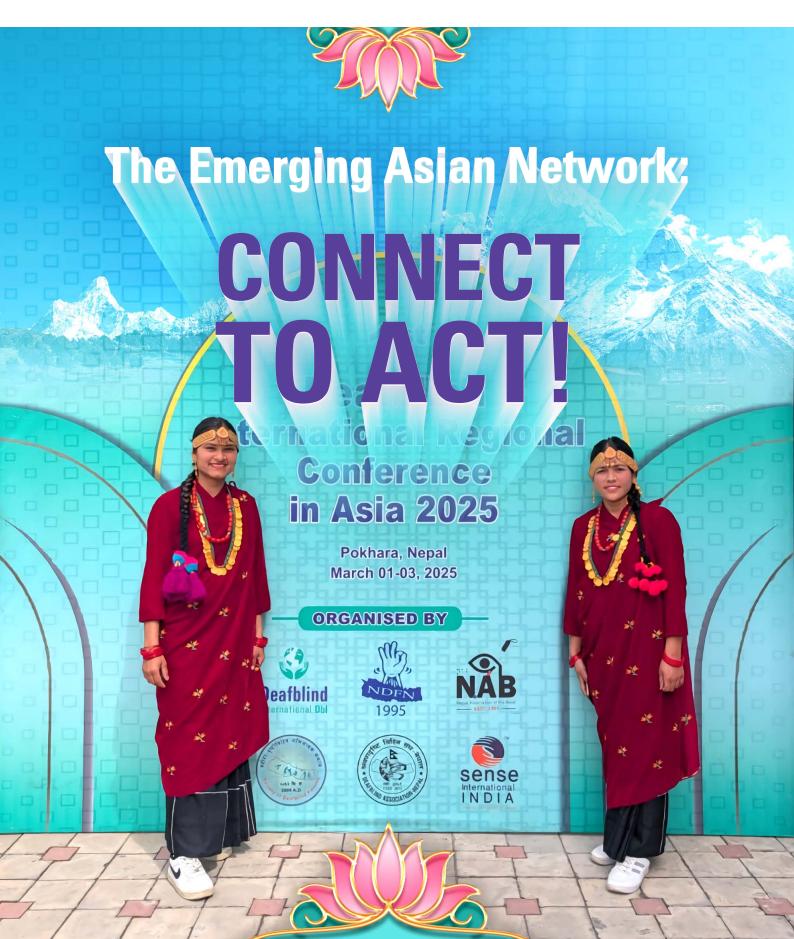
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THE MAGAZINE OF DEAFBLIND INTERNATIONAL

REVIEW





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**, Dbl 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 Dbl. For our organization, a component of our work together included helping cover the cost of their Dbl 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 Dbl. 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/

A WORD OF THE PRESIDENT



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NETWORKS AND NETWORK LEADERS



A WORD OF THE PRESIDENT



Dear DbI familiy,

With this issue of the DbI Review, we are celebrating and show-casing especially the wonderful work, the resilience, creativity and strength of people concerned and involved in Asia. While there are huge challenges in many countries in the region, there are also fantastic organisations and individuals who have overcome barriers and continue to make progress in the fight for the rights of people with deafblindness and for adequate services.

Of course, this focus is no accident. As part of our Global Education Campaign, we just had an excellent 1st official Regional Dbl Conference in Asia that took place in the Pokhara, Nepal, March 1-3, 2025. The conference exceeded all expectations. It reached more participants than hoped for, created a wonderfully inclusive conference atmosphere, came with an excellent program, a pre-conference on Comprehensive Sexuality Education and a post-conference inclusive trek. It received exten-

sive coverage on national news, empowered people, representatives of governments and supranational bodies, and organisations in attendance and resulted in many, many new connections.

The Regional Conference was certainly a most important milestone and showed once again how strong we are if we connect to act. DbI is incredibly thankful for all the cooperation that has been possible in and for Nepal. Together we can indeed make a difference!

Living and growing our DbI network is for sure vital for all of us, individuals and organisations, and even more so in an increasingly hostile political context. As terms such as diversity and inclusion are being axed, we need to connect and stand together and stand up against all forms of exclusion, discrimination and violations of human dignity and rights.

This was also one of the main common points during the Civil Society Forum prior to the 3rd



MIRKO BAUR
PRESIDENT OF
DEAFBLIND
INTERNATIONAL
BERLIN,
APRIL 4, 2025

A WORD OF THE PRESIDENT

Global Disability Summit in Berlin this April. To become stronger, we must connect with other groups with different focuses that are, of course, also part of our own network. The work of organisations that focus on children's rights, gender equality, LGBTIQ+, climate change, freedom of expression or humanitarian aid, to name just a few, are, of course, not only relevant for DbI as well, but their issues are issues of and for DbI members as well.

DbI as an organisation and DbI's members are wonderful connectors. So let us use this talent and connect even more, fully aware of our own intersectionality. Human Rights do indeed apply to all people.

But back to our focus on Asia: Guess who I met again in Berlin? Yes, a large group of friends from the Nepal conference. And immediately the network has grown again. Just have a look at this picture of Deafblind power taken yesterday, at the end of the Global Disability Summit: 27 fully involved persons with and without deafblindness.

Dive into Asia with this issue of the Dbl Review, enjoy all the other articles and news and stay connected.

Warm regards, Mirko

News from the Network Coordinator

Sometimes it is good to stand still and look back. When I started as a Dbl Network Coordinator in 2019 we had 13 DbI networks. This number has increased by four new networks in the past years and I expect a further increase in the future. Due to the active attitude of the network leaders and their commitment to organize activities for their interested members, most networks have grown. Not only in number of members but also in their visibility on social media. "Connect to act" is something we see during our online network leaders' meetings that we organize every three months. During these meetings we not only hear about the activities that each network organizes, but also see the network leaders increasingly seeking connection with each other. When I started as a Network Coordinator it was always my wish to find this connection. In addition to the own identity of each network, all networks have common themes and subjects as well. It is so good to see that this connection has emerged in the past years.

A good example of the search for common ground between the networks is the idea to organize a pre-conference during the DbI World Conference in Switzerland in 2027, where a number of networks will shape the content together. This idea is currently being investigated for feasibility by the network leaders.

Another important topic that has been worked on hard over the past year is the formation of

a small committee per network so responsibilities can be spread more. For example, each network leader now has a representative who can take the place of a network leader during our meetings if the network leader is unable to attend. In addition, the committee members are also involved in organizing webinars, writing newsletters, and other activities. We must not forget that in addition to their professional work, the network leaders do their tireless work on a voluntary basis. It is fantastic that all this work can now be spread more.

Finally, I have seen my activities in the role of a Network Coordinator grow in recent years, so it makes me very happy that my function is being supplemented with a Co-network Coordinator. Yvette Gallegos will fulfill this function. Yvette and I are currently mapping out all the tasks of a Network Coordinator to arrive at a division of tasks. I would like to give Yvette a very warm welcome!

In this DbI Review you can read about the organized activities or activities of some networks yet to be organized. It remains fantastic to see how the networks worldwide meet their members. I will therefore end with a word of thanks and respect for all network leaders, their representatives, and their other committee members. But also, a word of gratitude for all network members who were present at the various webinars and other organized activities of the networks.



TREES VAN NUNEN

DBI NETWORK
COORDINATOR

T.VANNUNEN@
KENTALIS.NL

Deafblind International Research Network Update



WALTER WITTICH
CHAIR OF THE
RESEARCH

NETWORK, PH.D.,

F.A.A.O., C.L.V.T.

The DbI Research Network is well into its 11th year of existence, and we continue to grow and expand. As of March 2025, we now have 367 members on our e-mail contact list.

Saskia Damen. Atul Jaiswal and Walter Wittich continue as moderators of the Deafblind International Research Network - Facebook (https://www.facebook. Group com/groups/158743377516989), currently at 1,463 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 212 members.

The main accomplishment of the Research Network this year. was the completion of the ICF Core Sets for Deafblindness. Deafblindness affects almost all aspects of human functioning, and can severely threaten quality of life, independence and the ability to participate. Given the heterogeneity of deafblindness, the International Classification of Functioning, Disability, and Health (ICF) can serve as a common language and will prove to be helpful in standardizing the development and selection of outcome measures for service delivery with persons living with deafblindness.

The development of the ICF Core Sets for Deafblindness is a global collaborative effort. The policy lead for this project is Ricard Lopez, representing the <u>European</u>

Deafblind Network. The scientific lead is Dr. Walter Wittich, based at the School of Optometry, Université de Montréal, Canada. Together with the World Federation of the Deafblind and Deafblind International, they brought together representatives and data from 54 countries across all six regions of the WHO.

The project encompassed a preparatory phase that included a systematic literature review, a qualitative study, an expert survey, an empirical study, and an international consensus conference, during which the Comprehensive, Intermediate and Brief ICF Core Sets for deafblindness were decided. Click on the following weblinks to access the publications which reported on these studies and on the international consensus conference:

- Protocol Publication: https://pubmed.ncbi.nlm.nih.gov/34905579/
- Systematic literature review Part 1: https://pubmed.ncbi.nlm.nih.gov/37458491/
- Systematic literature review
 Part 2: https://pubmed.ncbi.nlm.nih.gov/39235255/
- Expert survey: https://pubmed.ncbi.nlm.nih.gov/38502555/

- Qualitative study: https://pubmed.ncbi.nlm.nih.gov/39387852/
- Cross-sectional empirical study: accepted for publication in Otorhinolaryngology
- International Consensus Conference: https://doi.org/10.1177/02646196251320351

The **Comprehensive Core Set** consists of 218 codes covering every aspect that is relevant, including those important for advocacy and policy. Click here to access this core set: https://osf.io/a942k/

The Intermediate Core Set contains 137 chosen for interdisciplinary communication. Click here to access this core set: https://osf.io/627pf/

The **Brief Core Set** is made up of 33 codes prioritized for individual clinical encounters. Click here to access this core set. Click here to access this core set: https://osf.io/nk29i/

You can find ongoing updates on the project at https://whoisdeafblind.org/. For more information, feel free to contact the scientific lead Dr. Walter Wittich (walter.wittich@umontreal.ca).

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=tlaexmaaaaj&hl=en
- Ms. Caroline Gravel, Germany (core member) https://www.linkedin.com/in/carolin-gravel-4402ba298/

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



Deafblind International Communication Network Update



SASKIA DAMEN

PROF. DR.

<u>S.DAMEN@</u>

KENTALIS.NL

The Deafblind International Communication Network is planning plan to host two webinars in the middle of June 2025 focusing on practice sharing, creating an opportunity for network members to come together, share and discuss practice. Network webinars are held over two time zones to include members from different parts of the world.

During the webinars one of our network members will share a case study or story about their experience or work from within their region. The case studies/ personal stories will focus on communication, involving persons congenital deafblindness with (child or adult), present a current challenge that the presenter would like to discuss within a supportive network to gain ideas for next steps or presents a success story outlining strategies that have been effective in creating shared meaning/meaningful interactions. Video analysis will be used to support discussion and practice sharing.

We are now finalizing agreements with the presenters. A call for registration will be made once we have agreed on the presenters. The webinars will include an opportunity to discuss with members topics for future webinars.

Reminder: Network Member Facebook Group

The Dbl 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

News from the Dbl CHARGE Network

In this spring edition we'd like to share the experience we had with our very first online case discussions and announce our next event.

We started 2025 with two sessions of online case discussion in groups with participants from different countries.

Online case discussions

Every parent or professional involved with a child or adult with CHARGE syndrome will sometimes doubt how to support the individual with CHARGE best. Very often, if a 'problem' appears, we try to start 'solving' it as quickly as possible. Sometimes that makes us forget to reflect on a situation first.

Our aim in the online cases discussions was to explore real cases from daily practice and learn from reflection and different perspectives.

In both sessions, we found a member of our network willing to share a case with us. Both groups contained a small number of participants from different countries; both parents, professionals and researchers.

We used a simple but tightly structured method for the case discussions. The aim was to discuss difficult matters using reflection instead of offering 'ready-made' solutions or tips.

Asking questions, listening to different perspectives and sharing experiences in these case discussions was very interesting and yielded a lot for all participants, not just for the person who shared a case. The participants noticed many similarities with their own case(s) and it was very interesting to hear different ideas and ways of looking at a case.

