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DbI REVIEW

THE MAGAZINE
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INTERNATIONAL

Deafblind
International DbI

Anniversary Issue

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

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

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

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

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

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

A DbI membership offers a threefold benefit:

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

"We rise by lifting others."
Robert Ingersoll

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

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

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DbI is Celebrating Its 50th Anniversary!

MIRKO BAUR

DEAFBLIND INTERNATIONAL PRESIDENT

It is indeed true: in 2026, we will be celebrating the 50th anniversary of Deafblind International (DbI). Or rather: of Deafblind International as an independent organisation.

Our origins actually go back further. This is evident from the fact alone that the organisation was launched at the 6th (!) world conference. Interestingly, this took place in Sydney, Australia, on 3 September 1976, under the name International Association for the Education of the Deaf-Blind (IAEDB).

The first Chairman was, in fact, an Australian: Keith Watkins. Membership was strictly individual, at a cost of about EUR10 per year, which most members prepaid for four years at the world meetings. Due to the organisation's limited revenue, the IAEDB published a very small, mimeographed newsletter of about eight pages. There was no budget for any other activities, apart from the world conferences held every three or four years.

The roots of DbI go back to the 1950s, when just a few organisations from Europe, Russia and the USA were beginning to collaborate. They corresponded by post, sharing the results, successes and frustrations of their work with deafblind children and, on rare occasions, managing to visit one another. It was in 1962 that this group first met for a formal conference, "Teaching Deaf-Blind Children", hosted by Condover Hall School near Shrewsbury in the UK. Forty-one (!) people attended this first ever conference.

So, international exchange has always been at the heart of DbI, and world conferences and face-to-face meetings have always been particularly important for this. It is therefore no surprise that the name change to Deafblind International DbI coincides with another world conference, the one held in Lisbon, Portugal, in 1999. The organisational structure was reinvented, recognising that the organisation is essentially one with a strong network substructure, in which people with shared interests meet and interact more frequently between conferences.

As we celebrate DbI's 50th anniversary this year – with retrospectives and outlooks on our social media, with this edition of the DbI Review and an online event in September, which I'd like to keep under wraps for now – we have every reason not to be facing an organisational midlife crisis.

The power of collaboration, exchange and networking among our founders remains as strong as ever today. DbI has never had as many members or as many official DbI Networks as it does today; its communications have never reached a global audience as widely as they do now; and with its key projects – the Global Education Campaign and its associated Research Initiative, the ICF Core Sets for Deafblindness and the global definition – it is fully in tune with the vast amount of work that lies ahead of us – guaranteed to keep us busy for many years to come.

Deafblind International is indeed a very vibrant 50-year-old organisation, and in that respect we have every reason to be truly delighted: with our pioneering founders, with what has been achieved over the past 50 years through the sheer dedication, passion and expertise of everyone involved, and with the undoubtedly exciting future that lies ahead, in what is sure to be close and fruitful collaboration with the World Federation of the Deafblind (WFDB).

This naturally includes the very first JOINT World Conference of DbI and WFDB from 19–23 July 2027 in Davos, Switzerland – which will be preceded for the first time by a joint pre-conference of many DbI Networks on 18 and 19 July.

Here and now, however, we can look forward to the fantastic variety of contributions in this issue of the DbI Review. It is striking that DbI remains firmly rooted in practical work. Alongside news and four academic articles from Africa, Canada, Latin America and Europe, this issue is brought to life above all by first-hand accounts from around the world.

We sincerely hope you enjoy delving into this latest edition of the DbI Review. And do stay in touch regarding the anniversary event in September!

DbI & WFDB

World Conference

Davos, Switzerland 19-23 July 2027

Innovate + Empower
+ Collaborate

We have already received 110 submissions for the first Joint World Conference of Deafblind International and the World Federation of the Deafblind — and you still have time to submit your abstract. The new deadline is **June 15**.

You can submit your abstract through the online platform here:

https://app.oxfordabstracts.com/stages/81801/submitter

If you are unable to access the platform,
you may submit your abstract by email to:

abstract@deafblindinternational.org

Please use email submission only if the online platform is not accessible to you.

For more information visit DbI website

https://www.deafblindinternational.org/world-conference-2027-call-for-abstracts/

We look forward to receiving your submissions!

News from the Network Coordinator

TREES VAN NUNEN

DBI NETWORK COORDINATOR

T.VANNUNEN@KENTALIS.NL

In this Spring edition of DbI, I would like to start with fitting words such as growth, revitalization, and lightness. I will certainly come back to this later, but first, I want to take a moment to reflect on the passing of two fantastic women who meant so much to the deafblind community.

First **Maria del Carmen Schleske Morales** of the Family network. She was a pioneer in the field of deafblindness and multiple disabilities, and founder of CEMDYS (Centro Especializado Múltiple Discapacidad y Sordoceguera) in Mexico-City, a center dedicated to supporting people with deafblindness and multiple disabilities. Her experiences as the mother of a daughter with deafblindness strengthened her personal interest and involvement. As a result, she understood the needs of other families and individuals with deafblindness and multiple disabilities like no other.

Marianne Riggio, former leader of the network of the Americas, was a leading expert in deafblind education, dedicating by improving education and communication for children and young adults with deafblindness. She served as the leader of the Perkins School for the Blind's Educational Leadership Program. Together with Barbara Miles she was editor of the book Remarkable Conversations. Her work in the field of deafblindness spanned teaching program development and international advocacy. She coordinated educational programs in Asia, Africa, Eastern Europe, the Caribbean and the Middle East. In 2017 she received the Anne Sullivan Medal and in 2023 the DbI Lifetime Achievement Award.

These two exceptionally beautiful people will always live on in our hearts.

The transition from Winter to Spring and the concept of revitalization brings us, first of all, to the joyful news that, following an urgent appeal, enthusiastic members have responded to breathe new life into the APA network and the Rubella network. Yvette Gallegos (co-network coordinator) and I will be speaking with them shortly.

And speaking of growth, I am proud to announce that we have added an 18th DbI network: the Asia network. I would like to wish Lhakpa Nuru Sherpa, Sachin Rizal, and Nathalie Pigar every success in shaping this network. They are already actively involved in the other networks and in the organization of the pre-conference.

A year ago I mentioned in DbI Review 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. We are currently working hard to organize and realize this pre-conference. Thanks to the enthusiastic efforts of all network leaders and their representatives, and the constructive discussions during the network leaders meetings, the content of the pre-conference is increasingly taking shape.

In this DbI Review you can read about the organized activities of some of the networks. These activities range from webinars, topical discussions, and an outdoor week to a visit to a theme park. It is incredible how many network leaders, representatives, and network members dedicate themselves time and again to sharing knowledge, experiences, and expertise with each other in any form whatsoever. In the coming period, together with all DbI networks we will pay even more attention to diversity, equity and inclusion, ensuring that people with deafblindness are represented , empowered and supported worldwide.

PRECONFERENCE

DbI & WFDB

World Conference

Davos, Switzerland 19-23 July 2027

Innovate + Empower
+ Collaborate

**First time jointly organized by
all DbI networks**

•

Thematic discussions & case study analysis

•

**July 18th and 19th, 2027
Davos, Switzerland**

Deafblind
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Update of Network: DbI Communication Network

HELLE BUELUND
STEVE ROSE
MEREDITH PRAIN
SASKIA DAMEN

The DbI Communication Network has been busy with the organization of a webinar on **Thursday 23rd April 2026**. For this webinar, they invited a team of guest speakers: Louisa Willoughby from Australia, and Jonathan Reid and Jacky Smith from Scotland. These guest speakers have explored humour among both people with acquired and congenital deafblindness.

Humour is a central way that humans build relationships with each other. But navigating humorous interactions can also be challenging without access to visual and auditory cues. During the webinar the speakers introduced why humour is important for cognition and relationship building and explored examples of humorous interactions. These lead into a discussion of implications for practitioners and how and why we might foster humour in interactions with people with deafblindness.

The webinar series was aimed at **family members** of children and adults who were born with deafblindness or those with limited language (speech or sign) who wish to develop their own communication skills and the skills of their deafblind family member/s. Professionals were welcome to join bearing in mind the shared audience.

Open invitation

The intention of the DbI Communication Network is to keep organizing webinars on communication. They have been also taking part in discussions with other DbI networks about the organization of a joint preconference preceding the upcoming World Conference on Deafblindness in Davos. The current organizers of the DbI Communication Network are open to suggestions on topics and speakers from their members. They also invite members, especially those from the Global South and East or with lived experience, interested in helping organize webinars and other member activities, to make this known to them. So please contact dbicomnetwork@gmail.com if you want to share ideas or have an interest in joining our organizing committee.

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International DbI
COMMUNICATION NETWORK

Deafblind Education Network (DEN) News

DEAFBLIND
EDUCATION
NETWORK (DEN)

The Deafblind Education Network (DEN) is currently experiencing a lot of positive development. Since Autumn 2025, we have held 4 'Best Practice / Swap Market' webinars, which are scheduled every other month. Members of the DEN are invited via email and our Facebook page. Members of the DEN Committee prepare a 10-20 minute presentation on a chosen topic that is relevant to deafblind education, after which the floor is opened for participants to share their own experiences and examples on the topic. Each session is scheduled to last a maximum of 45 minutes. Our past topics were: 'Introducing yourself to a new student,' 'How to approach a deafblind baby' and 'Active Learning.' During our March 'Best Practice/Swap Market,' we had guest speakers from a working group in Germany and Austria, who wished to give a presentation on 'Orientation and Mobility.' We have seen great interest from participants in sharing their experiences during each presentation and can highly recommend this approach. And then there is the added benefit of human warmth by being able to say "Good morning" to Deafblind professionals in Argentina or North America and, in the same breath, saying "Good evening" and "Good night" to colleagues in Korea.

On our Facebook page, we have created an interactive series called 'Teacher Tuesdays'. We post relevant questions about the teaching profession to allow teachers to share their experiences and ideas and also learn about a particular topic. This has worked quite well, although we would of course always like more engagement. So keep an eye on our Facebook page, which you can find by searching for 'Deafblind Education Network' if you are not already a member. We look forward to engaging and connecting with all educators in whatever part of the world you may be in.

The DEN is excited to be involved in the upcoming pre-conference for the World Conference in July 2027. The plan is for several networks under DbI to collaborate on presentations, so that we can gain multiple perspectives on the same topic. We are very much looking forward to collaborating with other networks and putting together an exciting programme for the two or three sessions scheduled on each of the two days of the pre-conference. Please keep up to date here in DbI REVIEW or on the various relevant conference websites.

If you're interested in education for the deafblind, please join our network. Our Facebook page is open to anyone with questions about education – you might get a response from people on the other side of the globe. And our Facebook page is also the place where you can share examples of best practice in topics such as communication, multi-sensory approaches, assessment, curriculum adaptations, and functional academics.

At the time of writing, the network's active board consists of professionals from Argentina, Ireland, the Netherlands, Germany, Ghana, India and Denmark, and we hold board meetings every other month, except during the summer break.

Deafblind
International DbI
DEAFBLIND EDUCATION
NETWORK

News from the Anne Sullivan Foundation, Ireland

ANNE SULLIVAN FOUNDATION, IRELAND

It has been a busy few months for the team in Ireland. Some members of the deafblind community here have had the opportunity to participate in two pieces of research which we hope to be able to share more about in the next issue of DbI Review. There has been very little research done on deafblindness within the Irish context, so we are excited to read the report when it's published.

The Anne Sullivan Foundation is excited to expand our Assistive Technology (AT) Library over the coming months through additional funding we have received. The AT Library has quickly become one of the biggest parts of our jobs, offering clients the opportunity to trial difference pieces of equipment that support communication, independence and/or safety. We hope to develop tutorial videos and additional resource for both clients and family members/ support staff specifically on AT, so watch this space!

In 2025, we began a pilot course to teach Braille through Irish Sign Language (ISL) to one client. We had hoped to roll this out to more clients at the time but due to funding restraints, we started with just one client. This has been a huge success and a unique offering, with other clients expressing interest in completing the course. We are due to start another course soon for another client and we are hopeful to continue to expand.

The team are looking forward to the DbI World Conference and Pre-Conference in 2027, hope to see many familiar faces if we are lucky enough to be able to attend.

