



INCLUSIVE DANCE WITH LAURA SARAH DOWDALL

read in the new
section of the magazine

COMMUNITY CONNECTIONS

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Have you checked out a journal (like the Dbl 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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Dbl Communication Ambassador: Call for Action



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

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

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

What are the responsibilities of a Communication Ambassador:

1. Assist Dbl in ensuring that its social media posts are reposted on your organization pages within a short period of time (1-5 business days).
2. Assist Dbl by ensuring access to your media network and sharing Dbl press releases and communication with your media network within a short period of time (1-5 business days).
3. Assist Dbl 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 Dbl membership and can be posted on Dbl pages.
4. Dbl would be grateful to have the key contact act as an ambassador and connector within their geographic area.

Organizations serving as Dbl Communication Ambassadors will receive the official Dbl Communication Ambassador Logo to be used freely in all of their communication. You will have your finger on the pulse of Dbl's communication and be fully informed about worldwide developments in our field. Your organization will have a presence in the upcoming short film about Dbl'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 Dbl's communication.

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

Please reach out directly to Roxanna Spruyt Rocks about your interest at r.spruytrocks@deafblindontario.com.



Dear Dbl Review friends,
dear Dbl “family”,

As I write this, I am still very impressed by our ICF Consensus Conference in Salou and Barcelona. Not only because of the very important milestone it represented and represents for all those involved and concerned. Of course, the Core Set will be a great support for advocacy. It helps standardize identification of deafblindness and supports access to the right and specific services. In this way, the Core Set will help ensure that people with deafblindness can actually exercise their human rights and that these are not just on paper.

That alone is great and definitely a reason to celebrate. At the same time, the four-year process to achieve this result shows very clearly what we are as a worldwide network. The first version of the

comprehensive ICF Core Set for deafblindness, which is published here <https://doi.org/10.17605/OSF.IO/A942K>, is indeed a piece of art that required a lot of work, competence and great collaboration from people from almost every continent (except Antarctica, of course), with and without lived experience, and passion!

No version of the ICF Core Set will be able to show that. But we all know it as friends and members of Dbl and as you read this issue of the Dbl Review, you will come across this essence of Dbl again and again.

Our newly adopted core values also reflect this organisational identity. They are the result of input and perspectives from members, the Board, the Management Committee and a corresponding

MIRKO BAUR

PRESIDENT OF
DEAFBLIND
INTERNATIONAL

A MESSAGE FROM THE PRESIDENT

word cloud showing which values are mentioned most frequently. The result is:

- **The Power of Social Connection.** Sharing and fostering a community where people come first.
- **Diversity.** Promoting integrity and inclusion for each and everyone concerned and involved worldwide.
- **Passion.** People working together in a welcoming, open and helpful way.

And that was the spirit of the ICF Consensus Conference, too. There are very good reasons to be very grateful to the organisers and key scientific people behind this conference, in particular Ri-card Lopez and Daniela Anze, Walter Wittich and Shirley Dumassais. But we all contribute to this spirit and make it a reality every day, at every meeting, at every conference, at every challenge and at every celebration. So thanks a lot to all of you, dear members and friends of Dbl!

There is much more to reflect this. Let me just share the very good news from the Global Campaign for Education. It is indeed almost unbelievable that we have 24 concrete proposals for two-year projects from 23 countries in Africa, Asia and Latin America and the Caribbean. Not so long ago, for example, we hoped to be able to take our first steps in Africa. And guess what, we have found 17 members for the honorary Advisory Committee of the Research Initiative on the Education of Children With Deafblindness, which will be an important part of the Global Education Campaign. The

members of the Advisory Committee come from almost all parts of the world. The following are involved and committed (without academic titles and in alphabetical order of their first names): Ahsan Romadlon Junaidi, Alvaro Diaz, Anders Martin Rundh, Andrea Wanka, Beth Wambugu, Charles Omboto, Edna H. Jalotjot, Eline Heppe, Frances Gentle, Isabel Amaral, Martha Vergara Fregoso, Mary Franci Alvarez, Moa Wahlqvist, Pawlos Kassu (Chair), Saskia Damen, Susan Bruce and Victor Locoro. We owe them all our heartfelt thanks!

But again, just as with our spirit, each of you can contribute to the Global Education Campaign. There is a crowdfunding effort for the national projects, our first attempt at such an approach. Any donation towards this is, of course, a great help as we continue to work on sponsors and grants: https://fnd.us/letmein-dbi?ref=sh_8Dgi22

Also, the next conference is coming up, which is open to everyone and marks an important step for the Global Education Campaign, especially in Asia. It would be wonderful to meet you in Nepal in early March 2025. Please consider attending and visit the conference website for information, call for papers and registration: [1st Deafblind International Regional Conference in Asia 2025 \(deafblindasia2025.org\)](https://1stDeafblindInternationalRegionalConferenceinAsia2025.deafblindasia2025.org). This will surely be an experience of a lifetime, even without the inclusive trekking that will be organized as an optional post-conference extension.

Thank you again for making Dbl what we are and what we are becoming every day, and enjoy this new edition of our Dbl review.



Kind regards, Mirko

News from the Dbl CHARGE Network

The Dbl CHARGE Network has been participating in some exciting events during the last few months.

On August 8, we celebrated the very first International CHARGE Syndrome Awareness Day.

This marks the day the paper on the discovery of the CHD7 gene was published online by Professor Conny van Ravenswaaij-Arts (August 8, 2004). The awareness day aims to raise awareness of the variability of CHARGE syndrome and to help improve diagnosis and access to best practice interventions.

The idea was to create the word C-H-A-R-G-E in all kinds of creative ways, and share these creations on social media. It was really amazing to see so many people participating worldwide, using their creativity to increase awareness of CHARGE syndrome! Would you join us next year?

After the summer, we proudly presented our very first webinar, on the topic of Fathers' Involvement in the Care, Development and Education of their Children with Deafblindness and CHARGE syndrome in particular. Our very own Dr. Jerry Petroff, Ph.D, Professor at The College of New Jersey shared important insights resulting from his work with fathers. Among the attendants were also some fathers who shared their own experience. Very valuable! In case you missed this webinar, you

can look back on our Dbl CHARGE Network webpage (News section) or at the Dbl YouTube channel <https://youtu.be/3Cl83IgY78U?si=MrAXYTUXCiEwmkw5>

Our next focus will be on organizing online case discussions. We'd like to invite our members to share a case one is struggling with in any way. Goal of the case discussion is to reflect on the situation and examine the case from different angles. Not to provide 'ready-made solutions', but to gain some insights that might be helpful in regard to the case. We are aiming at the beginning of 2025 for these online case discussions, providing different languages. If you are interested but not yet a member, please join us in the CHARGE Network. We are looking forward to welcome you!

The CHARGE Network Committee

- **Andrea Wanka**, University of Education, Heidelberg, Germany
- **Anne Schoone**, Royal Kentalis, Netherlands
- **Heather Colson-Osborne**, Seashell Trust United Kingdom
- **Vimla Ramrakhiani**, Seashell Trust United Kingdom
- **Lourdes Quintana Baez**, CHARGE Syndrome Foundation, USA
- **Allison Mail**, CDBA, Canada
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Introducing the Deafblind Association of Kenya (DbAK)

WILSON MASINZ

FOR DEAFBLIND
ASSOCIATION OF
KENYA (DBAK)

We are happy to let you know that our organization has a new name: Deafblind Association of Kenya (DbAK). The Attorney General's office advised us to change our previous name, Kenya National Association of the Deafblind, and they have now approved the new name.

With this change, we remain dedicated to supporting and advocating for people who are deafblind in Kenya. DbAK will continue working to provide help, raise awareness, and ensure inclusion for the community we serve.

Thank you for your support as we move forward under our new name!

2024 Research Grants Awarded by the Deafblind International Research Network

For the past 2 years, Dbl's Research Network has been able to facilitate collaborative and international research grants to support the participation of individuals living with deafblindness and their family members. These 500 Euro seed grants are intended to pay participants, or cover costs related to research participation, such as interpreter fees or travel expenses.

