

In our Family the Word Blindness was Forbidden!

Natalia Demianenko about the ability to touch vividness, a trace she wants to leave behind, and why her life isn't a medical record.

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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.

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Dear friends and colleagues,

About four years ago I was asked how I see the coming years for Dbi, and what strategies and priorities would I envision going forward. I remember saying that Dbi will be building towards a strong team and clear focus, (diversity/inclusion, education, communication, and research). And that is what we did - by using the strength of the network organization that we are, we have built bridges with other relevant organizations in the field worldwide and most of all we have found ways to meet (conferences or otherwise) so we learn and share our stories, knowledge, and experience. We also did a lot so we can ensure that our focus is brought forward in the context of continuous co-development

and co-creation with other organizations. We were able to make a difference on global, regional, and national levels to ensure that focus is put on the needs of persons with deafblindness, their families, and the professionals who provide services. And so we became more and more THE point of connection in deafblindness. Outreaching communication is “key” in our global organization and with the input and creativity of ComCom and all our ambassadors we made major steps forward. Looking at the activity of all of our networks at the moment, the research that is initiated and shared, the development of the ICF core set, the collaboration with the International Communication Rights Alliance,

FRANK KAT

PRESIDENT OF
DEAFBLIND
INTERNATIONAL

■ ADDRESS BY THE PRESIDENT OF DBI

and the regional conferences we can say that those are all great examples of how we as a team, members, friends, and colleagues did work enthusiastically towards our goals. So what will the future bring? We will definitely keep our focus and grow further in the role of THE point of connection in deaf-blindness. One of the major activities will be

Thank you for being part of Dbi,
Frank Kat President

the call for immediate respect of the right to education for children who are deafblind and have similar needs, through our four-year global Campaign for education. We come from different places, have different stories and experiences, we have common goals and values and we can accomplish great and important things together!

Register Now for the 18th International World Conference Ottawa, Canada, July 22 to 28, 2023

Canada welcomes you to the 18th International World Conference taking place in our nation's capital, Ottawa, from Saturday, July 22 to Friday, July 28, 2023.

The conference will be held at the Shaw Convention Centre, internationally recognized as one of the most accessible venues. This venue is conveniently located within walking distances from the conference hotels and in the downtown core of Ottawa.

For the first time, this conference will be designed as a hybrid event offering the chance to attend it both online and in-person.

We are anticipating 600 in-person participants including DBI members and staff, content experts,

students, and key industry stakeholders.

Join us as we present keynote speakers like Rick Mercer from Canada and deafblind ambassador Kevin Frost among many other luminaries.

As part of the conference program, on July 26 at 7:00 p.m., there will be a screening of a film produced by Michael McNeely, an individual who is deafblind and supported by Deafblind and Sensory Support Network of Canada (Sensity). Michael shares the real-

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ity of living with deafblindness and the importance of self-advocacy, independence, and dignified living. Advocacy Club was created at the Canadian Helen Keller Centre in Toronto. This documentary focuses on the stories and successes of individuals and how they overcome barriers while advocating for change within their communities.

The Deafblind Network of Ontario (DBNO) is excited to present a unique Canadian experience, while delivering cutting-edge educational sessions and bringing together like-minded individuals from across the globe.

The theme of this year's conference is Global Connections: The Future in Our Hands.

Register at www.deafblindnetworkontario.com

Dbl Awards – It's Nomination Time

It is once again time to acknowledge the exemplary work of our colleagues.

The Dbl International conference will be held in July of this year in Ottawa, Canada. One of the highlights of our conference will be the recognition of the work of our colleagues. Dbl will once again be looking to present our Lifetime Achievement, Distinguished Service and Young Professional Leadership awards during the gala evening celebration on Thursday, July 27. Should you know of someone who has made a significant contribution to the international deafblind community and whom you feel might be deserving of one of these awards, please consider nominating them.

The completed nomination form and the letters of recommendation should be forwarded by email to the Dbl Secretariat at dbi-secretariat@sensity.ca by **Friday, May 26, 2023**. The nomination form and nomination details can also be found on the Dbl website at <https://www.deafblindinternational.org/conference-awards-nomination/> where it can be submitted directly to the secretariat. If submitting the form directly from the website, please email the summary and the letters of recommendation to the secretariat.

**CAROLYN
MONACO**

AWARDS
COMMITTEE CHAIR

Young Professional Leadership Award

This award recognizes an individual younger than 40 years of age who is providing high quality program opportunities. Examples of contributions when thinking about a possible nominee for the Young Professional Leadership Award might be:

- Recognition as an up-and-coming leader in the field of deafblindness;
- Demonstration of excellence, creativity, and initiative in their work;
- Provision of valuable service to improve the quality of life for individuals who are deafblind;
- Potential of future impact of nominee's work in the field of deafblindness.

Distinguished Service Award

This award recognizes an individual who has significantly contributed to the deafblind field or Dbl, internationally. Examples

of contributions when thinking about a possible nominee for the Distinguished Services Award might be:

- overall professional experiences;
- innovative practices;
- unique or extraordinary contributions to DbI;

- professional publications, research and/or staff training activities;
- leadership at the international level which has promoted or improved services to the individuals who are deafblind and their families.

Lifetime Achievement Award

This award recognizes an individual approaching to the end of their career who has made an outstanding, and continued contribution to services for the individuals who are deafblind on a national and international levels. Examples of contributions when thinking about a possible nominee for the Lifetime Achievement Award might be:

- Publications;
- Research;

- Development and/or practical application of new techniques, strategies, or procedures;
- Training of personnel;
- Advocacy;
- Dynamic leadership.

Thank you for recognizing the efforts and outcomes of our colleagues and for your support!



Carolyn Monaco,
Awards Committee Chair

Certification March, 2023

DeafBlind Ontario Services and CNIB Deafblind Community Services are excited to confirm that between July, 2022 and September, 2022, 100 Canadian intervenors took the Certified Deafblind Intervenor Specialist (CDBIS) certification beta exam at the Academy for Certification of Vision Rehabilitation and Education Professionals (ACVREP). The final exam was held on March 1, 2023.

KAREN MADHO

DEAFBLIND
ONTARIO SERVICES

The purpose of a beta exam is to determine how each of the questions of the exam performs. The exam was developed using professional certification psychometric services.

This certification was developed to ensure that individuals who are deafblind receive the highest standard of services and supports possible. It prioritizes specialized training for intervenors so they are equipped with the highest standards of professional integrity, competence, and ethics.

Certification is a strong step forward in professionalizing the field of Intervenor Services. It offers a clear and broadly accepted set of expectations for the role of intervenor. It is based on an im-

portant collaboration between the Intervenor Services sector in Ontario, Canada and the provincial government that was carried out in 2015 – 2018.

The collaboration, or Intervenor Services Human Resources Strategy (ISHRS), developed a distinct set of best practices in human resources as well as a set of behavioral and technical competencies, separate from the developmental services sector. DeafBlind Ontario Services and CNIB Deafblind Community Services took a leadership approach to create this certification program with ACVREP, which was in alignment with their shared commitment to making a real impact on the lives of the individuals who are deafblind.

For more details on eligibility, check out the CDBIS Handbook at <https://www.acvrep.org/certifications/cdbis-landing>

Yarn Bombing March, 2023. Making Connections on a Global Scale for Deafblind Awareness Month

KAREN MADHO

DEAFBLIND
ONTARIO SERVICES

Interested in raising awareness of deafblindness across the globe? Join us to yarn bomb to symbolically come together and increase awareness of deafblindness. One stitch at a time. Yarn bombing is a tactile art display with yarn that is knitted, crocheted or wrapped around objects in public spaces.

It's the 3rd year when Deafblind International's (DbI) Communication Committee encourages everyone to gather some yarn and knitting or crochet needles to celebrate and raise awareness of deafblindness during the month of June, designated as Deafblind Awareness Month.

With over 70 installations across 6 continents last year, we're looking forward to 2023 being the biggest year ever. We are excited to report that as of March 20, organizations, committees, groups, and individuals from cities and regions in the following locations plan to yarn bomb around the world: Argentina, Canada,

Croatia, Egypt, Ethiopia, France, Greece, Guatemala, Italy, Kenya, Netherlands.

Interested in yarn bombing but not experienced in knitting or crocheting? Be creative by exploring yarn crafts like pompoms or looms.

Help us spread the word. Use the social media hashtag #DbIYarnBombing2023 and share pictures of your creations that demonstrate how you are fostering a sense of fun for this global initiative.

Coming together to express yourself through these colourful tactile art displays offers a great way to unite the community with individuals, service and advocacy groups in the field, DbI members, and partners as well as with global public.

Special note. We will also be featuring yarn bombing at the DbI Conference in July, 2023 in Ottawa, Canada.

There's still time to make your plan to yarn bomb! For more details, check out <https://www.deafblindinternational.org/yarn-bombing/>

News from the Network Coordinator

Since I last reported on the networks, a lot has happened and many activities have been undertaken. Currently, there are 16 networks, among which the Family Network and the Africa Network are the youngest ones. There is even a 17th network on the way – the Deafblind Education Network.

The network leaders meet online every 3 months. It's nice to see this group of people getting closer and closer. We don't only inform each other on the activities of each network, but also exchange advices and tips with each other. The number of network members continues growing and that is, of course, fantastic. This means that we want to share knowledge and experiences in the field of deafblindness with each other worldwide and that we want to be connected.

Collaboration between the networks is becoming increasingly common and this is a wonderful development. For example, the Family Network already works closely with the Ibero Latin America Network. Online webinars on such topics as independent living, cortical visual impairment, and Usher syndrome have been recently organized.

The Communication Network has recently organized webinars in 3 different regions of the world, especially for parents and family members. This time, the topic was tactile hand positions.

The Acquired Deafblindness Network (ADBN) continued orga-

nizing short webinars and sending newsletters.

The Technology Network has organized online network meetings where the members informed each other on their knowledge in the field of technology.

The Outdoor Network was able to organize an adventure week for the 1st time after 2 years of Covid. This took place in the UK with 25 individuals who are deafblind and 62 volunteers.

There was a change of network leader at the network of the Americas. Marianne Riggio retired and Chris Montgomery took her place. At this point, I would like to thank Marianne again for her fantastic effort and involvement and a warm welcome to Chris.

The above is just a selection of all the activities organized by various networks in the past period. During the Dbl World Conference in Ottawa, the Research Network, the Usher Network, and the Communication Network will organize interesting pre-conferences.

Just like during the 1st Dbl Africa Conference in 2022, all network leaders will also introduce themselves in a separate meeting during the World Conference in Ottawa in July, 2023. In addition, separate network meetings will be organized during this conference.

The Dbl networks are as lively as ever and I would like to thank everyone who has again put in a lot of energy in the past period.



TREES VAN NUNEN

DEAFBLIND
INTERNATIONAL,
NETWORK
COORDINATOR

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DbI Communication Network Report March, 2023

**MARLEEN
JANSSEN**

CHAIR OF THE DBI
COMMUNICATION
NETWORK

In this report the main part is devoted to the Deafblindness Symposium organized on June 21, 2022 in Groningen and further the post and coming activities of the DbI Communication Network are presented. In July, during the DbI World conference, a new chair of this network will become in charge.

Herewith, I say goodbye to you all, as a chair of the DbI Communication Network, which I have been for 8 years. My job was to expand the network from a small expert network into a large global network and to make sure that webinars for parents and family members all over the world were organized. That job is done. I did it with a lot of pleasure and want to thank you all for your collaboration over the years. I wish my successors good spirits and much fun to go on with this very important and interesting network.

Report. New Perspectives on Deafblindness Symposium, June 21, 2022, Groningen

On June 21, 2022, the UG Institute for Deafblindness in collaboration with the Department of Inclusive and Special Needs Education organized an (inter)national symposium at the University of Groningen to mark the farewell of Marleen Janssen as a professor and the start of her work as Professor Emeritus. This symposium was recorded and will become available on the website of the UG Institute for Deafblindness.

It was an interesting program aimed at new perspectives in the field of deafblindness, besides the topic of Communication and Deafblindness, which has been and is the research topic from an educational perspective of Marleen Janssen and colleagues at the University of Groningen for almost 20 years. Many Master students and PhD students have graduated on this topic. At this symposium, it was celebrated what is achieved with a focus on the future.