Usher Network Newsletter

EMMA BOSWELL

NATIONAL USHER CO-ORDINATOR

USHER SERVICE

DEAFBLIND UK

We would like to invite you to take a look at our new revamped Usher Network webpage. A video has been circulated via social media and is available on the webpage also. Here at the Usher Network we are looking for two new committee members to support us in an exciting opportunity to raise and develop awareness about Usher syndrome. You may be a person with Usher yourself, a family member, a friend of a person with Usher or working as a professional with an interest in the field. We would welcome all nationalities, with applications from any country across the world. Desirable skills would be knowledge and awareness of Usher, social media/technology skills or any other relevant skills you could contribute. Please do contact us for more info.

We would also welcome new members to join us and find out more about our network.

The next DbI pre-conference will be held in Switzerland, July 2027, and plans are currently underway in collaboration with other networks to work together on an exciting programme - so watch this space!

Deafblind
International DbI
USHER NETWORK

King's Medal of Merit Awarded to Geir Jensen

SIGVE NEDREDAL

Geir Jensen has been awarded the King's Medal of Merit for his lifelong commitment to the rights of people with disabilities and his pioneering work for people with deafblindness in Norway and internationally.

A life-long champion for the rights of the deafblind

On Thursday 18 December, Geir Evan Boye Jensen was , presented the King's Medal of Merit by Jan Tore Sanner, the County Governor of Østfold, Buskerud, Oslo and Akershus. This prestigious award is conferred in the name of the King to individuals who have made particularly meritorious contributions to society.

For decades, Geir Jensen has championed equality, participation and rights, dedicating special attention to the deafblind community, a cause close to his heart as someone who lives with deafblindness.

During the presentation ceremony, Sanner highlighted Geir Jensen's invaluable contribution to the rights of the deafblind.

"Geir, it is an honour to present the King's Medal of Merit to you – for your efforts for the rights of people with disabilities, and especially for your fight for the rights of people with deafblindness, " said Tanner.

"For more than three decades, you have worked for a better, safer and freer everyday life for people with deafblindness, nationally as well as internationally, says Sanner.

Facts about the King's Medal of Merit

The King's Medal of Merit is a Norwegian royal honour awarded to individuals who have made particularly meritorious contributions to society over an extended period of time.

The medal may be awarded for contributions in fields such as:

- social and humanitarian work
- organisational and interest advocacy
- culture, education and research
- work for democracy, rights and inclusion

It has become a tradition for recipients of the King's Medal of Merit to also be invited to a reception at the Royal Palace on a later occasion. The formal gathering is hosted by the King and Queen and includes refreshments, speeches and often a musical performance.

Many statements of support

The application to award Geir Jensen the King's Medal of Merit was supported by six strong statements of support, including from the Norwegian Forum of Disabled Peoples' Organisations (SAFO), the Norwegian Association for Persons with Intellectual Disabilities, the Norwegian Association of the Disabled, the Norwegian Association of the Deafblind, the leader of the Christian Democrats, Dag Inge Ulstein, and former Minister of Labour and Social Inclusion, Bjarne Håkon Hanssen.

"All the statements of support highlight your invaluable efforts. A broad and united community wholeheartedly supported the proposal to award you the King's Medal of Merit", said County Governor Sanner.

Three decades of organisational work and rights advocacy

In 1995, Geir was elected chairman of the Norwegian Association of the Deafblind (FNDB), a position he held until his retirement on 1 July 2024 at the age of 81. He was also employed as a policy consultant for the association.

In the same year, he helped establish the Norwegian Forum of Disabled Peoples' Organisations (SAFO). Geir served as a board member of SAFO from its inception in 1995 until 2024, and he played a key role in strengthening the collective voice of people with disabilities toward the authorities.

International work for the rights of the deafblind

Geir's international involvement started in the late 1990s. From 2005, he held various roles in the World Federation of the Deafblind (WFDB), including severing as president of the federation for 10 years. During this period, he was also a board member of the International Disability Alliance (IDA).

Geir has contributed to global research reports on deafblindness and to putting the rights of the deafblind on the international agenda, including through meetings with the authorities and aid organisations.

Lasting changes in Norway

Geir has played a key role in efforts in Norway to ensure that the deafblind receive necessary services, such as specialist health services, adaptation courses, aids and interpreting and companion services.

His efforts have contributed to clarifying the state's responsibility and strengthening the rights framework for a small and vulnerable group.

Life experience as a driving force

Geir was born in Tana in 1943 with the hereditary retinal disease retinitis pigmentosa and impaired hearing. His vision gradually deteriorated and in 2001 the last remnant of his vision disappeared. He was registered as deafblind in 1985. He is now completely blind and deaf and has a cochlear implant as an aid.

Through his education, professional career and organisational work, Geir has encountered many of the barriers that disabled people still encounter in society. These experiences have been an important driving force in his tireless efforts with rights advocacy work.

Law studies against all odds

When his eyesight and hearing became too poor to continue in his profession as an electricity distribution fitter, Geir chose to study law at the University of Oslo. Despite severe sensory loss, he completed his studies with extensive adaptation, technical aids and enormous personal effort, graduating with the Norwegian equivalent of a Master of Law degree.

His legal education gave him a solid foundation in rights and public administration, which he has applied purposefully in his efforts to advance a more inclusive society.

Continued commitment

Geir remains active despite his recent retirement. His current roles include serving as a board member of the Norwegian Association of the Deafblind's contact club for the deafblind in Oslo and the surrounding area and of the Fund for the benefit of the deafblind in Oslo and the surrounding area.

The awarding of the King's Medal of Merit is a clear recognition of Geir's lifelong commitment characterised by fighting spirit, perseverance and a strong desire for equality and participation for all.

Lenketekst:

If you wish to be better acquainted with the person behind the commitment, you can read more about Geir Jensen's life in the article *A Champion of the deafblind steps down* https://www.dovblindhet.no/min-historie/en-forkjemper-trer-av/en-forkjemper-trer-av/.

DBWA Young Leaders Program Newsletter

DBWA YOUNG
LEADERS
PROGRAM

The Deafblind West Australians Young Leaders course has been running monthly since October, bringing together six participants with a mix of deaf, deafblind, blind, and low vision experiences. Each session begins with setting up the room for accessible communication and a check in to make sure everyone's communication needs are understood and respected.

A strong focus of the program has been developing empowered communication skills, learning to express access needs clearly and confidently in workplaces, education settings, health appointments, and community spaces. Participants have shared that these skills are already helping them navigate environments that aren't always designed with sensory disability in mind.

We've also explored the different forms of advocacy: self, family, individual, legal, and systemic. Self advocacy was a particular focus of ours and sparked especially rich discussion. Participants have begun setting their own goals and identifying changes they want to see in their communities.

A participant driven social change project is now underway, with ideas centered on raising awareness of sensory loss and highlighting the expertise that comes from lived experience. As part of this, we've started filming short videos where participants answer questions about daily life with sensory loss and share practical life hacks.

These will form part of the project and will also be published on the DBWA website.

The group recently enjoyed a teambuilding day at tenpin bowling, supporting one another with descriptions, shared strategies, and plenty of laughter. It was a great way to build trust and connection.

There is so much energy and leadership emerging from this group. DBWA hopes this course will help nurture the next generation of deafblind leaders, and we look forward to welcoming future board members from within this growing community.

DbI Youth Network Efteling 2025 Activity Report

DBI YOUTH
NETWORK

The DbI Youth Network attended Efteling World of Wonders during the final week of October 2025. The popular large, fantasy -themed amusement park is located in Kaatsheuvel, Netherlands.

Renowned for its immersive fairytale atmosphere and attractions suitable for all ages. It is one of the oldest and most visited theme parks in Europe. Efteling features a unique blend of traditional folklore, myths, and legends, with attractions ranging from thrilling roller coasters to a serene Fairy Tale Forest.

The youth network was represented from countries including the UK, Belgium, France, Germany and the host Country, the Netherlands. The young people experienced the park, making new friends and learning about peer group cultures.

Each day a meet up took place through sharing savoury and sweet cakes in a traditional onsite bakery, these moments we shared with great anticipation of what attractions within the park we wished to access.

Evening dinner was hosted at the Dutch Pancake House with a time to discuss all the fun experiences Efteling had to offer. Tales of adventure surrounded by magnificent cuisine.

Simon Allison, Youth Network leader said of the event, "It was wonderful to bring together Deafblind Youth for such a positive experience. The spacious environment ensured that the park was crowd free with only small waiting times for the rides. From the positive feedback we received the network is repeating the activity in October 2026".

Attendee Heleen also commented.

> "It was fantastic to meet other people and see how they communicate. I was hoping to connect with other parents and professionals working in the deafblind field, and I was very happy that those connections were successful I believe many more people could benefit from events like this, and I will certainly spread the word about next year's network days. The 2026 dates are already noted in my agenda! Once again, thank you so much for all the time and effort you put into making this networking event such a success"

To express an interest to attend the youth network 2026 event please email simon.allison@sense.org.uk

Deafblind
International DbI
YOUTH NETWORK (DBIYN)

The Deafblind International Youth Network is Pleased to Announce an Exciting Activity for 2026!

The venue is Efteling Theme Park Resort situated in the 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 27th / October 28th, 2026.

Take this unique opportunity to connect with other Deafblind youth from across the world. Our visit in 2025 was a huge success, with all attendees enjoying a wonderful, fun experience.

Included will be group gatherings for socialising, sharing Dutch cuisine and of course networking.

All attendees will receive a commemorative DbI youth network t-shirt / hoodie.

Please contact the network coordinator for an expression of interest simon.allison@sense.org.uk

Further information will then be shared including:

- Links to book for Efteling entry
- Links to offsite/onsite accommodation (onsite includes free park entry)
- Links to internal travel from airports/ports
- Accessibility guide for Efteling Theme Park Resort
- Zoom Q&A sessions with the youth network coordinator

On contacting the network coordinator, we will acknowledge your expression of interest and respond with requested additional information.

Warm Regards

Simon Allison (DbI Youth Network Coordinator)

Strategies to Stimulate Communication in Children with Visual Impairments Associated with Other Disabilities

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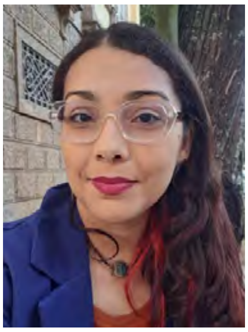

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Introduction

This research focuses on children with visual impairments associated with other disabilities and complex communication needs. In this context, the communication of these children can be supported or supplemented using tactile resources of augmentative and alternative communication, and these resources can also favor the communication of deaf-blind people.

Among these resources, the following stand out: reference objects, textured symbols, tangible symbols and tactile symbols. For this research, reference objects and tangible symbols were used.

The motivation for conducting this study arises from the following question: how can reference objects and tangible symbols favor the communication of children with visual impairments associated with other disabilities and complex communication needs through the guidance of teachers and family members?

As for the objectives, they were: to identify the challenges and possibilities on the guidance of teachers and families in order to promote communication in children with visual impairments associated with other disabilities and complex communication needs, and also to create a guide as an educational product based on the strategies and proposals developed in the research, using reference objects and tangible symbols.

Method

This is collaborative formative action research with qualitative approach, once it identifies how the school environment can provide a space for training and collaboration between teachers and their peers.

The research started in June 2024 and ended in December. The participants were: a chronologically 10-year-old female child who uses a wheelchair and does not use verbal speech to communicate, whose diagnosis is low vision; the mother; and the teacher of the participating child.

The chosen empirical field was a specialized public school, located in the city of Rio de Janeiro, in Brazil, whose focus is specifically on the early grades and in the classroom where the child studies. We can also mention the residence where the child lives.

The procedures used for data collection were: interviews, field notes and videos sent to the researcher made by the child's mother and teacher for the autoscopy sessions. The semi-structured interviews consisted of open-ended and flexible questions; filming was also used for data collection. Finally, the self-reflective script emerged after analyzing the videos sent by the adult participants to the researcher. This procedure is important for conducting autoscopy sessions, once it helps the researcher to mediate them. (Sadalla & Larocca, 2004).

Autoscopy was used to assist in the training of both the teacher and the child's mother. Considering the importance and need, it is essential to also train families for them to actively participate in the process of communication development.

This study resulted in a guide, as an educational product written in Brazilian Portuguese, aiming at guiding teachers and family members to establish communication using reference objects and tangible symbols with the target audience.

The guide can be accessed free of charge on the website: https://repositorio.ibc.gov.br by title: "Favorecendo a comunicação de crianças com deficiência visual associada a outras deficiências: guia para professores e familiares".

