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DbI REVIEW

THE MAGAZINE
OF DEAFBLIND
INTERNATIONAL

Deafblind
International DbI

Theme of the Issue

GLOBAL EDUCATION CAMPAIGN

Children with deafblindness are very often left behind. Our Global Education Campaign "Let Me In" is changing that.

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Have you checked out a journal (like the DbI Review), attended a webinar, participated on a committee, joined a network, attended a conference or even "shared" or "liked" something on social media? These are all great ways to learn about best practices, discover new research, explore innovative approaches with your peers **and expand your network!**

Deafblind International (DbI) is THE effective point of connection in deafblindness on a global scale.

DbI offers its members many ways to stay connected, starting with membership. With the new strategic plan for 2023 – 2027, DbI will focus on "connecting to maximize positive impact" for people with deafblindness, DbI members and to boost the organizational strategy.

Membership is the starting point to making these connections. For **DeafBlind Ontario Services**, DbI membership helps us offer employees professional development opportunities they cannot receive anywhere else. Membership opens the door to webinars, participation on working groups with international colleagues and professional growth experiences at international conferences (most recently, the 18th Global Conference held July 2023 in Ottawa, Canada).

DbI membership also offers insight on the experiences our colleagues across the globe face. For example, through **DeafBlind Ontario Services**' partnership with Asociación de Sordociegos de Nicaragua (ASCN) (or the Deafblind Association of Nicaragua), we learned about the importance of continued advocacy of disability rights and shared practical tips and techniques in orientation. We also gained insight about the resilience of people wherever they live, embraced the chance to share our learnings, and explored innovative ways to offer supports while building positive working relationships.

DeafBlind Ontario Services supports the work of our colleagues at ASCN – to build their connections with other organizations across the globe and by supporting their agency's membership with DbI. For our organization, a component of our work together included helping cover the cost of their DbI membership fees.

A DbI membership offers a threefold benefit:

- For the Deafblind Association of Nicaragua → access to rich, innovative, international resources
- For DeafBlind Ontario Services → alignment with our belief that *Engaging others makes us better. Each of us has something to learn and something to teach.*
- For DbI → member organizations who bring fresh perspectives, insight, and expertise

"We rise by lifting others."
Robert Ingersoll

Staying connected is the goal of DbI. If you are a large corporate member, we encourage you to sponsor a smaller member agency today and Connect to Act!

https://www.deafblindinternational.org/about-us/become-a-member/

WORD OF THE PRESIDENT

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“Going Tactile”: The New Protactile Book and the Global Education Campaign

MIRKO BAUR

PRESIDENT OF
DEAFBLIND
INTERNATIONAL

While I am writing this, I am sitting on a train taking me from the very South to the very North of Switzerland. If you know how tiny Switzerland is, this may seem like a rather amusing statement. However, this journey involves two different spoken languages and two different sign languages, two different cultures and two different climates.

You would immediately notice it in interaction and communication, in the social evaluation of proximity and distance or in the role attributed to central places in towns. To a certain extent, the South offers much more tactility.

That is, of course, a very central theme of being in the world if you live with deafblindness. I have just finished reading the latest book by Terra Edwards, the linguistic anthropologist who has followed and studied the emergence of the tactile language usually presented under the name “Protactile”. Drawing on long-term anthropological fieldwork, as well as analysis of interactional and linguistic data, her book tells the story of what she learned about language and life as the protactile movement formed and flourished.

While it has become so strong in this specific community, at this specific time and place, the world has certainly not gone tactile over the last 20 years. Our increasingly diverse and inclusive network is truly something of an exception in our maintained and perhaps even greater focus on the importance of touch.

That gives us a responsibility. Just think about the next generation of children with deafblindness. We want to ensure that they and their families find professional partners and educational settings that are highly attuned to a tactile way of being in the world. And that is what makes our Global Education Campaign so important.

This issue of the DbI Review is dedicated specifically to education and its power. Among other things, it will take you to Guatemala, Japan, Kenya, Malawi and Nepal and share news of the Deafblind Education Network. Of course, there is much more: this issue also reflects our many topics.

The Global Education Campaign is progressing well. Since the last DbI Review, we have selected 30 new research projects in Africa, Asia and Latin America. And we have chosen two wonderful teachers from Argentina and Zambia for a DbI nomination to the Varkey Foundation’s Global Teacher Prize.

However, we can do so much more. 23 countries in the “Global South” have developed practical, grassroots projects for the education of children with deafblindness. This is where we need the solidarity of our wonderful network. Any small donation can truly change the lives of the children involved, their families and educators. Thank you very much and enjoy reading this new edition of the DbI Review!

Global Education Campaign

Children with deafblindness are very often left behind. Our Global Education Campaign “Let Me In” is changing that. For real: with conferences like this year in Nepal, with 30 new research projects in Africa, Asia and Latin America, and with service projects in 23 countries across the globe.

Those service projects need our network also financially to be realized. Really any small amount can change the whole world of a child and their family – for example in Indonesia like Weni tells you under this link in her video https://www.facebook.com/dbiint/videos/1493265055140830/?rdid=06oMPimqlDgieYWi#

Please, please, please consider supporting Let Me In on fundrazr using this link https://fundrazr.com/letmein-dbi?ref=sh_8Dgi22_ab_8S5tKjyEOur8S5tKjyEOur or the qr code below.

Thank you so very much!

Network News: Deafblind Education Network

DEAFBLIND
INTERNATIONAL
EDUCATION
NETWORK

Greetings from the DEN. Formed in 2023, we are now running at full force and excited to share our updates.

Since the first meeting in Ottawa, Canada, we have held 9 Board meetings to date (roughly 5 per year) via Microsoft Teams. We discuss the goals of the network, news/updates from the field of Deafblind Education, and collaborate to plan webinars for teachers and others to attend and share ideas. We also encourage membership and spread campaigns such as the “Let Me In” global initiative.

The DEN has a Facebook page which was set up in 2023 that currently has 350 members (at time of writing). To access it and join the page as a member, search “Deafblind Education Network.” We also encourage DbI members to register to join the DEN via the Deafblind International website. We currently have 240 members who have joined this way.

We have completed our first event, called “Best Practice/Swap Mart,” which was an online webinar held on Sept 24, 2025. Roughly 14 people attended from around the world and ideas were shared on our first topic: “How to introduce yourself to your students of all ages.” DEN Members Gunther and Deirdre started off the topic with their best practice ideas and then opened it up to the attendees to share and ask questions. It was a lovely first event where deafblind educators could share how they introduce themselves to their students of all ages. We also asked attendees to send on topics they would like us to present in future. Our next “Swap Mart” is scheduled for Nov 17 at 3pm CET so watch our Facebook page for the link (or join the DEN as a member and you will get an email).

We meet every other month on Teams as well as anytime there is an opportunity to meet face-to-face during conferences. Looking forward to seeing DbI Review readers at our webinars and in person at the next conference!

Members of the Board of DEN:

- Anders Martin Rundh, Denmark (Chair)
- Deirdre Leech, Ireland (Co-chair)
- Yoni van der Linden, Netherlands
- Gunther Meyer-Reinhard, Germany
- Edem Jacqueline Dorleku, Ghana
- Kristin Carlson, USA

Deafblind
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DEAFBLIND EDUCATION NETWORK

Deafblind International – Research Network Update

DEAFBLIND
INTERNATIONAL
RESEARCH
NETWORK

The DbI Research Network is in its 11th year of existence, and we continue to grow and expand. As of August 2025, we now have 382 members on our e-mail contact list.

