined hearing and visual loss&quot;) AND (experience* OR engage* OR participat* OR involve*) AND (society OR community)</td>
</tr>
</tbody>
</table>

Other sources including

- Google and Google Scholar
- *Journal of Deaf Studies & Deaf Education*
- *Journal of Visual Impairment & Blindness*
- Online content of development organizations

<table>
<thead>
<tr>
<th>SN</th>
<th>Organization</th>
<th>Website</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>European Union</td>
<td><a href="https://europa.eu/">https://europa.eu/</a></td>
</tr>
<tr>
<td>2</td>
<td>National Centre on Deaf-blindness</td>
<td><a href="https://nationaldb.org/">https://nationaldb.org/</a></td>
</tr>
<tr>
<td>3</td>
<td>Sense UK</td>
<td><a href="https://www.sense.org.uk/">https://www.sense.org.uk/</a></td>
</tr>
</tbody>
</table>
The research team conducted a web search in Google and Google Scholar using keywords ‘deafblind’ and ‘experiences’ to identify any literature that had not been captured in original search. An *a priori* decision was made to screen only the first 100 hits (most relevant). In addition, reference lists of the most relevant articles were manually reviewed to identify additional studies, a technique called *snowballing*. Later, the team manually searched the online databases of *Journal of Visual impairment and Blindness* (JVIB) and *Journal of Deaf studies and Deaf education* (JDSDE) published since 1990. These journals were chosen due to their relevance to the field, the likelihood of finding a greater number of relevant articles, and the fact that not all their content is indexed electronically. The researchers retrieved and imported all relevant sources into the bibliographic manager Mendeley Desktop (2016) (Version 1.17.6.), and removed duplicates.

**Stage 3: Study selection.** A two-stage screening process was used to assess the relevance of studies – first, at the level of title/abstract, and second, at the level of full-text review. Consistent with the scoping review process, post hoc inclusion/exclusion criteria (Table 5) were established to assess the relevance of studies identified in the search. Associated
disability conditions (such as autism, cerebral palsy, cognitive impairment, etc.) were not included because of the likelihood that these co-existing conditions might influence the participation experiences of individuals with deafblindness. It is important to note that studies were not excluded if they had focus on experiences of persons with deafblindness/dual sensory loss, but might have also included non-disabled people or persons with single sensory impairment in their study sample along with individuals with deafblindness/dual sensory loss.

Table 5. Inclusion and exclusion criteria

<table>
<thead>
<tr>
<th>Inclusion criteria</th>
<th>Exclusion criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Study related to persons with deafblindness or dual sensory loss and their experiences of involvement in any life situations.</td>
<td>• Study related to persons with deafblindness with co-existing conditions such as autism, cerebral palsy, cognitive impairment, etc.</td>
</tr>
<tr>
<td>• Study population comprised with deafblindness irrespective of their age.</td>
<td>• Study population comprised parents, or professionals.</td>
</tr>
<tr>
<td>• Sources that were qualitative and quantitative studies, literature reviews, research reports, and personal accounts.</td>
<td>• Study focused solely on medical/rehabilitation interventions or educational programs.</td>
</tr>
<tr>
<td>• Study were produced from 1990 to date.</td>
<td>• Full text of the study was not available in English.</td>
</tr>
<tr>
<td></td>
<td>• Study lacked any clarity in relation to experiences of persons with deafblindness</td>
</tr>
</tbody>
</table>

Eligible sources were reviewed in full and a final list of sources was compiled in a spreadsheet using Microsoft Excel 2013. Two authors (A.J. and H.A) reviewed the compiled list of articles/sources and the other authors (M.M., W.W., and M.F.) were consulted for disagreements until consensus was reached. Details on identification, screening, eligibility and inclusion can be found in the PRISMA flowchart (Figure 1) (Moher et al., 2009).
Stage 4: Charting the data. The first and second authors held several meetings to discuss the list of descriptors in the data charting form in the spreadsheet. Extracted data included details regarding name of authors, year of study, journal title, location of study, study population, number of participants, focus of article, aim of the study, methodology used, key outcome, and
any other data significant to the scoping question. The same format was used for grey literature, and ‘not available’ was used if the information was missing from the source.

**Stage 5: Collating, summarizing, and reporting the results.** Consistent with recommendations of Arksey and O’Malley’s, and Levac and colleagues, results were reported using descriptive numerical summary and qualitative thematic analysis (Arksey & O’Malley, 2005; Levac et al., 2010). A summary of descriptive findings was collated from the spreadsheet and presented in the form of tables and figures. Braun and Clarke’s (2006) principles of thematic analysis were used to identify key themes from the extracted data by the first author (A.J.) and reviewed by the other authors to confirm the interpretation. Authors discussed findings to develop an overall understanding of deafblind research worldwide, and its major focus, key challenges, limitations, and gaps with reference to the experiences of persons with deafblindness.

### 2.5 Results

Out of 1172 sources identified, 860 sources were extracted from eight bibliographic databases; 286 were included from Google/Google Scholar, hand-searching references, and two academic journals (JVIB and JDSDE); and 26 research reports from deafblind-specific organizations. Fifty-four sources were ultimately accepted that met all selection criteria (Table 5). Information on number of sources identified, screened, found eligible and finally included in the study can be found in Figure 1 - PRISMA flowchart.

**Characteristics of the records included in the study.** Of the 54 sources that were included in the final review, the majority were empirical studies (n= 36), followed by reviews (n= 12), research reports (n= 4), and personal narratives (n= 2). The records presenting empirical research covered a broad spectrum of methodologies (e.g., quantitative, qualitative and mixed), designs (e.g., longitudinal, cross-sectional, case study, and participatory action research) and data collection strategies (e.g., interviews, focus groups, observations, short films/videos, document reviews, and surveys). The non-empirical records were primarily literature reviews, research
reports, and personal narratives. Table 6 provides details on study location, publication year and name of publication journal, while Table 7 provides an overview of selected studies with the study aim, focus, participant population and sample size. It is worthwhile to mention that the study population described in Table 7 includes different terminologies such as deafblindness, dual sensory impairments, and dual sensory loss that were reported in the respective studies.

Table 6. Characteristics of records included in the study (n=54).

<table>
<thead>
<tr>
<th>Authors</th>
<th>Year of publication</th>
<th>Journal details</th>
<th>Location of Study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Berry, P. et al.,</td>
<td>2004</td>
<td>Care Management Journals</td>
<td>United States</td>
</tr>
<tr>
<td>Bodsworth, S.M. et al.,</td>
<td>2011</td>
<td>British Journal of Visual Impairment</td>
<td>United Kingdom</td>
</tr>
<tr>
<td>Brennan, M., &amp; Bally, S.J.</td>
<td>2007</td>
<td>Trends in Amplification</td>
<td>United States</td>
</tr>
<tr>
<td>Brennan, M., Horowitz, A., &amp; Su, Y.P.</td>
<td>2005</td>
<td>Gerontologist</td>
<td>United States</td>
</tr>
<tr>
<td>Brennan, M.</td>
<td>2003</td>
<td>Generations</td>
<td>Not specified</td>
</tr>
<tr>
<td>Bruce, S.M., Zatta, M.C., &amp; Gavin, M.</td>
<td>2016</td>
<td>Journal of Visual Impairment &amp; Blindness</td>
<td>United States</td>
</tr>
<tr>
<td>Cimarolli, V.R., &amp; Jopp, D.S.</td>
<td>2014</td>
<td>Age and Ageing</td>
<td>United States</td>
</tr>
<tr>
<td>Dalby, D.M. et al.,</td>
<td>2009</td>
<td>Journal of Visual Impairment &amp; Blindness</td>
<td>Canada</td>
</tr>
<tr>
<td>Damen, G.W. et al.,</td>
<td>2005</td>
<td>International Journal of Rehabilitation Research</td>
<td>Europe (France, Germany, Ireland, Italy, Spain, UK, and The Netherlands)</td>
</tr>
<tr>
<td>Dammeyer, J.</td>
<td>2012</td>
<td>International Journal of Pediatric Otorhinolaryngology</td>
<td>Denmark (Europe)</td>
</tr>
<tr>
<td>Danermark, B.D., &amp; Moller, K.</td>
<td>2008</td>
<td>International Journal of Audiology</td>
<td>Not specified</td>
</tr>
<tr>
<td>Deafblind UK</td>
<td>2007</td>
<td>Research Report</td>
<td>United Kingdom</td>
</tr>
<tr>
<td>Ellis, L., &amp; Hodges, L.</td>
<td>2013</td>
<td>Research report</td>
<td>United Kingdom</td>
</tr>
<tr>
<td>Authors</td>
<td>Year of publication</td>
<td>Journal details</td>
<td>Location of Study</td>
</tr>
<tr>
<td>---------------------------------</td>
<td>---------------------</td>
<td>-----------------------------------------------------------</td>
<td>----------------------------------------</td>
</tr>
<tr>
<td>Emerson, J., &amp; Bishop, J.</td>
<td>2012</td>
<td>Journal of Visual Impairment &amp; Blindness</td>
<td>United States</td>
</tr>
<tr>
<td>Figueiredo, M. Z. de A. et al.,</td>
<td>2013</td>
<td>CoDAS</td>
<td>Brazil</td>
</tr>
<tr>
<td>Fletcher, P.C., &amp; Guthrie, D.M.</td>
<td>2013</td>
<td>International Journal of Disability, Community &amp; Rehabilitation</td>
<td>Canada</td>
</tr>
<tr>
<td>Fukushima, S.</td>
<td>2011</td>
<td>Personal Accounts in an Edited book</td>
<td>United Kingdom</td>
</tr>
<tr>
<td>Gibson, J.</td>
<td>2000</td>
<td>Journal of Adventure Education &amp; Outdoor Learning</td>
<td>United Kingdom</td>
</tr>
<tr>
<td>Gopinath, B. et al.,</td>
<td>2016</td>
<td>Age and Ageing</td>
<td>Australia</td>
</tr>
<tr>
<td>Guthrie, D.M. et al.,</td>
<td>2016</td>
<td>PLOS One</td>
<td>Europe &amp; Other two countries (Finland, Belgium, Canada, and US)</td>
</tr>
<tr>
<td>Heine C., &amp; Browning, C.J.</td>
<td>2002</td>
<td>Disability and Rehabilitation</td>
<td>Not specified</td>
</tr>
<tr>
<td>Heine, C., &amp; Browning, C.J.</td>
<td>2015</td>
<td>Gerontologist</td>
<td>Not specified</td>
</tr>
<tr>
<td>Heine, C., &amp; Browning, C.J.</td>
<td>2014</td>
<td>Frontiers in Aging Neuroscience</td>
<td>Not specified</td>
</tr>
<tr>
<td>Heine, C., &amp; Browning, C.J.</td>
<td>2004</td>
<td>Ageing and Society</td>
<td>Australia</td>
</tr>
<tr>
<td>Hersh, M.A.</td>
<td>2013</td>
<td>Journal of Deaf Studies and Deaf Education</td>
<td>Europe (Czech, France, Italy, Poland, UK, and Spain)</td>
</tr>
<tr>
<td>Hersh, M.A.</td>
<td>2013</td>
<td>Technology and Disability</td>
<td>Europe (Czech, France, Italy, Poland, UK, and Spain)</td>
</tr>
<tr>
<td>Högner, N.</td>
<td>2015</td>
<td>Journal of Visual Impairment &amp; Blindness</td>
<td>Germany (Europe)</td>
</tr>
<tr>
<td>Ingraham, C.L., &amp; Others.</td>
<td>1995</td>
<td>Journal of Visual Impairment &amp; Blindness</td>
<td>United States</td>
</tr>
<tr>
<td>Kamenopoulou, L.</td>
<td>2012</td>
<td>British Journal of Special Education</td>
<td>United Kingdom</td>
</tr>
<tr>
<td>Authors</td>
<td>Year of publication</td>
<td>Journal details</td>
<td>Location of Study</td>
</tr>
<tr>
<td>---------------------------</td>
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<td>----------------------------------------</td>
<td>----------------------------------------</td>
</tr>
<tr>
<td>McDonnell, M.C. et al.,</td>
<td>2016</td>
<td>Journal of Visual Impairment &amp; Blindness</td>
<td>United States</td>
</tr>
<tr>
<td>Miner, I.D.</td>
<td>1995</td>
<td>Journal of Visual Impairment &amp; Blindness</td>
<td>United States</td>
</tr>
<tr>
<td>Möller, K., &amp; Danermark, B.</td>
<td>2007</td>
<td>American Annals of the Deaf</td>
<td>Sweden (Europe)</td>
</tr>
<tr>
<td>Reid, C.</td>
<td>2010</td>
<td>Journal of Media and Culture</td>
<td>United States</td>
</tr>
<tr>
<td>Rönnberg, J., &amp; Borg, E.</td>
<td>2001</td>
<td>Scandinavian Audiology</td>
<td>Not specified</td>
</tr>
<tr>
<td>Saunders, G.H., &amp; Echt, K.V.</td>
<td>2007</td>
<td>Trends in Amplification</td>
<td>Not specified</td>
</tr>
<tr>
<td>Schneider, J.M. et al.,</td>
<td>2011</td>
<td>Journal of Aging and Health</td>
<td>Not specified</td>
</tr>
<tr>
<td>Sense UK</td>
<td>n.d.</td>
<td>Research report</td>
<td>United Kingdom</td>
</tr>
<tr>
<td>Simcock, P.</td>
<td>2016</td>
<td>Health &amp; Social Care in the Community</td>
<td>Not specified</td>
</tr>
<tr>
<td>Simcock, P.</td>
<td>2016</td>
<td>Ageing and Society</td>
<td>United Kingdom</td>
</tr>
<tr>
<td>Soper, J.</td>
<td>2006</td>
<td>British Journal of Visual Impairment</td>
<td>United Kingdom</td>
</tr>
<tr>
<td>Viljanen, A. et al.,</td>
<td>2014</td>
<td>European Journal of Ageing</td>
<td>Europe (11 countries)</td>
</tr>
<tr>
<td>Watters, C., Owen, M., &amp; Munroe, S.</td>
<td>2005</td>
<td>Research report</td>
<td>Canada</td>
</tr>
<tr>
<td>Yamada, Y. et al.,</td>
<td>2016</td>
<td>The Journals of Gerontology</td>
<td>Europe and Israel (the Czech Republic, England, Finland, France, Germany, Israel, Italy, and the Netherlands)</td>
</tr>
</tbody>
</table>
Table 7. Overview of records included in the study (n=54)

<table>
<thead>
<tr>
<th>References</th>
<th>Study population</th>
<th>Type of disability</th>
<th>Number of participants</th>
<th>Focus of article</th>
<th>Aim of the study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kamenopoulou, L. (2012)</td>
<td>Students with Db³</td>
<td>Not specified</td>
<td>4</td>
<td>Inclusion of students with deafblindness in mainstream schools</td>
<td>To explore the social inclusion and participation of four Db pupils in mainstream placements</td>
</tr>
<tr>
<td>Dalby et al., (2009)</td>
<td>Adults with Db</td>
<td>Mixed (Grp¹ 1 and Grp 2)</td>
<td>182 (Congenital -88, and 94 acquired) (94 M and 88 F)</td>
<td>Characteristics of individuals with congenital and acquired deaf-blindness</td>
<td>To compare participants with congenital and acquired Db</td>
</tr>
<tr>
<td>Gribs et al., (1995)</td>
<td>Older woman with Db</td>
<td>Acquired (Grp 2)</td>
<td>1</td>
<td>Life story of 87 year old lady</td>
<td>To understand her life in school, work, and other life domains</td>
</tr>
<tr>
<td>Wahlqvist et al., (2013)</td>
<td>Adults with Db</td>
<td>Usher Syndrome (Ush² Type II (Acquired) (Grp 2)</td>
<td>96</td>
<td>Physical and psychological health</td>
<td>To describe the physical and psychological health of persons with Usher syndrome Type II (Ush2) and to explore any differences in terms of gender</td>
</tr>
<tr>
<td>Lieberman, L.J., &amp; MacVicar, J.M. (2003)</td>
<td>Young adults with Db</td>
<td>Not specified</td>
<td>54 (34M and 20F)</td>
<td>Play and Recreation</td>
<td>To analyze the current recreational practices and barriers faced by 54 youths with Db</td>
</tr>
<tr>
<td>Miner, I.D. (1995)</td>
<td>Adults with Db</td>
<td>Usher Syndrome Type I (Acquired) (Grp 2)</td>
<td>39 (20F and 19M)</td>
<td>Psychological implications of Usher syndrome</td>
<td>To investigate psychological implications of Usher syndrome throughout the lifecycle</td>
</tr>
<tr>
<td>Bruce et al., (2016)</td>
<td>Students with or without Db</td>
<td>Congenital (Grp 1)</td>
<td>6</td>
<td>Socialization skills</td>
<td>To study socialization skills in six children with Db in the context of an arranged interaction space</td>
</tr>
<tr>
<td>References</td>
<td>Study population</td>
<td>Type of disability</td>
<td>Number of participants</td>
<td>Focus of article</td>
<td>Aim of the study</td>
</tr>
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</tr>
<tr>
<td>Correa-Torres, S.M. (2008)</td>
<td>Students with Db</td>
<td>Not specified</td>
<td>3 students, their mothers, teachers, and intervenors</td>
<td>Social experiences and opportunities for communication among students with Db, their sighted peers, and adults in inclusive settings</td>
<td>To investigate the nature of social experiences and opportunities for communication among students with Db, their sighted peers, and adults in inclusive settings</td>
</tr>
<tr>
<td>Ingraham et al., (1995)</td>
<td>Students with Db</td>
<td>Not specified</td>
<td>3 students</td>
<td>Social interactions</td>
<td>To explore the social interactions of three gifted students with Db</td>
</tr>
<tr>
<td>Emerson, J., &amp; Bishop, J.</td>
<td>Students with Db</td>
<td>Not specified</td>
<td>10 students</td>
<td>Access and communication using technology</td>
<td>To investigate the potential for increasing access and communication using videophone technology</td>
</tr>
<tr>
<td>Bruce, S.M., &amp; Parker, A.T.</td>
<td>Young adults with Db</td>
<td>Mixed (Grp 1 and Grp 2)</td>
<td>6</td>
<td>Experience of process of change</td>
<td>To learn more about how the youth with Db experienced the process of becoming change agents in the advocacy course</td>
</tr>
<tr>
<td>Yamada et al., (2016)</td>
<td>Nursing home residents with or without DSI*</td>
<td>Acquired (Grp 3)</td>
<td>Total - 1989; DSI-122</td>
<td>Cognitive decline and social engagement</td>
<td>To examine whether nursing home residents with DSI have a greater cognitive decline over time and whether social engagement modifies this association</td>
</tr>
<tr>
<td>Gopinath et al., (2016)</td>
<td>Older Adults with or without DSI</td>
<td>Acquired (Grp 3)</td>
<td>Total 1478 older adults (DSI not specified)</td>
<td>Dual sensory impairment (DSI) and incidence of falls</td>
<td>To assess the association between dual sensory impairment (DSI) and incidence of falls</td>
</tr>
<tr>
<td>Cimarolli, V.R. &amp; Jopp, D.S. (2014)</td>
<td>Oldest Old Adults with or without DSI</td>
<td>Acquired (Grp 3)</td>
<td>119</td>
<td>Prevalence of SI and association with functional disability</td>
<td>To explore associations of sensory impairments with functional disability in near-centenarians and centenarians</td>
</tr>
<tr>
<td>References</td>
<td>Study population</td>
<td>Type of disability</td>
<td>Number of participants</td>
<td>Focus of article</td>
<td>Aim of the study</td>
</tr>
<tr>
<td>-----------------------------</td>
<td>-------------------------</td>
<td>--------------------------</td>
<td>------------------------</td>
<td>---------------------------------------------------------------------------------</td>
<td>---------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Dammeyer, J. (2012)</td>
<td>Children with Db</td>
<td>Mixed (Grp 1 and Grp 2)</td>
<td>26 (Ush) and 17 (CHARGE)</td>
<td>Developmental characteristics of children with Usher syndrome and CHARGE syndrome</td>
<td>To describe the developmental characteristics of children with Usher syndrome and CHARGE syndrome</td>
</tr>
<tr>
<td>Schneider et al., (2011)</td>
<td>Older adults with DSI</td>
<td>Acquired (Grp 3)</td>
<td>Not applicable</td>
<td>Dual sensory impairment in older age</td>
<td>To examine the frequency and effects of DSI in older age</td>
</tr>
<tr>
<td>Heine C. &amp; Browning C.J. (2002)</td>
<td>Older adults with sensory loss</td>
<td>Acquired (Grp 3)</td>
<td>Not applicable</td>
<td>Sensory loss in older adults</td>
<td>To understand the communication and psychosocial consequences of sensory loss in older adults</td>
</tr>
<tr>
<td>Heine, C., &amp; Browning C.J. (2015)</td>
<td>Older adults with DSL</td>
<td>Acquired (Grp 3)</td>
<td>Not applicable</td>
<td>Effect of dual sensory loss in older adults</td>
<td>To critically evaluate the evidence from studies that examined dual sensory loss and its effects on older adults.</td>
</tr>
<tr>
<td>Dammeyer, J. (2014)</td>
<td>Not specified</td>
<td>Not specified</td>
<td>Not applicable</td>
<td>Literature review on deafblindness</td>
<td>To review literature on Db</td>
</tr>
<tr>
<td>Danermark, B.D., &amp; Moller K. (2008)</td>
<td>NA</td>
<td>Not specified</td>
<td>NA</td>
<td>Information and communication</td>
<td></td>
</tr>
<tr>
<td>Brennan, M., &amp; Bally, S.J. (2007)</td>
<td>Older adults with DSL</td>
<td>Acquired (Grp 3)</td>
<td>Not applicable</td>
<td>Psychosocial Adaptations to DSI</td>
<td>To review the prevalence and causes of dual impairment and its effects on functioning for both individuals affected and their families</td>
</tr>
<tr>
<td>Saunders, G.H., &amp; Echt, K.V. (2007)</td>
<td>Older adults with DSI</td>
<td>Acquired (Grp 3)</td>
<td>Not applicable</td>
<td>Effect of DSI</td>
<td>To present overview of DSI and research needs regarding rehabilitation strategies</td>
</tr>
<tr>
<td>References</td>
<td>Study population</td>
<td>Type of disability</td>
<td>Number of participants</td>
<td>Focus of article</td>
<td>Aim of the study</td>
</tr>
<tr>
<td>-------------------------</td>
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<td>--------------------</td>
<td>------------------------</td>
<td>----------------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Damen, G.W. et al.</td>
<td>Adults with Ush</td>
<td>Usher Syndrome</td>
<td>93 (50M &amp; 43F) (Ush)</td>
<td>Maintaining independence - access to information, communication and mobility</td>
<td>To understand the challenges faced by Usher patients in order to maintain independence with progressing age and increasing hearing/RP difficulties</td>
</tr>
<tr>
<td>Brennan, M., Horowitz,</td>
<td>Older Adults</td>
<td>Acquired</td>
<td>5151</td>
<td>DSL and functional competence</td>
<td>To examine the relation of dual sensory loss to functional competence among older adults</td>
</tr>
<tr>
<td>A., &amp; Su, Y.P. (2005)</td>
<td>with or without DSL</td>
<td>Grp 3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Simcock, P. (2016)</td>
<td>Persons with Db</td>
<td>Not specified</td>
<td>Not applicable</td>
<td>Vulnerability of persons with Db</td>
<td>To synthesize existing knowledge about the relationship between Db and vulnerability</td>
</tr>
<tr>
<td>Capella-McDonnall, M.E.</td>
<td>Older adults</td>
<td>Acquired</td>
<td>9832</td>
<td>DSL and depression</td>
<td>To determine the effect of dual sensory loss (i.e., combined hearing and vision loss) on depressive symptoms</td>
</tr>
<tr>
<td>(2005)</td>
<td>with or without DSL</td>
<td>Grp 3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hersh, M.A. (2013)</td>
<td>Adults with Db</td>
<td>Mixed (Grp 1 and Grp 2)</td>
<td>27 Db +1 mother of autistic Db</td>
<td>Experiences of communicatio, independence, and isolation</td>
<td>To discuss issues related to communication, independence, and isolation</td>
</tr>
<tr>
<td>Berry et al. (2004)</td>
<td>Older adults</td>
<td>Acquired</td>
<td>Not applicable</td>
<td>Challenges due to DSI</td>
<td>To outline the main issues faced by older individuals who experience dual sensory impairments</td>
</tr>
<tr>
<td></td>
<td>with DSL</td>
<td>Grp 3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>McDonnall et al. (2016)</td>
<td>Older Adults</td>
<td>Acquired</td>
<td>131</td>
<td>Needs and challenges of seniors with dual sensory loss</td>
<td>To identify the needs and challenges of seniors with dual sensory loss</td>
</tr>
<tr>
<td></td>
<td>with or without DSL</td>
<td>Grp 3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Viljanen, A. (2014)</td>
<td>Older adults</td>
<td>Acquired</td>
<td>27536</td>
<td>Prevalence and association with social inactivity</td>
<td>To describe the prevalence of sensory difficulties and whether sensory difficulties are associated with social inactivity in older Europeans</td>
</tr>
<tr>
<td></td>
<td>with or without DSL</td>
<td>Grp 3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>References</td>
<td>Study population</td>
<td>Type of disability</td>
<td>Number of participants</td>
<td>Focus of article</td>
<td>Aim of the study</td>
</tr>
<tr>
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<td>------------------------</td>
<td>------------------------------------------------------</td>
<td>----------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Brennan, M. (2003)</td>
<td>Older Adults with DSL</td>
<td>Not specified</td>
<td>Not specified</td>
<td>Prevalence and impact on quality of life</td>
<td>To describe prevalence and impact on quality of life due to DSL</td>
</tr>
<tr>
<td>Högner, N. (2015)</td>
<td>Adults with Ush</td>
<td>Usher Syndrome Type II (Acquired) (Grp 2)</td>
<td>262 (139F and 123M)</td>
<td>Psychological Stress</td>
<td>To assess stress in people with Usher Syndrome type II and the influence of personal variables such as age, gender, and employment on stress</td>
</tr>
<tr>
<td>Guthrie et al., (2016)</td>
<td>Older adults with or without DSI (Grp 3)</td>
<td>Acquired</td>
<td>Not specified</td>
<td>Demographic characteristics, functional and psychosocial outcomes</td>
<td>To compare older adults with DSI to all others across demographic characteristics, functional and psychosocial outcomes</td>
</tr>
<tr>
<td>Heine, C., &amp; Browning, C. J. (2004)</td>
<td>Older Adults with DSL</td>
<td>Acquired (Grp 3)</td>
<td>10 (8F and 2M)</td>
<td>Communication and psychosocial perceptions</td>
<td>To explore the communication and psychosocial perceptions of a group of older adults with single or DSL</td>
</tr>
<tr>
<td>Lieberman, L., &amp; Stuart, M. (2002)</td>
<td>Adults with Db</td>
<td>Mixed (Grp 1 and Grp 2)</td>
<td>51 (25M and 26F)</td>
<td>Leisure and recreation</td>
<td>To describe leisure and recreation for persons with Db</td>
</tr>
<tr>
<td>Rönneberg, J., &amp; Borg, E. (2001)</td>
<td>Persons with Db</td>
<td>Mixed (Grp 1 and Grp 2)</td>
<td>Not applicable</td>
<td>Behavioral and communicative research on deaf-blind individuals</td>
<td>To present primarily the last 10–20 years of behavioral and communicative research on Db individuals</td>
</tr>
<tr>
<td>Möller, K., &amp; Danermark, B. (2007)</td>
<td>Students with Db</td>
<td>Acquired (Grp 2)</td>
<td>34</td>
<td>Personal and environmental factors affecting participation</td>
<td>To describe environmental and personal factors that, from the student perspective, impede participation in education in secondary upper schools by students with post lingual Db</td>
</tr>
<tr>
<td>References</td>
<td>Study population</td>
<td>Type of disability</td>
<td>Number of participants</td>
<td>Focus of article</td>
<td>Aim of the study</td>
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<tr>
<td>Soper, J. (2006)</td>
<td>Adults with Db</td>
<td>Acquired (Grp 2)</td>
<td>5</td>
<td>Experience of cochlear implantation</td>
<td>To examine the experience of cochlear implantation in individuals with acquired Db, focusing on access to information, communication, and mobility.</td>
</tr>
<tr>
<td>Simcock, P., &amp; Manthorpe, J. (2014)</td>
<td>Young Woman with Db</td>
<td>Congenital (Grp 1)</td>
<td>1</td>
<td>Experience of vulnerability</td>
<td>To explore this unique impairment in the illustrative case of Beverley Lewis.</td>
</tr>
<tr>
<td>Bodsworth et al., (2011)</td>
<td>Adults with DSI</td>
<td>Not specified</td>
<td>539</td>
<td>Mental health experiences</td>
<td>To document psychological distress and unmet need among adults with DSI.</td>
</tr>
<tr>
<td>Deafblind UK. (2007)</td>
<td>Adults with Db</td>
<td>Not specified</td>
<td>486</td>
<td>Experiences of access to health services</td>
<td>To understand experiences of access to health services.</td>
</tr>
<tr>
<td>Ellis, L., &amp; Hodges, L. (2013)</td>
<td>Adults with Ush 1, 2, and 3</td>
<td>Acquired (Grp 2)</td>
<td>42 (16M and 26F)</td>
<td>Experiences of diagnosis</td>
<td>To explore experiences of being diagnosed with Usher and impact of diagnosis on the lives and experiences of people with Usher syndrome.</td>
</tr>
<tr>
<td>Watters, C., Owen, M., &amp; Munrooe, S. (2005)</td>
<td>Adults with Db, their parents, and professionals</td>
<td>Mixed (Grp 1 and Grp 2)</td>
<td>Total - 3306; 44 (Adults with Db) - 42 acquired + 2 congenital; (29F &amp; 15M)</td>
<td>Demographics, needs, and issues</td>
<td>(1) To provide demographic information about persons with congenital and acquired Db in Canada; (2) To discuss service needs of persons with Db and their parents; (3) To present an overview of the personal stories of the barriers and successes experienced by them; (4) To outline existing services; and (5) To provide directions for future research.</td>
</tr>
<tr>
<td>References</td>
<td>Study population</td>
<td>Type of disability</td>
<td>Number of participants</td>
<td>Focus of article</td>
<td>Aim of the study</td>
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<tr>
<td>Figueiredo et al., (2013)</td>
<td>Adults with Ush</td>
<td>Acquired (Grp 2)</td>
<td>11</td>
<td>Impacts of the disease on their daily lives</td>
<td>To characterize communication and main mechanisms that facilitate interpersonal relationships of Db, especially in relation to communication and locomotion and the impact of these aspects on Db</td>
</tr>
<tr>
<td>Fletcher, P.C., &amp; Guthrie, D.M. (2013)</td>
<td>Adults with DSL</td>
<td>Acquired (Grp 2)</td>
<td>7</td>
<td>Lived experiences of challenges associated with acquired Db</td>
<td>To examine the lived experiences of people with acquired Db</td>
</tr>
<tr>
<td>Crews, J.E., &amp; Campbell, V.A. (2004)</td>
<td>Older adults with or without DSI</td>
<td>Acquired (Grp 3)</td>
<td>Total 9447; 779 (Vision and hearing loss)</td>
<td>Health, activity, and social participation</td>
<td>To investigate the health, activity, and social participation of people aged 70 years or older with vision impairment, hearing loss, or both</td>
</tr>
<tr>
<td>Heine, C., &amp; Browning, C.J. (2014)</td>
<td>Older adults with DSL</td>
<td>Acquired (Grp 3)</td>
<td>Not applicable</td>
<td>Mental health experiences</td>
<td>To examine the mental health of older adults with DSL</td>
</tr>
<tr>
<td>Simcock, P. (2016)</td>
<td>Older adults with Db</td>
<td>Acquired (Grp 3)</td>
<td>Not applicable</td>
<td>Experience of ageing</td>
<td>To explore the experiences of those ageing with Db</td>
</tr>
<tr>
<td>Hersh, M.A. (2013)</td>
<td>Adults with Db</td>
<td>Mixed (Grp 1 and Grp 2)</td>
<td>27 Db +1 mother of autistic Db</td>
<td>Experiences of stigma in using assistive devices for communication and mobility</td>
<td>To discuss issues, including stigma, related to the use of assistive communication and mobility devices</td>
</tr>
<tr>
<td>Fukushima, S. (2011)</td>
<td>Adult with Db</td>
<td>Acquired (Grp 2)</td>
<td>1</td>
<td>Experience of deafblindness and disability studies</td>
<td>To characterize disability studies based on the author’s own experience as a Db person</td>
</tr>
<tr>
<td>Gibson, J. (2000)</td>
<td>Adult with Db</td>
<td>Congenital (Grp 1)</td>
<td>1</td>
<td>Experiences of Outdoor Activities</td>
<td>To document the experiences of a deafblind adult in a variety of outdoor activities in holidays</td>
</tr>
<tr>
<td>References</td>
<td>Study population</td>
<td>Type of disability</td>
<td>Number of participants</td>
<td>Focus of article</td>
<td>Aim of the study</td>
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<tr>
<td>Lieberman et al., (n.d.)</td>
<td>Adults with Db</td>
<td>Mixed (mostly Ushers - Grp 2)</td>
<td>18</td>
<td>Experience of recreation</td>
<td>To highlight recreational and leisure pursuits for individuals who are deafblind</td>
</tr>
<tr>
<td>Reid, C. (2010)</td>
<td>Adult woman with Db</td>
<td>Acquired (Grp 2)</td>
<td>1</td>
<td>Personal experience as a deafblind person</td>
<td>To narrate the life journey</td>
</tr>
<tr>
<td>Sense UK. (n.d.)</td>
<td>Adults with Db</td>
<td>Not specified</td>
<td>8</td>
<td>Experience of transition into adulthood</td>
<td>To understand the experiences of the transition process for young deafblind people</td>
</tr>
</tbody>
</table>