After handing in the training text and having the conversation about it, the researcher, alongside the teacher and the child's mother, chose the materials to represent the reference objects. According to Ockelford (2011, p. 9):

Reference objects are objects that have special meanings assigned to them. They play the role of something, almost in the same way as words, whether spoken, signed or written.

To represent the main activities and actions during the child's routine, the participants chose: spoon (eating), soap (bathing), book (library), among others. The objects were presented in a basket, anticipating the routine, and as such routine developed, the object would be placed in a cloth bag, which represented what was finished. Fig1 depicts such objects and their descriptions.

Fig1. Reference objects representing the routine of the participant child.
Source: author's personal inventory

Results

At the beginning of the research, the child's communication occurred through babbling, crying, screaming, body expressions – such as shaking her head, raising her arm, directing her gaze, among others –, and dropping unwanted objects. At the end of the research, the child could increase the time in which she held the objects, beginning to move the arm that hardly moved before; her hands were more open, she could press the voice device to call her mother. With time, the cell phone with music to calm her down was no longer necessary and the inappropriate behavior decreased.

Thus, this study contributed to the active participation of all people involved in the research and highlighted the importance of establishing communication using reference objects and tangible symbols with the target audience.

Social validation of the research

According to Loke (2014), the social validation of research is important so that participants can implement changes after the researchers' interventions.

Afterwards, the researcher sent two questions to the participants via messaging app: "Do you think the reference objects and tangible symbols brought benefits to the child?" and "Would you use these resources and/or recommend them to another child who needs them?".

The child's mother sent an audio message talking about the research. Part of the excerpt is as follows:

> Participating in this research was a turning point because I think it brought me even more peace of mind because today I realize how much Ana is responding, and besides her responding better, her attention is being much better understood. [...] You see the change in her behavior, choices and socialization because she begins to understand better the environment she goes, what's going to happen, [...]. (audio transcript, n.d.)

Other people who were not directly involved in the research also spoke. The father typed a message that said: "She is more attentive, her attention has improved a lot and she has been responding more, I would recommend it to other people."

A friend of the mother also reported on her impressions:

> I see Ana's progress. Her communication is much better, for sure. I've been following the process and seeing that Ana is much more communicative [...] her communication is very good [...] I think alternative communication is very worthwhile for her. It's been very good, yes. She has been progressing very well [...] these objects that she's picking up are ideal for her (Audio transcript, n.d.).

Leko (2014) affirms that social validation shows the importance of research and ensures that the interventions carried out can be implemented in other contexts, and the practice, performed by other people.

Final considerations

The resources used in this study assisted the research participants in the child's interaction and communication skills. At the end of the data analysis, inappropriate behaviors such as crying and throwing by the child decreased.

In summary, the training of the mother and teacher through the texts was essential for the beginning of the use of the reference objects. Over the months, after the first autoscopy sessions with the participants, it was noticeable that what was pointed out and discussed in the sessions was improved in the practices of the mother and teacher.

Therefore, this study favors the protagonism of children with visual impairment associated with other disabilities and complex communication needs and their families.

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Improving Livelihood Opportunities for People with Deafblindness in Uganda

KATO MARK NABIMANYA

Introduction

People with deafblindness in Uganda face significant barriers to education, employment, and full participation in their communities. These barriers affect their ability to earn a living, live independently, and take part in social and economic life. This article presents findings from a livelihood project that aimed to improve opportunities for deafblind youth and adults through an integrated approach combining vocational training, life skills, and community support.

Deafblindness is not a single, uniform experience. Individuals have different communication methods, levels of vision and hearing, and support needs. However, many face common systemic challenges, including limited access to education, inaccessible information, and discrimination. These challenges are well documented globally, with research showing that people with deafblindness are at greater risk of poverty and exclusion (Jaiswal et al., 2018; World Federation of the Deafblind, 2018).

A Holistic Approach to Skills Development

A key finding from the project was that combining vocational training with life skills, literacy, and financial education leads to better outcomes. Participants developed practical skills alongside confidence, communication abilities, and knowledge of health and wellbeing. This integrated approach helped individuals prepare for real-life work and business opportunities.

Seventy-eight deafblind participants completed vocational training, and many more gained business and financial skills. Participants reported increased independence and confidence. These findings are consistent with broader evidence that integrated, person-centred livelihood programs improve employment outcomes for people with disabilities (Mitra, 2018).

Strengthening Organisations of Persons with Disabilities

Organisations of Persons with Disabilities (OPDs) played a central role in the project. They supported participants, built peer networks, and strengthened advocacy. As a result of targeted capacity-building, most OPD leaders reported improved skills and confidence.

In Uganda, OPDs are supported by national structures such as the National Council for Persons with Disabilities, which is mandated to monitor implementation of disability laws and promote inclusion across sectors.

This reflects international evidence that OPDs are essential for ensuring that people with disabilities are represented in decision-making and policy processes (Banks et al., 2017).

Barriers to Employment and Inclusion

Despite progress, many barriers to employment remain. Communication barriers are a major issue. Many workplaces do not provide accessible communication methods such as tactile signing, braille, or interpreter-guides. This limits participation in meetings, training, and everyday workplace interactions.

The Persons with Disabilities Act 2020 requires accessible communication and recognises a wide range of communication formats, including braille, tactile communication, and assistive technologies. It also prohibits discrimination across employment, education, and access to services. However, the findings of this project show that these provisions are not yet fully implemented in practice.

Limited access to education is another key barrier. Many deafblind individuals have had restricted access to inclusive education, resulting in low literacy and numeracy levels. This significantly reduces employment opportunities. Globally, lower educational attainment is strongly linked to poorer employment outcomes for people with disabilities (Mitra, 2018).

Negative attitudes and stigma also continue to restrict participation. Employers and communities may underestimate the abilities of deafblind people, leading to exclusion or limited opportunities. These attitudinal barriers are widely recognised as a major factor in disability inequality (Shakespeare, 2014).

Even when individuals find employment, they often experience isolation, lack of workplace support, and limited access to training. These challenges can affect job retention and career progression.

Access to Information and Communication

Access to information remains a critical issue. Many families and communities lack knowledge of effective communication methods. Public information, including job opportunities and services, is often not available in accessible formats.

Uganda's policy framework recognises the importance of accessibility. The Persons with Disabilities Act 2020 defines communication broadly to include accessible information and communication technologies and alternative formats. In addition, the Revised National Policy on Persons with Disabilities emphasises the need for inclusive communication and access to services for all disability groups. However, gaps in implementation continue to limit access in practice.

Community Support and Social Inclusion

Community and peer support were key factors in participant success. Mentors and peer networks helped individuals build confidence, develop skills, and make informed decisions. Research shows that social support is strongly linked to improved wellbeing and participation for people with disabilities (Emerson & Hatton, 2008).

At the same time, some participants experienced overprotection from family members, which limited opportunities for independence. Supporting autonomy while maintaining appropriate support is essential.

Policy Context in Uganda

Uganda has a strong legal and policy framework for disability inclusion. The Constitution of the Republic of Uganda (1995) prohibits discrimination and promotes equal opportunities for persons with disabilities. The Persons with Disabilities Act 2020 strengthens these protections by mandating accessibility, reasonable accommodation, and inclusion across sectors.

The Act also establishes structures such as the National Council for Persons with Disabilities to monitor implementation and promote participation. In addition, Uganda's National Development Plan III includes disability inclusion as part of its human capital development strategy, highlighting the importance of participation in education and employment.

Uganda has also ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPD), which reinforces the right to work, education, and full participation in society. Despite these strong commitments, this project highlights a gap between policy and practice, particularly in relation to employment, communication access, and service provision.

Recommendations

The findings suggest that expanding integrated training programs is essential. These programs should combine vocational skills with literacy, financial education, and life skills. Education systems must become more inclusive through accessible materials, trained teachers, and appropriate support services.

Employers need support to create inclusive workplaces, including providing reasonable accommodations, accessible communication, and inclusive policies. Public investment in services such as interpreter-guides, assistive technology, and transport support is critical.

Improving access to information through accessible formats is also essential. Community awareness initiatives can help reduce stigma and promote understanding of deafblindness.

Finally, strengthening OPDs through funding and capacity-building will ensure that people with deafblindness can influence policies and programs that affect their lives.

Conclusion

This project demonstrates that people with deafblindness can achieve meaningful improvements in livelihood and independence when provided with appropriate support. An integrated approach that combines skills development, community support, and inclusive policy frameworks can lead to positive outcomes. However, ongoing efforts are needed to address persistent barriers and ensure that existing laws and policies are fully implemented.

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Dual Sensory Loss and Aging: What Research Tells Us About Social and Economic Conditions?

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Dual sensory loss (DSL) means having both vision loss as well as hearing loss. DeafBlind Ontario Services was part of a large study (Paramasivam et. al., 2025) about dual sensory loss in older adults. This study looked closely at how social and economic conditions affect the everyday lives of older people with DSL.

This study shows that older adults who have DSL experience challenges that are not just about aging or sensory loss. They experience challenges from how society is organized. These challenges include how the health care system works, how information is shared, how services are designed, and who gets support. Different sectors need to work together to improve the quality of life for older adults with DSL. This group is often overlooked and under-recognized, resulting in their unique needs being insufficiently understood and inadequately supported within existing service systems.

Why Do Social Conditions Matter So Much?

The study uses a well-known public health approach called the Social Determinants of Health. This means we look at the real-life conditions that shape people's health—such as where they are born, how they grow up, where they live, the work they do, and how they age. These everyday conditions have a strong impact on a person's health and overall quality of life (World Health Organization [WHO], 2022).

For older adults with DSL, the research shows that many challenges come from:

- low income or financial stress
- unsafe or inaccessible housing
- limited transportation options
- lack of social support
- difficulty accessing health care

These challenges are not random. They happen because social systems do not make plans that include older adults with DSL (Paramasivam et al., 2025).

Dual Sensory Loss Is Not Just a Medical Issue

Many systems treat hearing loss and vision loss as separate problems. This study shows that this approach does not work well for people who have both hearing and vision loss.

Older adults with DSL often experience:

- more isolation
- higher rates of depression and anxiety
- difficulties with mobility and daily activities
- early exit from work or community roles

These experiences happen when environments, services, and communication are not accessible to them (Paramasivam et al., 2025).

The United Nations Convention on the Rights of Persons with Disabilities (CRPD), says that disability is created when barriers in society prevent people from being able to participate as much as possible —not just by the challenges that people experience (United Nations [UN], 2006).

Communication Access Is a Basic Need

One of the strongest findings from the study is about communication.

Older adults with DSL often report that:

- doctors and health providers do not communicate well
- information is shared only in visual or spoken formats
- assistive technology is unavailable or unaffordable
- appointments feel rushed or unsafe

When communication is not accessible, people are:

- left out of decisions about their own health
- unable to ask questions
- more likely to avoid care altogether

Access to communication access is not "extra help." It is needed for safety, dignity, and for a person to make their own decisions (Paramasivam et al., 2025; Bright et al., 2023).

This is also an issue about a person's rights. The CRPD clearly states that people with disabilities have the right to accessible information and communication (Articles 9 and 21) (UN, 2006).

Impact on Both Older Adults with DSL and Service Providers

The study also shows that service providers are challenged.

Many providers want to offer good care but work in systems that:

- separate hearing and vision services
- do not fund communication supports
- do not offer DeafBlind-specific training
- prioritize speed over understanding

As a result:

- older adults with DSL feel misunderstood or unsupported
- providers feel unprepared and constrained

This is a system problem, not an individual failure.

The CRPD recognizes that governments must ensure professionals are trained and supported to work with people with disabilities (Article 4), and that people have the right to live and participate in their communities with proper supports (Article 19) (UN, 2006).

A Global Issue, Not Just a Local One

Most of the studies reviewed were done in high-income countries. This means we know much less about what older adults with DSL experience in:

- low- and middle-income countries
- rural areas
- Indigenous communities
- places affected by conflict or poverty

This lack of information makes people invisible—and when people are invisible in data, they are also invisible in policy (WHO, 2021a).

Global aging efforts, such as the UN Decade of Healthy Ageing, aim to support all older adults. But these goals cannot be met unless older adults with DSL are clearly included and planned for (WHO, 2021a).

What Does This Mean?