Saskia Damen, **Atul Jaiswal** and **Walter Wittich** continue as moderators of the Deafblind International Research Network – **Facebook Group** (https://www.facebook.com/groups/158743377516989), currently at 1,477 members and growing. Come look us up and join in the conversation! We continue to maintain our Deafblind International Research Network **LinkedIn group** (https://www.linkedin.com/groups/8339092/), currently with 218 members.

The Research Network recently launched this year's funding competition for international collaborative projects. This year, the eligibility criteria will favour projects that include investigators from at least 2 low- or middle-income countries, that are collaborative across different regions of the planet, and that include members of the research team with lived experience of deafblindness. Each of the individual five grants will be for approximately 500 Euro. Subscribe for the Research Network mailing list by joining the Research Network, to be notified when calls goes out to all members.

Later this year, the Research Network will update its members on the progress of a global definition of deafblindness. This project, which is currently being conducted in collaboration with the World Federation of the Deafblind, aims to provide a global framework that can describe deafblindness and includes the perspectives of persons with lived experience, the functional perspective as well as the traditional bio-medical aspects of deafblindness.

The current leadership team of the Research Network is composed of:

- Prof. Dr. Walter Wittich, Canada (Chair) https://opto.umontreal.ca/ecole/equipe/corps-professoral/fiche/in/in19631/sg/Walter%20Wittich/
- Dr. Saskia Damen, Netherlands (deputy) https://www.rug.nl/staff/s.damen/?lang=en

- Dr. Meredith Prain, Australia (core-member) https://meredithprain.com.au/
- Dr. Atul Jaiswal, Canada (core member) https://scholar.google.ca/citations?user=t_IAEXMAAAAJ&hl=en
- Ms. Carolin Gravel, Germany (core member) https://www.uni-due.de/sonderpaedagogik/hoeren/gravel_carolin

Please feel free to contact any one of us if you have any ideas for us, or other requests for research–specific information, we look forward to hearing from you, and please feel free to check out the networking opportunities on our web page http://research.deafblindinternational.org/

and contact us with your interests and thoughts.

Your Research Network Team.

News from the Deafblind International Acquired Deafblindness Network (ADBN)

“Outstanding! I can’t wait to share this information with my regular deafblind client”.

“Thanks for a great event! I loved all the wisdom and perspective on life”.

“It was the tops!”

PETER SIMCOCK
FEMKE KRIJGER
LIZ DUNCAN

CHAIR AND CO-CHAIRS OF ADBN

This is just some of the feedback received from ADBN members about our fourth series of webinars, which has been the main focus of the Network’s activities this year. Centred on our desire to connect members together and our aim to share knowledge, experiences and ideas, this year’s speakers drew on lived experience, research, and practice wisdom to enhance our understanding of acquired deafblindness. The webinars also offered members a chance to meet each other in a different way, providing an opportunity to ask questions that may not be asked in client-professional relationship frameworks.

Reflecting the theme of the series, ‘Balancing Potential and Loss’, our first speaker was ADBN co-chair Femke Krijger, who explored the balancing act between combined visual and auditory loss on the one hand and the rich potential of the unimpaired senses on the other. Telling of her personal journey, Femke moved members with her account of the ‘devastating grief of the harsh reality of Usher Syndrome’, and inspired us as she described realising that her perception was not merely diminished, but a literally different perspective; a perspective that has the potential to enrich all our lives.

Our second speaker was disability advocate, educator at SensesWA, and disability consultant Hannah McPierzie. Describing the highs and lows of her transition from full hearing and sight to acquired deafblindness as a result of Neurofibromatosis Type 2, Hannah explored how her immersion in deafblind culture enabled her to 'find her tribe' and inspired her to become a fierce advocate for accessibility and inclusion.

Vikram Choudhary, special needs educator at the Deutsches Taubblindenwerk (German Deafblind Centre), was our third speaker. Responding to the limited opportunities acquired deafblind people have for intergenerational peer relationships, Vikram presented findings from his Master's study, which investigated the feasibility of establishing an intergenerational programme for young people and adults with acquired deafblindness at a deafblind institute. Members were encouraged to hear of the ways in which acquired deafblind adults became role models for their younger peers, whilst those younger peers supported the adults to access information and motivated them to engage in a wide range of activities.

Our fourth and final speaker was Amanda Stevens, Executive Officer at Taringa Turi Kāpō Rōpū, Deafblind Association of New Zealand Charitable Trust. Describing her story as being one of a life shaped by unforeseen challenges, Amanda explained how her professional, personal, and creative identity threads weave together. Having found her true purpose in advocacy and creativity, Amanda shared with members examples of her inspirational creations.

As we celebrate the fact that our webinars were highly commended at the Birmingham City University, UK, Knowledge Exchange Awards, and that they have engendered a growing sense of community among network members, the ADBN Committee is now working on the fifth series, which will take place next year. We are grateful to all our speakers and also offer our thanks to Deafblind UK for providing access to Zoom. And if you were not able to join us for the webinars, please do check out our YouTube Channel, **ADBNow**, where you will find all the recordings.

In addition to our webinars, ADBN continues to share knowledge via its newsletter, **ADBNews**. Recently described by a member from Tanzania as 'a valuable source of knowledge, connection, and empowerment for members of the deafblind community… and a platform to raise our voices and highlight shared experiences', **ADBNews** is sent out to all 584 members in English, Spanish and French. This work is made possible thanks to members Jo Brady and Tracey Osbourne (Editors), and Carolina Cohoon and Ismael Byaruhanga (translation).

If you are interested in acquired deafblindness and wish to join our network, you are most welcome. For further details on how to join, please visit our website here.

Update on the Networks: Deafblind International Communication Network

DEAFBLIND
INTERNATIONAL
COMMUNICATION
NETWORK

The Deafblind International Communication Network hosts a webinar on 10th November 2025. The Network has been organising webinars since April 2021 each attract over 100 participants from all over the world. In this sixth webinar, the guest speaker is Timi Claeys M.Sc., Interpreter for Deaf and Deafblind persons and Intervenor for persons with congenital deafblindness from Belgium.

Timi shares her perspective on introducing protactile (PT), a natural bodily tactile language, to an adult person who is fully deaf and blind from birth. In PT the single modality of touch serves the purposes of linguistic information, attention getting, co-presence and backchanneling, all simultaneously. Protactile has been positively received by people with acquired deafblindness and has also been used for children with congenital deafblindness (CDB). However there remains a paucity of knowledge with regard to the introduction of protactile to adult persons with CDB. In this webinar Timi delves into her attempts to implement two principles of PT in the interaction with a person with CDB. She presents the findings of an exploratory study she carried out for the master Deafblindness at the University of Groningen, the Netherlands. In this study she introduced two PT principles, Reciprocity and PT perspective, and integrated them into the communicative dyad of an adult with CDB and his trusted communication partner.

The webinar will be recorded and published on DbI's website. Check this website for the latest updates: Communication Network – Deafblind International DbI.

Reminder: Network Member Facebook Group

The DbI Communication Network page is now up and running. If you are a member of the network or simply interested in our work, please join us. Information about webinars and other network activities will be published here first.

https://www.facebook.com/groups/dbicommunicationnetwork

Deafblind
International DbI
COMMUNICATION
NETWORK

A New Research Project on Developing Deafblind Education Programs Has Started in Japan

RISA NARA

I was diagnosed with low vision at the age of 17, and later with hearing loss at 23. In 2019, I became the first woman with both visual and hearing impairments to earn a doctoral degree in the field of special needs education from the University of Tsukuba, one of the most prestigious institutions for special education in Japan.

Last year, as part of a research project funded by the Japanese Ministry of Health, Labour and Welfare, I had the opportunity to visit the University of Birmingham and Deafblind Scotland. During that trip, I also learned about DBI through Jonathan's introduction.