*Db means deafblindness; Ush means Usher syndrome; DSI means dual sensory impairments; DSL means dual sensory loss; RP means Retinitis Pigmentosa and Grp means group

Almost all of the sources were from developed nations. Most studies were based in the continent of North America (n=20) [United States of America (n=17) and Canada (n=3)], and Europe (n=20) [United Kingdom (n=10) and other European countries (n=10)], followed by two studies from Australia and one study from South America (Brazil) (Figure 2). A range of 1–8 articles per year were published on topics related to experiences between 1995 and 2016 worldwide, while most records (n= 24) were published in the last five years (Figure 3).

Figure 2. Number of records - country wise
The records demonstrated variation in terminology with 11 different terms used across records to refer to the deafblind population (Figure 4). Using the groups identified above, this scoping review found that most studies included participants from Group 3 (n=18), followed by Group 2 (n=12), and Group 1 (n=3). Nine studies used mixed populations of Group 1 and Group 2 in their studies, and twelve studies did not specify the nature (congenital versus acquired) of disability of their participants (Figure 5).
Figure 4. Terminologies used to describe study population

![Terminologies used](image)

Figure 5. Categories of deafblindness represented across sources

![Type of study participants’ groups (Group 1, 2, and 3)](image)
In terms of life stage, a large number of sources had participants that were adults (age between 18-65 years) (n=23), followed by older adults (age above 65 years) (n=13), and children (age less than 18 years) (n= 7). Most of the literature (n=40) focused on characteristics, effects, challenges, and issues faced due to dual sensory loss or deafblindness and its impact on experiences of inclusion, social participation, engagement, physical and mental health. Some sources (n=14) addressed experiences of dual sensory loss and incidence of depression, isolation, and suicidal tendencies in older adults (Group 3). A few sources (n=4) also focused on experiences of leisure, recreation and physical activities.

**Major themes from the qualitative synthesis.** The themes that emerged from synthesis included experiences related to communication, mobility, functioning in daily life, social interactions, and feelings. While the Figure 6 provides a visual representation of the themes that emerged, Table 8 provides key findings across the three groups. Under each of the themes discussed below, the authors first identify the experiences that are common to all three groups and then highlight only those participation experiences that were only unique to a specific group.

Figure 6. Participation of persons with deafblindness
Table 8. Key findings across three groups

<table>
<thead>
<tr>
<th>Key Findings</th>
<th>Group 1 (congenital deafblindness)</th>
<th>Group 2 (acquired deafblindness)</th>
<th>Group 3 (age-related deafblindness)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication</td>
<td>Experiences greater difficulty with expressive communication</td>
<td>Experiences changing communication needs due to progressive sensory loss, reluctance to admit their hearing impairment with family, friends, and others</td>
<td>Experiences frequent communication breakdown, inability to perceive gestural cues, embarrassment and ‘failures’</td>
</tr>
<tr>
<td>Mobility</td>
<td>Nothing specific to this group reported;</td>
<td>Experiences embarrassment due to frequent bumping into objects/people; report feeling stigmatized to use assistive devices such as canes in public</td>
<td>Experiences lack of independence in indoor-outdoor mobility</td>
</tr>
<tr>
<td>Functioning in daily life</td>
<td>Nothing specific to this group reported;</td>
<td>Experiences more difficulty in maintaining independence; tend to need more help from others to remain independent when impairment worsens; experiences reduced independence in shopping, food preparation, reading, house cleaning, watching television, reading books, listening to music, and use of technology</td>
<td>Experiences decreased social participation with increased everyday functioning difficulties in their activities of daily living (ADL) and Instrumental ADL – dressing, meal preparation, shopping, moving around, using the phone, and managing medications</td>
</tr>
<tr>
<td>Social interactions</td>
<td>Experiences limited engagement with others in society and experienced severe difficulties in social interactions than the other groups</td>
<td>Experiences constant social isolation in life due to progressive impairments, ongoing loss of independence, and frequent worries</td>
<td>Experiences reduced participation in social activities; avoid social contact and hence, social circle is limited</td>
</tr>
<tr>
<td>Feelings</td>
<td>Feels insecure, unsafe, and vulnerable both in</td>
<td>Feelings of worthlessness,</td>
<td>Feels embarrassed, offended and</td>
</tr>
</tbody>
</table>

48
<table>
<thead>
<tr>
<th>Key Findings</th>
<th>Group 1 (congenital deafblindness)</th>
<th>Group 2 (acquired deafblindness)</th>
<th>Group 3 (age-related deafblindness)</th>
</tr>
</thead>
<tbody>
<tr>
<td>and outside their homes; high risk of depression and may experience heightened vulnerability amongst deafblind groups</td>
<td>loneliness, emptiness, uncertainty, fear of losing independence, and concerns about forming relationships, being rejected by relatives and friends, and constant concern for the future; feels depression and suicidal thoughts</td>
<td>isolated, and have increased likelihood of depression; experiences reduced quality of life, having symptoms of anxiety or lethargy, and feeling social dissatisfaction</td>
<td></td>
</tr>
</tbody>
</table>

**Communication.** Multiple studies reported that persons with deafblindness (Group 1, 2, and 3) faced communication difficulties (Dalby et al., 2009; Dammeyer, 2012; 2014; Ellis & Hodges, 2013; Figueiredo, Chiari, & de Goulart, 2013; Fletcher & Guthrie, 2013; Fukushima, 2011; Guthrie et al., 2016; Heine & Browning, 2004; 2015; Hersh, 2013a & b; Kamenopoulou, 2012; McDonnall, Crudden, LeJeune, Steverson, & O'Donnell, 2016; Schneider et al., 2011; Watters et al., 2005). Communication breakdown was reported in two of the articles as one of the main challenges affecting social inclusion and interpersonal interactions of persons with deafblindness (Kamenopoulou, 2012; Watters et al., 2005). Authors reported that persons with deafblindness felt that non-disabled people lacked knowledge about how to communicate with them, and this lack of awareness posed barriers to communication and social participation (Deafblind UK, 2007; Reid, 2010; Watters et al., 2005). A woman with deafblindness in her personal narrative expressed that although there are some non-disabled people who are willing to help, they do not know how to communicate and are therefore unable to help (Reid, 2010).

Authors also reported that alternative means of communication such as signing, Braille, print on palm, Tadoma (method of communication that involves individual with deafblindness placing their thumb on a speaker’s person's lips and their fingers along the jawline to feel their movements as they speak) (Hersh, 2013a), and assistive technology such as computer/interpreter-
facilitated communication means, videophone technology, and cochlear implants facilitated communication and social interactions of persons with deafblindness (Figueiredo et al., 2013; Gribs, Dougherty, & Pre, 1995; Soper, 2006; Emerson & Bishop, 2012; Reid, 2010). Additionally, strategies such as prior rehearsal of situations, use of communication repair strategies (for example asking for repetition or further clarifications from the conversational partner) and recreational activities could also be helpful in enabling successful communication (Heine & Browning, 2004; Lieberman & MacVicar, 2003; Lieberman, Haegele, & Marquez, n.d.). The reviewed literature also showed that challenges in communication manifested differently for each of the three categories of deafblindness.

Group 1: Authors reported that persons with congenital deafblindness or congenital anomalies (such as CHARGE syndrome) reported greater difficulty with expressive communication than the acquired group because those with congenital deafblindness very often use signs and gestures to communicate in comparison to those with acquired where speech is prevalent mode of communication (Bruce, Zatta, Gavin & Stelzer, 2016; Dalby et al., 2009).

Group 2: In contrast to Group 1, people with acquired deafblindness had some communication-related experiences that were unique due to their changing communication needs and progressive sensory loss, different accents, and lack of knowledge of sign language, and reluctance to admit their hearing impairment to family, friends, and others (Fletcher & Guthrie, 2013; Hersh, 2013b). One study reported that progressive loss of vision in Usher syndrome (Type 1) affects the ability to communicate with others, and causes depression and suicidal thoughts due to loneliness (Miner, 1995).

Group 3: A few sources focused on the distinct communication challenges and frequent communication breakdowns experienced due to age-related vision and hearing loss (Heine & Browning, 2002; 2004). For example, inability to perceive non-verbal and gestural cues (such as eye-gaze, facial expressions, lip-reading, and contextual cues) interferes with reception of spoken
messages, and at times older adults get embarrassed by this and view themselves as ‘failures’ (Heine & Browning, 2002; 2004). Communication challenges for this group were primarily related to understanding and being understood, resulting in negative feelings of left out or isolation, reduced quality of life, anxiety or lethargy, and social restriction (Capella-McDonnall, 2005; Guthrie et al., 2016; Heine & Browning, 2004; 2015; McDonnell et al., 2016; Schneider et al., 2011).

**Mobility.** Challenges related to mobility and orientation were common across all three groups (Capella-McDonnall, 2005; Crews & Campbell, 2004; Dalby et al., 2009; Kamenopoulou, 2012; McDonnell et al., 2016). Key challenges included access to information from the outside world, navigating one’s environment, and using public transportation (Crews & Campbell, 2004; Fletcher & Guthrie, 2013; McDonnell et al., 2016; Reid, 2010; Rönnberg & Borg, 2001). Some sources cited experiences of compromised mobility within the home and community as an impediment to participation (Crews & Campbell, 2004; Ellis & Hodges, 2013; Fletcher & Guthrie, 2013; Reid, 2010; Watters et al., 2005).

Those with acquired condition (Group 2) often experienced embarrassment due to frequent bumping into objects/people, and rejected use of assistive devices such as canes and hearing aids in public due to perceptions of stigma (Figueiredo et al., 2013; Fletcher & Guthrie, 2013, Hersh, 2013b; Miner, 1995; Reid, 2010). With reference to older adults (Group 3), lack of independence in indoor-outdoor mobility was found to exacerbate feelings of social isolation, caused by communication challenges (Capella-McDonnall, 2005; Crews & Campbell, 2004; McDonnell et al., 2016).

On the positive side, a few studies suggested that visual rehabilitation and training of remaining/residual senses in combination with environmental information such as the breeze of the wind, the warmth of a body, a radiator, sunlight, heavy traffic and other loud environmental
sounds could improve orientation and mobility for individuals with deafblindness (Figueiredo et al., 2013; Rönnberg & Borg, 2001).

**Functioning in daily life.** In addition to communication and mobility challenges, multiple sources reported that adults with deafblindness experienced difficulties in their daily functioning that significantly affected their social participation (Brennan, Horowitz, & Su YP, 2005; Cimarolli & Jopp, 2014; Crews & Campbell, 2004; Dalby et al., 2009; Fletcher & Guthrie, 2013; Guthrie et al., 2016; Heine & Browning, 2014; Saunders & Echt, 2007; Schneider et al., 2011). Two sources identified activities of daily living such as reading, cooking, dressing, walking in the community, shopping, attending social events, getting to a doctor’s appointment, accessing information via telephone, and answering machines, as those activities where persons with deafblindness experienced challenges on regular basis (Brennan et al., 2005; Watters et al., 2005). One survey-based study indicated high levels of unmet needs and experiences of psychological distress among men and women with deafblindness due to the loss of functional independence in their lives (Bodsworth, et al., 2011). Another source suggested that assistive technologies and environmental adaptations could help people with dual sensory loss regain their functional independence (Berry, Mascia, & Steinman, 2004). As with the earlier two categories, articles reported variations between the three groups of persons with deafblindness.

**Group 1:** No themes specific to group one were identified.

**Group 2:** Major problems faced by this group included functional independence in shopping, food preparation, reading, house cleaning, watching television, reading books, listening to music, and use of technology (Figueiredo et al., 2013; Fletcher & Guthrie, 2013). While considering the heterogeneity of this group, one article reported that individuals with Usher type I faced more difficulty in maintaining independence than type II; especially with progressing age (older) and worsening hearing or visual impairment, and they tend to need more help from others.
to be able to remain independent when their impairment worsened (Damen, Krabbe, Kilsby, & Mylanus, 2005).

Group 3: In the case of older adults, multiple studies reported that dual sensory loss in older adults was the strongest predictor of functional disability and need for assistance with daily activities (Cimarolli & Jopp, 2014; Gopinath, Mcmahon, Burlutsky, & Mitchell, 2016; Heine & Browning, 2004). A number of sources reported that older adults with dual sensory loss experienced decreased social participation with increased difficulty in performing activities of daily living (ADL) and Instrumental ADL, such as meal preparation, shopping, moving around, using the phone, and managing medications (Brennan et al., 2005; Cimarolli & Jopp, 2014; Crews & Campbell, 2004; Guthrie et al., 2016; Heine & Browning, 2014; Saunders & Echt, 2007; Schneider et al., 2011). In addition, this group experienced difficulty with maintaining employment, despite hearing aids. The authors attributed this particular experience to the stigma associated with sensory loss and use of hearing aids (Brennan & Bally, 2007).

**Social interactions and sense of isolation.** Multiple articles revealed challenges with social interactions leading to loneliness and isolation (Brennan & Bally, 2007; Dalby et al., 2009; Fletcher & Guthrie, 2013; Ingraham et al., 1995; McDonnall et al., 2016; Schneider et al., 2011; Viljanen, Törmäkangas, Vestergaard, & Andersen-ranberg, 2014; Yamada et al., 2016). For example, very often, people do not greet or inform the person with deafblindness of their presence and hence, persons with deafblindness have no information about who is available in the same environment, and this lack of information restricted their social interactions. Furthermore, Simcock (2016) reported that adults with deafblindness who are ageing with congenital/acquired impairments experience high levels of isolation due to changes in social networks and loss of friends as they get older (Simcock, 2016). Other sources reported that challenges in social interactions lead to social inactivity and reduced social participation in persons with deafblindness (Brennan & Bally, 2007; Dalby et al., 2009; McDonnall et al., 2016; Schneider et
al., 2011; Viljanen et al., 2014). Studies also suggested approaches to facilitate social participation through group participation and social skills training; learning alternative forms of communication; using assistive technology; devising alternative leisure or recreational activities; establishing social networks; and mobilizing social supports (Bruce & Parker, 2012; Correa-Torres, 2008; Gibson, 2000; Heine & Browning, 2004; Högner, 2015). Some of the studies reported challenges experienced by specific groups. For example:

Group 1: Specific to this group, authors reported that adults with congenital deafblindness had limited engagement with others in society and experienced more severe difficulties in social interactions than the other groups (Dalby et al., 2009).

Group 2: Studies reported that those with acquired deafblindness are more likely to experience constant social isolation in their lives due to the progressive impairments, ongoing loss of independence, and frequent worries (due to uncertainty about the process of the progressive loss and how to cope with it) (Correa-Torres, 2008; Dalby et al., 2009; Fletcher & Guthrie, 2013; Figueiredo et al., 2013; Högner, 2015).

Group 3: Unique to this group, multiple studies reported that dual sensory loss very often impacted the social interactions of older adults with family and friends and as compared to the past, they participated less in social activities such as getting together with friends, shopping, going to a restaurant, and attending church and movies (Brennan, 2003; Brennan & Bally, 2007; Crews & Campbell, 2004; Heine & Browning, 2015). Since the onset of loss, both the type and frequency of social interactions changed and they had limited their social circle by avoiding social contact (Heine & Browning, 2004).

Feelings. Multiple studies reported that adults with deafblindness experienced a myriad of feelings, including loss of independence, feelings of sadness, anger, depression, frustration, insecurity, and uncertainty about future (Ellis & Hodges, 2013; Fletcher & Guthrie, 2013; Wahlqvist et al., 2013; Watters et al., 2005). Authors in two survey-based studies revealed that
their participants experienced psychological distress due to impairment, and developed symptoms of anxiety, stress, depression, withdrawal, and suicidal behaviors (Bodsworth et al., 2011; Wahlqvist et al., 2013).

Group 1: Specific to the groups, in Group 1, authors reported that persons with congenital deafblindness were at high risk of depression and may experience heightened vulnerability to abuse and neglect amongst deafblind groups (Group 2 and 3) (Dalby et al., 2009; Simcock & Manthrope, 2014). People, in particular women, with congenital deafblindness often feel insecure and unsafe, and described their lived experiences of feeling vulnerable both in and outside their homes, even in the context of receiving care and support (Simcock, 2016; Simock & Manthrope, 2014).

Group 2: With respect to this group, authors reported that persons with acquired deafblindness were more likely to experience lost roles, and faced issues in adjusting to their impairment (Dalby et al., 2009). The findings indicate that in contrast to the congenital group, "although the acquired group has the capacity to function more independently in the community, given their functional and social skills, they are more socially isolated and more likely to report feeling lonely" (Dalby et al., 2009, p. 101). Authors in multiple studies found that those with Usher syndrome had constant feelings of worthlessness, loneliness, emptiness, uncertainty, fear of losing their independence, and concerns about forming relationships, being rejected by relatives and friends, and constant concern for the future (Ellis & Hodges, 2013; Fletcher & Guthrie, 2013; Högner, 2015; Miner, 1995; Sense UK, n.d.; Wahlqvist et al., 2013). This particular experience was explained with “awareness of an initially relatively intact function (i.e., vision in this case) – which is progressively deteriorating – is more traumatic, compared to the case when the individuals were born without a particular function” (Rönnberg & Borg, 2001, p. 72).
Group 3: In contrast to the feelings experienced by Group 1 and 2, authors reported that older adults with dual sensory loss feel stigmatized due to the sensory loss and required use of assistive aids/devices (Brennan & Bally, 2007). Multiple studies revealed that older adults feel embarrassed, offended and isolated due to impediments to communication and social participation, and have increased likelihood of depression that leads to reduced quality of life (Capella-McDonnall, 2005; Crews & Campbell, 2004; Heine & Browning, 2014; Schneider et al., 2011). They found the biggest challenge was acceptance of the vision and hearing loss, and felt that “once acceptance had been achieved, the enjoyment of life could begin” (Heine & Browning, 2004, p. 120).

2.6 Discussion

This scoping review identified global literature on participation experiences of people with deafblindness, examining 54 articles published over the last 27 years (1990-2017). The content of these studies indicated that people with deafblindness experience significant challenges in communication, mobility, daily living functioning, and social interactions. Often, articles reported participation experiences that were common to three groups of persons with deafblindness (Group 1, 2, and 3) and some experiences that were distinct to one group only.

Focus of study and research methods employed. A majority of studies focused on characteristics, effects, challenges, and issues faced due to dual sensory loss or deafblindness and its impact on their experiences of inclusion, social participation, engagement, and physical and mental health. In terms of methodology employed, the majority of studies were quantitative in nature (n=19) with use of survey data. Among those, only two studies were longitudinal and three were cross-sectional studies. Research in this area is dominated by quantitative studies that often rely on information from proxies (family members or professionals working with people with deafblindness). Researchers have argued that there is a need for more qualitative research to
develop an in-depth understanding of the needs and experiences of this population (Dammeyer, 2014, 2015; Danermark & Moller, 2008; Hersh, 2013b; Simcock, 2016; Viljanen et al., 2014).

**Geographic distribution and under-representation.** It is clear that deafblindness research has gained interest only in recent years. Still, there is very limited literature on deafblind persons’ experiences worldwide – particularly from low and middle-income countries (LMICs). All of the 54 publications in this review were from developed nations. Furthermore, it is worth noting that the majority of research participants included in the studies were those with acquired or dual sensory loss condition (Group 2 and 3). Those with congenital deafblindness (Group 1) were rarely included as participants, as also illustrated in other studies (Dammeyer, 2015). One of the studies reported the inability to include congenital population in the study sample as their limitation due to communication difficulties in conducting interviews (Fletcher & Guthrie, 2013). Consequently, individuals with congenital deafblindness are not getting opportunities to share their unique experiences and challenges.

Experiences of deafblindness in developing nations are under-represented in the literature due to one of three reasons: (a) a majority of the deafblind population in LMICs are from Group 1 as more than 100,000 children continue to be born with Congenital Rubella Syndrome each year worldwide (Sense International, 2015; World Health Organization, 2013), (b) less deafblind-specific interventions exist in these countries (Sense International, 2017), or (c) fewer research publications stem from the programs that do exist, in part, due to lack of funding and/or local expertise (Eide, & Ingstad, 2013; Sense International India, 2014). The gap warrants research publications in these contexts to inform disability policy, rehabilitation practice and research.

Another noteworthy observation is that out of 54 studies, the authors only found two personal narratives of women with deafblindness related to their life experiences (Gribs et al., 1995; Reid, 2010) and one article on the experiences of vulnerability by women with deafblindness (Simcock & Manthorpe, 2014). The case study on the death of a young woman
‘Beverley Lewis’ throws light on the fact that this population can experience heightened vulnerability to abuse and more studies are warranted to understand the complexity of vulnerability and awareness of the risk of abuse, their likelihood and severity, particularly among women with deafblindness (Simcock & Manthorpe, 2014; Simcock, 2016).

**Heterogeneity of terminologies used.** Researchers in twelve of the included studies did not specify the nature (congenital versus acquired) of disability of their participants in the study. The authors also found varied definitions of deafblindness across identified studies, and eleven different terminologies were used to refer and report deafblind population in the literature. Heterogeneity of this population, variation in terminologies used, and lack of clarity in study populations (congenital/acquired) presented challenges in the generalization of the findings. The variation in terminology might distort the understanding of this condition among researchers and professionals. For instance, it can lead to an assumption of deafblindness as a rare condition and hinder identification of people having combined hearing and vision impairment in society.

Available literature lacks a clear definition of dual sensory loss or deafblindness (Ask Larsen & Damen, 2014; Dammeyer, 2014; 2015) and that might be a reason behind this lack of clarity among researchers while reporting their study sample characteristics. Similar findings were reported by Wittich and colleagues (2013) in their study on existing terminology and its use related to combined vision and hearing loss in both the research community and among professionals working in the field of rehabilitation. Researchers in the field of deafblindness have emphasized the need to harmonize terminology across practitioners and researchers on deafblindness to enable clarity in communication between different stakeholders and facilitate knowledge translation of research findings in their respective fields (Dammeyer, 2015; Wittich et al., 2013).

**Heterogeneity of the population and participation experiences.** The heterogeneity of this condition leads to varied experiences related to participation and manifests in the varied
forms of communication difficulties, mobility restrictions, decline in functioning, social isolation, and the myriad of feelings (Bodsworth et al., 2011; Hersh, 2013a & b). Communication, which plays a key role in social participation for any individual, emerged as one of the most significant domains affected by deafblindness and is more likely to cause difficulties in social interactions (Aitken et al., 2000).

In general, the available scientific literature is silent on the experiences of people with congenital deafblindness. The authors found very few studies that clearly discussed the experiences of persons with congenital deafblindness in relation to their involvement in daily life (Dalby et al., 2009; Lieberman & Stuart, 2002; Simcock & Manthrope, 2014). Although the study by Dalby and colleagues (2009) revealed that people with congenital deafblindness experienced more challenges in communication, mobility, activities of daily living, and social interactions with others than did the acquired group, it is also important to understand how they are more vulnerable to abuse and neglect (Dalby et al., 2009; Simcock & Manthrope, 2014).

In case of Group 2 (those with acquired impairment), the struggles were more to adjust to progressing visual or hearing loss and its impact on their independence in daily life. Those with acquired deafblindness are more likely to experience lost roles and face issues in adjusting to their acquired dual sensory impairment and develop feelings of loneliness. Even within Group 2, people who have progressive vision loss versus progressive hearing loss had distinct experiences of challenges of participation. For example, those with progressive vision loss face challenges in adapting to the changing communication needs, ongoing loss of independence, and increased dependence on others to assist in mobility and navigating the environment (Fletcher & Guthrie, 2013; Högner, 2015; Miner 1995; Reid, 2010). Whereas those with progressive hearing loss reported their fear of not knowing about an emergency situation, significant difficulties in communication due to loss of audible inputs and required change to learn to use hearing aids or cochlear implants (Damen et al., 2005). The feeling of constant insecurity and lack of
belongingness (being included and being accepted) plays a critical role in shaping their experiences of participation in the world (Möller & Danermark, 2007).

In the case of Group 3, the older adults with dual sensory loss experience distinct problems of adjusting to sensory loss, frustration, depression, anxiety, lethargy and social dissatisfaction (Heine and Browning, 2004; McDonall et al., 2016). They are more at risk of mental health concerns as compared to other two groups and do feel stigmatized in the use of assistive aids for hearing and mobility (Hersh, 2013b). They also experienced two-fold struggles – first due to communication breakdowns caused by co-existence of age-related vision and hearing loss, and second due to difficulty in learning to use specific technology (for example, computer, iPad and cellular telephone) in later stages of life which could overcome their communication challenges (Heine & Browning, 2004; McDonall et al., 2016).

Overall, this scoping study synthesizes the literature on participation experiences of persons with deafblindness and summarizes a range of evidence that could inform the programs and policies for rehabilitation of persons with deafblindness. The study documents that persons with deafblindness, regardless of their group (congenital, acquired or age-related), experience difficulty in communication, mobility, functioning, and access to information; and feel socially isolated, insecure and uncertain about their future. They are also at high risk of developing mental health issues as their age advances, and that may further worsen their condition and restrict their participation in society. Therefore, rehabilitation interventions should be designed keeping in the mind these specific and unique challenges faced by persons with deafblindness.

2.7 Limitations

One major limitation for this scoping study is related to generalizability of its findings for the deafblind population from developing nations. Given the geographical location of the included studies are from developed nations, it is likely that a bias exists, reflecting the experiences of persons with deafblindness from developed nations only, especially from North
America and Europe. However, given that the authors were unable to find peer-reviewed and non-peer reviewed publications from LMICs on the participation experiences of persons with deafblindness, this study might be a helpful first step in helping LMIC stakeholders understand the experiences of people with deafblindness. Future research should explore their experiences in LMIC contexts.