This study is clear:

- Dual sensory loss in older age is an equity and human rights issue
- Barriers come from social systems, not from older adults with DSL themselves
- Communication access must be built into health and social care
- Older adults with DSL must be visible in aging, disability, and health policies

Research can help to change systems.

Older adults with dual sensory loss are not "hard to serve." People have trouble accessing systems.

When communication, services, and policies are designed with inclusion in mind, older adults with DSL can live healthy, connected, and meaningful lives.

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Humour and Reciprocal Understanding: a Case Example of a Young Man with Congenital Deafblindness

This article is based on a term paper I wrote in 2004, for a course on “Meaning creation and tactile sign language” at the University College in South Trøndelag, Norway, based on a video clip of an interaction between myself and my son Thomas. Detailed case examples are still rare in the field of congenital deafblindness (CDB), and in honour of the insights into the phenomenon of meaning-negotiation and humour my son gave to me, I want to again share it with others. Recent work on humour and congenital deafblindness includes a wonderful case example from colleagues in Scotland, who note that, “Perhaps most central to our learning has been the realisation that the framework within which humour may arise in these interactions requires a level of belief and investment by the communication partner.” (Smith & Reid, 2020, p. 40). This statement reflects a central theme of my original case presentation and is the core message of the present article.

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Introduction

In communication between people with congenital deafblindness (CDB) and their seeing and hearing partners, conversations around shared themes can be difficult to achieve solely by a partner perceiving their sign or expression. We partners are typically dependent on a process of negotiation about meaning (Nafstad & Røbroe,

2015). People with CDB frequently make use of a limited repertoire of signs and expressions in connection with a wide range of meanings and communicative goals (Schjøll-Brede, 2019). In approaching their expressions from a negotiation perspective, we can avoid fixing them to a single meaning. I have many examples of instances in which individual signs or expressions have had different meanings dependent on context, and not least, what my child with CDB wanted to *achieve* with his signs or expressions.

The video example presented here involves Thomas's use of a negotiated sign and the shared meaning it had in the situation, as well as the crucial roles communicative context and prior knowledge play in interpretations of meaning. My guiding question for the analysis was, how does Thomas express and confirm his sense of humour in this episode? The analysis of this episode demonstrates that people with CDB can express humour through linguistically based tactile signs and their own "authentic" expressions (Nafstad, 2015).

Humour and Thomas's humour

It seems difficult to find a comprehensive definition of humour. Paul McGhee (1979) describes it as, "the mental experience of discovering and appreciating laughter-provoking, absurd and incongruent ideas, events or situations" (in Søbstad 1995, p. 22). If a person finds something funny, this is dependent on whether they can perceive and enjoy the event or situation in question. Perception of humorous content is also contingent on a degree of cognitive development, and one of the signs of a child's successful socialisation is the ability to produce humour (McGhee, 1979). Two central conditions for developing a secure context for humour in interaction with children is a playful attitude and preparedness for humour (Ibid.).

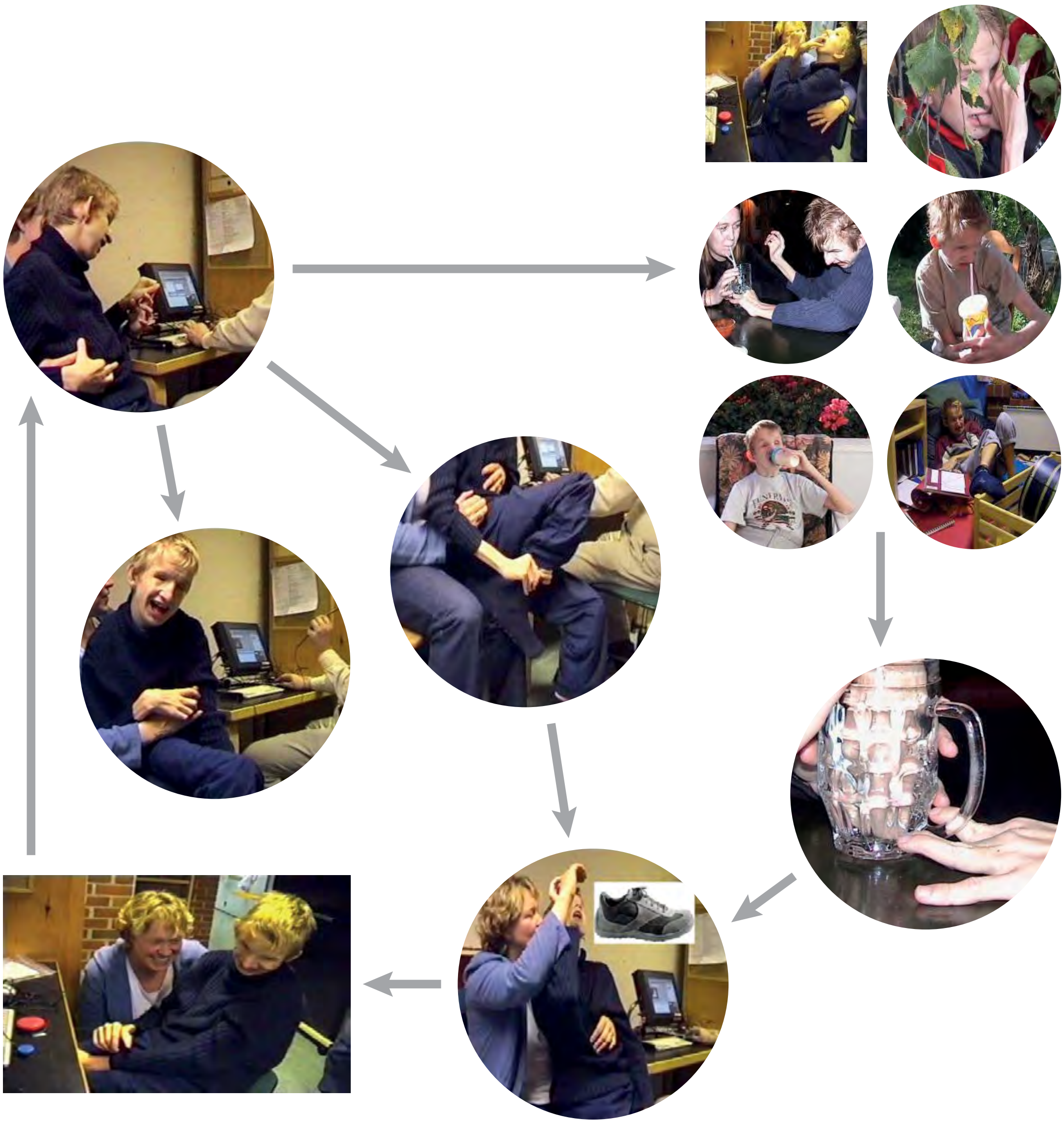
Thomas showed a robust sense of humour even as a young child, especially in communication. He was able very early in life to demonstrate awareness of what was funny and the ability to be funny. His first interest connected to humour was getting dressed "wrong". He would change his own clothes around so that his underpants would end up on his head, his socks on his hands, and so on. He would also collect his sisters' clothing from their dressers and put them on while smiling to himself. The most fun was had when I came back in to check on him and saw what he had done. I would comment on it in a dramatic tone of voice, touching his body where the clothes were, and then where they should have been. At this point his smiles would always turn to laughter. It was already clear that his humour had a social dimension.

When Thomas got older, his practice of humour expanded and had a steadily more social character. During one phase, his favourite game was to tease his sisters by asking for more milk during a meal with the intention of belching loudly once it was drunk. He had discovered, probably accidentally, that the girls complained loudly whenever he belched at the table.

To understand and practice humour, some understanding of cultural rules is necessary. For example, one must know how getting dressed works and which clothes should be put on which body parts. Without this knowledge and understanding, it is not possible to twist a situation to make it funny. In the same way, one must know cultural rules of good behaviour at the dinner table to bend these on purpose. As he got older, Thomas was also able to demonstrate his understanding of verbal in different social settings.

Incongruence humour

Among the many theories of humour, the one with the most relevance for Thomas's sense of humour seems to be that of incongruence. This involves the perception that something in a situation has broken with expectations and the term means *discrepancy*, anything that seems strange, surprising or out of place. McGhee (1971; 1979) describes stages in the child's early development of a sense of humour. His perspective draws on Piaget's theory of cognitive development and describes four stages in the development of incongruence humour. In stage 1 (1-2 years) children can play with objects in contexts in which they do not fit; at stage 2 (2-3 years), early language use appears in incongruous naming of things and events; at stage 3, (3-7 years), conceptual incongruence is shown in changing aspects of a concept (i.e. saying that the cat says "moo" instead of "meow"); and finally, at stage 4 (7 years on) the child is engaged in exploiting the fact that a word can have several meanings (McGhee, 1979). The video case example presented here suggests that Thomas's humour was moving towards the Stage 3 level, even though his language use was early Stage 2.



Humour and play

Søbstad (1999) describes the relationship between play and humour and highlights several shared criteria. Both require moving out of the known and into a new experience of reality. In each, context creates the requirements for how the ensuing action is to be interpreted. The central message is that of leaving everyday reality and going into "a closed world of meaning within the dominant reality" (Berger & Luckman, 1966). In addition, both can be seen to require certain forms of metacommunication (Bateson, 1991).

In play and humour there is alteration of a phenomenon from one form or meaning to something else. Intersubjective agreement is important that what is happening is play or humour, and with this, the physical, psychological and social requirements to prevent disruption and rejection (Bateson, 1956; Berger, 1997/2014). Although both can be pursued individually, each takes place in the context of the lived world and thus, both are fundamentally social (Søbstad 1999). Thomas most likely perceived the situation in the video as play. In it, he was the speaker (most of the time), and I interpreted by noticing how each sign was produced in the context and applying my prior knowledge.

Description and analysis of the video sequence

The video shows Thomas and myself in a situation in which I try to explain to him the purpose of a speech machine (Roll Talk). Thomas is in his classroom with two men who had developed the program for the machine, and me. One of the men is sitting at a table and has entered several words into the speech machine so that it can repeat these when activated. I knew that Thomas had a schematic for machines and that he could get sound out of them. The speech machine was not a completely new object for him and could be manipulated in a more varied way than his cassette player. It had a similar function and therefore could be viewed as belonging to the same category.

At the start of the sequence, Thomas and I are sitting with the speech machine. Four words have already been programmed in, three of which chosen based on Thomas's interests: water, swim and shower. Thomas has also chosen "dog". These words demonstrate how the speech machine works and are accessed by pressing a button. We are about to try out a more advanced function of the machine: pressing to select several given topics (categories) and then choosing words or sentences within these.

As the video starts, the word "drink" is heard from the speaker. Thomas indicates uncertainty about this situation by shaking his right hand. At the same time, he answers me when I ask him what the machine has said by signing DRINK. He then makes a sign that I interpret as BREAD. After reviewing the video many times, I finally decided that it might be the sign for WATER Thomas is using, a comment about the machine saying "drink". Thomas wants to put in more words, so perhaps his sign is that for BREAD.

Thomas stretches out his arm as though searching for something or someone. It appears that he wants to check that the man programming the machine is in place. He moves over to the "programming man" and steers him into his chair. This produces laughter from everyone in the room including Thomas. The man asks Thomas what the machine should do, then suggests he select the drink category. Thomas checks the man is still in place using his leg. I suggest the words milk, juice and water be read into the machine. Thomas again makes a sign that I interpret aloud as BREAD and confirms this vocally. I answer that I have seen the sign and heard him say "Yes", but that the category is drink. He then makes the sign for DRINK.

I remark to Thomas, "You could decide, right? and then the machine said what you wanted". Thomas shows delight at this and appears to be about to sign SHOE. A little while later I see that he wants to suggest the word *shoe* for the machine. Together we review the words programmed so far using both speech and sign. During this, Thomas is suppressing a giggle and indicates that he is about to make the sign SHOE.

When the words belonging to the drinks category are heard from the machine, Thomas repeats these using signs, then makes the sign SHOE. He continues with this when I ask if we are going to joke about drinking shoes. When I reviewed the video sequence, I saw that he was also saying MORE, probably meaning that he wanted the situation to continue.

Thomas did not distinguish between signs for shoes, boots, socks, but instead used his sign for SHOE to say that he wanted to put on "shoe" and go out or take off footwear once inside again. Yet another meaning was *when he wanted to stay longer somewhere he was visiting*. He could also very pointedly refuse to take his shoes off (the norm indoors in Norway) if he was somewhere visiting and wanted to ensure that he could leave if he chose – *"I'll only stay if I don't have to remove my shoes"*. When I saw the sign used here, I decided it had achieved yet another function as a tool to express humour. Thomas could play with words lying outside the category spoken about in the moment.