In a separate research project, I visited Finland, Italy, and Switzerland in May this year. Thanks to Jonathan's connection, I had the great pleasure of meeting you, Mirko. You kindly introduced me to Andrea from Germany through an online meeting, which was incredibly inspiring. That experience motivated me to apply for a new research grant from the Japanese Ministry of Education—and I am pleased to share that it has been accepted.

Over the next two years, I will conduct three research projects:

Developing a pilot graduate-level program for training teachers in deafblind education in Japan. I plan to collaborate with Andrea from Germany on this curriculum development.

Creating video-based training content for Japanese teachers to learn about *Social-Haptic Communication*, based on the work of Riitta from Finland.

Conducting a pilot study on how AI can be used to improve access to educational resources for deafblind learners in Japan.

I am truly grateful to be connected with the international DbI community. These opportunities have opened up new horizons for me as a researcher, and I am committed to contributing to the advancement of deafblind education through my work.

Thank you once again for your support and for being part of this important journey.

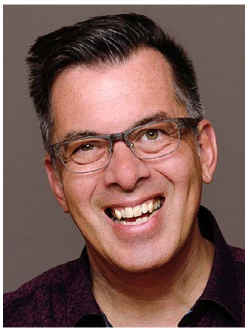
The link to our crowdfunding page to support 'A research project for Japanese Special Needs Education":

https://www.gofundme.com/f/funds-for-a-research-project-for-japanese-special-education

Advancing the UN Sustainable Development Goals through the ICF Core Sets for Deafblindness: From Classification to Inclusion

Recognition of deafblindness, a combined impairment of vision and hearing loss, is essential for equitable access to healthcare, education, employment, and social participation. Despite long-standing advocacy from international organizations, many countries still fail to recognize deafblindness as a unique disability, limiting access to services and support. Research demonstrates that deafblind individuals face disproportionately high risks of poverty, health inequities, educational exclusion, and employment barriers. These intersecting challenges highlight the urgent need for data-driven policy grounded in global equity frameworks such as the UN Sustainable Development Goals (SDGs). To address this gap, an international team developed the WHO ICF Core Sets for deafblindness, a standardized tool capturing functional priorities across life domains. Based on data from 54 countries and input from diverse stakeholders, three Core Sets support assessment, interdisciplinary collaboration, and policy development. These are the Brief Core Set (Wittich et al., 2025a), the Intermediate Core Set (Wittich et al., 2025c), and the Comprehensive Core Set (Wittich et al., 2025b). The project's dissemination strategy includes open-access resources, sign language videos, and localized implementation in countries such as Sweden, Germany, and Canada. This initiative marks a critical step toward improving visibility, service design, and policy for people with deafblindness, aligning research with SDGs on health, education, gender equality, innovation, and inclusion. Its success exemplifies global partnership, inclusive research, and the transformative potential of evidence-informed policymaking.

Recognizing the existence of a health condition is crucial for advancing its treatment and rehabilitation. It allows for the development of effective interventions and facilitates better communication and collaboration between members of an interdisciplinary healthcare and social service team and the individuals living with the condition. One such low-prevalence condition that continues to struggle for recognition is deaf-



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blindness, the combined impairment of vision and hearing. Deafblindness has multiple diagnostic causes and can vary widely in in severity, type, and age or order of onset. It is functionally defined by prohibiting individuals from using one sense to compensate for the loss of the other when conducting activities of daily living (Nordic Leadership Forum on Deafblindness, 2024). Thereby, the combined impairment creates a new and unique functional condition that requires specific accommodations by the affected individual, those around them, and society in general, to integrate them and facilitate their independence, participation, and quality of life.

The recognition of deafblindness as a unique impairment has long been the goal of global efforts driven by the *World Federation of the Deafblind* and *Deafblind International*. While some institutions such as the European Parliament (2004) have taken steps in recognizing the rights of deafblind individuals, to this day many countries do neither recognize nor provide specialized services for them. However, research on deafblindness yields critical insights that intersect with multiple Sustainable Development Goals (SDGs), spanning multiple aspects of functioning that intersect with health care, education, policymaking, and social inclusion (World Federation of the Deafblind, 2024).

SDG 1(No Poverty). Given the complexities associated with multiple impairments, it comes as no surprise that persons with deafblindness are more likely to be poor, even when compared to individuals with single sensory impairments and/or with other disabilities. Deafblindness is characterized by the need for alternative communication modalities, many of which require the assistance of others, such as intervenors or visual/tactile sign language interpreters. However, such access if often limited given the cost involved, jeopardizing social interaction and all activities that require communication, including education or employment. Many regions do not provide such access, in part because deafblindness is not recognized as a unique disability, making many individuals ineligible for the necessary resources.

SDG 3 (Good Health and Well-Being). Many syndromes causing deafblindness are linked to other comorbidities, causing limitations in motor function, communication, cognition, mental health and intellectual development. For individuals with congenital deafblindness, cognitive development is jeopardized while for persons with age-related deafblindness, cognitive maintenance is threatened. In all cases, care provision is further complicated by communication barriers with service providers, resulting in reduced care quality.

SDG 4 (Quality Education). Access to education remains difficult for children with all disabilities, but the presence of deafblindness further complicates things, given the accessibility needs to facilitate access to information. As a result, there is a vast gap, especially in low-resourced regions of the world, between the proportion of deafblind children who receive any kind of formal education, and their unimpaired peers. Families and education institutions generally underestimate the potential of children with deafblindness and learning outcome measures are not designed to capture progress in this population.

SDG 5 (Gender Equality). The experience of stigmatization, discrimination and violence is known to be higher towards women and girls, particularly those with disabilities, including deafblindness. Given the need for external communication support, women and girls with deafblindness are at particular risk for abuse (sexual, physical or otherwise) because tactile communication and physical guidance during mobility require close physical proximity. Access to, and instructions on the use of, sexual and reproductive health products can be problematic, putting women further at risk of unwanted pregnancies.

SDG 8 (Decent Work and Economic Growth). Given the need for accessibility adaptations, deafblind individuals are known to experience more barriers to employment than persons with other disabilities. In addition, stigma and prejudice reduce the probability of finding employment because employers lack the education and experience to comprehend the potential of deafblind employees. Vocational rehabilitation is often rudimentary, while available opportunities may be below the actual capacity of the deafblind person.

SDG 9 (Industry, Innovation and Infrastructure). Even though the ongoing development of assistive technologies has been hailed as the great equalizer for persons with disabilities, access to such technologies remains dependent on cost. Given what we know about poverty, as well as lack of education and employment among deafblind individuals, access to digital communication devices is often out of reach. Furthermore, the use and usability of mainstream devices is closely linked to access to the internet, which remains highly variable across countries and regions.

SDG 10 (Reduced Inequalities). Several societal participation limitations for persons with deafblindness are directly linked to information access. Basic inaccessible information such as the content of the daily news, or procedural information about local or national elections create participation barriers, resulting in a decision-making process that does not consider the functional priorities of deafblind individuals. This lack of access results in under-representation of their needs, excluding them further.

SDG 17 (Partnership for the Goals). Given their relatively small number, and the intersectionality of these variables, the situation of individuals with deafblindness is more likely to improve through global collaboration and partnership. Local, national and international organizations representing deafblind individuals as well as the formal and informal health and social service providers have come together to create a standardized description of the functional priorities of persons living with deafblindness, based on the World Health Organization's International Classification of Functioning, Disability and Health (ICF): The Core Sets for deafblindness.