The Chairman of the day was Prof. Alexander Minnaert. He welcomed the guests who came to Akerk, a historical and beautiful church in the town of Groningen, as well as many (inter)national online participants of the symposium. He emphasized that what the author has achieved was unique and devoted very beautiful words to her. He introduced each presentation in a very enthusiastic manner in which he showed that he had immersed himself in each presenter and each topic.

The first presenter was Dr. Jolanda Dwarswaard, Director of the Kentalis Academy of Royal Dutch Kentalis in the Netherlands. The start of her career was at a school for the individuals who are deafblind, now Kentalis Rafael. Besides a very beautiful speech for the author, Jolanda has an important announcement to make. A new Endowed Professor will be appointed, and their activities won't be focused only on deafblindness, but also on the individuals with multiple disabilities. This appointment will be made in terms of collaboration between Royal Dutch Kentalis and the University of Groningen.

By now, in March, 2023, the name is known. On September 1, 2022 Prof. Saskia Damen was appointed as Endowed Professor of Development and Learning of People with Multiple Disabilities and Complex Communication Needs and People with Congenital and Early Acquired Deafblindness. Here, I congratulate Saskia on her appointment, which is well deserved. She worked very hard for it, and I am very happy that our collaboration of over 15 years led to a new professorship. This means that the work and many beautiful projects will go on at the University in Groningen.

After this important announcement, it was presented a film by Lisa van der Mark, an individual who is deafblind due to the Usher Syndrome. Lisa is a Ph.D. student at the University of Leiden. She introduced Protactile Communication to the audience. She told us that Protactile Communication is tactile-centric and goes beyond the tactile reception of sign language as it is more than communication through the hands. Protactile Communication makes use of contact space, the touchable surface on the listener's

body, so that the listener can experience and embody what is being said. Protactile Communication started out in the US and has been spreading beyond the country borders to also set foot in Europe. You can watch the film online as well as find another interesting clip about Protactile Communication by John Lee Clark and Jelica Nuccio and the research of Terra Edwards on Youtube.

"Listen to the voices of parents of the individuals with congenital deafblindness," was an important take-home message of Dr. Rosemarie van den Breemer and Liliast Liston (MSc in Communication and Deafblindness). They represented family members of the individuals with congenital deafblindness and clearly demonstrated that it is of great success to include parents in research projects or even let them lead these projects. Rosemarie works on different research projects in Norway and Liliast in the UK. They are speaking also at the DBI World Conference in Ottawa in July, 2023.

Prof. Timothy Hartshorne from Michigan University and Prof. Walter Wittich from the University of Montreal presented the content of two academic volumes on deafblindness for Oxford University Press. Three of us are the editorial team in this exciting book project. The 1st volume is entitled Communication with People who are Deafblind: Assessment and Intervention and includes the following sections: identification, assessment, social interaction and behavior, communication development and intervention, dialogical approaches to communication, tactile communication, tactile sign language and interpretation. The 2nd volume is entitled Learning, Education and Support of Deafblind Children and Adults and includes the following sections: identification, specific learning approaches, learning, self-determination and education, participation, work and recreation, family perspective, professionalization and interdisciplinary support and research, technology and innovation. Over 150 authors around the globe have worked on these volumes. And the 3rd volume led by the authors who are deafblind is in progress.

An exciting book project of the Groningen Study Group on Diversity in Communication

is in progress as well. Presentations related to this project were held at this Symposium in Groningen. Prof. Ivana Markova from Stirling University Scotland spoke about dialogical single case studies. Dr. Paul Hart from Sense Scotland held an interesting presentation about the case study of Fiona, in which different theoretical concepts were explained. Dr. Marlene Daelman from Brugge Belgium (live) with Anne Nafstad, Psych. Cand. from Statped Norway (online) prepared a presentation about the dialogical concept of the 2nd perspective and illustrated that with an interesting video. Jacques Souriau, psychologist from France, reflected on different epistemological issues. This book will be written in the coming 2 years in collaboration with the UG Institute for Deafblindness in Groningen.

The last presentation of this Symposium made in English was of Saskia Damen, Associate Professor at the University of Groningen. She presented several new research topics with a focus on the future and

started with 4 PhD projects illustrated with interesting videoclips. The 1st study was that by Marianne Rorije and was related to the effects of interventions on tactile communicative agency and sign language, and an investigation on the role of the communication coach in these interventions. The 2nd study presented was that by Kim Tosolini. It was entitled Thinking in Dialogue and aimed at improving partner strategies focused on the zone of proximal development regarding the cognitive abilities of students with congenital deafblindness. The 3rd study by Mijkje Worm was focused on multiparty communication with children and adults and the 4th study by Rita Gerkema-Nijhof was focused on storytelling. Saskia told about all relevant variables, research designs, and aims of the different studies. As for other goals for the future, she was looking forward to the implementation of studies on interventions, inclusion of parents in research, peer interaction benefits, tactile sign language, dynamic assessment, and inclusion of technology and innovations.

Activities of the DBI Communication Network

On November 17, we organized a worldwide webinar entitled Tactile Communication and the Use of Different Hand Positions. During the webinar, there were practical activities in trying out different handpositions. The webinar was inspired by the work of Barbara Miles and Michael Cyrus. It was presented by Helle Buelund Selling, member of the Nordic Network on Tactile Language and Development and consultant at the Center for Deafblindness and Hearing Loss in Aalborg, Denmark. See also the videos on our website <https://www.deafblindinternational.org/webinar-on-tactile-communication-and-different-hand-positions/>

We are preparing the preconference for Ottawa, Canada in July 2023, which will last for 2 days and will be divided into 4 parts aimed at the individuals who are deafblind, professionals, families, and researchers. The themes are as follows:

- Best practice for the children and adults who are deafblind, presented by Caroline Lindstrom and Ann Sofie Sundqvist;

- Supporting communication development in the tactile mode, presented by Esther Keller and Lisa Monen;
- Family experiences: informing research practice; the presenters still have to be confirmed;
- Experiencing the transition to tactile language, presented by Femke Krijger.

These 2 days are organized by our network team and the idea is mainly to exchange and discuss experiences and viewpoints of each other and especially of the individuals who are deafblind and their family members. Bookings can be made at the conference website <https://canplan.swoogo.com/DBI2023#>

During the world conference in Ottawa, a network meeting will be organized. There, new plans for the future will be discussed with all the interested network members who will join the conference.

Another main activity for 2023 is composing and publishing an Overview Book of 40 Years of Communication Articles in the Deafblind International Review journal which will be finished in 2023.

The organizing team of our Communication Network, besides myself, consists of Saskia Damen from the Netherlands, Meredith Prain from Australia, Helle Buelund from Denmark, and Steve Rose from the UK.

And if you are interested in this Dbl Communication Network, you can become a member by visiting the website of Deafblind International

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

For more information, or if you have any questions about this network, contact Marleen Janssen, on behalf of the Dbl Communication Network team: h.j.m.janssen@rug.nl



Marleen Janssen gives her farewell lecture



Lisa van der Mark (in film) explains protactile communication



Rosemarie van den Breemer demonstrates tactile bodily gestures

DBI Outdoor Network Adventure Week 2023

First announcement



WHAT?

A week of fun, exploration, challenges and a lot of fresh air. Exciting and adventurous Outdoor Activities and the opportunity to meet old friends or make new ones.

WHEN?

September 25-29, 2023.

WHERE?

Scoutinglandgoed Zeewolde.
Nulderpad 5, 3896LV Zeewolde.
The Netherlands.

[Avonturenhuis | Ga op avontuur | Scoutinglandgoed Zeewolde](#)

PRICE?

The price has not been determined yet, but it will be around €525 per person. (i.e. 1 adult who is deafblind + 1 caregiver = €1.050) A maximum of 2 supervisors per person is required.

WHAT IS INCLUDED IN THE COST?

All food, drinks, accommodation, activities, and equipment.



Scoutinglandgoed Zeewolde, avonturenhuis



HOW DO I FIND OUT MORE AND BOOK?

For more information and bookings contact Margot and Ingrid by email ikorenstra@bartimeus.nl

Tel: 0031(0)624341653

WHEN IS THE DEADLINE?

Previous years participants have priority when they register before May 1, 2023. This possibility will expire after this date.

Overall deadline: June 1, 2023.

PROGRAM?

The program will be available soon!



DBI Technology Network Meeting

March 30, 2023

Virtual; 21 participants

MIJKJE WORM

DBI TECHNOLOGY
NETWORK, CHAIR

The meeting was organized to discuss issues in advising technology to the individuals having vision and hearing loss, the individuals who are deafblind. Network members brought their questions to the table. In 3 breakout rooms, we studied the issues from various viewpoints and developed possible solutions.

Case 1. iPad use (Mads Quist-Lund, Consultant RN)

The case was around Ellie, an adult woman with congenital deafblindness. She has limited fine motor skills and uses an Apple iPad to do different kinds of things, for example communicates with her parents on FaceTime. The questions were: How can she be supported to have an optimal use of her iPad? How can she keep up with new features and options as independently as possible?

Define the user needs

To help Ellie and the caregivers around her, we need to understand her unique situation and identify the specific accessibility features that would best suit her needs. This includes conducting an assessment to identify her strengths and weaknesses, her level of comfort with technology, and what specific activities she wants to do on her iPad. It is also important to communicate with her caregivers and support network to better understand her

needs, preferences, and abilities. By maintaining ongoing communication with them, we can ensure that we are providing the most effective and appropriate support for Ellie's evolving needs.

Introduce the technology

It is essential to teach Ellie and the caregivers different accessibility features available on her iPad and to explain how they work. This includes such features as Voiceover, Switch Control, and Assistive Touch. We need to demonstrate how these features work and show her how to enable and customize them. During the discussion, many examples of technologies were given:

- <https://www.tobiidynavox.com/>
- <https://support.apple.com/en-us/HT201370>
- <https://www.youtube.com/watch?v=kQq8KilGvss>

- <https://www.ablenetinc.com/hitch-2/>
- <https://www.inclusive.com/uk/pal-pad-switches.html>

Provide ongoing learning

We need to provide Ellie and the caregivers with resources, such as user guides, online tutorials, and videos that can help her stay up to date with the latest accessibility features and updates. It is also helpful to recommend relevant online communities or forums where they can get in contact with other individuals with similar needs and learn from their experiences.

Customize and personalize

We need to assist Ellie and the caregivers in customizing and personalizing her accessibility settings on her iPad. We can help her adjust the screen brightness, font size, or color contrast to better suit her vision needs. We can also assist her in customizing Switch Control settings to work with her specific switch type or in setting up voice commands to control her iPad. And we are still searching for better usable features.

Provide ongoing support

We need to provide ongoing support to ensure that Ellie and the caregivers continue to have access to the latest assistive technologies and features. This includes sched-

uling regular follow-up sessions to check on her progress, answering any questions she and the caregivers may have, and making necessary adjustments to her accessibility settings.

Conclusion

During the discussions, there were raised several points that should be considered when working with assistive technology features on the iPad and helping the individuals with congenital deafblindness. For example, it can be challenging to use apps that match the individual's needs. Also, we need to keep in mind that people with congenital deafblindness often have hard time using screen readers or other technologies on their own, so we need to find solutions that work for them, as well as for the caregivers surrounding them. Finally, we need to make sure that all solutions are damage-resistant since young individuals can be easily frustrated, and iPads (unlike wired PCs) are a useful tool as they can take a lot of beating especially when being protected by a hard shell or cover. In summary, we can help and guide Ellie and the caregivers by defining her unique needs, introducing her available technology, providing ongoing learning, customizing, and personalizing the technology to her specific needs, and providing ongoing support. By doing so, we can help her maintain and even expand her independence and achieve her goals.

Case 2. Screen Reader advice (Fereshteh Halimi, Eikholt)

This case was around an adult man having vision and hearing loss. A 60-year-old man who runs a farm and does his finance on the computer. He currently uses SuperNova, but there are other screen readers with different characteristics. It might be better for him to change to Jaws, but he prefers to remain stuck to Supernova that he is acquainted with. What should we advise him?