Conclusion

Throughout this situation, Thomas must repeatedly select a word that either belongs or does not belong to a given category. His experience of the effect of his answers depends on my responses as interaction partner. When I accord him the quality of being a person with a practice of being humorous, my responses become a way to say, "you're you and I'm me and we're a lot alike" (Nafstad & Rødbroe, 2015). Thomas's comedic contribution is socially addressed and involves the communicative intention of creating humour in the situation. As Smith and Reid (2020) indicate, the attitudes of communication partners to the humour of the person with CDB in large part determine whether the person continues to share it with them.

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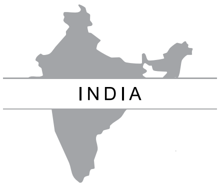
Sports for Persons with Deafblindness and Multiple Disabilities in India: Expanding Opportunities Beyond the Doorstep…

SACHIN RIZAL

HEAD OF CAPACITY BUILDING AT SENSE INTERNATIONAL INDIA, led the project implementation on Sports for persons with deafblindness. The article is written by him on behalf of Sense International India.

UTTAM KUMAR

CHIEF EXECUTIVE OFFICER AT SENSE INTERNATIONAL INDIA, and have contributed to the development and review of the article.



Introduction

Deafblindness—a combined visual and hearing impairment—poses significant challenges in communication, mobility, and independent living. Individuals with deafblindness frequently encounter neglect, discrimination, and restricted access to fundamental rights such as education and healthcare. In India, an estimated 500,000[1] individuals live with deafblindness. Sense International India (Sense India) has played a pivotal role in addressing these challenges by strengthening comprehensive service delivery through a network of 64 partner organisations across 24 states, reaching over 88,000+ individuals. Its sustained advocacy has contributed to the recognition of deafblindness as a distinct disability under the Rights of Persons with Disabilities Act, 2016. The organisation has also extended its technical expertise to neighbouring countries, including Bangladesh, Nepal, Malaysia, and Sri Lanka.

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[1] Based on estimated population of 0.04%; Govt of India Census data 2011.

Sports for Persons with Deafblindness

Sports and recreation are not merely optional activities but fundamental rights, as affirmed by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), particularly under Article 30.5. For persons with deafblindness, engagement in sports serves as a powerful medium for holistic development, enhancing motor, communication, mobility, social, and cognitive abilities. Participation fosters self-confidence, independence, and a sense of achievement, while simultaneously promoting inclusion and challenging societal stigma. It also facilitates meaningful social interaction and teamwork, contributing to greater social integration and mutual understanding.

In addition to promoting inclusion, sports offer extensive physical and psychological benefits. Regular participation improves strength, balance, endurance, flexibility, coordination, and overall functional capacity, while also enhancing immunity and reducing health risks. From a mental health perspective, sports contribute to improved self-esteem, emotional well-being, and confidence, while mitigating anxiety, depression, and behavioural challenges. They further support cognitive development and learning capacity. For children with deafblindness, sports are integral to overall development—they are, first and foremost, children, and their right to play and participate must be recognised and upheld.

A notable initiative supported by Sense India, in collaboration with the Blind People's Association, Ahmedabad demonstrates the transformative potential of structured sports programmes. A comprehensive one-year capacity-building programme on understanding sports of persons with deafblindness was implemented in the year 2024 (still continuing) to equip special educators working with children with deafblindness and multiple disabilities with the necessary skills and physical preparedness.

Following one year of training provided to special educators, an assessment was conducted for 20 children and adults with deafblindness who were selected for the sports programme. The assessment comprised two components: (1) a physical assessment to understand individual strength and capabilities, and (2) a nutrition assessment to determine specific dietary requirements. This process also established a baseline of each participant's physical abilities and nutritional needs.

Based on the assessment findings and individual preferences, tailored physical exercise plans were developed, followed by the selection of suitable sports such as ball dribbling, skating, football, basketball, badminton, table tennis, bocce, shot put, yoga and softball throwing, The outcomes have been highly encouraging, with participants demonstrating increased participation, confidence, and enjoyment. For many families, witnessing their children actively engage in sports has been both empowering and transformative.

To ensure a holistic approach, the programme integrated nutritional support under the guidance of a qualified nutritionist Ms. Khushboo Keswani, inputs from a sports physiotherapist Dr. Eshwar kapur to design appropriate exercise regimes, and technical training from a sports instructor Mr. Amit Asodiy. Parents—particularly mothers—were also engaged through structured yoga and fitness sessions, contributing to improved physical and emotional well-being.

The impact of the programme has extended beyond sports, with noticeable improvements in classroom engagement and overall developmental progress among the children.

Impact:

Individual achievements further underscore the potential of sports as a incentive for empowerment. Kush, a 15-year-old participant, secured a gold medal at the National Paralympic Games in Patna, Bihar (India), along with a cash award of INR. 100,000 (approx. USD 1064), bringing recognition and pride to his family and community. Similarly,

Ms. Kathayat (L) has emerged as a notable athlete with deafblindness in powerlifting, gaining recognition for her accomplishments in the deadlift category.

Mr. Blessing (R), who progressed from district-level competitions to competing at the National Championship held at IIT Palaj, Gandhinagar, in June 2025. His performance earned him selection for the national training camp, placing him on a pathway towards potential participation in the 2027 International Special Olympics in Santiago, Chile. His journey reflects the transformative impact of sustained support, structured training, and personal determination.

While these achievements are significant, there remains a critical need to strengthen and scale an inclusive sports ecosystem for persons with deafblindness. This requires a strategic and multi-layered approach encompassing early intervention, capacity building, accessible infrastructure, and systemic integration within education and sports frameworks.

Recommendations

- Ensuring equitable access to sports opportunities for persons with deafblindness through inclusive and targeted programmes.
- Integrating adapted sports and physical education into both special and inclusive school curricula from an early age.
- Developing specialised training frameworks for coaches, physical education teachers, and rehabilitation professionals, with a focus on adapted sports and communication strategies.
- Establishing and disseminate standardised national guidelines for adapted sports for persons with deafblindness, including safety protocols and sport-specific modifications.
- Strengthening accessibility of sports infrastructure through tactile adaptations, assistive devices, and inclusive design.
- Promoting the use and availability of adapted sports equipment to facilitate effective participation.
- Organising structured competitive platforms at district, state, and national levels to enhance exposure and motivation.
- Fostering partnerships with national and international sports bodies, including the Paralympic and Special Olympics movements, to ensure representation and recognition of more sports in the event.
- Encouraging active engagement of families and communities to address stigma and promote participation, particularly among girls and women with deafblindness.
- Investing in research, documentation, and evidence-based practices to inform policy and programme development.
- Advocating for dedicated funding and policy inclusion of deafblind-specific sports initiatives within government frameworks.
- Creating pathways for leadership, employment, and professional development in sports for persons with deafblindness.
- Establishing robust monitoring and evaluation systems to assess programme effectiveness and ensure continuous improvement.
- Promote inclusive sports platforms that bring together persons with and without disabilities, fostering social cohesion and mutual respect.

Expanding sports opportunities for persons with deafblindness is not merely a programme intervention—it is a commitment to inclusion, dignity, and equal participation. With the right investments and systemic support, individuals with deafblindness can go beyond barriers and realise their full potential, beyond any limits.

Finding Our Own Community. Facilitating Inclusion!

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Corey and I met in 2017 when he joined a new Tremplin day program at DeafBlind Ontario Services. I was hired as one of his intervenors and obtained my rating as a CDBIS. Corey is deafblind from birth with some residual hearing and uses alternative methods of communication. As Corey's intervenor, I enhance his experiences by being a bridge of connection so he can express and receive information. Recently, I shared and facilitated Corey's introduction to, immersion in, and inclusion as part of the local wrestling scene.

His introduction to wrestling started during COVID lockdown while I was supporting him and his peers. Corey, often awake while others slept, watched hockey games. I offered him a variety of new sports on a big screen in a dimmed room. When I showed him wrestling videos, he told me in every way possible that he was loving those. Since Corey doesn't use traditional words or expressive signs, I interpreted his positive vocalizations, facial expressions, enhanced body motions, directed attention, alertness, and visible excitement all to mean one thing: Corey wanted to watch wrestling! Since Corey and his team developed a 'Now/Finish' calendar system and choice system with tactile concrete cues (objects that represent a concept or activity), I sat down with him to create a cue for this new communication. By exploring materials with Corey and hand-under-hand crafting, we created a mock-up of a WWE championship belt in crimson and black on a neon yellow strap for contrast. Corey could now use this object to ask for wrestling. It could have stopped there; Corey enjoying a new activity he can request using this new cue, but as his intervenor, I wanted more.

COVID lockdown didn't last forever. Soon, Corey was able to go out in the community and enjoy sports games, cinema, and arcades. I notified Corey and his team of anything he might enjoy. In 2024, I noted a new promoter selling tickets - Project X Wrestling, live and local!

A February show was scheduled, and I arranged for Corey to attend. He went with his roommates, a friend from the house on the next block, and various support personnel. I contacted one of the wrestlers, asking about wheelchair access and promoting use of an intervenor. Advocacy was done easily and wheelchair sections were taped off around the room just for them. Serving as in-

tervenor for two people, I was able to see Corey enjoying the up-close live experience. It was a good show, and everyone enjoyed the trash talking and theme music. Corey made his enjoyment evident as he laughed, clapped, shouted and smiled. It was clearly a great time. He met fellow fans, organizers, and the wrestling stars, and I networked to form connections for an opportunity to bring Corey back to a wrestling show. Corey, for his part, had a new shirt, a new experience tool made from his autograph sheet, and a renewed energy when he chose to watch wrestling on tv.

June of 2024 brought the next opportunity - “Nickel City Slam.” My networking connections resulted in free VIP spots at a table at the front or the event. Corey and I took a van to the event, using his calendar with his van ride cue and wrestling cue to build anticipation. We got to our VIP table, and I angled Corey’s field of vision toward the ring. Much to my delight, he showed immediate excitement as the music started and he looked at all the friendly faces who had invited us and provided our tickets. I explained where we were and introduced him using verbal French paired with tactile use of Langue Signe Quebecois (LSQ), Corey’s preferred receptive languages.

The barker called out the match and Corey became focused, attentive, and alert. When cheers, jeers, and stunts began, Corey became active and vocal. I knew he was loving it because he was rocking his torso, smiling, laughing, and doing clapping motions. I provided LSQ short forms of announcements, chants, and cheers, as well as any conversation at the table. Our new friend, Charlie, noticed me signing, so he used me to talk to Corey, setting the tone for everyone. I signed the table talk to the best of my ability, challenging myself and really practicing my finger dancing. Corey turned 29 at midnight and was celebrated by everyone around the table.

Throughout the evening, Corey was surrounded by people who wanted to make sure he was having a good time. He let them know he was having fun by being vocal with lots of laughs and body motions. I acted as an extension of Corey; his directed looks, his body language, the specific tones of his vocalizations, all became part of his social interaction as I relayed information from Corey to the table, and from these new friends directly to Corey.

At intermission, I brought Corey all around the arena, and despite the line, he was able to meet wrestlers who touched hands with him and signed his programme. Corey was humming and smiling away. Everyone at the event came together, moving chairs and tables to make room for Corey and his wheelchair so we could get back to our table. We made it just in time as intermission ended. One new friend, Chris, had taken time to shop and bought a wrestler merch necklace. He gave it to Corey, who spent the rest of the night wearing it proudly. Corey was even more vocal after intermission with loads of laughter and almost bouncing right out of his chair. By this time, he didn’t need an intervenor at all for the table to understand his enthusiasm and joy. The bridge of connection had been forged and now Corey had real social relationships with friends at the VIP table.

In a main match, one of the stunts went wrong and a wrestler was injured. Corey had a concerned expression and was no longer laughing when paramedics arrived. Everyone helped reassure him that good doctors and nurses would help. Once Corey cheered up, we said goodbyes and boarded a taxi. Corey received back pats and handshakes during goodbyes once I explained that he enjoys physical contact. Corey expressed this himself by turning his face toward each friend in turn and making happy vocalizations.