Although at first it may feel very vulnerable to share a case with a group of people you may barely know, all participants experienced this way of discussing a case as very respectful and safe. Having experienced this, some of the participants in these first two sessions, announced that they would like to share a case next time.

We hope to continue this way of reflecting on real cases with each other in the CHARGE Network.

We are planning a next round of online case discussions after the summer, on September 24, 2025.



ANNE SCHOONE

CO-CHAIR DEAFBLIND INTERNATIONAL CHARGE NETWORK

A.SCHOONE@ KENTALIS.NL

NEWS

Webinar by dr. Timothy Hartshorne

We are also planning a webinar by dr. Timothy Hartshorne; 'Thoughts on behavior in CHARGE'. This presentation will address Tim's thinking about behavior in CHARGE syndrome and how it has evolved over the past 30 years. Tim will talk about some of the reasons for the behavior and how recognizing the communicative rela-

tionship around behavior can help us to change it.

This webinar will take place on May 21, 2025.

If you are interested in our activities but not yet a member, please join us in the CHARGE Network. We are looking forward to welcome you!

The CHARGE Network Committee

- Andrea Wanka, University of Education, Heidelberg, Germany
- Anne Schoone, Royal Kentalis, The Netherlands
- Heather Colson-Osborne, Seashell Trust United Kingdom
- Vimla Ramrakhiani, Seashell Trust United Kingdom
- Lourdes Quintana Baez, CHARGE Syndrome Foundation, USA
- Allison Mail, CDBA, Canada
- Jerry Petroff, College of New Jersey, USA

News from the Network of the Americas

Our network planning committee continues to meet monthly to discuss and organize presentations that we believe will be of interest to the members of our network. As a network based on geographics we are committed to ensuring that all presentations and related discussions are available simultaneously in English, Spanish, Portuguese and ASL.

The Dbl Network of the Americas sponsored a two-part topical discussion, on September 19th and November 14th, 2024. Our presenter, Chris Montgomery (who is also a member of the Network of the Americas planning committee) provided an overview on interaction, communication and language for congenitally deafblind (CDB) learners that was very well received by persons from all over the Americas. Below is an excerpt and short summary of the presentations.

"When we say "tactile perspective" most seeing-hearing people think primarily of what we touch through our hands. To understand the tactile perspective of a child who is deafblind, especially one who is born deafblind, we must think further than our own fingertips.

Consider what information is gathered through the hair moving on our arms when the breeze is gently blowing on a sunny day. We feel the sun on our face even if we may not pay particular attention to it. We are aware of the breeze even though we might be more focused on something else. These sensations come to us tactually. Automatically.

Much like visual and auditory information. However, if we lack the visual reference of the sun in the sky or the auditory reference of the breeze moving through the trees, how might we relate these concepts? What is the language we use to communicate this tactile-bodily feeling of the breeze in our hair or the sun on our face?

Surely the English word "sun" has a different meaning here; not one that is bright, yellow, or setting on the horizon. From a tactile-body perspective, we might use language such as warm or hot, and express that language through movement and touch sensation. What does the word breeze or wind mean in this context? It is not enough for us to speak or sign these words. We must express ourselves through the modal context of the tactile bodily experience. It is my belief that if we want to help our child who is deafblind learn our language, we must first learn their language."

During part-one, discussion included thoughts on the tactile-bodily experience; the importance of touch, conversation as an interactive event, and the co-creation of tactile language The discussion concluded with an interview clip that Chris had done in 2016 with Dr. Jan Van Dijk.

In part-two, discussion resumed with ideas on embodied cognition and how meaning is created through the body's physical experiences, or through "the body's act of doing". We applied these thoughts to how we might create meaningful, functional routines



CHRIS MONTGOMERY



MONACO

NETWORK OF THE AMERICAS

NEWS

for deafblind learners. Discussion also included thoughts and strategies for creating calendar systems that support the meaningful development of language, literacy and concepts of time. Tactile working memory and the telling of one's story, through autobiographical memory strategies, to provide context and conceptualization of past events and the development of a sense of self were also a part of the presentation.

There were many video examples along the way. Questions and dialogue from the attendees were encouraged. Robust conversation concluded both topical discussions with many participants expressing a new level of curiosity and insight.

The two-part series was not intended to provide a step-by-step guide. Unfortunately, time did not allow for in-depth training on specific learning strategies. The hope was that

our presentation might prompt reflection on what it means to be a person who is deafblind. To ask what our role should be as educators and family members who hope to connect on a deeper level. Can we open ourselves to the child's expertise and learn from him or her about the rich landscape that exists in their tactile world? My colleague, Robbie Blaha, used to tell me; "it's all about adding drops to the bucket until the bucket overflows". Hopefully we have added some of those drops.

Learn more about our presenter, Chris Montgomery at: https://www.chrismontgomerydb-ed.com

Our 2025 topical discussions will take place on the following dates and with the following presenters. Each session is 90 minutes in length and starts at 3:30 Pacific time, 4:30 Mountain time, 5:30 Central time, 6:30 Eastern time and 7:30 Atlantic time.

DATE	PRESENTER	TOPIC
Thursday April 10, 2025	Nancy Steele	The Communication Matrix & Beyond
Thursday July 10, 2025	David Brown	The Forgotten Senses
Thursday November 6, 2025	Maria Bove	Inclusive Systems Supporting Accessibility

The **mission** of this network is to provide opportunities and platforms where members can share their successes, challenges and practices toward creating a barrier-free life for people who are deafblind.

To join the network please go to the Deafblind International website, join DbI and then join The Network of the Americas.

We look forward to welcoming you to The Network of the Americas!







News from the Deafblind International Outdoor Network



JOE GIBSON

DEAFBLIND
OUTDOORS@
GMAIL.COM

Deafblind International Outdoor Network has been meeting as an informal group since 2006 and as an official DbI network since 2012. The annual meetings are a way of sharing outdoor activity experiences, seeing how other people do activities and meeting new and old friends. The 2024 meeting was held in a seaside town, Largs in the west of Scotland from 23rd to 27th September with our accommodation being the SportScotland Training National Centre Inverclyde. The group of 50 people that attended comprised of 19 participants and their carers/support staff from Scotland, England, Northern Ireland, Denmark and The Netherlands.

We had four new participants to the outdoor network this year and another returning after a 12year hiatus!

The group reconnected over the week by taking part in some great outdoor activities including a trip on the ferry to the Isle of Cumbrae on the first full day where we had an art session on the beach. With some surprisingly beautiful weather, participants alongside their support staff were encouraged to create art on pieces of clay which were then fired in a portable kiln by our Sense

NEWS

Scotland arts tutor, Imelda, later in the week. Everyone got to take their work home as a signifier of their outdoor week. Some of our participants also braved a ride on a quadricycle along the beach front – for some this was their first experience of using a bike, feeling pedals beneath their feet and the momentum of moving in tandem with others – this was a hit!

A day of walking trails at Dean Castle Country Park included trying to find some hiding haggis in the forest as well as being introduced to taxidermy pieces by the park rangers – this was a tactile and sensory experience for those who chose to participate.

A wet and windy experience followed at Castle Semple on the last full day of the outdoor week. Our participants enjoyed a very bumpy ride on a speedboat across the loch, including our wheelchair users who used a fabulous accessible wheelyboat! For others, a ride on bikes on a trail was more preferable – this came with lots of laughing and navigating with the help of carers and volunteers.

The final evening of the outdoor week was an introduction to traditional Scottish music and dance. A piper guided two highland dancers into our party area where they dance beautifully for us. This encouraged a few of our participants to start dancing – this is when the ceilidh kicked off! Members of the Sense Scotland arts & music team, David, Dave & Matthew performed for the rest of the evening with some help from Murray our outdoor week participant, who played his accordion alongside them. The evening was emotional, fun and very lively and a fitting end to a week in Scotland.

The main organiser of the outdoor week in Scotland, Emma, explained her feelings of the week in Scotland:

"Having attended three previous amazing Outdoor Network weeks as a carer, I was aware of the importance of inclusivity in terms of activities but also felt that the week had to reflect Scotland.

The most exciting part of the week was welcoming everyone – especially our new participants, some of whom had never experienced anything like this before. It was an honour getting to know them, and a privilege to witness the friendships made on these annual events which have nevertheless lasted for years, emphasizing the importance of the Outdoor Network.

The impact of being around people who are deafblind is one that I can't always put into words - I am constantly humbled and in awe of what they can achieve. I am incredibly appreciative of how much effort was put in by all of the participants, carers and volunteers who attend the week in Scotland, and being a part of this group effort has been the highlight of my career thus far."

Feedback from carers who attended the week included;

"All the activities were suitable & appropriate and well received. The friendship is on show at all times. Several people have remarked that they felt welcome and included despite some nervousness beforehand. This is the beauty of the DBI Outdoor Network!"

"I think being amongst friends and around people who understood them was the best part for the person I supported to the Outdoor Network"

When asked if the experience of the outdoor week had a positive impact on the participant, one parent explained;

"At the ceilidh, this improved his dancing and musicality in general. He is now up for dancing for the first time ever at any event he attends. This has increased his confidence and participants in local events. His gentleness with the ladies that he chooses to dance with is gorgeous to watch".

The 2025 meeting will be held at the end of September in Denmark. Look out for the announcements in the DbI Review or online.

News from the Deafblind International Educational Network

This is a teaser that the interactive world map will soon see the light of day on the DbI website and thus have its world premiere. 150 addresses around the world are currently listed; from NGOs to large multinational organisations.

When you view the map, you can point to a country with the cursor and immediately you can read which organizations are involved in deafblindness in that country.

If you feel that your organisation and work in the field of deafblindness is not mentioned, please do not hesitate to fill out the template attached under the world map as a link. Information from you is beneficial for the dynamics and development and not least for our world around deafblindness. Accessibility, proximity and self-help for everyone.

As inventor and founder, I will also do my part to make the world map as comprehensive as possible. If you have any questions, please don't hesitate to contact me via email: anmaru@rn.dk or irina@deafblindinternational.org who will be in charge of the daily running.

ANDERS MARTIN RUNDH

CHAIR OF THE DBI EDUCATIONAL NETWORK MARCH 2025

Education Map Test



Click on country to see its education facilities list.

Drag the globe to rotate it.

Zoom with the mousewheel.

Inventor and founder Anders M. Rundh, Aalborgskolen, Denmark

Deafblind UK and Birmingham City University Open Groundbreaking Centre for Education and Research

DEAFBLIND UK, LONDON, UK. INFO@DEAFBLIND. ORGUK



The launch of the new Deafblind UK Centre for Education and Research at Birmingham City University (BCU) marks a significant milestone in the field of deafblindness. This pioneering initiative will connect researchers, practitioners, and those impacted by deafblindness to raise awareness and enhance knowledge of the condition.

The Centre is the first of its kind and will also provide training for junior researchers and professionals, equipping them to lead future research and practice, and creating a new generation of specialists. It is hoped that this will act as a catalyst for innovation and new approaches to supporting people affected by deafblindness.

Deafblind UK CEO Nikki Morris highlighted the need for greater insight into the condition: "There's an urgent need to better understand the impact of deafblindness on people and their loved ones. This new Centre will help to fill that gap."

David Childs, Associate Professor and Head of College of Education and Social Work at BCU, agrees, saying: "The research undertaken in this area is low. The new Centre won't just meet the knowledge gap, it will be an important beacon of hope to those affected by dual sensory loss."

Dr. Peter Simcock, Chair of the DbI Acquired Deafblindness Network, (ADBN) and internationally renowned researcher, is leading the new Centre. Dr. Simcock and his team will ensure the research informs support services and influences policy decisions.

The Centre will not only enhance our understanding of deafblindness but will also shape the development of future support services, ensuring that people with sensory loss receive the best possible care and support. The research will be instrumental in influencing decision-makers, developers and practitioners to ensure that services are created with deafblind people in mind.

Deafblind UK and BCU have been collaborating since 2019 and, together with a consortium of charities, co-created that the Certificate and Diploma in Professional Studies (Deafblind Studies) in 2021.

For updates on this groundbreaking project, follow #DBUKresearchBCU on social media or visit www.deafblind.org.uk.

The Emerging Asian Network: Connect to Act!

DEAFBLIND INTERNATIONAL Dbl launched the idea of an Asian Network at the 1st Dbl Regional Conference in Asia, held in Pokhara, Nepal, from March 1-3, 2025. While the Asian Network is not yet an official Dbl Network, we can certainly speak of an emerging Network, thanks to the high level of interest and enthusiasm shared by participants across the region.