In the 2024 competition, we are excited to announce that six teams were funded. They are:

Kato Mark (Uganda) and Mr. Otim (Uganda): "Fieldwork Environment Observations: Advocacy, Access, Communication, Education, and Health for Deafblind Individuals in Uganda"

Walter Wittich (Canada), Saskia Damen (The Netherlands), Meredith Prain (Australia), Helle Buelund Selling (Denmark), Lucía D'Arino (Spain), Marguerite Tibaudo (USA), Henriette Olesen (Denmark) and Caroline Gravel (Germany): "Exploring the Sense of Deafblind Identity"

Joyce Kanyong'o (Malawi): "Investigating global efforts and challenges in promoting inclusive education with individuals with deafblindness in Malawi, Zambia and Ghana"

Mwanasha Kasha (Tanzania) and Asha Jumanne Amani (Tanzania): "Voices of Hope: Supporting Education For Deafblind Children"

Richa Bhutani (India), Sanu Khimbaja (Nepal) and Shurti Lata Singh (India): "Status of Students with Deafblindness in their Access to Education in India and Nepal"

Mary Maragia (Kenya), Beth Wambugu (Kenya) and Kelvin Tanui (Kenya): "Empowering Individuals who are Deafblind through Inclusive Vocational Training in Kenya: Best Practices and Challenges"

Congratulations to all teams! We look forward to your project reports next year.

The Dbl Research Network Team

Walter Wittich, Atul Jaiswal, Caroline Gravel, Meredith Prain and Saskia Damen.

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Deafblind International Regional Conference in Asia 2025

Pokhara, Nepal • March 1-3, 2025

Nepal 2025: Registration and Call for Papers are OPEN

DbI
INTERNATIONAL

It will be the 1st DbI Regional Conference in Asia. And it will take place in just about 5 months. Time to register. And, if you like, time to respond to the call for papers.

This conference, which will take place in beautiful Pokhara, the tourism capital of Nepal at the foot of the Himalayas, will be an experience of a lifetime and will revolve around the theme “Innovative

Deafblind Inclusion: Education, Occupation, and Community Engagement”.

Join us on March 1-3, 2025! Get in touch with our network in Asia. Connect and contribute for next steps forward.

[Here is your link](#) for your registration.

And [here the link](#) to the call for paper.

Perkins in Latin America: Navigating Challenges in Strengthening Educational Programs

In 2019, aligned with the United Nations' Sustainable Development Goal #4, Perkins School for the Blind launched the "Model Program Approach" in Latin America. Partnering with governments in Argentina, Brazil, and Mexico, the initiative aimed to support inclusive education systems in public schools and early education programs, focusing on students with visual impairments, multiple disabilities, and deafblindness.

The Model Program Approach empowers public schools by providing training, coaching, monitoring, and tools for educators to foster inclusive learning environments. This evidence-based approach consists of three building blocks:

1. **An annual assessment:** using a set of indicators across seven domains, Perkins assesses the quality of the school in its ability to provide quality and inclusive learning to all children, including those with disabilities.
2. **An improvement plan:** based on the assessment data, Perkins, the school team and the government agree on a comprehensive action plan and goals for quality improvement.
3. **Year-long Implementation:** Perkins provides training, coaching, planning, and leader-

ship development for teachers, administrators, and families to support inclusive practices.

Since its launch, the program expanded from 9 to 63 schools, positively impacting students, teachers, and families. However, eight schools withdrew due to challenges such as overwhelming workloads, resistance to change, and external influences like changes in government or school management. The COVID-19 pandemic also contributed, as schools struggled to balance crisis management and program participation. These challenges highlight the need for flexibility and adaptability in large-scale educational programs.

This article provides insights into the reasons behind these withdrawals and shares lessons learned to strengthen the program's sustainability through the model program improvement process.



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Fig 3. A teacher, Angie, is interacting with a student, Allan

Key Lessons from the Model Program

1. **Government Collaboration:** Strong partnerships with governments are essential. Governments must not only sign formal agreements but also actively engage in implementation. Their involvement ensures that schools receive necessary training and support, particularly through Perkins International Academy (PIA) courses, which build foundational knowledge. Governments also facilitate access for Perkins staff to conduct assessments and implement action plans.
2. **Presenting the Model Program Approach:** The way Perkins teams introduce the project is crucial to ensuring access to schools and personnel. When changes occur in government or school leadership, reintroducing the project helps maintain support. If progress stalls, revisiting the project and reviewing its current status can reinforce the commitment.
3. **School Management Engagement:** School leaders, including principals and coordinators, play a critical role in aligning their institution's vision with the program's goals. Their leadership is crucial for fostering a collaboration and embracing the necessary changes for becoming a "Model School."
4. **Capacity Building:** Educators are at the heart of the Model Program. Perkins International Academy courses (3 level courses) equip them to support students with disabilities, while ongoing mentorship from Perkins staff ensures they feel confident implementing inclusive practices. Data-driven decision-making, through the set of indicators, empowers educators to refine their teaching strategies.
5. **Empowering Families:** Families are key collaborators. By building strong partnerships between schools and families, Perkins ensures that students are supported both at home and at school. Open communication fosters trust, creating a positive and inclusive environment for students.



Fig. 4. Ana Beatriz, a student with blindness, uses her hands to feel a textured map of Brazil while two adults, Ana Lucia and Gloria, assist by pointing at different parts of the map.

Conclusion

The journey of educating children and youth presents both challenges and opportunities. Drawing from experience, Perkins emphasizes the importance of selecting partners carefully, respecting each party's unique attributes while remaining adaptable to the dynamic nature of educational institutions and global contexts.

Perkins' Model Program Approach is helping to transform educational outcomes for children with disabilities in Latin America, creating sustainable models of inclusive education.

Success relies on strong partnerships with governments, school leaders, educators, and families. Over the past five years, the program has demonstrated the importance of collaboration, capacity building, and flexibility.

As the program continues to evolve, Perkins remains committed to ensuring every child has access to a high-quality education. Through collective efforts, the Model Program has the potential to create lasting change, empowering schools to lead in inclusion and advocacy for students with disabilities.

Acknowledgements

Thanks to Gloria Rodríguez-Gil, Karina Medina and Marta Elena Ramírez for the collaboration to this article.

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Vocational Assessment: Test run at German Deafblind Association

The German Deafblind Association in Hanover is a non-profit organization that supports children and adults with deafblindness in various areas since the year 1967. The German Deafblind Organization aims to provide everything that people with deafblindness need to live as independent and self-employed as individually possible.

The Taubblindentechnische Grundausbildung, which best can be translated into basic training for people with deafblindness, offers education and training for adults mostly with acquired deafblindness or else who are most likely to acquire deafblindness in the future for example due to Usher syndrome. People learn anything they need to live an independent daily life in their individual state of life. However, the Taubblindentechnische Grundausbildung is not a vocational rehabilitation service. Its main goal is to teach skills that lead to an increase of participation in society but it does not focus on participation in the job market. Since there are no other vocational services and aids in Germany for people with deafblindness and a high number of people with deafblindness looking for corresponding trainings there is a desperate need to install these kind of trainings in Germany.

Therefore, the German Deafblind Association is part of the project

Wege in den Beruf (best translated to: Paths to Employment). Wege in den Beruf has started in 2020 and is funded by the Aktion Mensch Foundation. It is a cooperation between the Nikolauspflge – Foundation for blind and visually impaired persons, the SFZ Förderzentrum GmbH and as stated above the German Deafblind Association (you can also take a look in DBI Review #67 to read more about the project). The project Wege in den Beruf has created several concepts for vocational education so far. Concepts that have been designed are for instance: a vocational assessment, a vocational preparation course, a vocational rehabilitation service and vocational training in two sectors: information technology and housekeeping.

People with deafblindness are very heterogeneous in their needs and resources. Therefore, it is very important to identify which parts are important to focus on regarding any kind of vocational educa-



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tion. The assessment concept aims to get a clearer view to identify which vocational education suits the most and aims to create a new perspective for the future.