After a taxi ride through the city by night with many pretty lights, we returned home where a joyful Corey used his calendar’s ‘finish’ box to complete our outing, transferring his cues for van ride and wrestling out of the ‘now’ box and into ‘finish’. We added another page of autographs to his experience tool so that it would grow with him to reflect his expanding experience and new memories.

My friend, Michael, asked if I could bring Corey to a show in February of 2025. He shared that he had enjoyed meeting Corey and made friends with him at the prior show. It is important to me that Corey spends time doing things he loves with people who celebrate him like Michael, Chris, and Doug, who were all attending, so I promised to make this happen. I confirmed with Corey's team, then set everything up.

This event was a great expansion of Corey's immersion. As Corey and I waited in line, he was received by our friends and began looking around with little smiles as they called him by name, welcoming him. He met Rocky and Howler, mascots for the local basketball team and hockey team. Corey had positive interactions and took photos with them, and then met the wrestlers, some of whom remembered him. We got a programme for this event and collected autographs before joining our friends at our ringside table. I challenged myself to provide total communication, and sat facing Corey, giving the best possible sign language summary while verbally interpreting his responses for his friends. I signed the announcements and the trash talk. Corey was visibly excited, loving the experience with table talk, cheers, chants, and jeers and reacting to the upclose body slams and wrestling moves. At intermission, we reconnected with the wrestlers. Next was a royal rumble match! Corey was wholly immersed, focused and reactive. One of Corey's friend-wrestlers was victorious, and Corey let out a long, loud vocalization as the crowd cheered along.

I then helped Corey say goodbye to friends both old and new, as they expressed that they hoped to see him back on April 11th for the next big event. Our taxi home was next, then Corey added his new autographs to his experience tool so he can reminisce and chat about his good times with wrestling while waiting for the next show.

I brought Corey and a fellow intervenor to the next Project X show in April. I shared my skills, insights and techniques with the other intervenor, training her to enrich Corey's experience. Michael and I invited them to the VIP table in front of the action. I showed his intervenor all the tricks of manoeuvring the location and brought her around with Corey to say hi to his favourite wrestlers. I managed to teach some LSQ and some French words while interpreting for Corey. Everyone had a magnificent time, and I was pleased to be able to facilitate the event. Corey was becoming a real regular in the fandom.

There was a charity wrestling match Corey attended on April 26th with me. It was a smaller group at a different venue, but some of the same friends were present. Corey cheered, jeered, celebrated and yelled with the crowd as the wrestlers performed feats of athleticism and showmanship.

An annual community festival, Valley East Days, in September featured "Rumble In The Valley." I took Corey to the outdoor ring to attend various matches. This was an opportunity to explore local vendors and service providers and hang out with other wrestling fans. Corey was recognized by some and greeted immediately. As his intervenor, I helped him explore stalls with friends between wrestling show and introduced Corey to others. The wrestling scene was growing and becoming more popular, and Corey's experiences were growing too.

This brings me to January 2026; an adventure in advocacy and promoting access. I found a wrestling event at the Polish Combatants Hall, but there's a significant wheelchair barrier of stairway entry at every door. Nonetheless, I wanted Corey to grow his experiences within the wrestling community. I bought an extra VIP ticket for him, coordinated transportation arrangements, networked with the organizer, and partnered with the wrestlers for creative access. The night of the wrestling event, Corey and I took the van to the hall. We met with the promotion team and I introduced Corey. Wrestlers came out in full costume and helped me carry Corey in his wheelchair into the venue. Corey rode like a king. I ensured Corey was provided a front row seat using his best-known field of vision. I met his orientation, mobility, and communication needs while we reconnected with friends. Corey very visibly enjoyed the evening and at the end, he got a wheelchair carry-out from wrestlers who thanked him for coming.

Finally, this past February, I was delighted to escort Corey to another event called

"Toxic Behaviour." All the possible obstacles were easy to overcome. Since Corey and I are now regulars at Project X, many barriers were pre-handled by the setup crew who managed the event. Corey was positioned in optimal viewing, with friends and fellow fans, completely catered to and set up for success. The spot at the VIP table has become 'Corey's spot'. He returns to wrestling events at every opportunity and is fully immersed in the fan community, forming genuine relationships and bonds with some of the wrestlers, crew, and his fellow fans. He is greeted as a friend by many, and this friend group is always happy to see him. They save him a seat and genuinely enjoy him on his own terms as they share his cheers and jeers. He has found his own place in the local wrestling community, and I love that for him, both as his intervenor and as a fellow fan.

3D-printed Referential Objects for the Days of the Week

WANDA FREDERIKS

At Bartiméus, a set of seven referential objects had been developed as an addition in communication with people with combined hearing and vision loss and an intellectual disability.

The set was created by the Bartiméus Expertise Centre deafblindness, in collaboration with speech therapist and the Bartiméus FabLab.

Why referential objects for the days of the week?

Many professionals already use objects that refer to activities in their communication with individuals with deafblindness and an intellectual disability. Examples are a cup that refers to drinking coffee or a swimsuit referring to swimming. However, practice showed that objects representing the days of the week were

still missing. As a result, it can be difficult for individuals to ask questions such as: "What day is it?", "When will the activity happen?" and "What did we do yesterday?".

What has been developed?

Our experts designed a set of seven 3D-printed referential objects. Each object can be clearly distinguished through:

- Differences in shape and texture
- Tactile markings on the top (e.g., Monday = one point)
- The corresponding day written on the back (in Dutch)
- Color use

These referential objects enable communication through touch, colour, and shape about:

- Which day is it
- The sequence of the week
- When something is going to happen
- A day that had already passed

Want to learn more or get started yourself?

On the Bartiméus webpage you will find the complete English manual with:

- Guidelines for introducing referential objects to individuals
- A step-by-step familiarization plan
- Suggestions for observation an evaluation

Would you like to start using referential objects yourself or are you curious to learn more? Please click here: Verwijzers voor de dagen van de week - Bartimeus

Haptics: Pocket Edition — A New Start for a Global Resource

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Ingress

Haptics: Pocket Edition is an app designed to give users access to standardized haptic signals. The app is developed for people who are blind or deafblind and makes it possible to receive information about the environment, people and emotional atmosphere, through touch. Now, the app is entering a new chapter. Eikholt, the Norwegian National Resource Centre for the Deafblind, has taken over responsibility for the app. Together with the Hapti-Co company, they have redeveloped it to be more accessible, more stable and better tailored to those who use it.

Picture 1. Employees from Eikholt and Hapti-Co: Thomas Øverby, Than Tøgard, Kathrine G. Reder, Inger-Lise Vincent, Hildebjørg Bjørge og Roar Meland

What are haptic signals?

Haptic signals are a method of conveying information through touch, usually on the upper back or upper arm. Haptic signals can supplement spoken or sign language. They can be used to obtain information about surroundings, events, moods, people and more.

What the App Contains – and What Is New

The app continues to include all 144 standardized haptic signals, each presented with an image, text description and video demonstration, features familiar to longtime users.

The new version introduces several improvements designed to increase usability and accessibility:

- **Favorite lists:** Users can create personalized collections of frequently used signals.
- **Sharing:** Favorite lists can be shared with others, for example, between professionals and families, or within teams.
- **High-contrast mode:** An important feature for users with low vision.
- **Dynamic text size:** The app now follows the device's system settings for text size.
- Language options: Users can choose Norwegian or English.

These changes respond to long-standing requests from users around the world. It is a significant milestone that the app is once again available in Google Play (Android) and the App Store (iOS), making it accessible to anyone who wants to learn or use haptic communication.

Picture 2. The Haptics: Pocket edition app on a smartphone

A Brief History – The Desire to "Capture the Environment"

The development of haptic signals for people with deafblindness is closely tied to the pioneering work of Trine Næss. Living with combined vision and hearing loss herself, Næss was driven by a strong desire to "capture the environment" more fully. Her motivation led to the establishment of a system of standardized haptic signals, now used internationally.

After her passing, Hapti-Co, the company which developed the system of haptic signals in Norway, was encouraged by Næss' closest network to carry on with her work. In collaboration with The Association for visual and hearing impared/deafblind people (LSHDB), and with support from the Foundation Dam, Hapti-Co published a book collecting the full set of basic haptic signals. The book was later translated into English, enabling dissemination far beyond Norway. Hapti-Co travelled extensively, contributing to training, development and knowledge sharing worldwide.

When the COVID19 pandemic in 2020 halted travel, Hapti-Co used the unexpected pause to develop something long envisioned: a digital version of the haptic signal resources. Through intensive work, the first edition of Haptics: Pocket Edition was created, a tool that quickly became essential for learners, professionals and families involved in deafblind communication.

However, the app later disappeared from Google Play. To secure the longterm future of the app, Hapti-Co eached out to Eikholt, asking if the national resource centre could take over responsibility. In the summer of 2025, the collaboration formally began.

Haptics: Pocket Edition: a globally available resource

Today, both Hapti-Co and Eikholt share a clear ambition that anyone who wants to use haptic signals, users, relatives or professionals, should have access to a high-quality and globally available resource. *The Haptics Pocket Edition* app is still under active development. Our goals include making the app available in additional languages and adding new haptic signals.

The project is led by Thanh Tøgaård, Senior ICT Advisor at Eikholt. Throughout the spring, she will invite course participants and interpreters visiting Eikholt to test the app and provide feedback.

Picture 3. Eikholt National Resource Centre for the Deafblind

About Eikholt – The Norwegian National Resource Centre for the Deafblind

Eikholt holds a national mandate from the Norwegian Labour Welfare Administration (NAV) to provide customized courses for individuals with combined vision and hearing loss, as well as their families. These courses are a legal right under the Norwegian National Insurance Act.

Eikholt also contributes to the Norwegian National Advisory Unit on Deafblindness (NKDB), under a contract with the Northern Norway Regional Health Authority. This involves developing and disseminating knowledge relevant to people living with combined vision and hearing loss.

With this competence, infrastructure and longterm responsibility, Eikholt is well positioned to ensure that *Haptics: Pocket Edition* remains a living, accessible and evolving resource supporting users across countries, cultures and communication systems.

Sound Senses. Music Education Through Deafblind Perspective

ORLA O'SULLIVAN

ANN SULLIVAN CENTRE, DUBLIN

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I am Orla O'Sullivan. I am a registered individual who is deafblind. But that did not stop me from qualifying as a Deafblind Multi-Instrumentalist Music Teacher. I taught mostly piano for 30 years. I gave lessons both to the pupils who are deaf and to those without hearing loss in my own studio. I also taught at a local primary school. Click on my website www.orlaosullivan.ie where you will find reference to my goals and accomplishments.

My musical journey began a short time after I was born. Mine was a difficult birth. I was seriously ill. Although medication saved my life, I was left with profound hearing loss and vision loss.

As a child, my mother, who was a primary school teacher, would sit with me on her lap at the piano in our home. She noticed that I was fascinated with the sounds and vibrations coming from the piano. She noted that I paid close attention to what she was playing. She also taught me how to speak by putting my hand under her chin as she was speaking. The vibrations and her encouragement helped me learn speech.

This led to my mother asking a music teacher who lived nearby to assess if I could be taught to play the piano, understand music notation, memorise, and play.

My music teacher was Jean Downey, who went on to become a lecturer in music at the University of Limerick, Ireland.

I went on to study music at the Bishopstown Community Secondary School where I was the first registered individual who is deafblind to pass the Leaving Certificate Music Exam.

From here I applied for the third level education to further my qualifications. The major universities were unable to enroll me because at that time they did not have interpreters and facilities to teach me. My sister, a primary school teacher, knew one of the staff, a director of Cork City Music College who agreed to take me as a student. Joseph Leake and Celine Garvey were my innovative teachers. As a result, I graduated as a Qualified Music Teacher with a Trinity College London Associate Diploma (ATCL) in Piano Performance, a Teacher's Certificate Diploma from the Victoria Conservatoire of Music, a Diploma in Youth Work Practice from University College Cork (UCC), and a Music Management and Sound Certificate from Coláiste Stiofáin Naofa (CSN), Cork.

I learnt how to play the organ at the St. Fin Barre's Cathedral, Cork.

Afterwards, I opened my own music studio. Most of my students were individuals without hearing loss and some of them reached all grades including Diploma Level. I also taught individuals having hearing loss, one of whom passed her Junior Grade Exam. She was the first. I also gave lessons at a local primary school, St. Columba's GNS with Facility for Deaf Children, Douglas, Cork. My mother and sister were then teachers there.

In 2010, my first CD, Sound Senses, was launched by Dr. Evelyn Grant at the Cork School of Music.

