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# **How to enhance societal participation of individuals with deafblindness or dual sensory impairment**

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# Acknowledgements



- **Thesis Defense Committee Members**
- **Thesis Advisory Committee:**
  - Dr. Heather Aldersey & Dr. Marcia Finlayson (Supervisors)
  - Dr. Mansha Mirza, University of Illinois at Chicago
  - Dr. Walter Wittich, University of Montreal
- **Thesis Comprehensive Exam Committee:**
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## Funding support



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## Research partners



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

***Imagine  
what it is like  
to be a  
person with  
deafblindness***



# Groups within deafblind population

## Congenital

## Acquired

**Group 1**  
(*pre-lingual*)

**Group 2**  
(*post-lingual*)

**Group 3**  
(*age-related deafblindness*)



(Dammeyer, 2014; Wittich et al., 2012)

# Groups within deafblind population

## Congenital

## Acquired

**Group 1**  
(*pre-lingual*)

**Group 2**  
(*post-lingual*)

**Group 3**  
(*age-related deafblindness*)



**Low Income Countries**

**High Income Countries**

(Dammeyer, 2014; Sense International India, 2014; Wittich et al., 2012)



**Helen Keller**

Year 1904



Year 2016



**Haben Girma**



## At risk of exclusion from CRPD and SDGs implementation:

Inequality and Persons with Deafblindness

Considered to be as a low incidence population  
(**0.04% of total population**).

However, current estimates (2018) suggest that around **2% of the world population** has this impairment.

- Approx. **150 million in the world**



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

## Knowledge Gap

- Evidence - persons with physical or single sensory impairments and limited to high-income countries.



- Yet, little is known about their lived experience of participation, influencing factors, and ways to enhance it in the Indian context to inform service delivery.

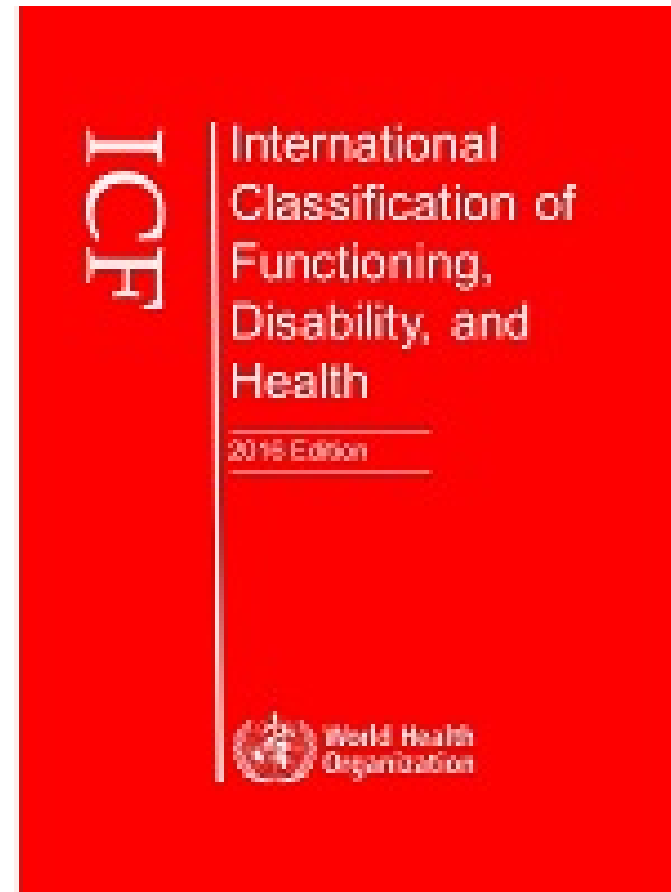
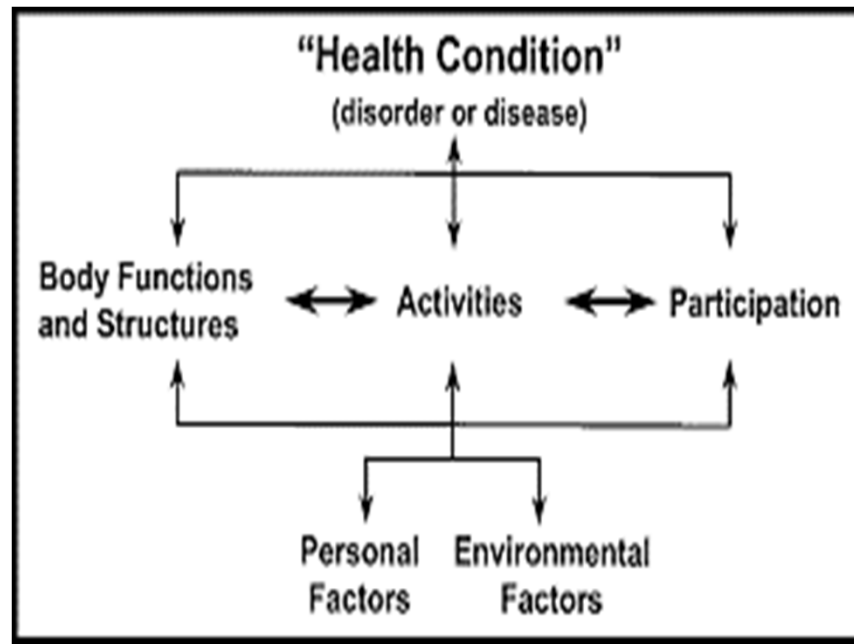
**Overarching purpose**

**Participation experiences  
and  
Ways to enhance their participation  
of  
persons with deafblindness  
in India**



## Guiding Framework

- International Classification of Functioning, Disability and Health (ICF) framework by the World Health Organization.



(WHO, 2001)

## Research Phases

PHASE	PURPOSE	METHOD
<b>PHASE 1</b>	To synthesize the existing literature reports on the participation experiences of persons with deafblindness in society ( <b>STUDY 1</b> )	Scoping review of literature (peer-reviewed and grey)
<b>PHASE 2</b>	To understand what participation means to persons with deafblindness in India ( <b>STUDY 2</b> )	Interview with PwDb
	To explore the contextual factors that influence the participation of persons with deafblindness in Indian society from the perspectives of persons with deafblindness ( <b>STUDY 3</b> )	
<b>PHASE 3</b>	To explore the contextual factors that influence the participation of persons with deafblindness in Indian society from the perspectives of rehabilitation service providers ( <b>STUDY 4</b> )	Focus group discussions with rehabilitation service providers



# Study 1- Scoping Study

## Research Question

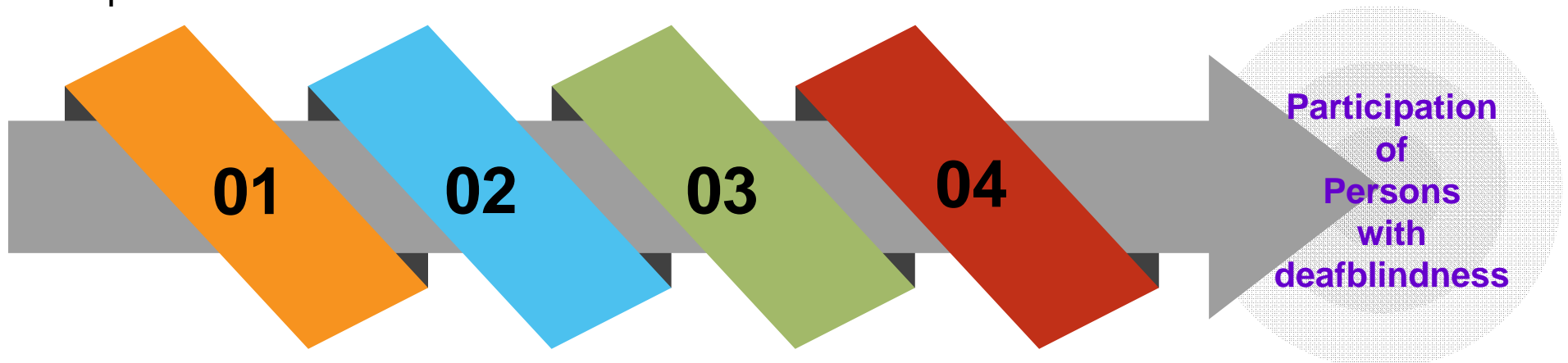
**What does the existing literature report about the participation experiences of persons with deafblindness or dual sensory loss?**