This study only reported results from articles published in English, which may have contributed to the absence of LMICs publications, as those articles may indeed exist in the local context and local language. Conducting the literature search in languages other than English would permit more confident claims regarding the comprehensiveness of the findings in this scoping review. Additionally, while this review was focused on experiences of persons with deafblindness, it is possible that including the perspectives of caregivers and professionals on the same focus might have enriched and complemented the findings (Wittich et al., 2016). Also this was not a systematic review so methodological rigor of studies was not evaluated.

2.8 Conclusions

The United Nations 2030 Agenda for the Sustainable Development Goals (2015) reiterates the principle of “leaving no one behind”, and the United Nations Convention on the Rights of Persons with Disabilities (2006) promotes the goal of maximizing participation of persons with disabilities, including deafblindness, in society (United Nations, 2006; 2015). However, individuals with deafblindness are often absent in rehabilitation research due to the complex nature of the disability and methodological challenges involved with recruitment and data collection. Therefore, conducting research on deafblindness and raising awareness of this distinct disability is imperative so that persons with deafblindness receive needed deafblind-specific rehabilitation services to enhance their participation and quality of life.

This review demonstrated that persons with deafblindness, regardless of the nature of their impairment, experience significant challenges in participation in day-to-day lives (especially
in communication, mobility and social interactions) and are at high risk of developing mental health issues as their age advances. Researchers very often associated the challenging participation experiences with the impairment rather than the environmental factors, locating the problem within the individual. Participation experiences of persons with deafblindness are shaped by dynamic interactions between personal factors (such as onset and type of impairments) and environmental influences (such as attitude, technology, and supports). A better understanding of these participation experiences may help rehabilitation professionals in placing emphasis on affected participation domains to design services that strive to enhance participation of persons with deafblindness. Moreover, the review of global deafblind-specific literature reveals that there is an absence of research literature on deafblindness from the LMICs and warrants research in these contexts to inform policy, practice and research.

2.9 References


Hersh, M. (2013b). Deafblind people, stigma and the use of communication and mobility


Chapter 3

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


Funding Acknowledgment: Queen Elizabeth II Diamond Jubilee Scholarship provided funding to the first author (AJ) for his doctoral study.

Disclaimer: This manuscript chapter is mostly similar, but not entirely identical, to the published version.
3.1 The Fit of Manuscript 2 within the Dissertation

Manuscript 2 builds upon the findings of the first manuscript by examining the meaning and experiences of participation for 16 individuals with deafblindness in India. This study also identifies the domains of life that are important to these individuals to participate. The findings of this empirical study generate some evidence to address the knowledge gap on the topic of participation experiences of persons with deafblindness from low- and middle-income countries. The knowledge generated advances the conceptual understanding of participation from the perspective of those with deafblindness and hints of contextual factors that influence participation for the further exploration in the third and fourth manuscripts.
3.2 Abstract

Deafblindness, also known as dual sensory loss, creates a distinct condition more disabling than either deafness or blindness alone. The participation experiences of persons with deafblindness have not been understood well. This phenomenological study aims to understand the meanings of participation for persons with deafblindness and identify the domains of life that are important to them. I used the International Classification of Functioning, Disability and Health as a guiding framework. Sixteen adults with deafblindness were interviewed between March and May 2017 in India using a qualitative interview guide. Findings suggest participation as a dynamic, individualized construct that is not just an end outcome. Rather, it is a means to achieve other goals important to the participants such as gaining respect, autonomy, independence, support and relationships, to fulfil aspirations and responsibilities, and to feel included and recognized in society. Life domains that they deemed important for participation were communication and access to information, mobility, relationships, education and productivity, and recreation and leisure. In order to enhance participation of people with deafblindness, a significant change in the focus of rehabilitation services is required which involves professionals viewing participation as both a means and an end outcome while designing interventions.
3.3 Introduction

The concept of participation has gained importance in the healthcare and rehabilitation fields since its inclusion in the International Classification of Functioning, Disability and Health (ICF), a framework published by the World Health Organization (WHO) in 2001 (Hemmingsson & Jonsson, 2005; World Health Organization, 2001). The ICF provides a biopsychosocial perspective on human functioning and disability and defines the term participation as “involvement in a life situation” (World Health Organization, 2001, p.229). Participation in society is a highly valued rehabilitation outcome, a primary goal for people with disabilities, their families, and a focus of disability rights conventions such as United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (Mallinson & Hammel, 2010; Mirza, Kim, Stoffel, Carroll, & Maga, 2015; Perenboom & Chorus, 2003; United Nations, 2006; Whiteneck, Bogner, & Heinemann, 2011).

Although the concept of participation is widely adopted by rehabilitation institutions and professionals, scholars highlight ambiguity in the best way to conceptualize and measure this construct among professionals and other rehabilitation stakeholders (Dahl, 2002; Dijkers, 2010; Eyssen, Steultjens, Dekker, & Terwee, 2011; Hammel et al., 2008; Magasi, Hammel, Heinemann, Whiteneck, & Bogner, 2009; Masala & Petretto, 2008; Perenboom & Chorus, 2003; Whiteneck et al., 2011). This conceptual ambiguity poses a risk of understanding participation in a way that is incongruent with the experiences and goals of persons with disabilities (Mirza, Magasi, & Hammel, 2016). Furthermore, the use of targets or benchmarks such as “full participation” or “equal participation” lacks clarity and warrants more research (Cornwall, 2008; Eversole, 2012). Improved understanding of participation and associated benchmark terms is critical for the advancement of rehabilitation practice, policy, and research.

Researchers trying to operationalize the concept of participation have found its meaning highly individualized for people with disabilities (Cardol, Jong, Ward, 2002) and argue that the “best judge of participation is the responder himself [sic]” (Perenboom & Chorus, 2003, p.578).
Scholarly debates highlight that ideal participation should be characterized by how and why one participates (meaningfulness of participation experiences) rather than how much one participates (frequency of involvement) (King, 2013; Whiteneck et al., 2011). Researchers also emphasize that this concept should be understood based on the individual’s choice and the meaning an activity has in one’s life (Cardol et al., 2002). To adequately assess and understand participation, researchers recommend focus on participation experiences, meaning and domains of participation and use of insider perspectives, especially for those people with disabilities whose participation is not well understood (Brown, 2010; Eyssen et al., 2011; Hammel et al., 2008; Hemmingsson & Jonsson, 2005; King, 2013; Magasi et al., 2009; Martin Ginis, Evans, Mortenson, & Noreau, 2017; Mirza et al., 2016). For example, Hammel and colleagues (Hammel et al., 2008) used insider perspectives of people with disabilities to identify a set of core participation values. While their study provided a comprehensive understanding of participation for people with disabilities, it did not capture the participation experiences of individuals with multisensory disabilities such as deafblindness. Moreover, most contemporary participation measures (standardized questionnaires) focus on objective aspects of participation (Eyssen et al., 2011; Martin Ginis et al., 2017), and may not be applicable for specific disability groups such as those with deafblindness (Gray, Hollingsworth, Stark, & Morgan, 2006; Magasi et al., 2009).

Deafblindness, also known as dual sensory loss, is a condition characterized by a combination of visual and hearing impairment among people of all ages (Dammeyer, 2014, 2015). The deafblind population includes three distinct groups: first, people with congenital/pre-lingual deafblindness (at birth or at an early stage of life before the development of language), second, people with acquired/post-lingual deafblindness (acquired both impairments following language development) and third, age-related deafblindness (due to age-related changes in older adults) (Brennan & Bally, 2007; Dammeyer, 2014; Jaiswal, Aldersey, Wittich, Mirza, &
Finlayson, 2018; Perfect, Jaiswal, & Davies, 2018; Simcock, 2017; Wittich, Barstow, Jarry, & Thomas, 2015).

A recent 2018 global report by the World Federation of the Deafblind reveals that around 2% of the global population are persons with deafblindness and they are more likely to live in poverty and have lesser opportunities for education and employment than other persons with disabilities (World Federation of the Deafblind, 2018). There has been growing interest in the scientific community about the rehabilitation of deafblind population due to evidence suggesting an increase in the prevalence of this condition among older adults (Guthrie et al., 2018; Guthrie, Declercq, Finne-Soveri, Fries, & Hirdes, 2016; Wittich et al., 2016). Population prevalence estimates there will be 14 million older adults due to age-related dual sensory loss in the United States by 2030 and similar increase is anticipated in other countries where the aging population is increasing rapidly (Brennan & Bally, 2007; Swenor, Ramulu, Willis, Friedman, & Lin, 2013; Wittich et al., 2016).

Previous research revealed that persons with deafblindness experience communication difficulties, functional limitations and participation restrictions (Fletcher & Guthrie, 2013; Hersh, 2013a; LeJeune, 2010; Roets-Merken et al., 2017; Schneider et al., 2011). Given the combined impairment of vision and hearing creates a distinct condition more disabling than their sum (Dammeyer, 2015), the participation experiences of persons with deafblindness might be different from that of persons with physical or mobility impairments (Jaiswal et al., 2018). To my knowledge, there is only one empirical study by Möller (Möller & Danermark, 2007) that documents participation experiences among persons with deafblindness, but was limited to the experiences of 34 students with post lingual deafblindness in Swedish school. The study findings indicate that there are barriers in the natural and social environment that restrict participation of students with deafblindness in aspects of education (Möller & Danermark, 2007). Using the ICF as a guiding framework, the study concluded that participants with deafblindness had difficulties
in all forms of activities and participation (Möller, 2003). Yet the literature about participation of persons with deafblindness is insufficient to draw conclusions to inform clinical practice.

Furthermore, existing literature on people with deafblindness fails to take account of lived experiences of those individuals from low and middle-income countries (LMICs) such as India (Jaiswal, Kumar, & Paul, 2018; Paul, Mathew, Kumar, Rizal, & Jaiswal, 2016; Wittich, Jarry, Groulx, Southall, & Gagné, 2016). The global disability literature is often dominated by the researchers from the developed world and there is “a one-way transfer of ideas and knowledge” from the developed to the developing world (Grech, 2011; Meekosha, 2011, p. 688). There is scarcity of literature on deafblindness from LMICs because of lack of awareness and recognition of deafblindness, limited deafblind-specific interventions, and fewer research publications describing existing programs (Jaiswal et al., 2018a; 2018b; Sense International, 2017; World Federation of the Deafblind, 2018). The lack of research about deafblindness throughout India and other LMICs poses a significant risk of discounting the voices of people with deafblindness by professionals when deciding rehabilitation goals and designing interventions. The recent global report on deafblindness highlights the issue of invisibility of this population and claims a significant risk of exclusion of persons with deafblindness from the inclusive Sustainable Development Goals (World Federation of the Deafblind, 2018).

Estimates indicate that there could be more than 500,000 individuals with deafblindness in India (Paul et al., 2016). They face challenges ranging from missed diagnoses, limited access to appropriate services, and inadequate representation in mainstream research and development (Paul et al., 2016). On December 28, 2016, the Government of India officially recognized deafblindness as a distinct disability condition for the first time in the newly enacted the Rights of Persons with Disabilities Act, 2016 (Government of India, 2016). The new law is expected to guide the design of new rehabilitation programs and inform professionals to optimize the participation of people with deafblindness in society. However, the current understanding of the
concept participation that applies to persons with deafblindness does not yet exist, and available literature do not offer a concrete understanding that could inform clinical practice specific to this population. Given this Act now in place in India and the push towards the UNCRPD goal of the right to full and effective participation, this study is therefore timely to contribute to the development of conceptual understanding of participation specifically for persons with deafblindness in Indian society. This study addressed the following research questions:

(1) What does “participation” mean to persons with deafblindness in India?

(2) What are the life domains that the persons with deafblindness deem important to participate?

Understanding the perspectives of persons with deafblindness about the meaning of participation in their lives and the participation domains they value will enhance the ability of professionals to design rehabilitation services directed towards improving their participation in society. This understanding may also inform the development of participation measures from the perspectives of people with deafblindness.

3.4 Methods

**Conceptual framework.** I used the ICF as the conceptual framework for this study because it emphasizes the concept of participation as “involvement in a life situation” and serves as an effective guide to identify the areas of life that are important for participation of persons with disabilities (World Health Organization, 2001, 2002, p.10). The ICF is a universal classification of disability and health and is a radical shift from emphasizing people’s disabilities to focus on their level of functioning from an enablement perspective i.e., emphasizing what they can do given the right supports (World Health Organization, 2002).

**Study design.** I adopted a constructivist paradigm to understand the socially constructed meaning of participation from the perspectives of persons with deafblindness (Creswell, 2013). I chose qualitative research methodology to develop a conceptual understanding of participation phenomena as suggested by other rehabilitation researchers (Dijkers, 2010; Hammel et al., 2008;
Whiteneck & Dijkers, 2009). I used descriptive phenomenology (Moustakas, 1994) to explore and describe the meanings of participation for individuals with deafblindness and domains of life that they deem important for participation. This method follows an inductive style of building knowledge by focusing on lived experiences of participation as it is consciously experienced by persons with deafblindness (Liamputtong, 2013; Moustakas, 1994).

**Study setting.** I conducted the study in India with the help of my study knowledge translation partner - *Sense International India* ([www.senseintindia.org](http://www.senseintindia.org)) - a national-level organization working to provide comprehensive rehabilitation services for individuals with deafblindness in India. I obtained ethical approval from the Queen’s University Health Sciences Research Ethics Board (HSREB#REH-674-17). *Sense International India* also approved the study locally and helped with participant recruitment and data collection in India.

**Sample.** I used purposive sampling to recruit participants from different regions of India (Patton, 2002; Sandelowski, 1995). The inclusion criteria for the participants were (1) aged 18 or above, (2) formal diagnosis of deafblindness (combination of hearing and visual impairment affecting access to information, communication, and mobility) documented in the service files of *Sense International India*, (3) observed ability to communicate through the use of either speech, sign language, tactile sign language or other communication technology. Participants were excluded if they had associated disability conditions in their formal diagnosis (e.g., cerebral palsy, intellectual impairment, autism, or other impairments) that may have interfered with their cognitive or physical status. Associated disability conditions were not included because of the likelihood that these other conditions would influence the participation experiences. I used the event of National Conclave of Networks (an annual event for members of a national network of adults with deafblindness) on December 4, 2016 to inform the potential participants about the study. The professional staff of *Sense International India* facilitated the sign-up process.
Out of the 23 people who expressed interest, five were ineligible due to the presence of associated conditions and another two chose not to participate due to their unavailability during data collection period (Figure 7 for a summary flowchart of recruitment and enrolment process). Finally, 16 participants were enrolled in the study. Participants included a diverse range of people by age, gender, type of impairment, place of residence, education, employment, marital status and living arrangements (Table 9), all of whom were using diverse communication modes such as speech, sign language, tactile sign language, and alternate forms of communication technology (Patton, 2002; Sandelowski, 1995).

Figure 7. Flowchart of study recruitment and enrolment process
Table 9. Participants demographic characteristics (N =16)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
</tr>
<tr>
<td>18-29</td>
<td>9</td>
</tr>
<tr>
<td>30-39</td>
<td>4</td>
</tr>
<tr>
<td>40 and above</td>
<td>3</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>11</td>
</tr>
<tr>
<td>Female</td>
<td>5</td>
</tr>
<tr>
<td><strong>Type of impairment</strong></td>
<td></td>
</tr>
<tr>
<td>Congenital</td>
<td>3</td>
</tr>
<tr>
<td>Acquired</td>
<td>13</td>
</tr>
<tr>
<td><strong>Age of onset of impairment</strong></td>
<td></td>
</tr>
<tr>
<td>Hearing impairment</td>
<td></td>
</tr>
<tr>
<td>- Birth to infancy (0-3 years)</td>
<td>10</td>
</tr>
<tr>
<td>- From childhood (3-12 years)</td>
<td>4</td>
</tr>
<tr>
<td>- From adolescence (12-18 years)</td>
<td>2</td>
</tr>
<tr>
<td>Vision impairment</td>
<td></td>
</tr>
<tr>
<td>- Birth to infancy (0-3 years)</td>
<td>8</td>
</tr>
<tr>
<td>- From childhood (3-12 years)</td>
<td>4</td>
</tr>
<tr>
<td>- From adolescence (12-18 years)</td>
<td>2</td>
</tr>
<tr>
<td>- From adulthood (≥18 years)</td>
<td>2</td>
</tr>
<tr>
<td><strong>Place of residence</strong></td>
<td></td>
</tr>
<tr>
<td>City</td>
<td>8</td>
</tr>
<tr>
<td>Town</td>
<td>5</td>
</tr>
<tr>
<td>Village</td>
<td>3</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
</tr>
<tr>
<td>Less than High School</td>
<td>2</td>
</tr>
<tr>
<td>College/University degree</td>
<td>4</td>
</tr>
<tr>
<td>Special school/Open school</td>
<td>10</td>
</tr>
<tr>
<td><strong>Employment</strong></td>
<td></td>
</tr>
<tr>
<td>Student/Vocational trainee</td>
<td>6</td>
</tr>
<tr>
<td>Unemployed</td>
<td>2</td>
</tr>
<tr>
<td>Employed</td>
<td>6</td>
</tr>
<tr>
<td>Self-employed</td>
<td>2</td>
</tr>
<tr>
<td><strong>Socio-economic status</strong></td>
<td></td>
</tr>
<tr>
<td>Lower (Annual income* ≤ 2000 $)</td>
<td>5</td>
</tr>
<tr>
<td>Middle (Annual income 2000 $ ≤ 6000 $)</td>
<td>10</td>
</tr>
<tr>
<td>High (Annual income ≥ 6000 $)</td>
<td>1</td>
</tr>
<tr>
<td><strong>Marital status and living arrangements</strong></td>
<td></td>
</tr>
<tr>
<td>Married; living with spouse and children</td>
<td>3</td>
</tr>
<tr>
<td>Never married; living alone</td>
<td>3</td>
</tr>
<tr>
<td>Never married; living with parents</td>
<td>10</td>
</tr>
</tbody>
</table>

*1$ = 50 Indian National Rupee
**Data collection.** A semi-structured qualitative interview guide was developed in consultation with the programme team of *Sense International India* and *Deafblind Ontario Services* (a not-for-profit organization that helps individuals who are deafblind increase their independence and improve their quality of life through specialized services across the Canadian province of Ontario), and revised based on their feedback. I conducted three pilot interviews with adults with deafblindness to test the interview guide (Table 10). I underwent training by *Sense International India* for three days to understand the different communication modes used by persons with deafblindness such as Braille, sign language, writing on palm, large print, and use of assistive technology such as refreshable braille devices.

Table 10. Interview guide

<table>
<thead>
<tr>
<th>Question: Please tell me about yourself.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Probe: name, age, region, onset, time and duration of intervention</td>
</tr>
<tr>
<td>Question: What does the word “participation” mean to you?</td>
</tr>
<tr>
<td>Probe: what does it mean “to participate” and why is participation important?</td>
</tr>
<tr>
<td>Question: What areas of everyday life are most important to you to participate in?</td>
</tr>
<tr>
<td>Probe: activities and settings most important to participate in</td>
</tr>
<tr>
<td>Question: What problems have you experienced while participating in society?</td>
</tr>
<tr>
<td>Question: strategies most needed to promote and support your full participation in society</td>
</tr>
</tbody>
</table>

(Adapted from Hammel et al., 2008)

I interviewed sixteen adults with deafblindness between March to May 2017, and asked participants about their preferences for the interview process (e.g., face-to-face, online using communication technology, or with the help of sign language interpreter) to facilitate their independence. I provided interview questions one week in advance to help participants prepare for the interview. Diverse communication modes were used and questions were made accessible to participants with support of communication technology (computers with accessible features [software - Job Enabled Speech software (JAWS)], refreshable braille devices, and magnification features), large print, Braille, print-on-palm, lip reading, and using interpreters for sign language,
tactile sign language, and gestures (Table 11). Face to face interviews were audio-recorded in Hindi and transcribed by a data transcriptionist who was a native-Hindi speaker. Four interviews that were conducted using online communication technology such as Facebook and Skype were in English. Interview data were managed using NVivo Pro 11 software (QSR International, 2017).

Table 11. Modes of communication used by participations during interviews

<table>
<thead>
<tr>
<th>Mode</th>
<th>During interviews*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Speech</td>
<td>7</td>
</tr>
<tr>
<td>Sign language (using interpreter)</td>
<td>6</td>
</tr>
<tr>
<td>Technological aids (e.g., Refreshable braille display, JAWS)</td>
<td>5</td>
</tr>
<tr>
<td>Braille</td>
<td>5</td>
</tr>
<tr>
<td>Print-on-palm</td>
<td>5</td>
</tr>
<tr>
<td>Large print</td>
<td>5</td>
</tr>
<tr>
<td>Gestures</td>
<td>4</td>
</tr>
<tr>
<td>Tactile Sign language (using interpreter)</td>
<td>3</td>
</tr>
<tr>
<td>Voice amplification (specific pitch by interpreter)</td>
<td>2</td>
</tr>
<tr>
<td>Lip-reading</td>
<td>2</td>
</tr>
<tr>
<td>Magnifier</td>
<td>2</td>
</tr>
<tr>
<td>Writing on paper (contrast background)</td>
<td>1</td>
</tr>
<tr>
<td>Finger spelling</td>
<td>1</td>
</tr>
</tbody>
</table>

*Many participants used more than one mode to communicate

In-person interviews were between 1.5 to 2.5 hours in length while interviews using online technology were between 2 to 5 hours. I conducted member checks with all the participants by summarizing the key points of discussion at the end of each interview, and then sending them an encrypted (password protected) copy of their transcripts to check the accuracy (Creswell, 2013). Out of the 16 participants interviewed, 10 expressed no concerns with the accuracy of transcripts and six did not offer any feedback.

**Data analysis.** The data was analyzed using the qualitative data analysis framework developed by Moustakas (Moustakas, 1994). Being proficient in both English and Hindi, I analysed the transcripts independently in the source language (Hindi or English), and conducted coding, clustering, and synthesis. The research assistant (SG) (proficient in both the languages with training in research) conducted an independent review of coding and synthesis for
confirmability. The process of data analysis started by reading and re-reading the verbatim interview transcripts. Having read the transcript several times, I developed broad categories using open coding. These categories addressed aspects of the lived experience of participation for person with deafblindness. All coding was conducted by reading transcripts line-by-line and marking each non-repetitive, non-overlapping statement or phrase [referred as “invariant horizons or constituents” (Moustakas, 1994, p.121)] that seemed to be of equal value, essential, or revealing aspects of the topic under study. This process has been referred as “Horizonalization” (Moustakas, 1994, p. 120). Later, invariant constituents were related and clustered into emerging themes. Consolidated themes were then synthesized and a “textual-structural description” was developed at the end (Moustakas, 1994, p.121). The final themes, subthemes and definitions are provided in Table 12.

Table 12. Themes, subthemes and definitions generated through the analysis process

<table>
<thead>
<tr>
<th>Themes</th>
<th>Subthemes</th>
<th>Definitions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Meaning of Participation</td>
<td>Independence and autonomy</td>
<td>Reflect statements where participants express the importance of decision-making, personal control and choice to participate in the society.</td>
</tr>
<tr>
<td></td>
<td>Fulfill aspirations and responsibilities</td>
<td>Statements reflecting aspirations and progress in life and demonstrating being able to fulfill responsibilities towards family and society as meaning of participation. Or statements reflecting importance of functional and economic independence to be able to participate.</td>
</tr>
<tr>
<td></td>
<td>Meaningful engagement, social involvement and recognition</td>
<td>Reflect statements where participants consider being involved within the mainstream society and recognized as its crucial member, get respect and equal treatment.</td>
</tr>
<tr>
<td>Domains of life important for participation</td>
<td>Communication and access to information</td>
<td>Statements reflecting importance of conversation and discussion with others and using communication devices and techniques for accessing and using information.</td>
</tr>
<tr>
<td></td>
<td>Mobility</td>
<td>Statements reflecting importance of moving around in the community and using public transportation, such as accessing and riding in buses or other transportation systems.</td>
</tr>
</tbody>
</table>
In the final stages of analysis, I extracted direct quotations that were relevant to the research question from transcripts and translated into English (Santos, Black, & Sandelowski, 2015). The research assistant conducted back translation of the quotations from English to Hindi to confirm accuracy (Chen & Boore, 2010). The second author (HA) independently coded English transcripts and evaluated English-translated excerpts for confirmability of my findings. Later, English-translated excerpts were further evaluated by other authors (WW, MM, and MF) for confirmability. Rigor was maximized by using an audit trail, maintaining a field journal, following coding-recoding procedure, providing thick description, conducting peer-debrief, reflective analysis, and conducting member checks with the participants (Krefting, 1991).

### 3.5 Results

The findings are organized under two major themes, namely *meaning of participation* and *domains of life important for participation* for study participants with deafblindness. To disguise participants' identities, quotes are referred to by numbers at the beginning of each quote. It is important to note here that direct quotes from the participants had some grammatical errors, hence, I edited quotes used in text for readability. The content in the square brackets within the quote provide more clarity of the context. The content in the square brackets after the quote provide information about onset of hearing impairment (HI) and visual impairment (VI).

<table>
<thead>
<tr>
<th>Themes</th>
<th>Subthemes</th>
<th>Definitions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relationships</td>
<td></td>
<td>Reflect statements where participants express the importance of engaging in activities that result in successful interaction at different levels of interaction and intimacy (include both formal and informal relationships e.g., friends, family, peers, school, work)</td>
</tr>
<tr>
<td>Education and</td>
<td>productivity</td>
<td>Reflect statements where participants consider economic self-sufficiency such as remunerative employment or similar activities crucial. Includes vocational training, school education or higher education with an aim to get paid work.</td>
</tr>
<tr>
<td>Leisure and</td>
<td>recreation</td>
<td>Statements about engaging in any form of play, activity or entertainment such as listening to music, watching television, playing sports or games, reading.</td>
</tr>
</tbody>
</table>

<table>
<thead>
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</tr>
</tbody>
</table>
**Meaning of participation.** I asked participants to describe what participation meant to them. Subthemes that emerged across the interviews were: (i) independence and autonomy, (ii) fulfilling aspirations and responsibilities, and (iii) meaningful engagement, social involvement and recognition. The subthemes are described with quotes that illuminate their significance (Table 13).

Table 13. Themes and invariant constituents emerged from the data analysis

<table>
<thead>
<tr>
<th>Themes and quotes: Meaning of participation</th>
<th>Subthemes</th>
<th>Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Independence and autonomy</td>
<td>P10: “I want to be independent so that I can develop myself and get involved in challenging work outside so that I do not remain dependent on others.”</td>
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</tr>
<tr>
<td></td>
<td>P10: “Being dependent is like we can’t do what we like to do…we do what others want us to do…we don’t like that…”</td>
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<tr>
<td></td>
<td>P1: “I try to do things on my own, thinking I may be able do it independently if I try and practice. If my eyes and ear were okay, I would be doing everything on my own…”</td>
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<tr>
<td></td>
<td>P2: “I have no power (in decision making).”</td>
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<tr>
<td>Fulfill aspirations and responsibilities</td>
<td>P10: “I want to study further and do a lot [of things]. I want to watch movies and travel independently as other people [like non-disabled] do. I want to commute in bus, train and everywhere…alone…”</td>
<td></td>
</tr>
<tr>
<td></td>
<td>P6: “I want to teach children, help differently abled people, I have to help.”</td>
<td></td>
</tr>
<tr>
<td></td>
<td>P8: “I have to participate in responsibilities like earning money, take care of my son and other family members for fulfilling their responsibilities I have to participate as jointly of family that’s why participation is important for me.”</td>
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<tr>
<td></td>
<td>P4: “When we meet others [non-disabled people] and remain in contact with them, we learn about their lives, we understand our shortfalls and what they have in abundance, and we try to adopt that in our life and come on the path of progress.”</td>
<td></td>
</tr>
<tr>
<td>Meaningful engagement, social involvement and recognition</td>
<td>P7: “I want to go with my wife to enjoy [in the company of] each other. In marriage function, I want to have dinner with others [in society]. I want to be like non-disabled.”</td>
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</tr>
<tr>
<td></td>
<td>P7: “YES, WHEN THEY [non-disabled] TREAT ME EQUAL AND RESPECT ME, I FEEL HAPPY AS EQUAL AND WE ENJOY EACH OTHER, WHEN THEY MEET [Emphasis by the participant].”</td>
<td></td>
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<tr>
<td></td>
<td>P1: “I thought that I am different from others, I would do something and show to the school so that they feel that I can also achieve something. Because of the participation [in sports]…I moved ahead and today my friends, my teachers and my family support me.”</td>
<td></td>
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<tr>
<td></td>
<td>P1: “If I did not participate [in sports], then all the kids would continue to make fun of me, tease me, irritate me and no one would help me, therefore participation is very important in my life…”</td>
<td></td>
</tr>
</tbody>
</table>
**Independence and autonomy.** The theme of not being dependent on others was repeatedly identified as a crucial aspect of participation. When asked “What does participation mean to you?”, participants expressed that not requiring help from others and enjoying personal choice, control and freedom in their lives is what participation is for them. Many of them (P1, P3, P4, P7, P10, P12, and P15) voiced that having freedom to choose, decide, travel and pursue their life goals defines the meaning of full participation for them.

Participants stressed that independence is important to gain self-respect and dignity. They said that their need to ask for help reminds them of their dependency on others and gives them a feeling of being inferior. They believed that this dependency was detrimental to their autonomy, self-respect, personal choice and control in life. They said that dependency on family members, friends, interpreters, and/or teachers, was somewhat helpful in their day-to-day function but at the same time, led them to feel restricted, as illustrated by one participant.