Answer

The general answer of taking the client and their wishes into account as a starting point for answering the question is similar to the former case. Many of the advices

formulated there also apply to this case. Yes, Jaws currently has the best functionality, but since the person already knows SuperNova and has no wish to change a screen reader, you can also choose to optimize his use of SuperNova. It is not always the best program that you need to advise, but our advice also takes personal characteristics into account. For example, what is the person already used to? Which support has this person when they get stuck? Which functionality is essential for this person and which is optional, etc. Many issues can be resolved in either program, but you need to sit down with the person, show different options and see what is motivating and/or

assistive for that person. All our advices will be individual, since the individuals with vision and hearing loss usually have specific, non-regular needs.

Other practical ideas for screen reader advice, were:

3. Other questions

The last breakout room gave the opportunity to discuss other questions that were not presented as a case. Each breakout room discussed different questions. In this report we summarize some of the questions and answers. Note that there may be other possible solutions, because these questions were not discussed extensively and were considered only in a small group.

Bart

In my work practice, I regularly hear clients complaining when they can no longer find their own things in the house, because they have been moved by, for example, caregivers or family members. I would like to know if there is something (available or under development) that can detect lost items in the house in a tactile way.

Answer

Options could be:

- [Tile | Tile](#) or other kinds of tags. Disadvantages are that these tags are not cheap and they run on batteries;
- In the future, Google Glass may be an answer for this problem;
- AirTag (or similar) now have much better precision (N-Theory centimeters);
- SeeingAI has a function that can already be tested for the purpose of finding (maybe larger) things;
- Structure the home environment in such a way that things are encouraged to be put back in the assigned places.

Bart

Is there or could there be made a practical or technical adaptation for the individuals

- [NVDA Screen Reader - Babbage](#)
- Use a smartphone or iPad instead of a PC. Sometimes things are easier and more direct on the smartphones;
- You can also help the person in creating shortcuts, smart buttons, etc.

who are deafblind in order to operate touch screens on household devices like cooktops?

Answer

Options could be:

- [Talking household appliances and aids | Feelware](#)
- It would be nice to use virtual assistants that can tell what's on the touchpads and how to operate them;
- Sometimes it may help to mark the touchpads with stickers.

Pia

One of my customers who are deafblind has a problem with reading Braille. This is due to sensory/tactile issues in his fingers. It's impossible for him to feel the dots. Is there any way to enhance the Braille pattern, or has somebody heard anything about another solution? He has no problems with typing on a keyboard.

Answer

Perhaps, one of the solutions mentioned below fits this client's needs:

- <https://www.visionaid.co.uk/dot-watch>
- <https://xtactor.com/>
- <https://venturebeat.com/business/taptap-a-wristband-that-makes-morse-code-the-language-of-love/>
- <https://yourstory.com/2019/01/app-fridays-good-vibes-deaf-blind-morse-code>
- The use of vibration patterns may help;

- The solution may be based on <https://www.sense.org.uk/information-and-advice/communication/tadoma/>
- Brainport. <https://www.wicab.com/brainport-vision-pro>
- Idea. Bigger Braille elsewhere on the body, or Braille lip reading. [Blind student learns to read Braille with her LIPS because her fingertips are not sensitive enough to feel bumps | Daily Mail Online](#)
- Kelvin has shared information about [See Me Cane Project – SeeMeCane](#)

Closing and thank you

We had a very good session where all attendees enriched their knowledge on technical aids for the individuals having vision and hearing loss and enlarged their net-

work of others who are active in this area. We thanked all participants and especially Fareshteh and Mads for bringing their cases into discussion.

Our next meeting will be held during the DBI Conference in Canada on July 25, 2023 at 5:30 – 6:30 p.m. UTC-4. This will be a hybrid session. We hope to meet conference attendees that may join our session and possibly also join the network. Network members will be invited and can join the meeting online even if they are not attending the rest of the conference. We will try to make it an interesting session both for the people who are in Canada and for the online participants. Any suggestions for this are warmly welcomed!

With many thanks to Mads, Charlotte and Kirsten for their contribution to this report.

Pedagogical Strategies for Children with Cortical Visual Impairment: Addressing the Unique Challenges in the Educational Process

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Abstract

The article discusses the educational process of children with cortical visual impairment (CVI). It explains the challenges that teachers face when working with the children with CVI, such as difficulty in accessing information, navigating their surroundings, and fatigue. The article also highlights the learning difficulties that children with CVI may face, such as visual attention, visual memory, and visual discrimination problems. Furthermore, it explores the strategies that teachers can

employ to facilitate learning, including a multi-sensory approach, the use of visual aids, and creating a supportive learning environment. Collaboration between the teachers, therapists, and families is essential in supporting the educational needs of children with CVI. Early identification and intervention are crucial for promoting positive educational outcomes for these children.

Keywords: Cortical visual impairment, education, early intervention, multi-sensory approach.

Introduction

Cortical visual impairment (CVI) is a neurological condition that affects the visual cortex of the brain, leading to vision impairments that cannot be attributed to the eye itself. CVI is a leading cause of visual impairment in children in developed countries, with an estimated prevalence of 0.4–2.5 per 1000 live births (Dutton & Bax, 2010). The symptoms of CVI are highly variable, ranging from

mild visual impairments to total vision loss. Common symptoms include difficulty in recognizing faces, objects, or colors, poor depth perception, and sensitivity to light (Roman-Lantzy, 2018).

The educational needs of children with CVI are complex and require specialized approaches to support their learning. This article aims to explore the peculiarities

of the educational process in children with CVI, including the challenges faced by the

teachers and the strategies that can be employed to facilitate learning.

Challenges in educating children with CVI

Educating children with cortical visual impairment represents several challenges to the teachers. The visual impairments associated with CVI can impact a child's ability to access information and participate in classroom activities. For example, children with CVI may struggle to read printed materials, understand visual aids, or follow visual instructions. They may also have difficulty in navigating their environment, finding their way around a classroom or school building, and recognizing people or objects in their surroundings (Roman-Lantzy, 2018).

According to the current research, a number of learning difficulties can be identified in children with cortical visual impairment, including:

- Difficulty in visual attention. Children with CVI may find difficult to attend to visual stimuli, maintain visual fixation, and shift visual attention between stimuli;
- Visual-motor integration problems. Children with CVI may struggle with fine motor skills, such as manipulating small objects, and gross motor skills, such as catching a ball or running;
- Difficulty with visual memory. Children with CVI may have difficulties in remembering visual information and recognizing previously seen objects or faces;
- Visual-spatial processing problems. Children with CVI may have difficulties in

understanding visual-spatial relations, such as size, distance, and orientation;

- Difficulty with visual discrimination. Children with CVI may have difficulties in distinguishing similar visual stimuli, such as letters, numbers, or shapes.

Another challenge in educating children with CVI is high variability in symptoms and severity of the condition. Children with CVI may have different visual impairments and may require different accommodations and interventions to support their learning. Therefore, teachers need to have a comprehensive understanding of each child's individual needs to provide effective support.

As mentioned earlier, because of the difficulty of accessing the visual world, children with CVI may become overwhelmed and quickly fatigued. This can lead to problematic behaviors that are often misinterpreted, such as inattention or non-compliance. The teachers and therapists need to understand these challenges and develop strategies to support the child's learning and behavioral needs.

CVI can also come with other disabilities or developmental delays, such as motor coordination challenges or speech disorders, further complicating the educational process. Therefore, a multidisciplinary approach that addresses the child's unique needs is crucial in providing effective educational support for children with CVI.

Strategies for educating children with CVI

Several strategies can be employed to support the learning of children with CVI. These strategies aim to address the challenges outlined above and promote the child's engagement and participation in classroom activities.

One of the key strategies is to provide a multi-sensory approach to learning. Children with CVI may benefit from using multiple

senses, such as touch, hearing, and smell, to access information. For example, teachers can use tactile materials, such as textured objects or raised-line drawings, to teach concepts and ideas. They can also use auditory cues, such as verbal instructions, sound effects, or music, to reinforce learning.

Another strategy is to use visual aids that are specifically designed for children with

CVI. These aids may include high-contrast images, simplified pictures, or visually salient materials that draw the child's attention. Teachers can also use visual schedules and organizers to help children with CVI understand routines and sequences of events. Simplified pictures that have clear outlines or bold colors can also help the child focus on the key elements of a visual representation. Visually salient materials, such as brightly colored objects, can help draw the child's attention to important information.

It is also important to create a supportive learning environment that is tailored to the

child's individual needs. This may involve modifying the classroom layout to minimize visual clutter, reducing visual distractions, or providing extra lighting to aid visibility.

Overall, these strategies provide a framework for the teachers and therapists to help children with CVI access the curriculum, engage in learning, and ultimately reach their full potential. By taking a personalized and multi-disciplinary approach to educating children with CVI, we can ensure that all students have the support they need to thrive in the classroom.

Collaboration and early intervention

Collaboration between the teachers, therapists, and families is essential in supporting the educational needs of children with CVI. Educators should work closely with families and therapists to develop individualized education plans (IEPs) that address the child's specific needs and goals. This may involve regular communication and feedback between all parties involved.

Early intervention is also crucial for promoting positive educational outcomes for children with CVI. Early identification and intervention can help to mitigate the impact of visual impairments on a child's development and learning. It can also help identify any additional disabilities or developmental delays that may be present, allowing for early intervention and support.

In addition to collaboration and early intervention, it is important to mention function-

al vision assessment. A functional vision assessment is an important step in accurate estimation of a child's visual abilities and selection of educational strategies accordingly. Functional vision assessment may involve using specialized assessments to evaluate a child's visual skills, including visual acuity, contrast sensitivity, visual fields, and visual processing speed. This information can be used to determine the most effective methods of instruction and to identify any specific visual accommodations or technologies that may be necessary to support the child's learning. Regular monitoring and re-evaluation of a child's functional vision can also help track progress and adjust educational plans as needed. By incorporating functional vision assessment into the educational process, the teachers and therapists can ensure that children with CVI receive the most appropriate and effective educational support.

Conclusion

Educating children with cortical visual impairment requires specialized approaches that address the unique challenges faced by these individuals. Strategies, such as a multi-sensory approach to learning, the use of visual aids and adaptive technologies, and creating a supportive learning environment, can help facilitate learning and promote engagement. Collaboration between

the teachers, therapists, and families, as well as early intervention, are critical components in promoting positive educational outcomes for children with CVI. By understanding and addressing the peculiarities of the educational process in children with CVI, educators can provide effective support to promote the development and learning of these children.



Figure 1. Class with a child aimed to develop visual perception. Source: Prepared by the author



Figure 2. Adapting space for activities with children engaged in the early intervention. Source: Prepared by the author



Figure 3. Adaptation of the training manual. Source: Prepared by the author

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Proposal for Standards to Enable Tactile Observation in Museums, etc.

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Introduction

Currently, an increasing number of Japanese museums, art galleries, and other facilities (hereinafter referred to as “museums, etc.”) are taking initiatives, such as audio guided tours, giving audio commentary, and installing commentary panels with Braille and tactile graphics as considerations for the individuals with visual impairments (Moriya & Izuka, 2020). However, there are strong requests from the individuals having vision loss for permission to directly touch exhibits rather than to get audio or Braille commentary (Hirose, 2012). Therefore, based on the results of a field survey of 5 museums and other fa-

cilities in Japan carried out from October, 2021 to January, 2022 (Tokyo Metropolitan Foundation for History and Culture, 2022), this paper examines the criteria for enabling the individuals having vision loss, including the individuals who are deafblind (hereinafter “individuals having vision loss, etc.”), to view and observe (hereinafter referred to as “tactile observation”) by means of the sense of touch. The accessibility museums, etc. exhibits are proposed by examining standards to enable the individuals having vision loss, etc. to view and observe exhibits through touch (hereinafter referred to as “tactile perception”).

Creation of draft tactile observation accessibility criteria, version O

Based on the 1st author’s actual experience, the draft tactile observation accessibility criteria draft, version O, was developed for 3 patterns: when all exhibits can be touched, when some of them can be touched, and when a model can be touched instead of an exhibit.

Draft tactile observation accessibility criteria, version O:

A. Cases where all of the exhibits can be touched

- A1. Is there a panel in Braille that provides basic information on

its size, shape, materials, hazards, and warnings against tactile observation near the object?