# Methods

## STUDY 1

Evidence synthesis  
on participation  
experiences of PwDb



**Framework:** Scoping review by Arksey & O'Malley, 2005

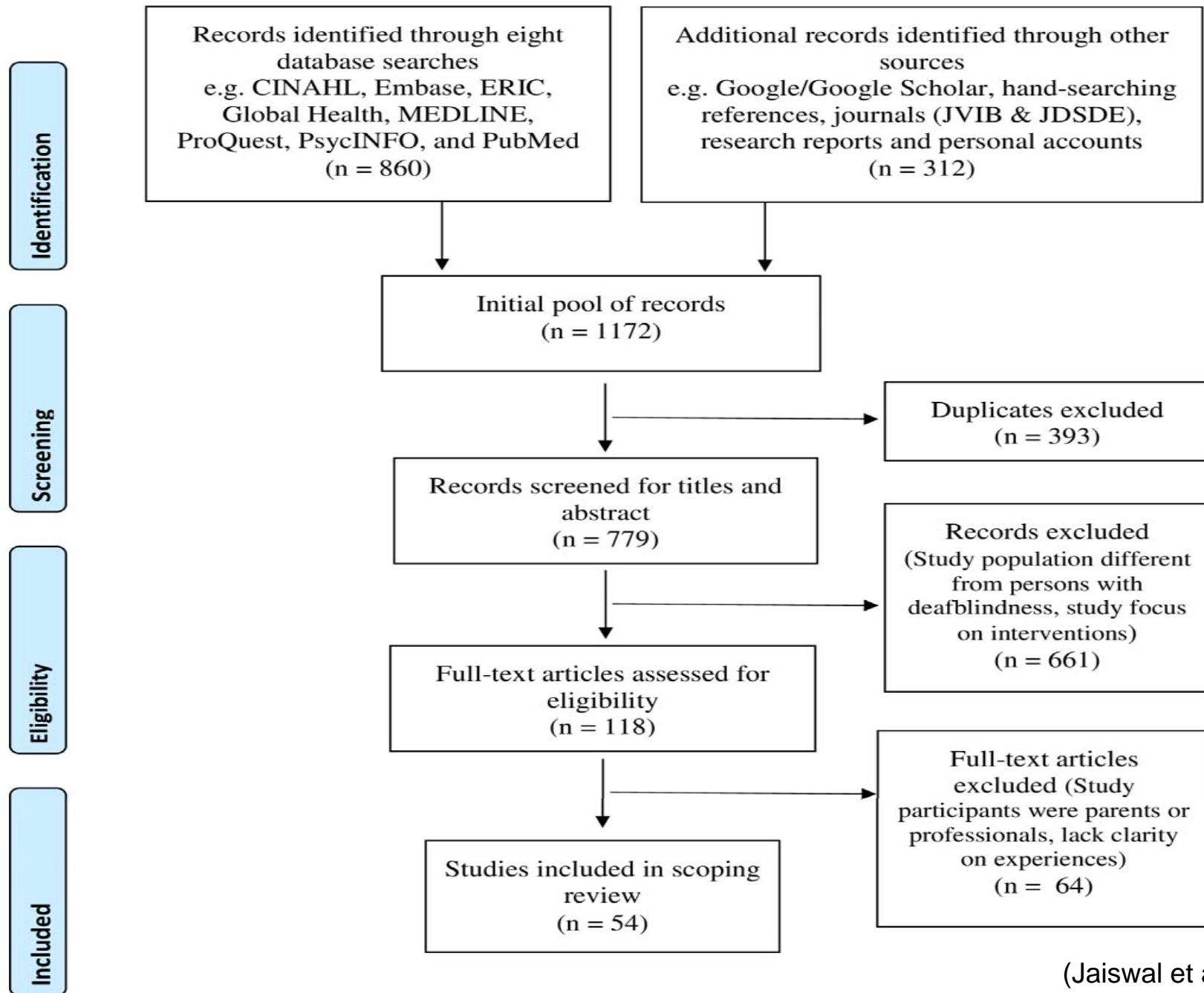
### Data Sources:

1. Peer-reviewed literature from 8 scientific databases
2. Gray literature from research reports of 16 deafblind-specific organizations around the globe

## Sources and search terms

Research databases searched	Search terms
<ul style="list-style-type: none"> <li>• Cumulative Index to Nursing and Allied Health Literature (CINAHL)</li> <li>• Education Resources Information Centre (ERIC)</li> <li>• Embase</li> <li>• Global Health</li> <li>• MEDLINE</li> <li>• ProQuest</li> <li>• PsycINFO</li> <li>• PubMed</li> </ul>	<ul style="list-style-type: none"> <li>• (deafblind* OR deaf-blind* OR (“deaf and blind”) OR "dual sensory loss" OR "dual sensory impairment" OR("combined hearing and visual impairment") OR ("combined hearing and visual loss"))</li> <li>AND</li> <li>(experience* OR engage* OR participat* OR involve*)</li> <li>AND</li> <li>(society OR community)</li> </ul>
<p>Other sources including</p> <ul style="list-style-type: none"> <li>• Google and Google Scholar</li> <li>• Journal of Deaf Studies &amp; Deaf Education</li> <li>• Journal of Visual Impairment &amp; Blindness</li> <li>• Online content of development organizations</li> </ul>	<ul style="list-style-type: none"> <li>• deafblind AND experiences</li> <li>• deafblind AND experiences</li> <li>• deafblind AND experiences</li> <li>• deafblind AND experiences</li> </ul>

# PRISMA flow chart



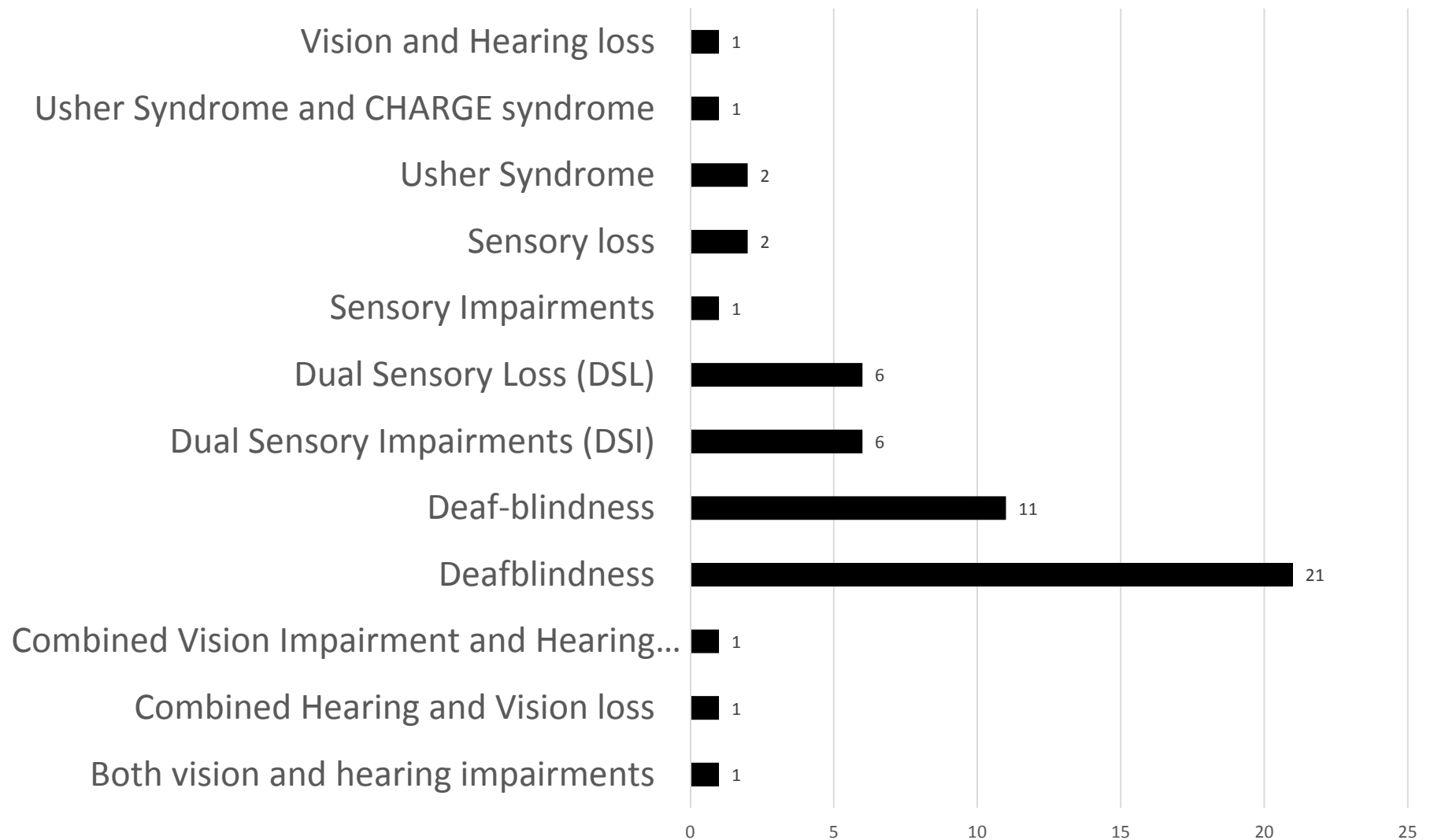
(Jaiswal et al, 2018)