People with deafblindness are currently testing the designed concepts since they are the experts for themselves. In September 2024 the assessment concept was given a try at the German Deafblind Association in Hanover. The participant of the test run is a middle-aged man with Usher syndrome type 3 who is currently employed in a job in which he is in charge of data management. The participant is looking for specific vocational services to gain new strategies and skills to be able to continue working in his job even though the Usher syndrome is most likely to have impact on his vision in the future due to its progressive process. The following topics have been part of the test run of the assessment concept in order to make inform choices towards the participant's further training programs: functional hearing and vision including individual aids for visions and hearing, psychological assessment, personal and vocational resources and challenges, communication skills, orientation & mobility, skills for daily life, technical skills and computer skills and last but not least the assessment of soft skills.

During a three week test run both the participant and the professionals at German Deafblind Association had the chance to identify challenges and resources in the dif-

ferent topics above and in conclusion framed a following modular vocational rehabilitation service for the participant that can assure an effective participation in the job market.

The test run contains two different goals. On the one hand, the test run is currently being evaluated (interviews and questionnaires) to reveal, if there are any adjustments necessary to bring the concept into a practical working model. On the other hand, the vocational assessment for people with deafblindness is not only new to the participant but also to the German Deafblind Association and its professionals. Being experts on the topic of dual sensory loss the sector of specific vocational services is a new specific topic that has just started at the German Deafblind Association. Professionals have to adjust to a shift in topics due to the focus on vocational participation. There is also a need for new organizational commitment and new facilities. Furthermore, additional professionals will be necessary in order to fulfill the multiprofessional designed concepts as well.

As you can tell: there are still some things to figure out but there currently is an innovative change noticeable in Germany to work on new vocational offers for people with deafblindness. The German Deafblind Association is looking forward to increase opportunities and accessibility on the topic of employment for people with deafblindness.

If you have any questions, please feel free to contact us.

Hey! Let's help Mr. Lobato's fish?

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The concept of emergent literacy serves to highlight the different ways in which children perceive and engage with reading and writing. It is a dynamic and unique process that begins at birth and involves many aspects throughout the child's life (Stratton, 1996).

Emergent literacy takes place from the child's first verbal and nonverbal interactions with other people and with the surrounding environment, through explorations (Stratton, 1996). Hands-on experiences with a variety of elements made of so many different materials, textures, smells, sounds and tastes allow the child to experience skills and learn more about the environment. Thinking about literacy possibilities through this perspective reflects the break with traditional models, focused only on readiness for reading and writing (Williams, 2004). When children realize that abstract symbols have meanings and that people use them to represent different concepts, they expand their intentional language and their abilities to explore objects, which is essential for concept formation (Erickson; Hatton, 2007).

Children with visual impairment and multiple disabilities often re-

ceive information in a fragmented way, making the perception of meanings a great challenge (Goldware; Silver, 1998). In addition, some of these children demonstrate tactile defensiveness when touching certain materials. Therefore, the objectives of educational practice should include multimodal options and encourage the child's active and successful participation in their surrounding environment.

But in practice, how can we involve a child with visual impairment and multiple disabilities in emergent literacy activities? What emergent literacy is this? The objective of this study was to organize a pedagogical sequence for creating personal experience books for children with visual impairment and multiple disabilities. It is believed that the publication of this study may inspire other teachers to develop meaningful activities with their students to create books of personal experiences.

Method

This is an experience report carried out between March and June 2024, during individualized alternative communication sessions,

carried out by this teacher/researcher, once a week, lasting 50 minutes, at an institution specialized in visual impairment in Brazil.

P1's grandmother also participated in these sessions. The participating student, identified here as P1, is seven years old, has cerebral palsy, is hypertonic, has complex communication needs, and has epilepsy. The information was recorded through filming, which was watched only by this teacher/researcher. It is important to explain that four stories were

created from the adaptation of children's songs. Instead of telling stories in a traditional way, the children's songs were transformed into olfactory, tasting, tactile, and sound experiences. First, concrete experiences and then the creation of two-dimensional representations. Table 1 shows a schedule with the songs and the content of the videos.

Table 1. Experience Report Schedule.

Schedule		
Theme	Dates	Brief Description Of The Videos
<p>Story with experiences about holidays and carnival</p> <p>Music: carnival music</p>	<p>03/20/2024</p> <p>03/27/2024</p> <p>04/03/2024</p>	<ul style="list-style-type: none"> • readaptation: welcome; songs and games related to carnival; remembering what you did on vacation;
<p>Story with experiences about the caterpillar that turns into a butterfly,</p> <p>Songs: painted caterpillar, caterpillar turns into a pupa and a butterfly</p>	<p>04/17/2024</p> <p>05/08/2024</p>	<ul style="list-style-type: none"> • activity with music: Caterpillar painted with body parts, caterpillar made with modeling clay, glue caterpillar on paper and paint the caterpillar); • activity with music: Painted caterpillar, hungry eater, make caterpillar with modeling clay, choose between two foods, smell and taste, glue caterpillar on paper, glue food piece of chosen food on paper); • experiment box of the caterpillar/butterfly story (activity and music: Caterpillar turns into a pupa, research pupa, make pupa with clay and glue it on paper); • activity: Caterpillar turns into a pupa and becomes a butterfly and music: Little butterfly, play with pan and wooden spoon, smell and taste chocolate, make butterfly with clay and plastic
<p>Story with experiences about Mr. Lobato's fish</p> <p>Music: Mr. Lobato's fish (adaptation)</p>	<p>05/15/2024</p> <p>05/25/2024</p>	<ul style="list-style-type: none"> • box of experiments from the story of Mr. Lobato's fish (activity and song Mr. Lobato's fish, searching for fish, helping fish, transferring water between containers using a sponge); • searching for fish, putting and removing fish from the water, catching fish, painting water with blue paint on paper); • Start signal; opening and closing hands and the window; use of reference objects related to their referents; use of concrete symbols yes/no; use box of experiments from the story of Mr. Lobato's fish (activity and song Seu Lobato's fish, searching for fish, helping fish again, transferring water between containers using a sponge); umbrella to get the student's attention; finished signal; • activity and song Seu Lobato's fish, searching for fish, putting fish in the water, catching fish, gluing rubber fish to the painting of water with blue paint

Schedule		
Theme	Dates	Brief Description Of The Videos
Story with experiences about the pirate's treasure Music: Pirate Captain Billy One-Eye	05/29/2024 06/05/2024 06/12/2024	<ul style="list-style-type: none">• Pirate Story Experience Box (Captain Billy One-Eyed Pirate activity and song, search for items from the Pirate Experience Box, choose items to play with, search for boat and place it in the water);• Captain Billy One-Eyed Pirate activity and song, search for items from the Pirate Experience Box, search for boat, place it in the water, make origami boat and glue it to the paper;• Captain Billy One-Eyed Pirate activity and song, search for items from the Pirate Experience Box, search for boat, place it in the water, search for pirate flag, make pirate flag with paper and glue it to the paper boat);

Source: Own elaboration.

Pedagogical sequence for creating personal experience books

The individualized alternative communication sessions were organized into a beginning, middle, and end, as described below:

Beginning: greet the child with a tactile body signal to begin and a tactile body signal to say okay. Then, play by opening and closing hands using coactive movements.

Middle: use of reference objects to present the actions of playing, hygiene for washing hands, and eating. To play, this teacher provided elements that gave meaning to the characters and the scenario described in each of the children's songs used in this

report. After the child was encouraged to participate coactively in these activities, he or she was invited to wash his or her hands, and finally, this teacher/researcher offered the child a cookie.

End of the session: to represent the end of the session, this teacher/researcher caressed P1's hands using moisturizing cream and then sprayed lavender water to give a goodbye scent.

This is the pedagogical sequence for creating the experience books.

Results

Considering the amount of information collected in this experience report, only one of the stories of student P1's personal experiences is presented here. The story chosen was Mr. Lobato's fish. This teacher/researcher adapted the lyrics of this song:

Mr. Lobato has a farm
And on his farm he has a fish
But one day it was so hot
that the lake almost dried up

And Mr. Lobato's fish got really hot
Hey! Let's help Mr. Lobato's fish?