> Participation [is] not requiring much help… being able to do things on my own… I don’t like asking [to do things for me] from anyone… I feel I am dependent… where for everything I have to ask someone.  
> (P15) [HI (by birth) and progressive VI (diagnosed at the age of 3 years)]

Participants felt they could participate in their surrounding environment only to a certain extent, depending on the willingness of others to put extra efforts to communicate with them, explain things to them and help them experience the world. A few (P1, P4, and P10) highlighted that they try to do things on their own with a hope to learn new things and participate independently. As one participant shared, “it is important to keep ourselves independent. Dependency is the biggest grief… we should try to stand as much as possible on our feet and [try to be independent]…” (P4) [VI (by birth) and HI (at the age of 13 years)].

**Fulfilling aspirations and responsibilities.** The majority of participants expressed participation as a means to fulfil their aspirations and desires in life, though these aspirations varied based on their age and stage in life. For young participants (P2), (P3) and (P12),
aspirations included getting married, owning a house, having a job and economic sufficiency, and opportunities to go out for social outings. Their statements also reflected a sense of responsibility towards their parents. One participant said: “My parents are ill… I want to get them treated…I don’t want to be a burden on my father and rather want to bear their expenses” (P12) [HI (at the age of 8 years) and VI (at the age of 10 years)]. Male participants who were married conceptualized their participation as fulfilling their family responsibilities of an income earner, a spouse and a parent. For example, one participant explained participation as “fulfilling responsibility towards my family and society” (P8) [HI (by birth) and VI (at the age of 24 years)]. Similarly, for another participant, participation meant: “to work hard and earn for my family” (P7) [HI (by birth) and VI (at the age of 9 years)]. He said “…I am married and have a daughter so I am working hard to support my family…”

Even among those who were not married, fulfilling responsibilities was an important indicator for participation. For example, two participants (both males) shared that although they would like to get married and start a family, they are unable to because they are not financially and functionally independent to take care of a spouse and fulfil the responsibility of a husband.

Some participants (P1, P10, P12, and P15) expressed their wish to do something different and meaningful to progress in life. For example, a participant in a full-time job (P15) expressed her aspirations as “I want to pursue higher studies in the field of finance or accounts and do something different” (P15) [HI (by birth) and progressive VI (diagnosed at 3 years)]. Another participant expressed her aspiration to pursue higher education and lead an independent life as per her choice. She said:

Although I am like this [a person with deafblindness], I want to do something…I want to make progress, become successful. I want to see and hear properly, move forward in sports… in my way, on my own, using my own money, so that I can do something for my family to improve their situation. (P1) [Progressive HI and VI from the age of 12 years]
Participants also stressed the significance of mutual support and responsibility towards each other for participation. For example, in some cases, such as P6 and P16, the pursuit of participation was linked with their aspiration to help others, especially people who face similar challenges.

(3) **Meaningful engagement, social involvement and recognition.** The subtheme of meaningful engagement, social involvement, and recognition was repeatedly captured from the experiences that participants shared. Some participants (P1, P15 & P16) defined participation as involving oneself or taking part in an activity while others summarized it beyond just taking part in an activity. Rather they saw participation as working with others where they can feel cohesiveness and have a sense of belongingness:

> Participation according to me is to involve everyone and work together. When we work in groups, we exchange ideas and form a true relationship. Therefore, working together is called participation.
> (P13) [HI (at the age of 10 years) and VI (at the age of 29 years)]

Recognition and inclusion were central to the feeling of participation, as one participant described: “full participation means to respect and welcome disabled people, and bring everyone together. Deafblind [people] should have equal rights” (P7) [HI (by birth) and VI (at the age of 9 years)]. Their (P1, P7, and P15) statements reflected their wish to be treated equally and participate on an equal basis as others.

Another participant (P4) voiced the need for respect and social involvement for people with deafblindness, and expressed his desire to join mainstream society. Though he said that to join the mainstream, they need to contribute to the economic and social fabric of their society and hence engage in productive work. This is illustrated by his quote:

> I want to do some sort of work so that I can join the mainstream of society. I also want to be invited in social events, participate like other people and get respect. If I have any job, I can earn for my subsistence and future, and can prosper like other people in
Other participants shared how their participation helped them to create opportunities for their inclusion and recognition in life. For example, a participant (P1) expressed that her participation in sports helped her gain recognition and support from others. She said she chose to participate to gain respect, social recognition, and friendship in her school. She shared how her efforts to participate have transformed her life. She said that she feels more accepted, has friends, and receives support from the people around her, especially in school.

**Domains of life important for participation.** Domains of life that emerged as important for participation were: (1) communication and access to information, (2) mobility, (3) relationships, (4) education and productivity, and (5) recreation and leisure. Based on their lived experiences, participants placed emphasis on these life domains, associated challenges, and effect on their lives. The subthemes on life domains with relevant quotes are described here (Table 14).

<table>
<thead>
<tr>
<th>Subthemes</th>
<th>Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication and access to information</td>
<td>P10: “Challenge is that even interpreters don’t interpret everything; they interpret only things that they want to… it is difficult to communicate everything with everyone.”</td>
</tr>
<tr>
<td></td>
<td>P8: “I want to share [my] thoughts with others, [but] due to communication barriers I am not able to participate properly.”</td>
</tr>
<tr>
<td></td>
<td>P7: “People don’t want to talk through writing on palm, they feel scared touching [my] palm.”</td>
</tr>
<tr>
<td></td>
<td>P1: “As I am totally different from the normal [non-disabled] children, I cannot play like them and cannot read like them, cannot see everything, cannot hear, and cannot even know new things, that means I am missing lot of my things, which if I would have…. due to the problem of my ear and eye, I am not able to do all that.”</td>
</tr>
<tr>
<td></td>
<td>P10: “When the normal people are sitting and talking, and I do not understand anything, I feel alone even in a group. I used to feel it a lot earlier but now it is not so much. Even at home, sometimes I feel isolated… people think that if they will talk to us we won’t be able to understand, so they do not even speak [to me], they leave.”</td>
</tr>
</tbody>
</table>
### Subthemes and quotes: Domains of life

<table>
<thead>
<tr>
<th>Subthemes and quotes</th>
<th>P1: “I can’t go alone anywhere… I want to go out for sports but I face lots of difficulty in auto [mode of transportation in India], bus or metro [public transit] due to which I cannot go anywhere alone, I have to ask for help from my sister.”</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mobility</td>
<td>P15: “I have problems travelling because there is a lot of noise [outside] and I feel I cannot concentrate what people next to me are saying… In places where there is no facility for public transport… I have to take someone’s help.”</td>
</tr>
<tr>
<td></td>
<td>P10: “First I used to feel scared while crossing [the roads], now I cross slowly because running is not okay. Like if someone else is crossing the road, I cross it at the same time, or when people see I have a stick, they hold my hand and help me cross the road. Now I do it [cross road] with a stick… Initially, I had to explain that I need to cross the road and had to take help.”</td>
</tr>
<tr>
<td></td>
<td>P8: “I use [a] cane. It is safe [to use cane] to go from here to there, [it] saves [me] from falling and [I] do not bump into objects. I can fall from train or bus but my cane helps me prevent that. When roads are crowded, I get access with its support.”</td>
</tr>
<tr>
<td></td>
<td>P8: “My wife and family members are very important for me for participation in day to day activities. Without them, I am unable to participate in all areas [of life].”</td>
</tr>
<tr>
<td></td>
<td>P4: “When we meet people in our community, when we get their support we feel a sense of belonging.”</td>
</tr>
<tr>
<td></td>
<td>P13: “Doing prayers in the morning, talking to my mother, having a brisk walk, exercises on the beach, and chatting with friends in the evening and express my happiness and feelings to my sisters and friends [are important to me].”</td>
</tr>
<tr>
<td></td>
<td>P15: “I enjoy spending time with family and friends… Every Saturday, I go to a blind school called [name of school] to teach computers to students.”</td>
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<tr>
<td></td>
<td>P8: “I feel that I also should get married but I see that is not possible when I am not able to earn independently. If she comes and I am not able to earn, people from the community will curse me for that.”</td>
</tr>
<tr>
<td></td>
<td>P6: “I want to be a teacher because I want to teach children.”</td>
</tr>
<tr>
<td></td>
<td>P10: “Even after studying whole year, I couldn’t get good grades in exams. Friends had problems [in communicating with me], they did not talk much at school, because of my hearing problem. I couldn’t understand what teacher is teaching and couldn’t see what she writes on board”.</td>
</tr>
<tr>
<td></td>
<td>P5: “I wanted to study further but I could not, because I was not able to see.”</td>
</tr>
<tr>
<td></td>
<td>P7: “I have to work hard and earn for my family. I am married and have a daughter, so I am working hard to support my family and [fulfill] responsibilities towards family”.</td>
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<tr>
<td></td>
<td>P3: “I like going out with friends.”</td>
</tr>
<tr>
<td></td>
<td>P1: “I enjoy watching TV, chatting like other [non-disabled] people, drawing or reading stories, I like all these a lot.”</td>
</tr>
<tr>
<td></td>
<td>P7: “I want to go with my wife to enjoy [in the company of] each other. In marriage function, I want to have dinner with others [in society].”</td>
</tr>
<tr>
<td></td>
<td>P10: “I used to very much like the music first but I can’t listen to it properly due to which I feel hurt [now] and it gets annoying.”</td>
</tr>
<tr>
<td></td>
<td>P16: “Speaking [conversations] and playing with my friends and learning [together] too makes me happy.”</td>
</tr>
</tbody>
</table>
(I) Communication and access to information. Due to the nature of impairment resulting from deafblindness, communication and access to information emerged as the most significant area for participation for all participants. Participants strongly expressed that communication with others and access to information are integral to their social interactions, and that they feel happy “talking to people, spending time with family and friends” (P15) [HI (by birth) and progressive VI (diagnosed at 3 years)]. However, they said they do not have enough opportunities to do so, as illustrated by this quote: “…I like to watch movies…I want to read [the] newspaper… [I] want to communicate with [the] whole world but I live [a] very narrow life” (P7) [HI (by birth) and VI (at the age of 9 years)].

Participants shared how difficulties in communication and access to information were related to the difficulties they faced in many other domains of life such as independent mobility, gaining education, holding jobs and maintaining social relationships. One participant elaborated: “Due to lack of hearing and vision, I feel restricted… because I am not able to see, I face difficulty in walking, and because of hearing issues, it is difficult to talk to people, just as it is happening right now” (P4) [VI (by birth) and HI (at the age of 13 years)]. Another participant highlighted “in meetings I find it hard to hear what a person far from me is saying. I find it difficult to be involved in large group discussions” (P15) [HI (by birth) and progressive VI (diagnosed at 3 years)].

Participants shared the feelings of isolation, depression, frustration, and exclusion due to their inability to communicate effectively. Many participants noted that lack of willingness of others to take their needs into consideration and put extra efforts to include them in conversations make them feel like a burden. A participant (P1) shared that she felt she is different from her peers as she cannot see, read and learn the same way as they do, which creates a void in her life and she is missing out on many aspects of life. The communication barriers between them and
others lead them to live a narrow life and create feelings of being neglected. Feelings of being “not normal” or “less” than their counterparts were commonly expressed. These feelings were not only common in their formal relationships but also prevalent in their close relationships. A participant shared: “Many of my dear ones are ignoring me. They have to talk loud and they have no patience in bearing with me” (P13) [HI (at the age of 10 years) and VI (at the age of 29 years)].

Many participants shared that they make efforts to improve their communication with others. For example, one participant learned various modes of communication that improved his interpersonal interactions, and subsequently his participation experiences. He said: “I learnt many communication methods like tactile sign language, print-on-palm, computer skills, Braille… so that I can communicate with others” (P8). Two participants (P12 and P15) also pointed out how technology such as cochlear implants and hearing aids have improved their access to information and communication, and now they feel they are more interactive with others, and participating in society.

(2) Mobility. Mobility and transportation were other main areas of high importance for participants. Their statements reflected the importance of moving around in the community and using public transportation, such as accessing and riding in buses or other transportation systems. Especially, crossing the roads and using public or private transportation emerged as an important domain within mobility where participants felt lack of independence and had to ask for help:

If I have to go alone then there [are] a lot of problems, especially in the darkness. I fall sometimes… it hurts, I have to tell others by writing that I don’t see, I don’t hear…to go home I have to ask for help.
(P3) [HI (diagnosed at age of 6 months) and VI (night blindness at the age of 3 years)]

Participants’ experiences were unique to their specific condition and situation. While a few participants were able to go out independently with the help of an assistive device or aid,
several others were completely homebound and reliant on others for any activity outside the home. For many, mobility constraints were a serious impediment to their participation and had an exacerbating effect on their personal and economic independence, often leading to social isolation. As one participant noted:

I can’t go out…I can’t drive any vehicle independently…that means I am in dark life…I can’t cross the road independently, and I have to wait for someone to take me across the road

(P7) [HI (by birth) and VI (at the age of 9 years)]

For those with night blindness, mobility in the dark was a major concern. Some of them (P1, P3, P5, and P10) highlighted that though they can go outside individually, they find mobility outside of home challenging and feel scared because of their vulnerability of getting hurt and being lost. Other participants (P2 and P8) also shared similar experiences where they faced fear of falling. Nevertheless, despite the fear, participants mentioned that they tried to go out as often as possible. Many of them used aids such as canes to be as independent as they can in mobility. They reported using a cane was helpful to prevent falls and commute safely.

(3) Relationships. Developing and maintaining social and personal relationships was highlighted as a vital part of life for many participants. They highlighted friendships and family relationships were important for them to feel supported, to be part of their community, and to fulfil their responsibilities. They mentioned how their impairment has affected their social relationships especially with friends, and limited the number of friends they had. Those with a progressive condition mentioned they were losing friends as their vision and hearing loss was increasing. One participant said:

Because I am different from others, no one is talking to me, and it is very annoying…why it happened to me…I miss my previous days…how I was before [the onset of deafblindness] …before I had so many friends…to talk and play with them, but now I am not able to do all that.

(P1) [Progressive HI and VI from the age of 12 years]
Participants mentioned that they had limited opportunities to develop new relationships with other people. Their relationship network was limited to someone who had been with them since childhood or someone who had similar impairment (i.e., deafness, blindness or deafblindness). They could develop meaningful relationships with only those who could communicate with them using different or alternative modes such as sign language and facilitate their involvement by interpreting for them. These type of meaningful relationships were, however, very rare and few. One participant said “I have involvement with only close family members…it is less with outsiders or who are distant relatives. There is even less [involvement] with new people” (P10) [HI (at the age of 9 years) and VI (at the age of 5 years)].

Among my participants (n=16), only three had a spousal relationship while rest of them were either living alone or with parents and never married. When asked about intimate relationships, participants who were single or never married highlighted the importance of having a spousal relationship in their life and expressed their willingness to marry. Though they mentioned that they would like to marry a person who is not deaf or blind, who can help them navigating the world and live a balanced life. A participant said:

> If I marry a deaf girl, then I will have problem in explaining to her, so I will marry a normal [non-disabled] girl, so that if we go somewhere out and if I am not able understand anything, she will help and explain things to me.
> (P6) [HI (by birth) and VI (diagnosed at the age of 2 months)]

Those living with families reflected that sometimes their family members or service providers (such as school teachers, and/or interpreters) exerted a degree of power and dominance in those relationships where participants felt they were not being listened to or they had no contribution to make. Many times, they were also being compared with other non-disabled counterparts such as their siblings or other individuals of similar age in the community. These comparisons affected their self-esteem and made them feel less capable in fulfilling aspirations and responsibilities.
(4) Education and productivity. Every participant in my study stressed the importance of being educated and engaging in a productive or economic activity. Participants considered their economic self-sufficiency such as remunerative employment or similar activities crucial to participate in society. They viewed their engagement in vocational training, school education or higher education, as productivity, with an intent to get paid work.

Depending on the age and stage of life in which participants were, their life goals varied. A few of them (P10 and P14) wanted to pursue higher studies while many of them (P1, P2, P3, P11, P12, and P13) wanted to start a professional career or job. Their statements reflected how education and employment were essential for them to be self-sufficient, gain economic independence, bear family responsibilities, fulfil aspirations, and earn respect. A participant stated:

We should be given work so that we should arrange for our intellectual development. We want to develop some qualities in ourselves so that we could be involved in the mainstream of society like other people…so that people also call us in social activities, we too can be respected…We also need work so that we could earn, and through which we could get money, we could help the family…such work can get us respect in society. (P4) [VI (by birth) and HI (at the age of 13 years)]

Presence or lack of support and accommodations provided by the teachers or employers were critical that shaped the participation experiences in education or economic activities in a positive or negative way. For those with congenital deafblindness, support of teachers had such a strong influence that they wanted to be teacher in their life. One participant with deafness and night blindness (P3) who joined a full-time job shared that because his employer could not accommodate his need for leaving early from office before getting dark, he quit his job eventually. This participant and his family found this experience stressful. Though the participant wanted to be productive, he refused to consider private employment again.
(5) **Recreation and leisure.** Throughout the interviews, participants expressed their desire to have opportunities to enjoy time with their friends and family, go on outings, pursue their hobbies or sports, and participate in cultural programs or social gatherings. Participation in sports and leisure activities was an important medium for some of the participants to engage with the outside world. One of the participants (P1) shared that her participation in sports was an opportunity for her to engage with other non-disabled peers, beyond her immediate family.

Many participants discussed activities such as watching movies, playing with or talking to friends, and going out for dinner that make them happy:

> I enjoy listening to music. I play keyboard… I love playing music. I like listening to new stories… I watch films using YouTube or any apps over the phone… or I go out on Sundays with my family.  
> (P15) [HI (by birth) and progressive VI (diagnosed at 3 years)]

Some participants expressed their willingness for independent travel indicating the value of travel for them as a means for increasing self-confidence, social exploration, and escaping enforced dependence:

> There are many things in which I want to participate. I am stuck at a single place in whole city [name of the city], I want to go out of here and see what are the different programs here in [name of the city] such as different festivals… I want to see everything.  
> (P10) [HI (at the age of 9 years) and VI (at the age of 5 years)]

However, other participants shared that they faced difficulties in pursuing their favourite activities during their free time. Indeed, most of the leisure activities in which the participants engaged were passive and solitary. For example, very often, the participants were engaged in indoor leisure activities such as watching television, reading books, or listening to music.

### 3.6 Discussion

This study describes the lived experiences of 16 persons with deafblindness to understand the meaning they attribute to their participation in society. Results highlight the specific aspects
of participation for people with deafblindness and provide participation domains that they value and related challenges.

**Participation as a means and as an outcome.** Existing literature suggests that participation is an important rehabilitation outcome (Dijkers, 2010; King, 2013; Martin Ginis et al., 2017; Perenboom & Chorus, 2003). This study extends our understanding of participation beyond treatment outcomes and reveals how people with deafblindness view and value their participation. Across the interviews, I heard participants describing their participation as an outcome as well as a means to accomplish other important goals in life (Figure 8). On one hand, participation became an end outcome to overcome feelings of dependency, being left-out, loneliness, lack of belongingness, limited development, social isolation, and physical/social space restrictions for study participants. On the other hand, it also became a means to achieve other goals important to their life such as gaining respect, independence, autonomy, social recognition, support, to form relationships or to fulfil aspirations and responsibilities. This expanded conceptualization of participation both as an end and as means presents a novel perspective for rehabilitation professionals to think “beyond participation” while framing interventions goals. Furthermore, the participation domains that the participants value in their life can inform the future development of outcome assessments and interventions directed towards measuring and improving participation of individuals with deafblindness respectively.
Figure 8: Participation as an end outcome and as a means
**Heterogeneity and its impact on participation experiences.** The scoping review in Chapter 2 highlighted that the heterogeneity among persons with deafblindness may lead to varied participation experiences with regard to associated challenges in communication, mobility, functioning, and social interactions (Jaiswal et al., 2018). This study deepens this understanding between the diverse nature of participants’ conditions and their participation experiences. Participants interviewed in this study represented a heterogeneous population that varied with respect to age, gender, type of impairment, age of onset of deafblindness, modes of communication they were familiar with and used, their access to resources, and levels of support. Consequently, the study showed that the participants’ experiences related to meanings of participation and domains of life they valued were somewhat shaped by these factors.

Participants with acquired deafblindness who had one impairment since birth/childhood and later developed the second impairment reported more negative participation experiences as compared to those who had congenital deafblindness. Participants who had a progressive condition shared that they had to learn/change communication modes, for example, from lip reading/sign language to Braille/tactile sign language as their condition progressed.

For those with congenital deafblindness, their participation experiences were shaped by the limited experiences or interactions they had with the non-disabled world or with the deafblind community. For them, participation meant having autonomy, being productive, and engaging and helping others in society. But, those with acquired deafblindness had a previous understanding of participating in the ‘normal’ world and compared their participation in the non-disabled world before and after the onset of impairment. These findings are in line with the limited number of studies that have indicated challenges in communication, mobility, daily functioning, and social interactions with others, and advance the understanding of participation experiences of not only persons with acquired deafblindness but also with congenital deafblindness (Dalby et al., 2009;
Impact of access to resources and services on participation. Given the 16 participants in this study belonged to different socio-economic strata, the availability, affordability, and access to resources for people with deafblindness differed, and that influenced their participation. Resources such as deafblind-specific education and rehabilitation services, communication training, and technology/aids (such as hearing aids, cochlear implant, refreshable braille display, magnifier etc.) were helpful to achieve autonomy, independence, and a sense of control in their life. It is important to note that access to these resources enabled participation for even those with severe impairments or congenital deafblindness. However, not everyone had access to those resources and financial capacity to afford the cost of assistive technology aids.

The study findings suggest that the awareness of deafblind specific communication modes by non-disabled people was an important element that influenced the extent of participation of participants. These findings are congruent with other studies that suggest that the lack of knowledge among non-disabled people about how to communicate with persons with deafblindness is a main barrier to communication and social participation for people with deafblindness (Hersh, 2013a; Reid, 2010; Watters et al., 2005). The findings also support the previous work that suggests the knowledge of alternative modes of communication such as Braille, signing, and assistive technology (computer/interpreter-facilitated communication) and cochlear implants for individuals with deafblindness were helpful in improving access to information, communication and social interactions, and thus enhancing societal participation (Emerson & Bishop, 2012; Gribs; Dougherty; Wily, 1995; Hersh, 2013a, 2013b; Perfect et al., 2018; Reid, 2010; Soper, 2006; Wittich et al., 2016; Zannon De Andrade Figueiredo et al., 2013).

Cultural nuances interplaying with participation experiences. Interestingly, the participation meanings and domains were influenced by the gender roles defined in Indian culture.
where males are expected to earn income and fulfil familial responsibilities. Although many male participants expressed a desire to get married they could not due to societal attitudes that made them feel they are not financially and functionally independent to take care of a spouse and fulfil familial responsibilities.

The study findings also indicate that regardless of the type and level of impairment, those with deafblindness have to rely on others in their environment to a certain extent for participation. Given that 95% of learning happens through hearing and vision (Gallagher, 2002), dependency on others for access to information, communication, and mobility outside familiar environments makes the participation experiences of persons with deafblindness distinct from others. In the light of this fact, the emerging idea of ‘interdependence’ which is gaining popularity in disability studies discourse (Carnaby, 1998; Grills, 2015; White, Lloyd Simpson, Gonda, Ravesloot, & Coble, 2010) may not fully apply to this population as the lack of reciprocity perhaps makes ‘interdependence’ unrealistic and meaningless for them. However, this study does highlight the salient feature of the collective approach within Indian society where family support accommodates for the functioning limitations and participation restrictions experienced by persons with deafblindness.

**ICF as a framework to understand participation in deafblindness.** Although the ICF defines participation as “involvement in a life situation” (World Health Organization, 2002, p.10), this study goes beyond this conceptual understanding of participation and posits meaning of participation for individuals with deafblindness as independence and autonomy; fulfilling aspirations and responsibilities; and meaningful engagement, social involvement and recognition. Though participation is an individualized construct (Perenboom & Chorus, 2003), these common elements emerged as valuable indicators of participation for individuals with deafblindness. This conceptualization of participation was apparent across all five domains of life that participants deemed important – access to information and communication, mobility, relationships, education
and productivity, and recreation and leisure. These five domains of life were consistent with five ICF chapters: Chapter 3 communication, Chapter 4 mobility, Chapter 7 interpersonal interactions and relationships, Chapter 8 major life areas, and Chapter 9 community, social and civic life (World Health Organization, 2001).

Interestingly, of the nine ICF activities/participation domains only five domains were reflected primarily in the participation experiences of participants with deafblindness. Chapter 1 learning and applying knowledge and Chapter 2 general tasks and demands did not emerge as relevant themes due to their close proximity with activities domains (Coster & Khetani, 2008). The reason Chapter 5 Self-care did not emerge as a key theme could be partially because most participants were being supported by their families in their daily lives. Chapter 6 Domestic life did not come up as well because most participants did not have spousal relationships although desiring one. However, the two chapters - Chapter 3 communication and Chapter 4 mobility that are very often linked with activities domains (Coster & Khetani, 2008; Whiteneck & Dijkers, 2009) came up strongly as significant participation domains for persons with deafblindness. The findings refute the arguments made by previous research on distinction between activities and participation chapters that places communication and mobility domains in the activities component (Coster & Khetani, 2008; Whiteneck & Dijkers, 2009). Though these two domains, in combination with access to information, seem to occur at the individual level, they directly influence the participation experiences of those with deafblindness and were reported by participants across all interviews. This notion should be taken into account when developing participation measures or ICF core sets for persons with deafblindness.

This study was in line with literature stating that the understanding of participation cannot be complete without understanding different personal dimensions such as sense of being included, accepted, or recognized, and being engaged in personally meaningful/value activities or areas of life (Hammel et al., 2008; Möller & Danermark, 2007). Conceptualizing participation
merely in terms of involvement in life situations risks ignoring the insider perspective— the meanings and values that an individual places on participation (Brown, 2010; Hammel et al., 2008; Magasi et al., 2009; Mirza et al., 2016). This study confirms this understanding and provides supporting examples. Insider perspectives of persons with deafblindness have the potential to inform future research on participation, guide intervention goals and policy initiatives, and aid in development of standard frameworks such as the ICF and its Core Sets on deafblindness.

To my knowledge, only one study (Möller, 2003) has applied the ICF framework for persons with deafblindness and concluded that despite few limitations, the ICF should be used to show the impact of deafblindness. My study exposed two shortcomings of the ICF as a framework when applied to understand the lived experiences of participation. First, access to information (which emerged as an important theme in the study and an important domain affected in deafblindness) is not captured in the ICF. Second, when using the ICF as a guiding framework, it is difficult to capture the complexity and variability in participation experiences resulting from the heterogeneous nature of impairments among people with deafblindness. Nevertheless, my study also recommends the use of the ICF due to its strengths—universal, broad framework, and flexibility (Dahl, 2002; Simeonsson, Björck-Åkessön, & Lollar, 2012). Rather, we can improve the ICF by testing and using it in research, policy and practice (Möller, 2003; Threats & Worrall, 2004).

3.7 Limitations

This study has some limitations that warrant consideration for future studies. Although I tried to represent demographic variation within participants, due to logistical considerations, there was a lack of equal gender representation in the sample. Moreover, this study had a majority of participants from cities or towns, and only a few from rural areas hence, future studies with
participants from rural areas may provide new perspectives on participation of individuals with deafblindness in rural settings. For a few participants where sign language interpreters acted as facilitators between the participants and researcher, there might have been instances where I may not have completely captured the true meaning of what the participants were trying to communicate. Another limitation could be that culture-specific nuances might have been lost in translation from Hindi to English of the quotes used during data analysis though we conducted back translation of the quotes from English to Hindi to confirm accuracy (Chen & Boore, 2010; van Nes, Abma, Jonsson, & Deeg, 2010). The coding and synthesis of data were primarily done by me and confirmed by the research assistant, though there might be few limitations stemming from variable experiences and familiarity with the topic between the coders. However, I employed a number of methods to maximize rigor, including member checking, peer review, rich description, logging field notes, and reflexivity. The senior authors (HA, WW, MM, and MF) independently evaluated English-translated excerpts for confirmability of my findings. Furthermore, this study addressed only perspectives of individuals with deafblindness and did not take into consideration perspectives of family members and caregivers. Participation is a relational concept, and its meaning might change if I was to incorporate caregivers’ perspectives.

### 3.8 Conclusions

This study is the first known to examine participation experiences of persons with deafblindness in India. Results indicate that persons with deafblindness feel isolated and appear to have limited avenues for participation, particularly in the unfamiliar environments. For them, participation is a dynamic, evolving, individualized construct that is not just an end outcome in itself. Rather, it is a means to achieve other goals that the participants deemed valuable in their life such as to gain respect, independence, support and relationships, to fulfil aspirations and responsibilities, and to feel included and recognized in society. Given the significance of participation in everyone’s life, this understanding of participation as a means and as an outcome
may change the focus of designing rehabilitation services to remove dependency and social isolation for those with deafblindness. Additionally, heterogeneity within the deafblind population requires that services be customized to each individual’s unique needs and challenges. Despite a wide range of participation experiences and priorities, persons with deafblindness expressed a common sentiment that they want to be treated equally and aspire to participate in all aspects of life alongside their non-disabled counterparts. Positive attitudes of others and opportunities to participate are interrelated and are critical for acceptance and inclusion of people with deafblindness in the society.