- A2. Are the aisles wide enough to allow tactile observation around the objects?
- A3. In case if the exhibit consists of several parts, are the original shapes visible?

B. Cases where parts of the exhibit can be touched

- B1. Are there panels with basic information in Braille on their

size, shape, materials, and hazards, including warnings against tactile observation in the immediate vicinity of the objects?

- B2. Is there a description of the shape of the untouchable part or an alternative model?

C. Cases where models of exhibits can be touched

- C1. Is there a panel in Braille with basic information on size, shape, materials,

cautions, and risks of tactile observation near the model, etc., as well as information on the contrast with the object on display?

- C2. Is the model, etc. size suitable for tactile observation?
- C3. In case if the model consists of several parts, are the original shapes of the parts recognizable?

Verification of the draft tactile observation accessibility criteria, version O

Based on the results of the survey conducted at 5 museums in Japan, we verified whether the draft standard, version O, presented in the previous section is appropriate.

Validity of A1, A2, and A3 of the draft criteria, version O

The validity of the proposed criteria was checked at an exhibition where it was possible to touch all of the exhibits. There was an example where a high platform was provided around the perimeter of an exhibit that was 2 m high and 2 m thick. It was possible to touch every corner of the entire exhibit, but the aisles were narrow, and there were no lighting protection or Braille panels to explain information and alert visitors. Thus, A1, and A2 of the draft standard, version O, are satisfied. However, it was found that in the case of large exhibits, it is necessary to prepare a reduced model that can be touched with both hands without moving the whole object while touching the actual object.

Validity of B1 and B2 of the draft criteria, version O

In the permanent exhibition room, where several interactive replicas are displayed, visitors can actually cross a bridge about 25 m long and 8 m wide, reproduced at full scale and half the distance. Visitors can touch parts of the inner walls and pillars made of wood to get a sense of the overall size and materials. In the Hands-on Exhibition section, there is a reduced-scale metal model of the exhibit, which is small enough to touch with both hands and which allows visitors to get

an idea of the exhibit's overall shape. In addition, the Braille explanation panels installed near the miniature provide information on the size and shape of the exhibit, so B1 and B2 of the proposed criterion, version O, are satisfied. On the other hand, the findings indicate that the experiential replica and the Hands-on Exhibition section are at a distance from each other, which means that attempts to compare them would involve movement, and that they should be adjacent to each other.

Validity of C1, C2, and C3 of the draft criteria, version O

The proposed criteria's validity was verified using a reduced-scale model made of metal that is being produced in a facility where a full-scale cultural and historical building has been relocated, restored, preserved, and exhibited. The model is about the size of an A4 sheet, and the details are accurately reproduced by unevenness, so that the shape of the windows and roof can be understood with both hands. As of February, 2023, there is no Braille explanation panel to provide information on the material and size of the model compared to the exhibit, but this can be expected in the future, so it was decided to use the model as a reference. C1, C2, and C3 of the draft standard, version O, are satisfied. In addition, regarding materials, it can be said that they correspond to the materials in draft criterion C1, as it is possible to learn about the timber and tiles used in the interior walls and floors, etc., through the tour of the building. On the other hand, it is clear that there is no way to know the exterior materials and interior details.

Proposal of draft tactile observation accessibility criteria, version 1

Draft criteria version 1

In the previous section, several examples were examined using the draft standard, version 0. The proposed tactile observation accessibility criteria, version 1, which focus on the size of the exhibits to be touched and the relation between the exhibits and the models, rather than on whether the exhibits are directly touched or not, is proposed as follows.

Draft tactile observation accessibility criteria, version 1:

A. Necessary criteria for tactile observation

- A.1. Size.

The object's size should be such that it fits in a palm of a hand or can be touched with both hands without difficulty, and if the actual object is larger than this, a reduced model should be provided in conjunction with the object. Similarly, if the actual object is so small that it is difficult to understand its shape, an enlarged model should be provided in conjunction with it;

- A.2. Shape.

If it is not possible to understand the shape of an actual object in its entirety, a 3D model should be prepared to the extent possible and installed in the same direction as the actual object. In particular, protrusions should be used to express features, such as unevenness of building walls, window frames, etc.;

- A.3. Materials.

Wherever possible, materials that can be felt directly, such as wood, should be made so that they could be directly touched and felt. If the materials cannot be fully felt because they are out of reach, the model should be made using these materials or materials, such as

wood, bricks, stones, tiles, etc., should be prepared separately.

B. Relation between the model and the real object

- B.1. Positional relations.

Wherever possible, a model should be placed in the vicinity of a real object so that the real object and the model can be compared in the same place. A visitor should be able to smoothly check the actual object after touching the model, or check the model after touching the actual object. Also, the models should be placed at a height that allows visitors to touch them while standing, so that they can tactilely observe them without strain. A stable table should also be provided;

- B.2 Informational content of Braille and audio panels.

When installing Braille and audio panels, in addition to the title and outline of the exhibits, information on the size of the actual objects (e.g. scale factor of the models), information that is insufficient for independent tactile observation (e.g. different materials used in the models, features that cannot be reproduced in the models), and visual information should also be provided.

C. Environment required for tactile observation

- C.1. Posting of precautions.

If there is a risk of falling during tactile observation of the exhibits, or if the exhibits are sharp, or if other precautions are required, a written or audible cautionary note for tactile observation shall be posted;

- C.2. Safety measures.

Install fall prevention fences around large exhibits.



Figure. Tokyo Photographic Art Museum. Atsushi Mori (to the left), Yutaka Osugi (to the right)

Relation between the actual object and the model

In order to make visitors having vision loss, etc. understand the shape, size, and materials of exhibits through tactile observation, museums, etc. should not only increase the number of actual objects available for tactile observation, but also prepare appropriate models. For example, in exhibitions of old houses and other structures, it is difficult to physically touch everything, even if visitors are allowed to simply touch the walls and doors. To understand the shape of places that are inaccessible, such as the roof, it is necessary to be able to confirm the building's overall shape,

including the roof, using a model of a size that allows observation with both hands, and to display the materials used for the roof by the model, so that visitors can tactilely observe them. In addition, the accessibility of the exhibits for the individuals having vision loss, etc. may be enhanced by setting up a model tactile observation course that allows visitors to walk around the building to check its size and to see the materials and layout during an interior tour, and by installing Braille and audio panels at the entrance to explain how to do this and what to look out for.

For individuals having vision loss, etc., tactile observation is an alternative source of information to the eye. Just as it is difficult for an individual without sensory challenges to visualize an exhibit's shape by listening to a verbal description with their eyes closed, even if a perfect Braille or audio guide is provided, accessibility is not high unless an individual can touch the exhibit. The individuals who are deafblind have difficulty in tactile observation of exhibits while listening to explanations from a guide using tactile sign language, etc. It is thus extremely important

to consider accessibility standards for tactile observation of exhibits that take "touch," rather than "hearing" or "seeing," as the primary starting point.

This research was conducted in collaboration with the Creative Well Project of the Tokyo Metropolitan Foundation for History and Culture as part of the Agency for Cultural Affairs 2021 project to promote cultural and artistic activities in the individuals having disabilities (including the promotion of a symbiotic society through culture and the arts).

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Video Analysis of Educational Practices for Children Having Multiple Disabilities and/or who are Deafblind in Latin America and the Caribbean is Analyzed Through Films¹

Abstract

The purpose of this article is to contribute to the knowledge of the educational practices that promote learning in the children who have multiple disabilities and who are deafblind in Latin America and the Caribbean (LA&C) and to complement the observation tool with the new categories: Collaborative and Cooperative Teamwork with the Families and Community, Universal Design for Learning (UDL) and Play as a Teaching Resource. To accomplish this, filmed materials of professional

practices in formal and non-formal settings were analyzed following an action protocol. The determination of present indicators and of the ones emerging as a result of practical activities that are aimed to facilitate access to learning will be significant findings to improve those services that fail to identify the important educational processes in this population.

Keywords: multiple disabilities, deafblindness, inclusion, educational practices, learning.

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Introduction

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006) and the United Nations Sustainable Disability Goals 2030 (UNSDGs,

2015) marked a shift from a medical-biological perspective to a right-based one to give place to a paradigm based on dignity, freedom, and equality.

World Federation of the Deafblind (2021) affirms, “Children who are deafblind are up to 23 times less likely to be in school than typically developing children, and also less likely to be in school than children with other disabilities” (p. 31).

Hence, the research team wondered which educational practices have significant age-appropriate influence on children who have multiple disabilities and who are deafblind in LA&C as a way to help the dissemin-

nation of new experiences where they have not been identified yet.

To guarantee the right to education in all formal and non-formal environments, and promote quality educational paths, the goal of this article is to describe those practices that promote learning in children who have multiple disabilities and who are deafblind and to share the Buchanan protocol emerging new categories.

Methodology

Subject of study: children who have multiple disabilities and who are deafblind in the age between 6 and 12 years old in formal and non-formal settings in Spanish-speaking LA&C countries to be observed by video-films in actual teaching-learning situations, maximum 8 min.

The protocol to be followed was Operational Definitions of Best Practice UTAH (Buchanan, 2015). It was selected as the most appropriate, plus it experienced professionals' observations.

The categories are as follows:

- A: Communication intervener prepares a child for an activity;
- B: Communication intervener announces who is interacting and what will happen;
- C: Student is involved in the entire process of the activity;
- D: Communication intervener provides and uses special adaptation;
- E: Waiting time and consistent prompting;
- F: Activities useful in a variety of environments;
- G: Intervener models higher forms of communication;

- H: Student has multiple opportunities to communicate;
- I: There are opportunities for peer/sibling involvement;
- J: Communication intervener uses consistent cues;
- K: Communication intervener provides appropriate feedback;
- L: Communication intervener communicates the end of an activity;
- M: The activity develops concepts;
- N: Instructional planning;
- O: Professional practice/collaborations.

Fifteen of the total of 16 videos received from Argentina, Brazil, Dominican Republic, Ecuador, Guatemala, and Panama were used, since one didn't show educational practices.

The steps of the analysis were as follows:

- Observation of videos;
- Identification of categories;
- Analysis of video-films.

Outcome

The video-films were formed into groups according to the categories. The tables demonstrate the observed practices that facilitate learning. The term “Present” stands for the observable category, “Absent” – is

not applied, “Non observed” – sequence interruption, and the term “Mixed” stands for the categories “Present”, “Absent” or “Non observed”.

In the 1st group of 5 videos we observed:

Figure 1. References and categories studied in the 1st matched group

Reference	Categories
Present	A – C – F – M – O
Absent	G
Non observed	–
Mixed	B – D – E – H – I – J – K – L – N

Figure 2. Categories analyzed by video-film in the 1st matched group

Observable practices	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O
Video 4															
Video 6															
Video 7															
Video 10															
Video 15															

In the 2nd group of 5 video-films, we observed application of appropriate positioning and reasonable support, different environments, meaningful activities, and family participation.

Mixed: ways of presentation, adapted equipment, time, student's interest, family participation, use of signs, objects and movement, feedback, and announcement and attention to individual profiles.

Figure 3. References and categories analyzed in the 2nd matched group

References	Categories
Present	C – M
Absent	H – K – N
Non observed	
Mixed	A – B – D – E – F – G – I – J – K – L – M – O

Figure 4. Categories analyzed by video-film in the 2nd matched group

Observable practices	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O
Video 1															
Video 5															
Video 8															
Video 12															
Video 16															

Present: physical and verbal support and games.

Mixed: posters, autonomous drinking, support, association of names to photos, higher communication, signs and verbal communication, parents' guidance.

Figure 5. References and categories analyzed in the 3rd matched group

References	Categories
Present	G - H - O
Absent	B - D
Non observed	
Mixed	A - C - E - F - I - J - K - L - M - N

Figure 6. Categories analyzed by video-film in the 3rd matched group

Observable practices	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O
Video 2															
Video 3															
Video 14															

Present: natural gestures, choosing, teaching, higher communication.

Mixed: positioning, use of adhesives, verbal support, actual situations, interaction, listing, teacher confirmation, task end, matching, training of assistants.