(source: own adaptation)

For each song, elements were provided that gave meaning to the setting and characters. In the song Mr. Lobato's fish, the following were provided: a plastic fish, two plastic basins, water, a sponge, and a plastic tray. Image 1 shows these elements:



Image 1. Let's help Mr. Lobato's fish?

Source: personal archive.

First, this teacher/researcher sang the song Mr. Lobato's fish. Then she invited P1 to save the fish. Since P1 is hypertonic, his grandmother did the activity with him. They had to transfer water from the large bowl

to the small bowl to help the fish, which was very hot and had no water. After doing this activity, it was time to represent these actions in a two-dimensional way, as shown in image 2:



Image 2. Pages from the story of Mr. Lobato's fish

Source: Personal archive.

This fish activity took place on May 15 and May 25, 2024. In the first activity, P1 had to save the fish from the heat. In the second activity, P1 had to save the fish from the hook and then place the fish on the beach. In the second activity, this teacher/researcher brought a fishing rod and plastic fish for P1 to catch. There was also a plastic toy boat.

It is worth noting that everything was done with the help of P1's grandmother.

The other activities for creating the stories of the painted caterpillar and the pirate Billy One-Eyed followed the same organization: objects, food, smells, textures and music to represent the characters and settings.

Final consideration

Following the traditional literacy model, the student P1 would not be able to create pages of a book of personal experience, nor would he be able to understand the meaning of the songs. However, the emergent literacy model is inclusive and values all forms of learning and commu-

nication. Although it is not possible to state that P1 understood the meaning of all the activities, one cannot underestimate the ways in which he may have perceived the smells, sounds, tastes and different textures through touch, smell, hearing and perception of light/dark.

Children with visual impairments and multiple disabilities are at a disadvantage in relation to instructions, anticipation of activity transitions and therefore need the physical help of others to explore the surrounding environment (Goldware; Silver, 1998). In this sense, the use of story boxes for practical and two-dimensional representation of children's songs that can become stories, can be very useful to enrich the educational practice and the receptive and expressive communication of students with complex communication needs (Goldware; Silver, 1998).

The use of the pedagogical sequence served to determine the beginning, middle and end of the activities, thus preventing P1 from being surprised and frightened.

Another positive aspect of this pedagogical sequence for creating personal experience

books refers to the practical experiences that were offered to promote P1's learning and communication. According to Straton (1996), practical experiences are essential to instigate the perception of information and strengthen children's relationship with their surrounding environment. These children may even have cognitive delays and restrictions on movement, however, interactions with the environment favor the formation of concepts.

Changes in the environment can increase the possibilities of perception and engagement of these children, in addition to improving aspects of the child's development, including emergent literacy. Obviously, this experience report is not intended to end this subject, but rather to share an experience and provoke reflection on this subject.

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Shifting Perspectives: A Complexity Approach to Congenital Deafblind Education

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Abstract

The education of children with congenital deafblindness presents unique challenges that necessitate innovative approaches. Distinguishing between complicated and complex systems can guide educators and caregivers in developing effective strategies tailored to each child's individual needs. While complicated systems are predictable and linear, complex

systems are adaptive, dynamic, and often unpredictable. This article explores complexity theory and its application to the education of children with congenital deafblindness. It also critiques the limitations of mechanical thinking and underscores the importance of adaptive, individualized educational methods in addressing the complex needs of these children.

Introduction

Children born with congenital deafblindness experience the world differently due to simultaneous impairments in both vision and hearing. These dual sensory losses significantly impact their ability to communicate, learn, and interact with their environment (Dammeyer, 2014). Traditional educational approaches, which often rely on linear progressions and predictable responses, may not effectively address the unique needs of these children. Understanding the distinction between complicated and complex systems is crucial in developing educational strategies that are responsive to the dynamic and indi-

vidualized experiences of children with congenital deafblindness.

Pioneers such as Jan van Dijk and Anna M. Nafstad have advocated for educational approaches that align with complexity theory, emphasizing individualized and adaptive strategies for communication and learning (Janssen et al., 2003; Nafstad & Rødbroe, 1999).

This article examines the differences between complicated and complex systems, explores their historical development, and provides practical guidance for educators and caregivers working with children who are congenitally deafblind.

Historical Background of Complexity Theory

The foundations of complexity theory are deeply rooted in the mid-20th century developments in systems theory and cybernetics. These interdisciplinary fields sought to understand the behavior of systems by transcending traditional reductionist approaches, where individual parts are analyzed in isolation. Instead, they promoted a holistic view, where the relationships and interdependencies within a system are crucial to understanding its overall function and behavior.

Ludwig von Bertalanffy (1968), a pioneering biologist, laid the groundwork with his General Systems Theory. He argued that a system is more than the sum of its parts and that analyzing isolated components fails to capture the essential dynamics that emerge from the interactions between elements. Bertalanffy's approach shifted scientific inquiry toward viewing systems as wholes, interconnected networks that could only be fully understood by studying their evolving properties, not just their individual elements.

Norbert Wiener (1948), another key figure, introduced the field of cybernetics, which

explored control and communication mechanisms in both biological organisms and machines. Wiener's work underscored the importance of feedback loops—self-regulating processes where a system's output influences its future inputs. These feedback mechanisms are essential for understanding the adaptability of systems, particularly when distinguishing between complicated and complex systems. While complicated systems, though intricate, remain predictable and governed by linear cause-and-effect relationships, complex systems are characterized by emergent behaviors that cannot be predicted solely from knowledge of their parts. Cybernetics emphasized how unpredictable outcomes arise in systems with nonlinear interactions, thus laying the foundation for the modern study of complexity.

These early insights into systems theory and cybernetics helped shape the contemporary understanding of complex systems, providing the intellectual framework for addressing the unpredictability and adaptability seen in various natural, social, and technological systems.

Complex vs. Complicated Systems

Complicated systems are characterized by numerous components that interact in predictable, linear ways. Such systems can be analyzed, understood, and controlled by dissecting their parts and understanding the rules governing their interactions. Examples include mechanical devices like clocks or engines, where each component has a specific function, and the system's behavior is the sum of its parts.

Complex systems, on the other hand, involve components that interact in nonlinear, dynamic ways, leading to emergent behaviors

that cannot be predicted solely from understanding individual parts (Mitchell, 2009). Examples include ecosystems, weather systems, and human societies, where interactions among components lead to unpredictable outcomes.

In the context of education, complex systems recognize that learning is influenced by a multitude of interacting factors, including individual cognitive processes, emotional states, social interactions, and environmental contexts (Byrne & Callaghan, 2014).

Application of Complexity Theory in Deafblind Education

Understanding Congenital Deafblindness as a Complex System

Children with congenital deafblindness represent complex systems due to the inter-

play of their sensory impairments, cognitive development, emotional experiences, and

environmental interactions. Their learning processes are dynamic and individualized, influenced by factors that may vary

significantly from one child to another and even within the same child over time (Bruce, 2005).

Limitations of Mechanical (Complicated System) Approaches

Mechanical or complicated system approaches in education assume that specific inputs will result in predictable outputs. In the case of deafblind education, this might involve structured interventions with the expectation that consistent exposure to stimuli will yield uniform learning outcomes. However, such approaches often fail to account for the variability and unpredictability inherent in the experiences of children with congenital deafblindness (Hersh, 2013).

Mechanical thinking overlooks the complexity of how these children perceive and respond to stimuli, potentially leading to rigid and ineffective educational practices. It does not accommodate the nonlinear developmental trajectories, sensory variability, and emotional factors that significantly influence learning in this population (Dammeyer, 2014).

Embracing Complexity in Educational Practices

Adopting a complexity-informed approach involves recognizing the dynamic and emergent nature of learning in children with congenital deafblindness. Educators and

caregivers must be flexible, adaptive, and responsive to the child's cues, adjusting strategies in real-time to meet the child's evolving needs.