3.9 References


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Simcock, P. (2017). One of society’s most vulnerable groups? A systematically conducted


Chapter 4

Using the ICF to examine contextual factors that influence participation of persons with deafblindness in India

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Disclaimer: This manuscript chapter is mostly similar, but not entirely identical, to the published version.
4.1 The Fit of Manuscript 3 within the Dissertation

Manuscript 3 builds upon the findings of the first two manuscripts by examining the contextual factors that influence participation for persons with deafblindness in Indian society. The manuscript advances the understanding of participation experiences from the previous two manuscripts to include personal and environmental factors that may act as enabler or barrier to the participation of persons with deafblindness in India. Thus, the manuscript compliments the overall theme of the thesis by identifying and describing the contextual factors, and suggesting evidence on ways to enhance the participation of those with deafblindness.
4.2 Abstract

The objective of this study is to identify and describe the contextual factors that influence the participation of persons with deafblindness in Indian society. This was a qualitative study, using directed content analysis approach and the International Classification of Functioning, Disability and Health as a framework to analyze the data. I interviewed sixteen individuals with deafblindness using accessible modes of communication. Study findings indicate that the age of onset and nature of impairment (deafblindness), and willingness to explain the condition (functional consequences of deafblindness) and ask for help from others emerged as important personal factors, whereas the availability of services and policies specific to deafblindness, societal attitudes, presence of support and relationships, and access to technology emerged as significant environmental factors affecting participation of those with deafblindness. 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 towards disability were perceived as most critical environmental barriers that influence participation of people with deafblindness in India. Professionals need to acknowledge aspects of the environment in conducting assessments and delivering interventions and understand the dynamic interactions between environment of the individual and their concurrent vision and hearing impairments. Approaches to enable participation require rehabilitation professionals to work with those with deafblindness to advocate for removal of environmental barriers and ensure provision of appropriate resources from the government to facilitate their participation. Social policy and government should ensure emphasis on awareness about deafblindness, access to deafblindness specific services, positive societal attitude, and opportunities to participate for full participation of people with deafblindness in society.
4.3 Introduction

Around 2% of the world’s population are living with deafblindness (World Federation of the Deafblind, 2018). Deafblindness is a condition in which an individual has a combination of hearing and visual impairment (Ask Larsen & Damen, 2014; Wittich, Southall, Sikora, Watanabe, & Gagné, 2013). Deafblindness can be congenital or acquired and ranges from mild loss in hearing and vision to complete deafness and blindness (Dammeyer, 2014; Wittich, Watanabe, & Gagné, 2012; World Federation of the Deafblind, 2018). Deafblindness is a distinct condition as the combination of impairments is more than the sum of its parts, and multiplies the total effect, because the impairment in one sense (e.g., vision) cannot be compensated by another sense (e.g., hearing) (Dammeyer, 2014, 2015; Saunders & Echt, 2007). Existing research on deafblindness is limited to high income countries and focuses on characteristics of individuals, their impairments, and their impact (Bodsworth, Clare, & Simblett, 2011; Dalby et al., 2009; Dammeyer, 2010, 2012; Fletcher & Guthrie, 2013; Guthrie, Declercq, Finne-Soveri, Fries, & Hirdes, 2016; Hersh, 2013a, 2013b; Moller, 2003; Rönnberg & Borg, 2001; G. H. Saunders & Echt, 2007; Watters, Owen, & Munroe, 2005; Wittich et al., 2012). These studies suggest that persons with deafblindness experience participation barriers and social isolation as also highlighted in the Chapter 2 (Jaiswal, Aldersey, Wittich, Mirza, & Finlayson, 2018), yet little is documented about contextual factors that shape these experiences.

In order to better understand such contextual factors, the World Health Organization proposed the International Classification of Functioning, Disability and Health (ICF), a biopsychosocial framework that conceptualizes human functioning and disability in relation to its context (World Health Organization, 2001). The ICF includes six components: body function; body structure; activity; participation; personal factors; and environmental factors (World Health Organization, 2001). While personal factors are not elaborated by developers of the ICF, environmental factors are classified in five main chapters: products and technology; natural
environment and human-made changes to environment; support and relationships; attitudes; and services, systems, and policies (World Health Organization, 2001).

To my knowledge, there is only one study that documents factors that influence participation among persons with deafblindness, and it was limited to the experiences of students with acquired deafblindness in Swedish schools (Möller & Danermark, 2007). The study findings indicate that there are participation barriers in the environment (e.g., levels of light and color in other parts of the school other than the classroom, hearing devices, adapted school books, slower signing, peer awareness about deafblindness, and the teacher’s awareness of the need for special attention in communication) for students with deafblindness in aspects of education (Möller & Danermark, 2007), though this evidence is insufficient to draw conclusions to inform clinical practice. Furthermore, most participation literature focuses on persons with physical or mobility or single sensory impairments from North America or Europe (Eyssen, Steultjens, Dekker, & Terwee, 2011; Hammel et al., 2008, 2015; Mallinson & Hammel, 2010; Martin Ginis, Evans, Mortenson, & Noreau, 2017; Meulenkamp, Cardol, van der Hoek, Francke, & Rijken, 2013; Mirza, Kim, Stoffel, Carroll, & Maga, 2015; Perenboom & Chorus, 2003; Rudman et al., 2016; Tsai et al., 2017; Wong et al., 2017) and very little is known about the participation of individuals with deafblindness in low and middle-income countries (LMICs) such as India (Jaiswal, Kumar, & Paul, 2018; Paul, Mathew, Kumar, Rizal, & Jaiswal, 2016). The knowledge of what and how contextual factors influence participation will help rehabilitation professionals to design participation-enabling interventions for persons with deafblindness. In this study I addressed this knowledge gap by answering the following research question: What self-reported contextual factors influence the participation of persons with deafblindness in India?

4.4 Methods

I used the ICF as a framework to identify and describe the contextual factors that affect participation of persons with deafblindness in India. I recruited participants with the help of a
community partner - *Sense International India* (www.senseintindia.org), a national level organization working with individuals with deafblindness in India. I obtained ethics approval from the Queen’s University Health Sciences Research Ethics Board (HSREB) (HSREB#REH-674-17) and local approval from *Sense International India*.

**Sample.** I used purposive sampling to recruit participants (Patton, 2002; Sandelowski, 1995) using set eligibility criteria (Table 15). The community partner informed potential participants about the study. A total of 23 adults expressed interest, out of which five were ineligible (due to presence of associated conditions), and another two were unavailable to participate during the study period. Table 16 provides summary characteristics for the 16 participants.

Table 15. Eligibility criteria

<table>
<thead>
<tr>
<th>Inclusion criteria</th>
<th>Exclusion criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Age: 18 years or over,</td>
<td>1. Persons with deafblindness with co-existing disability conditions (such as cerebral palsy, intellectual impairment, autism, or other impairments that may have interfered with their cognitive or physical status).</td>
</tr>
<tr>
<td>2. Formal diagnosis of deafblindness documented in the service files of <em>Sense International India</em>,</td>
<td></td>
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<tr>
<td>3. Observed ability to communicate through the use of either speech, sign language, tactile sign language or augmentative and alternative communication.</td>
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</table>

*Were excluded as these associated conditions may have also influenced the participation experiences.*

Table 16. Characteristics of participants

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Value</th>
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</thead>
<tbody>
<tr>
<td>Number of participants, n</td>
<td>16</td>
</tr>
<tr>
<td>Median age in years (range)</td>
<td>25.5 (18-45)</td>
</tr>
<tr>
<td>Gender, female n (%)</td>
<td>5 (31.3%)</td>
</tr>
<tr>
<td>Type of impairment, acquired, n</td>
<td>13</td>
</tr>
<tr>
<td>Education college or university degree, n</td>
<td>4</td>
</tr>
<tr>
<td>Work status, employed, n</td>
<td>8</td>
</tr>
<tr>
<td>Family annual income* (range)</td>
<td>INR 1 Lakh – 3 Lakhs**</td>
</tr>
<tr>
<td>Marital status, single, n</td>
<td>13</td>
</tr>
</tbody>
</table>

*1 Lakh = CAD 2000<br>** In comparison to average incomes in India, study population belongs to low to middle income category.

**Data collection.** I interviewed participants (age 18-45 years; 5 female and 11 male; 3 congenital and 13 acquired) using a qualitative semi-structured interview guide (Creswell, 2013)
at the community partner’s premises between March and May 2017 (Interview guide in Table 17). Please note that the interviews were conducted once (for study 2 and 3) and the data from the second part of the interview on contextual factors were used for this manuscript.

Table 17. Interview guide

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td>1. What are the factors that affect your participation in society?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Probe: attitudes, policies, services, natural and built environment, technology, resources, etc.</td>
</tr>
<tr>
<td>2. What are the supports that facilitate your participation in society?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Probe: technology, resources, information, family, etc.</td>
</tr>
<tr>
<td>3. What strategies are most needed to promote and support your full participation in society?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(Adapted from Magasi et al., 2009)</td>
</tr>
</tbody>
</table>

I used diverse communication modes and made questions accessible to participants with support of different technical aids such as computers with accessible features (*Job Access With Speech* [JAWS], refreshable braille devices), magnifiers, large print, Braille, print-on-palm, lip reading. Certified interpreters helped with visual and tactile sign language. In-person interviews ranged from 1.5 to 2.5 hours in length, while interviews using online platforms were of 2 to 5 hours duration. Data saturation was attained after 14th interview as no new codes were emerging, however, I interviewed two more participants to confirm saturation (Saunders et al., 2018).

**Data analysis.** Interviews were audio-recorded, transcribed, and then managed using QSR NVivo Pro 11 software (QSR International, 2017). I used a directed content analysis approach to analyze transcripts specific to personal and environmental factors (Hsieh & Shannon, 2005). Themes relating to environmental factors were organized according to the ICF environmental chapter descriptions (Table 18 provides themes, subthemes, and their guiding definitions). All coding was done originally in the source language (e.g., Hindi or English) by the first author and a research assistant, both proficient in both languages. To maximize rigor, transcripts were coded independently by these individuals and any discrepancies were resolved by discussion with the second author (HA) (Krefting, 1991). To achieve confirmability,
dependability, and credibility, I used peer-feedback (with supervisors and professional colleagues from *Sense International India*), maintained an audit trail, and conducted member checks with participants (Krefting, 1991). In the final stages of analysis, I extracted direct quotes verbatim from transcripts and translated those in Hindi into English.

Table 18. Themes, subthemes and definitions

<table>
<thead>
<tr>
<th>Themes</th>
<th>Subthemes</th>
<th>Definitions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal factors</td>
<td>Onset and nature of impairment</td>
<td>Statements demonstrating where onset or nature of disability such as those with congenital or acquired disability, or progressive or non-progressive disability affected participation of the individuals.</td>
</tr>
<tr>
<td></td>
<td>Willingness to explain and ask for help</td>
<td>Willingness to explain about disability condition, challenges associated and ask for help or assistance.</td>
</tr>
<tr>
<td>Environmental factors</td>
<td>Products and technology</td>
<td>Statements where equipment, products or technology used by the participants influenced their participation, for example products or technology for receiving or delivering information, communication with others.</td>
</tr>
<tr>
<td></td>
<td>Natural environment</td>
<td>Statements that express the influence of natural environment and human-made changes to the environment influence experiences of participation in a positive or a negative way. For example, time-related changes, light, climate etc.</td>
</tr>
<tr>
<td></td>
<td>Support and relationships</td>
<td>Statements where physical or emotional support of and relationships with individual family members, peers, colleagues, neighbours, service providers, teachers or community members influenced experiences of participation of the participants.</td>
</tr>
<tr>
<td></td>
<td>Attitudes (Positive or Negative)</td>
<td>Statements reflecting positive or negative attitudes of family members, peers, colleagues, neighbours, service providers, teachers or community members that influence experiences of participation. It includes both positive or motivating as well as discriminatory or neglecting attitudes.</td>
</tr>
<tr>
<td>Themes</td>
<td>Subthemes</td>
<td>Definitions</td>
</tr>
<tr>
<td>------------------------------------</td>
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<td>-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Services, systems, and policies</td>
<td>Statements where structured programs, administrative systems, social benefits, or policies established by the government or any formal authorities affected participation or experiences of participation of the participants. For example: employment, educational, social support or health services, systems, and policies.</td>
<td></td>
</tr>
</tbody>
</table>

Source: WHO, 2001

4.5 Results

Adults with deafblindness perceived their participation experiences to be shaped by a range of personal and environmental factors (WHO, 2001). Tables 19 and 20 highlight participants’ quotes reflecting subthemes for personal and environmental factors. To disguise participants’ identities, quotes are referred to by numbers at the beginning of each quote. It is important to acknowledge that I edited quotes used in text for readability as direct quotes from the participants had some grammatical errors. The content in the square brackets within the quote provides more clarity of the context, while the content in the square brackets after the quote provides information about the onset of hearing impairment (HI) and visual impairment (VI).

**Personal factors.**

(1) *Age of onset and nature of impairment.* Participation experiences varied with respect to the participant’s age of onset of deafblindness (i.e., early versus late onset) and nature of impairment (i.e., static versus progressive loss of vision and hearing). For individuals who had congenital or early onset deafblindness before 3 years of age, understanding and experience of participation was abstract. Since they never experienced the world in a “typical” way before the onset of their impairment, they did not distinguish whether their participation experience was limited or compromised. However, individuals who had progressive loss faced functional and psycho-emotional challenges as they adjusted to gradual loss of visual and hearing function. One participant with an acquired condition mentioned: “The problems have increased after the onset
of my deafblindness…especially in walking…since my hearing [ability] has started to decline, I feel very sad because of this.” (P4) [VI (by birth) and HI (at the age of 13 years)]. Participants with acquired conditions highlighted that their life changed after the onset of impairment compared to before. In addition, their daily functioning deteriorated and their life goals and aspirations changed with the progression of sensory loss.

Table 19. Subthemes and reflecting quotes: Personal factors

<table>
<thead>
<tr>
<th>Subthemes and quotes: Personal factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Subthemes</td>
</tr>
</tbody>
</table>
| Onset/nature of impairment            | P5: “I do not see, because of that reason I cannot go alone to my shop… If I go alone, I will be hit by a vehicle and hurt myself.”  
P1: “I am totally different from the normal children, I cannot play and read like them, cannot see and hear everything, and cannot even learn new things… that means I am missing on many things. Due to the problem of my ear and eye, I am not able to do all that.”  
P8: “I became deaf by birth and I lost my vision at the age of 24 years. When I had my vision, I did not face many problems. But when I became deafblind, many problems came in my way.”  
P4: “I feel lacked because of inability to see and hear. Vision impairment caused problems in mobility and hearing impairment caused problems in communication.” |
| Willingness to explain and ask for help | P1: “I used to explain to my friends what I do not understand [in class] or not able to hear [properly]... And then I ask them to help me, then they help me”.  
P3: “As I do not hear and don’t have speech, I communicate through writing with others”.  
P3: “I tell them [others in society] that I cannot see and hear… if I am lost I ask them to leave me home.”  
P10: “I have to explain to people that I need to cross the road and I need their help to do it”.  
P10: “If I confidently go and ask to help me, then all of them [others in society] would help very well by writing or explaining me.” |

(2) Willingness to explain the condition and ask for help. It emerged that participants’ willingness to ask for help especially in the areas of mobility and communication enhanced their experiences of participation with others and within their environment. Many participants (P1, P3, P10, P14, and P15) shared that they made others understand their deafblindness by educating
them about the specific functional consequences and asking for their help. For example, a participant said:

> They [school friends] do not know [about my disability], but I have told them slowly, they have understood this thing [now]. As I have difficulty listening, they speak loud. I have difficulty seeing too, they give me a copy to take home and complete school work.
> (P14) [VI (by birth) and HI (at the age of 3 years)]

**Environmental factors.** I have organized themes relating to environmental factors using the ICF environmental chapter descriptions. Table 20 highlights participants’ quotes reflecting subthemes for environmental factors. Table 21 provides a summary of ICF environmental factors identified by participants in order of importance related to their participation.

Table 20. Subthemes and reflecting quotes: Environmental factors

<table>
<thead>
<tr>
<th>Subthemes</th>
<th>Quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Services, systems, and policies</td>
<td>P7: “They [society] should help me to advocate for Braille display device to be cheaper and ask for access to information for deafblind people. Education should be imparted to deafblind children in the country like me. People should understand deafblindness properly… should respect deafblind [people].”</td>
</tr>
<tr>
<td></td>
<td>P14: “We have problems in walking, watching, and listening. There should be training to [overcome] all these problems, then we will be able to gradually start working like normal people. I have an interest in drawing and I want a drawing teacher who can teach me drawing.”</td>
</tr>
<tr>
<td></td>
<td>P15: “They [government] should provide enough resources in terms of technology to help deafblind persons…Society should try to help.”</td>
</tr>
<tr>
<td></td>
<td>P4: “The people of society should treat us equally as they treat others. They should be kind to those who are living with disabilities and limitations. It is the responsibility of the government to give us a job or open school for us.”</td>
</tr>
<tr>
<td></td>
<td>P14: “I would like to raise awareness [about deafblindness] among people so they understand about our problems.”</td>
</tr>
<tr>
<td></td>
<td>P10: “The government should set up awareness camps in every school. With awareness, people will understand that although we are deafblind, we can be independent. All services should be available that can help in getting jobs for deafblind [people].”</td>
</tr>
<tr>
<td>Attitudes (Positive or Negative)</td>
<td>P7: “Non-disabled people do not like to talk to the deafblind [person] through print on palm. They only help and keep them [deafblind] aside and do not allow them to touch everything.”</td>
</tr>
<tr>
<td>Subthemes and quotes: Environmental factors</td>
<td>P13: “One of my friends did not treat me well. He always ignored me. And this is happening after the onset of my disability. He think that I cannot do anything now due to deafblindness, although we were very good friends since childhood.”</td>
</tr>
<tr>
<td>Support and relationships</td>
<td>P1: “At first there was no [help] when [my] hearing started getting worse, but now [after winning in a sports competition] they help.”</td>
</tr>
<tr>
<td>Products and technology</td>
<td>P4: “The society often respect only those who can benefit the society, and for the ones society has no benefit, they ignore them… even if they support [us], they hate [us] equally.”</td>
</tr>
<tr>
<td>Natural environment</td>
<td>P4: “There is a feeling of inferiority towards us [those with deafblindness] in the people, when they invite others [for community events], we are not included.”</td>
</tr>
<tr>
<td>Support and relationships</td>
<td>P4: “Our development and progress is impossible without cooperation from others. We cannot do anything without support. There is a great importance of support in our lives, we need support at every stage.”</td>
</tr>
<tr>
<td>Products and technology</td>
<td>P10: “At home, my parents used to do everything to help my studies… Mom-dad, friends, interpreter, relative are all very big supporters.”</td>
</tr>
<tr>
<td>Natural environment</td>
<td>P15: “They [school staff] took some time to understand me. They used to say that it would be very difficult for me. But when I passed their test, they understood that I am capable. Miss [name] was the best teacher. She always paid special attention to me… ensured that I understood the concepts. The Principal was helpful and very cooperative too.”</td>
</tr>
<tr>
<td>Support and relationships</td>
<td>P4: “My village people support me… they help me find my way… the community also supports. If I want to go in the community meetings, they help me get there.”</td>
</tr>
<tr>
<td>Products and technology</td>
<td>P14: “When I was not able to get admission anywhere, my deafblind school helped us to get admission in mainstream school. We got a lot of support from here [deafblind school].”</td>
</tr>
<tr>
<td>Natural environment</td>
<td>P12: “After applying cochlear implant, my life is quite good. After that, with speech therapy and practice, I gradually improved.”</td>
</tr>
<tr>
<td>Products and technology</td>
<td>P15: “I use android phone, and I use JAWS* to work in the office. I use android apps to recharge internet, [to top up] phone currency, to book cab, to buy things etc. I use android apps for banking transaction. I use a debit card. I use JAWS in computer to search for information and download songs etc.”</td>
</tr>
<tr>
<td>Natural environment</td>
<td>P4: “Earlier when my machine [hearing aid and amplifier] used to work, I did not feel so lonely, but when my machine got damaged... I started feeling lonely because very few people talk to me.”</td>
</tr>
<tr>
<td>Products and technology</td>
<td>P7: “Braille Display Device** helps me to work independently”</td>
</tr>
<tr>
<td>Support and relationships</td>
<td>P4: “When I had an ear machine, I used to hear, then I would listen to the voice of the customer and give them material, but when I am not able to hear, customers do not want to speak too.”</td>
</tr>
<tr>
<td>Products and technology</td>
<td>P15: “My mother used to scan all of my books and edit it to convert to Braille. Editing used to take a long time. Converting to Braille would cost a lot… I never thought that I would get a Braille for myself.”</td>
</tr>
<tr>
<td>Natural environment</td>
<td>P8: “Vision was not clear…there is darkness everywhere…could not move properly. Sometimes collided with stones, slipped, and difficulty in getting to toilet.”</td>
</tr>
</tbody>
</table>
Subthemes and quotes: Environmental factors

P10: “It happened yesterday, I got hurt in the foot, from the stone [in the way]. There is a problem where potholes are deep. If it is a bit dark then I collide with objects.”
P13: “Traveling in the dark night is really a tough struggle.”
P15: “The major problem started when I went for 1st standard. The classroom was little dark and the teachers used to change the place [seating] every day.”

* JAWS (“Job Access With Speech”) is a computer screen reader program for Microsoft Windows that allows people with visual impairment to read the screen either with a text-to-speech output or by a refreshable braille display.
** Braille Display is a device, typically attachable to a computer keyboard that allows a person with visual impairment to read the contents of a display one text line at a time in the form of a line of Braille characters.

Table 21. ICF environmental factors identified by participants in order of their importance

<table>
<thead>
<tr>
<th>Environmental factors (e)</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Services, systems and policies</td>
<td>15</td>
</tr>
<tr>
<td>Attitudes</td>
<td>14</td>
</tr>
<tr>
<td>Support and relationships</td>
<td>13</td>
</tr>
<tr>
<td>Products and Technology</td>
<td>12</td>
</tr>
<tr>
<td>Natural environment and human-made changes to environment</td>
<td>7</td>
</tr>
</tbody>
</table>

N = Number of participants out of total 16 participants who identified the specific factor as important

(1) Services, systems and policies. Among the five ICF contextual factors, services, systems and policies emerged as the most significant factor reported by participants as relevant to their participation. This theme illustrates the experiences of participants with their school services, administrative systems, social benefits schemes, or policies established by the central and local government that affected their participation. Participants shared that the services they received were often not adequate, and did not meet their deafblind-specific needs. A participant shared: “There was no interpreter in my previous school, that’s why I couldn’t participate there… Here [in deaf-blind school] I can take part in everything.” (P10) [HI (at the age of 9 years) and VI (at the age of 5 years)]

Participants highlighted the need for special services and advocacy for people with deafblindness.

When asked what the government should do to help you, a participant shared:

Technology should be accessible to everyone… I feel the available resources and technology are not completely accessible
to deafblind persons. Since I am blind and hearing impaired, I want equal opportunities like others. I feel that is not there. (P15) [HI (by birth) and progressive VI (diagnosed at 3 years)]

Participants (P4, P8, P9, P10, P14, and P15) strongly advocated for improving awareness about deafblindness and creating opportunities for people with deafblindness. They feel that improving knowledge about deafblindness among others would facilitate acceptance, support, and inclusion of persons with deafblindness in society. A few suggested training non-disabled students in sign language to build knowledge about deafblindness in schools.

(2) Attitudes. Attitudes of other people, such as friends, family, teachers, and strangers, played a significant role in participants’ lives and affected whether they felt supported or ignored. Some participants received substantial support from their parents, teachers, and friends that shaped their experiences, as reflected in the previous discussion of supports. However, participants also repeatedly referred to instances when they felt left out, isolated, and not-supported by other people. For example, some participants (P7, P15, and P4) shared that non-disabled people do not want to or sometimes are uncomfortable while interacting with them:

There are few people who ask "do you need help" or "how can I help you" etc. but there are some people who don’t even care even if we ask for help… maybe they are in a hurry… maybe they feel uncomfortable. (P15) [HI (by birth) and progressive VI (diagnosed at 3 years)]

(3) Support and Relationships. Many participants acknowledged that the support they received from their family, friends, teachers, and deafblind organizations was crucial for their progress and participation in life. One participant mentioned:

My major support is my family and friends. My parents always encourage and motivate me to do anything I want to do. They teach me a lot of things...help me in all ways...in my day to day activities like travelling...my friends gifted me a Braille and an Embosser which helped me to convert my notes into Braille. (P15) [HI (by birth) and progressive VI (diagnosed at 3 years)]
Another participant (P1) shared how teachers helped and supported her learning, though in her case this support was conditional: “Ever since I won [in a sport activity], they [school teachers and fellow students] feel I can progress in life, so they are helping me…at the exam time, they [teachers] bring bigger sheets for me.” (P1) [Progressive HI and VI from the age of 12 years]

(4) Products and technology. Participants reported that access to technology enabled their participation. All participants used some form of technological device to aid in daily functioning related to mobility, communication, or access to information. Most commonly used aids were hearing devices, walking canes, and internet technology. For example, a few participants (P10 and P12), said that a magnifier helped them read books, novels, and the news. For others (P6, P7, P15, P16) who had no speech, internet technology using refreshable braille display/Job Access With Speech (JAWS) emerged as a powerful tool to help them get connected to the world – using emails, text messages, accessing news, entertainment, online shopping, and communicating with others. A participant shared:

When I was in 11th grade… I got a much better hearing aid…after which I became more active in communicating with others… I started asking more questions in class. I was very happy that I could interact with everyone. Overall I became more active… it (hearing aid) is of great help. Without that I cannot manage to hear anything properly. I am completely dependent on that for hearing [sic].
(P15) [HI (by birth) and progressive VI (diagnosed at 3 years)]

However, there were two participants (P1 and P4) for whom hearing aids were not helpful due to the progressive nature of their hearing impairment, malfunction of the device, or the discomfort using it. Some participants (P4, P7, P10, and P15) also shared that technological aids were expensive to buy and maintain. For example, a participant said: “Braille Display Device is [more] expensive than ordinary equipment… it is made in America. I have to dispatch it to America for repair and wait for more than one or two months…” (P7) [HI (by birth) and VI (at the age of 9 years)]
(5) **Natural and built environment.** Many participants reported that the natural and built environment influenced their functioning and participation. For example, for some participants who had residual vision (P10, P13, and P15), low levels of illumination emerged as the biggest challenge that affected their mobility and productivity. A participant (P3) who had night blindness said “It feels good in the morning but nights are scary” and left his job that required him to work after sunset. The fear of falling or hitting or hurting oneself was substantial. Many participants (P1, P3, P4, P8, P10, and P12) had fallen several times due to obstacles such as stones and potholes in the road and hurt themselves, making accidents and falls a common phenomenon in their lives. For example, while using a bus with automatic gate lock system, a participant (P12) was often hurt by the door, especially entering and exiting the bus.

### 4.6 Discussion

This study is the first of its kind to identify factors that individuals with congenital and acquired deafblindness perceive as important for their participation in Indian society. This work extends existing research on participation that is limited to high income countries and on persons with physical or mobility or single sensory impairments (Eyssen et al., 2011; Hammel et al., 2008, 2015; Mallinson & Hammel, 2010; Martin Ginis et al., 2017; Meulenkamp et al., 2013; Mirza et al., 2015; Perenboom & Chorus, 2003; Rudman et al, 2016; Tsai et al., 2017; Wong et al., 2017). My study is unique as it not only focuses on a group (individuals with deafblindness) that is rarely studied, but it was conducted in a country that is not usually included in this type of participation research (World Federation of the Deafblind, 2018). Similar to the study (Möller, 2003), my work also found the ICF as a suitable framework to identify factors that influence participation of those with deafblindness.

Participation experiences of those with deafblindness are influenced by a dynamic interaction between the person and their context (personal and environmental factors) (Möller & Danermark, 2007). It is important to note that participation experiences vary considerably
between those with congenital versus acquired deafblindness (Dalby et al., 2009; Dammeyer, 2015; Fletcher & Guthrie, 2013). Though personal factors such as onset and nature of impairment are beyond someone’s control, individuals with deafblindness can overcome participation barriers with the help of technology, environmental adaptations, and societal support. In addition, willingness to explain deafblindness to others and proactive outreach is a crucial factor that can significantly influence the likelihood of gaining support from others in enabling participation.

In addition to personal advocacy and proactive outreach, it is important to consider the role of the environment in enabling/impeding participation. My study asserts the importance of assistive technology, social support, and deafblind-specific services as facilitators of participation for adults with deafblindness, in line with findings from other studies (Emerson & Bishop, 2012; Hersh, 2013a, 2013b; Perfect, Jaiswal, & Davies, 2018; Southern & Drescher, 2005; Wittich, Jarry, Groulx, Southall, & Gagné, 2016). Although what the study reveals is not new for high income countries, we as the global community need to ponder why these supports are still not in place in LMICs. There are huge disparities in terms of resources and infrastructure that could support rehabilitation and participation of those with deafblindness in LMICs such as India. The socio-political environment plays an important role in determining how the system, services and policies are organized in any given country and who benefits from such institutional support.

Although there are obligations on the Indian government due to international conventions such as United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006) and national legislations such as the Rights of Persons with Disabilities Act, 2016 (Government of India, 2016) to ensure the rights of persons with disabilities including those with deafblindness are met, the Indian government currently places more emphasis on removal of architectural barriers versus addressing institutional or attitudinal barriers to enable participation of those with disabilities (Government of India, 2018; Sharma, 2016). Contrary to the understanding that accessibility of the built environment is a key enabler of participation for
persons with mobility or visual impairments (Badertscher et al., 2012; Barclay, Mcdonald, Lentin, & Bourke-Taylor, 2016; Clarke, Ailshire, Nieuwenhuijsen, & de Kleijn - de Vrankrijker, 2011; Hammel et al., 2015; Hanzen, van Nispen, van der Putten, & Waninge, 2017; Salminen & Karhula, 2014; Tsai et al., 2017; Wee & Lysaght, 2009), my study participants identified architectural barriers as less important and placed greater emphasis on institutional barriers related to services, systems and policies. They identified attitudinal barriers, followed by products and technology as the most influential factors (Table 21). This finding was similar to the recommendations by McGrath and colleagues (2017) where they advocated for socio-political and institutional change in systems and policies to address the deeply-rooted social exclusion and discrimination, and going beyond physical accessibility in the built environment to develop age and low-vision-friendly environments.