Figure 7. References and categories analyzed in the 4th matched group

References	Categories
Present	C - D - E - F - G - H - J - K - M
Absent	-
Non observable	B - I - O
Mixed	A - L - N

Figure 8. Categories analyzed by video-film in the 4th matched group

Observable Practices	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O
Video 9															
Video 13															

Present: interaction, anticipation, support, appropriate activity, higher communication, options, consistency, appreciation, temporal concept.

Mixed: calendar, end, teacher preparation.

Discussion

All the programs apply the authors' theories: a student recognizes who they are interacting with and parents and siblings are involved. Besides, many services leave communication in the hands of a speech therapist.

In those programs the intervener uses anticipation and completion of activities, turn taking, waiting time, modeling of higher forms of communication and feedback practices according to the communication level of a student.

Waiting time is very important to encourage the processing of information by a student. Perhaps, for cultural aspects or lack of training it is not a universal practice. Governmental regulations on the contents to be developed in the educational programs and the duration of each class are likely to have influence on this issue.

Now, inclusion allows schools to be open to families, friends, and other members of the community. Adaptation facilitates com-

fort, predisposition, and participation in the classroom but sometimes the socioeconomic situation of the families, absence of public policies, and limited opportunities for training human resources hinder their use.

According to Jacob (2021), functional activities are now applied in different environments and so it will also be in the future.

Under the rehabilitation paradigm, the functional curriculum focused on the acquisition of habits. Modern approach allows a meaningful, more complex learning for life that covers different areas of the curriculum appropriate to chronological age.

Partial versus total participation are important indicators. Participation prevents the acquisition of erroneous or partial concepts while excessive support from adults limits full participation of students who feel dependent.

Teaching Planning and Professional Practice/ Collaboration require a proposal from a holistic point of view. In LA&C there is a lack of

human and material resources, and working as a team is essential.

We highly value the training of both family and community members to extend the school work to home and the community and vice versa.

Three new categories emerged during our analysis: Working with the Family in the Classroom Context, Universal Design for Learning, and Play as a Resource for Teaching.

- Collaborative work favors the transmission of what has been learnt at school to the home and vice versa;
- Some video-films show 3 Universal Design for Learning principles.

Principle 1: Music to start the day, following the student's interest and motivations, it helps the organization of mental schemes and anticipation.

Principle 2: A daily calendar with pictograms accompanied by gestures, conventional signs and verbal communication promotes the participation and achievement of skills to be able to function in other situations.

Principle 3: Respect to diversity;

- Participation in, exploration of, and interaction with the environment promotes motivation.

The categories pointed out by Buchanan (2015) are mostly present in the professional practices of the reporters in this study. These antecedents reaffirm the competencies that anyone who works in this field should have. We suggest the addition of 3 action points mentioned above to minimize the risks of exclusion of students who have multiple disabilities and who are deafblind.

Conclusions

The categories described by Buchanan (2015) are applied in a significant number of LA&C programs. Three others emerged: Working with the Family in the Classroom Context, Universal Design for Learning, and Play as a Resource for Teaching. They appeared in response to students' needs, interests, potentialities, and learning styles within formal and non-formal educational environments.

The data show which aspects require attention: career proposals should provide competencies, quality practices, and research. Permanent training is needed to update human resources (professionals, family, and

community). Public policies should favor the functional perspective, the organization of class schedules consistent with actual needs, and the provision of nursing services for medically fragile children, as well as cognitive, methodological, and sensory accessibility. Hence, we reaffirm the importance of interministerial cooperative work.

Finally, we recommend the inclusion of 3 new categories in Buchanan's (2015) protocol and their validation so that our regional practices facilitate learning and the studying of other categories to reduce the risks of exclusion and make significant changes in incipient educational programs.

The full version of this article is published on the website: <https://www.deafblindinternational.org/wp-content/uploads/2023/05/Full-Article-Video-analysis-through-films-ENG.pdf>

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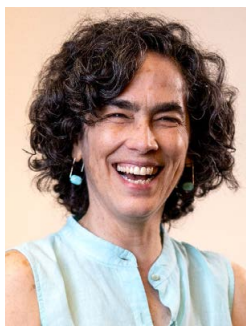
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Model School: Quality and Leadership in Education of the Individuals Having Vision Loss, Multiple Disabilities, and the Individuals who are Deafblind

Introduction

A Model School is a place of constant search for improvement, a leader in self-assessment and innovation, committed to the revision of practices based on each individual's demand. It is a school with social awareness as they see themselves as a school of reference and support, a training site, a model for other schools.

Educational access in Latin America is influenced by multiple factors, including each child's unique needs, availability of resources in their home communities and the local economy (Unicef, 2021). As a result, children, especially the ones having vision loss, multiple disabilities and/or the ones who are deafblind, often face significant barriers to accessing quality education. Additionally, education systems lack supports

that assure participation and learning and there is a shortage of teachers with adequate training to design and implement educational trajectories for the children having disabilities.

In this context, as well as considering Perkins School for the Blind's 30+ years of work in Latin America in collaboration with governments and civil society organizations, progress continues in elevating the educational oppor-

tunities for children and youth having vision loss, multiple disabilities and/or who are deafblind.

From 2019 to 2022, in Brazil, Argentina, and Mexico, Perkins developed its Model School concept, a replicable strategy that transforms education opportunities, access, and systems for the individuals having vision loss, multiple disabilities and/or who are deafblind. The same project included research that aimed to record the process of change in teachers and students from the participating schools.

This article collects the results and reflections on this experience in 9 schools. Of

these, 8 are public schools, and 1 is a non-profit school recognized by the government. Further, 3 of them are regular schools with inclusive programs, while the other 6 are special education schools. All 9 schools had the potential to become Model Schools due to their strong infrastructure and human resources, and promising practices noted by a Perkins representative during an initial observation session. Additionally, each school was staffed by enthusiastic teachers and administrators who wanted to learn, welcomed evaluations, training, and coaching, and were open to changing their practices in collaboration with education authorities.

Model of change: general approach

Perkins' Model School approach is fundamentally linked to the concepts of evolution and change. Now, more than ever, schools are asked for flexibility to incorporate social changes (Anijovich, 2007) such as recent heightened awareness around inclusion, diversity, equity, and access. The Model School concept of change relates to each school's responses to current societal, cultural, and community issues. It is individually defined and developed based on each school's unique needs, in context and in response to local conditions.

When put into practice, this Change Model contributes to deep understanding of the unique and varied experiences and internal cultures of different schools. Likewise, it identifies common ground, defining a process that cements the Model School concept as the central axis of change, to ensure a sustained improvement process. Model Schools follow Perkins' core principles on children and education. These are:

- All children can learn;
- All children communicate, and communication is connection;
- All children are unique, so educational plans must be individualized;
- The family/caregivers are essential in the education of children;

- Education should promote social relationships and quality interactions;
- Education should increase autonomy, promote collaboration and support, and be sustained in a pleasant context.

These principles guide our decision-making and actions, guaranteeing a consistent alignment with ongoing global changes in education and disability, and a model that adjusts to accommodate for diversity of cultures. Likewise, these principles promote universal actions for change, while also recognizing the importance of situations that are unique to a particular student or school. As a result, schools can define a unique educational style and method that obtains tangible results. This method recognizes the learning and communication potential of a student with DV/DM/SC from a perspective of the Convention on the Rights of Persons with Disabilities (CRPD), and proposes emancipatory practices for the student that incorporate families as part of the team.

The impact of Perkins' training and support of 9 schools in our project was evident in numerous ways. Changes were observed in the attitudes and values of the team members, in the appropriation of new knowledge resulting in shared best practices, and in the practitioners' reflections and resulting decisions about which actions to prioritize during the change process.

The schools went through the Perkins Quality Improvement Process for becoming Model Schools, which included:

- Selection of schools with the Secretaries and Ministries of Education or municipalities;
- Baseline and yearly evaluations using the Perkins Quality Indicators to score the school on a model program continuum;
- Perkins International Academy training of at least 3 professionals per school (an online or hybrid 3-level training of 120 hours per level);
- Increasing family engagement in their child's education by strengthening teach-

er/parent collaboration, training teachers to support the child's at-home learning, and coaching families on how to become active members of their child's educational team;

- A series of specific trainings based on teachers' needs, with follow-ups and mentorship from specialists in the field;
- The school's self-evaluation using the Perkins indicators, identification of areas in need of improvement, and strategy sessions to map out ways to improve these areas;
- Information exchanges with schools from the same country and among schools from other countries participating in the study.

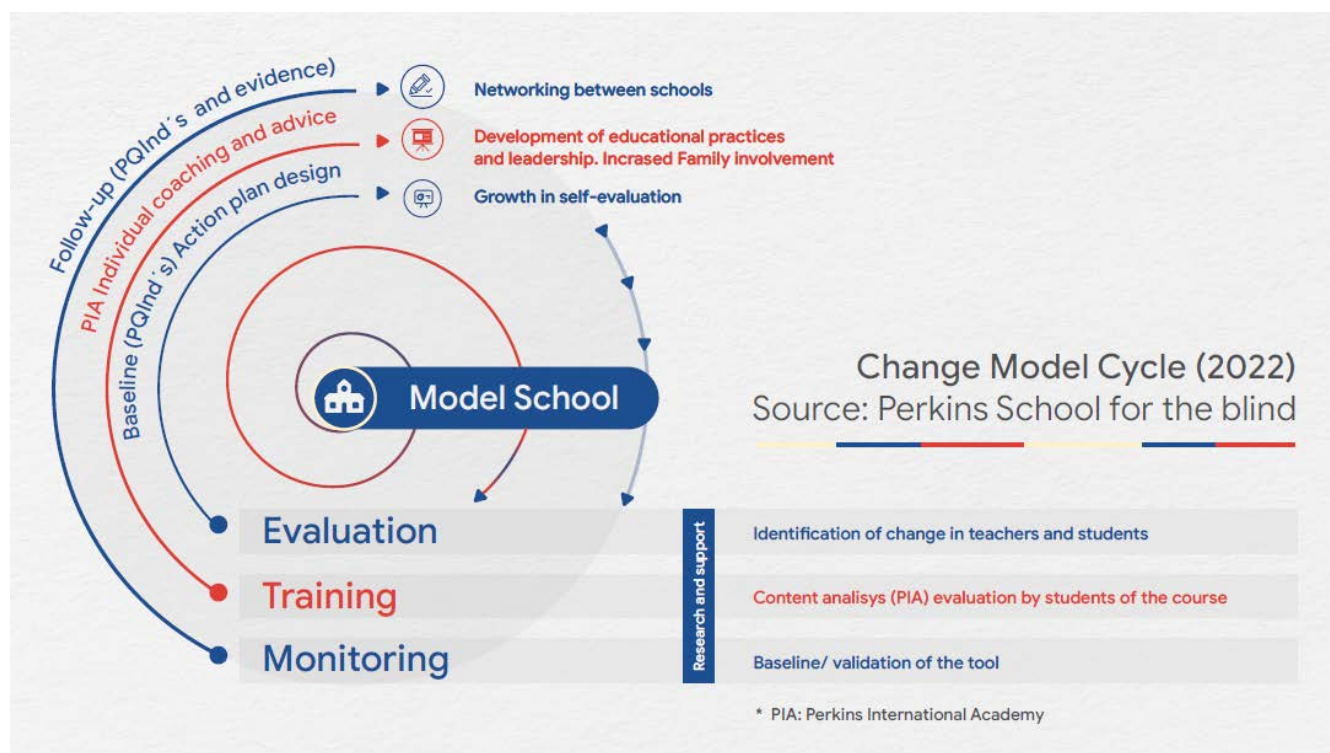


Figure 3. Change Model Cycle (2022). Source: Perkins School for the Blind

Perkins supported the school teams by providing specific training on educating people with DV/DM/SC so that team members could actively participate in the change process. Though this process varied to some extent among the individual schools, it also had shared points that clearly define common stages of change, ranging from simple to complex.

At each stage, the change process started with a member of the educational commu-

nity taking the initiative for improvement in response to training. These stages are:

- Changes in concrete actions, focused on generating alternative actions to improve teaching processes. The actions arise from a diagnostic evaluation process with an objective tool. This results in identification of the school's needs and priorities, with the goal of achieving immediate improvement;

- Changes from shared reflections on student learning processes, defining collective goals, and growing in the autonomy of improvement processes;
- Innovative changes and projections, characterized by the school's conversion into an educational community that promotes the practice of unbiased self-evaluation and constant study to seek and nurture innovation, so that the search for new approaches becomes the norm and not the exception.