As part of our usual process, we're reaching out to everyone who has already expressed interest in joining the Network during the Nepal conference.

This is an exciting step toward deeper regional collaboration and community building in Asia.

Interested in joining?

Select "Emerging Asian Network" from the dropdown and become part of this growing and supportive community. https://www.deafblindinternational.org/become-a-member/individual-members/register/

For more information or to express your interest, please contact:

- Sachin Rizal, Head of Capacity Building, Sense International India sachin@senseintindia.org
- Lhakpa Nuru Sherpa,
 President, Society of DeafBlind
 Parents Nepal
 sdbpnepal@gmail.com





Deafblind International Youth Network Activity for 2025

Efteling Theme Park Resort

Situated in North Netherlands

The enchanting world of wonders set in a spacious environment twice the area of Disneyland Paris!

The activity will take place over two days

October 28th / October 29th, 2025

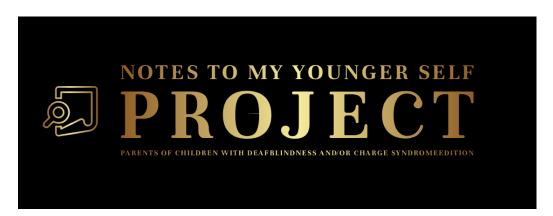
Take this unique opportunity to connect with other Deafblind youth from across the world

For information on travel, accommodation and access to Efteling please contact the network coordinator simon.allison@sense.org.uk





Notes to My Younger Self Project



JERRY G. PETROFF

PH.D.

THE COLLEGE OF NEW JERSEY

The "Notes to My Younger Self Project" is a research initiative that attempts to gather the wisdom, perspectives, advice and of encouragement parents, grandparents, and guardians of children, youth and adults with Deafblindness and/or **CHARGE** Syndrome and create a repository of the thoughts from experienced parents and caregivers. The central focus of this study is to identify key themes and collective advice of parents with children who are deafblind and/or have CHARGE Syndrome through submission of a Letter written to themselves at the birth of their child expressing advice, encouragement and hope.

A simple vehicle to gather data has been developed and implemented in an on-line survey that asks identified parents one question or prompt: Looking back, what advice would you give to your younger self at the beginning of this journey with your child with deafblindness and/or CHARGE Syndrome? You may consider writing a letter to yourself at the birth of your child with deafblindness and/or with CHARGE Syndrome expressing advice, encouragement and hope.

Please consider participating in the research study by accessing this online survey with the following link:

Notes to My Younger Self Project

If you have any questions or need further clarity please contact: Jerry G Petroff, PhD at petroff@tcnj.edu. Thank You for considering participating in this study that focuses on yielding information by parents for parents.

The Dbl Outdoor Network Week 2025 in Denmark

Friluftscenter Sletten, Søhøjlandet. September 22-26

CALO@RN.DK

AND

J.PETERS@RN.DK



Friluftscenter Sletten (https://friluftscentersletten.dk/) is a scouts campground situated in a beautiful area surrounded by forests and lakes. The activities during the Week will mainly take place in the surrounding area. We will be going on a small bus ride one of the days for a boat trip.

Useful information: We recommend using Billund Airport if you are flying to come join us – we can help organize bus transport from and to Billund.

We will need to help each other out with small chores during the day. Such as doing the dishes, sweeping floors and so on.

Unfortunately, there are no special needs aids (e.g. beds and lifts) available at the campground.

We expect the price to be approx. 4800 DKK per person attending. This includes activities, meals and accommodation. For example, one person with additional needs + one carer = 9600 DKK.

ri

Book now - or before JUNE 1.: Register by filling in this form: https://skema.rn.dk/LinkCollector?key=T3GTK743J591 Please note: a deposit of 800 DKK is required to reserve a space. Please use the information below:



Kontohaver: REGION NORDJYULLAND

IBAN: DK87 3000 0013 3398 99

BIC/SWIFT: DABADKKK

Create And Connect

Beyond Barriers: Expressions for All Senses

This year we are excited to announce **#CreateAndConnect**, a social media campaign that allows organizations, supporters, allies, and those with lived experience to choose and share their own creative expression or activity that fosters global connection, awareness, and joy, sparking meaningful conversations, and shared experiences.







Examples of creative expression:

- Tactile art that engages the senses
- Cooking as a medium for storytelling and connection
- Yarn bombing transforming everyday spaces into vibrant displays ofcolor and texture
- Dancing that allows for movement

Be creative - creative expression can be made of anything!

Showcase these moments on your social media and using **#CreateAndConnect** to help spread awareness. Leading up to June we will be sending out tips and ideas on how to make this campaign a success!

Keep an eye on your inboxes for more details to come!

'Deafblind Asia': Meet the Global Education Campaign Projects in the Region



MIRKO BAUR

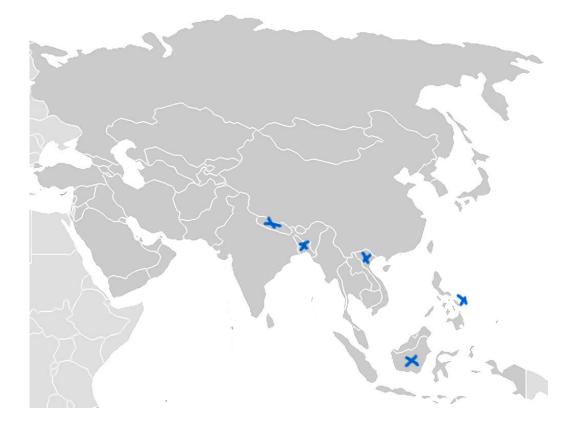
PRESIDENT OF
DEAFBLIND
INTERNATIONAL

What does the term 'Asia' mean to you? And what do you think while reading 'Deafblind Asia'?

According to worldatlas.com, Asia is the world's largest continent in terms of land area and population. It covers around 17 million square miles and is home to over 4.5 billion. Asia consists of 48 countries, three of which are trans-continental

There are five major regions of Asia. These are Central Asia (with countries like Tajikistan or Uzbekistan), East Asia (with countries like China or North Korea), South Asia (with countries like India or Iran), Southeast Asia (with countries like Malaysia or Thailand), and Western Asia (with countries like Georgia or Oman).

Obviously, 'Asia' refers to a huge part of the world with a huge amount of diversity in many aspects. There are indeed many Asias, or also many South Asias, for example.



There are even more 'Deafblind Asias' if we apply this term to the lives of people with deafblindness in certain parts of Asia. It is therefore simply impossible to cover 'Deafblind Asia' in this article. Based on the latest population projections from the United Nations in 2024 and the proportion of up to 2% from the 1st Global Report of the World Federation of the Deafblind WFDB from 2018, we would have to account for 95,560,080 different lives.

We could tell individual stories instead. But then, of course, the question would arise as to why we are telling these stories and not others, and which stories cannot be told because they are not accessible to us. And there are certainly many of those.

Instead, we will share a little about what we have learned about 'Deafblind Asia' from the Global Education Campaign.

Plans for projects have been drawn up in five Asian countries as part of the campaign: In Bangladesh, Indonesia, Nepal, the Philippines and Vietnam.

The project in **Bangladesh** aims to empower teachers to close the existing inclusion gap for learners with deafblindness.

Bangladesh recognised deafblindness and multiple disabilities as separate disability categories in 2013. However, no clear guidelines have been established and no government measures have been developed. Education policy and strategies have not addressed the issue of including these children in the regular education process.

Against this background, the project has the following objectives:

- Strengthening teachers in mainstream primary schools through training or capacity-building workshops
- Creating sustainable peer support systems for teachers

If enough funds can be secured, the project will be implemented in the district of Sirajganj in the central north. This district is geographically prone to floods and riverbank erosion. Children with disabilities are

often excluded from all forms of education, and children with deafblindness are not identified and their needs are not taken into account.

The project is led by the Centre for Disability in Development (CDD), which has established the National Resource Centre for Deafblindness (NRCDB) in collaboration with Sense International and Sense International India.

The project in **Indonesia** would involve three key institutions: the only school in Indonesia specialising in deafblindness, the Helen Keller School in Yogyakarta, and two institutions in Jakarta and a province about 100 km outside Jakarta that accept students with deafblindness.

The project aims to develop a model programme for the transition and vocational training of young people with deafblindness.

Vocational training programmes are increasingly the focus of discussion and attention in Indonesia. However, these efforts are often based on school decisions and do not take sufficient account of the uniqueness of the students and their families. This situation is even more difficult for students with severe disabilities, including deafblindness. Not many students with deafblindness are successful in their adult lives after leaving school.

Therefore, the project plans to offer comprehensive training and mentoring for educators and families by conducting workshops and training sessions and providing ongoing support and mentoring.

Indonesia needs such a pioneering vocational training programme and individual role models: students with deafblindness who successfully transition into adult life.

In Nepal, our conference partners from the Deafblind Association Nepal, the Society of Deafblind Parents Nepal and the National Federation of the Deaf Nepal have developed two projects. One project aims to create a comprehensive framework for the early identification and early intervention of people with deafblindness. The other project aims to create a framework for adapt-

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ing curricula and supporting teachers and peers in demonstrating how inclusive education can benefit children with deafblindness in schools, special education classes and home-based education.

The current situation in Nepal shows that there are significant gaps in the identification of people with deafblindness. Those involved lack awareness and understanding of deafblindness. The education of children with deafblindness is still a relatively new field. Although efforts have been made to improve their educational opportunities and significant progress has been achieved, considerable challenges remain. One of the biggest challenges is the lack of training for teachers. Many teachers do not have the necessary skills and knowledge to effectively support children with deafblindness. This lack of training leads to difficulties in adapting the curriculum to the special needs of these children.

The project in the **Philippines** is being carried out by Resources for the Blind, a Christian non-profit organisation that has been working with people with visual impairments since 1988, in collaboration with the Early Childhood Care and Development Council and the Department of Education. The aim of the project is to develop a resource guide for teachers and service providers working with learners with deafblindness and multiple disabilities.

For over a decade, the Philippine Department of Education's K-12 curriculum has been adapted to meet the educational needs of children with disabilities. In response to the COVID-19 pandemic, the Ministry introduced the K-12 Transition Curriculum for Learners with Disabilities and additional curriculum content for visual impairments. However, these measures remained too general and insufficient to meet the specific needs of learners with deafblindness and/or multiple disabilities.



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For this reason, the project focuses on a comprehensive guide that provides tailored educational support, teaching methods and strategies specifically for deafblindness and multiple disabilities. This guide is based on a joint writing workshop conducted by a team of special education experts, parents, service providers and consultants.

Finally, the project in **Vietnam** aims to establish early identification and early intervention for children with deafblindness in Ho Chi Minh City and the surrounding provinces. Currently, there is no data available in Vietnam and very few services are available for this group of children. Almost all of them live at home, are not identified, registered or recognised, and are excluded from education. The situation is dramatic and life-threatening – there is no other way to describe it.

This could change with this consistent and very important project by the Nhat Hong Centre for the Blind and Visually Impaired in cooperation with the Faculty of Special Education at the University of Education in Ho Chi Minh City, the Support Centre for

People with Disabilities in Cu Chi, Ho Chi Minh City, and the Support Centre for the Development of Inclusive Education in Binh Duong Province.

The project focuses on identification, intervention, research and awareness-raising and aims to find and support 10 children with deafblindness in its first year.

Obviously, all these projects could make a huge difference in the lives of children with deablindness and their families. They all focus on the greatest local needs, are based on national, inclusive networks and cost an average of just EUR 20,000.

DbI is a wonderful global network. Together, we have great resources and can achieve a lot. So if you or your organisation would like to make a financial contribution to one of the projects described, please do so and help open doors in Asia. You can find more information about the Global Education Campaign, including a link to our ongoing crowdfunding campaign, on this page of our website: Global Education Campaign — Deafblind International DbI

1st Regional Deafblind International Conference in Asia

IRINA MOISEEVA

DEAFBLIND
INTERNATIONAL
INFORMATION
OFFICER,
PSYCHOLOGIST,
DEAFBLIND
SUPPORT
RESOURCE CENTER
"YASENEVA
POLYANA",
FOUNDATION
"CON-NECTION"

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BLINDINTERNA-

"Are you also attending the conference?"

"Yes, I am." - I just stopped for a moment near the local souvenir shop on my way to the conference hall.

"A big conference, yes? A lot of people, a lot of countries, right?"