My findings revealed that the lack of awareness about deafblindness, associated negative attitudes, limited access to information and resources, and inaccessible built environments act as significant barriers to participation of persons with deafblindness in India. A previous study showed that lack of knowledge about deafblindness impeded the participation of deafblind students in the school setting (Möller & Danermark, 2007). My study asserts that lack of knowledge about deafblindness is not only the barrier to participation within the school context, but also applies to the larger societal context.

Current rehabilitation assessments and interventions primarily focus on the client (person) and her/his immediate (micro) environment (Baum & Law, 1997; Hammell, 2006, 2015; Law, 1991), whereas the findings from my study suggest that rehabilitation interventions for individuals with deafblindness should be designed considering the influence of contextual factors at the micro-, meso- and macro-levels. In addition, rehabilitation professionals should consider areas such as learning, communication, mobility, functional independence, forming relationships, and community life that are affected most by deafblindness while designing interventions for this

Overall, it can be argued that there is a need for a multi-level approach where, on the one hand, society (meso and macro environments) needs to be aware of and consider the distinct needs of the deafblind population, and, on the other hand, persons with deafblindness (individuals) need to be willing to inform others about their condition and be proactive in order to obtain specific support from them. For example, a person with deafblindness who uses lip/speech reading needs to inform communication partners about this need and ask others to be considerate of this requirement. Proactive outreach for accommodation and inclusion is a way to assert one’s rights rather than request favors. Understanding the dynamic relationship of personal and environmental factors affecting participation of those with deafblindness can help care providers and care recipients find collaborative ways to support their inclusion in society.

4.7 Limitations

The study findings are limited to perspectives of individuals with deafblindness; gathering perspectives of family members, and deafblind-specific organization staff could have provided a more comprehensive understanding of the contextual factors. It is worth noting that the study population represented either middle or low income subgroups, mostly from cities or towns, and majority were males (n=11). Though the study participants were from different parts of the country and might have similar access to deafblind specific services from community partner organization, it is worth considering the extent to which the study findings could be generalized to 500,000 persons with deafblindness in the light of cultural, religious, linguistic and other forms of diversity found in India. The findings may also not generalize to other countries where the level of services available are higher or lower. Another limitation is that culture-specific nuances might have been missed in cases where interpreting (e.g., from tactile language
to spoken English) was employed for data collection, and in translation from Hindi to English of the quotes used during data analysis.

4.8 Conclusion

The participation deficits of individuals with deafblindness are manifested in the dynamic interactions between environment of the individual and their concurrent vision and hearing impairments. This understanding enhances our ability to promote facilitators of participation and mitigate barriers to the full participation of persons with deafblindness in society. Professionals must acknowledge aspects of the environment in conducting assessments and delivering interventions. Knowing how participation is influenced by the environment and which factors are most influential can be used to develop appropriate rehabilitation interventions. Approaches to enable participation may require rehabilitation professionals to work with those with deafblindness for removal of environmental barriers and ensure provision of appropriate resources from the government to facilitate their participation. Social policy and government need to ensure emphasis on awareness about deafblindness, access to deafblindness specific services, positive societal attitude, and opportunities to participate for full participation for people with deafblindness in society. To mitigate participation barriers at the grassroots level, the current national disability policy of India needs to be translated in its full faith to the level of local governance to ensure the rights of persons with deafblindness are met and their participation is enhanced in their own local community.

4.9 References


World Federation of the Deafblind. (2018). *At risk of exclusion from CRPD and SDGs*

Chapter 5

Rehabilitation service providers’ perspectives on factors that influence participation of persons with deafblindness in India

Citation: Jaiswal, A., Aldersey, H., Wittich, W., Mirza, M., & Finlayson, M. (under review). Rehabilitation service providers’ perspectives on factors that influence participation of persons with deafblindness in India. Disability and Rehabilitation.

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5.1 The Fit of Manuscript 4 within the Dissertation

Manuscript 4 builds upon the findings of the first three manuscripts by developing an understanding of the contextual factors that influence the participation of persons with deafblindness in India from the perspectives of those involved in providing rehabilitation services to them. The manuscript advances overall study findings by adding what service providers think about the participation of persons with deafblindness, personal and environmental factors that influence participation of those with deafblindness, and strategies to improve their participation. Thus, the manuscript compliments the overall theme of the thesis by exploring and adding the perspectives of rehabilitation service providers who work with persons with deafblindness in India.
5.2 Abstract

Evidence to inform rehabilitation service delivery for individuals with deafblindness, especially in an Indian context, is inadequate. Rehabilitation service providers often find it challenging to design rehabilitation interventions that promote participation for those with deafblindness. Therefore, the purpose of the study was to understand the contextual factors that influence the participation of persons with deafblindness in India from the perspectives of those involved in providing rehabilitation services to them. Using the International Classification of Functioning, Disability and Health (ICF) as a framework, I conducted two focus group discussions with sixteen rehabilitation service providers in India. I used a directed content analysis approach to examine the data. Rehabilitation service providers perceived participation barriers to be linked primarily to the social environment. Only a few barriers were perceived to be linked to the individual. Specifically, participants identified four major barriers, including (a) lack of awareness about deafblindness; (b) negative attitudes and stigma associated with disability; (c) lack of access to resources such as assistive technology and interpreter support; and (d) communication challenges associated with severe impairments. Recommended strategies to improve the participation of persons with deafblindness included access to affordable technology, provision of interpreters and personal support workers, vocational training opportunities, and training on deafblindness for parents, professionals, and the community. Lack of knowledge about deafblindness among rehabilitation professionals has significant implications for identification and assessment of individuals with deafblindness and their access to rehabilitation services. Training of individuals with deafblindness and their service providers in multiple modes of communication could improve the participation of even those with severe impairments. Future research should explore the effect of interpreters and technology support on enhancing the participation of those with deafblindness in both structured and unstructured environments.
5.3 Introduction

Participation, defined as “involvement in life situations” (p.36) by the International Classification of Functioning, Disability and Health (ICF) is one of the most important rehabilitation goals for people with disabilities (World Health Organization, 2013). As participation directly relates to community integration, quality of life, and overall life satisfaction for people with disabilities and their caregivers, it is a highly valued outcome for rehabilitation professionals (Hammel et al., 2008; Hammell, 2015; Magasi, Hammel, Heinemann, Whiteneck, & Bogner, 2009). However, ambiguity in defining the concept of participation causes difficulty in measurement, assessment, planning, and delivery of rehabilitation interventions directed towards enhancing participation of people with disabilities (Whiteneck, Bogner, & Heinemann, 2011; Whiteneck & Dijkers, 2009). Moreover, most participation research focuses on participation experiences of people with mobility-related impairments living in high-income countries (Hammel et al., 2008, 2015; Magasi et al., 2009; Mallinson & Hammel, 2010; Martin Ginis, Evans, Mortenson, & Noreau, 2017; Meulenkamp, Cardol, van der Hoek, Francke, & Rijken, 2013; Mirza, Kim, Stoffel, Carroll, & Maga, 2015; Tsai et al., 2017; Wong et al., 2017) and hence may not adequately identify the challenges faced by people living with sensory impairments, and those in low or middle-income countries (LMICs) (Jaiswal, Kumar, & Paul, 2018).

Stakeholders directly involved in providing assistive, educational, or therapeutic services to persons with sensory disabilities play a crucial role in improving their participation and supporting them to fulfill their life goals (Alma, Van der Mei, Groothoff, & Suurmeijer, 2012; Salminen & Karhula, 2014). Deafblindness is a sensory disability that involves a combination of visual and hearing impairment in the same individual (Ask Larsen & Damen, 2014; Dammeyer, 2014; Wittich, Southall, Sikora, Watanabe, & Gagné, 2013). People with deafblindness need a variety of assistive, educational, and therapeutic services. Challenges in communication, accessing information, and mobility experienced by persons with deafblindness may hinder many
aspects of functioning and participation, therefore creating complex challenges for rehabilitation (Dammeyer, 2015; Hersh, 2013a, 2013b; Moller, 2003; Wittich, Jarry, Groulx, Southall, & Gagné, 2016). Key rehabilitation service providers and support staff for this population include special educators, sign-language interpreters, family members, optometrists, audiologists, occupational therapists, social workers, speech and language pathologists, computer accessibility or hearing technology experts (Wittich, Watanabe, & Gagné, 2012). Service providers face challenges while working with this population because of their limited understanding of deafblindness and factors that influence participation of those with deafblindness (Wittich, Barstow, Jarry, & Thomas, 2015; Wittich, Jarry, Barstow, & Thomas, 2017; Wittich, Canuto, & Overbury, 2013).

In India, an estimated 500,000 individuals are affected by deafblindness (0.04% of the general population) (Jaiswal et al., 2018; Paul, Mathew, Kumar, Rizal, & Jaiswal, 2016). Rehabilitation services available for these individuals are limited due to a lack of trained manpower, knowledge, and resources (Paul et al., 2016). This situation reflects widespread gaps in rehabilitation services for people with disabilities in LMICs. Soon after the release of the World Report on Disability in 2011, the World Health Assembly asked the World Health Organization (WHO) to develop guidelines for strengthening national rehabilitation services in line with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (United Nations, 2006; World Health Organization & World Bank, 2011). The resulting guidelines highlighted large gaps in the provision of and access to rehabilitation services in many LMICs. Member states were urged to take appropriate measures to improve the full inclusion and participation of all people with disabilities, including those with deafblindness (World Health Organization, 2011). A recent global report by the World Federation of the Deafblind (2018) on situation and rights of persons with deafblindness reveals that people with deafblindness are left
behind and are at risk of exclusion from UNCRPD and Sustainable Developmental Goals implementation (World Federation of the Deafblind, 2018).

In order to strengthen rehabilitation services to enable participation of individuals with deafblindness, it is essential to explore the perspectives of all stakeholders including individuals with deafblindness and service providers who work with them. As part of my thesis study, I interviewed 16 persons with deafblindness to explore the meaning of participation (chapter 3) (Jaiswal, Aldersey, Wittich, Mirza, & Finlayson, 2018) and the contextual factors that influence participation for individuals with deafblindness in India (chapter 4) (Jaiswal, Aldersey, Wittich, Mirza, & Finlayson, under review). Here, I attempt to understand the contextual factors that affect participation of persons with deafblindness from the perspectives of service providers involved in rehabilitation care for this population. Exploration of these perspectives may improve the understanding of barriers and facilitators faced by service providers in India while working to enhance participation of individuals with deafblindness. In addition, this approach may offer solutions to improve the planning and delivery of rehabilitation services in India and other similar contexts.

5.4 Methods

The ICF guided all aspects of the study, including data collection and analysis. I used a qualitative approach to address the study aim, using focus group discussions (FGDs) to collect data from rehabilitation service providers. Focus group guide questions were developed based on the themes highlighted as contextual factors in the ICF. Focus group discussions are recommended for generating rich data that often results from the synergy and spontaneity of group dynamics and in-depth discussion between participants who may have similar or divergent views (Krueger & Casey, 2000).

Study setting. This study was conducted in India in collaboration with a community partner, Sense International India. I obtained ethical approval from the Queen’s University
Health Sciences Research Ethics Board (HSREB #REH-674-17). Sense International India locally approved the study and facilitated recruitment of rehabilitation service providers working with persons with deafblindness. Recruitment sites included Regional Learning Centres on Deafblindness (RLC) in two cities of India: New Delhi and Ahmedabad. The RLCs function as a centre of expertise and technical knowledge on deafblindness (Sense International India, 2016), in addition to delivering early intervention, education, and vocational training to individuals with deafblindness. The RLCs also provide training to professionals, families and disability organizations on how to work with individuals with deafblindness.

**Sample.** I used convenience sampling to recruit participants who met the following inclusion criteria: (1) a minimum of one-year experience working with individuals with deafblindness, and (2) the ability to communicate fluently in Hindi. Sixteen individuals were recruited and informed consent was obtained from all.

**Data collection.** Two FGDs were held with the 16 participants, with eight individuals in each discussion. Each FGD took place at one of the two RLCs where participants were working. I followed recommendations of Krueger and Casey’s approach (Krueger & Casey, 2000) to facilitate the discussions. Table 22 provides the focus group guide. I acted as a moderator and facilitated introductions, convened group interactions, and presented discussion summaries to the group at the end. A research assistant acted as a note-taker, and recorded non-verbal information. FGDs were each 90 minutes in duration and were conducted in Hindi, the native language of the participants.

**Table 22. Focus group discussion guide**

1. What defines full participation for you and describe the activities most important to participate in?
2. What are the factors that influence participation of persons with deafblindness in society?
   Probe: attitudes, policies, services, natural and built environment, technology, resources, etc.
3. What are the barriers that influence participation of persons with deafblindness in society?
   Probe: attitudes, policies, services, physical environment
4. What are the supports that facilitates participation of persons with deafblindness in society?
   Probe: technology, resources, information, family, etc.

Adapted from Magasi et al., 2009
**Data analysis.** Data from the FGDs were audio-recorded, transcribed verbatim in Hindi, and managed using NVivo Pro 11 software (QSR International, 2017). Being proficient in both English and Hindi, I analysed the transcripts independently in the source language (Hindi). A directed content analysis approach was used, where the goal is to conceptually extend a theoretical framework or theory (Hsieh & Shannon, 2005). Guided by the ICF, themes and subthemes were organized into environmental and personal factors and their respective chapter descriptions. The research assistant (proficient in both the languages), who was involved in note taking while conducting FGDs, conducted an independent review of coding and analysis for confirmability. In the final stages of analysis, I extracted direct quotations that were relevant to the research question from transcripts and translated into English (Santos, Black, & Sandelowski, 2015). The research assistant conducted back translation of the quotations from English to Hindi to confirm accuracy (Chen & Boore, 2010). To ensure rigour, an audit trail was maintained, and each participant was mailed a set of preliminary results for member-checking, and was asked to comment if inaccuracies were noted (Krefting, 1991). Nine participants agreed with results and expressed no concerns with the accuracy and the remaining individuals did not offer any feedback.

**5.5 Results**

**Participants demographics.** Participants included service providers who were providing rehabilitation care in the two RLCs on deafblindness. These include ten special educators, two vocational instructors, two support workers (who provided personal ADL support), an occupational therapist, and a rehabilitation worker (field worker for community-based rehabilitation services). Although I attempted to recruit physiotherapists and speech-language therapists, they could not join because of other commitments. Participants were primarily female (n=13) and had training in different modes of communication used by people with deafblindness. The average years of experience for service providers in the deafblind field
was 12 years. It is important to note here that five of the 16 participants were also either a parent or sibling of an adult with deafblindness. Table 23 provides the participants’ demographic characteristics.

Table 23. Characteristics of focus group discussion participants (N = 16)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Age (years)</td>
<td></td>
</tr>
<tr>
<td>Average</td>
<td>41</td>
</tr>
<tr>
<td>Range</td>
<td>25-56</td>
</tr>
<tr>
<td>• Gender</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>3</td>
</tr>
<tr>
<td>Female</td>
<td>13</td>
</tr>
<tr>
<td>• Professional Background</td>
<td></td>
</tr>
<tr>
<td>Special educator</td>
<td>10</td>
</tr>
<tr>
<td>Vocational instructor</td>
<td>2</td>
</tr>
<tr>
<td>Support worker</td>
<td>2</td>
</tr>
<tr>
<td>Occupational therapist</td>
<td>1</td>
</tr>
<tr>
<td>Rehabilitation worker</td>
<td>1</td>
</tr>
<tr>
<td>• Years of experience in the profession</td>
<td></td>
</tr>
<tr>
<td>Average</td>
<td>12</td>
</tr>
<tr>
<td>Range</td>
<td>1-19</td>
</tr>
<tr>
<td>• Knowledge of usage of mode of deafblind communication</td>
<td>No. of participants</td>
</tr>
<tr>
<td>Sign Language</td>
<td>15</td>
</tr>
<tr>
<td>Tactile sign language</td>
<td>13</td>
</tr>
<tr>
<td>Braille</td>
<td>6</td>
</tr>
<tr>
<td>Tadoma</td>
<td>1</td>
</tr>
<tr>
<td>Print-on-palm</td>
<td>4</td>
</tr>
<tr>
<td>Haptic communication</td>
<td>5</td>
</tr>
<tr>
<td>Gestures</td>
<td>6</td>
</tr>
<tr>
<td>Communication technology</td>
<td>2</td>
</tr>
</tbody>
</table>

Service providers agreed on a set of personal and environmental factors that they perceived to influence participation of those with deafblindness. When asked about participation barriers, 12 service providers believed these barriers are located in the environment, and 4 identified barriers inherent to the individual. Based on the analysis, services, systems and policies followed by attitudes were the most frequently mentioned factors that rehabilitation service providers perceived to influence participation of those with deafblindness. This section presents subthemes that emerged under personal and environmental factors and participants’ quotations
that reflect those subthemes. The content in the square brackets is to provide more clarity of the context.

**Personal factors.**

(1) **Nature and severity of impairment.** Some service providers believed that the nature of the sensory impairment, its severity and progression affect the extent of participation for individuals with deafblindness. An experienced special educator (also a mother of a young adult with deafblindness) shared that the individuals who do not have severe impairments and are able to communicate, show fast progress and are accepted by society: “Once their communication is established, they are able to participate in society, and mothers and educators both are motivated to work with them.” Another participant believed that progression of impairments (in those with acquired deafblindness) reduces their mobility and thus their level of engagement with others in society:

Due to progressive vision loss, she [female with acquired deafblindness] is now limited to her home though earlier she was independent in moving around everywhere in the village. (Rehabilitation worker)

(2) **Additional conditions and/or behavior issues.** Some participants discussed that the presence of additional conditions, such as an intellectual impairment, have a direct influence on participation of individuals with deafblindness. They said that it is difficult for parents to manage children with behavior issues that are often associated with severe impairments. One participant (special educator) shared that “though parents agree that participation for these adults is important, sometimes it becomes almost impractical due to behavior issues in public spaces such as in the movie theatre or market.” Another participant stated:

When an individual with deafblindness has some speech and does not have additional conditions such as an intellectual impairment, he may function in a normal school. . . . Even when there is some communication difficulty, there is technology available to help. (Special educator)
(3) Knowledge of and ability to use different modes of communication. All service providers perceived communication as the biggest barrier to participation of persons with deafblindness. Many believed that the knowledge of various modes of communication determines the level of participation. They shared that within their practice, individuals who knew multiple modes of communication were able to participate more than those who knew only one mode of communication. For example, participants shared that the individuals who only knew tactile sign language were limited to interacting with others familiar with tactile signing. This limited sphere of interaction could lead to dependency and limit opportunities for an individual with deafblindness to participate and interact with others.

Each individual [with deafblindness] uses a distinct mode of communication and it is very difficult for everyone [in society] to communicate accordingly and understand the individual’s needs. In such a case, the individual with deafblindness becomes dependent [for communication] on those who understand her or him properly. (Special educator)

Environmental factors.

(1) Services, systems and policies. Among all factors, service providers rated this theme as the most important factor that influences the participation experiences of individuals with deafblindness in Indian society. They talked at length about how services, systems and policies affected all aspects of participation and shared that services from the central government are not adequate to meet the rehabilitation needs of these individuals. They argued that, although deafblindness is included in the new Disability Act (Government of India, 2016), the support and infrastructure required to enable access to information and communication for these individuals are yet not in place. A special educator shared, “The support of assistive devices, aids, and one-on-one interpreters is crucial for access to information and communication [for individuals with deafblindness], and thus their participation.” Another participant added:
For a person with vision and hearing loss, there is no provision of one-on-one individual interpreter support in India. If you [learner with disability] want to study in a mainstream school, you have to have partial hearing and vision. For those with total blindness and profound hearing loss, it is very difficult to function without one-to-one interpreter support. (Special educator)

Service providers in this study unanimously advocated for a policy that ensures provision of one-on-one interpreters and support workers for those with deafblindness, as explained by one rehabilitation worker, “Adults with deafblindness are often limited to their homes because there is no one to help them to go out. If that support is provided, it would improve their participation.”

The occupational therapist who participated in this study reflected on government supports and services:

In a country like India where the technology is not advanced, money is a problem, modifications are not often possible because of limited resources, providing adequate services suiting specific needs of these individuals is the main issue...I think we need to improve our services. (Occupational therapist)

Some participants shared that rehabilitation services are often focussed on meeting just the essential needs of the individual with deafblindness, for example making them independent in self-care or activities for daily living. Hence, enabling participation becomes a secondary goal. Participants strongly advocated for improving awareness about deafblindness to improve acceptance, support and inclusion of persons with deafblindness in society. They emphasized how the Indian government has to play a proactive role in ensuring that laws are implemented in full faith and professionals are aware of these regulations. One rehabilitation worker shared, “The government of India has made laws, but it remains only on paper.” A special educator added, “No one is fully aware about deafblindness and what could be done.” Participants mentioned that in their experience, few individuals with deafblindness receive some disability benefits through the Government’s National Pension Scheme and they believed that a lack of awareness among government officials and general public about deafblindness is the main reason for limited access
to resources and participation for those with deafblindness. Further, a rehabilitation worker highlighted:

Even doctors who work in government [public] hospitals and issue disability certificates [an identification document issued by the government to get access to disability supports in India] are often not aware of the condition and hence do not recognize the need to improve access to disability supports for those with deafblindness. (Rehabilitation worker)

Participants also discussed that media plays a significant role in shaping the understanding of disability and deafblindness among different community stakeholders. Very often, media (TV or newspapers) portray deafblindness in a way that elicits sympathy among members of the public, but does not promote dignity or respect for these individuals. They also shared that media often dramatizes the content of the message to capture readership without realizing the negative influence that it could have on public opinion.

Participants also talked about the new emerging opportunities in India that can help individuals with deafblindness. They highlighted ongoing efforts such as advanced vocational training for adults with deafblindness; a Corporate Social Responsibility policy through the government [an act that requires corporations to share some portion of their net profit in social welfare projects]; and research at engineering and design institutes to develop local technology to benefit individuals with deafblindness (e.g., smart canes for mobility). However, participants urged the government to subsidize the costs of technology devices (such as refreshable braille displays and magnifiers) so that more people can afford them. They said that although the overall situation in India is improving, there is a need for more proactive efforts from the Indian government, society, professionals, and parents to facilitate the participation and inclusion of individuals with deafblindness in society. As one participant remarked:

Although it is impractical to fix their limitations, their situation can be improved with constant support and adequate resources. The government needs to be proactive in providing facilities at every stage for at least next 10 years until everyone is aware
about deafblindness and adequate services are provided for them...such as in schools or those related to transportation, recreation, and jobs. Then only they will be integrated. (Occupational therapist)

(2) Attitudes. Attitude of parents, service providers and society emerged as the second most important factor influencing participation of those with deafblindness. Service providers in this study perceived that parents’ attitudes significantly determine how well the individuals will progress in their life once they become adults.

Sometimes parents take a backseat and start withdrawing... they stop sending their kids to schools because their enthusiasm to work with the child is getting over...they get tired of the caregiving role...For a child [with severe impairment] who is 18 years and still not able to communicate for toileting, it becomes very difficult [for parents] to work with them. (Special educator)

Some participants felt that some parents get discouraged and tired with age whereas some parents, right from the beginning, do not provide enough opportunities to their children for learning and participation. They have a limited mindset about what their child can do and feel uncertain about their future. One special educator shared, “Parents very often ignore their child who has deafblindness and focus on their child without disability as they have an expectation that the non-disabled child will earn and provide care to them when they get old.” Participants believed that such attitudes depend on level of the parent’s education, financial capacity, other family responsibilities, presence of other children without disability, and what parents value in their life. Participants shared that stigma associated with disability forces parents to isolate their child from the world outside home.

Society will not come to these children. If you will hide them in your house and do not let them interact with your guests, in your circle of friends and in your family gatherings, then your child will become isolated and that ends their participation. (Special educator)
Another participant (special educator) said, “If they [individuals with deafblindness] are not going out, they will not be exposed to any information from the outside world.” Others added to the discussion, “if the environment is limited to a room only, their access to information is significantly restricted and that is not good for the one’s understanding of world outside home.”

Another participant (special educator) shared a parent’s perspective to explain why it is so:

People often compare individuals with deafblindness with others of similar age, and ask the same questions repeatedly. Then as a parent, you sometimes feel that rather than answering the same questions again, it is better not to go there…you prefer to go where the child feels included and you are comfortable.

One parent, who also became a special educator, argued “If you keep hiding your child, then it is convenient for society…they do not need to interact with them. Parents have to become thick skinned and learn how to tackle those questions.”

Participants felt that the attitude of professionals also determines how well the individual will function and engage with their environment. One study participant who had a professional background admitted, “It is ethical and professional to always give equal attention to all but in actual reality it is natural tendency that individuals [with deafblindness] who are doing well, get more attention.” Another professional (vocational instructor) added, “We sometimes hesitate to refer our students [adults with deafblindness] for further vocational training [to other centres] because we think that they [staff in other centres] will not accept these individuals as their trainee.”

One participant also reflected that participation challenges become more evident in informal/unstructured environments where neither the professionals nor the parents are responsible or answerable for inclusion of an individual with deafblindness. In a structured setting such as classrooms or workshops, professionals or parents interpret for their students or child with deafblindness. This is how individuals with deafblindness access information about what is
happening, people around them, and then they participate, but the same levels of effort for inclusion are not applied in informal settings.

Study participants believed that the attitude of society towards those with deafblindness plays a significant role and determines whether they are participating in society or are isolated. Participants repeatedly referred to instances when community members had expressed negative or ignorant attitudes: “Very often, people in society think – How they [individuals with deafblindness] will be able to do this task [study or work]? It is impossible for them. They will never learn anything” (special educator). Another participant added:

Community is not ready to accept those with deafblindness because people are apprehensive about what an individual with deafblindness can do or accomplish. For example, they are not sure whether the person can attend a festival or social gathering. (Rehabilitation worker)

Another professional (special educator) shared:

Regardless of how many times I as a professional take these individuals in society for community visits to facilitate their participation with others, not many people are willing to engage with them and come forward to interact with individual with deafblindness.

Participants also shared that the government takes the charity approach where they believe that monetary support or aids are enough for rehabilitation of these individuals. Overall, they emphasized that we, as a society, have not been able to create the kind of inclusive environment that can enable participation for individuals with deafblindness.

(3) Support and Relationships. Service providers perceived parents, teachers, and service organizations as three main sources of support to enhance participation of individuals with deafblindness. They believed that most of this support should focus on promoting self-reliance and developing vocational skills for income generation. One participant (rehabilitation worker) shared: “Some of the adults with deafblindness who are vocationally trained are
participating in the family business.” Another participant (vocational trainer) added how a woman with deafblindness was trained to get involved in a cooking business run by her mother.

The importance of family support was also evident in the case of an adult with deafblindness who was an orphan and lived in a hostel for adults with visual impairment. A participant (vocational instructor) who worked with this adult shared that he faces many challenges on a daily basis, as there is no one to provide one-to-one support and take care of him, particularly when the working hours of professional staff who support him are over. Highlighting the relevance of the Indian family structure and values, another participant remarked:

There is always an extended family… because here the government does not provide a one-on-one interpreter or support services like group homes [in high-income countries], it is the family that provides support to the individual. (Special educator)

Participants stated that parents, siblings, and extended family members try to help the individual; however, very often, the mother is the main caregiver who works with the individual with deafblindness in school and at home and provides support in interpretation, mobility, and daily functioning. Participants further reflected that individuals with deafblindness face difficulties in forming supportive relationships beyond their mother or teacher. Due to communication challenges, very often siblings and extended family members find it difficult to engage with their family member with deafblindness. Because only the mother and teacher can better understand the individual, they are cut off from others. One of the participants, who was the parent of an adult with deafblindness and a trained special educator, emphasized that very often the world of individuals with deafblindness is limited to only those with whom they could interact – parents, teachers, and at most friends at service organizations. She said that to reduce social isolation, family members should make efforts to take the child out of the home to provide them with opportunities to meet others in the community.
When we go for a movie, we should take our child with us. When we go for a walk in the park, we should take our child just like others. If there is a family function, ensure the child is equally participating, and then only we can remove isolation from their lives. (Special educator)

Interestingly, service providers who were also parents of adults with deafblindness shared that though parents always try to support their child, teachers [special educators] provide instrumental support in making these individuals self-reliant. A participant (support worker and mother of an adult with deafblindness) expressed:

Though parents provide support to the child from the beginning, teachers are the biggest support. Children with deafblindness learn and follow what is taught to them by their teachers in school. As parents, we believe teachers provide indispensable support to children.

Participants also acknowledged the support provided by deafblind service institutes for teaching basic skills, providing education, and training for individuals with deafblindness. They emphasized how these non-governmental organizations (NGOs) are making efforts to reach out to individuals, identify them, and provide them with services. These organizations provided seed money to support income generation activities, resulting in many adults with deafblindness earning income, progressing well in life and receiving respect in their communities.

(4) Products and technology. All participants acknowledged the significance of technology support in the lives of individuals with deafblindness. For example,

A person [with deafblindness] can be equally competent and independent if technology is developed in a way that it fills the gap in a person’s life that is created due to dysfunction of their body part. (Special educator)

Service providers in this study reflected that adults with deafblindness use technologies such as mobile phones and magnifiers to access information and remain connected to the world.

One participant shared:
Many of our adults with deafblindness use mobile phone technology to send messages or talk through voice or video call to communicate with teachers and family, which they find very useful. (Rehabilitation worker)

Another participant cited an example: “One of my clients [person with acquired deafblindness] uses a magnifier camera to check the phone number of the call he missed and then dials back to respond to the call.” However, one special educator pointed out:

The individuals whose brain functions are good, only they get the benefit of technology…Not everyone can use it…Those who are developing technology should consider how technology could help those with severe impairments also.

In terms of technology use, it emerged that access to technology for individuals with deafblindness depends on its affordability, availability and benefits.