Child-Guided Approach by Jan van Dijk

Jan van Dijk, a Dutch educator and researcher, developed the child-guided approach, which aligns with complexity theory principles (Janssen et al., 2003). This approach emphasizes the following:

- **Following the Child's Lead:** Educators observe the child's interests, behaviors, and signals, using these observations to guide interactions and learning activities.
- **Building on Natural Motivations:** By engaging with what naturally interests the child, educators can facilitate more meaningful and effective learning experiences.
- **Dynamic Interaction:** The educator and child engage in reciprocal interactions, with the educator adapting strategies based on the child's responses.

This method acknowledges the unique and evolving nature of each child's experience, embracing the complexity inherent in their learning processes.

Co-Creating Communication: Anna M. Nafstad and Inger Rødbroe

Anna M. Nafstad and Inger Rødbroe developed the co-creating communication approach, which also embodies complexity theory in deafblind education (Nafstad & Rødbroe, 1999). Key aspects of this approach include:

- **Reciprocal Interaction:** Communication is seen as a two-way, dynamic process, where both the child and the communication partner influence each other.
- **Emergent Communication:** Instead of teaching communication through predetermined steps, communication emerges from shared experiences and mutual engagement.
- **Adaptation and Responsiveness:** Communication partners adapt their methods based on the child's responses, facilitating the development of individualized communication systems.

This approach recognizes that communication development in children with congenital deafblindness is a complex, dynamic process that cannot be fully planned or predicted.

Practical Implications for Educators and Caregivers

1. Flexible and Adaptive Teaching Strategies

Educators should adopt flexible teaching methods that can be tailored to each child's unique needs and responses (Booth & Ainscow, 2011). This involves ongoing assessment and adaptation, allowing educators to respond effectively to the child's cues and adjust strategies accordingly.

2. Emphasis on Relationships and Interaction

Building strong, trusting relationships is fundamental in facilitating learning for children with congenital deafblindness (Nelson et al., 2009). Educators and caregivers should focus on creating meaningful interactions, recognizing the impor-

tance of emotional connection and mutual engagement in the learning process.

3. Individualized Assessment and Goal Setting

Assessment practices should reflect the nonlinear and individualized nature of development in children with congenital deafblindness. Traditional metrics may not capture the progress or learning that occurs. Instead, assessments should be personalized, focusing on the child's strengths, interests, and incremental achievements over time (Dammeyer, 2014).

4. Avoiding Mechanical Thinking

Educators and caregivers should be cautious of mechanical thinking, which may lead to rigid practices that do not accommodate the child's dynamic needs. Embracing complexity requires a shift away from expecting predictable outcomes and towards facilitating environments where learning can emerge naturally through interaction and adaptation (Hersh, 2013).

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GaViD Sinne – Holistic Care Centers & Interdisciplinary Diagnostics for People with Dual Sensory Impairments

Background

It is well-known that numerous studies on the prevalence of deafblindness show that there is a considerable number of unidentified cases of deafblindness in people of all ages. These people often receive inadequate or incorrect care, which can lead to additional (mental) health issues and illnesses.

The diagnostic process and medical care of people with deafblindness in hospitals or other medical facilities are often subject to a variety of barriers. The lack of appropriate means of communication, lack of time as well as physical and/or cognitive limitations when participating in diagnostic

procedures make the process of medical diagnosis, provision of (medical) aids, and consecutive counseling challenging.

Currently, there is no comprehensive care system for individuals with deafblindness and additional disabilities in the healthcare sector throughout Germany. As a result, a large number of specialized clinics and facilities are required; also, the waiting times for appointments in diagnostics and counselling are long. This often results in inadequate care for the individual and unnecessary costs to the healthcare system due to ineffective clinical practices/activities.

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GaVid-Sinne – Holistic Care Centers and Interdisciplinary Diagnostics for People with Dual Sensory Impairments

A consortium of (pedagogical) competence centers for the deafblind, university medical centers, health insurance companies, self-help organizations, and researchers aims to counter these difficulties. The existing gap in care is intended to be closed by establishing holistic care centers (HCC) for people with deafblindness and the development and establishment of concepts for this unique

cooperation. The four HCC locations are set up in Hanover, Berlin, Stuttgart/Tübingen, and Würzburg.

The institutions Deutsches Taubblindenwerk, the Blindeninstitutsstiftung and Nikolauspflge have formed an association with the university medical centers of Hanover, Berlin, Würzburg and Tübingen as well as the health in-

surance AOK Baden Württemberg. On September 1st, 2024, the pilot project GaVid-Sinne was officially initiated thanks to the approval of application by the Federal Joint

Committee (Innovationsfonds des Gemeinsamen Bundesausschusses). The duration of the project is between September 2024 and August 2027.

Goals of the Project

The primary goal is to provide a coordination and interface for individualized, specific diagnostics and care for hearing and vision in order to meet the needs of people with deafblindness. This offer is intended to be accessible to all people with deafblindness of all ages throughout their lives, regardless of additional disabilities. This also includes the large group of elderly people with dual sensory impairments.

The long-term aim is to incorporate these measures and clinical services in the German

healthcare system to ensure that the current gap in care for people with deafblindness is eliminated. The project is evaluated by SEVERA, a research facility that focuses on a variety of areas within healthcare research, at the University Medical Center Freiburg. The evaluation of the new care offers and the resulting effects on health status as well as the activity and participation of the clients are intended to provide a basis for a possible adoption of the project into health insurance care.

Client Acquisition & Procedure

The network of consortium partners as well as committees for people with deafblindness and partial impairment of one of the two remote senses provides corresponding contact data in order to present the new care offer in a target-oriented approach and to acquire clients.

Clients with suspected or known deafblindness are referred to the HCC from the specialist facilities of the consortium partners and institutions of the AGTB (Working Group of Facilities and Services for Deafblind People in Germany), as well as patients from clinics and doctors in private practice. The HCC offers an initial consultation with the client to determine their needs. The aim is to identify whether prior diagnostics at university medical centers are necessary or if an educational assessment and assessment of the functional hearing and vision at the HCC is initially sufficient. The HCC ensures communication during the examinations and, if necessary, assists in organizing interpreters and deafblind assistants.

Relatives and confidential persons are involved during the whole process, which may significantly improve the validity of the results of people with additional cognitive impairments. If necessary, interdisciplinary case discussions and consultations on aids, therapies and educational programs are subsequently conducted. A team of experts ensures that different forms of communication (e.g. (tactile) German sign language, lormen, haptics, etc.) are used to ensure communication throughout the process the diagnosis and consultation.

At the HCC, all information on the client's hearing and vision is gathered, holistic questions are developed to guide functional diagnostics and, if necessary, clinical findings are incorporated through collaboration with medical professionals. All this information is collected prior to developing ideas for further care and providing advice (fig. 1).

Timeline

Presently, the project is in the initial coordination and planning phase at the respective locations. The project team, consisting of 12 members, is divided into individual working groups and regional teams. Experts in the

field of orthoptics, audiology, psychology and special needs education to develop and implement the nationwide concept. Following the preliminary coordination and planning phase, the first interventions are scheduled

to begin in June 2025. Until then, the communication and documentation channels must be established, training courses for project staff must be completed (e.g. sign language courses, work shadowing at other institu-

tions, etc.) and structured public relations work must be implemented. At present, the facilities are being converted to create barrier-free access to waiting rooms, examination rooms, lavatories and offices.