Methodology

The Core Set development process is laid out by Selb et al. (2015), and consists of a systematic literature review on the topic of interest, qualitative interviews with individuals with lived experience, a survey with service providers and experts in the field, and a multicentred clinical evaluation study that explores the most frequent difficulties reported by patients during functional assessments. These four preparatory studies are designed to represent the perspectives of researchers, persons with lived experience, experts and clinicians, respectively. The data collection process for all phases needs to include as many of the six regions of the World Health Organization as possible (Africa, the Americas, Europe, the Eastern Mediterranean, the Western Pacific, and South-East Asia). This aspect is specifically important for the development of documents that are intended to inform global policy recommendations, as the perspectives and priorities from low-, middle-, and high-resourced regions can vary widely.

The synthesis of the data relies on the standardized process of matching the content onto the relevant codes available among the over 1,400 ICF codes. The coding process is aligned with the structure of the ICF, and divides into aspects of Body Structure, Body Function, Activities and Participation, as well as Environmental and Personal Factors. The resulting codes are then synthesized during a consensus conference with participants that represent all stakeholders, including individuals with lived experience. This final step gives rise to the codes of all Core Sets. In the case of deafblindness, a more detailed overview has been published elsewhere (Wittich & Dumassais, 2025).

Results and Implications

Across all four preparatory studies, the resulting Core Sets for deafblindness are based on data from 54 countries representing all six regions of the World Health Organization. Given the heterogeneity of deafblindness, the consensus process was complex, resulting in what are arguably too many codes to be easily implemented. Therefore, the team decided to create three Core Sets, each with a different purpose: The Brief Core Set (Wittich et al., 2025a) consists of 33 codes that were selected to facilitate one-on-one service assessment encounters; the 137 items in the Intermediate Core Set (Wittich et al., 2025c) are intended to facilitate communication among members of an interdisciplinary team; whereas the 218 codes contained in the Comprehensive Core Set (Wittich et al., 2025b) were chosen to be all-inclusive to express the complexity of deafblindness and to assist managers, directors, and policy-makers in their efforts to inform their discussion and decision-making process with evidence-based data. The consensus process selected codes that are most representative of functional needs across all age groups and severity levels.

The Core Sets have been promoted on the website of the ICF Research office and are now freely available through the Open Science Framework (Wittich et al., 2025b, 2025c, 2025a). Their dissemination now takes on various formats. For example, their distribution needs to consider accessibility and communication modalities when it comes to the population of deafblind individuals who contributed substantially to their creation. Therefore, we have created summary videos available in American Sign Language to inform individuals who use signed communication formats (Wittich, 2025). Translation and interpretation in multiple other signed languages is currently planned into Dutch in The Netherlands, and into French in Quebec, Canada; however, it is difficult to find funding for such knowledge mobilization activities, placing the burden of communication often on members of the deafblind community themselves, relying on the good will of volunteers and family members. The team members in Spain organized interdisciplinary presentations to government and policy leaders in Barcelona, Catalonia, to update them on the project outcomes. The communications office of the team in Canada at the Université de Montréal published a project overview that was picked up by several media outlets, reporting on the creation and relevance of the Core Sets. In addition, The World Federation of the Deafblind and Deafblind International distributed the Core Sets to their membership and linked their social media accounts to the open-access sources.

Validation efforts are currently in the planning specifically for subpopulations within the deafblind community, such as older adults with age-related deafblindness, and sign language users living with any form of Usher Syndrome. The implementation of the Core Sets for Deafblindness has already started to take shape. For example, a team in Sweden has translated and published the Core Sets, using the Swedish version of the ICF Codes, specifically to facilitate their dissemination and implementation in assessments locally. Their goal is to use this information to adapt and extend their current Swedish tools to reflect the rich data available in the Core Sets. In Germany, health records contain assessments that are structured around the general principles of the ICF classification; now, the availability of the Core Sets for deafblindness opens the door of personalizing the assessment structure and outcomes relevant to deafblind clients according to these evidence-based priorities. Given the unique situation those with congenital or early-onset health conditions, the ICF considers Core Sets specifically for children and youth. Therefore, the Core Set team has now initiated the process of repeating the preparation studies specifically with a focus on the functional needs of children and youth living with deafblindness.

Research on deafblindness offers powerful contributions toward fulfilling the United Nation's SDGs. In health and rehabilitation, evidence calls for tailored services that address communication, orientation, and mental well-being to reduce inequities (GSD 3 and 10). In education and communication, adaptive strategies and tactile or multimodal communication methods are essential for achieving meaningful inclusion and quality outcomes (GSD 4 and 9). Policy development rests on data-driven decision-making and structural support for deafblind people to access justice and services (GSD 10 and 17). Technological innovation, especially when grounded in participatory design and tested beyond prototype stages, can enable communication and independent mobility, supporting accessibility in both physical and digital environments (GSD 9). Finally, qualitative studies affirm that social inclusion, cultural representation, and civic participation are vital for dignity, independence, and equitable societal engagement (GSD 5 and 8).

The success of this collaborative effort is rooted in the persistence of the team members, and the cooperative efforts of partners around the globe. They united for the purpose of bringing a low-prevalence condition to the centre of the discussion in a timely fashion where their numbers are rising due to increasing infant survival, extended life expectancy and global aging. These efforts perfectly aligned with the recent recognition of the first International Day of Deafblindness, on June 27, presented by the United Nations (2025), in honour of Hellen Keller's birthday.

Funding and acknowledgements

On behalf of the ICF Team, I would like to gratefully acknowledge the invaluable contributions of our collaborators and supporters whose involvement has been essential to the success of this project. We extend our deepest gratitude to the Canadian Hearing Services, the Centre for Interdisciplinary Research in Rehabilitation of Greater Montreal, Diputació de Barcelona, Deafblind International, Deafblind Ontario Foundation, and the Vision Sciences Research Network funded by the Fonds de Recherche du Québec – Santé for their generous grant support. We also thank the European Deafblind Network, World Federation of the Deafblind, Deafblind Ontario Services, Canadian National Institute for the Blind, Canadian Helen Keller Center, Centre National de Ressources Handicaps Rares – Surdicécité, Deafblind Association Nepal, Society of Deafblind Parents Nepal, Sense India, Hope City Foundation Egypt, and the DeafBlind Association of Zambia for their partnerships and assistance with recruitment. We further appreciate the financial support and collaboration provided by Statped Noruega, Royal Kentalis, Able Australia, Centre de réadaptation Lethbridge-Layton Mackay du CIUSSS du Centre-Ouest-de l'Ile-de-Montréal, Institut Nazareth et Louis-Braille du CISSS de la Montérégie-Centre, National Centre for Deafblindness, Federación Española de Sordoceguera, SensesWA, Deafblind Information Australia, and the University of Melbourne. Finally, we are deeply thankful to all those who were key contributors to the scientific portion of this project. Our recognition includes master's students, PhD candidates, post-docs, and international research assistants, as well as the dedicated research coordinators, caregivers, intervenors, and interpreters who facilitated our work. We also wish to acknowledge the numerous research and health centers that supported us along the way.

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Voices of Hope: Lessons and Experiences from the Deafblindness Program of the Benemérito Comité Pro-Ciegos y Sordos de Guatemala

BENEMÉRITO COMITÉ PRO CIEGOS Y SORDOS DE GUATEMALA

Introduction

On July 21, 1998, a milestone was marked in the history of rehabilitation in Guatemala: the creation of the Deafblindness Program of the Benemérito Comité Pro-Ciegos y Sordos. This pioneering initiative in Latin America set out from the start to address an often overlooked need—comprehensive care for people with combined vision and hearing loss. More than two decades later, the program stands as a national benchmark, offering communication tools, family support, and training for independence.