For our kids [with deafblindness], we talk about Braille display machines and devices… but these machines are not affordable. Refreshable braille display is very expensive in India…parents are not even able to afford computers…how can we expect that they will afford Braille… technology should be affordable and developed considering the needs of those with severe communication difficulties. (Special educator)

Because many technology-based learning materials are not available or affordable in the Indian context, all participants advocated for provision of augmentative and alternative communication (AAC) for individuals with severe communication challenges. They suggested developing educational technologies and materials using local resources to enable learning and engagement of persons with deafblindness.

(5) Natural and built environment. Service providers in this study reflected that both natural and built environments influence the participation of individuals with deafblindness. They shared that it is very difficult for individuals with deafblindness to use hearing aids and magnifying glasses when it is raining because raindrops cause damage to hearing aids, stick to the
glass, and obscure vision. Another participant who is a vocational instructor and a sibling of an adult with deafblindness shared:

Adults with deafblindness face challenges in rain as it becomes difficult for them to see and hear [with their residual functions] because of raindrops and the sound it produces. Once [an individual with deafblindness] was in the BRTS [public transit] bus going home, his bus broke down due to thunderstorm and flooding. All the passengers left for another bus but he became so nervous not knowing what to do and where to go. It was very difficult for him to walk in the continuous pouring rain and floods. (Vocational instructor)

Participants believed that people with deafblindness, in general, have limited access to information from the environment and hence their problem solving and spontaneous decision-making skills in emergencies may be hampered. They highlighted how individuals with deafblindness find it difficult to understand sudden changes in their surroundings and how to respond to it. One participant shared:

Imagine a situation when someone starts banging your door suddenly, we can see and understand that somebody needs something urgently, but a person with deafblindness might be scared and hesitant to respond. (Rehabilitation worker)

Another aspect that some participants reported as significant was the accessibility of built environments. One participant shared an incident when three adults with deafblindness fell in a manhole and it was difficult to rescue them. They shared that very often accessibility tends to be defined narrowly and equated with presence of ramps in public spaces. Consequently, broader accessibility needs of those with deafblindness are often overlooked. Overall, participants agreed on the necessity of building awareness in society about creating accessible environments that take into consideration the needs of individuals with deafblindness.

5.6 Discussion

The purpose of this study was to understand the contextual factors that influence participation of persons with deafblindness from the perspectives of rehabilitation service
providers. Participation is a core concept in rehabilitation and is an important outcome for clients with disabilities (Cardol, Jong, & Ward, 2002; Hammel et al., 2008; Magasi et al., 2009; Mirza, Magasi, & Hammel, 2016; World Health Organization, 2001). This outcome is especially relevant to rehabilitation professionals because very often attaining full participation for clients with disabilities is the standard goal in rehabilitation practice (Hammel et al., 2008; Hemmingsson & Jonsson, 2005; Imms & Granlund, 2014; King, 2013; Meulenkamp et al., 2013; United Nations, 2006; World Health Organization, 2001). This study illuminates the perceptions of 16 service providers who have worked closely with individuals with deafblindness in India. Participants shared their views about factors that influence the participation of individuals with deafblindness in India. Results indicated that all participants perceived a distinct set of personal and environmental factors that act as barriers and supports to participation of those with deafblindness. The rehabilitation service providers strongly argued that we, as an Indian society, have not been able to create the kind of inclusive environment that enables participation for individuals with deafblindness. It was interesting to note that participants shared that the participation challenges become more evident in unstructured environments such as public spaces, as compared to structured environments such as schools or vocational training centres.

This study complements the findings from a parallel study (Chapter 4) where I explored the insider perspectives of sixteen individuals with deafblindness on factors influencing their participation in society (Jaiswal et al., under review). It is interesting to note that individuals with deafblindness and rehabilitation providers both perceived services, systems, and policies followed by attitudes as the top two factors that influence the participation of those with deafblindness. Study participants located most participation barriers primarily in the environment, with only a few inherent to the individual, similar to previous research on participation of persons with disabilities (Hammel et al., 2015; Magasi et al., 2009; Möller & Danermark, 2007; Tsai et al., 2017; Wong et al., 2017). Barriers to participation that emerged were communication challenges
associated with severe impairments, lack of awareness about deafblindness among service providers and the community at large, negative attitudes and stigma associated with disability, and lack of technology and interpreter support.

To my knowledge, only Möller and Danermark (2007) have previously assessed factors affecting participation of students with deafblindness in schools. The authors found that lack of knowledge about deafblindness and considerateness among non-disabled students impede the participation of those with deafblindness (Möller & Danermark, 2007). My study adds to this existing knowledge, and highlights factors that could act as supports for participation of those with deafblindness. Supportive factors include accessibility of the built environment for multisensory impairments, access to resources (affordable technology, provision of interpreters and personal support worker, and vocational training), and training on deafblindness for parents, professionals, and community members (Hersh, 2013b, 2013a; Perfect, Jaiswal, & Davies, 2018; Wittich et al., 2016).

In this study, the ICF was helpful as a relevant guiding framework to classify factors that may influence participation of those with deafblindness from the rehabilitation stakeholders’ perspective. This study is unique in highlighting three personal factors that are not listed in the ICF (World Health Organization, 2001, 2013). In this study, personal factors such as nature and severity of impairment, presence of additional conditions, and knowledge of and ability to use different modes of communication were found to be relevant to participation experiences of those with deafblindness. Given the heterogeneity of the deafblind population, an understanding of these personal factors is essential for individualization and person-centered approaches in rehabilitation service delivery (Geyh et al., 2011), especially in case of those with multi-sensory disabilities such as deafblindness.

This study results have implications for rehabilitation practice, policy and research. I found that rehabilitation service providers believed that individuals with deafblindness who were
able to communicate using multiple modes were more likely to experience greater participation. In addition, technology was identified as a useful tool to enhance daily functioning of individuals with deafblindness. This finding implies that if people with deafblindness are encouraged and trained in using multiple modes of communication, it may improve their participation. For example, training young individuals to use computer technology may improve their capacity to engage with the outside world and thereby enhance their participation. For individuals with severe communication challenges, study participants advocated for the development of technologies (such as augmentative and alternative communication) using local resources to enable learning and engagement of persons with deafblindness. To ensure affordability and availability, the government of India may consider to incentivize assistive technology research and development and provide financial support for assistive aids that could cater to the needs of even those with severe impairments.

It is important to note here that in high-income countries, rehabilitation care for individuals with dual sensory impairments is provided by a team of professionals comprising special educators, sign-language interpreters, optometrists, ophthalmologists, audiologists, otolaryngologists, occupational therapists, social workers, speech and language pathologists, computer accessibility or hearing technology experts (Wittich et al., 2012). However, in a country like India, it is the special educators who, with some support from rehabilitation therapists and other support workers, primarily provide rehabilitation care to individuals with deafblindness at deafblind specific organizations. In light of limited resources (workforce and funds) in LMICs, the model of rehabilitation care for those with deafblindness has yet to develop an interdisciplinary approach with appropriate provision and involvement of interpreters, optometrists, audiologists, social workers, and technology experts. This workforce gap calls for existing rehabilitation training institutes to include courses on deafblindness in their training curricula. Moreover, professionals and paraprofessionals involved in delivering healthcare and
rehabilitation interventions are often not aware and trained on how to deliver services to those with deafblindness and may undermine the unique challenges of this population (Guthrie et al., 2011; Guthrie, Declercq, Finne-Soveri, Fries, & Hirdes, 2016; Wittich et al., 2015, 2017). Therefore, special training on deafblindness should be available and provided to professionals and paraprofessionals who deliver care to them.

This study also found that training of individuals with deafblindness on communication modes is subject to the availability of resources such as affordable technology, trained work force, and motivation of rehabilitation professionals and parents to work with those who have deafblindness. Due to a lack of government support, the burden of care has been on parents, teachers and a few disability organizations that are working for people with deafblindness in India. Therefore, I suggest that the Indian government take an active role in creating special programs under the Disability Act to improve access, availability and affordability of services related to health, education, employment and social participation of people with deafblindness in India (Government of India, 2016). Such programs can provide a dedicated budget and funding resources to improve lives of people with deafblindness through initiatives such as workforce trainings, intervenor or interpreter services, affordable aids and technology, accessible infrastructure, vocational training, group homes, or adapted services for those with severe impairments (European Deafblind Network, 2014; Sense International, 2017; Sense International India, 2014).

Rehabilitation service providers who participated in this study also highlighted the general lack of awareness on deafblindness in India. This could have significant implications for identification and assessment of individuals with deafblindness, and their access to rehabilitation services. Very often people who have deafblindness, their parents, and society members are unaware of the services that exist to benefit them (Paul et al., 2016; Sense International India, 2014). Community awareness drives can be supported by government and non-government
organizations. Such drives can help to reduce negative attitudes and stigma in society associated with this disability and will garner more support for participation of those with deafblindness.

Given that the Government of India has recognized deafblindness recently in the current Disability Act (Government of India, 2016), this is the appropriate time to advocate for the rights for people with deafblindness. The Act attempts to implement the UNCRPD principles for empowerment of person with disabilities including full and effective participation and inclusion in society. It emphasizes the rights of persons with disabilities including deafblindness and suggests steps for accessibility, reasonable accommodation, non-discrimination, and services so that those with disabilities may participate in social life on an equal basis with others (Government of India, 2016). Participants in this study emphasized the role of government to ensure the rights of those with deafblindness are preserved by providing adequate rehabilitation provisions and services. Non-profit organizations working for deafblindness should engage in strong advocacy efforts to ensure the Rights of Persons with Disabilities Act, 2016 is implemented in its full faith and services are provided with a rights-based intent.

5.7 Limitations & future directions

This study has some limitations that warrant consideration. The FGDs were conducted with rehabilitation service providers working at RLCs on deafblindness in India. Therefore, the extent to which these findings can be relevant to providers working in other organizations or settings in India is uncertain. Although I attempted to have a diverse group of service providers in the FGDs, the sample primarily consisted of special educators. Therefore, study findings must be interpreted with caution. Another limitation of the FGDs could be the influence of power dynamics within the organizational staff of RLCs. Although I attempted to give an equal opportunity to everyone to speak, I believe that participants with more years of experience in the deafblind field were more vocal and might have influenced the group discussions. In addition, we (AJ and research assistant) might have missed culture-specific nuances in translation of
participant quotations from Hindi to English during data analysis. This study only presents the views of one group of stakeholders – service providers, while my parallel study (Chapter 3) takes into account the perspectives of those with deafblindness. Keeping these limitations in mind, future research may explore practices and initiatives around the world to improve participation, quality of life, and overall life adjustment and satisfaction of individuals with deafblindness. More specifically, researchers can study the effect of individual services such as interpreter and technology support on enhancing the participation of those with deafblindness in both structured and unstructured environments. Efforts should be made to understand challenges faced by individuals who have severe impairments and identify strategies that can help them achieve a satisfying life.

5.8 Conclusions

To my knowledge, this study is the first to examine perspectives of rehabilitation service providers working with persons with deafblindness in India. Given the international emphasis on improving rehabilitation services and enabling the participation of people with disabilities in developing countries, it is important to consult with those who provide rehabilitation services to people with deafblindness. The aim in this study was to understand service providers’ perspectives on factors that influence participation of persons with deafblindness in India. Access to resources such as assistive technology and positive attitudes and support of others emerged critical for inclusion and full participation of people with deafblindness in India. Lack of knowledge and training on deafblindness among rehabilitation service providers has significant implications for identification and assessment of individuals with deafblindness and their access to rehabilitation services. The Government of India must take an active role and provide resources that cater to the needs of people with deafblindness and promote their inclusion and participation. Future research should study the benefits of interpreters and technology support on enhancing the participation of those with severe impairment.
5.9 References


Wittich, W., Canuto, A., & Overbury, O. (2013). Overcoming barriers to low-vision rehabilitation
Chapter 6

Conclusion

The overall purpose of this doctoral thesis was to build an understanding of participation experiences of persons with deafblindness in India and to identify ways to enhance their participation in society. In particular, the aims were to synthesize the existing literature on the participation experiences of persons with deafblindness in society (Phase 1); to understand what participation means to persons with deafblindness in India (Phase 2); and to describe the contextual factors that influence the participation of persons with deafblindness from the perspectives of those with deafblindness and their service providers (Phase 3). The different phases of the thesis contribute to an emerging understanding of participation of individuals with deafblindness and from these findings, I offer recommendations for enhancing their participation in Indian society. In this final chapter, I summarize key findings, discuss the strengths and limitations of the three phases, and present implications of the findings for future research, policy and practice in the field of sensory rehabilitation.

6.1 Summary of key findings

The first phase (Phase 1) comprised a scoping study titled “Participation experiences of people with deafblindness or dual sensory loss: A scoping review of global deafblind literature” (Jaiswal, Aldersey, Wittich, Mirza, & Finlayson, 2018). The review synthesized existing literature about participation experiences of persons with deafblindness, and, to my knowledge, is the first study, worldwide, to focus on this topic. To identify global deafblind literature, I searched the major eight research databases for peer-reviewed literature. In addition, I included non-peer reviewed (grey) literature in the form of online published reports of research projects by 16 deafblind-specific organizations across the globe (Peters et al., 2015).
As noted in the introduction of this thesis, the deafblind population includes three distinct groups: Group 1 (people with congenital/pre-lingual deafblindness), Group 2 (people with acquired/post-lingual deafblindness) and Group 3 (age-related deafblindness) (Brennan & Bally, 2007; Dammeyer, 2014; Simcock, 2017; Wittich, Watanabe, & Gagné, 2012). Each of these groups vary in severity of impairments and participation experiences. However, to date, the literature is siloed and no overarching analysis has been conducted that provides a comprehensive understanding on the distinct participation experiences of these three groups (Dammeyer, 2015; Wittich, Jarry, Groulx, Southall, & Gagné, 2016). The strength of this scoping review lies in its synthesis of the global evidence (in English) and description of these participation challenges across the three groups.

In this scoping study, I presented key findings across three groups, wherein I first presented the participation experiences that are common to all three groups and then highlighted those experiences that are unique to any specific group. The themes that emerged as relevant to the participation experiences of those with deafblindness addressed various life domains including communication, mobility, daily living functioning, social interactions, and feelings. An important finding of this study was that persons with deafblindness, regardless of the origin of their impairment, experience participation challenges in these life domains. Furthermore, the study revealed that, while experiences may vary between individuals with congenital versus acquired conditions, individuals generally feel socially isolated, insecure and uncertain about their future (Jaiswal et al., 2018).

The growing evidence on participation challenges and social isolation among the three groups calls for attention of those designing policy and programs for two reasons. First, the global population of older adults is likely to double by 2050, and the prevalence of age-related deafblindness (Group 3) is expected to rise in next two decades (Caban, Lee, Gómez-Marín, Lam, & Zheng, 2005; Smith, Bennett, & Wilson, 2008; World Health Organization, 2018). Moreover,
the emerging evidence strongly indicates that individuals from Group 3 experience social isolation and mental health concerns (Guthrie, Declercq, Finne-Soveri, Fries, & Hirdes, 2016; Raina, Wolfson, & Kirkland, 2018; Simcock, 2016; Wittich et al., 2016; World Federation of the Deafblind, 2018). Second, when the individuals from Groups 1 and 2 grow older, their experiences of isolation might be distinct from Group 3 and pose additional mental health risks (LeJeune, 2010; Simcock, 2016).

I expect this scoping study will increase readers’ awareness of the heterogeneity of the deafblind population and their experiences. The study also indicates how healthcare and social service systems have to adapt considering the distinct participation needs and challenges of people with deafblindness, similar to the recommendations of Guthrie and colleagues (2016). This scoping study also underscores some crucial aspects to be considered for future research and practice, specifically greater consistency in terminologies used, more clarity in reporting research methods, and need for qualitative and longitudinal studies on participation-enabling rehabilitation interventions for those with deafblindness (Dammeyer, 2015; Jaiswal et al., 2018; Parfyonov, Mick, Pichora-Fuller, & Wittich, 2016; Simcock, 2016; Wittich et al., 2016; Wittich, Southall, Sikora, Watanabe, & Gagné, 2013).

This study also illuminates the knowledge gap in sensory rehabilitation field that exists related to the participation experiences of persons with deafblindness from low- and middle-income countries (LMICs) such as India. This gap warrants further research in these contexts to inform disability policy, rehabilitation practice and research. In relation to Phases 2 and 3 of this thesis that were conducted in India, this scoping study (Phase 1) informed the key elements of participation experiences that I explored during these subsequent phases. The scoping study results also provided an indication of the domains of life that matter most for participation for people with deafblindness (Jaiswal et al., 2018).
Building on the scoping study, the second study (Phase 2) titled “Meaning and experiences of participation: A phenomenological study with persons with deafblindness in India” aimed to understand the meanings of participation for persons with deafblindness and identify the domains of life that are important to them to participate (Jaiswal, Aldersey, Wittich, Mirza, & Finlayson, 2019). This study strengthened our knowledge of participation of individuals with deafblindness in two ways. First, it helped us understand participation experiences from the perspectives of individuals with deafblindness, who are often less studied in scientific research (Dammeyer, 2014, 2015; Wittich et al., 2016). Second, it allowed us to understand participation in the context of a lower middle-income country such as India, which is often not represented in mainstream research (Jaiswal et al., 2018; Jaiswal, Kumar, & Paul, 2018).

Scholars have argued that there is a lack of commonly agreed conceptualization of participation that accounts for people’s subjective experiences (Dijkers, 2010; Hammel et al., 2008; Martin Ginis, Evans, Mortenson, & Noreau, 2017; Whiteneck & Dijkers, 2009), in particular for those individuals with multi-sensory impairments. This phenomenological study addressed this knowledge gap and revealed the meaning of participation based on the lived experiences of 16 adults with deafblindness in India. To my knowledge, this was the first investigation of its kind and adds a novel contribution to the participation literature by describing participation experiences, meanings, and domains of life important for persons with deafblindness in the Indian context. Moreover, this study was the first in India and the second worldwide (the first study was by Möller & Danermark, 2007) to use the International Classification of Functioning, Disability and Health as a guiding framework to describe participation in people with deafblindness.

The study findings and conclusions provided insights into how services and policies could be (re-)designed to facilitate participation of those with deafblindness in India. The most important finding of the study, which has direct implications for the rehabilitation field, was that
meaning of participation for individuals with deafblindness goes beyond the understanding of participation as involvement in a life situation (World Health Organization, 2001). In this study participants who had lost their independence post onset of impairment valued independence and autonomy as most important, whereas those who had impairments since an early age (0-3) focused more on meaningful involvement in productive and economic activity. Participation for all these individuals was uniquely shaped by their lived experience and the value they placed on certain goals and aspirations (Jaiswal et al., 2019). This finding supports the argument made by scholars that the construct of participation is complicated and encompasses much more than merely being involved in a set of life situations (Hammel et al., 2008; Martin Ginis et al., 2017).

Moreover, the study advances the current participation literature that is limited to physical and single sensory impairments (Chang, Otr, Coster, & Otr, 2014; Eyssen, Steultjens, Dekker, & Terwee, 2011; Hammel et al., 2008; Martin Ginis et al., 2017; Rudman et al., 2016; Salminen & Karhula, 2014; Witteveen, Bogner, & Heinemann, 2011), and provides insight into nuances of the conceptual understanding of participation from the perspective of those with deafblindness. Specifically, the findings highlight that participation is a dynamic, individualized construct that is not just an end outcome. Rather, it is a means to achieve goals important to the participants, such as gaining respect, autonomy, independence, support and relationships, fulfilling aspirations and responsibilities, and feeling included and recognized in society. This study also underscores how these participation meaning units are interrelated and should be considered in relation to each individual’s context while designing services (Jaiswal et al., 2019).

The second important finding was the understanding of life domains that participants with deafblindness deemed important. Participants found communication and access to information, mobility, relationships, education and productivity, and recreation and leisure as important for their participation in life. This result supported and advanced the findings of the scoping study (Phase 1) by identifying life domains that were affected by deafblindness and
mattered most for participation for people with deafblindness (Jaiswal et al., 2018). These findings have direct implications for rehabilitation research, practice, and policy and call for changing the focus of participation-enabling services in alignment to what individuals deem valuable in their lives. This study’s findings may be used to redesign services to improve the quality of participation experiences for those with deafblindness in India.

This study also provided insights about the placement of communication and mobility domains within specific ICF components with respect to persons with deafblindness. The findings of this study refute arguments made by previous researchers about the distinction between activities and participation components, and the placement of communication and mobility domains in the “activities” component (Coster & Khetani, 2008; Whiteneck & Dijkers, 2009). Though these two domains, in combination with access to information, seem to occur at the individual level, they directly affect the participation experiences of those with deafblindness. This notion should be taken into account when developing participation measures or ICF core sets on deafblindness. A systematic review of 103 participation measures also contends that future research should focus on affected participation domains (Eyssen et al., 2011).

While exploring the participation experiences of persons with deafblindness, it was evident that access to services and resources for those with deafblindness were some of the most salient contributors to their positive participation experiences. A striking finding to note in this study was how access to deafblind-specific services and technological aids shaped the participation experiences and enabled participation for even those with severe impairments or congenital deafblindness (Jaiswal et al., 2019). This fact becomes even more important to consider in the context of developing economies such as India where resources are scarce in comparison to the demand (World Bank, 2009). For example, the data revealed how participation challenges were related to access to technological aids that could improve communication, access to information, and social engagement with the world. However, not every participant had access
to technological aids that they required for their participation on a daily basis, even though all the participants in this study had free access to deafblind-specific services and I believe this access to services also contributed to their participation experiences (Jaiswal et al., 2019).

Phase 3 included two parts. The first part comprised a study entitled “Using the ICF to examine contextual factors that influence participation of persons with deafblindness in India”, which identified the contextual factors that persons with deafblindness perceived as influencing their participation in Indian society (Jaiswal, Aldersey, Wittich, Mirza, & Finlayson, under review). This study built on previous work (Möller & Danermark, 2007) that identified personal and environmental factors influencing the participation of students with acquired deafblindness in Swedish schools using the guiding framework of the ICF. This study extends our knowledge and provides insights into the nuanced way these factors interact with each other within the Indian context.

The study findings revealed that participation experiences of those with deafblindness are influenced by a dynamic interaction between the person and their context (personal and environmental factors). It is important to note that understanding of participation experiences cannot be complete without considering the significance of the context where participation takes place (Hammel et al., 2015; Law, 1991; Magasi et al., 2015; Tsai et al., 2017; Wong et al., 2017). This study reiterated the fact that because context has a significant influence on participation, solutions to enhance participation must be designed keeping in mind service and policy environments (Hammel et al., 2015; Martin Ginis et al., 2017; Wong et al., 2017). Within this study, institutional barriers related to services, systems and policies, followed by attitudinal barriers, were the most significant environmental barriers to participation. Another significant contribution of this study was identification of personal factors such as the onset and nature of impairment, and the participant’s willingness to explain deafblindness to others and proactively reach out for help as a coping style. Moreover, I found that participation of individuals with
deafblindness could be enhanced with the help of building awareness about deafblindness in the public, improving access to technology, adapting the environment, and ensuring societal support. This finding is supported by Parfyonov and colleagues (2016) who found that there is a need for social support and community-based interventions to increase participation and reduce social isolation for those with dual sensory loss (Parfyonov et al., 2016).

The second part comprised a study entitled “Rehabilitation service providers’ perspectives on factors that influence participation of persons with deafblindness in India”, which further extends our understanding of contextual factors that influence the participation of those with deafblindness from the perspectives of rehabilitation service providers (professionals and paraprofessionals) (Jaiswal, Aldersey, Wittich, Mirza, & Finlayson, under review). In this study, I explored how participation of persons with deafblindness was perceived by those who worked with them and which contextual factors influenced the participation experiences of people with deafblindness in India. This study complemented our conceptual understanding of participation experiences of persons with deafblindness and suggested ways to enhance their participation in Indian society.

Interestingly, similar to results of the first Phase 3 study, this study found that rehabilitation service providers also perceived institutional barriers related to services, systems and policies followed by attitudinal barriers as the most significant environmental barriers to participation of individuals with deafblindness. Another similar finding was that the service providers perceived participation barriers to be linked primarily to the social, policy and systems environment. Participation barriers perceived were: (a) lack of awareness about deafblindness at the community level; (b) negative attitudes and stigma associated with disability; (c) lack of assistive technology and interpreter support; (d) and communication challenges associated with severe impairments.
Strategies identified by rehabilitation service providers to enhance participation were access to affordable technology, provision of interpreter and personal support workers, creation of vocational training opportunities, training on multiple modes of communication for those with deafblindness and those who work with them, and training on deafblindness for parents, professionals, and community. Similar recommendations were suggested by other researchers in field of deafblindness (Dammeyer, 2015; Hersh, 2013; Simcock, 2017; Wittich et al., 2016; World Federation of the Deafblind, 2018) who also advocated for research infrastructure, international cooperation, and interdisciplinary teamwork in deafblind research and practice.

The overall findings of the thesis fill important knowledge gaps for researchers and practitioners and present practical implications for the rehabilitation field. First, the findings can potentially guide rehabilitation service providers in developing quality participation outcomes and how to achieve them by taking into consideration the meaning of participation, essential life domains, contextual factors, and strategies to enhance participation for those with deafblindness. Moreover, from a theoretical perspective, the findings of the last two studies (Phase 3) provide a common conceptual understanding between professionals and people with deafblindness about the contextual factors that influence participation and ways to enhance participation of those with deafblindness in India.

At a policy level, both these studies (Phase 3) call for the Indian government to support programs and interventions to ensure quality participation of their 500,000 citizens with deafblindness. This call is in alignment with the human rights principles enshrined in the recently enacted Rights of Persons with Disabilities Act, 2016 that legally recognizes deafblindness as a disability for the first time and highlights provisions for enhancing participation (Government of India, 2016). While this is very important, one also needs to understand that participation of persons with deafblindness in society is vital for reducing social isolation and improving their well-being and quality of life (Baum & Law, 1997; Hammel et al., 2008; Martin Ginis et al.,
Persons with deafblindness, their family members, professionals working with them, and deafblind-specific organizations have to come together as advocates to ensure that the Disability Act, which is in alignment with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), is implemented in its full faith, and services are provided with a rights-based intent (United Nations, 2006).

A recent global report by the World Federation of the Deafblind provides evidence of invisibility and risk of exclusion of persons with deafblindness from disability movements and mainstream development around the world (World Federation of the Deafblind, 2018). The report invokes the UNCRPD and Sustainable Development Goals (SDGs) and calls for a universal recognition of deafblindness as a distinct disability and demands support from the government, disability organizations, and the public for participation and inclusion (United Nations General Assembly, 2015; World Federation of the Deafblind, 2018).

In the next section, I discuss the strengths and limitations of the thesis, and present implications of the findings for future research, policy and practice.

### 6.2 Strengths of the doctoral thesis

The first strength of this thesis relates to its methodology. Existing literature on deafblindness calls for the development of proper methodology that could be applicable for diverse populations of those with deafblindness (Hersh, 2013; Wittich et al., 2016). This thesis not only directly informs service-delivery for persons with deafblindness in India, but also offers some methodological guidelines for how to conduct research with persons with deafblindness. In particular, the approaches that I used in this thesis might be instrumental in supporting researchers seeking methods for data collection with this population.

Influenced by the principles of emancipatory disability research (Stone & Priestley, 1996), I used accessible formats and multiple modes to communicate with participants (with
heterogeneous characteristics) to enable their active participation in the study (Jaiswal et al., 2018). By using these innovative and inclusive methods, this thesis aimed to give voice to the under-researched population of those with deafblindness and to shift the conceptual lens through which participation was examined. The lens focused on barriers in the environment rather than problems of impairment (Stone & Priestley, 1996). Study findings might help raise the critical consciousness (Freire, 1970) of the participants, enable their understanding of disabling barriers to their participation, and help them take action to remove the disabling barriers. As suggested by some emancipatory researchers (Stone & Priestley, 1996; Zarb, 1992) to ensure accountability and practical benefit to the people with deafblindness in India and elsewhere, I continue to engage with participants to decide how to translate these study findings into tangible actions to remove disabling barriers. Using the thesis, it will be possible to develop an educational manual on ways to enhance the participation of persons with deafblindness for capacity building of families, professionals and deafblind-specific organizations in India.

The second strength of this thesis lies in its use of the ICF as a guiding framework. Although there is scope for further improvement (Möller, 2003), I found the ICF helpful to map the participation domains and to classify personal and environmental factors that may influence participation of those with deafblindness from the perspectives of persons with deafblindness and their rehabilitation service providers. My thesis might be helpful in developing ICF-based participation measures or ICF core sets for persons with deafblindness. Moreover, a synthesis of the global evidence and a description of common and unique participation challenges across the three deafblind groups in my scoping study might inform the first stage of ICF core sets development for deafblindness, as prescribed by Bickenbach and colleagues (Bickenbach, Cieza, Rauch, & Stucki, 2012).

The third strength of this thesis relates to the inclusion of multiple perspectives across the thesis studies. For example, the topic of participation was explored from perspectives of persons
with deafblindness, and rehabilitation service providers, including professionals (e.g., special educators, occupational therapist, vocational instructors, rehabilitation workers, and support workers) and family members (who are also trained special educators, vocational instructors, and support workers), who provide rehabilitation services to those with deafblindness. The literature synthesis (Phase 1) adds another global perspective on the same topic. As a result of this inclusion of multiple perspectives, I developed a rich and comprehensive understanding of participation and ways to enhance participation for those with deafblindness in India.

The fourth strength of this thesis is that it helps to advance the current conceptual understanding of participation. This thesis adds insights and perspectives of those with deafblindness to the existing literature on participation, which is limited to experiences of individuals with physical and uni-sensory impairments (Chang et al., 2014; Eyssen et al., 2011; Hammel et al., 2008; Martin Ginis et al., 2017; Rudman et al., 2016; Salminen & Karhula, 2014; Whiteneck et al., 2011).