In practice, those responsible for the implementation of this Change Model branched into new roles and responsibilities and revealed the diverse work contexts of each school and the extent of their impact.

In 2022, Martins Bruno, P.R., Manager of Special Education, Tocantins, Brazil, said,

The training with the entire team of the School Unit and the greater dialogue with the families of the students was a strength achieved...this also allowed the multiplication of the training for the teachers of the State Network...what Escola Beira Rio received through Perkins, impacted not only the school, but the entire local society in the area of health, for medical referrals and social assistance with the active search program for students who didn't attend the school...we are a school that is working on the vision beyond the walls and fulfilling its social role.

Concrete actions allow transformations that give an immediate response to the students' educational needs, and this inspires other team members to get involved in a process that initially may only seem relevant to a smaller portion of the professional team.

In 2022, Poplar M., Teacher at Arena Institute of Special Education, Cordoba, Argentina, said,

Being able to make a relationship between behavior and communication helped the entire team of professionals to reflect on ways to address certain challenging and disruptive behaviors...particular situations aroused interest in learning about adjustments that were made in the classroom so that our students can access the information and interact socially.

The coordinated work of the teams grew according to each school's individual rhythm and pace, defining roles and responsibilities, which transformed the way student needs of varying levels are responded to and met.

Vargas Lopez, S.L (2022), Director of the Multiple Attention Center, Morelos, Mexico, said,

The increasingly transdisciplinary work, where the look of the student is shared by all the members of the team. It has made it possible to individualize the attention to all our students at all levels to a greater extent. The work plans...in collaborative construction, more directed to the interests of the students, allowed to apply at all times the spiral learning that is so necessary for students having disabilities...The transformation of the classroom spaces little by little unified the work strategies...

Accompanying this process of change towards the formation of Model Schools has expanded our knowledge about the scope of the schools' achievements and has also allowed for clarification of Perkins' Change Model. The latter allows us to support schools in creating an effective work plan with shared values and principles, and to intensely monitor and evaluate implementation plans. These evaluations reveal the quantity and intensity of change, and the development of leaders who can reach more and more students.

Conclusion. Model schools as the central axis of change

In practice, the Model Schools were defining a process of change, combining cultural and organizational dimensions in a diversity of Latin American settings. After 4 years of

study, we can say that the Model School is an organization committed to flexible and dynamic transformation. The ongoing quest for improvement is the Model School's cen-

tral quality and this translates to a state of constant revision and change. The Model School does not aspire to reach a definitive state or goal, but rather is continuously evolving and searching for enhancement.

The leadership that this concept proposes and that each school develops is linked to classroom management, as well as to institutional management, where the characteristics of the services, the actions of teachers and managers, and the participation of the family are understood.

Guaranteeing equal opportunities requires working towards broad recognition of inclusion as a basic human right. Improving the educational environment for students with DV/DM/SC means maintaining an attitude of ongoing monitoring and self-reflection, and implementing practices that promote student autonomy and independence. Forming teams of professionals trained in developing communication and participation plans for the individuals with DV/DM/SC and their families is a key part of this work.

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International Training Program on Deafblindness Had its Kick-Off in Zambia and Malawi

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**KENNETH
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On November 17, 2022, 24 excited African teachers and lecturers experienced the kick-off of an International Training Program on Deafblindness in Malawi and Zambia. The teachers had been selected from a larger group of 47 African applicants. The aims of the training program are twofold: 1) to support teachers and lecturers in Zambia and Malawi to develop professional expertise in educating learners who are deafblind, and 2) to support these teachers and lecturers in enhancing their academic skills.

The international training program on deafblindness is a collaboration between the Signo Foundation in Norway, the University of Groningen (UoG) in the Netherlands, Chisombezi Deafblind Center in Malawi, and Bauleni Special Needs Project in Zambia. Lecturers who are trained in the program come from Zambia Institute of Special Education, Montfort Special Needs Education College of Malawi, and the Catholic University of Malawi. Additionally, resourceful participants from organizations of the deafblind such as Deafblind Association of Zambia are included.

During the program, 12 full-day seminars are provided in each of the 2 African countries. The topics

addressed in the seminars are diverse and include categories and etiologies of deafblindness, the impact of deafblindness on interaction, communication and language, theory on (sign) language and concept development, outdoor activities, meaning-making, fundamental psychological theories, research methods, cultural awareness, and academic writing. During the seminars, participants gather in groups in each country to follow 3 parts of the seminar: 1) group discussion on articles and book chapters which have been distributed prior to the seminar by the lecturer, 2) a lecture provided through Zoom, 3) group discussion and group video-analysis after the lecture.

EXCHANGE OF EXPERIENCE

The lectures are provided by a diverse group of lecturers, involving project leader Kenneth Verngaard of Signo, and lecturers of the International Master program on deafblindness at the UoG in the Netherlands: Bebbie van den Bogaerde, Joe Gibson, Paul Hart, Jude Nicholas, and Saskia Damen. Alette Arendshorst, who is an internationalisation officer of the UoG, and Marianne Rorije and Kim Tosolini, who are two PhD students of the UoG, are also involved in lecturing. In addition, supervision during the group discussion is provided by several African graduates of the Master program on deafblindness at the UoG: Cosmas Goliati, Sr. Emma Kulombe, Douglas Gawani, Hellen Shakele, and Simate Simate.

The teachers and lecturers who take part in the program reported that the knowledge they have gained through the program will help them interact and communicate with the children who are deafblind and follow up and advise their families. The lecturers reported that now they have the knowledge and confidence to teach students in a 3-year diploma program in deafblindness offered in both Malawi and Zambia. A teacher says, "As a teacher, I will pay particular attention to the attachment theory in relation to the interactions and communication with the learners

who are deafblind as well as expose them to outdoor life activities to enhance environmental experiences." Another teacher explains that the new knowledge gained will help her improve meaningful communication with the learners who are deafblind. Participants also say that the training will help them deliver powerful advocacy messages to promote the rights of the individuals who are deafblind in these 2 countries. Some of the lecturers also explain that they feel that the seminars on quantitative and qualitative social research methods will strengthen research on the situation of the individuals who are deafblind as they are now better prepared to both conduct their own research and to support their students to do the same.

After the 12 full-day seminars, 2 of the most talented lecturers from Malawi and Zambia will be able to receive financial support from Signo that enables them to apply for a 1-year international Master program in deafblindness in the Netherlands.

For more information on the Master program in deafblindness see [Deafblindness | Pedagogische wetenschappen | Rijksuniversiteit Groningen \(rug.nl\)](#) or mail s.damen@rug.nl



Online international training



Group photo of participants from Zambia



Jude Nicholas zoom lecture for Zambians



Group photo of participants from Zambia project leader Kenneth Verngaard

Tactile Working Memory Scale at Perkins

[Tactile Working Memory Scale](#) (TWMS) is an assessment and intervention tool for the individuals having congenital deafblindness (CDB). It is published by the Nordic Welfare Centre (NVC) and written by Jude Nicholas, Annika Johannessen, and Trees van Nunen. The co-authors are members of the Cognition Network at NVC.

This dynamic collaborative assessment tool evaluates perceptual, cognitive, and social cognitive tactile working memory skills. The scoring sheet is divided into 3 processing domains: Encode (detection and initial interpretation), Maintain (temporarily retaining), and Manipulate (actively controlling attention). Twenty items can be scored as present, emerging, absent or not applicable. After implementation of suggested intervention strategies, the team re-assesses the skills.

The authors provided TWMS supervisory training to give participants the ability to conduct TWMS assessments. Activities in this training included 2 online interactive webinars plus 3 days of face-to-face training at NVC. Participants were expected to

present an assessment case, which is the focus of this paper.



Figure 1. Yandi and Sara share tactile attention

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Background and TWMS experience

Chris and Bernadette have a considerable background in tactile reciprocal interaction and video analysis. Bernadette has been a trainer and coach in her Deafblind Interaction Program in the Netherlands and brought this training to Chris when he was a

consultant at the Texas Deafblind Project.

In May, 2022, Chris joined the initiative as a TWMS trainee. He was collaborating with Bernadette throughout the process. In July, 2022, Chris moved to Perkins and

gathered a team for the TWMS process. Two

months later he received a TWMS assignment.

Phase 1

A typical team conducting a TWMS assessment includes a student who is deafblind and those directly involved with them. Chris also decided to engage the Deafblind Program's leadership team in the process. The case study student, Yandi, is an 8-year-old boy with some light perception in one eye, wears a BAHA and loves movement activities. At

our 1st meeting with the team, we introduced the TWMS. We reviewed 15 videos of Yandi and his teachers in a variety of settings. At the 2nd meeting, we employed a video analysis process which led the team to discover questions about Yandi's tactile-bodily expressions.

Phase 2

Using videos and team reflections, we conducted the assessment and scored the results. Yandi's scores had an erratic distribu-

tion across the domains. (Figure 1.) Among the TWMS trainees at NVC, this was a common experience.

Yandi – TWMS Score Sheet

DOMAINS	Encode						Maintain						Manipulate							
Present (P)	×	×	×	×			×				×				×	×				
Emergent (E)					×	×		×												
Absent (A)									×	×		×	×	×			×	×	×	×
N/A																				
Items	1	2	3	5	6	8	4	7	10	11	12	15	16	9	13	14	17	18	19	20
BEHAVIORAL DESCRIPTIONS	Tactile focused attention	Object manipulation (ventral stream function)	Tactile object identification (ventral stream function)	Tactile object location (dorsal stream function)	Spatial navigation (dorsal stream function)	Social Working Memory: person oriented	Tactile object recognition (ventral stream function)	Tactile spatial recognition (dorsal stream function)	Social Working Memory: mutual & joint attention	Social Working Memory: retaining social info	Tactile sustained attention	Sustained attention: interaction-time	Selective attention: interaction-novel condition	Social Working Memory: emotion-perception	Tactile selective attention	Attentional switching	Attentional switching: interaction-topic change	Attention manipulation: long-term working memory strategies	Attention manipulation: maintenance cognitive strategies	Attention manipulation: metacognitive strategies

Figure 2. Yandi's TWMS scoring sheet

Bernadette created a follow-up scoring sheet, that was separating physical and social scoring items. Yandi excelled at tactile working memory skills related to objects

with emerging skills related to spatial navigation. In interactions with others, he showed mostly absent skills. (Figure 2.)

TWMS Scoring Sheet: Physical Environment

Domain	Activities and Tasks: Objects and Spatial Navigation/Location									
Present	X	X	X	X	X			X	X	X
Emergent						X	X			
Absent										
Items	1	2	3	4	5	6	7	12	13	14

TWMS Scoring Sheet: Social Environment

Domain	Interpersonal Interactions									
Present										
Emergent	X									
Absent		X	X	X	X	X	X	X	X	X
Items	8	9	10	11	15	16	17	18	19	20

Figure 3. New scoring sheet shows scores separated into physical and social environments

After reaching agreement on scoring results with our team, they expressed a need

for support in tactile reciprocal interaction strategies.

Phase 3

Our first intervention focused on our team's shifting to the tactile-bodily perspective. We used the movie and reflection exercises of Landscape of Touch (Van den Tillaart, Vege, Miles, & Hart, 2014). This was not mentioned as an intervention strategy in the TWMS manual.

It was followed by our next intervention: the social cognitive strategies of noticing, recognizing, and affirming Yandi's tactile-bodily initiatives. A process of video analysis and in-person coaching in the classroom was still ongoing when our formal TWMS training with NVC concluded. Ongoing intervention and re-assessment will continue.

Reflections and discussion Quality of TWMS

TWMS is an exceptional tool that looks at a critical aspect of learning for a CDB student.

The training model used by the developers is sound.

New additional scoring sheet: physical versus social environment

We feel that the additional scoring sheet we developed was extremely beneficial. We be-

lieve that others might find it a useful complement to the TWMS.