In fact, there were 320 participants from 23 countries, many of whom had lived experience.

Warm wind, bright blue sky, a group of young women with badges hurrying up the narrow street, then another two women in orange, pink, and purple saris passing by. One of the women is blind, and the other is guiding her.

The street turns, and a stunning view of Annapurna forces me to slow down.

At the next turn, there's a crowd, people talking and moving - almost immediately you can feel excitement and joy in the air. Later I will find here researchers, service providers, and parents from all over the world, but of course mostly from India, Nepal, and other Asian regions. There were people from different parts of the world connected with each other for years through their work and studies in the field of deafblindness. Others just met for the first time. Some staying in touch for years online, but met each other in person for the

first time. Such as Sunil and Akiko who communicated for the first time during the interview for the **Dbl** Communication Committee (ComCom). It took three interpreters to make this dialog happen, and a moment to communicate directly through touch as Akiko and Sunil are people with deafblindness. You can watch interviews with both Akiko and Sunil on the Dbl YouTube Channel, and you will find there even more interviews with conference attendees and leaders of the deafblind community in Asia https://www.youtube. com/@deafblindinternational3406

Each of the three days of the conference was filled with great presentations (about 70 in total), speaking up for children and adults with deafblindness, emphasizing the role of communication, inclusion, and learning from each other, networking, and sometimes—even dancing between the sessions.

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Photo 1. Sampada Shevde during her presentation

Education, occupation and community engagement were critical themes at the conference, with discussions on adapted curriculums, micro-entrepreneurship support, and overcoming policy barriers for people with disabilities in South Asia. Keynote speeches by leaders highlighted global advocacy efforts, the need for self-advocacy, and systemic reforms to secure rights and recognition for the deafblind community. Technological innovation was discussed through presentations on assistive technology, tactile communication systems, and the use of braille embossers and haptic feedback tools. Underlying all sessions was a commitment to human rights, empowerment, and the "Nothing about Deafblind without Deafblind" principle, reinforcing the need for representation, participation, and systemic change in policy and practice across Asia.

During the conference the Awards Ceremony took place. Awards Chair Carolyn Monaco honored three outstanding individuals for their exceptional contributions to the field of deafblindness.

Two Distinguished Service Awards were presented:

 Dr. Namita Jacob (India) for her global impact as an educator, trainer, and advocate, improving the lives of people with

- deafblindness and empowering others through collaboration and inclusion.
- Sunil Abbas (India) for his leadership, advocacy, and technical innovation, enhancing accessibility and independence for people with deafblindness in India and beyond.
- The Lifetime Achievement Award was presented to Graciela Ferioli (Argentina) for over four decades of pioneering work in Latin America and the Caribbean, her leadership in Dbl, educational influence, policy advocacy, and her creative energy in driving the organization forward.

On the third day of the conference, a wonderful mix of cultures was blended, and presenters from Europe also began their speeches with "namaste."



Photo 2. Carolyn Monaco giving an award to Sunil Abbas

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Photo 3. Poon Hill Trek. (Meredith Prain's photo archive)



Photo 4. Poon Hill Trek. (Meredith Prain's photo archive)

The support and passion of local organizations, professionals, parents, and people with lived experience were remarkable and an inspiring example of dedication. During the sessions, the halls were full, and here

and there, you could see mothers with young children with deafblindness on their laps, groups of people signing, or watching the sign language interpretation.

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On the final day of the conference, Mirko Baur, President of Deafblind International, announced a new emerging DbI Network — the Asian Network. You could tell from the applause and cheering in the audience that this news was highly appreciated!

After the conference closed, networking continued on an inclusive trek through the Pokhara hills.

People with deafblindness participated in the trek for 5 days too. Participants noted that this trek was a great experience of international collaboration.

The conference will hopefully have a longterm impact in Asia, as it generated a great deal of interest, enthusiasm and optimism for progress in the field of deafblindness and resulted in many new contacts.

II Congress of Rare Diseases 'Alex Garcia' Celebrates Success!

PROF. ALEX GARCIA

February 29th is a rare date, which only happens in leap years, which is why it is the Rare Disease awareness date.

It is estimated that in Brazil around 13 million people have some rare or ultra-rare health condition. And the topic needs to be debated and clarified so that PWDs no longer suffer prejudice.

Within the proposal of Inclusion and Diversity through Information, last Thursday, February 29th, the II Congress on Rare Diseases "Alex Garcia" was held, bringing together speakers from all regions of the country and broadcast online to everyone.

The in-person event space, in Osasco, had maximum capacity. The online broadcast via YouTube started at 10:30 am and ended at 5:30 pm, and participants received certificates. There were more than 1500 participants from all regions of the country and also international participants from the most diverse areas such as health, law, fashion, as well as researchers, students, rare and ultra-rare patients and families, achieving the objective of Diversity and Information.

The accessible and anti-disability production, as well as the differentiated programming of Tudo Sobre Indições Consultoria, was designed especially for the II

Congress on Rare Diseases 'Alex Garcia'.

The event was attended by some such authorities as Gilberto Almazan (Ratinho), President of the Metalworkers Union of Osasco and Region and several directors, João Batista da Costa - General Secretary of the Metalworkers Union of Osasco and Region, José Elias Gois - President of the CISSOR Inter-Union Health and Safety Council of Osasco and Region, several leaders from the Trade Union of Osasco, From the Federation of Trade Workers of the State of São Paulo was Eunice Aires Camilo, advisor in the area of training and programs and Carlos Clemente President of Espaço da Citizenship. The councilors of the Osasco City Council: Batista Comunidade, Elsa Natal de Oliveira and Ralfi Rafael da Silva and the presence of Salomão Junior, Municipal Secretary for People with Disabilities and rare Osasco syndrome. Also participating were Cristiane Oliveira, counselor and second secretary of the Municipal Council for People with Disabilities (COMPED) in the city of São Paulo, Fátima Rocha from Unidiversidades and Daniel Mendes, Relationship Manager at Brasil Eco Fashion Week and Creative Director at Âmagôh.

Highlighted with international support in the launch of Mitocon Brasil , by President Dr. Pedro Mendes and director Alexandre Braun of the Brazilian Association of Mitochondrial Genetics and Mitochondrial Diseases, being a member of the IMP – International Mito Patients (International Federation that brings together mitochondrial disease associations). It will be the first time that a Latin American country has become a member of the IMP, which puts Brazil and Latin America on the path of studies, experimental treatments and cooperation with the global community.



Photo 1.



Photo 2.

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Photo 3.

The program included the following actions:

The "Rare Female Entrepreneurship" axis with 2 speakers on diversity and adapted fashion; Ana Luh Garritano, Modeling teacher at Senac Lapa Faustolo and social entrepreneur Grace Santos who brought the idea of Braille and QR Code in pieces adapted for the audience to see and surprised everyone with their innovation at a congress and their respect for their role.

"Listening to Grace Santos' lecture on "Diagnosis is not a sentence" was a life lesson", said Glenda Felippe e Silva, blind, who is a Social Security Technician – INSS present at the Congress.

100 sunflower lanyards were distributed free of charge to those who registered, (law 14.624/23) as a symbol of identification for people with hidden disabilities. In addition to raffles for shirts without and with BRAILE and mugs donated by Grace Santos and other event giveaways. The SAS de LIBRAS Choir performed two songs.

The non-profit event also had a food drive for the NGO AMAMOS, which serves children and teenagers in Osasco.

Renowned "rare" speakers, including Professor Alex Garcia, one of the best-known deafblind people in the world and founder-president of the Gaúcha Association of Parents and Friends of the Deafblind and Multidisabled – AGAPASM. Alex Garcia, deafblind person, with hydrocephalus and a rare health condition, who spoke about "The importance of Congress on the day of the rare and voice in authority".

Dr Pedro Mendes Ferreira Neto spoke about "Public Policies for people with rare diseases in Brazil: from current paradigms to the necessary construction of new foundations".

Dr. Têmis Maria Félix Geneticist brought the topic "Rare Network and patients with highly complex rare diseases".

Dr André Naves spoke about "The Law and Rare Disease – a path to Citizen Emancipation".



Photo 4.

Prof. Alex Garcia talked about his inspiring trajectory "His experience in Inclusive Education and the education of deafblind people for their autonomy and independence".

Carlos Aparício Clemente spoke about "The importance of the Quota Law and the fight for its compliance".

And Pamela Pimentel on "Occupying spaces. the need to perceive disability as part of human diversity".

Cristina Cagliari spoke about Ultra Rare Diseases.

Ana Luh Garritano explained "How to be Rare in the world of Fashion".

Grace Santos spoke about "Diagnosis is not a sentence".

For more information about the event and organization: Tudo sobre Indições Consultoria on the website www.tudosobreinclusao.com.

Credits: Paulo Speranza Congress photographer

About ICT - Everything about Inclusion Consulting

It is a Hub with a multi-diverse team called "Agents of Transformation" in actions for lectures, courses and workshops. They have a multidisciplinary nature specializing in Fashion, Sustainability, Law, Customer Service, Design/Visual Merchandising, Crafts, Event Production, Psychology, among others, with a broad and holistic approach through DEI&I – Diversity, Equity, Interaction (Inclusion) and Equality. They work in social, private and governmental organizations to create more welcoming, affectionate, healthy, equitable, accessible environments, as well as products and services that serve the entire diversity of people.

They work in line with the Brazilian Law on the Inclusion of Persons with Disabilities, Law No. 13,146, of July 6, 2015, which is a set of devices designed to ensure and promote,

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on equal terms with other people, the exercise of rights and fundamental freedoms for people with some disability condition, aiming at their social inclusion and citizenship.

TIC promotes events with a focus on architectural accessibility, comfortable environments and autonomy for access. They use inclusive language and empathy that take

into account the representativeness, accessibility and audience interaction of audiovisual products for everyone who needs this resource: translating images into alternative words or texts and words/voice in Brazilian Sign Language for the deaf. Contact: Cristiane Mayworm. Producer and CEO. Cell phone: +55 11 91008.7477. contato@tudosobreinclusao.com - www.tudosobreinclusao.com

Facilitating Participation in Inclusive Research for Persons with Pre-Lingual Deafblindness — A Service Provider's Perspective

This article highlights DeafBlind Ontario Services' involvement in a global research project that facilitates the participation of people with pre-lingual deafblindness¹. The initiative builds on DeafBlind Ontario Services' service model, which is centered on lifelong partnerships with people who are deafblind, their families, and professionals.

One of DeafBlind Ontario Services' strategic plan objectives is to improve the quality of life for people who are deafblind. The organization collaborates with academic institutions to explore innovative ways to provide quality services to people who are deafblind as well as people who experience dual sensory loss.

Background

The World Health Organization (WHO) developed the International Classification of Functioning, Disability and Health (ICF) to describe health and functioning, providing a universal framework for communication among stakeholders. Although ICF Core Sets exist for various health conditions,

none had been developed for deafblindness.

Importance of the Core Sets

The ICF Core Set for deafblindness is vital for people who are deafblind, as they are often excluded from social participation, policies, and services. It will significantly impact healthcare professionals, policymakers, researchers, service providers, and people with deafblindness by facilitating communication and improving support among all stakeholders.

Development of the ICF Core Set

The process of developing an ICF Core Set involves four key studies: (1) a systematic literature re-

1 https://wfdb.eu/wp-content/uploads/2023/03/ENG WFDB-2nd-Global-Report -FINAL-V6.pdf

RENU MINHAS

DEAFBLIND ONTARIO SERVICES, CANADA

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view, (2) a qualitative study capturing the experience of people who are deafblind, (3) an expert survey on healthcare professionals' perspectives, and (4) an empirical study focused on clinical perspectives. A Consensus Conference finalizes the Core Set. The studies are conducted using principles outlined by the ICF Research Branch for development of ICF Core Sets.

The Collaboration

In 2020, DeafBlind Ontario Services partnered with Ricard Lopez (WCPDB) and other organizations to include people with pre-lingual deafblindness in a qualitative study. The global research team included researchers from the University of Montreal, Orebro University and Queen's University along with national and international community organizations.

DeafBlind Ontario Services' Role

DeafBlind Ontario Services helped overcome communication, time and environmental barriers for people with pre-lingual deafblindness so they could participate. The organization worked with Dr. Walter Wittich from the University of Montreal to ensure ethical research conduct and to help participants engage meaningfully.