# Results

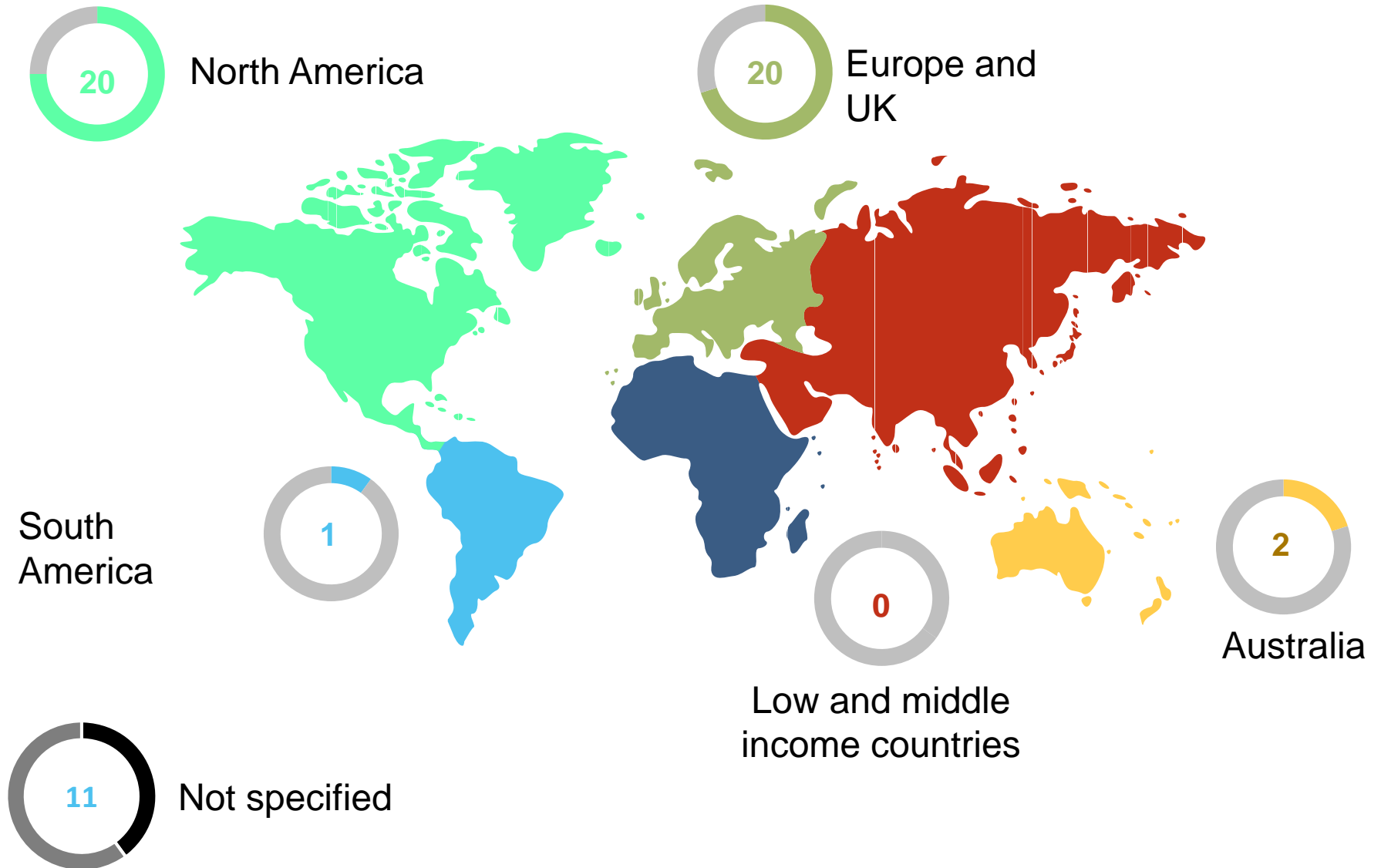


# 11 different terminologies used

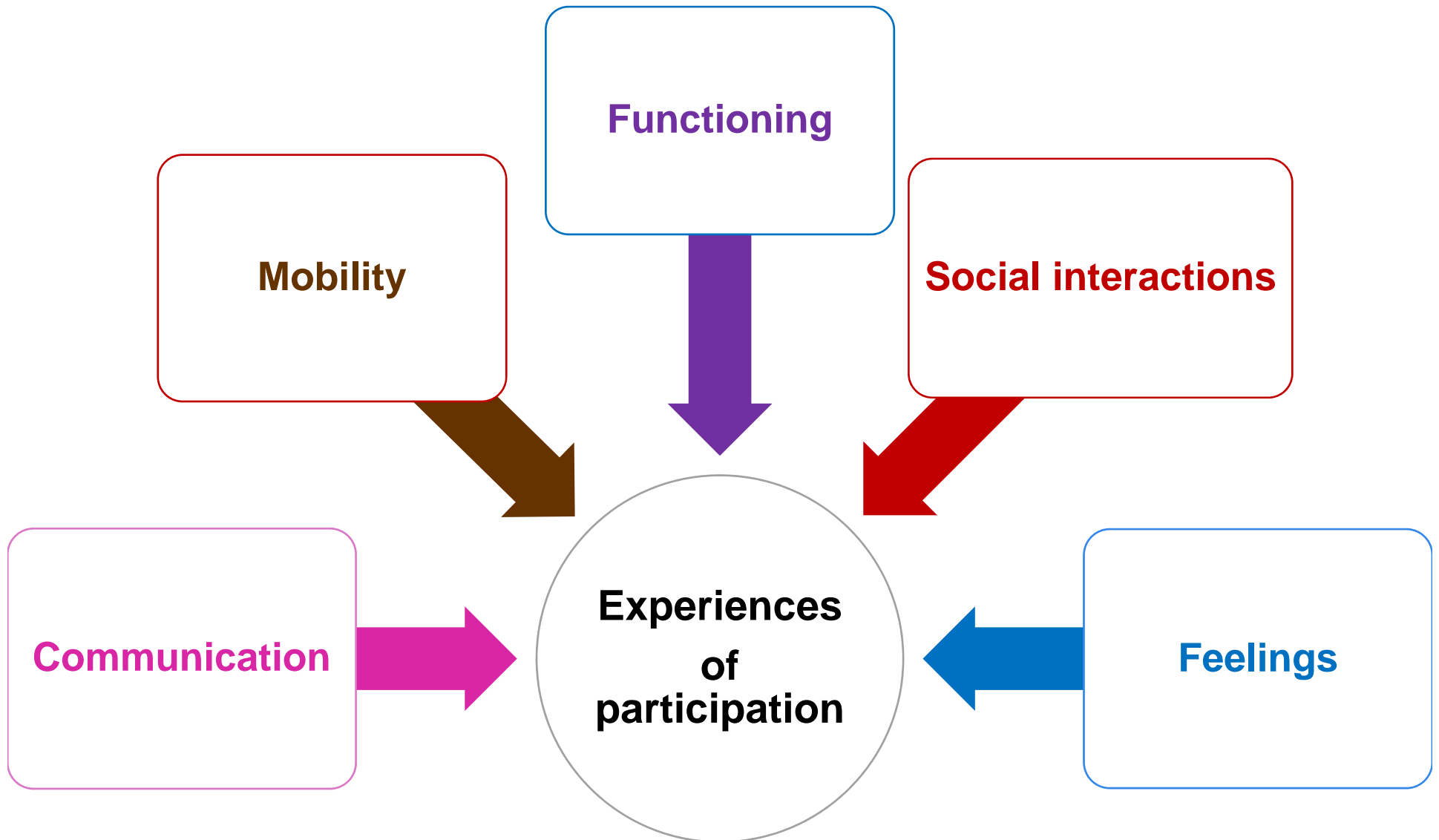
Terminologies Used



# Characteristics of records (n=54)