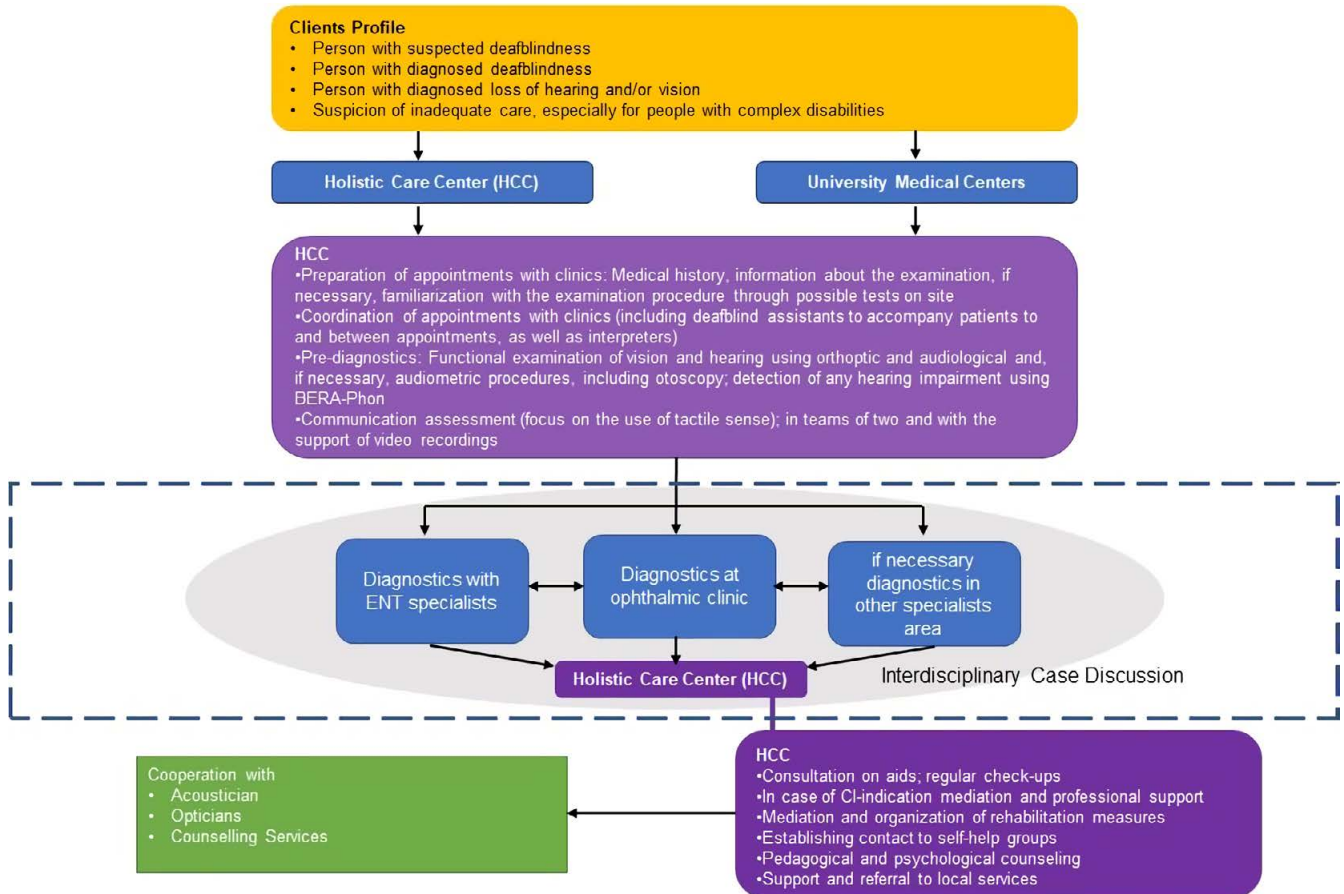


Figure 1. Preliminary overview of the recruitment and admission of clients.

IS THERE LIFE BY TOUCH?



Help deafblind people
stay connected to the world

so-edinenie.org

Is there life by touch?

The charitable foundation for the Support of the Deaf-Blind Con-nection has launched the campaign “Is there life by touch?”.

Now everyone can briefly come into contact with the world of people who cannot see and hear.

There have been situations in everyone's life in which sensory skills were limited. Do you remember the feeling when you're half asleep and reach for your phone to turn off the alarm, because you don't want to open your eyes? Or when you get out of the shower and feel around for a towel while the water is still dripping down your eyes. We can easily open our eyes or brush water from our face. However, for deaf-blind children and adults, everything is different. Touch is one of the main ways we learn about the world. To let everyone come into contact with this state, to tell how the surrounding space is felt with the help of smells, tastes, and most importantly, fingertips, we launched the “Is there life by touch?” campaign. We know for sure: of course there is. For example, when a person becomes deaf-blind, his sensitivity and memory develop. A person learns foreign languages more easily, and by touching another person's hand, he can determine their height and build, even their mood!

Natalia Sokolova, executive director of the Con-nection foundation:

— We receive more than 80% of information through hearing and sight. And if they are not there, what remains? Smells, tastes, touches. For deafblind people, hands are an opportunity to explore the world around them. Our wards communicate with each other by placing their hand in the palm of another person — literally speaking “hand in hand”. The life of totally deaf-blind people is lived by touch. It is important for us to talk about this in order to make this people visible. To this end, we are launching a social advertising campaign “Is there life by touch?”

The key visual of the campaign “Is there life by touch?” is a video about the fine line between the world of the deaf-blind and the sighted and hearing. It is on the project's landing page: touch.socdinienie.org. Here you will also find answers to other frequently asked questions about deaf-blindness.

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A Successful Amalgamation and Innovative New Service Model



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Introduction

On April 1, 2021, DeafBlind Ontario Services and Array Community Support Services officially amalgamated with the aim of creating a unified approach to supporting

people who are deafblind, as well as people who live with developmental disabilities and are Deaf, hard of hearing, or use non-traditional communication methods.

Challenge

The primary challenge of this amalgamation was to develop a comprehensive service model that addressed the varied needs of the people supported. It is individualized and holistic, led by the wishes of each person. It supports DeafBlind Ontario Services' belief that everyone has the right to decide their own future, to make their own decisions, and to

have all information given to them in their preferred mode of communication.

To ensure everyone has an opportunity to live their best life, the new service model challenges people to try new things, methods, and activities in an effort to seek out new relationships and enriching experiences.

Development of the New Service Model

In November 2021, DeafBlind Ontario Services took a significant step by hiring a Project Manager to spearhead the development of a new service model. This process involved gathering internal feedback through Town Halls, surveys, and interviews, as well as researching existing service models from various organizations.

The new service model, "Living My Best Life," is structured around four core pillars:

1. My Wellbeing
2. My Experiences
3. My Independence
4. My Relationships

These pillars were designed to align with the person-centered approach DeafBlind Ontario Services already uses to meet each person's specific needs.

Creation of the Working Group

A working group was created to develop and implement the service model. This group included representatives from various departments, including Services, Human Resources (HR), Communications, Information Technology (IT), and Specialized Training and Research. Each department played a crucial role in shaping the new model:

- **Services Team:** Focused on creating a planning process where people supported can participate in developing their personal plans and set goals that are meaningful to them within the structure of the four pillars.
- **Human Resources (HR):** Developed career advancement paths for employees in direct support roles, introducing three levels of professional growth: Direct Support Professional (DSP), Communication Support Professional (CSP), and Certified Deafblind Intervenor Specialist (CDBIS). The CDBIS is a certification through the Academy for Certification of Vision Rehabilitation & Education Professionals (ACVREP). This career structure aims to enhance professionalism and provide a clear career progression.
- **Quality Assurance and Planning Professionals (QAPP):** Ensured that communication mechanisms, resources, and personalized plans were correctly implemented and monitored. As the direct specialized support roles provide the services within the model, the QAPP supports the person with creating, monitoring, and measuring progress within their plans and goals.
- **Communications Team:** Created a comprehensive communication plan to keep everyone informed about the development and implementation phases of the new service model. This included bi-weekly updates, written and graphic memorandums, plain language materials, and regular Town Halls.
- **Information Technology (IT):** Redesigned the existing database and training portal to support the new service model while providing ongoing technical support throughout training.

Evaluation and Ongoing Improvement

To ensure the service model remains effective and relevant, the working group developed a collaborative evaluation plan. This plan includes collecting data through chart-

ing and interviews, with annual reports submitted to the Chief Executive Officer (CEO) and Chief Operating Officer (COO) for review.