6.3 Limitations

This thesis has some limitations, giving rise to suggestion for improvements for future studies. The first limitation relates to the generalizability of its findings. While in Phase 1, it was not certain that findings from a scoping study apply to persons with deafblindness from LMICs as the included studies were conducted in high-income countries. Similarly, the extent to which conclusions from Phases 2 and 3 can be generalized to 500,000 persons with deafblindness in India is worth considering, as it is unlikely that this thesis has represented the massive cultural, religious, linguistic and other forms of diversity found in India.

The second important limitation (Phase 2 and 3) relates to the participants. Participant recruitment took place with the support of the study partner Sense International India (a national level organization) where participants were either direct beneficiaries of their services (Phase 2 and 3), or program staff working at Regional Learning Centres on Deafblindness of Sense
International India (Phase 3). As a result, the participants included in this thesis might not represent the experiences of all persons with deafblindness in India, in particular those living in rural parts of the country. Even though we know that there are three distinct groups (Group 1, 2, and 3) within the deafblind population, people with age-related deafblindness (Group 3) were missing from my sample owing to the fact that Group 3 is not being identified and served in India by any deafblind-specific organizations. The research gaps are evident in LMICs specific to Group 3, and this calls for future studies documenting their stories. Future studies might also consider including persons with deafblindness (Group 1, 2, and 3), their caregivers, and professionals from other regions and organizations.

A third limitation relates to the data collection and analysis. There were communication challenges related to interviewing participants with deafblindness and I relied on sign language interpreters and accessible modes to communicate. It is worth considering that there might have been instances where I may not have completely captured the true meaning of what the participants were trying to communicate. In addition, culture-specific nuances might have been lost in the translation of the quotes used during data analysis from Hindi to English. Possible suggestions to reduce the loss of meaning could be deciding the timing of translation (early-phase versus late-phase translation), ensuring conceptual equivalence, and employing strategies such as back translation and including a professional translator (someone who is proficient in both the source language and target language and is knowledgeable about the cultural context) in the team from data collection to analysis (Chen & Boore, 2010; Squires, 2009; van Nes, Ahma, Jonsson, & Deeg, 2010).

As this study adopts a cross-sectional descriptive design with a limited time frame (April to June 2017) for data collection, more time allocation for research fieldwork and prolonged engagement with participants might have helped with gaining more rich data. Future studies
might explore how participation meanings might change over a period of time in longitudinal study design.

Another most important consideration is my reflexivity and position as a non-disabled researcher, which might have influenced data collection, analysis and interpretation of findings (Clancy, 2013; Hopkins, Regehr, & Pratt, 2017). I maintained a field journal to document my own insights, wrote analytical memos and used peer-feedback (with supervisors and professional colleagues from Sense International India) from time to time to consciously be aware of my positionality and own assumptions not influencing my data analysis and interpretation of findings (Clancy, 2013; Hopkins et al., 2017; Tufford & Newman, 2012). The involvement of two experts on my thesis advisory committee, Dr. Mansha Mirza, an occupational therapist and an academic with extensive research on participation, and Dr. Walter Wittich, an academic with expertise in deafblindness research, further aided in mitigating this limitation. As rightly mentioned by Moustakas (1994) that epoché is rarely perfectly achieved despite practice, it is the intention, the attitude, the energy, and efforts of reflection and self-dialogue by researcher, that significantly reduce the influence of preconceived thoughts, and helps the researcher to remain open to receive whatever appears in consciousness, as such (p. 90).

6.4 Implications

Based on the thesis findings, some critical implications for rehabilitation research, education, policy and practice are presented below:

6.4.1. It is important for rehabilitation researchers to include the voices of people with communication disabilities and bring attention to their needs through research. Very often, people with communication disabilities, including deafblindness, are excluded from mainstream research because of challenges involved in recruitment and data collection. The absence of their voices defeats the purpose and principles of human rights declarations such as UNCRPD and SDGs that call for equal opportunities and inclusion (United Nations, 2006; United Nations General
Though this thesis has set the stage for participation-focused research in the Indian context for people with deafblindness, future studies using inclusive methodologies are warranted by local researchers and practitioners to address the knowledge gap that exists on this topic between high-income versus LMICs (Jaiswal et al., 2018).

6.4.2. Another important consideration for future researchers could be the need to explore in detail how technology could be useful in enhancing the participation experiences of persons with deafblindness across all three groups. Though my thesis lends support to the positive role of technology for people with congenital/pre-lingual deafblindness (i.e., Group 1) and people with acquired/post-lingual deafblindness (i.e., Group 2), more research is needed to explore the unique challenges involved in training and utilization of technological aids or assistive devices by older adults with age-related deafblindness (i.e., Group 3). In-depth understanding of technology challenges, reasons behind those challenges, and possible solutions might help to increase access to and use of participation-enhancing technology for this diverse population (Perfect, Jaiswal, & Davies, 2018; Wittich et al., 2016).

6.4.3. In this study, I used the ICF as a guiding framework to identify participation domains and contextual factors that influence participation. The development of ICF Core Sets for deafblindness could be a valuable contribution to guide clinical assessment, planning and performing interventions and outcomes evaluation for professionals (Bickenbach et al., 2012). Future research might seek to develop ICF Core sets on deafblindness.

6.4.4. With respect to education of professionals in the rehabilitation field, it is important to consider the unique experiences of deafblind populations and how rehabilitation professionals should be prepared to provide optimal rehabilitation care and participation-enabling interventions to them. Given the number of people with deafblindness is going to rapidly increase in the next two decades worldwide (Brennan & Bally, 2007; Hämäläinen et al., 2018; Swenor, Ramulu,
Willis, Friedman, & Lin, 2013), it is important that the healthcare and social service workforce is prepared adequately to meet their needs. Findings from the study can inform practitioners about ways to enhance participation of those with deafblindness. With respect to India, there are only three training centres providing workforce training through a diploma in special education in deafblindness (Jaiswal et al., 2018; Paul, Mathew, Kumar, Rizal, & Jaiswal, 2016). Though special educators trained in deafblindness play an integral role in the education of individuals with deafblindness, other members of multi-disciplinary rehabilitation teams (e.g., occupational therapists, speech and language pathologists, audiologists, ophthalmologists, optometrists, social workers, computer accessibility or hearing technology experts) require equal exposure, skills and knowledge to contribute to positive rehabilitation outcomes for this population (Wittich et al., 2012). To adequately prepare the workforce, deafblind-specific courses need to be designed and included in the education curricula for all professionals and disciplines working in the field of rehabilitation (Guthrie et al., 2016; Wittich, Barstow, Jarry, & Thomas, 2015; Wittich, Jarry, Barstow, & Thomas, 2017; Wittich et al., 2016, 2012).

6.4.5. My thesis can help rehabilitation service providers to understand that the participation experiences of those with deafblindness are different than those of individuals with mobility impairments or single sensory impairments. As illustrated in a quote attributed to Helen Keller “Blindness cuts us off from things, but deafness cuts us off from people”, the combination of these two impairments isolates a person from other people and the world (Gallaudet University Library, n.d.; Rooth, 2017). While visual impairment negatively affects a person's perception of the world, hearing loss significantly affects their communication and causes social isolation (Rooth, 2017). In other words, I contend that the experience of social isolation for those with deafblindness is compounded due to their dual sensory impairments. Hence, I recommend that practitioners emphasize ways to reduce social isolation and enable participation for this population with distinct needs as highlighted by the recent global report on deafblindness (World
Federation of the Deafblind, 2018). Similarly, participation of those with mobility impairments is very often restricted due to challenges in getting around and transportation, whereas in the case of deafblindness, participation challenges are evident in domains of communication and access to information, in addition to mobility and transportation. This combination of impairments interacts with environmental barriers to create a disabling situation unique to this population. The essence of participation challenges lies in the what and how of the subjective experiences. For example, a person with deafblindness might not only have limited (quantity/frequency) social interactions with others but might also experience reduced quality (content/with whom) of those interactions. Thus, participation challenges cannot be understood in isolation but need to be viewed as the “person in context”. This conceptualization of participation has direct implications for rehabilitation practice that often place emphasis on individuals and their impairments and overlooks the environment while designing interventions. Hence, to achieve quality participation for those with deafblindness, rehabilitation practitioners are encouraged to consider a holistic understanding of the meaning of participation, domains, and contextual factors for those with deafblindness.

6.4.6. A major emphasis in the UNRCPD and the Disability Act of India is on the empowerment of persons with disabilities, including deafblindness, with a main outcome of full and effective participation and inclusion in society (Government of India, 2016; United Nations, 2006). With respect to the policy environment of India, the Disability Act is rights-based and could be instrumental for accessibility, reasonable accommodation, non-discrimination, and support services so that those with disabilities may participate in social life on an equal basis with others (Government of India, 2016). Up until December 2016, at which point deafblindness was officially recognized in the Disability Act of India, the role of the Indian government was minimal in delivering deafblind-specific services in the country. Rather, services were primarily delivered by civil society organizations such as Sense International India and its nation-wide
partners in 23 States of the country. It is difficult for civil society organizations to meet the rehabilitation needs of the estimated 500,000 individuals in India without government intervention and support (Paul et al., 2016; Sense International India, 2014). Hence, as suggested by the study findings, there is a strong need for advocacy by rehabilitation stakeholders to ensure the Disability Act is implemented in full faith and the government of India fulfills its role to ensure the rights of those with deafblindness are met. One of the ways to meet those rights could be through the adequate provision of rehabilitation services. To mitigate participation barriers at the grassroots level, the current national disability policy of India needs to be translated in its full faith to the level of local governance to ensure the rights of persons with deafblindness are met and their participation is enhanced in their own local community.

6.5 Conclusion

This thesis has provided an in-depth exploration of participation experiences for persons with deafblindness and has suggested ways to enhance their participation considering the participation meanings, domains they value, and factors influencing the participation of those with deafblindness in India. The thesis is the first from India and second worldwide to use the ICF as a guiding framework to map the participation domains and identify contextual factors that influence participation from the perspectives of persons with deafblindness and the rehabilitation stakeholders those who work with them.

My findings suggest participation for persons with deafblindness is more than just engagement with others but is a means to achieve respect, autonomy, independence, support and relationships, to fulfil aspirations and responsibilities, and to feel included and recognized in society. My findings suggest that that services and policies for persons with deafblindness need to be designed considering the meanings they associate with participation and life domains that they value - communication, access to information, mobility, relationships, education and productivity, and recreation and leisure. The suggested ways to enhance participation are provision of
deafblind-specific rehabilitation services, alternative communication modes, and technology/aids that improve access to information, communication and social interactions, and thus enhance participation. Simultaneously, it is equally important to address environmental barriers such as lack of awareness about deafblindness, negative societal attitudes, and limited resources to support the participation of those with deafblindness. The Government of India may take an active role to remove participation barriers and provide resources that cater to the needs of people with deafblindness and thus, promote their inclusion and participation.

I anticipate that researchers and practitioners in the rehabilitation field will use the findings of this thesis to better understand, develop, and evaluate participation experiences for persons with deafblindness in India. I hope that through improved knowledge on participation experiences and ways to enhance participation, programs and services will be designed with a primary goal of facilitating participation of those with deafblindness. Ideally, with this study, I anticipate that participation of persons with deafblindness will be enhanced in India and elsewhere, and that persons with deafblindness will enjoy all the rights that are enshrined in the UNCRPD.

6.6 References:


Appendix A

Queen’s HSREB Ethics approval

QUEEN’S UNIVERSITY HEALTH SCIENCES & AFFILIATED TEACHING HOSPITALS
RESEARCH ETHICS BOARD (HSREB)

HSREB Initial Ethics Clearance
February 22, 2017

Mr. Atul Jaiwal
School of Rehabilitation Therapy
Queen’s University

ROMEOTRAQ: #6020111
Department Code: KEH-674-17
Study Title: Participation of Persons with Deafblindness in India
Co-Investigators: Dr. H. Aldersey, Dr. M. Finlayson
Review Type: Delegated
Date Ethics Clearance Issued: February 22, 2017
Ethics Clearance Expiry Date: February 22, 2018

Dear Mr. Jaiwal,

The Queen’s University Health Sciences & Affiliated Teaching Hospitals Research Ethics Board (HSREB) has reviewed the application and granted ethics clearance for the documents listed below. Ethics clearance is granted until the expiration date noted above.

- Demographic Sheet – Phase 2 – Adults with Deafblindness
- Demographic Sheet – Phase 3 – Rehabilitation Professionals
- Interview Guide – Phase 2 – Adults with Deafblindness
- Focus Group Guide – Phase 3 – Adults with Deafblindness
- Focus Group Guide – Phase 3 – Rehabilitation Professionals
- Recruitment Notice and Sign Up Sheet
- Information/Consent Form – Adults with Deafblindness
- Information/Consent Form – Rehabilitation Professionals

Document Acknowledged:

- CORE Certificate – A. Jaiwal
- Sense International India – Letter of Support – January 5, 2017
- Interpreter Confidentiality Agreement

Amendment: No deviations from, or changes to the protocol should be initiated without prior written clearance of an appropriate amendment from the HSREB, except when necessary to eliminate immediate hazard(s) to study participants or when the change(s) involves only administrative or logistical aspects of the trial.

Renewals: Prior to the expiration of your ethics clearance you will be reminded to submit your renewal report.
QUEEN'S UNIVERSITY HEALTH SCIENCES & AFFILIATED TEACHING HOSPITALS
RESEARCH ETHICS BOARD (HSREB)

HSREB Renewal of Ethics Clearance

February 16, 2018

Mr. Anil Jaiswal
School of Rehabilitation Therapy
Queen's University

ROMEO/TRAQ #: 6020111
Department Code: KEH-674-17
Study Title: Participation of Persons with Deafblindness in India
Review Type: Delegated
Date Ethics Clearance Effective: February 22, 2018
Ethics Clearance Expiry Date: February 22, 2019

Dear Mr. Jaiswal,

The Queen's University Health Sciences & Affiliated Teaching Hospitals Research Ethics Board (HSREB) has reviewed the application. This study, including all currently approved documentation has been granted ethical clearance until the expiry date noted above.

Prior to the expiration of your ethics clearance, you will be reminded to submit your renewal report through ROMEO. Any lapses in ethical clearance will be documented below.

Yours sincerely,

[Signature]
Chair, Health Sciences Research Ethics Board

The HSREB operates in compliance with, and is constituted in accordance with, the requirements of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2); the International Conference on Harmonisation Good Clinical Practice Consolidated Guideline (ICH GCP); Part C, Division 5 of the Food and Drug Regulations; Part 4 of the Natural Health Products Regulations; Part 3 of the Medical Devices Regulations, Canadian General Standards Board, and the provisions of the Ontario Personal Health Information Protection Act (PHIPA 2004) and its applicable regulations. The HSREB is qualified through the CTO REB Qualification Program and is registered with the U.S. Department of Health and Human Services (DHHS) Office for Human Research Protection (OHRP). Federawide Assurance Number: FWA#: 00004184, IRB#: 00001173

HSREB members involved in the research project do not participate in the review, discussion, or decision.
Appendix B

Letter of support from Sense International India for research study

January 5, 2017
Atul Jaiswal,
PhD Candidate
School of Rehabilitation Therapy
Queens University, Canada

Dear Atul,

I am writing this letter to approve our support on behalf of Sense International India for your doctoral research study titled “Participation of Persons with Deafblindness in India”. We are pleased to be the research partner in this study and offer you our support and cooperation throughout the study, particularly in participant recruitment, data collection, translation/interpreter support for interviews, and in knowledge dissemination. We have read through your detailed proposal, tools for data collection, letter of information and consent letters, and found it appropriate. We have not found anything which is risky or harmful for the participants involved in the study and hence, provide ethical approval from our end for this study.

Sense India will be facilitating the recruitment of participants (10-12 adults with deafblindness and staff of Regional Learning Centre on Deafblindness – North & West) and help in dissemination of research findings in 2019. We have already assisted you with framing research agenda (using preliminary meeting with adults with deafblindness and their parents/teachers in June 2016), deciding on methodology, and informing the participants about the study on December 04, 2016 to facilitate the participants’ recruitment. Sense India will facilitate access to data (specific resources such as materials in private records, or personal interviews) and provide support for widespread dissemination of the knowledge generated through research. At the end of the research, we would also facilitate development of an educational manual on “Ways to Enhance the Participation of Persons with deafblindness” to build capacities of the families, professionals and organizations working with persons with deafblindness in India. National Conclave of Networks and National Partners meet (for partner deafblind organizations) will be used as a platform to disseminate the knowledge generated among key stakeholders in 2019.

Thank you for choosing to research in the field of deafblindness and collaborating with us. We believe your research will enhance our services and benefit deafblind population in India. We offer you full support in this regard.

Sincerely,

Akhil S Paul,
Director

Sense International India
2nd Floor, Admin Block
Arvind Mandir Campus
Vastral\nAhmedabad 380 015

Deafblind helpline 1800 233 7913

All donations to Sense International India enjoy 100% exemption u/s 35AC and 50% exemption u/s 80G of Income Tax Act, 1961
Appendix C
Manuscript 1 publication

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

Atul Jaiswal*, Heather Aldersey*, Walter Wittich**, Mansha Mirza***, Marcia Finlayson†

1 School of Rehabilitation Therapy, Queen’s University, Kingston, Ontario, Canada, 2 School of Optometry, University of Montreal, Montreal, Quebec, Canada, 3 School of Physical and Occupational Therapy, McGill University, Montreal, Quebec, Canada, 4 Department of Occupational Therapy, University of Illinois at Chicago, Chicago, Illinois, United States of America

* These authors contributed equally to this work.
† These authors also contributed equally to this work.
** 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.

Methods
A comprehensive literature search of eight databases (CINAHL/EBSCO, Embase, ERIC, Global Health, MEDLINE, ProQuest, PsycINFO, PubMed) was performed in accordance with the Preferred Reporting Items for Systematic Reviews (PRISMA) during January 2017 and last updated in June 2017. In addition, non-peer reviewed (grey) literature was also retrieved in the form of online published reports of research projects by 16 deafblind-specific organizations across the globe. To be included, sources had to be published after 1990, had persons with deafblindness as the focal population, and focused on their participation experiences.

Results
A total 1172 sources were identified of which 54 studies were included. The findings reveal that persons with deafblindness, regardless of origin of their impairment, experience...
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

To cite this article: Atul Jaiswal, Heather M. Aldersey, Walter Wittich, Mansha Mirza & Marcia Finlayson (2019); Meaning and experiences of participation: a phenomenological study with persons with deafblindness in India, Disability and Rehabilitation, DOI: 10.1080/09649805.2018.1564943

To link to this article: https://doi.org/10.1080/09649805.2018.1564943

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Archives of Physical Medicine and Rehabilitation

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Article in Press

Using the ICF to examine contextual factors that influence participation of people with deafblindness in India

Ayu Jainaul, PhD Candidate in Rehabilitation Science, Heather Alderson, PhD, Walter Wilton, PhD, FAAO, CLVT, Manisha Vriza, PhD, OTRL, Narda Phanison, PhD, OTRL

Abstract

Highlights

1. This study used the ICF to explore factors affecting participation of individuals with deafblindness. The population is often excluded from research owing to their communication challenges, especially within the context of low- and middle-income countries like India.
2. Participants identified deafblindness-specific barriers, access to products and technology, and attitudinal barriers as the most influential environmental factors affecting participation.
3. Participants also highlighted that positive outreach was a crucial personal factor that can significantly affect the likelihood of gaining support from others to enable participation.
Appendix D

Interpreter confidentiality agreement

Study Title: Participation of Persons with Deafblindness in India

Atul Jaiswal, School of Rehabilitation Therapy
Queen’s University at Kingston
Kingston, Ontario K7L 3N6
Feb 08, 2017

I have read and retained the Letter of Information concerning the research ‘Participation of Persons with Deafblindness in India’ being conducted by Atul Jaiswal. In my role as interpreter for the researcher, I understand the nature of the study and requirements for confidentiality. I have had all of my questions concerning the nature of the study and my role as interpreter answered to my satisfaction.

A. Maintaining Confidentiality
   I agree not to reveal in any way to any person other than the researcher any data gathered for the study by means of my services as interpreter.

B. Acknowledgement of My Services as Interpreter
   I understand that the researcher will acknowledge the use of my services in any reporting on the research. I have indicated below whether I wish that acknowledgement to be anonymous or whether it may recognize me by name.

   ___ I do not wish my name to be associated with the acknowledgement of the use of an interpreter in data gathering for the research.
   OR
   ___ I agree that the researcher may associate my name with the acknowledgement of the use of an interpreter in data gathering for the research.

C. Identification and Signature Indicating Agreement

   Name: __________________________________________
   Email: __________________________________________
   Telephone: _______________________________________
   Mailing Address: ________________________________
   Signature: _______________________________________

Should you require further information please feel free to contact me <Atul Jaiswal> at the School of Rehabilitation Therapy, L.D. Action Building, George Street, Queen’s University, Kingston, Ontario, Canada- K7L 3N6; Telephone number- 343-333-0777; and email- atul.jaiswal@queensu.ca.

For questions, concerns or complaints about the research ethics of this study, contact Dr. Marcia Finlayson, Director of School of Rehabilitation Therapy at 613-533-2576 or Dr. Albert Clark, Chair of the Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board (HSREB) at 1-844-535-2988 or clarkaf@queensu.ca.
Appendix E
Letter of information and consent form for interviews

Study Title: Participation of Persons with Deafblindness in India
Name of Student doctoral researcher: Atul Jaiswal, SRT, Queen’s University
Name of Supervisors: Dr. Heather Aldersey & Dr. Marcia Finlayson, SRT, Queen’s University

Invitation to participate in a research study:
I am Atul Jaiswal, a PhD candidate in the School of Rehabilitation Therapy (SRT), working under the supervision of Dr. Heather Aldersey & Dr. Marcia Finlayson. The overarching aim of the study is to develop a set of indicators of participation for people with deafblindness in India according to insiders’ (adults with deafblindness) and outsiders’ (rehabilitation professionals) perspectives. The objectives of this study are to explore and understand how persons with deafblindness define and experience “participation”; and describe the contextual (personal and environmental) factors influencing their participation in society. I will engage persons (adults) with deafblindness to develop an understanding of the meaning and indicators of participation that could inform the services to enhance their participation in society.

If you agree to take part, I will interview you two times for 60-90 minutes at a public location of your choosing. I will ask you to share what participation means to you, your experiences of participation in the society, and the factors affecting your participation in Indian society. The interview will be audio-recorded and later transcribed. I might approach you later over Skype if there is need for further clarifications of your comments. I also need your consent to allow me to access your service records. There are no known risks for taking part in this study. While there are no direct benefits to you as a participant, the findings of the study may improve the understanding of the meaning and indicators of participation that could inform the services to enhance the participation of persons with deafblindness in society.

There is no obligation for you to say yes to take part in this study. Your participation is entirely voluntary and you don’t have to answer any questions you don’t want to. You can stop participating at any time without penalty. Your decision to withdraw will not affect the services that you receive from Sense International India or Regional Learning Centre on Deafblindness. You may withdraw from the study up until Feb 28, 2017 by contacting me at atul.jaiswal@queensu.ca.

I will keep your data securely for at least five years. Your confidentiality will be protected to the extent possible by replacing your name with a pseudonym for all data and in all publications. The code list linking real names with pseudonyms will be stored separately and securely from the data. Other than me and my supervisors, only an interpreter/transcriber who has signed a Confidentiality Agreement will have access to any of the data.
I hope to publish the results of this study in my doctoral thesis and academic journals and present them at conferences. I will include quotes from some of the interviews when presenting my findings. However, I will never include any real names with quotes, and I will do my best to make sure quotes do not include information that could indirectly identify you. During the interview, please let me know if you say anything that you do not want me to quote.

For taking part in this research, you will receive $20 for two interview sessions.

If you have any ethics concerns please contact Dr. Albert Clark, Chair of the Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board (HSREB) at 1-844-535-2988 (Toll free in North America) or email at clarkaf@queensu.ca.

If you have any questions about the research, please contact me, Atul Jaiswal at (+343-333-0777) or (atul.jaiswal@queensu.ca) or my supervisors, Dr. Heather Aldersey at (hma@queensu.ca) or 613-533-6088 or Dr. Marcia Finlayson at marcia.finlayson@queensu.ca or 613-533-2576.

This Letter of Information provides you with the details to help you make an informed choice. All your questions should be answered to your satisfaction before you decide whether or not to participate in this research study.

Keep one copy of the Letter of Information for your records and return one copy to the researcher, Atul Jaiswal.

By signing below, I am verifying that: I have read the Letter of Information and all of my questions have been answered.

Name of Participant: ___________________________________

Signature: ____________________________________________

Date: ________________________________
Appendix F
Letter of information and consent form
for focus group discussion

Study Title: Participation of Persons with Deafblindness in India

Name of Student doctoral researcher: Atul Jaiswal, SRT, Queen’s University

Name of Supervisors: Dr. Heather Aldersey & Dr. Marcia Finlayson, SRT, Queen’s University

Invitation to participate in a research study:

I am Atul Jaiswal, a PhD candidate in the School of Rehabilitation Therapy (SRT), working under the supervision of Dr. Heather Aldersey & Dr. Marcia Finlayson. The overarching aim of the study is to develop a set of indicators of participation for people with deafblindness in India according to insiders’ (adults with deafblindness) and outsiders’ (rehabilitation professionals) perspectives. One of the objectives of this study is to understand the barriers and facilitators identified by rehabilitation professionals that they face when working to enhance the participation of persons with deafblindness in Indian society.

If you agree to take part, I will request you to participate in a focus group discussion for 60-90 minutes at the conference room of Regional Learning Centre on Deafblindness. I will ask you to share what participation means to you and your perceptions of barriers and facilitators to the participation of persons with deafblindness in Indian society. The discussion will be audio-recorded and later transcribed. I might approach you later over Skype if there is need for further clarifications of your comments. There are no known risks for taking part in this study. While there are no direct benefits to you as a participant, the findings of the study may improve the understanding of the meaning and indicators of participation that could inform the services to enhance the participation of persons with deafblindness in society.

There is no obligation for you to say yes to take part in this study. Your participation is entirely voluntary and you don’t have to answer any questions you don’t want to. You can stop participating at any time without penalty. Your decision to withdraw will not affect your job that you hold in the Regional Learning Centre on Deafblindness. You may withdraw from the study up until Feb 28, 2017 by contacting me at atul.jaiswal@queensu.ca.

I will keep your data securely for at least five years. Your confidentiality will be protected to the extent possible by replacing your name with a pseudonym for all data and in all publications. The code list linking real names with pseudonyms will be stored separately and securely from the data. Data from the study will be viewed only by me and my supervisors.
I hope to publish the results of this study in my doctoral thesis and academic journals and present them at conferences. I will include some of the quotes from the discussion when presenting my findings. However, I will never include any real names with quotes, and I will do my best to make sure quotes do not include information that could indirectly identify you. During the discussion, please let me know if you say anything that you do not want me to quote.

You will receive some snacks/refreshments for participating in this study.

If you have any ethics concerns please contact Dr. Albert Clark, Chair of the Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board (HSREB) at 1-844-535-2988 (Toll free in North America) or email at clarkaf@queensu.ca.

If you have any questions about the research, please contact me, Atul Jaiswal at (+343-333-0777) or (atul.jaiswal@queensu.ca) or my supervisors, Dr. Heather Aldersey at (hma@queensu.ca) or 613-533-6088 or Dr. Marcia Finlayson at marcia.finlayson@queensu.ca or 613-533-2576.

This Letter of Information provides you with the details to help you make an informed choice. All your questions should be answered to your satisfaction before you decide whether or not to participate in this research study.

Keep one copy of the Letter of Information for your records and return one copy to the researcher, Atul Jaiswal.
By signing below, I am verifying that: I have read the Letter of Information and all of my questions have been answered.

Name of Participant: ________________________________

Signature: __________________________________________

Date: ________________________________________________
Appendix G
Demographic information sheet for persons with deafblindness

Your data will be used for research purposes only. The information will allow us to provide an accurate description of the sample. Data will be pseudonymous and handled confidentially. No third party will have access to data.

For the following items, please select the one response that is most descriptive of you or fill in the blank as appropriate.

Pseudo Name ____________________________

A. General information
1. Year were you born in? 19__ __; Place of birth: Village □ Town/city □
2. Sex: Female □ Male □ Other □
3. Place of current residence: Village (rural) □ Town/city (urban) □
4. Age of onset of disability: _________
5. Communication mode: Speech □ Sign language □ Tactile sign language □ Others ___________
6. Living condition: Staying alone □ With family □
7. Religion: Hindu □ Muslim □ Christian □ Sikh □ Others ___________
8. Socio-economic status: Below Poverty line □ Above Poverty line □
9. Highest education that you have received: Never been to school □ Special School □ Primary □ High School □ College/University □
10. Current marital status: Single □ Married □ Widowed □ Separated/divorced □
11. Current employment status: Not working □ Volunteer □ Sheltered Workshop □ Working part time □ Working full time □
Appendix H
Demographic information sheet for rehabilitation service providers

Your data will be used for research purposes only. The information will allow us to provide an accurate description of the sample. Data will be pseudonymous and handled confidentially. No third party will have access to data.

For the following items, please select the one response that is most descriptive of you or fill in the blank as appropriate.

Pseudo Name ______________________________________________________________

General information

1. Year were you born in? 19__

2. Sex: Female ☐ Male ☐ Other ☐

3. Job title: ________________________________________________________________

4. Professional education: __________________________________________________

5. Years of work experience with deafblind population: _________________________

6. Knowledge of different deafblind communication mode:
   Speech ☐ Sign language ☐ Tactile sign language ☐ Others _______________________