New intervention strategy: shift to tactile-bodily perspective

Our team needed this support before we could start coaching other intervention strategies. We feel that this intervention

strategy may be beneficial for other TWMS teams as well.

Prerequisite for the TWMS training

To achieve a valid result on the TWMS and implement effective interventions, we believe assessors should be well-versed in the use

of tactile reciprocal interactions. Therefore, it may be beneficial to verify these skills before participating in the TWMS training.

Need for interaction training

Basic tactile reciprocal interaction strategies for working with the individuals having congenital deafblindness may not necessarily be a part of the knowledge base of most teachers in the United States. Given the

number of the individuals having congenital deafblindness in the US, we question how a sufficient cadre of professionals skilled in dialogical tactile reciprocal interaction can be developed.

Future plans at Perkins

We envision the TWMS becoming an integral part of the Perkins Deafblind Program. We are exploring how to effectively include TWMS as a cognitive evaluation to guide student's IEP goals and intervention strategies. We also hope to continue our professional development for dialogical reciprocal interaction strategies as a foundation for the (cognitive) development of our students.

Our goals in terms of collaboration with the others in the field of education of the individuals who are deafblind includes helping to

raise awareness of TWMS, collaborating with the authors to possibly expand the cohort of assessors, and develop a train-the-trainer program in the US.

Finally, based on our experience, we determined that assessors and all participants of the TWMS process need training in tactile reciprocal interactions. Although ambitious, our hope is to share interaction training, currently taking place for Perkins staff, with the others in the US.

Conclusion

The TWMS training was an enriching experience for the student, the team, and for us as assessors. TWMS supports cognitive development, and therefore holds the po-

tential for becoming a standard tool in our Deafblind Program at Perkins School for the Blind and in the field of education of the individuals who are deafblind.

German-Speaking Countries Establish a Professional Training to Become a Competent Communication Partner for the Individuals Having Congenital Deafblindness or Similar Needs

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The Co-Creating Communication booklet published by Anne Nafstad and Inger Rodbroe in 1999 initiated a far-reaching change in European deafblind education and expanded the self-image of the teacher or companion of an individual having congenital deafblindness to his partner.

Since the publication of 4 Communication and Congenital Deafblindness¹ booklets by the DBI Communication Network, the question of how the concepts contained therein – which are fundamental for deafblind education – could be communicated more effectively to the circle of supporters of the individuals who are deafblind has been becoming more and more urgent in the German-speaking countries.

Only by reading and individual examination of the theoretical contents, transition to the practical work seemed to be difficult. An exchange of knowledge and insights in groups and the willingness to rethink one's own practice by

means of video analysis seemed to be a promising way.

Under the guidance of Prof. Dr. Andrea Wanka, a project on the Professionalization of Pedagogical Concepts through the Development of a Qualification Program in the European Deafblind System, PropäK EQuaT for short, was finally launched and funded by the EU (Erasmus+ Strategic Partnerships, 2015–2018). Colleagues from Germany, Austria, Switzerland, the Netherlands, and Denmark were involved in this process.

In course of this project, a manual with the focus on communication and congenital deafblindness was

¹ German edition of the Booklets, 2014, Bentheim Würzburg.

developed in 2018 as the grounds for staff training, based on the theoretical concepts and thoughts of 4 booklets and the later publication of Communicative Relations by A. Nafstad and I. Rødbroe¹.

Participants of these trainings are expected to become competent partners in the communication development of the individuals having congenital deafblindness or similar needs in communication or to enhance their already existing competencies in this area.

The manual serves as a kind of a treasure chest, i.e. it represents a collection of ideas and suggestions for the implementation of the training units and shows possibilities for conveying specific content. However, it leaves it up to the instructors to decide how to convey the individual topics to the group. Accordingly, the content and methods described are primarily of an advisory nature. In this way, the level of the entire qualification can be adapted to the needs and individual questions of the participants.

The managements of the AGTB (Deafblind Workshop) in Germany, the ÖHTB in Austria and the Tanne in Switzerland support and promote the implementation of 120-working-hours training program.

In the meantime, the 2nd pilot run of the staff training program is taking place with 16 participants from the countries mentioned.

The participants can deepen their knowledge, reflect on their behavior and draw conclusions for their future actions within various training forms: on-site days, personal transfer time, educational partnership meetings, online sharing (a clearly expanding element as a result of Covid effects). And it always comes with the inclusion of their own or exemplary video excerpts. During the training phase of 14 months, they present their personal development and learning progress to each

other and to interested colleagues at a so-called learning congress.

The feedback so far has been consistently positive and successes appear to be lasting. The establishment of learning partnerships, where participants freely come together in relation to a thematic focus in order to exchange questions, insights, and suggestions with each other, has proven to be particularly favorable. In this way, networks are created across various deafblind centers in German-speaking countries. In order to consolidate the network and to enable a continuous exchange and gain in professionalism, it is planned to organize a seminar day every 2–3 years, which will take up and deepen a topic chosen by the training graduates.

The on-site days take place at different locations of institutions for and with the participation of the individuals who are deafblind in German-speaking countries. During the 3-day meetings, thematic aspects are dealt with theoretically, if possible deepened in self-awareness rounds and practiced in tasks with a high practical relevance, including video evaluation.

Transferring thematic contents to the individuals with similar needs² additionally forms an essential focus of its own. It is evident that the proportion of this group of individuals, in addition to the individuals who are deafblind, is constantly growing and therefore urgently needs to be taken into account in practical support concepts.

Outside of the on-site days the participants are asked to work with the concepts of communication development within their field of activities and to make a personal transfer of what they have learnt into their field of practice related to the children or adults who are deafblind and/or have similar needs.

At the end of the training, the participants present their findings on a topic chosen at their own discretion at the learning con-

1 German edition of the Kommunikative Beziehungen, 2018, Bentheim Würzburg.

2 This group includes the individuals who, in addition to hearing or visual impairment, have cognitive development disorders or special needs in the area of communication due to physical and motor impairments.

gress. And here they are given a great deal of personal creativity freedom.

The individual results presented after the first pilot implementation and the wide

range of creative implementation left lasting impressions on both the graduates and the teachers and visibly fulfilled the expectations placed in the employee training program.

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First Ever Trek by Deafblind Delegates from India in Nepal – a Unique Adventure

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History was created when a unique group of individuals who are deafblind went for trekking in Nepal from India. This has never happened before where a determined group of the individuals who are deafblind decided to travel to another country to take up the challenge and showcase to the world that they can also do it!



Group photo of the delegates

This interesting activity was organized by Sense International India in collaboration with National Federation of the Deaf Nepal (NDFN) and was supported by Nelumbo Foundation.

Deafblindness is a condition in which 2 of the major senses re-

quired for learning and development of an individual are affected in varying degree. This affects the communication and daily living activities. Receiving and processing information also becomes challenging.



Group photo of the delegates

From February 23 to March 5, 2023, 9 adults who are deafblind from India went to Nepal under an international exchange visit supported by Nelumbo Foundation along with their caregiver. During the 11-day visit, they met the members of Deafblind Association of Nepal (DAN) at their office in Pokhara with all caution and safety measures in place.

The journey started with the group of 8 individuals who are deafblind (3 females and 5 males) that gathered from all the regions of India and assembled in Delhi on February 23, 2023 for their flight to Kathmandu.



Participants during the trek



Participants posing on the view point

■ EXCHANGE OF EXPERIENCE

After landing in Kathmandu, they travelled to Pokhara next day by 8-hour long bus ride. After their meeting with representatives of Deafblind Association of Nepal in Pokhara they went for the 4-day and 3-night trek (Pokhara-Ghandruk-Chemrukh-Landruk-Pokhara).

The group was led by Ms. Shrutilata Singh from Sense International India. As the Networks Support specialist, she coordinates the activities of Udaan, the National Network of the adults who are deafblind where more than 250 of them are registered. Udaan members engage in regular activities to become independent in decision-making and important life skills. Sense International India works with the individuals who are deafblind and their family members

throughout India providing them the platforms to exchange information and advocate for their rights.

Altogether, 30 youth who are deafblind and 20 interpreters along with a guide from India and Nepal went for this 5-day trek including 2-day travel to and from Pokhara. Their efforts showcased their ability, sending out the message that environment and cultural life shall be for everybody and that the barrier shall be removed.

During the trek, the group was walking 5-7 hours per day. Their selection was made considering their fitness level and degree of disability. Also, an easy trek was chosen for this very first initiative. But now the group is ready to take up more challenging treks in future.

For more details, please contact info@senseintindia.org



In our Family the Word Blindness was Forbidden!

Natalia Demianenko about the ability to touch vividness, a trace she wants to leave behind, and why her life isn't a medical record.

**VLADIMIR
KORKUNOV**

Among the people who are deaf-blind, there are only few of those who, as Natalia Demianenko, can surround you with warm words. And in an instant, you feel comfortable as if you were talking to a person who you have always known. You aren't interacting with a person who is deafblind, you are interacting with a person. The limitations and particularities get forgotten at once. Herewith, the destiny wasn't kind to Natalia. It didn't stop at taking her vision and hearing away, but also seated her in a wheelchair. So how did Natalia Demianenko manage to remain optimistic and maintain positive attitude to life? Where does she have so much emotional warmth from?

And desire to explore something new, to conquer the unknown: whether these are countries or different sports. During this interview preparation, Natalia has flown in a wind tunnel. Right! If you can't walk, then fly and surmount the hurdles! Later on, she wrote about it, "Now I know what is it to soar. It was as if I became the air flow myself and joined the speechless but animated conversation of a hundred of winds". Our conversation, of course, wasn't the one of winds, but it also contains much freedom, conventionalities overcoming and miraculous beauty of the soul of my wonderful interlocutor.



Natalia, in the essay about yourself you have written that you wouldn't like your story to turn into a medical record. It seems to me, that this is a problem of the individuals with disabilities in general. Sadly, people pay attention to what is in evidence. What can one do to make people see a person rather than everything else?

Hearing of, reading about an individual with challenges that they could become the same as the others notwithstanding the fact of being an individual with disabilities I always contract. Looks like a person has made much effort just to fly under the radar. When I think of it, Watches by Sergei Lukyanenko always call to memory. A person is born as other, with certain capabilities. Herewith, whether they take light or dark side depends on their personal traits: ambitiousness, selfishness or propensity for altruism instead and so on. I guess, it is quite the same with us. At some point, I realized that I would never be as everyone else. Well, that's how my life is. Then I have to stand out of people not because of something that arouses compassion and grief but something that will bring joy and

make a positive contribution. For that purpose, I have to find what I'm good at. Find and try to be even better at it in order to wish to share it, amaze the world in a positive way. And also I think that an individual with disabilities, especially with visual impairment, should pay much attention to appearance. Willing or not, surrounding people can see us, and the first impressions are always made by proverbial clothes. In the ideal case, the very same clothes as well as the hairdo and other appearance details that depend on us should attract, generate sympathy and respect instead of a wish to cry alongside.

However, the medical record can't be omitted. Because it is a part of your personal history after all. Were you born without any challenges? How did it happen that you started to lose your vision?

Yes, I was born without any challenges. When I was 10 months old I started to walk. When I was a year and 9 months old I took a cold. Mother did inhalation for me. My sister was half a year old in those times. She began crying, mother ran to her, and I dropped a pot with hot water on my foot. All sole was burnt. The ambulance arrived, I got tetanic anatoxin vaccination and they left. A few hours later, I started to lose consciousness. We called ambulance again and they took me to the hospital. And there I got one more tetanus vaccination. They sent me to the infectious disease ward because of the cold. Mother couldn't stay with me, because she had to be with Tamara, my sister. Three months before this episode, father left us. Of course, I personally don't remember it. I dread to think of what my mother, being 21 years old, felt.

In hospital, my foot went septic. The doctor warned my mother that I would be limping unless they do surgery and transplant skin from my hip to the foot. Mother agreed.

After the hospital, mother and grandmother weren't noticing anything for a while. Then, little by little, they started paying attention that I was bumping into objects and wasn't reacting to visual stimuli. They thought these were intellectual disabilities. But later, the doctor told them that I was losing my vision. And after that, during the examinations

in the hospital, they decided that general anesthesia and double vaccination initiated negative processes in my organism. Even at that time the doctors told that, probably, it wouldn't be limited to the vision loss. But, you know, I still don't have an official diagnosis...

