



Deafblindness across global contexts: Exploring two pathways and outcomes in relation to the UN sustainable development goals

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ABSTRACT

The life trajectories of individuals living with deafblindness can vary substantially across global contexts, yet comparative evidence between the Global South and the Global North remains limited. This qualitative study explores similarities and differences in healthcare, employment and educational access, supports and outcomes among individuals with congenital or early-onset deafblindness across both sides of the world. Semi-structured interviews were conducted with adults from the Global South and the Global North, recruited through international partners and organizations of and for people with deafblindness. Interviews were audio-recorded, transcribed, and analyzed using a framework analysis approach. Findings highlight contrasts in formal education opportunities in urban and rural areas, availability of accommodations and professional support. In the context of employment, access appeared to be facilitated in collectivistic cultures, where community structures support skill development, whereas individuals in more individualistic cultures encountered greater challenges in accessing employment. The study underscores the importance of contextual factors, including urban-rural settings and cultural importance of community, in shaping educational and employment trajectories. These findings emphasize the need for equitable, context-responsive educational, employment and healthcare policies and global collaboration to improve inclusion for individuals with deafblindness across the world.

SPECIFICATIONS TABLE (All sections are mandatory unless marked otherwise)

Subject area	2713 – Epidemiology (Health Sciences) Cultural Education Health Political Societal
Category/categories of societal impact	GOAL 1: No Poverty GOAL 3: Good Health and Well-being GOAL 4: Quality Education GOAL 5: Gender Equality GOAL 8: Decent Work and Economic Growth GOAL 10: Reduced Inequality GOAL 17: Partnerships to achieve the Goal
Sustainable Development Goals (SDGS) the research contributes to	
Related published article	
<i>Author(s), Title, Journal, Volume / Issue, Year of Publication, DOI</i>	
Research Project	
<i>Project description. Grants - Issued by XXXX. Link to the summary of the project – www.xxxxx</i>	
Conference Paper	
Book chapter: Kamenopoulou, L., Simcock, P., Boie, N.R. & Wittich, W. (2025). Exploring education and employment facilitators in low-	

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In Progress

CRediT authorship contribution statement

S. Dumassais: Writing – review & editing, Writing – original draft, Visualization, Validation, Investigation, Formal analysis, Data curation, Conceptualization. **P. Simcock:** Writing – review & editing, Writing – original draft, Visualization, Validation, Supervision, Resources, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization. **L. Kamenopoulou:** Writing – review & editing, Writing – original draft, Visualization, Validation, Supervision, Resources, Project administration, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization. **W. Wittich:** Writing – review & editing, Writing – original draft, Visualization, Validation, Supervision, Resources, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization.

In 2025, the United Nations officially recognized deafblindness as a distinct disability and designated June 27 as International Deafblindness Day [1]. Such recognition is a significant milestone, highlighting that individuals living with deafblindness experience unique functional, communication and participation needs [1]. The development of WHO International Classification of Functioning, Disability and Health (ICF) Core Sets for deafblindness [2] also marked an important global initiative to understand how individuals with deafblindness function in daily life and interact with their environment and those around them. While this cross-sectional effort considered both environmental and personal factors across geographical regions, the role of socio-cultural factors received less attention. Moreover, comparative empirical evidence on the lived experiences of deafblindness across the globe remains limited, with most research originating from high-income countries and only scarce evidence available from low- and middle-income countries.

Systemic inequities between high-income countries (Global North, GN) and low- and middle-income countries (Global South, GS), as conceptualized by the Brandt Line [3], influence how individuals living with deafblindness navigate through life. Evidence reveals that persons with deafblindness experience disproportionately high rates of poverty, limited access to healthcare, and significant barriers to education and employment. For example, a multi-country analysis found that children with deafblindness in low- and middle-income countries were less likely to attend primary school [4,5]. Among working-age individuals with deafblindness, those who are unemployed are far less likely to be actively seeking work compared to non-disabled unemployed individuals [5]. Gender and ethnicity further exacerbate these inequities. Indeed, women with deafblindness are even less likely to be working than women with other impairments [5]. Racialised minorities face the typical communication barriers associated with deafblindness on top of existing systemic racial discrimination [6]. In relation to health, the prevalence of co-existing health conditions in deafblind individuals is high, between 20% and 75% which further affects their quality of life and the management of their health [5]. Overall, deafblind people in high-income countries report greater coverage of their needs in national education policies (45%) and health systems (55%) compared to those in low- and middle-income countries (18% and 36%, respectively) [5], highlighting a significant gap. Evidence also suggests that common barriers faced by people with deafblindness (for example, access to assistive technology, societal stigma and lack of awareness) are more acute in low- and middle-income countries [7,8]. These disadvantages amplify social exclusion and limit opportunities for participation in education, employment and wider community life.