According to the National Disability Survey (ENDIS, 2016), 10.2% of the Guatemalan population lives with some form of disability. Although deafblindness is not always reported separately in statistics, international estimates (World Federation of the Deafblind [WFDB], 2018) suggest that between 0.2% and 2% of the population may live with this condition. Behind these numbers are stories of resilience and transformation that underscore the importance of programs such as the one led by the Benemérito Comité.

The Deafblindness Program

When it was launched in 1998, the program offered only training in the manual alphabet. Over the years, and especially following the 2020 pandemic, it evolved into a comprehensive service that now combines in-person, virtual, and home-based care. Its services include:

a) Orientation and mobility

b) Braille

c) Abacus

d) Daily living skills

e) Communication systems

Today, the program's reach extends beyond the capital city to other departments of Guatemala, serving users that range from older adults to school-age youth. This diversity has provided unique insights into how rehabilitation can be adapted to the social, economic, and family realities of each individual.

Stories that Inspire

Miriam, 79 years old

Miriam's story demonstrates that it is never too late to learn. She joined the Rehabilitation Program for Older Adults with Visual Disabilities in 2010 after being diagnosed with glaucoma in both eyes, and in 2024 she entered the Deafblindness Program as progressive hearing loss increasingly limited her activities. Today, she perceives only shadows and uses hearing aids; yet her enthusiasm for learning has never waned.

> "I enjoy the personalized care because I learn more that way, and I am very grateful to the program," she shares. Her daughter confirms that, thanks to the support received, Miriam continues to live independently—managing activities at home and always going out with a companion for safety" (Personal communication, 2025).

Ricardo, 30 years old

Ricardo, from San Marcos, has participated virtually in the program since 2021. Diagnosed with retinitis pigmentosa and hearing loss, he uses hearing aids and a cane for mobility. At first, he was very shy, but rehabilitation has empowered him. Today, he runs an agricultural business with his mother, has formed a soccer team, and dreams of becoming a teacher.

> "Despite my limitations, I enjoy learning math with the abacus and moving around with my cane. My goal is to support other young people in their learning," he proudly states. His story reflects the transformative power of rehabilitation when combined with perseverance and family support" (Personal communication, 2025).

Lessons Learned

After more than 25 years of experience, the Deafblindness Program of the Benemérito Comité Pro-Ciegos y Sordos de Guatemala has gathered valuable lessons that transcend borders:

a) **Communication is the foundation of inclusion.** Without access to communication systems, people who are deafblind remain isolated. Teaching sign language, braille, or the manual alphabet opens the doors to social participation and ensures the exercise of fundamental human rights such as freedom of expression and access to information.

b) **Independence is possible at any age.** The testimonies of Miriam and Ricardo show that both older adults and young people can develop skills that enable them to maintain autonomy in daily life.

c) **Rehabilitation must adapt to context.** The program's success lies in its flexibility—offering virtual, in-person, and home-based care tailored to the economic, cultural, and linguistic realities of each user. In Guatemala, four peoples coexist (Maya, Garífuna, Xinka, and Ladino), and more than 20 Mayan languages are spoken in addition to Spanish. This diversity represents both a challenge and an asset in rehabilitation processes. Adapting teaching to these specificities—whether by respecting the mother tongue, considering family customs, or adjusting methodology to rural or urban living conditions—has allowed the program to remain inclusive and meaningful for every person who is deafblind.

A program teacher summarizes it with a powerful metaphor:

“Being part of this team has meant guiding people from darkness into light, giving them tools to feel useful and achieve their dreams” (Personal communication, 2025).

Final Reflection

The Guatemalan experience shows that with commitment and creativity, the lives of people with deafblindness can be transformed. The Benemérito Comité Pro-Ciegos y Sordos has demonstrated that rehabilitation is not only about restoring autonomy to individuals, it also strengthens families and enriches society as a whole.

In a world where deafblindness remains one of the least recognized disabilities, Guatemala offers a vital lesson: inclusion begins by listening to and amplifying the voices of those living with this dual sensory condition. Strengthening the Deafblindness Program means opening new doors to hope, participation, and dignity. By investing in rehabilitation, we not only return independence to each person, but also build more resilient communities, living out the principles of the Convention on the Rights of Persons with Disabilities, which affirms equal opportunity and the inherent dignity of every individual.

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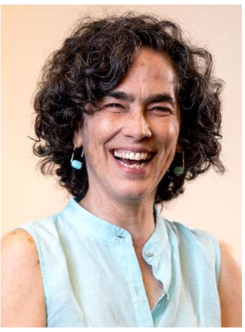
The Co-creation of Evolving Understanding



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This article expands on a recent paper delivered at the International Society on Early Intervention (ISEI) in Lisbon, Portugal, where Mary Vázquez, our researcher and quality control officer for Perkins in Latin America, and I shared findings from our ongoing work with early education programs in Argentina, Brazil, and Mexico. Both the paper and this article focus on what we call the Model Program Approach (MPA), an inclusive, child- and family-centered strategy across all stages of education. This article specifically centers on early childhood education services.

The MPA is grounded in collaborative work between local governments, early childhood care services, and families, emphasizing inclusion and prevention. It is designed to strengthen child development from the earliest years by ensuring quality education in diverse, often vulnerable contexts. Central to this strategy is the belief that sustainable impact emerges from building local capacity, building partnerships, and adapting to the unique needs of each community.

To deepen and ground the MPA in everyday practice, this article focuses on two key tools that put its vision into meaningful action for children, families, and service providers: the Transition Passport (also known as the Communication Passport or Personal Passport) and the Relationship Map, drawn from "personal-centered planning. These tools are instrumental in enabling a collaborative identity-building process with families and service providers, shifting the focus from a child's diagnosis toward a deeper understanding of who the child is, and building from the network of relationships that support them from the very early years of their journey. It can also evolve into an ongoing collaboration between the family, services providers, and a broader support network across the different stages of the child's life.

Theoretical Framework: Identity as Co-Creation

This work is grounded in theories that understand **identity** not as a *fixed attribute*, but as a *social and relational construct*. As Bruner (1996) notes, identity is shaped through the narratives we construct about ourselves and others. Wenger (1998) expands on this view, arguing that identity is formed within communities of practice—in this case, families, educators, and caregivers who collectively shape a child's experience and understanding of the world. More recent studies have revisited and deepened these ideas, showing that identity is not only narrative and social, but also dynamic, multiple, and situated (Negru-Subtirică et al., 2024; McLean et al., 2019). Thus, identity is understood as a continuous process of negotiation—between personal narratives, trajectories of participation in various groups, and the cultural and institutional contexts that enable or constrain certain ways of being and belonging.

In inclusive education, this perspective shifts our focus: the child is not simply a recipient of services, but an active participant in an ongoing, shared process of meaning-making. The Reggio Emilia approach, with its strong emphasis on listening, observation, and co-construction, further reinforces this idea (Rinaldi, 2006).

This theoretical framework is especially critical when we are working with very young children who are deafblind or have other complex disabilities. Children who may be difficult to "read", they may communicate differently, move in atypical ways, experience significant health challenges, or appear more inwardly directed. Understanding who they are requires time, curiosity, and collective learning. Families and service providers must work together to discover the child's capacities, preferences, and personality beyond their most visible needs or diagnoses.

As David Brown (2004) notes in his article Knowing the Child – Personal Passports:

> "Empowering parents in this challenging situation, 'humanizing' the child in other people's minds, and including everyone as a positive player in the child's developmental program can seem like an overwhelmingly tough prospect, but one helpful low-tech idea might be to develop a Personal Passport."