DeafBlind Ontario Services made several contributions, including:

- Supporting Dr. Wittich's hiring of a Research Assistant for the literature review phase.
- Ensuring written informed consent and preparing participants for their roles.
- Contributing to knowledge advancement and capacity building within the organization
- Offering perspectives of people with pre-lingual deafblindness whose needs differ from those who acquire deafblindness later in life.

Direct Involvement

DeafBlind Ontario Services contributed to several phases of the research process, such as:

- 1. Assisting with the systematic literature review by screening articles.
- Participating in the Expert Survey (Intervenors).
- Facilitating collection of qualitative data from people with pre-lingual deafblindness and their families.
- 4. Reviewing recommendations at the Consensus Conference.
- Co-authoring three key publications on ICF Core Sets for deafblindness.

How We Did It

DeafBlind Ontario Services ensured ethical research practices by obtaining written informed consent from all participants, their families, and intervenors. Orientation sessions were held to prepare the community for their roles. The organization also coordinated logistics for virtual interviews and kept stakeholders informed throughout the process.

Employee Perspectives

Employees shared their experiences:

- Lorraine: "Being part of this research initiative has been rewarding. It's not just about academic knowledge; it's about giving voice to those who are often unheard."
- Annette: "This research has opened my eyes to the challenges and strengths of individuals with deafblindness. I am glad their needs are the forefront of global discussions on disability and health."
- Rhonda: "I'm proud to be part of a team that actively works towards inclusivity in global research."

Research Team Perspectives

Dr. Walter Wittich, Principal Investigator, commented: "The work on the ICF Core Sets is only relevant if organizations like DeafBlind Ontario Services see its value and support its progress. Our collaboration with them has allowed us to identify shared research priorities and be productive together."

Norman Robert Boi, Interviewer, added: "Partnering with DBOS enriched the data

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collection process. Their knowledge of participants' preferred communication methods made the research experience valuable for everyone involved."

Conclusion

This global research initiative allowed DeafBlind Ontario Services to contribute to the development of ICF Core Sets for deafblindness, impacting service delivery for current and future generations of people who are deafblind. Through this collaboration, DeafBlind Ontario Services demonstrated its commitment to inclusivity, ethical research practices, and improving the quality of life for people with pre-lingual deafblindness.

A Little Miracle (Al and Individuals who are Deafblind)

ROGER WILSON-HINDS

ROGER@ SCREENREADER. NET While we are all so busy focusing on our own obsessions, a little AI miracle has just happened for those of us who have significant vision and hearing loss and want to do well on the web.

Best find it all out for yourself! Download Copilot or Gemini on your PC or smartphone and take a little time to explore how it works, for example using the computer keyboard. Tab, Shift Tab, the arrow keys and Enger key will fill your mind and imagination to the brim. A minimal knowledge of tapping, double tapping and swiping will work just as well on your smartphone. All you have to do is to start a conversation with the AI on any topic using either the keyboard, the smartphone screen, or your voice, and see where it takes you. The AI is not confused by the accessibility limitations that frustrate us, individuals who are deafblind, so much. The AI sorts it out allowing you to see, hear or use the Braille display to access everything you need. If you want to keep any of what you find, copy it and paste it into Microsoft Word or Google Docs, perhaps spend a little time editing it and then store it all where you can find it. Maybe worrying about Alt Text, labelling buttons and all the other issues is a thing of the past for us. I don't suppose Copilot or Gemini were invented for the individuals who are blind or even deafblind but the inventors have not excluded us.

Interested? If so, let's take a closer look at what's happening in the world of Al.

I have spent a good deal of time over the past months curiously investigating four apps on a laptop and a smartphone. The apps are:

- Microsoft Copilot
- Google Gemini
- Be My Eyes
- NotebookLM

The apps are free and easy to use, require no deep knowledge of how the web works, specific keystrokes or gestures which have been such a big part of our Internet learning and frustration over recent years. It seems that the website designers may be about to be let off the hook when it comes to meeting the needs of the individuals who are blind or deafblind. If there is no Alt Text to describe images, the buttons are not labeled, the screens are cluttered or the fonts are unreadable or inappropriately coloured... well, the AI doesn't have disabilities as we do and it sorts it out for us. In case you may be wondering, no! I don't fully understand AI and how it works, but I do understand how it can work for me and others like me.

Artificial Intelligence or AI is marketed everywhere as the big thing that will change the world, as well as our working and leisure lives. Everyone, it seems, has an opinion about AI. However, this is not what I am concerned about here. Of the four apps listed above, only Be My Eyes was invented for us. The others are designed to improve productivity and efficiency in education and work. The professional versions are quite expensive and do indeed promise to disrupt the working lives of many professionals. So, almost incidentally, the crumbs from the rich man's table have fallen into our laps and we can choose to take the time to reap the benefits if we want to.

In this article, I will focus solely on Copilot to illustrate what is going on. If you have a modern Windows 11 PC, Copilot is probably already available for you. If you have an older computer or if you use a smartphone, you will need to download the app.

I think of Copilot as a super simple version of Google for us. I ask and the app responds with information. I can type my question or press the TAB key once and speak it. To hear the response, I press the Shift Tab key three times and listen because I am still able to hear clear speech over my headphones and hearing aid. If you read Braille or need large font, press Shift Tab three times, then press Control A to highlight the results, Control C to copy the results to the clipboard, paste them with Control V into Microsoft Word or Google Docs and read at your leisure, choosing the font size or via the Braille display. All commands are straightforward and familiar. Smartphone users will only need to double tap and swipe.

But this is only the beginning. Braille or large font users will, of course, need to get back into Copilot from their document. Non-Braille users will press the Tab Key to get back to the text entry line or press Tab Key four times to speak again. Either way, you can interrogate Copilot for increasingly specific information as many times as you wish, listen to it or copy/paste it into Microsoft Word for Braille or large font.

OK so far!!! It seems, there is no limit to what you can search for. I have learned to think of the interrogation procedure as a kind of a relaxed conversation between me and the AI, Copilot. I can change topic at any time, rephrase my question and just quit when I have had enough or the responses are not satisfactory. There are a couple of buttons that allow you to evaluate each response as good or bad. They tell us that Copilot is learning from its customers but my experience is that it is me who is learning how to make better requests.

If you like the idea of this easy conversation with AI, you might like to explore much further. You, for example, can ask Copilot to write a poem or a story. You can request a written crossword puzzle or jokes. You can engage in philosophical debate or get quickly to considerable detail of medical conditions or even emotional needs. In all this and more, you can even tell Copilot how many words you expect in the responses. You always need to learn to be specific regarding the topic or task on your mind.

Over the past few months, I have found that Copilot has greatly enhanced my ability to have fun and to learn. I have no doubt that it provides me with stuff to think and talk about and makes me a more interesting individual who is deafblind and presumably improves my chances of interacting with other human beings.

As mentioned at the beginning of the article, Google Gemini and Google NotebookLM operate in a manner similar to Microsoft Copilot. Be My Eyes is rather different and I plan to write about the benefits of Be My Eyes for us, individuals who are deafblind, in a subsequent article.

Contact details

Roger Wilson-Hinds is a retired teacher. He can be contacted by email at roger@screenreader.net He has a book on Amazon Kindle: My Early Blind Life. Roger feels strongly that the voice of the individuals who are deafblind is rarely heard and is often drowned out.

Training Profiles of Professionals who Work with Deafblind People: Results of a Global Survey

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Introduction

The first global report of the World Federation for the Deafblind notes that access to "a professional interpreter-guide service can be the key to accessing other services and fundamental rights, such as education, employment, healthcare, culture and recreation" for deafblind people (2018, p. 5). Yet access to such services is far from universal. Partly this is a funding issue, but the second global report of the World Federation for the Deafblind (2023) also foregrounds that the issue is compounded by a lack of training and certification programs for professionals work-

ing with deafblind clients in much of the world.

A challenge in establishing training programs is ascertaining what skills should be covered and what models of delivery might work best. In this article we report key findings from a global survey of professionals working with deafblind people (Willoughby et al., 2023). Our research aimed to provide a better understanding of the training landscape internationally, including respondents' experience with pre-service training, professional development and barriers to training.

Methodology

In order to ensure global reach, our survey was distributed in

five languages: English, Chinese, French, Japanese and Spanish.

The questionnaires were distributed through a variety of electronic channels, including Facebook post by key deafblindness service providers/ networks, newsletters and direct emails to our contacts. The survey was open from July-October 2021.

We received 324 completed responses from professionals working with deafblind clients across 36 countries. Australia (27%) Japan (23%) and Canada (10%) were the most rep-

resented countries. Just under half (46%) of our respondents worked solely or mainly as interpreters, 23% as support workers and 30% in mixed or other roles. Respondents were generally well educated: just over half (52%) held a bachelor degree or higher. Many were also highly experienced: over half of the interpreters but only 31% of support workers had been working in the field for more than 10 years.

Results

Preservice training

The survey showed very different levels of post-secondary education between support workers and interpreters. Only two support workers held a relevant bachelor degree or higher qualification specifically focused on support work, whereas 28% of interpreters held interpreting degrees at that level. This suggests that the interpreting pathway is much more professionalised, but only 37% of interpreters reported having had any interpreter training, either on-the-job training or a short course.

It is important to note that the majority of interpreters did not report having specific training in deafblind interpreting. Instead, they hold more generic sign language interpreting qualifications. Two exceptions to this rule were interpreters from Japan and Norway, though they operate at opposite ends of the spectrum in terms of depth of training. In Japan, all but one of the interpreters was a registered interpreter-guide for deafblind people [盲ろう者向け通訳・介助員] or a registered guide helper [同行援護従事者]. These designations relate to credentials

that are based on quite short trainings: 42 hours of mandatory training and an optional 42 additional hours for 'registered interpreter-guides' and 20 hours of general training plus 12 hours of specific deafblind training for 'registered guide helpers'. In contrast, in Norway, all respondents were sign language interpreters who had been trained through an interpreting Bachelors degree program which includes specific training and assessment in deafblind interpreting (Erlenkamp et al., 2014). In Australia, a number of interpreters reported that they had completed an optional module (i.e. 'Communicate with deafblind people') on deafblindness as part of a vocational Diploma in Auslan (i.e. a language acquisition course taken before formal training as an interpreter). However, this elective module was not compulsory and not a pre-requisite for people to work with deafblind clients. It also focuses on giving an overview of different aspects of deafblind communication rather than on interpreting between spoken English and tactile sign language.

Professional development experience

Around half of our respondents had less than 15 hours of professional development in this area across their entire careers. This speaks to a dearth of training in the area, which was confirmed from responses to subsequent questions. The most common training that people had accessed was deafblind awareness training (accessed by

around 80% of respondents) and guiding deafblind people (accessed by over 65% of respondents). Between 40-60% of respondents had attended a short training in visual frame signing, introduction to tactile signing and haptics, while less than 30% had any training at all in protactile or specialised aspects of tactile signing (e.g. use of space, use

of pronouns). Respondents were, however, extremely enthusiastic about the trainings that they had been able to attend, reporting average satisfaction ratings of 4.2-4.6 out of 5 for the vast majority of trainings that we asked about. They also gave average scores above 4 on the same scale when asked their interest in receiving more training in these areas.

At the end of the survey, respondents had the opportunity to give open-ended responses about aspects of training that they had found particularly useful or instructive/beneficial? Alongside comments highlighting particular skills learned, three major themes emerged from these responses:

- the majority of respondents feel that they are learning their skills in this area much more through working on-the-job with specific clients than through professional development;
- if respondents attend training in a communication practice that their clients don't use (e.g. haptics) they quickly forget the skill;
- good professional development needs to have hands-on components and include deafblind people at its core. This enables participants to gain a real understanding of their experiences. It also enables practical opportunities to communicate with deafblind people in a simulated and safe environment.

Barriers to training

Respondents who indicated that they hadn't undertaken training in an area were asked about barriers to this. 49% indicated that there was no training available in their area to attend and 14% indicated that training had been offered but the timing hadn't suited them. 29% provided write-in responses to this question where most reported that they had either already learnt that skill on the job, or that they were themselves involved in training delivery rather than attending training. As one might expect, respondents who were delivering training generally had been practicing for more than 11 years and had often indicated earlier that they began their career before formal qualifications as (Deaf) interpreters were established. A number of respondents who hadn't attended trainings raised issues around their attendance at training being unpaid and thus making it difficult to attend (both to cover the costs of the training and the income forgone in not working that day).