These realities align closely with several United Nations' Sustainable Development Goals (SDGs), including SDG 1 (No Poverty), by addressing economic inequity; SDG 3 (Good Health and Well-Being), through reducing health inequities and improving access to care; SDG 4 (Quality Education), by ensuring inclusive and equitable education; SDG 5 (Gender Equality), by addressing gender-based discrimination; SDG 8 (Decent Work and Economic Growth), by promoting employment opportunities; and SDG 10 (Reduced Inequalities), by addressing systemic disparities. To achieve these goals, SDG 17 (Partnerships for the Goals) is critical. Global, participatory research is essential to generate context-

sensitive evidence that informs policy and practice [9]. While initiatives like the ICF Core Sets for deafblindness have advanced understanding of functional and environmental factors, socio-cultural dimensions remain underexplored. Without research that reflects diverse lived experiences across GN and GS contexts, strategies will fail to address the local, structural and cultural barriers that contribute to inequity.

The study reported here aimed to map the factors contributing to resource and service disparities between the GN and the GS and to explore how these differences or similarities have impacted the lives of deafblind individuals. Comparing GN and GS contexts provides a broader perspective on deafblindness by highlighting complementary strengths, including innovative low-cost solutions developed in resource-constrained settings and effective interventions that may warrant investment. This approach fosters mutual learning while informing practice on a global scale. Therefore, we explored deafblind individuals' life pathways across countries, in relation to accessing and navigating education, employment, healthcare, and social services. This study highlights how local contexts shape lived realities, and its findings have implications for national and international policy, research, and practice, which aims to advance more accessible and inclusive systems for people with deafblindness.

Methodology

Ethical considerations

Ethical approval was obtained from the institutional review boards of the Université de Montréal (CERC 2024-5560), the Centre de Recherche Interdisciplinaire en Réadaptation du Montréal Métropolitain (CRIR-7608), the Centre Intégré Universitaire de Santé et de Services Sociaux du Centre-Ouest-de-l'Île-de-Montréal (MEO-50-2025-3990), the Centre Intégré de Santé et de Services Sociaux de la Montérégie-Centre (MP-50-2024-1991), the University College London Institute of Education Research Ethics Committee (ExREC20020), and the Health, Education and Life Sciences Faculty Academic Ethics Committee at Birmingham City University, UK (#13111/sub2/R(B)/2024). Depending on each participant's preferred communication modalities, informed consent or assent was obtained verbally, through text, through signed or tactile communication/language, or with the support of a communication facilitator, as recommended in previously published, established guidelines [10,11].

Participants

Seventy-four participants were recruited from seven countries across the Global North ($n = 22$) and 15 countries in the Global South ($n = 52$). Participants reported diverse etiologies of deafblindness, including congenital and genetic conditions (e.g., Usher syndrome, CHARGE syndrome), infectious diseases (e.g., rubella, cytomegalovirus, malaria, and typhoid fever), neurological and sensory disorders, and acquired causes, including trauma and surgical complications. For some participants, the etiology of deafblindness was unknown, unspecified, or not reported. Participants were aged 19–72 years ($M = 34.3$, $SD = 11.6$);

52.7% were female ($n = 39$) and 45.9% were male ($n = 34$). Most participants lived with family and/or friends (78.4%), while 10.8% lived independently or alone; 6.8% resided in group or supported accommodation, and 4.1% did not report their living arrangements. The majority of participants ($n = 46$, 62.2%) resided in an urban area while 22 (29.7%) lived in rural settings and four participants (5.4%) reported residing in suburban or semi-urban settings.

Materials

The research team developed a semi-structured interview topic guide consisting of eight subsections designed to facilitate in-depth discussions about participants' life experiences and trajectories: 1) demographic information, 2) deafblind identity, 3) communication modalities, 4) health and social services, 5) education, 6) communication across the lifespan, 7) family and employment, and 8) technology. This interview topic guide is available in [supplementary material](#).