The Model Program Approach in Latin America

This aims to strengthen educational programs to better respond to student diversity through a continuous improvement approach. It brings together essential processes such as teacher training, mentorship, systematic evaluation, and technical-pedagogical support to help create learning environments that are accessible, inclusive, and responsive to the needs of all students.

At the heart of this model is the Model Program Approach (MPA), which seeks to ensure quality education for students with visual disabilities (DV), deafblindness (DB), and/or multiple disabilities (MD). The MPA promotes collaborative work among all members of the educational community, recognizing that inclusive education is a shared responsibility.

The model is structured around three core pillars:

1. Ongoing professional development for teachers and technical support for schools.
2. The strengthening of the school-family relationship, acknowledging families as key partners in the educational process.
3. Continuous evaluation of educational programs to ensure effectiveness and relevance.

Implementation is based on a contextualized approach that values the diversity of educational systems, institutional cultures, and local conditions. Central to its success is the recognition that strong, collaborative partnerships between schools and families are essential for creating inclusive, equitable learning environments where every student can thrive. From this foundation, families and service providers can co-create the child's identity and recognize the relationships that support both the child and the family, fostering a shared understanding of the child and recognizing the existing network that will evolve throughout time.

Tools for co-creation and support

(1) Transition Passports

A Transition Passport, or the communication passport, or the personal passport (passport) is a personalized document capturing the child's preferences, communication, cultural background, routines and personality. Developed in partnership with the family, it accompanies the child through transitions between services or educational settings.

These passports serve a dual purpose: they support educators and other service providers in ensuring their continuity of the child's education and affirm the identity of the child as more than a diagnosis.

In many cases, in these early years, it is the first time the family and the service providers come together to share what they know about the child, offering insights from their unique perspectives as caregivers and professionals. Through this exchange, building the passport together, they begin to discover new dimensions of the child, creating a fuller understanding of who the child is. This shared understanding becomes the foundation for setting new goals and opening up meaningful opportunities for this child's development.

(2) Relationships Map

Another important tool well known in our field is the Personal Center Planning. This plan includes the Relationship Map. This map includes immediate and extended family, peers, educators, and community figures. In many cases, this mapping brought to light the power of grandparents, community health workers, and siblings, figures often overlooked in traditional assessment.

The construction of the Relationship Map may also represent the first time that the family and providers realize that the child and the family is not alone. It offers an important opportunity to recognize the value of the network of people surrounding the child, a network that must be nurtured, supported, and allowed to evolve over time.

A meaningful discussion often follows the creation of the first Relationship Map:

Who are these people? What has the family done to build and sustain these relationships?

Reflecting on these questions helps highlight how vital these connections are—not only for the child's development but also for the family's well-being as they navigate the different stages of life together.

Policy and Practice Recommendations

To promote systemic inclusion, we propose:

- Embedding narrative tools in early childhood transition protocols
- Training educators in listening and collaborative documentation
- Adapting tools to reflect local culture, language and family structures
- Creating feedback opportunities so families shape identity narratives over time

Such strategies not only improve service delivery but deepen the humanization of care and education.

Conclusion

Identity and relationships are not fixed, they are co-created, evolving over time. The tools described in this paper, Transition Passports and Relationship Maps, support the process with care and intention.

This is not just technical work. It is ethical and emotional labor. It is about honoring stories, centering voices, and co-building futures.

Each child deserves to be seen in their full humanity—not as a diagnosis, not as a statistic, but as a person with relationships, meaning, potential, and a path.

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Walking Together: Teacher Experiences in Deafblind Education in Malawi

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When I first started working with trainee teachers in deafblind education, one of them said to me: *"I thought teaching a child who cannot see and hear would be impossible. But after the workshop, I realized it is not impossible — it just requires patience, creativity, and love."*

That statement has stayed with me because it reflects both the challenges and the hopes we carry in Malawi. Deafblind education here is still new. Many teachers know about visual impairment or hearing impairment, but when the two come together, they feel unprepared.

At Montfort Special Needs Education College, we are trying to change this. We introduce teachers to tactile communication, guiding techniques, and simple ways to adapt learning materials. One of the most exciting moments is when teachers create low-cost tactile resources from local materials — bottle tops, seeds, cardboard, and fabric. Suddenly, a lesson becomes more alive for a child who relies on touch to learn.

We have also seen the power of refresher workshops. Teachers return from the field with stories of trial and error — sometimes of frustration, but also of small victories. Sharing these stories helps them realize they are not alone. They form networks, encourage each other, and discover new ways of supporting learners who are deafblind.

The journey is not without struggles: resources are scarce, and continuous professional development is limited. But each step matters. Every time a teacher finds a way to connect with a learner who is deafblind, we see a child's world opening wider.

As one teacher recently said after a training: *"Now I believe these children can learn, and I can be part of their journey."* That belief is what keeps us moving forward.

About the Author

Sadock Banda is a lecturer at Montfort Special Needs Education College in Malawi. His passion is in strengthening teacher education for learners with deafblindness.

Building Confidence and Expertise: Sensity's Professional Development Pathway in Deafblindness and Intervenor Services

LINDSAY BORDER

DIRECTOR OF TRAINING & CONSULTATION

Supporting individuals who are deafblind is a unique and deeply impactful role—one that calls for specialized knowledge, thoughtful communication, and a commitment to inclusive care. At the forefront of training in this field is Sensity, the Deafblind & Sensory Support Network of Canada, offering a series of asynchronous professional development courses that guide learners through the essential principles and practices of Intervenor Services.

Each course is structured into weekly modules, spanning 8 to 10 weeks. Learners engage with curated content, complete assignments, and participate in discussion posts that foster reflection and peer learning. While there are no live sessions, the courses are facilitated with clear deadlines, allowing participants to work at their own pace while staying connected to a learning community.

Begin with the Foundation: Deafblindness & The Role of the Intervenor

The journey begins with Deafblindness & The Role of the Intervenor, an 8-module foundational course that is required before enrolling in any of the advanced offerings. This course introduces learners to the diverse experiences of Deafblindness, exploring how individuals navigate the world when both vision and hearing are affected. It provides a deep dive into the human sensory system, helping learners understand how sensory input is processed and how its disruption impacts communication, mobility, and independence.

Participants also explore the philosophy of Intervenor Services, learning about the intervenor's role as a facilitator of access—someone who supports individuals in making choices, engaging with their environment, and building meaningful relationships.

Apply Practical Strategies: Methods & Techniques

Once the foundational course is complete, learners can enroll in Methods & Techniques, an 8-module course focused on the practical tools and strategies used in daily support. This course covers many techniques including the use of routines, repetition, environmental management, and use of residual senses. Learners explore how these techniques can be tailored to meet individual needs and promote engagement, comfort, and learning.

Foster Communication: Communication & Concept Development

Communication is central to human connection, and for individuals who are deafblind, it often requires creativity and adaptation. In the 10-module Communication & Concept Development course, learners explore a variety of communication methods—from tactile signing to object cues—and learn how to support the development of meaningful concepts.

Plan with Purpose: The Role of the Intervenor in Activity Planning

Activities are more than just tasks—they are opportunities for growth, joy, and connection. In The Role of the Intervenor in Activity Planning, learners examine how to design inclusive and enriching experiences. The course introduces the SMART goal planning process, helping intervenors set clear, achievable objectives. It also explores how bias, influence, and risk can shape experiences and outcomes, encouraging thoughtful and ethical planning through weekly reflections and assignments.

Support Across the Lifespan: Health, Wellness & Aging

Health, Wellness & Aging, addresses the evolving needs of individuals who are deafblind as they age. Learners explore how to promote healthy lifestyles, support individuals during medical appointments, and navigate the aging process with dignity and care. Weekly modules guide learners through real-world scenarios, encouraging them to think holistically about wellness and long-term support.