Respondents had the opportunity to give open-ended comments about the training they desired, with over 90 respondents listing training in specific communication skills or methods that they would like to see, including 39 respondents whose preference was to attend anything and everything, as they had had little to no formal training to date. A lack of more advanced trainings was commonly raised as was the need to formalise training pathways that people can access prior to commencing work in the field. In agreement with the conclusions of the global report of the World Federation for the Deafblind (2023), respondents saw formalising training pathways as a key step in ensuring workforce quality.

Conclusion

This article has highlighted the global lack of structured training available to professionals working with deafblind people, but also the clear appetite for more training among this cohort. The majority of respondents had already completed in excess of 15 hours of professional development on deafblind com-

munication, but were very keen for more: especially at a post-elementary level. Lack of training opportunities was the most widely identified barrier to participating in more professional learning, Lastly, training that features deafblind people and their experiences was seen as most useful and relevant.

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Addressing the Mental Health Needs of People with Deafblindness



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Introduction

Deafblindness is a complex disability that combines significant hearing and visual impairments. This condition poses severe challenges, limiting communication, mobility, and access to information. Often, individuals with deafblindness experience neglect, discrimination, and isolation, which lead to critical mental health concerns.

Mental health challenges, while common among the deafblind community, are often misunderstood or overlooked. Feelings of frustration, isolation, and dependency can escalate into anxiety, depression, or behavioral disor-

ders if left unaddressed. These concerns are compounded by a lack of awareness and specialized resources, making mental health interventions a critical need.

At the forefront of this issue, Sense International India has been working to address these challenges through innovative and inclusive programs. Reaching over 400,000 individuals across 24 states, the organization's initiatives focus on capacity building, advocacy, and direct interventions to promote mental well-being among children and young adults with deafblindness (CYDb).

Mental Health Needs of People with Deafblindness

The pandemic brought the mental health challenges of CYDb into sharper focus, as isolation and disruptions to routine aggravated existing vulnerabilities. A survey conducted by Sense International India revealed a pressing need to address issues such as:

- Feelings of isolation and loneliness due to communication barriers.
- Behavioral issues arising from unmet emotional needs.

 Psychological strain on families and caregivers, impacting the well-being of CYDb.

Mental health challenges are unique in the deafblind community because they stem not only from internal struggles but also from external barriers like societal stigma, lack of accessible mental health services, and limited awareness among professionals.

A Pioneering Approach to Mental Health Interventions

Sense International India, supported by Grand Challenges Canada (GCC), launched a

pilot project to address mental health needs comprehensively.

Screening and Assessment:

The project developed the first-ever mental health screening checklist specifically for CYDb. Based on globally recognized tools like the WHO-5 Well-being Index and Self-Reporting Questionnaire (SRQ-20), this checklist was tailored to capture the unique

emotional, behavioral, social, cognitive, and physiological challenges of CYDb.

Special educators administered the checklist to ensure culturally relevant and sensitive assessments, uncovering patterns that had long been overlooked.

Intervention Activities:

To address the identified needs, the program introduced creative, low-cost, and engaging interventions:

- "My World" Activity: This storytelling activity helped participants articulate their emotions and share their experiences, fostering self-expression and connection.
- Clay Activity: A hands-on exercise that reduced stress and encouraged creativity, helping participants process emotions non-verbally.
- Relaxation Breathing: Simple breathing techniques to manage anxiety and enhance emotional regulation.

Counselling Support:

For CYDb with severe mental health concerns, the program connected them to psychiatrists and psychologists for targeted

interventions. In-house psychologists also provided ongoing counseling to support participants and their families.

Training Mental Health Professionals:

Recognizing the lack of expertise in addressing the mental health needs of the deafblind community, Sense International India developed specialized training for mental health

professionals. This training emphasized cultural and regional contexts and equipped professionals with the skills to provide inclusive care.

Expanding the Focus to Families and Siblings

The mental health of individuals with deafblindness cannot be addressed in isolation. Families, particularly siblings, play a crucial role in their lives but often face emotional strain and neglect themselves.

Sibling Network:

Sense International India has pioneered the development of a sibling network to:

- Foster a supportive environment for sharing experiences and strategies.
- Strengthen caregiving abilities through targeted resources and training.
- Improve siblings' mental and emotional well-being, empowering them to advocate for their deafblind family members.

 The interconnected nature of family well-being means that addressing the mental health of parents and siblings can significantly enhance outcomes for CYDb.

Broader Learning and Insights

Several key lessons emerged from the pilot project:

- Mental health needs of CYDb vary significantly by region, requiring localized approaches.
- In-person training conducted in local languages has a greater impact on engagement and outcomes.
- Adapting mental health activities to the specific needs of CYDb ensures relevance and effectiveness.
- Low-cost, sustainable interventions make mental health care accessible to marginalized communities.
- Regular home visits by professionals help gain deeper insights into the challenges faced by CYDb and their families.

Overcoming Barriers

The project faced challenges in scaling interventions, including:

- Adapting programs for the diverse spectrum of deafblindness.
- Overcoming language barriers and cultural differences.
- Resistance from parents hesitant to seek mental health care for their children.
- Engaging a wide pool of mental health professionals across regions.
- Despite these hurdles, the initiative has laid a strong foundation for future efforts.

A Vision for the Future

To build on the success of this program, Sense International India aims to:

 Expand the target population to include younger children and additional stakeholders like parents, siblings, and educators.

- Advocate for policy changes to prioritize mental health care for the deafblind community.
- Train a larger pool of professionals to deliver tailored mental health services.
- Develop referral mechanisms to connect CYDb with specialized care across regions.

Conclusion

Mental health is a critical yet often neglected aspect of care for individuals with deafblindness. Addressing this need requires a holistic approach that integrates emotional support, family involvement, professional training, and systemic advocacy.

Sense International India's efforts demonstrate that meaningful change is possible

through innovative interventions and collaborative partnerships. By prioritizing mental health, we can empower individuals with deafblindness to overcome barriers and lead fulfilling lives, while fostering resilience within their families and communities.

For more information or to support these initiatives, visit www.senseintindia.org

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Project Report: Use of the My Assistive Technology Outcomes Framework with Adults with Deafblindness in Kenya

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Introduction

Assistive Technology (AT) is the umbrella term for assistive products and the services needed to ensure their safe assessment, distribution and use (WHO and UNICEF, 2022).

The value of AT for people with deafblindness is well recognised. However, research literature on deafblindness largely focuses on those living in high-income countries, with limited research on the AT needs and rights of people with deafblindness in less well-resourced contexts, like Kenya.

The project reported on here, builds on the work of Bell, Prain and Layton (2021), who explored the relevance and face validity of the My Assistive Technology Outcomes Framework (MyATOF) in relation to deafblindness in the Southern African Development Community.

The MyATOF was developed in Australia in partnership with AT users (Layton et al. 2019). It is a tool for data collection and storytelling, or articulation of needs, and is intended for use by AT users, their care partners and the health or education professionals that support them. The MyATOF has six domains - supports, out-

The current project aimed to address these research questions:

comes, rights, costs, service pro-

vision and satisfaction.

- What do participants report regarding supports, outcomes, costs, human rights, service delivery and customer experience (the domains of the MyATOF)?
- Do participants' articulation of AT needs (self-advocacy)

change after completing MyATOF?

3. What were participants' views about usability and effectiveness of the MyATOF tool?

Method

Approval from a Human Research Ethics Committee for this study was granted by the Research Ethics Committee of the Institute of Education (IOE), UCL's Faculty of Education and Society (Data protection registration number: Z6364106/2024/02/70).

Participants were recruited through the networks of Deafblind International and members of the project team.

Online interviews were conducted with participants before and after responding to questions related to each section of the My

Assistive Technology Outcomes Framework

The interview data were analysed used codebook thematic analysis with a priori codes.

A methodological consideration of this project was the composition of the research team. Bringing together a team with diverse perspectives, including from the local context, and with lived experience of vision impairment, and from diverse professional backgrounds including education and allied health, helped to ensure appropriateness, accessibility and relevance of the research methods.

Results

Four participants were recruited. These included two females and two males all living in Kenya. The sample was diverse, with ages ranging from 23 years to 58

years, communication modes (two participants were supported by an interpreter), residential settings, and personal and professional backgrounds (See Table 1).

Table 1. Characteristics of participants

	Gender	Age (years)	Commu- nication mode	Where do you live?	Deafblind- ness	Back- ground
P1	Female	31	Sign Language	Village	Acquired full blind- ness. Born fully deaf.	Lives with family. Has a job from home.
P2	Male	23	Oral	City	Born fully blind and partially deaf.	Lives with family. College student.
Р3	Male	58	Sign Language	Town	Born par- tially blind and fully deaf.	Lives with family. Disability advocate.

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	Gender	Age (years)	Commu- nication mode	Where do you live?	Deafblind- ness	Back- ground
P4	Female	34	Oral	City	Acquired full blind- ness and acquired partial deafness.	Lives with family. University student and employed at an organization.

The results from the analysis of the interviews showed the participants use a broad range of AT, as well as relying on human supports such as sign language interpreters. The study highlights challenges in accessing AT and navigating AT systems in Kenya. Participants noted the need for better training, improved environmental and information access, and more affordable and reliable AT options.

The MyATOF proved effective in helping participants articulate their needs and advocate better for themselves.

Some region specific challenges which impacted the research included internet connectivity and the availability of trained interpreters.

Discussion

The study highlights the importance of tailored policy, interventions and enhanced AT systems to support individuals with deaf-blindness in less-resourced settings.

Three key overall observations can be made from analysis of the data generated in this study. Firstly, the value of self-reflection. The MyATOF provided participants with a structured approach to think critically about their current assistive technology (AT) use, and AT needs, something many had not done previously. This led to increased awareness of potential AT solutions and a clearer articulation of their needs.

Secondly, potentially improved self and systemic advocacy. By discussing their AT needs, participants gained confidence in advocating for their rights and accessing nec-

essary supports. The questions asked in order to complete each section of the MyATOF encouraged participants to consider not only what they currently use but also what they might need, fostering a proactive approach to self-advocacy. It also helped them frame their disability according to the social model of disability, that is, to think what supports and adaptations they need to enable their participation, instead of taking it for granted that they have to face daily challenges.

Thirdly, the challenges in expression that exist for this cohort. Despite the benefits noted above, some participants found it challenging to articulate their needs, potentially due to a lack of previous experience in using reflective tools like the MyATOF.

Conclusion

This study adds to the developing evidence base supporting the relevance and appropriateness of using the MyATOF with people with deafblindness in Africa. The evidence generated from the interviews with four adults with deafblindness from Kenya, points again to the critical role of context (particularly policy, funding and information services) in enabling the participation of people with deafblindness.



Note: A manuscript based on the project findings has been submitted to Disability and

Rehabilitation: Assistive Technology and is currently under review

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Understanding Time for Congenitally Deafblind Individuals Bridging Julian Barbour's Temporal Concepts with Jan van Dijk's Calendar System

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Abstract

Teaching the concept of time to congenitally deafblind individuals poses unique challenges due to their limited access to auditory and visual temporal cues. Traditional time models are inaccessible, but Julian Barbour's theory of time as an emergent property of change offers a practical framework. This article integrates Barbour's theory with Jan van Dijk's tactile calendar system, using sequential tac-

tile representations to teach time through relational changes in daily events. By conceptualizing time as tactile "calendar cells" akin to film frames, learners move from temporal stagnation to dynamic understanding. This approach bridges theoretical insights with practical strategies, making time accessible and relevant to deafblind education.

Introduction

Time profoundly influences cognition, behavior, and social interaction, with typically developing learners gradually acquiring temporal concepts through auditory and visual cues—observing the sun's movement or hearing a clock's ticking (Fraisse, 1984; Boroditsky, 2001). Language further refines these temporal understandings, allowing individuals to communicate nuances of dura-

tion, sequence, and expectation (Boroditsky, 2001). However, congenitally deafblind learners lack direct access to these sensory and linguistic inputs, making the acquisition of temporal concepts exceptionally difficult (McInnes & Treffry, 2016).