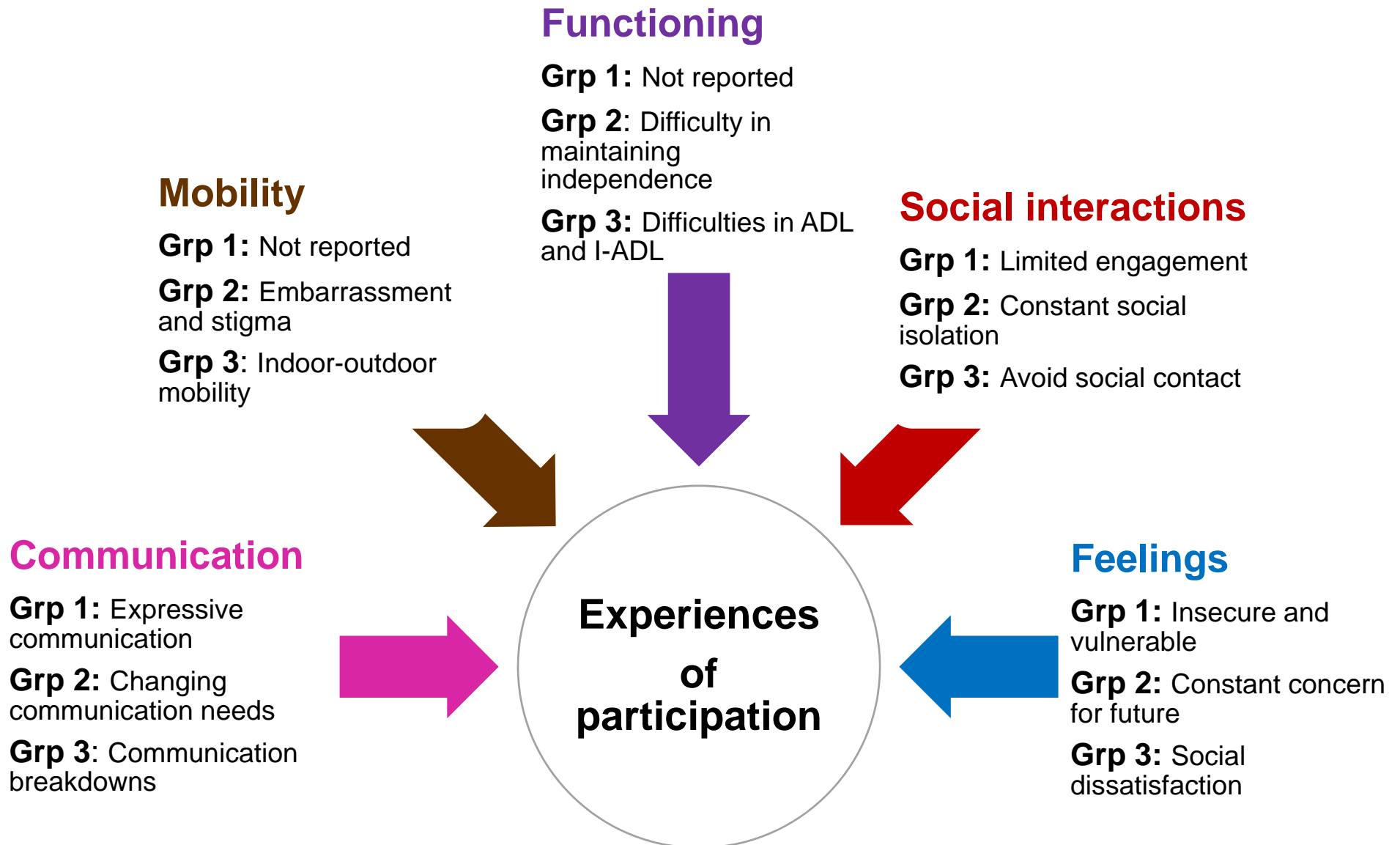
# Themes representing participation experiences



(Jaiswal et al, 2018)

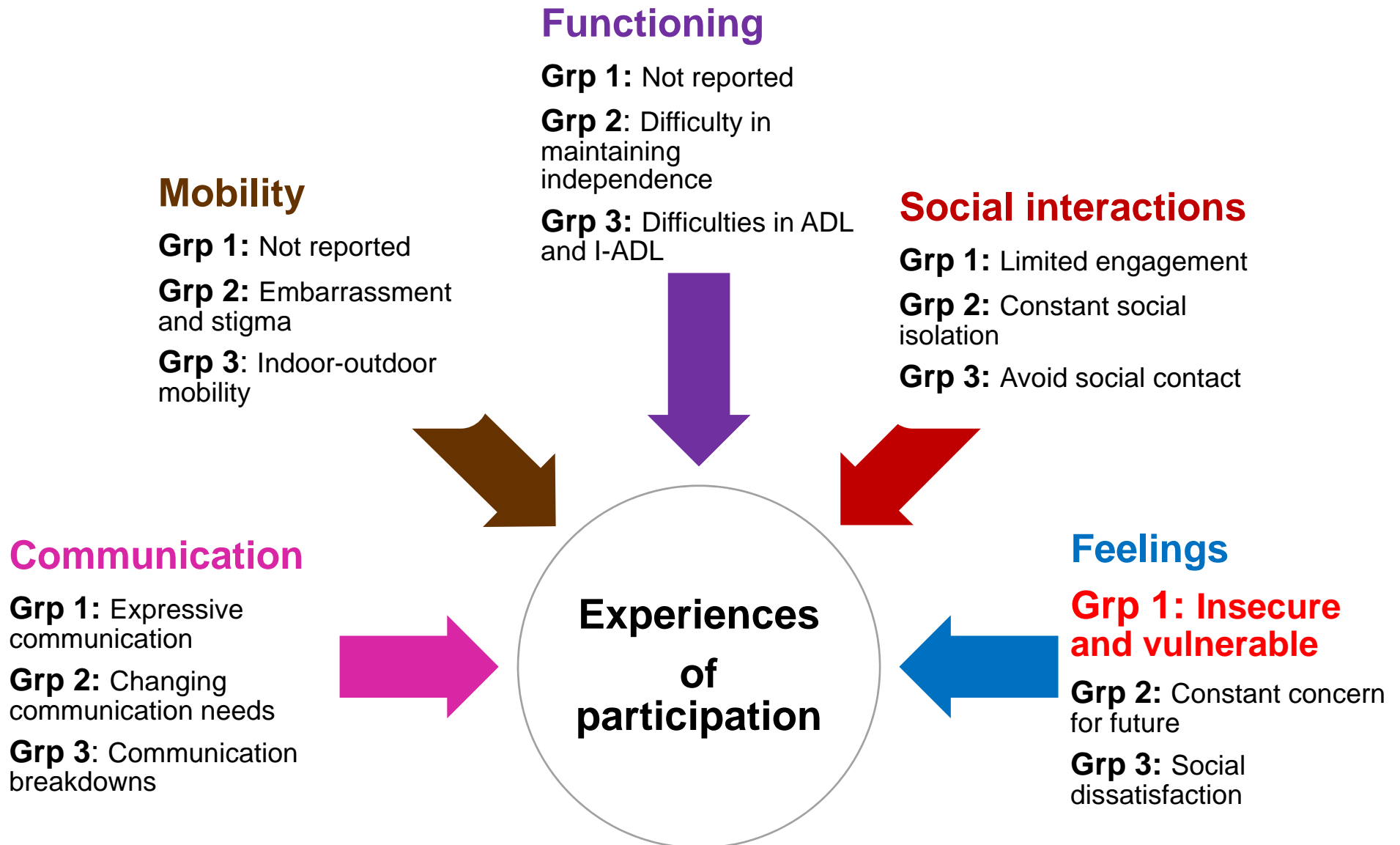
# Participation experiences across three groups:

Grp 1 (Congenital); Grp 2 (Acquired); & Grp 3 (age-related deafblindness)



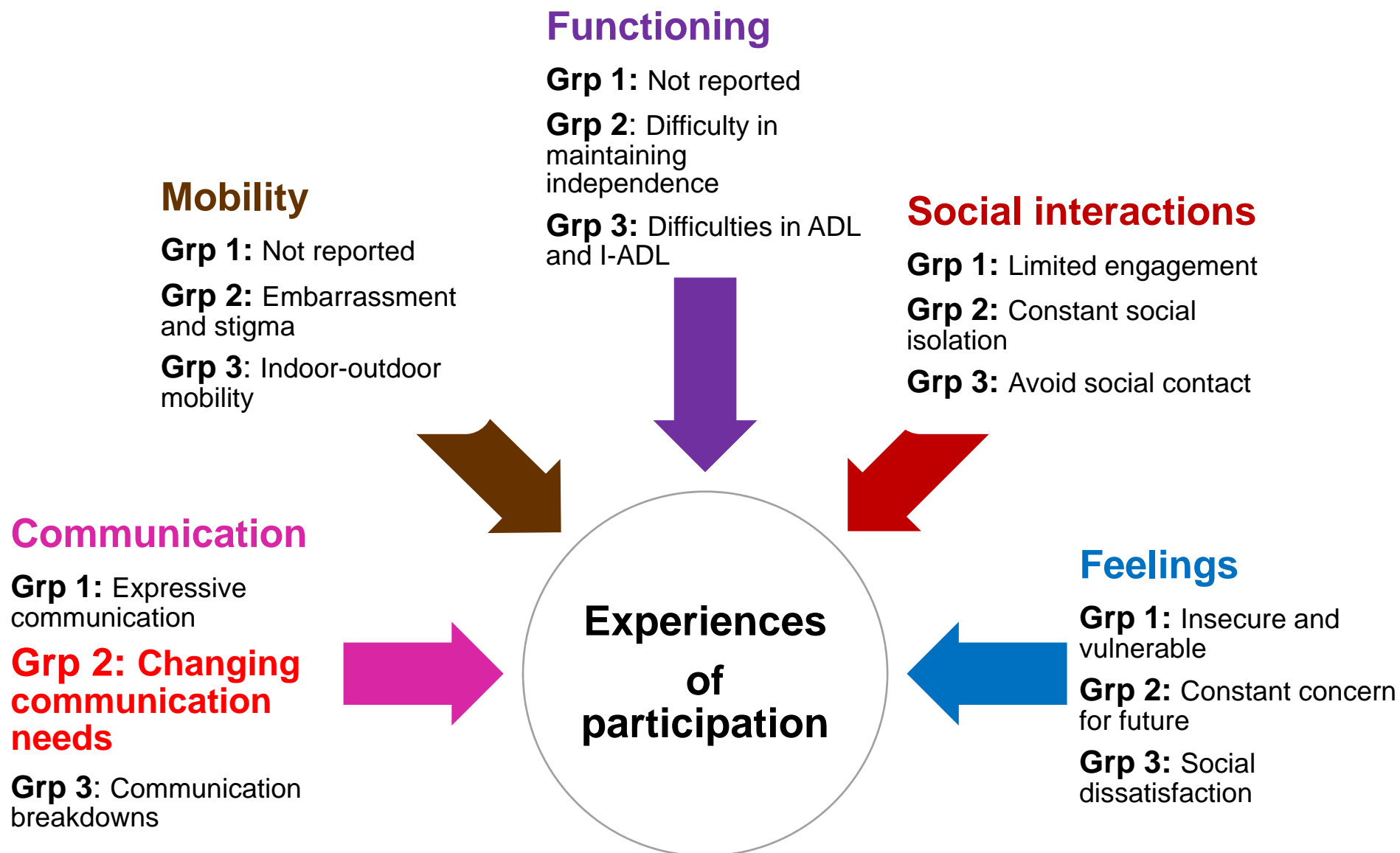
# Participation experiences across three groups:

Grp 1 (Congenital); Grp 2 (Acquired); & Grp 3 (age-related deafblindness)



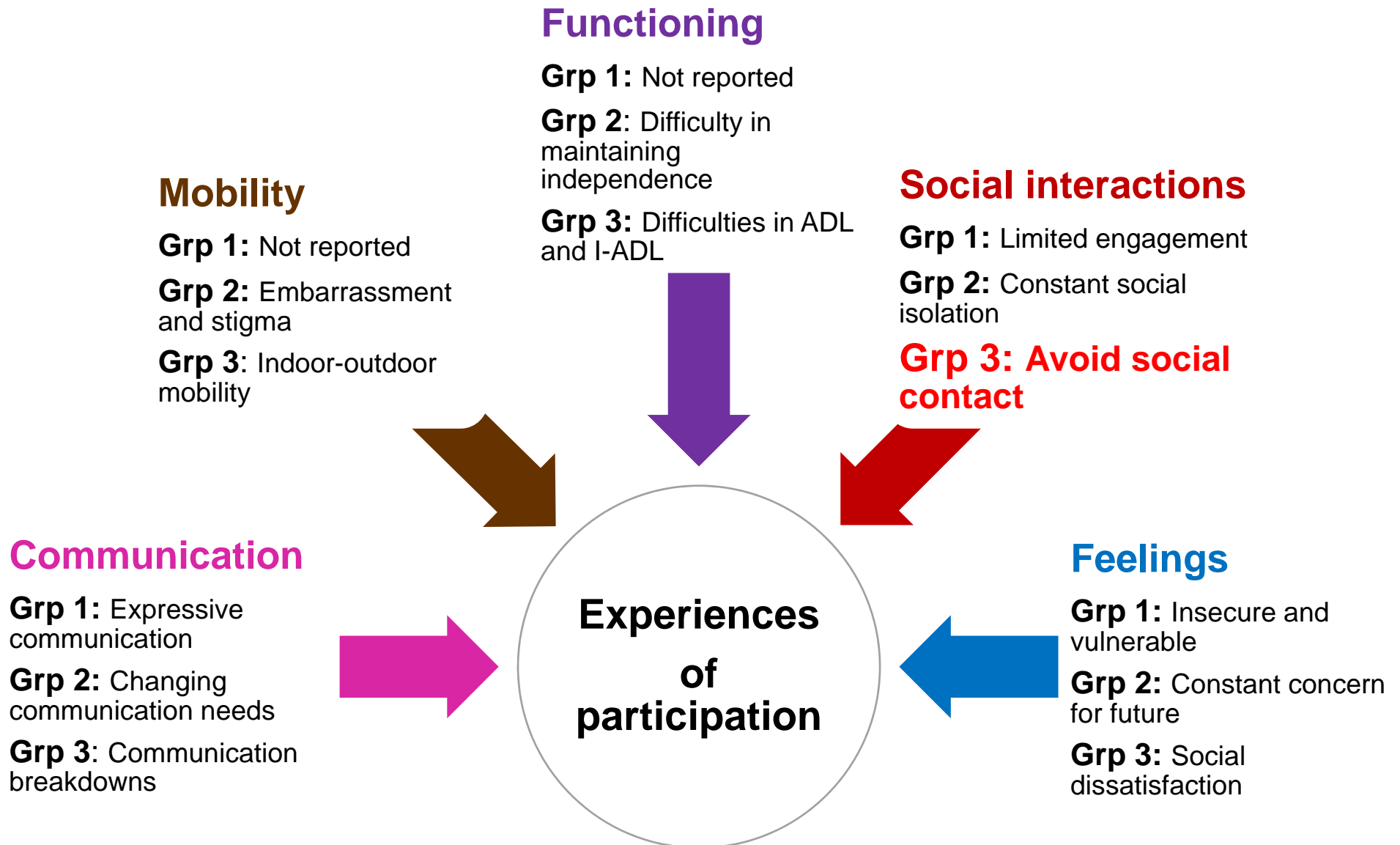
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# Participation experiences across three groups:

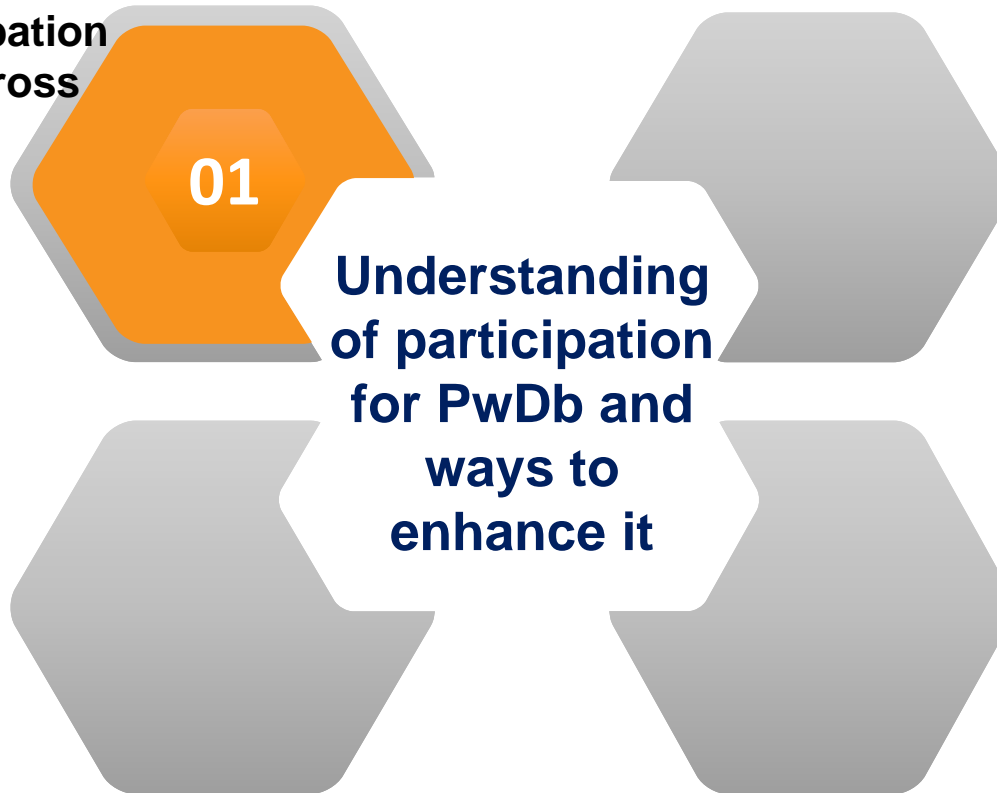
Grp 1 (Congenital); Grp 2 (Acquired); & Grp 3 (age-related deafblindness)



# Salient outcome of the study 1

## STUDY 1

- Distinct participation experiences across three groups
- Highlighted the evidence gap



RESEARCH ARTICLE

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

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 OPEN ACCESS

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## 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.

# Study 2

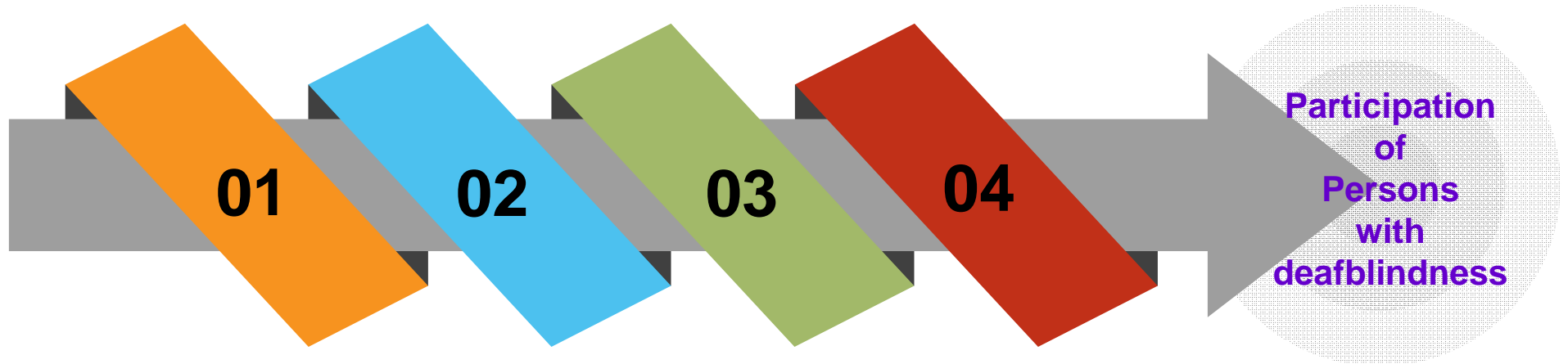
## Research Question

**What does “participation” mean to persons with deafblindness in India?**

# Methods

## STUDY 2

Meaning of participation for  
PwDb in India



**Sampling** – Purposive (Sandelowski, 1995)

**Data Collection** - Semi-structured qualitative interviews with 16 PwDb using diverse communication modes.

### **Data Analysis**

– Audio-recorded, transcribed, and managed using NVivo Pro 11 software.

## Modes of communication used during interviews (N =16)

Mode	Participants' number and type of disability
Speech, large prints, braille	P14 (Acquired)
Speech, lip reading, writing on paper	P2 (Acquired)
Speech, lip reading, large print, sign language	P1 (Acquired)
Speech, large print, magnifier, signing (using interpreter)	P12 (Acquired)
Speech, large prints, magnifier, finger spelling, signing (using interpreter)	P10 (Acquired)
Speech, braille, voice amplification (specific pitch by interpreter)	P4 (Acquired)
Speech, braille, print-on-palm, voice amplification (specific pitch by interpreter)	P11 (Congenital)
Signing (using interpreter), gestures	P9 (Acquired)
Signing (using interpreter), gestures, print-on-palm	P5 (Acquired)
Signing (using interpreter), gestures, print-on-palm, large prints	P3 (Acquired)
Tactile signing (using interpreter), gestures, braille, print-on-palm	P8 (Acquired)
Tactile signing (using interpreter), braille, technology (Refreshable braille display)	P6 (Congenital)
Technological aids (JAWS and magnifier in computer), internet (Facebook)	P13 (Acquired)
Technological aids (JAWS and magnifier in computer), internet (Skype)	P15 (Acquired)
Technological aids (Refreshable braille display), internet (Skype), tactile sign	P16 (Congenital)
Technological aids (Refreshable braille display), internet (Facebook), print-on-palm	P7 (Acquired)

Note – The modes are placed according to their usage during interview (for example, first in the list is the main mode used followed by others to support communication). (Jaiswal et al, 2019)



- 
- 2 States
  - 23 Individuals
  - 2 Partner NGOs

*18 years later...*

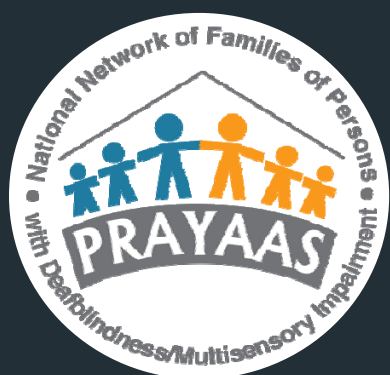
- 23 States
- 71,500 individuals
- 57 Partner NGOs



- **Technical expert organization in South-east Asia** on deafblind service development.
- **first and only national level organization** to support the development of comprehensive services for PwDb throughout India.
- **Accredited by the United Nations.**
- **Inclusion of deafblindness** in the 'Rights of persons with Disability Act 2016' - recent successes of SII advocacy.