Launch and Impact

On September 29, 2022, DeafBlind Ontario Services proudly launched the “Living My Best Life” service model. The service model name en-

capsulates the core vision of the model, reflecting the importance of quality of life and supporting people in achieving their personal best.

Conclusion

The DeafBlind Ontario Services and Array Community Support Services amalgamation has created a robust and inclusive service model that effectively addresses the diverse needs of people who are deafblind, as well as people who live with developmental disabilities who are Deaf, hard of hear-

ing, or use non-traditional communication methods. Through meticulous planning, collaboration, and ongoing evaluation, the new service model promises to enhance the quality of life for those supported, embodying the belief that everyone can be “Living My Best Life.”

Report on Activities of Mr. Ezekiel Kumwenda at the United Nations during COSPP17 from 10-14 June 2024

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Introduction

Mr. Ezekiel Kumwenda, representing the World Federation of the Deafblind, participated in the 17th session of the Conference of States Parties to the Convention on the Rights of Persons with Disabilities (COSP17)

held at the United Nations Headquarters in New York. This report outlines the key activities and engagements of Mr. Kumwenda and his team during the event.

Day 1: Election of Committee Members

The team observed the Election of the members of the Committee on the Rights of Persons with Disabilities. Malawi field-

ed Mr. Bonface Massah as a candidate. Unfortunately, Malawi's bid was unsuccessful.

Day 2: Presentations and Roundtables

In the morning, Mr. Kumwenda presented a paper during the session on "Matters related to the implementation of the Convention: Roundtable 1." The focus was on "International cooperation to promote technology innovations and transfer for an inclusive future." His presentation emphasized the importance of leveraging technological advancements to create inclusive environments for persons with disabilities.

In the afternoon, the team attended "Roundtable 2: Persons with disabilities in situations of risk and humanitarian emergencies." This session addressed the unique challenges faced by persons with disabilities during crises and the need for inclusive emergency response strategies.

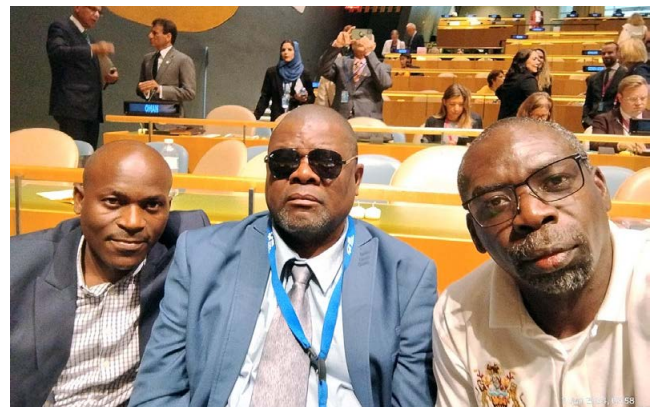


Day 3: Roundtable Discussions and Interactive Dialogue

The morning session included participation in the roundtable discussion on "Promoting the rights of persons with disabilities to decent work and sustainable livelihood." This session was co-chaired by H.E. Ambassador Evangelos Sekeris, Vice President of the Conference (Greece), and Mr. Ezekiel Kumwenda. The discussions highlighted strategies to enhance employment opportunities and ensure sustainable livelihoods for persons with disabilities.

In the afternoon, the team attended the "Interactive Dialogue among States Parties, the United Nations system, and other stakeholders on the Implementation of the Convention." This session facilitated a com-

prehensive exchange of ideas and experiences between States Parties and the UN system on effective implementation strategies for the Convention.



■ EXCHANGE OF EXPERIENCE

Acknowledgements

The team expressed gratitude to Sightsavers International for facilitating their transport, meals, and accommodation in New York. They also acknowledged the support of the

International Disability Alliance for their assistance with visa processes and interpretation fees.



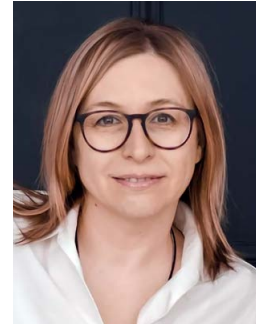
Conclusion

Mr. Ezekiel Kumwenda's participation in COSP17 was marked by active engagement in key discussions and presentations. The sessions attended and the paper presented by Mr. Kumwenda underscored the critical need for international cooperation and

innovative solutions to promote inclusivity for persons with disabilities. The support from Sightsavers International and the International Disability Alliance was instrumental in enabling the team's successful participation in the conference.

Together with Joy and Usefulness

A regular Mother's School meeting was held in Nizhny Novgorod region at the end of May. A regular, but not a common one. Its participants were the families of the most active regional community members.



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This one-week meeting intended to approach several aims at once: children's diagnostics involving recommendations on further teaching framework as well as holding individual and group lessons, experience exchange between mothers, and collaborative work of a large interdisciplinary team of specialists.

Diagnostics involving experienced specialists team and parents and also specialists that work with children in home settings is one of the crucial steps in organizing

development environment for the children who are deafblind. Both parents and specialists need new information and support. It isn't only one hour and a half observation, but thoughtful and coherent team work of several people. And each meeting differs. Because the children, parents, circumstances, progress directions and specialists working with a child and their family are so different. And requests are also different. Some of them need recommendations for everyday use, simple and ade-

■ EXCHANGE OF EXPERIENCE

quate. Others ask for support in developing an education program for a child in school settings. Many of the children who went to the summer school already knew the specialists and practically it was a supervision. There were also newcomers who got to know the specialists for the first time. One of diagnostics observed a seven-year old boy who is deafblind. Several teachers from the school that he was going to start in September came. Together with the headmaster. Because for them that's a new experience. How nice it is to see parents and specialists' collaborative work that serves the interest of a child.

There was a separate program for the mothers. The most active ones gathered. From Saint Petersburg to Novosibirsk and Tyumen. And how much we made it to do! We shared experience on organizing "time out" in different regions, we took part in a drawing workshop which was actually held by one of the mothers, discussed important issues relative to our children's development and also to education system and social services development. We laughed a lot, walked, went to a swimming pool and were nothing but a family and with the family. Many of the fathers supported the initiative and came with their families, that was really very important and joyful. The fathers also had rest,

acquired new knowledge and even went fishing.

Volunteers accompanied the children at the lessons and during walking in order to help parents and let them have a rest before proceeding with their challenging path. These were young teachers and students for whom the trip became a valuable internship site. Moreover, they observed specialists' work, studied, acquired new knowledge, tested themselves, overcame fears and learnt to develop communication not only with the children, but also with the parents and older and more experienced colleagues.

And of course, we appreciate the specialists who came from all over the country (Moscow, Krasnoyarsk, Yekaterinburg, Saint Petersburg, Kirov, Nizhny Novgorod) to make part of interdisciplinary team. The team comprised teachers of the individuals having vision loss, teachers of the individuals having hearing loss, speech pathologists, physical therapists, adaptive physical culture specialists, sensory integration and alternative communication specialists, specialists teaching social and domestic skills and orientation and mobility, music therapist, and psychologist. Working in a team of like-minded fellows, sharing experience, seeing results and parents' gratitude are a huge load, responsibility and joy.





Marina, mother.

The Time Out in Mother's School at the Community of the Families of the Individuals who are Deafblind is an unusual two-in-one project. I took part in it as a Time Out project coordinator. The week was very busy, we shared experience on implementing Time Out in regions, participated in interesting discussion groups, got inspired by each other's success!

Even though my son couldn't come with me for reasons of health, I brought home new ideas of how to interact with him, because I had an opportunity to be present at the lessons with the children taking part in Mother's School project and see the ways of communicating with them in practice. And of course, I acquired priceless experience of communicating with the mothers and fathers of the Community, accumulated energy and new ideas! Thanks to everyone involved for such an opportunity!

The trip was held from May, 20 to May, 26. It was organized by the Community of the Families of the Individuals who are Deafblind with the support of Connection Fund. 15 families from regions lived in eco-park and three families from Nizhny Novgorod came specifically for carrying out diagnostics.

35 specialists and volunteers took part in Mother's School work.