Despite advances in deafblind education, a persistent gap remains: how to teach time without

relying on sighted or auditory constructs. Traditional models rooted in Newtonian or Einsteinian frameworks are inaccessible due to their abstract nature and dependence on visual or auditory representations (Hersh & Johnson, 2008). This article addresses that gap by integrating Julian Barbour's reinterpretation of time as emergent from changes in configuration with Jan van Dijk's tactile educational tools, specifically his calendar system. By doing so, we offer a novel, scien-

tifically grounded approach to convey temporal concepts—one that turns abstract intervals into tangible, manipulable sequences. Here, each component of the calendar can be viewed as a still frame, and the progression from one tactile "cell" to the next creates an experience similar to moving through frames of a film. This metaphor transports the deafblind learner from a state of temporal stagnation to perceiving a continuum of change.

Historical Background of Temporal Concepts

For centuries, time was considered a uniform, absolute entity. Isaac Newton described it as a steady, universal flow independent of events (Newton, 1687/1999). In conventional educational contexts, this model is illustrated by observing uniform time increments or hearing auditory signals or inputs inaccessible to congenitally deafblind learners.

Einstein's theory of relativity (Einstein, 1916/2005) introduced time as part of a four

dimensional spacetime continuum, flexible and influenced by gravity and velocity. While revolutionary, Einstein's conceptualization requires complex diagrams and mathematical representations. Both Newton's and Einstein's frameworks demand senses and cognitive operations that congenitally deafblind learners cannot easily utilize (Hersh & Johnson, 2008).

Challenges with Traditional Models for Deafblind Education

Using Newtonian or Einsteinian models in deafblind education is challenging. Newton's notion of absolute time relies on auditory and visual intervals, while Einstein's model involves abstract mathematical constructs and visual metaphors of warping dimensions (Hersh & Johnson, 2008). Moreover, the linguistic structures describing these

concepts are often inaccessible, limiting psycholinguistic processing (Verschueren, 1999). To effectively teach temporal concepts to congenitally deafblind individuals, educators need models that are inherently tactile, experiential, and grounded in the learner's immediate environment.

Julian Barbour's Perspective on Time

Physicist Julian Barbour (1999) offers a radical departure from conventional notions, suggesting that time is not a separate dimension. Instead, time emerges from relational changes in the configuration of matter, an approach known as shape dynamics

(Barbour & Ó Murchadha, 2010). In Barbour's view, the universe consists of a series of static "Nows," each a unique arrangement of particles in a configuration space he terms "Platonia."

Time as an Illusion

Barbour's concept posits that the passage of time is an illusion born from our consciousness experiencing configurations sequentially. This aligns with the philosophical notion of "becoming," where reality is in a state of constant flux rather than static being (Heidegger, 1927/1962). Instead of a universal time flow, there is a succession of changes - alterations in arrangement - experienced as temporal progression.

Shape Dynamics and Change

Shape dynamics focuses on relationships and geometry, not on time as a separate entity (Barbour & Ó Murchadha, 2010). The arrow of time, conventionally linked to increasing entropy (Eddington, 1928), is replaced by the directedness of sequential config-

urations. These relational changes offer a tangible, observable foundation, resonating with psycholinguistic insights that temporal concepts often emerge from experiential grounding (Evans, 2004).

Differences from Traditional Models

By eliminating the need for a dedicated time dimension, Barbour's theory lends itself to tactile representation. Instead of explaining abstract intervals or four dimensional constructs, educators can highlight successive environmental changes. This shift aligns with psycholinguistic perspectives that emphasize experiential grounding in the development of temporal understanding (Evans, 2004).

Relevance to Congenitally Deafblind Individuals

For congenitally deafblind learners, the environment itself becomes the primary source of perceivable change. By focusing on tangible alterations rather than unseen or unheard intervals, Barbour's model becomes

accessible. Educators can present a series of tactile "Nows" that, when rearranged or changed, communicate the experience of temporal progression without relying on visual or auditory cues.

Jan van Dijk's Calendar System

Jan van Dijk pioneered educational strategies for deafblind individuals using tactile and kinesthetic experiences (van Dijk, 2001). His calendar system is composed of tactile / accessible symbols or objects that represent sequences of daily events. As learners manipulate these tactile symbols, they experience changes that map onto temporal progression.

Calendars as Chronographs and Filmic Frames

Van Dijk's calendar system can be understood as a chronograph; a tactile device that tracks the progression of events. Each "cell" or tactile marker within the calendar functions like a single still frame in a film roll. Viewed individually, these frames represent isolated snapshots of activity configurations, offering no inherent sense of temporal flow. However, as the learner moves from one cell to the next, removing or altering objects after completing activities, these frames are "played" in sequence. This creates an embodied sense of progression, much like watching a series of still images coalesce into a moving picture. Thus, the tactile calendar transforms time from a static abstraction into a dynamic, experiential sequence that the learner can comprehend directly.



Fig. 1. Example of a tactile calendar system.

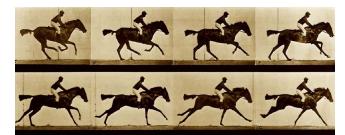


Fig. 2. Part of a famous study by Eadweard Muybridge, used to analyze animal locomotion.

Focusing on Change of Configuration

This approach aligns with Barbour's notion that time emerges from changes in configuration. Just as a filmstrip gains meaning when frames are viewed successively, the tactile calendar gains temporal significance when objects are rearranged to reflect completed tasks and upcoming activities. This irreversible sequence of transformations mirrors the arrow of time and fosters the sense of "becoming" as the learner actively participates in temporal unfolding.

Parallels with General Human Perception of Time

The way congenitally deafblind individuals derive temporal meaning from changing tactile configurations parallels universal human perception. Sighted, hearing individuals also rely on environmental transformations,

shifting shadows, clock hands, to infer temporal passage (Fraisse, 1984). Language and metaphor further shape these perceptions (Lakoff & Johnson, 1980; Whorf, 1956).

Linguistic and Psycholinguistic Understanding of Time

Language both encodes and influences temporal thought (Boroditsky, 2001). For congenitally deafblind individuals, tactile symbols and gestures become their language. The tactile calendar system thus doubles as a communication tool that encodes tempo-

ral concepts ("before," "after," "morning," "afternoon") in sequences of objects (Rowland & Schweigert, 2000). Psycholinguistic development is thereby supported as these learners anchor temporal cognition in concrete, manipulable items (Dammeyer, 2014).

The Concept of "Becoming" in Temporal Understanding

Philosophically, "becoming" highlights the continuous transformation of reality (Heidegger, 1927/1962). By integrating this perspective, educators encourage deafblind learners to experience time as a process of

change rather than a static condition. The tactile calendar, structured as sequential frames, reinforces that events unfold, one after another, reflecting a lived experience of becoming.

Integration with Barbour's Theory

Barbour's model, emphasizing configurations over an abstract temporal dimension, dovetails seamlessly with van Dijk's tactile calendars. Each step in the calendar process matches a new configuration, a new "Now", that when recognized as part of a sequence, conveys the illusion of temporal flow. This embodied learning approach renders complex theoretical concepts accessible.

Integrating Barbour's Theories with van Dijk's Calendar System

Practical Applications

By merging these theoretical and pedagogical approaches, educators can create tangible representations of time, helping congenitally deafblind learners move through sequences of still frames to experience a coherent narrative of change.

Daily Activities: Arrange objects representing daily activities (e.g., a toothbrush for morning grooming, a spoon for breakfast) as a series of still frames. Removing each item after its associated activity is done "advances the film," fostering a sense of progression.

- Weekly Routines: Assign distinct textures for days of the week. As learners move from one textured marker to another, they "scroll" through frames, gaining a sense of longer-term temporal structure.
- Seasonal Changes: Introduce tactile symbols for each season. Progressing from one season's symbol to the next is like moving through a longer film reel, reinforcing that broader environmental changes also represent sequential configurations.

Implications for Education and Development

This integrated approach enriches comprehension by grounding time in direct sensory experience. Anticipating events through tactile sequences reduces anxiety and fosters autonomy (McInnes & Treffry, 2016). Communication improves as caregivers and educators reference the same tactile

"frames" to discuss sequences, promoting social integration and shared understanding (Bruce et al., 2018). Psycholinguistic processing is supported as learners develop a tactile language of time (Rowland & Schweigert, 2000).

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Active Learning with a Tray of Treasures from the Bottom of the Sea



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Incorporating movement into early childhood education classes is a common practice in many schools. Whether through intuition or specific studies, teachers know that physical activity promotes learning and encourages student engagement (Lindt & Miller, 2017). Activities involving dance, gestures, and other movements can have a positive impact on learning, motivating children to engage and become more physically active (Lindt & Miller, 2017).

However, for children with visual impairments and additional disabilities and with complex communication needs, movement – in some cases – can be extremely challenging. This is because some of these children have reduced mobility, cerebral palsy with hypertonia or hypotonia (Moreira, 2024).

Due to the complexity of their disabilities, many of these children are unable to access information adequately. This can affect the child's motivation to initiate interactions, explore objects and the surrounding environment, and actively participate in daily situations (Chen & Dot-Kwan, 1995).

An inclusive environment is characterized by creating opportunities for all children to participate in activities according to their potential. Dr. Lilli Nielsen believed that all children learn through

play through natural curiosity, comparisons, and active engagement in their environment (Shafer, 2005). For this reason, she encouraged adults to structure the environment so that children with visual impairments and additional disabilities and complex communication needs could develop their skills (Shafer, 2005).

When children learn through their own physical movements, they internalize and transfer these learnings to other situations. Dr. Lilli Nielsen designed several devices to support the cognitive development and motor skills of children with visual impairments and additional disabilities and complex communication needs (Johnson et al., 2000).

In her study of spatial awareness in congenitally blind infants, Nielsen (1992 apud Johnson et al., 2000) observed seven stages:

- accidental movements allow the child to perceive objects
- deliberately touching or touching objects
- grasping and releasing, and then grasping and holding objects
- immediately repeating an activity
- exploring an object in different ways
- simultaneously listening and performing a tactile-kinesthetic activity
- intentionally searching for two objects and comparing their properties

Congenitally blind children face many challenges in orienting themselves, moving around, and locating objects in the environment. For children with other disabilities associated with visual impairment, these difficulties can be even more challenging. With this in mind, Dr. Lilli Niensen designed several pieces of equipment to provide opportunities for these children to actively participate in their environment.

Among these pieces of equipment, the treasure box stands out. A box filled with small

Development

This is an experience report structured according to the principles of active learning. Experience reports originate from academic and professional experiences, supported by teaching, research and extension. Its main characteristic is intervention, provided with theoretical foundation and critical reflection (Mussi et al., 2021).

Thus, the experience reported here took place in November 2023 and originated from teaching. It took place in a classroom located within the Early Childhood Education sector of the Benjamin Constant Institute². The participants were four four-year-old children,

objects for the child to explore. Thinking about this treasure box, the idea came up of placing several small objects inside a container and relating them to a children's song, creating a theme around which a group of four children, three of whom were blind and one with visual impairment associated with other disabilities, could talk, play and handle these objects. This idea became a practical activity carried out on a sunny day when the heat called for a game with water.

But could a children's song, represented by objects, spark the interest of this group of children? The objective of this activity was to present a circular tray containing items related to the bottom of the sea, which were related to the children's song: Little Fishes of the Sea1. The importance of this experience report is to publicize the importance of the active learning approach to favor the teaching-learning process, to expand the possibilities of interaction between blind children and children with visual impairment associated with other disabilities, in addition to instigating the dissemination of other experience reports and research on this theme that is so enchanting for Special Education.

two blind girls, one blind boy and one boy with visual impairment associated with other disabilities.

The activity was based on the treasure box, whose variation in this study corresponded to the tray of treasures from the bottom of the sea, a round white tray with six circular dividers and one more central divider. Different objects were placed in each compartment: colored aquarium rocks, shells, small pebbles and large pink sequins. A brown plastic boat, a rubber crab and starfish and small rubber fish were also used. The image below illustrates this activity better.

¹ There are different versions of this song, but in this experience report the version presented in this link here was used: https://www.youtube.com/watch?v=PSZUT6OAGZY

² Benjamin Constant Institute, a century-old institution located in Rio de Janeiro/Brazil. More information at: https://www.gov.br/ibc/pt-br



Image 1. Tray of treasures from the bottom of the sea. Source: Personal collection

The children were invited to sit around these materials. Then, they were invited to explore the objects: what do we have here? The activity consisted of listening to the song Peixinhos do mar and then placing seashells, pebbles, sequins, the crab, the starfish and the little boat inside the basin. The following image shows the moment when the children handled the objects, placing them in the water.