Take the Next Step

Whether you're a professional in the field, a caregiver, or someone passionate about inclusive support, Sensity's courses and workshops offer a powerful opportunity to deepen your knowledge and make a lasting impact.

Join the mailing list today to be notified when registration opens:

Email: training@sensity.ca
Subject line: Add me to the mailing list

Not Ready for a Full Course? Try a Workshop Instead

Not sure what path will best meet your needs yet? Not able to commit to an 8–10 week course right now? Sensity also offers an introductory workshop-based curriculum, featuring a variety of half-day and full-day courses that you and your team can benefit from. These workshops are available in both in-person and virtual formats, making it easy to fit professional development into your schedule.

To learn more about available workshops, reach out to the Training & Consultation team at training@sensity.ca

Empowering Deafblind Students: Teaching Digital and Vocational Skills

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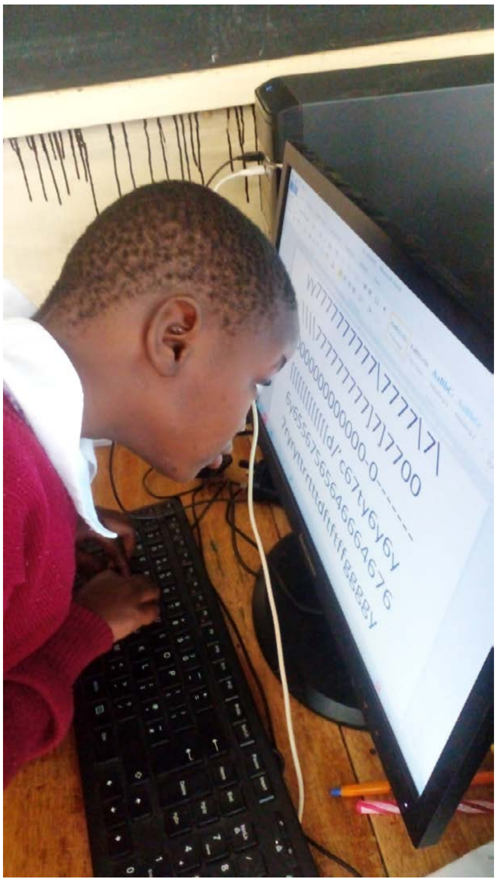
As a Deaf teacher of Deafblind students, I've witnessed firsthand the transformative power of education. In today's digital age, it's crucial to equip Deafblind students with essential skills to thrive. In our school, we're pioneering a unique approach to teaching digital and vocational skills.



Digital Skills:

We use tactile graphics, Braille displays, and assistive technology to introduce Deafblind students to computer programming, online safety, and digital citizenship. By adapting teaching methods to individual needs, we've seen students develop confidence in navigating the digital world.

Vocational Skills: Woodwork

Our woodwork program combines tactile learning with practical skills. Students learn carpentry, woodcarving, and furniture making, developing fine motor skills, problem-solving, and creativity. This hands-on approach fosters independence, self-esteem, and employability.

Benefits:

1. Enhanced digital literacy and online accessibility
2. Vocational skills for future employment
3. Increased confidence and independence
4. Improved social interaction and communication

As a Deaf teacher, I understand the importance of accessible education. By sharing our experiences, we can inspire others to provide similar opportunities, empowering Deafblind students worldwide to reach their full potential.

Unexpected but Beneficial Application of the Methodology of Working with Deafblind to Psychological Work with Children in Coma

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Like all professionals, I strived to explore new approaches, methods, and techniques in my psychological work with deafblind multihandicapped. Five years ago, I received an offer to work with children in coma after severe brain injuries, with the recommendation to develop a working methodology. The goal of these activities was stimulation aimed at awakening the patient from coma. I discovered that these two very different groups of patients shared common characteristics: a lack of communication, minimal perception of the outside world, limited contact, and ambiguous reactions. This suggested that the same or similar methods could be used.

I began with intensive multisensory stimulation, well-known and frequently used in early-stage work with deafblind children. In the hospital environment, which lacked attractive stimuli, experiencing a variety of tactile and tactile sensations was a stimulating experience for them. Feeling different textures and temperatures, the heaviness and elasticity of objects, was a significant change from only feeling the touch of bedding and hands during a medical examination and position change. In the Intensive Care Unit (ICU), patients are exposed to constant artificial light illuminating their bed, requiring constant supervision and careful observation. This light is too harsh, artificial, unnatural, monotonous, and cannot be a source of positive experiences. I tried to offer them other, more attractive sources of visual sensations (reflections, colors, and moving, intense objects). Similarly, in the ICU, the repertoire of sounds is limited, and patients hear only the sounds of equipment and alarm signals. Occasionally, they hear music or sound from the TV, watched by staff or parents. Therefore, it was important to introduce unusual, surprising, pleasant sounds, and musical pieces preferred by the person in a coma. I often used information from the family about the type of music the child enjoyed before the accident. This was consistent with the principle of reminiscence therapy, which utilizes stimuli with a strong emotional charge for the patient – those previously liked and evoking pleasant associations and positive emotional responses. Here, I utilized the principle from my work with deafblind of interrupting positive stimulation to motivate child to give signals that "I want more." I was delighted to see the first, very subtle responses appear, such as eye blinking, facial grimacing, or finger twitching.

Of course, in such situations, doubts always arise as to how much of this stimulation is registered by the patient and whether their reactions are not merely random automatisms. Such a reaction, even minimal, requires enormous effort from the patient. Furthermore, they have no feedback on whether the effort was effective and the reaction was noticed. Therefore, if it is not reinforced, it will fade. Therefore, I introduced a principle, known from my work with the deafblind, of reinforcing and rewarding even the slightest reaction, initially without knowing whether it was intentional or accidental. I named and interpreted the perceived reaction and the slightest change, for example, "I see a blink of an eye, I think you mean yes." When I observed an increase in such reactions, it was time to give the patients a sense of agency, meaning they would carry out their cues. For example, I interpreted lip movements as the message "I want to drink" and placed a drop of juice in their mouth, triggering further movements and facial grimaces. Hand movements could mean "I want to play," so I put a favorite toy in the patient's hand. As a result, these responses became more and more frequent. Their repetition in a specific context confirmed their purposefulness. This meant the patient transitioned from a coma to a minimally conscious state, a significant difference and a direct path to wake up. A turning point in this work for me and the medical team members, who were even more doubtful than I was about the wisdom and usefulness of these actions, was the behavior of a certain teenager, comatose and with multiple injuries following a traffic accident. During our meetings, he increasingly made small movements with his right hand resembling writing. One day, I took a risk, placed a pencil in his hand, and offered him a writing pad. A moment later, he wrote, "Hug me, Mom," drawing astonishment from the doctors and tears of joy from his parents. Today, that framed note hangs in my office, and the boy is a high school student.

After achieving consistent and adequate patient responses, the next step was to establish alternative communication methods, individually tailored to the patient's needs and capabilities. This is fully consistent with the rules of work with deafblind children.

Most patients benefited greatly from this stimulation and awoke from their comas. Many returned home, to school, and to play with their peers, albeit at a lower level than before the injury.

Of course, for the purposes of this article, I have presented this process briefly and generally. It was indeed lengthy and required a great deal of additional work. The course of this process and its results confirm the value of the methods used in working with deafblind multihandicapped children and their usefulness for other children with special needs.

Life Without Limits – The Story of a Deaf Woman Who Travelled the World

KOULA SOMARAKI

"It doesn't matter where you come from or what challenges you face – the world is full of possibilities.

As a deaf woman with Usher syndrome, I travelled to 88 countries with my husband and proved that life has no limits.