From here I came to the attention of media. Hidden Hearing company, Ireland did marketing promotions that involved giving excellence awards to people involved in the community of individuals having hearing loss. I was asked to apply and won Excellence in the Workplace award 2012. This achievement was widely covered in the print media.

That exposure and promotion resulted in radio and television reporting which led to other awards: RTE and Rehab People of the Year Award 2013, and WXN Trailblazers Award 2014. In 2017, RTE1 released Good Vibrations documentary about my life. Christine Thornton, FireBrand produced it.

Around this time a South Korean deafblind activist and advocate Young Chan visited me to see my work. A news clip of our meeting was later broadcast on South Korean TV.

Also, around that time we contacted a musician and an innovator Brian Leach. He offered to build a vibration box device that would generate and transmit specific note vibrations to your feet. More research led to me finding and contacting Ciaran O'Kelly of CronDesign.Com who allowed me to use his VisualAudio (VA) software application.

Interspersed with all this, my partner, Daniel Elliott, and I went on an extensive tour of Irish universities, schools, rehab, Anne Sullivan Centre, and deaf associations. We were also invited to SENSE UK to make a presentation in London in collaboration with a Deafblind Music Therapist Russ Palmer.

We brought survey forms to these tours and visits and asked individuals without hearing loss, individuals having hearing loss, and individuals who are deafblind to share their feedback on the project. Out of 500+ participants that took part in the survey, 99% commented how interesting, entertaining and therapeutic the experience was.

Good Vibrations documentary came to the attention of Padraig Cleary, MayDay Management, and Ronan Kett, Excelsior Consulting, whose support helped attract innovation funding from the Local Enterprise Office in Cork City.

This funding and our own personal matching funds enabled us to approach Dolmen Innovation and Design Dublin who built a prototype Vibration Device. They also looked at the Ciaran O'Kelly's VisualAudio. Dolmen's conclusion was that the project was not viable as an enterprise because it was too expensive and advised us to go to our local engineer. We then collaborated with Nimbus of Munster Technological University (MTU). They also advised that the technology as described was not financially viable in the mass market. It could however be used as a vibro-acoustic floor in education centres, music schools, university community centres, and related facilities.

How it works: I was part of the team that developed assistive technology to enable individuals having hearing loss and individuals having dual sensory impairment to enjoy and learn music in an innovative and inclusive way. That is See the Music, Feel the Music, Experience the Sounds in Vibrant Colours.

This is achieved through the use of a Wi-Fi application linked to a digital piano, connected to a laptop and displayed on a screen.

The hardware device vibrates in all frequencies.

Interview – Parents Share Their Experiences

At CRESAM, we are regularly asked by grandparents, support services for parents, some schools and child care services, and also by hospitals about parenthood. Some examples of their questions are: how to be a deafblind parent nowadays? what is the pathway of parenting?

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Resources are missing to meet those requests. Indeed, these are scarse publications and studies on parenthood for deafblind people in France. As part of the "Parenthood and Deafblindness" project, we collaborated with "Droit Pluriel" (an organization for the accessibility rights of disabled persons), to ask two mothers' testimony of their journey and their condition:

My advice to parents in my situation would be to tell it like it is. As a parent, you always want to show your strength. Yet you are the way you are; you have weaknesses, you may have shortcomings, you can make mistakes…it's only human.

I am married and I have 11-year-old twin girls. I've been on sick leave since my disability grew: I have level 2 Usher syndrome, which makes me visually and hearing impaired to a great extent. I was born with this genetic disease and it made me hesitate for a long time before having children. However, I have always pulled through. I got a degree, I've had a job for a long time, a house, nothing could stop me. During the pregnancy I was very anxious. I was afraid that my children would have the same syndrome. As soon as we were able to run the tests, we found out that they didn't have it and it was a great relief.

As the children grew up, I had to take care of them with increasingly reduced visual acuity. By the time they were in first grade, I couldn't tolerate any luminosity. We had to rethink everything. How was I going to cope? I was afraid to pick them up from school. I was afraid of how people would look at me. In the end, everything went well: the advantage of being visually impaired is that I can't see what goes on around me.

I had my daughtersfollowed by a psychologistso that they could talk freely about my disability and that it would not have any repercussions on them. As for me, I spent four months in a centre to readapt to my increasingly poor eyesight and to learn to use a white cane. I was in tears during the first lesson. But in hindsight, I realise I learnt to live a new life thanks to this new independence. I can move around more easily. When I came back from the rehabilitation centre, I wasin for a huge shock. I used to be in charge of running the whole house, but I didn't fit in anymore. I couldn't help the children with their homework,

I couldn't cook, I felt useless. I found it hard to reprise the role of their mother; my husband and children tend to do everything for me, to foresee my actions. It is psychologically very hard when you're made to feel helpless.

Fortunately, I have a very close my relationship with my daughters. I have always told them the truth, without ever being defeatist: I have always been a fighter. You have to find the right words, for them to understand, at their own level.

Since we all love animals, I told them that I was going to get a guide dog, to help them better accept the white cane. As time goes by and as they grow up, I feel that they can help me and that it is only natural. In a broader sense, I feel that they are more aware, more open to diversity.

Céline Bauza, 44 years old

If I had any advice at all for parents in my situation, I would tell them that nothing is taboo; misunderstandings.

I am deafblind, I have Usher syndrome, I'm married and have two children aged 18 and 15. My partner is deaf and both my children are able to see and hear. For 15 years, I co-taught kindergarten children with the organisation Deux Langues Pour une Education (2LPE). I had to stop working for health reasons: my eyesight started to fail due to Usher syndrome. Despite this, I was never told that I could not have children or that I could not work or participate in any way in social life. The urge came naturally to me, without any apprehension. I didn't feel radically different, I felt capable and confident enough to become a mother. For indeed, I was born deaf with Usher, benefited from a bilingual education in French sign language (LSF) and

was supported by very positive narratives. I have built a clear identity with which I have no inner conflict, and I have always felt very independent. Deafness is normal for me, everyone around me speaks sign language and this communication seems natural to me. When my eldest son was born, I did not yet have any difficulties related to my sight loss. Later on, we adapted by switching to tactile sign language, especially when there was little light. I built a strong bond with him, he understood my specificities right away. When my daughter was born, my eyesight had deteriorated considerably but my daughter quickly adapted. I noticed that at the age of three and a half she had already developed automatisms where I was involved. Probably because she had observed my difficulties and also those of her uncle. One evening at a school party, after the show was over, she came straight away to take me home: I hadn't said anything to her, but she had understood that I couldn't see after dark. In general, we talk freely about everything: the special orange glasses, the white cane… I also feel it is important to inform them of the changes in my visual problems. Unlike my deafness, which is not progressive, my vision is declining and I have to communicate about what I can or cannot do.

Sometimes my children speak around me and I try to make them understand that when I am present, they have to use LSF (French Sign Language) or LST (tactile sign language), because otherwise, I am excluded from the conversation. The most difficult thing has been to help with their homework with my degraded eyesight. We hired private help for this but it was difficult because we didn't have any specific financial assistance for this and the technical equipment to compensate for my visual impairment is already very expensive.

I am lucky to have a lot of support. With my brother, who is deafblind and has Usher like me, we have come up with many ideas and accessibility solutions. Sometimes I need help, but that doesn't take away from the independence I have in other ways. And I have always been able to cope with my needs and those of my children. They can speak three languages: French, French sign language (LSF) and tactile sign language (LST). As a result, during my son's internship in a shop, he was able to greet a deaf customer in sign language. My children are immersed in a multicultural environment every day, as they have both hearing and hearing impaired friends. This has a big influence on their open-mindedness. My dream was to have children and to have a happy home, and I am delighted that this is now the case.

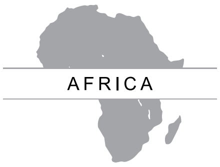
Angélique Dutrinus, 43 years old

The Unseen Bond: a Mother's Love Knows No Limit

HELLEN SHAKELE

My name is Hellen Shakele, a proud super mom of a child born with congenital deafblindness. I am the third-born in the family of four. I was born on 8 July 1983 in a small town called Chingola, the cleanest town in Zambia. I am Ila by tribe and I come from Mumbwa which is located in the central part of Zambia. I started my primary education at Chingola Primary School and completed my secondary education at Chingola High School. In 2004, I enrolled at Mufulira Teacher's Training College and graduated in 2006. In 2007, I headed to Lusaka, the capital city of Zambia, where I got a job as a Preschool Teacher. I taught at a nursery school for a year and then, in 2008, I was deployed by the government of Zambia. In the same year I got married and got pregnant and that is how I started my family life and my daughter was born.

In this story there is a little girl called Luyando and she is famously known as "Lulu". She is my first-born child with congenital deafblindness caused by Rubella syndrome. Luyando was born on 8 July 2009, she is named after my late mother "Loveness". My mother was one of the most beautiful-hearted women. I had named her Luyando before she was born in honour of my late mother. Luyando is a Tonga name from the southern part of Zambia where her father comes from. In Tonga, "Luyando" means "love". Tonga people speak Bantu and inhabit the southern part of Zambia and neighboring areas of northern Zimbabwe and Botswana.



My delivery was normal and she cried at birth. At the age of three, Lulu was diagnosed with bilateral cataracts. This was due to Rubella which is also known as German measles. I had Rubella when I was pregnant. It occurs and disappears in three days, sometimes unnoticed. It is short and very difficult to discover, and starts with small normal rashes on limbs and trunk and disappears without causing upset to the body system. Sometimes a person may have a fever above 38°C and the only time I had a fever above 38°C accompanied with red rash was before pregnancy, so doctors suspected that I had had Rubella before getting pregnant. I knew immediately that life would never be the same. The doctors explained that she was born with congenital deafblindness, and at that moment, my heart was filled with both fear and fierce determination. I understood that every challenge, every triumph, and every setback would be something we would have to navigate together.

When I was told about the deafblindness, the words hit me like a physical blow. I remember standing there staring at her tiny face and wondering how would I ever reach her or how would I connect with a child who cannot see my smile or hear my voice? The fear was paralyzing but beneath it something stronger took root, a fierce unshakable determination. I made a promise to myself at that moment. I would move mountains if that was what it took to give her the life she deserves.

In the beginning, communication felt impossible. I could not rely on spoken words or visual cues, so I turned to touch, the sense that still connects us. I have learnt how to speak using gentle presses and rhythmic taps to convey meaning in our daily conversations. A squeeze means "I am here", a small rub in her eyes means "sleep". I started using these signs when I learnt about tactile signs and other communication types for the individuals who are deafblind. Over time she began responding through her tiny fingers curling round mine in recognition. It is not a language that most people know but it is ours and it is very beautiful. As she was growing up, I faced a lot of challenges, especially stigma which was perhaps the heaviest burden. Society often looked at her with a pity, sometimes even fear. People whispered, questioned, and doubted her abilities. Schools hesitated, resources were scarce, and educators were often unprepared to meet her needs. Her education was a constant struggle, a fight for inclusion, understanding, and for the simple right to learn. There were days when I felt exhausted, defeated by systems that seemed unwilling to bend. But she never gave up, and so neither did I. Teaching her how to sit and walk was a challenge. Most children learn by watching others but my daughter had to navigate the world through touch and trust.

I guided her feet with mine, letting her feel each step before taking it. There were falls, of course, and times when she stumbled but she made her first independent steps: her hands outstretched, her face alight with triumph. At that moment I realized something profound. Her victories were not measured in milestones but in courage. Children who are deafblind often sit and walk differently; their bodies are adjusting to the world they cannot fully perceive. My daughter's steps were cautious, her posture sometimes uncertain, but each movement carried determination. She learnt to trust the ground beneath her feet, to sense vibrations, and to rely on touch for balance. Watching her walk was like watching courage in motion. Every step – a victory over fear.

There are many causes of deafblindness, including infections, age-related problems, accidents, and genetical causes. In my daughter's case, she was diagnosed with Rubella syndrome which is also known as German measles. Deafblindness also comes in spectrums. Individuals may be totally blind or totally deaf, totally blind with partial hearing loss, totally deaf with partial vision loss or may have partial hearing and vision loss. My daughter falls into the category of total deafness and total blindness. At the age of three, she underwent a surgery to remove the bilateral cataracts.