**Sense International India (SII)** is  
strengthening the voice of persons with  
deafblindness through

## **3 National Networks**



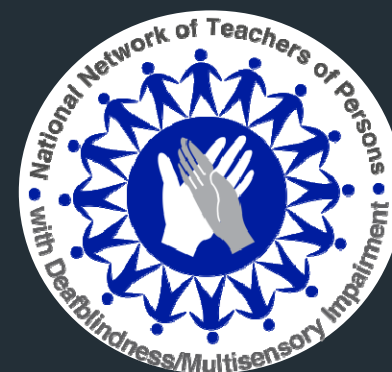
### **PRAYAAS**

National network  
of families of  
PwDb



### **UDAAN**

National  
network of adults  
with  
deafblindness



### **ABHI-PRERNA**

National  
network of  
teachers of  
PwDb

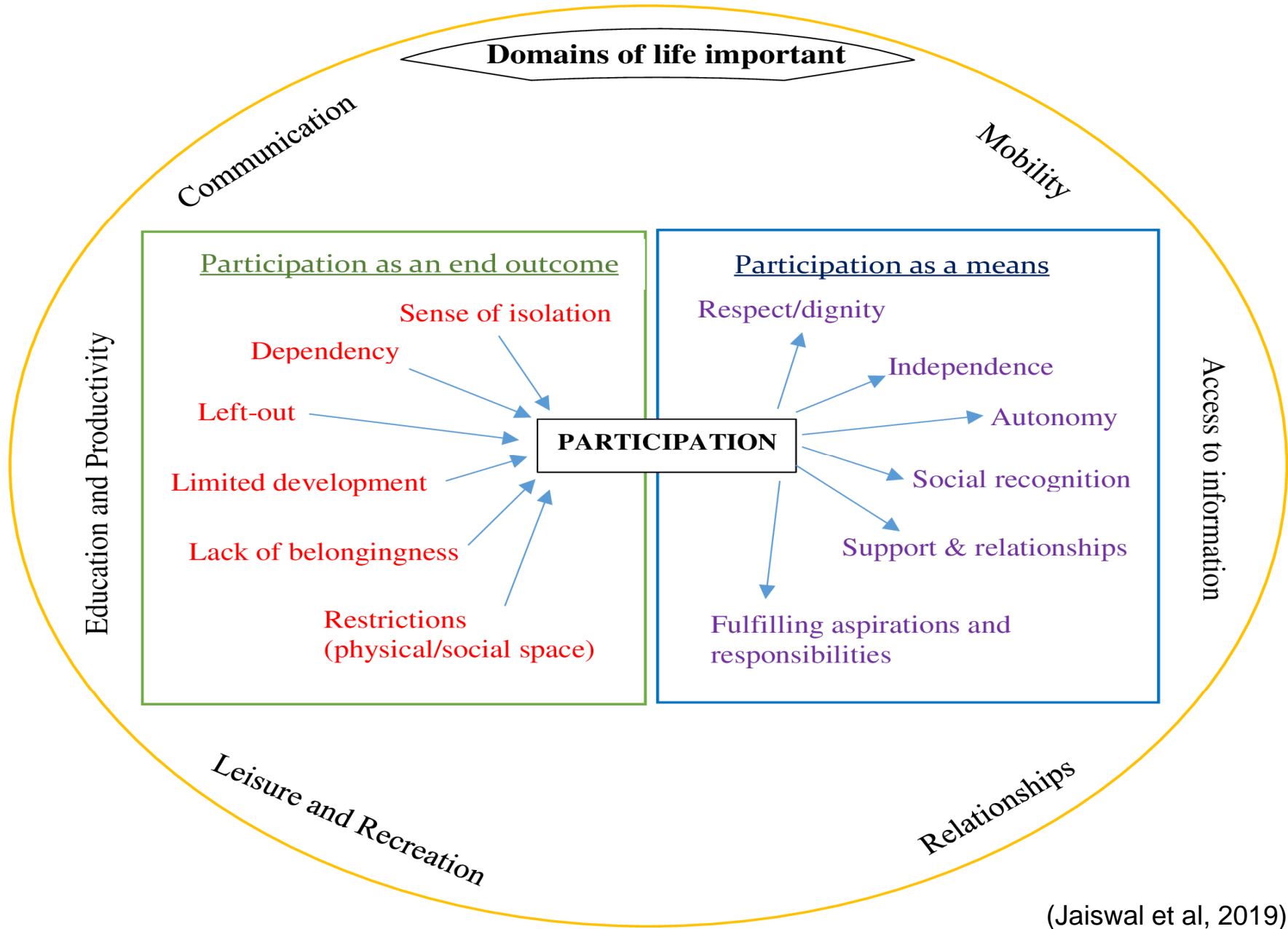
# Results



## Key findings: Six domains of life important for participation



# Key findings: *Participation as an end outcome and as a means*



# Salient outcomes of the Study 2

## STUDY 1

- Distinct participation experiences across three groups
- Highlighted the evidence gap

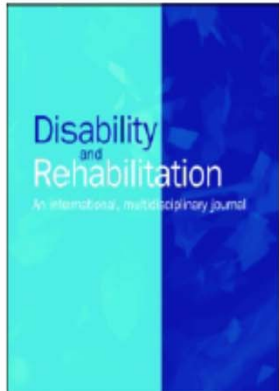


## STUDY 2

- Participation as an end outcome and as a means
- Methodology to conduct interviews with PwDb



**Understanding  
of participation  
for PwDb and  
ways to  
enhance it**



## Disability and Rehabilitation



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

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

**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: [10.1080/09638288.2018.1564943](https://doi.org/10.1080/09638288.2018.1564943)

# Study 3

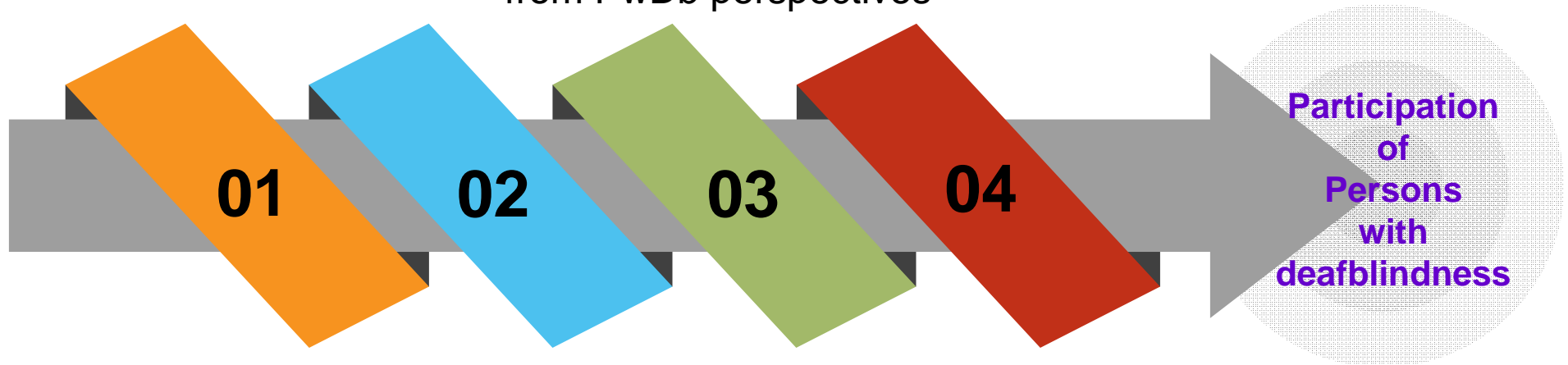
## Research Question

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

## Methods

### STUDY 3

Contextual factors that influence participation from PwDb perspectives



**Sampling** – Purposive (Sandelowski, 1995)

**Data Collection** - Semi-structured qualitative interviews with 16 PwDb using diverse communication modes.

### Data Analysis

- Data managed using NVivo Pro 11 software.
- Directed content analysis approach was used (Hsieh & Shannon, 2005)

# Results



## **Key findings**

### **Personal factors**

1. Onset and nature of impairment
2. Proactive outreach to others

### **Environmental factors**

1. Services and policies specific to deafblindness
2. Societal attitudes
3. Support and relationships
4. Access to technology

## Key findings

### Enablers

- Willingness to ask for help (proactive outreach)
- Deafblind- specific services
- Awareness about deafblindness in general
- Support from friends, family and society
- Technological aids and devices
- Suitable opportunities for deafblind people

### Barriers

- Progressive sensory loss
- Fear of falling or injury
- Negative societal attitudes
- Costlier products and technology
- Lack of policies to provide institutional support to people with deafblindness
- Inaccessible built environments (e.g., low visibility and illumination at public spaces)

# Salient outcomes of the Study 3

## STUDY 1

- Distinct participation experiences across three groups
- Highlighted the evidence gap



**Understanding  
of participation  
for PwDb and  
ways to  
enhance it**

## STUDY 2

- Participation as an end outcome and as a means
- Methodology to conduct interviews with PwDb



## STUDY 3

- **Factors that influence participation from PwDb perspectives**
- **Barriers and enablers**

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ORIGINAL RESEARCH

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

Atul Jaiswal, PhD,<sup>a</sup> Heather M. Aldersey, PhD,<sup>a</sup> Walter Wittich, PhD, FAAO, CLVT,<sup>b</sup> Mansha Mirza, PhD, OTR/L,<sup>c</sup> Marcia Finlayson, PhD, OTR/L<sup>a</sup>

From the <sup>a</sup>School of Rehabilitation Therapy, Queen's University, Kingston, Ontario, Canada; <sup>b</sup>School of Optometry, University of Montreal, Montreal, Quebec, Canada; and the <sup>c</sup>Department of Occupational Therapy, University of Illinois at Chicago, Chicago, Illinois.