Dreams don't belong only to the able-bodied or the hearing.

They belong to the brave. You just need to take the first step."

ΚΟΥΛΑ Μ. ΣΩΜΑΡΑΚΗ

Η Ζωή μιας δραστήριας και θαρραλέας κωφής

(αυτοβιογραφία)

αγάπη

ελπίδα

θάρρος

επιτυχία

ΕΚΔΟΣΕΙΣ «ΚΑΜΕΙΡΟΣ»
ΑΘΗΝΑ

My name is Koula Somaraki, and I am a deaf woman with Usher Syndrome from Greece. Together with my deaf husband, Makis, we have travelled to 88 countries so far — and we are still counting!

I was born profoundly deaf, and in my early adulthood I was diagnosed with Usher Syndrome, which affects both hearing and vision. But I never let that stop me. Instead, I made a promise to myself: to live fully, to travel the world, and to prove that deaf people can do anything — even what others think is impossible.

From deserts to glaciers, and from Asia to Africa and the Arctic, we have explored the world using sign language, visual communication, and lots of courage. In 2024–2025, we completed a round-the-world journey in 59 days, crossing 11 countries and 45,000 kilometers by plane.

In 2023, I published my first book in Greek titled "Η ζωή μιας δραστήριας και θαρραλέας κωφής" (The Life of a Brave and Active Deaf Woman), which tells my personal story from childhood until today — through challenges, education, love, travels, and activism.

Now, I give book presentations, inspire others through social media, and prepare my next books in both Greek and English. I believe that every deafblind or deaf person deserves to live with dignity, freedom, and adventure.

I am currently working on translating the book into English and would be happy to share photos, excerpts, or more information if you are interested.

My message is simple: Life has no limits – only courage opens the way.

You can follow our story through my page:

DeafCouple Travels in World

Dominican Republic – Me interacting with local deaf children on the beach during our stay in the Caribbean

New York City – Standing at Times Square, one of the most iconic places in the world, during our 59-day round-the-world trip

Uzbekistan – Inside the train from Khiva to Samarkand, a unique experience on Central Asia's railways

Bali, Indonesia – Visiting the beautiful rice terraces of Tegallalang, surrounded by nature and peace

Kyrgyzstan – Exploring Fairy Tale Canyon, a surreal natural wonder shaped by the wind

Svalbard, Norway – Riding a sled through the Arctic snow during our journey in the northernmost part of Europe

Here is the list of countries and territories I have visited so far (88+). I'm happy to send more photos soon.

Europe:

Greece, Cyprus, Turkey, Albania, North Macedonia, Kosovo, Serbia, Montenegro, Bosnia and Herzegovina, Croatia, Slovenia, Italy, San Marino, Vatican City, France, Monaco, Spain, Andorra, Portugal, Malta, Germany, Austria, Switzerland, Liechtenstein, Belgium, Netherlands, Luxembourg, United Kingdom, Ireland, Norway, Sweden, Finland, Denmark, Iceland, Faroe Islands, Svalbard, Czech Republic, Slovakia, Poland, Hungary, Romania, Bulgaria, Moldova, Northern Ireland, Wales, Scotland, Latvia, Lithuania, Estonia, Ukraine, Isle of Man, Guernsey, Jersey.

Asia:

Russia, Georgia, Armenia, Azerbaijan, Kazakhstan, Uzbekistan, Kyrgyzstan, Tajikistan, China, Hong Kong, Philippines, Indonesia (Bali), United Arab Emirates, Bahrain, Oman, Kuwait, Israel, Palestine, Lebanon, Jordan, Pakistan, Thailand, Malaysia, Singapore, Maldives, Artsakh (Nagorno-Karabakh).

Africa:

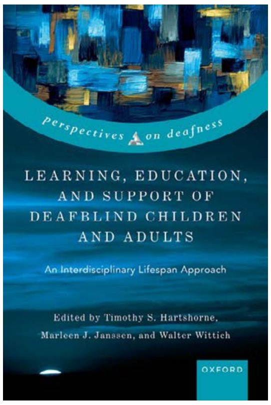
Morocco, Tunisia, Egypt.

Oceania:

Australia, New Zealand.

North America:

United States, Mexico, Cuba, Dominican Republic.



Oxford Releases First of Two Books on Deafblindness: An Interdisciplinary Approach

EDITED BY TIMOTHY S. HARTSHORNE, MARLEEN J. JANSSEN, AND WALTER WITTICH

We are excited to announce that the first of two books focused on deafblindness has just been released by Oxford Publishing. **“Learning, Education, and Support of Deafblind Children and Adults: An Interdisciplinary Lifespan Approach”** is co-edited by **Timothy S. Hartshorne, Marleen J. Janssen, and Walter Wittich**. The book contains 33 chapters, covering topics such as Identification of deafblindness, Specific Learning Areas and Interdisciplinary Support, Learning, Self-determination, and Education, Participation, Work, and Recreation, Family Perspectives, Professionalization and Interdisciplinary Approaches, and Research, Technology, and Innovations.

https://global.oup.com/academic/product/learning-education-and-support-of-deafblind-children-and-adults-9780192887221?cc=de&lang=en&

Inspiring Story of a Deafblind Girl

SANTOSH SUBEDI

I want to share with you an inspiring story of a deafblind child that deeply moved me. Their journey is a powerful reminder of resilience, courage, and the limitless potential of the human spirit.

Here is the video link:
https://youtu.be/LZxSjiS_xis?si=XP4jboBbTpPVmK_A

I believe you will find this story as touching and thought-provoking as I did.

Interview with Mirko Baur, President of Deafblind International (DbI)

Bob and Gracia Kabashi from inDicaPéd (Democratic Republic of Congo) speak with **Mirko Baur, President of Deafblind International (DbI)**, about the organization’s mission, network, and global initiatives for the deafblind community. Read the full interview to discover how international collaboration is advancing inclusion and equal opportunities worldwide.

https://empreinterdcmag.com/2025/10/30/entretien-avec-mirko-baur-president-de-deafblind-international-dbi/

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DbI Communication Ambassador: Call for Action

Deafblind
International DbI
AMBASSADOR

DbI's newly formed Communication Committee (DbI ComCom) is reaching out your help!

We expect an Ambassador to take DbI's communication to the next level by leveraging your knowledge and expertise in this area. As the old saying goes, it takes a village.

We assume that an Ambassador has well established communications with local, regional and maybe national media, an inspiring website and/or an involving social media presence. We believe that these resources could help us to spread the word about deafblindness, quality services and DbI all over the world.

What are the responsibilities of a Communication Ambassador:

1. Assist DbI in ensuring that its social media posts are reposted on your organization pages within a short period of time (1-a5 business days).
2. Assist DbI by ensuring access to your media network and sharing DbI press releases and communication with your media network within a short period of time (1-5 business days).
3. Assist DbI by having the key contact keep his/her ears to the ground to assist in sourcing regional news and information that could be shared with DbI membership and can be posted on DbI pages.
4. DbI would be grateful to have the key contact act as an ambassador and connector within their geographic area.

Organizations serving as DbI Communication Ambassadors will receive the official DbI Communication Ambassador Logo to be used freely in all of their communication. You will have your finger on the pulse of DbI's communication and be fully informed about worldwide developments in our field. Your organization will have a presence in the upcoming short film about DbI's Communication Committee ComCom. In addition, twice a year you will be invited to join an online meeting with ComCom to discuss the collaboration and the further development of DbI's communication.

Help us to make a difference for people with deafblindness worldwide and join us as a DbI Communication Ambassador! We are looking forward to your answer.

Please reach out directly to Leslie Giesbrecht about your interest at leslie@deafblindinternational.org.