Image 2. What is at the bottom of the sea? Source: Personal collection

After the concrete activities, handling the objects and playing with water, it was time to represent all of this in a two-dimensional way. The children were encouraged to paint the water with blue paint the color of the sky. But where is the sky? It is up high, so high that we cannot reach it from the ground. The children were also encouraged to stretch their hands up high to try to reach the sky. We talked about the sun,

which is also up high in the sky, very high, but we cannot reach it from the ground. But we can feel the heat of the sun on our skin. We also talked about how the little fish were out of the water and might be hot, so how about sticking the little fish with glue to the water made of paint? That's what we did! The following image shows the representation of this activity in two-dimensional form.









Image 3. Who taught you to swim? Source: Personal collection

In addition to representing the practical activities in a two-dimensional way, the children also put into practice the concepts of laterality, up and down. The round shape that represented the sun had to be glued to the right side and at the top of the paper. The representation of the water with blue paint had to be done below the string and

the rubber fish had to be glued below the string as well.

It is important to mention that all of these activities were done coactively, that is, the children received physical and verbal support from this teacher. The image below shows the finished work.



Image 4. Two-dimensional representation. Source: Personal collection

Play is a great way to teach concepts and encourage children to explore their surroundings. Dr. Lilli Nielsen believed that all children are capable of active learning, rather than being mere recipients of stimuli (Shafer, 2005).

Final considerations

Active learning is a precious skill that needs to be increasingly incorporated into the classroom routine and also into individualized care. However, many teachers are still unfamiliar with it, thus revealing the need to conduct and disseminate research with evidence-based practices that attest to the benefits of this approach.

This experience report showed that the concrete representation of the song Peixinhos do Mar, through objects and practical activity, aroused the interest and led to the engagement of the four children, including the child with visual impairment associated with other disabilities. It is important to offer activities and objects similar to those that children like, and they also need opportunities to practice and make comparisons (Shafer, 2005). According to Dr. Lilli Nielsen,

when children learn through their own physical movements, they learn skills that, when internalized, can occur in other situations (Johnson et al., 2000). Thus, when a circular tray containing items related to the bottom of the sea, which were related to a children's song, was provided, the children moved around, handled objects and made comparisons, played with water, colored the objects in the water, tried to reach the sky, and felt the warmth of the sun on their skin. It is believed that the activities described in this experience report certainly provided an opportunity to expand their skills, which could occur in other contexts. Against the backdrop of the pedagogical proposal around which children are encouraged to do things and think about what they were learning (Johnson et al., 2000).

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The IKI-TAU Tool for Assessing Functional Vision and Hearing to Identify People with Deafblindness/Hearing and Visual Impairment

So far, the diagnosis of hearing and vision in people with deafblindness/hearing and visual impairment in Germany has been conducted either in medical centers or clinics. However, it is often noted afterward that the person is not testable. In most cases, it remains unclear whether a hearing and/or visual impairment is present and to what extent. To address this issue. the IKI-TAU project (Identification of Children, Adolescents, and Adults with Deafblindness/Hearing and Visual Impairment) was initiated in 2019. This project developed a two-stage screening procedure to assess functional hearing and vision. The project was completed in 2024 and published in a kit containing materials and an app through Edition Bentheim.

In the first stage of the screening process, a questionnaire is used—either app-based or on paper—to assess vision, hearing, tactility, and hearing-visual impairment. This questionnaire can identify irregularities in vision and/or hearing.



Fig. 1. The IKI-TAU Kit



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Fig. 2. The IKI-TAU App

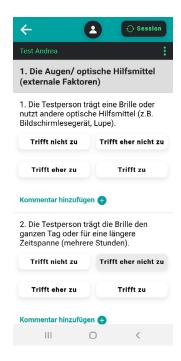


Fig. 3. Excerpt from the Screening Questionnaire

The screening questionnaire serves as an initial assessment tool. With the help of 44 items, observable vision and hearing behaviors, as well as specific (tactile) behaviors related to deafblindness/hearing and visual impairment, are evaluated. The screening questionnaire is fully integrated into the app. The user can select an answer for each question ("does not apply," "rather does not apply," "rather applies," "applies"). If a hearing or visual impairment has already been diagnosed, the user can skip the relevant questions by selecting the option "already diagnosed." The app evaluates the responses, displays "conspicuous" or "not conspicuous," and provides recommendations for further steps.

Additionally, comments can be added to individual items to specify answers. These comments are displayed in the documentation like notes but do not influence the evaluation.

Particularly, the possibility of digital evaluation offers a significant advantage in terms of usability, resource conservation, and error minimization!

If both distance senses or one distance sense show irregularities, the second stage of the process is initiated with the hearing and/or vision modules.

- For each visual function, there are assessment procedures (tests) for two
 different target groups: those who communicate conventionally and those who
 do not.
- Each procedure is accompanied by tutorial videos and descriptions in the manual. All materials are included in the kit.

The Vision Assessment Tool

The vision assessment tool consists of various standardized and non-standardized test procedures to assess:

- Visual field
- Visual acuity (or equivalent)
- Contrast sensitivity

Visual Field Measurement:

- IKI-TAU Visual Field Tests Jessle Screen
- Deafblind-specific adaptation of the tangent screen
- The goal is to determine the outer boundaries of the central visual field by detecting a green light point moving from the periphery into the central visual field.

Visual Acuity (or Equivalent) Measurement:

- For individuals with conventional communication, two test procedures assess visual acuity at near and far distances.
- The measured visual acuity can also be described as recognition acuity, as the tests use optotypes of varying sizes that must be identified (Henriksen & Laemers, 2016, p. 119). These standardized procedures require an understanding of symbols from the tested individuals.
- Since recognition acuity cannot be measured for individuals without conventional communication due to a lack of symbolic understanding, discovery acuity can be assessed using the Point Detection Test.
- Recognizing the shape of a visual symbol is not necessary. The focus is on whether the test person (without conventional

communication) can detect the presence of points without naming them.

Contrast Sensitivity Measurement:

- Various test procedures are used to measure contrast sensitivity.
- For individuals without conventional communication, the Hiding Heidi™ Contrast Sensitivity Test is used.
- This test presents schematic faces with varying contrast levels, observing visual reactions to determine contrast perception.
- For individuals with conventional communication, the SZB-LCS Test measures low contrast sensitivity using Landolt rings in different contrast levels.

Assessment of Vision Functions:

Fig. 4. Overview of Functional Vision Assessment Procedures

Vision Function	Test for Conventional Communicators	Test for Non-Conventional Communicators	
Central Vision Field Boundaries	IKI-TAU Visual Field Test Jessle Screen	Searching Susi Confrontation Method (for peripherial vision)	
Visual Acuity / Equivalent	LEA SYMBOLS® Near Test LEA SYMBOLS® Distance Test	Point Detection Test (PET)	
Contrast Sensitivity	SZB-LCS Test for Low Contrast Sensitivity	Hiding Heidi™ Contrast Sensitivity Test	

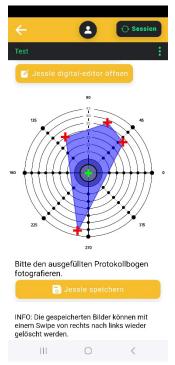


Fig. 5. Screenshot from the IKI-TAU App – Jessle-Screen Evaluation

The Hearing Module

The hearing module is app-based. Using a device and the app, everyday sounds and/ or self-recorded sounds—preferably songs or voices—are used to assess functional hearing. Observations are documented and evaluated. Preparation, documentation, and evaluation are described in detail in the IKI-TAU Kit manual.

The hearing module can only be conducted using the app. The app allows playback of six different everyday sounds. Additionally, users can record and play custom sounds based on the test person's preferences. Voices are particularly valuable, as they are highly motivating for a hearing response. If a Brüel & Kjaer decibel and sound level meter is available, it can be directly connected to the app, storing frequency and decibel values within the app.

The IKI-TAU App will be available in the Apple iOS and Google Android app stores. Upon purchasing the IKI-TAU Kit—which includes

a manual, test materials, and a QR code for app activation—all app functions will be accessible to users.



Fig. 6. Screenshot from the IKI-TAU App

Video Tutorials for Low-Threshold Access

To ensure an accessible approach to the assessment tools, the IKI-TAU team has developed video tutorials. These tutorials provide users with an easy way to familiarize themselves with the vision and hearing module procedures. Each tutorial (approx. 5 minutes) introduces a procedure and demonstrates its execution. This enhances the efficiency of the two-stage screening process by reducing the need to read lengthy manuals and instead offering a clear, visual explanation.

The following video tutorials will be available in the app:

Hearing Module Execution:

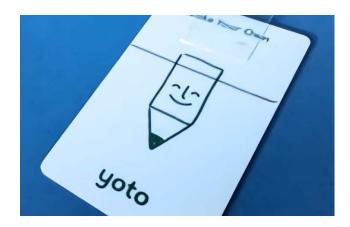
- Positioning and test execution
- dB device
- Hearing reactions and documentation
- Sound level meter B & K

Vision Module Execution:

- Searching Susi Confrontation Method (for non-conventional communicators)
- Jessle Screen Visual Field Test (for both target groups)
- Near Visual Acuity Test (LEA Symbols Near Test) (for conventional communicators)
- Distance Visual Acuity Test (LEA Symbols Distance Test) (for conventional communicators)
- Visual Equivalent (Point Detection Test) (for non-conventional communicators)
- Contrast Sensitivity (Hiding Heidi) (for non-conventional communicators)
- Contrast Sensitivity (SZB-LCS Test) (for conventional communicators)

Framework Conditions

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Musical Calendar: An Innovative Approach for Deafblind Communication

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As a Person-Centered Planning and Navigation Specialist, I work with individuals who are deafblind, creating tailored communication systems. One individual I support currently lacks a calendar system. Using residual hearing and touch, she identifies objects but relies little on vision.

Together with her intervenor services team, we designed an accessible calendar system focused on auditory cues. We wanted a system that could evolve with her changing senses and communication abilities. After exploring options, we chose a Yoto Player, a simple music player using

credit-card-sized cards that can be loaded with custom audio tracks. This would serve as an "Auditory/Tangible Symbol" calendar, combining sound and potential tactile or scent cues.

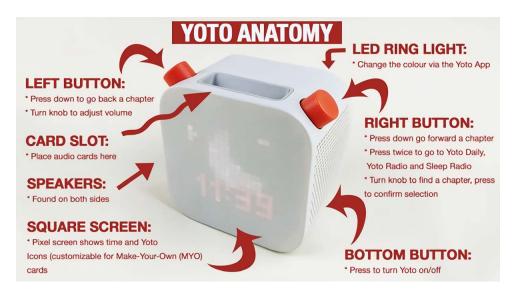
We began with a song for a familiar daily task—brushing teeth. A catchy, farmthemed song was created to serve as both an activity cue and timer, lasting the recommended brushing time. The individual quickly recognized and enjoyed the song, showing anticipation when it was missing.

"One time the player was uncharged, and when the Intervenor initiated Brush Teeth time without it, she kept asking, 'Where is my song?' This was a wonderful sign that she was recognizing its meaning and anticipating the song" shared her Intervenor.

Building on this success, the team brainstormed a similar system for exercise. A 30-minute playlist of her favorite songs motivated her to exercise longer. We plan to refine the system by adding mid-session reminders and eventually incorporating tactile and scent elements for greater independence.

Ultimately, the goal is to build a full calendar board, where the individual can independently select and recognize activities through touch, smell, and sound.

If you're interested in setting up a Musical Calendar, you can find more information at: https://ca.yotoplay.com/



COMMUNITY CONNECTIONS



Scene from a movie "Planet of snail"



Scene from a movie "Planet of Snail"

Exploring Deafblindness Through Film: Planet of Snail

IRINA MOISEEVA, DBI INFORMATION OFFICER

Young-Chan is a poet, a sculptor, and an actor. And he is also an individual who is deafblind. He lost his vision and hearing due to a fever when he was a child. He tries to find his own words to describe the world, and his wife describes the world to him. A South Korean documentary shows the everyday life of an individual who is deafblind that is so similar to and yet so different from all others', full of so ordinary and yet philosophical scenes. If you are interested in the lives of the adults who are deafblind, deafblindness in different cultures, and deafblindness as a psychological phenomenon, this 2011 movie comes highly recommended.

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Dbl Communication Ambassador: Call for Action



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

We expect an Ambassador to take Dbl'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).
- 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. Dbl 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.