Procedure

Participants were recruited using convenience sampling with a maximum variation strategy, considering age, sex, severity of impairment, and etiology of deafblindness. Recruitment methods varied by context, including client databases of rehabilitation centers or organizations providing services to or advocating for individuals living with deafblindness, as well as snowball sampling. Individual interviews were conducted either online through Zoom or Microsoft Teams videoconferencing software or in person, locally. This methodological choice enabled participants to share in-depth, contextualized understanding of their complex real-world experiences, particularly in relation to the geographical and socio-cultural aspects emphasized in this study. Participants were given as much time as needed to share their experiences.

Data analysis

Given the phenomenological objective of this project, a qualitative case study design was adopted. All participant interviews were recorded and transcribed verbatim using Microsoft Word. Interviews conducted in a language other than English were translated by a native speaker into English. Where interviews were interpreter mediated, the interpreters' words were transcribed, paying careful attention to conceptual equivalence. Data were then entered in AtlasTI [12], a software supporting the organisation and analysis of qualitative data. We employed Framework Analysis [13] to facilitate a structured way of understanding and mapping the identified factors and how they were experienced by participants. Every transcript was analyzed by an independent reviewer.

Results and implications

Jason (pseudonym) is a 34-year-old man living in rural Democratic Republic of Congo, Central Africa (GS). Very early on in his life, he was diagnosed with Usher Syndrome Type I, which resulted in congenital deafness and progressive sight loss. Although he was enrolled in elementary school, his family ultimately withdrew him because the school was unable to provide the accommodations and resources that would support his learning. Following this setback, he began acquiring farming skills at home. He learned by closely observing, touching and imitating his father's actions, picking up on tactile and proprioceptive cues. Today, Jason works as an independent farmer and volunteers as a scout in his local church community.

Nicole (pseudonym) is a 44-year-old woman from an urban city in British Columbia, Canada (GN). Her deafblindness started at birth as a result of congenital rubella syndrome (CRS), congenital cataracts and secondary glaucoma. Nicole had to complete kindergarten twice because she initially lived in a rural area with no suitable pre-school options. Her second experience was more positive, as relocating to an

urban area enabled her to receive learning support from a teaching assistant. During elementary school (around ages 5 and 12 in Canada), she attended specialized classrooms for deaf students and received assistance from intervenors from grade three through 10 (around ages 8 and 15 in Canada). Ultimately, she completed her education with post-secondary certificates in *Applied Business Technology* and in *Emergency Management*. Despite these accomplishments, Nicole has struggled to secure stable paid employment and has only been able to obtain intermittent work.

These two case studies represent how socio-cultural context matters for most of our participants who grew up with deafblindness. Deafblind individuals' life trajectories are shaped by the environments in which they grow up, particularly when comparing urban and rural settings. The contexts of many of our sample influenced access to services, opportunities for participation, and social activities. It is possible that individuals living in urban settings are better able to benefit from formal, accessible resources. In Jason's case, growing up in a rural area of the Democratic Republic of Congo, the lack of available formal support meant relying on informal resources, including his family's teaching of farming skills. A similar pattern emerges in the education system: participants like Nicole were only able to access specialized educational supports after moving to an urban area, while participants similar to Jason's profile were unable to complete even elementary school in his rural community. These disparities in educational resources most likely influenced their education options. Nevertheless, Jason secured full time self-employment and a stable income, whilst Nicole struggled to find stable employment over time. Such difference in experience suggests that in collectivist contexts, where family and community networks are central, individuals living with deafblindness can be better included in social, civic and community life. In individualistic contexts, where independence is emphasized, the expectations of being a self-sufficient individual remain, even for people living with deafblindness.

Our sample consists of more participants from the GS than GN, which limits the comparisons we can make between them. More robust inferences would be possible if our samples would be more balanced. Nonetheless, many of our participants illustrate various life experience patterns. This study's findings highlight how the lives of people with deafblindness in the GN and the GS have evolved across education, employment, and other aspects of daily living. Our findings demonstrate that achieving the SDGs for individuals with deafblindness is a substantial challenge. By revealing barriers and facilitators to living a full life in high- and low- and middle-income contexts, the findings can help shape more inclusive policies, strengthen social systems and improve access to essential services. Importantly, these findings can support the identification of country-specific gaps in health, education, social services, and employment by comparing participants' life trajectories with normative data. For instance, resources such as *Our World in Data* provide country-level normative data on education. By integrating our international data, we can conduct national comparisons to highlight the gaps and needs [14]. Therefore, our study can provide evidence-based guidance for local policymakers, service providers and international organizations to develop practices aimed at reducing gaps not only between high- and low-middle income countries but also between non-disabled people and those living with deafblindness. For high-income countries, findings help clarify which needs should be prioritized within political and policy agendas.