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**Abstract**

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

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

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

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

**Interventions:** Not applicable.

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

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

**Conclusions:** Professionals must acknowledge aspects of the environment in conducting assessments and delivering interventions and understand the dynamic interactions between environment of the individual and his/her 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 must ensure emphasis on awareness about deafblindness, access to deafblind-specific services, positive societal attitude, and opportunities for full participation for people with deafblindness in society.

Archives of Physical Medicine and Rehabilitation 2019; ■: ■ ■ ■ ■ - ■ ■ ■ ■

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# Study 4

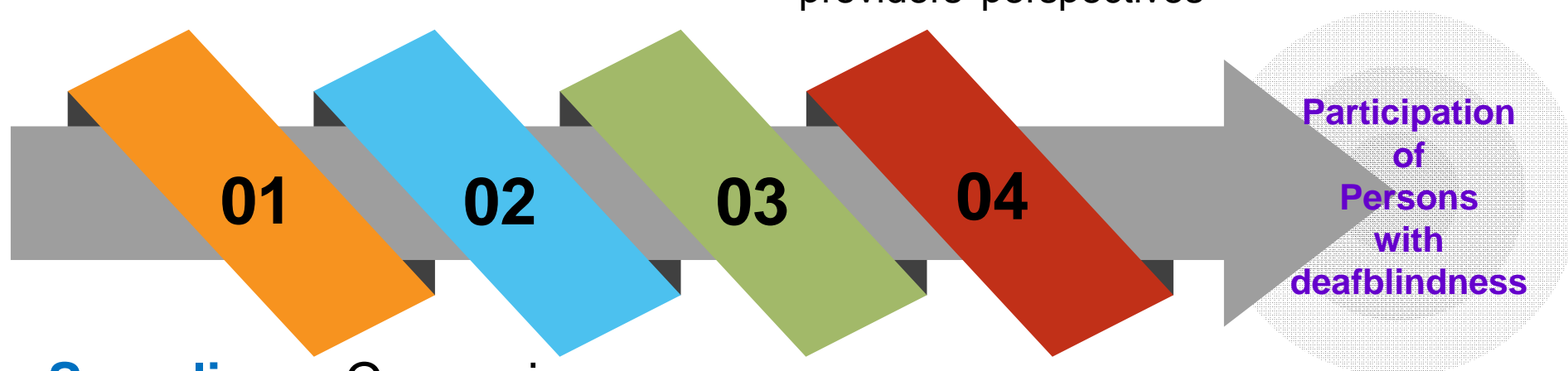
## Research Question

**What are the contextual factors identified by rehabilitation service providers that influence the participation of persons with deafblindness in India?**

## Methods

### STUDY 4

Contextual factors that influence participation of PwDb from service providers' perspectives



**Sampling** – Convenience (Sandelowski, 1995)

**Data Collection** - 2 focus group discussions with 16 service providers at Regional Learning Centres on Deafblindness.

### Data Analysis

- Data managed using NVivo Pro 11 software.
- Directed content analysis approach (Hsieh & Shannon, 2005)

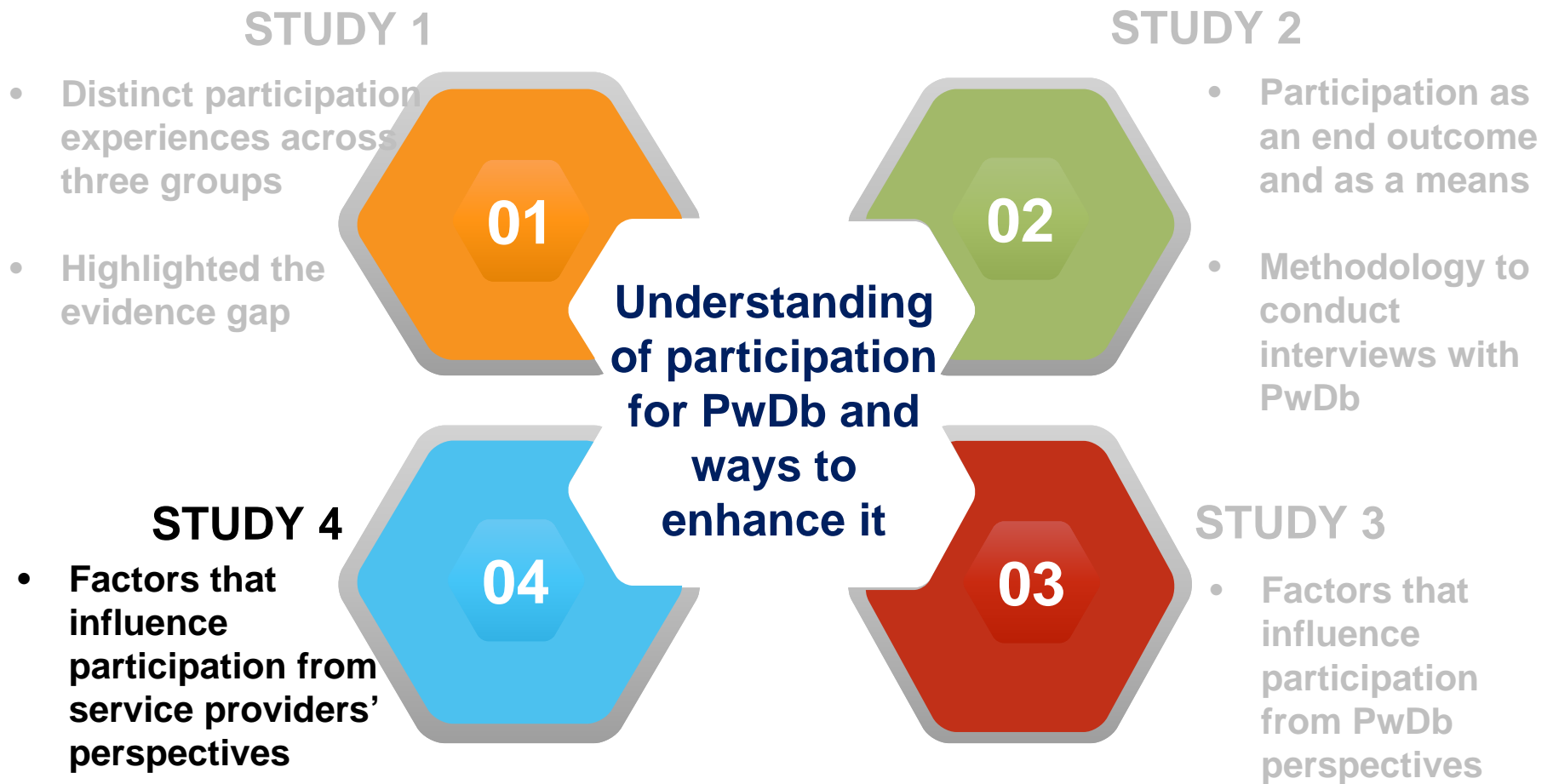
# Results



## Findings

- Four major barriers to participation:
  - (a) lack of awareness about deafblindness
  - (b) negative attitudes and stigma
  - (c) lack of assistive technology and interpreter support
  - (d) communication challenges associated with severe impairments.
- Participation challenges - more evident in unstructured environments (public spaces) versus structured environments (vocational training centres).

# Salient outcomes of the Study 4



**Study 3 and 4 suggested ways to enhance participation for persons with deafblindness**

## Suggested ways to enhance participation from Study 3 and 4



# Implications of Overall Study



## Conclusions

- **Persons with deafblindness**
  - experience significant challenges in participation.
  - feel isolated and
  - limited avenues for participation in the unfamiliar environments.
- Participation **as a means and as an outcome** may change the focus of designing rehabilitation services.
- Improving **enablers** (such as services, technology, and supports) and removing **barriers** (such as negative attitude, stigma, and influencing personal factors) could improve the participation experiences.

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# THANKS...



“Alone we can do so little; together we can do so much.”

Helen Keller

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