After the surgery, her sight still did not improve. Instead, I continued showing her love and supported her in so many ways. It was challenging for me because by then I had never met a fellow parent with a child like mine with whom we could share experiences, nor was there a parents' group where I could get in contact with others and discuss these things. I had so many thoughts, questions, and, most of all, emotions surrounding my daughter's condition. Still, I remained a happy and focused mom, as seen in the picture below.

My daughter was introduced to school at the age of five. At that time, she was still carried on my back as she could not walk properly. Later, I trained her to walk and she started walking long distances on her own. She really used to enjoy it and never wanted to be held. The first day I took her to school, she was welcomed by the children having hearing loss. Some of them signed into her hands, others touched her head, tapped her on the back or hugged her. It was such a wonderful experience.

Swimming became another chapter in her exploration. I discovered that my daughter has a special ability and that is swimming. Through touch, she learnt the rhythm of strokes, the buoyancy of water, and the safety of my guiding hands. The pool became a place of freedom, where she could move without obstacles and glide with confidence.

Her bond with me is rooted in touch. She knows me not by sight or sound, but by the warmth of my hands, the rhythm of my heartbeat when she leans against my chest, and the unique way I hold her. That recognition is profound and represents the proof that love transcends the senses. Her interactions with siblings are equally remarkable. They have become her playmates, her guides, her teachers. She explores their faces with her hands, memorizing the contours of their cheeks and the shape of their smiles. They have learnt to include her in games through touch and movement, creating a world where she is never left behind. Exploring surroundings is her daily adventure. She has mapped spaces with her hands, traced walls and furniture, and built mental pictures through touch. She manages her environment with a kind of quiet intelligence, finding ways to adapt and thrive.

My daughter's journey has transformed me. What began as a struggle to raise her in the world that did not understand has become a mission to ensure that others like her are seen, heard, and valued. She is my inspiration, my strength, and the reason I believe that even in silence, there is a voice powerful enough to change the world. The advocacy led me to pursue a Master's degree in Deafblindness. I immersed myself in research, theory, and practice, driven by desire to amplify voices like my daughter's. It was not easy – balancing studies, single parenting, stigma, and advocacy stretched me to my limits – but every page I read, every paper I wrote, felt like a step toward justice. I am now writing a book on deafblindness which is not just a story of my daughter and me but a story of countless families, children, and individuals whose lives are shaped by silence and light. It is a testament to resilience, a guide for those who walk similar paths, and a call to society to see beyond disability and recognize humanity.

Raising my daughter has been the most profound journey of my life. She has taught me patience beyond measure, resilience in the face of uncertainty, and the true meaning of communication. I have learnt that connection is not limited to sight or sound but it may be found in touch, in presence, and in love. Along the way, we discovered new ways to learn and grow. We have embraced tactile sign language, sensory-based learning, and assistive technologies that have opened doors once thought closed. Each innovation is not just a tool but a bridge to independence, dignity, and self-expression.

This journey is never mine alone. Together with other parents, educators, and advocates in Zambia, we have built networks of support. We have launched awareness campaigns, created inclusive programs, and are working tirelessly to ensure that individuals who are deafblind are seen, heard, and valued. Our strength lies in community, and our progress is born from solidarity.

As a parent I have celebrated every milestone – whether a child learns a new sign, navigates space independently, or simply expresses joy in their own unique way. These victories may seem small to some, but for us they are monumental. And we celebrate the collective achievements too. When advocacy leads to policy changes, when schools open their doors wider, when society begins to understand. Our journey has been marked by unforgettable milestones. The first breakthrough in communication, the first steps toward independence, the first time our voices as advocates were heard by policymakers. Each milestone reminds us that progress is possible, and that the future holds promise.

To sum up, I want to say that raising a child with congenital deafblindness is not a story of limitation but a story of transformation. It is a story of love that redefines strength, of innovation that reimagines possibility, and of community that reshapes society. Together, we are not just raising children, we are raising awareness, raising hope, and raising future where every individual who is deafblind can thrive.

DEAFBLIND PRIDE!!!!!!!!!!!!

Through Darkness, I Found My Own Light

FOTINI TATAKI

PANHELLENIC ASSOCIATION OF DEAFBLIND PEOPLE,

PARENTS, GUARDIANS AND FRIENDS OF DEAFBLIND CHILDREN,

“THE HILIOTROPIO”, ATHENS, GREECE

FOTATAKI@HOTMAIL.COM

My name is Fotini Tataki. I was born deaf, and later, during elementary school years, I noticed that my peripheral vision wasn’t clear—but at the time I didn’t pay much attention to it. When I joined middle school, my classmates started noticing my vision issues: “Why can’t you see?” or “Are you just being careless?”. Some people misunderstood me, and that convinced me to visit eye specialists. That’s when I was diagnosed with Usher Syndrome.

It was a huge shock for me because I realized I had two conditions, and I struggled to accept it. I’ve always been an athletic person; I loved sports, especially those involving a ball, like volleyball or racket sports. As long as I was still able to see clearly, I kept playing. But I wasn’t courageous enough to tell others about my Usher Syndrome because I felt embarrassed.

Last year, I visited Germany to join a European youth camp for deafblind individuals. That experience was a real “awakening” for me—I understood that I wasn’t alone. There were many people with similar experiences; I met new people and felt truly accepted.

I returned back to Greece full of confidence and I realized that I needed to act and show the world there is no reason to be ashamed of having a second condition.

What matters most is accepting who we are and loving ourselves.

Today, I proudly say that I am a deafblind person, and I’m no longer ashamed. On the contrary, I feel strong and grateful for everything I’ve achieved so far. As for sports, I found new ways to express myself, such as through acrobatic dance, which has been incredibly supportive for my emotional well-being.

I no longer try to hide who I am. I am Fotini, and through darkness I found my own light. And that light is something I want to share with others.

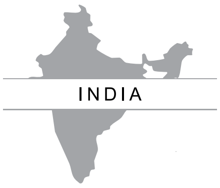
Udaan Fellowship Programme: A Pathway to Independence for People with Deafblindness

SHRUTILATA SINGH[1]

Introduction

“Independence does not begin with ability—it begins with opportunity.”

This statement strongly reflects the reality for persons with deafblindness. Deafblindness is a combination of impairments in two major senses that are essential for overall growth, learning, and development. Due to challenges in communication, people with deafblindness often miss out on important learning experiences everyday — things that may seem small but are taken for granted by others. These communication barriers affect confidence, clarity, and access to opportunities. Employment, or financial independence, is a dream for all. However, for people with deafblindness, this journey often involves multiple layers of struggle. Many do not have access to formal learning environments or structured guidance. While everyone starts as a beginner, the label of deafblindness often prevents individuals from even being given that chance.



The Fellowship Programme

At Sense International India, we acknowledged this gap and initiated a pilot four-month fellowship programme in the year 2022 to provide an opportunity to adults with deafblindness with real-life work experience. Selected candidates with deafblindness supported by a designated support person from their local area were placed at Sense India’s partner organisations. A structured work plan was developed for each fellow, including tasks such as data entry, document translation, and compiling information. Fellows also visited government departments to address local issues related to disability certification, pensions, and entitlements. Over a period of 4 years, we now have a group of fellows undergoing this specialised work experience.

With guidance from support persons, some fellows also took initiative in sensitizing schools and communities about deafblindness.

This programme has brought significant change in the persons with deafblindness. Families and educators observed increased confidence, especially in public speaking, and a better understanding

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[1] Shrutilata Singh is working as Senior Specialist – Network Support and spearheading advocacy at Sense International India. Bringing her lived experience as persons with deafblindness herself, Shruti has been advocating for the realization of rights of persons with deafblindness in the country for almost a decade. This article is written on behalf of Sense International India.

among fellows about their rights and how to express their needs. The provision of a stipend further contributed to a sense of dignity and belonging, as fellows experienced working in a formal environment.

To strengthen learning, an Annual Fellows' Meeting was introduced, where 45 fellows come together to share experiences and build additional skills. These sessions include practical training on resume building, interview preparation, teamwork, and time management. Fellows are also introduced to Organizations of Persons with Disabilities (OPDs), where they learnt about advocacy, networking, and collective action.

The aim of the fellowship is to provide exposure to diverse skills that can support long-term employment and independence.

Reflections from Interns

The Fellowship has enabled young persons with deafblindness to learn, practice new skills, and gain confidence in representing themselves. Their reflections highlight both the impact and the areas that need strengthening.

One of the fellows, Mr. Amit from Uttar Pradesh shared that the fellowship helped him explore accessibility features on his phone, allowing him to work more independently. With support from colleagues, he gained confidence to travel to new places on his own. However, he noted that lack of awareness in society remains a barrier, and financial support is needed to help interns share their learning with others.

Another fellow Nasir from Telangana described his journey during 2022–23, where the absence of a support person initially limited his participation. Once support was available, he learned to prepare plans and reports, engage in sensitization activities, and use technology effectively. He later mentored another the programme, which strengthened his leadership skills. He emphasized that being treated as an equal team member—rather than "just a service user"—made a significant difference in his confidence and contribution. He also overcame his fear of public speaking and began actively representing his disability and raising awareness on deafblindness. Participation in the Annual Fellows' Meeting in Delhi further enhanced his confidence.

Ananda Kumar shared that he gained knowledge of the Rights of Persons with Disabilities (RPwD) Act, 2016, and learned how technology can be a powerful tool for independence. While he faced challenges in communicating with persons with other disabilities, he remains motivated to continue building his skills through further opportunities.

A sensitization program conducted by two adult deafblind interns with a group of students at a local school.

Key Learnings and Way Forward

The experiences of interns highlight several important areas:

- Accessibility and Support: Timely availability of support persons is essential for meaningful participation.
- Inclusive Work Culture: Equal treatment enhances confidence and encourages active contribution.
- Awareness Building: Greater awareness in society and institutions is needed for true inclusion.
- Technology Training: Digital skills significantly improve independence and productivity.
- Financial Support: Assistance with travel and related costs enables wider outreach and peer learning.
- Continuous Opportunities: Ongoing internships and platforms are critical for building long-term skills and leadership.

"When opportunity is created and support is ensured, independence is no longer a distant goal—it becomes a lived reality."

Meet DbI's First Celebrity Ambassador, Mireia Mendoza Bonnin

I am writing to you as a proud deafblind member of DbI to share some exciting news. I have been officially invited and nominated by the Miss + Mister Deaf Universe Organisation to represent my country as Miss Deaf Spain.

The 13th edition of this international pageant will take place from September 18th to September 28th, 2026, in Batumi, Georgia. This event is a unique global platform aimed at promoting social inclusion, protecting human rights, and reducing discrimination against the deaf and hard-of-hearing community. As a deafblind participant, I am eager to use this opportunity to raise awareness about our specific community and demonstrate the strength of our inherent dignity.

My goal is not what is said about who I am, but that we work together to remove barriers and drive accessibility, inclusion, and equality. My deafblindness is an identity, and my commitment is to turn respect and empathy into real actions that make true inclusion a reality for our community.

Additionally, you can find more details and share my journey through my recent Instagram post: https://www.instagram.com/p/DWKhY7mCFdc/?igsh=MWg5ajBuMXo3amlyNg==

Beyond Methodology: Field Lessons from Deafblind Research in Zambia

DR. LACEY LONG
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Dr. Lacey Long, Project Director of the ND Dual Sensory Project, and Abby Zurliene, Family Engagement Coordinator from the Illinois DeafBlind Project, have created a quarterly newsletter highlighting access technology for students who are deafblind.

Spring 2026:
https://mailchi.mp/a59fde10d066/on-deck-newsletter-springedition2026

Winter 2025:
https://mailchi.mp/68fa3be359e2/on-deck-newsletter-winteredition2025

Fall 2025:
https://mailchi.mp/5d21867d2a1e/on-deck-newsletter-falledition2025

Field Reflections from Ongoing Deafblind Research in Zambia

STEPHEN KANGWA CHILOBWA
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Stephen Kangwa Chilobwa shares a set of reflections emerging from my ongoing research on deafblind education here in Zambia. As the fieldwork and analysis have progressed, a number of practical insights have surfaced, particularly around community engagement, access challenges, and lived realities on the ground.

I've captured these in a short reflection piece, which I thought may be of value to the DbI community, especially for those working in similar contexts.

https://www.deafblindinternational.org/beyond-methodology-field-lessons-from-deafblind-research-in-zambia/

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DbI Communication Ambassador: Call for Action

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

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

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

What are the responsibilities of a Communication Ambassador:

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

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

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

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