You can watch video from the Mother's school in Nizhniy Novgorod here:

<https://rutube.ru/video/de7e4560b7f66ff39dc8681d8865b754/?r=a>

My name is Liza. I am the mother of Vanya, a child having multiple complex developmental disorder.

The summer camp appeared to be beneficial for me and Vanya! We were lucky to have Yulia, an experienced volunteer who followed us all this time! She would give advices on how to dress, feed and communicate with my son better. She would correct mistakes in communication or propose me other solutions to an occurred problem.

Diagnostic consultation was another important element for Vanya. We discussed Vanya's capabilities and what to expect in education and household activities in case some aspects would be improved. Specialists gave answers to relevant questions and developed education plan for both me and the teacher.

I went away not only with a bundle of practical knowledge but also with specific skills. I and Yulia taught Vanya to wear a T-shirt! I hadn't even imagined that it was possible to do in such a short period of time. We simply showed Vanya how to do it correctly and he managed.

There were a lot of families with such children as mine and I could share and exchange experience with other parents.

Summing up the results of my trip to a camp I realize that now we have an activities plan for at least one year. I haven't expected such a positive result of this trip!

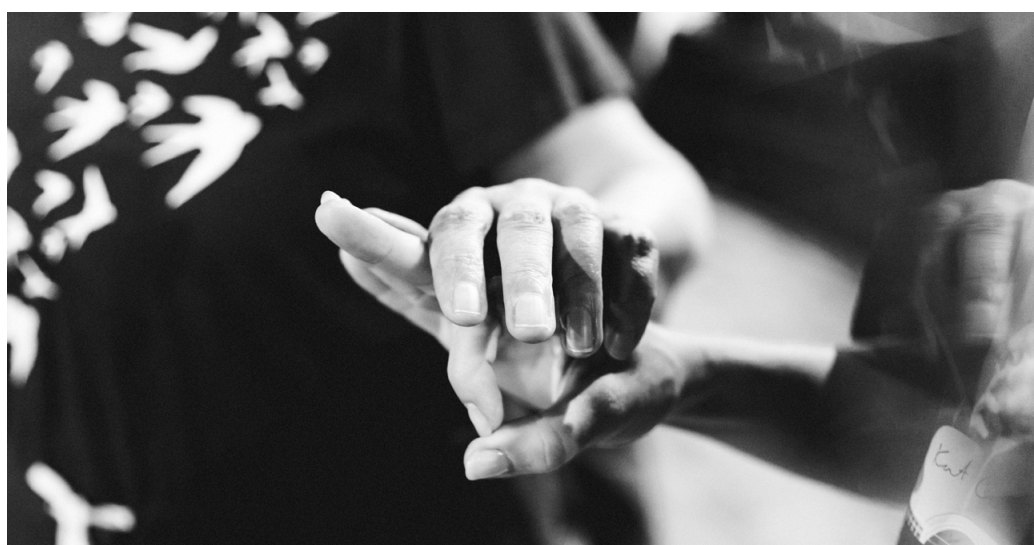
Staying In Touch

IRINA SHULGA

CENTER FOR THE
IMPLEMENTATION
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PROJECTS
"INCLUSION"

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On October 11th, the New Space of the State Theater of Nations in Moscow hosted the premiere of the In Touch 3.0. The fresh version of the play that has already won the hearts of Russian and foreign audiences features stories of several new deaf-blind characters that open windows to the world of people who cannot see or hear.



The original In Touch play was created in 2015, when the newly established Con-nection Deafblind Support Fund was looking for a colorful way to tell the wide audience about people with hearing and visual impairment. The performance was staged in cooperation with the Theater of Nations. The initial idea of the play belongs to Yevgeny Mironov, the People's Artist of Russia and a member of the Fund's Board of Trustees.

The play was the first and at that time the only large-scale sociocultural project in Russia. The international version of In Touch that made its appearance in 2017 was performed in the UK, France and the Netherlands. This version was co-directed by British direc-

tor Jenny Siley, the co-creator of the opening of the London 2012 Paralympic Games. Each performance of the play features famous theater and film actors.

Today In Touch is the flagship performance of the Inclusion Center for Creative Projects, the theatrical division of the Fund.





In 2024, Con-nection Fund celebrated its 10th anniversary, as well as 10 years since the first draft of *In Touch*. The lives of its deafblind participants have changed greatly over these years. “The play in its previous form has already outgrown itself. All the participants want to move on”, says Ruslan Malikov, the director of the performance. “We have a very vibrant, very kinetic story. It’s not that we would like to reshape the play, but the play itself reshapes us all so much that we eager to go further.”

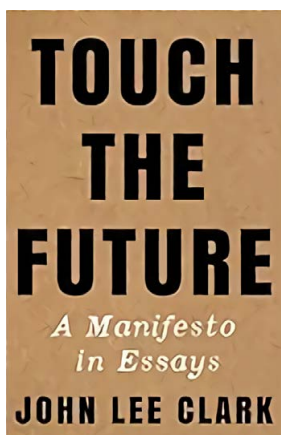
The rehearsals of the new version of the play started in August 2024. The Con-nection Fund has offered its sponsees the opportunity to take the stage, adding four new deafblind characters and their stories to the cast. Some of the actors who had their parts in the play for the last ten years could not participate in the current version for personal reasons. For example, the deafblind actress Alena Kapustyan has recently become a mother and is caring for her baby.

The new production, as before, is based on the life stories of its participants told in different languages: Russian, English, sign language and body language. It was not easy for the new actors to reveal themselves, because they had to tell about the most important experiences in their life, about their dreams and plans, about how they manage to listen to music, dance, love and simply live in the absence of hearing and sight.



Among the deafblind actors of the current cast are the artist, writer and actress Irina Povolotska-ya, the triathlete Alexei Gorelov, the teacher Dmitry Guryanov, the vice-president of the society of social support for the deafblind Nadezhda Golovan and others. The play premiered on October 11th in the New Space of the well-known Moscow Theater of Nations. As before, the new version of the play is translated into English and is accompanied by simultaneous translation into Russian sign language.

“*In Touch* has its distinct energy, it is a motivating performance about personal overcoming and about life beyond the limits of deafblindness. To push these limits was a super task”, says the actress and assistant director Irina Povolotskaya. “New participants bring to the play their own experience of moving beyond the limitations. And for our audience, it is a play about love and truth, about kindness and patience, about the light of the soul.”



Reading with Roxanna Spruyt: 'Touch the Future: A Manifesto in Essays' by John Lee Clark

ROXANNA SPRUYT-ROCKS
DEAFBLIND ONTARIO SERVICES DBI GOVERNANCE OFFICER

Roxanna Sprut recently shared a thought-provoking book titled **'Touch the Future: A Manifesto in Essays'** by John Lee Clark. She highlighted it as an inspiring introduction to protractile communication, making it a must-read for those eager to explore this intriguing subject.



Inclusive Dance with Laura Sarah Dowdall

Art is always a wonder in a sense. It aims to unite people through shared feelings, creating connections despite cultural, social, or other differences.

We got to know about the work of one of our Deafblind International members - Laura Sarah Dowdall, who is a dance artist, performer, choreographer, inclusive dance facilitator.



Laura has been working at the Deafblind Centre in Ireland for the past decade, creating movement and dance for wellbeing programs for residents there. Reflecting on her journey, she notes, "It has been a special experience to witness the progress and benefits we achieve through our collaboration with both residents and staff."

Laura has collaborated with the Anne Sullivan Centre in Ireland since 2015. The classes in the community that Laura teaches are with participants of all levels of vision and deafblindness and different abilities; some have guide dogs with them, and some people use wheelchairs.

Currently, Laura is leading a 10-week series of workshops in Dublin City.

To learn more about Laura's meaningful work in inclusive dance, visit <https://runningblind.ie/about/> for videos and insights celebrating art's ability to connect and inspire.

2024 TV interview about Running Blind Dance Project - <https://youtu.be/jcy36hdh9tY?si=Pyvq7IGL-lmE3s5f>



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