Ethics declaration

Written informed consent to take part in the study and to publish the article has been obtained from all participants or their legal representatives. The privacy rights of participants have been observed.

This study was performed in compliance with relevant laws, regulatory frameworks and guidelines where the research took place. This study was approved by the Université de Montréal, Centre de Recherche Interdisciplinaire en Réadaptation du Montréal Métropolitain, Centre

Intégré Universitaire de Santé et de Services Sociaux du Centre-Ouest-de-l'Île-de-Montréal. (Approval No. CERC 2024-5560 and MP-50-2024-1991).

Declaration of Competing Interest

All three authors report no competing interests.

Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at [doi:10.1016/j.socimp.2026.100207](https://doi.org/10.1016/j.socimp.2026.100207).

References

- [1] United Nations, Recognizing Deafblindness: a distinct disability requiring specialized support and inclusion, International Day of Deafblindness 27 June. [Online]. Available: <https://www.un.org/en/observances/deafblindness-day>.
- [2] W. Wittich, S. Dumassais, A. Jaiswal, T.O. Ogedengbe, R. Lopez, and S. Granberg, "The WHO ICF Core Set for Deafblindness: The comprehensive core set.," Open Science Framework. [Online]. Available: <https://doi.org/10.17605/OSF.IO/A942K>.
- [3] W. Brandt, North South: a Programme for Survival; report of the Independent Commission on International Development Issues, MIT. Massachusetts, United States of America, 1980.
- [4] S. Rotenberg, C. Davey, L.M. Banks, Health, education and well-being for children with deafblindness: a secondary analysis of 36 Multiple Indicator Cluster Surveys, Arch. Dis. Child. 110 (6) (June 2025) 480–486, <https://doi.org/10.1136/archdischild-2025-328675>.
- [5] World Federation of the Deafblind, At risk of exclusion from CRPD and SDGs implementation: Inequality and Persons with Deafblindness, 2018. [Online]. Available: <https://wfdb.eu/wfdb-report-2018/>.
- [6] C. García-Fernández, Intersectionality and autoethnography: deafblind, deafdisabled, deaf and hard of hearing-latinx children are the future, jcscore 6 (1) (2020) 40–67, <https://doi.org/10.15763/issn.2642-2387.2020.6.1.40-67>.
- [7] L. Kamenopoulou, P. Simcock, N.R. Boie, W. Wittich, Chapter 15: exploring education and employment facilitators in low-and middle-income countries. Volume 2 of Oxford Handbook on Deafblindness., Oxford University Press, 2025, p. 165.
- [8] The World Federation of the Deafblind, Good Practices and Recommendations for the Inclusion of Persons with Deafblindness. Second Global Report on the Situation of Persons with Deafblindness. 2023. [Online]. Available: https://wfdb.eu/wp-content/uploads/2023/03/ENG_WFDB-2nd-Global-Report-FINAL-V6.pdf.
- [9] A. Roy, K.R. McVilly, B.R. Crisp, Working with Deafblind people to develop a good practice approach, J. Social. Work. 21 (1) (2021) 69–87, <https://doi.org/10.1177/1468017319860216>.
- [10] A. Paramasivam, A. Jaiswal, R. Minhas, W. Wittich, R. Spruyt-Rocks, Informed consent or assent strategies for research with individuals with deafblindness or dual sensory impairment: a scoping review, Arch. Rehabil. Res. Clin. Transl. 3 (2) (2021) 100115, <https://doi.org/10.1016/j.arret.2021.100115>.
- [11] W. Wittich, N.R. Boie, A. Jaiswal, Methodological approaches to obtaining informed consent when conducting research with individuals with deafblindness, Int. J. Qual. Methods 22 (2023), <https://doi.org/10.1177/16094069231205176>.
- [12] Scientific Software Development GmbH, ATLAS.ti, 2023. <https://atlasti.com>.
- [13] J. Ritchie, L. Spencer, Qualitative data analysis for applied policy research. Analyzing qualitative data, Routledge, 2002, pp. 173–194.
- [14] Our World in Data, Research and data to make progress against the world's largest problems, Our World in Data. [Online]. Available: <https://ourworldindata.org/>.