What is the most difficult about having vision loss? What is lacking most of all?

The most difficult thing is dependence. I think, that vision loss makes this element of discomfort related to disability the most considerable. Go somewhere on your own, cook something – things that an individual without vision loss doesn't even have on their mind, for an individual with vision loss might be a real challenge that can't be overcome in a single go. I've got a recent example. We're doing pickled products for winter. I need to weigh, but I can't. It's a trifle, but it's noticeable.

And one more important peculiarity. The world is beautiful. It's clear even by sense of touch. Take for example a regular leaf, let it be a birch leaf. Each vein is drawn gently and the edges are carved as if someone has been working on them with a magnifying glass. And what if we take something more complicate, a rose, for instance? Each super-fine and very delicate rose petal, they are all fitted up in such a graceful cup. You explore it with your fingers and it takes your breath away. What impression might be when you see it! I don't even talk of a living being, especially of a human body. Everything is beautiful in it. That's what I'd wish, this beauty. I feel much lack of it. Talking about architecture, I can't picture it to myself at all. I just know that it's beautiful. Being an individual who has lost vision early, I can imagine it only in parts, but not the overall pattern of a temple, palace...

Let's remember of the times when you attended a special nursery school. How did you feel there? Did you manage to make new friends? What skills did you learn? What did you play with?

When I started to attend the special nursery school, mother got a job there. She made it to graduate from a secondary medical school. She learnt to be a maternity nurse.



When I lost vision and it became clear that I would have to attend a special nursery school, mother received qualification of an eye nurse. I remember walking out to the nursery school hall with our group and myself expecting to see my mother. But the vision was almost lost, so the same situation occurred again and again. A person in white passes by, I come for them crying, "Mum!". At times, to considerable embarrassment of both the one I put down for mother and mine.

At first, mother sent me to the group for visually impaired. It was rough. Everything was oriented to visual perception. I already couldn't draw, couldn't see pictures. In a pre-school group I was transferred to the children having vision loss. Some of them had little remaining of vision. Later, I asked my mother, why didn't she send me to the group of children with vision loss at the very beginning. Mother told, "Do you think it is easy to admit to yourself that your child can't see at all?"

Main pleasant memories are related to this group. Teachers used to read for us a lot.



We played with construction sets, with mosaic. I loved to play with mosaic a lot. A soft carpet stuck in memory. You had to take off your slippers before stepping on it. There was a playground on that carpet. You can run about and fall as much as you like. I and 2 of my girlfriends liked to play role games with the dolls. On the same carpet, in the corner, there were a small chair, a small table and a bowl with toy cookies in it. As far as I understand, those cookies were edible, but

they were very salty and maybe even peppered so the children wouldn't make use of them as intended. But we were very excited about biting a cookie while the teacher didn't see us. I made friends exactly in that group. The world is a small place, and the world of the individuals with vision loss is all the more small. That's why I entered the same school and the same class with a girl named Masha and a boy named Seryozha. A girl named Vika, having little remaining of vision, went to another school, but she has been telling hello through common acquaintances for many years.

You were finishing school at home. Moreover, on a wheelchair. How did it happen that you moved into it? You must have been an excellent pupil at school!

Oh, no! I wasn't an excellent pupil at all! Do I make an impression of a nerd? (Smiles.) But you know, I still have the same nightmare. Only 5 minutes left till geography class, and I haven't only failed to start getting prepared for it, but also wasn't even going to do it. I anxiously open the textbook and clearly realize that I don't have a chance to learn anything in time. I don't know, why is it exactly geography, I have a solid B in it, although I've got zero point zero of knowledge left. The subject I didn't like, didn't know and wasn't even trying to change something in this direction is math. Straight from the times when we started to learn numbers and till the high school it didn't excite me at all. What I liked and was good at were literature, Russian, and history. In a secondary school certificate, I've got A also in astronomy...

I've been studying at school till the 8th grade. Straight before the New Year's party, for which I was getting ready a lot, the temperature raised. It turned out that I had furunculosis. And it was that bad that I got to the hospital. They had to do surgery. Mother was trying hard to get across to the doctor that they couldn't do general anesthesia. He replied that anesthesia dose was so insignificant that it couldn't harm at all. But after the surgery I couldn't walk independently anymore. Psychologically, it was very hard to sit on a wheelchair. When mother and grandmother were starting to talk about it, I was just beginning to chin. My uncle persuaded

me. He told, "You have always been independent. And now you depend on the others. Don't you want at least to go for a walk on your own?" I realized, that I wanted it a lot. Exactly on my own. Then I sat on a wheelchair and has walked around Petergof alone for the first time. At the beginning, my hands were getting rubbed to bleeding. And I was often falling. Although the district was familiar, it turned out that not everything, accessible while you are walking, is accessible when you are on a bulky wheelchair. Sometimes, I was getting lost literary in 2 metres. For example, I failed to make correct estimations, missed the turn and stopped understanding where I am. It happened to me, I got into a muddle in the street. I heard that someone was passing by. I asked if the Aleksandria park was far from there. And a woman answered in a disgruntled voice, "Don't you see? In front of you it's written Aleksandria Park. What else do you need?" But for me these walks meant a lot. Unfortunately, they ended up when we moved from Petergof. Our country house is in another place now. And here I didn't manage to orient myself as I'd like to, although I have been trying to at the beginning.

Excuse me, one more complicated question. In the age of 20 you started to lose hearing. If we turn to that time, what did you feel? How did you come through this circle closing from all sides?

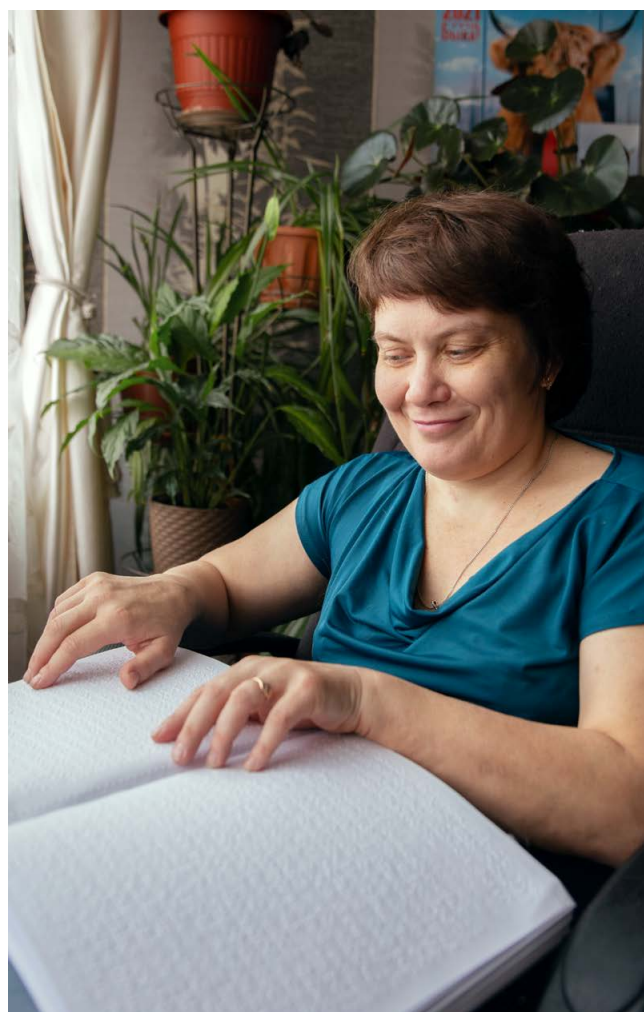
I've been thinking of it, but not during the time I was losing my hearing. Significantly later, when I was writing something like autobiographic story. I have an impression that destiny is continually trying to calm me down. If having lost your vision you can't live serenely and you stick neck out, then get seated on a wheelchair. If you haven't calmed down again, try to live with a hearing loss.

Or maybe, it's the opposite. Loss of sensory capabilities invokes to look at yourself, give thought to your life, and maybe, tell something to the others.

Losing hearing was hard. It is the only thing I still can't put up with. At that time everything depended on hearing. I was talking by phone, listening to audiobooks, playing the guitar. At first, it seemed to my family, and

to me indeed, that I was just inattentive. That I mused, didn't pay attention to what someone was telling me. By the way, I had appointments at otolaryngologist. They were insistently telling that I had perfect hearing. After that it was almost coming to a scandal at home. Mother was often telling that I was ignoring her for purpose. Then I stopped hearing TV and recorder at habitual volume of sound and was constantly asking those around to repeat what was said. And the most difficult part, I was losing possibility to communicate by phone. If previously friends' calls were making me happy, at some point I realized that I started to be afraid of them. Then, doctors admitted hearing loss. And they couldn't find any hearing aid that would fit.

At that time, I began to hold active correspondence in Braille, and later on I got a computer.



And what about education? What higher education did you receive? And how was the process organized? As far as I understand, it was distance learning?

You can't imagine how I want to coquet and tell lies now. To tell that yes, it was hard, but I'm allegedly so strong and extremely good and coped with all the problems. In fact, it was in a way that the memories of it still hurt... I managed to get a refreshable Braille display with the help of a musician, composer, and music expert who had vision loss and was living in Italy at that time. His name for Vladimir Kallistov. When he was in Russia, he came to our house, helped to configure the display, taught me how to use it. He was texting me in the display entry. Before him, everybody in Saint Petersburg refused to do it. They just didn't know how to do it. So I learnt how to use email and started to hold correspondence with Vladimir Kallistov. He floated me an idea of higher education. I began to search for distance higher education institution. I found the Institute of Open Education at Moscow State University of Printing Arts. They have many different faculties, and I wanted to enter the Faculty of Journalism, Publishing and Editing Department. The education was fee-based, but the price was affordable. Thirty thousand Roubles per year. The exam was in the form of e-testing. The worst grade I received was in Russian. But I passed it. Entered the university. Then I wrote to Vladimir Kallistov. He called my mother and was just crying, he was very touched.

The studies were rough. Even though I was studying all the time. First of all, computer skills were missing. I didn't know how to reformat textbooks and my Microsoft Word skills couldn't be worse. What do you think about such a situation, for instance? I was doing my term project in the topic of The Picture of Dorian Gray. We needed to do it of a specific length. I selected the text to see the number of characters. I checked the number and got curious what would be if I pressed Space button. Will the number change? I pressed it. Well, you know, what happened next, don't you? Now, if I did such a thing, I would immediately undo the command or just wouldn't save the file. But at that time I was crying for a long time and

began rewriting the whole thing... Another difficulty resided in lack of help. Mother was working, grandmother had passed away, sisters had babies. I could count only on myself.

The program included progress tutorials with the teachers in a discussion group. At first, I took it seriously, I was preparing question, but at the scheduled time none of the teachers joined the discussion group... My paperwork was checked only once. The others were just vanishing into thin air. At the end of the 2nd year I was getting ready for an e-exam in printing industry. Having opened the list of question, I realized that they weren't anyhow connected to what I had studied. That's when I gave it up and decided to leave.

Honestly, I regret now. Not because of knowledge, but because of the status. Anyway, having higher education sounds great. Moreover, having completed the 1st year I received a letter from Vladimir Kallistov. He wrote that he had cancer and wouldn't live long. I often flash back to his words. He wrote, that getting acquainted to me and his participation in my learning of computer were, probably, the major events in his life. And that he was happy to leave knowing that he had done it. He was beseeching me to acquire the higher education and approve myself in this life. I feel sad, because in terms of education I didn't justify the confidence of this incredibly big man, whom I respected a lot...

I can't also say that it was a bad idea to enter the university. Exactly at that time, Natalia Kremnyova offered me a job in the editorial board of Your Interlocutor magazine in order to get some practical skills. It had an incredible effect on my life and changed it for the better.

Did you meet your husband Vladislav at that period or later?

I met Vladislav earlier. We started to communicate in 2005. He was living in Sergiev-Passad orphanage. An alumnus of a school for the individuals who are deafblind. I saw his notice in a magazine. Exactly at that time I felt myself having total hearing loss. I wanted to learn, how people live with it. That's why I wrote to Vlad. I was surprised by his

childish and very kind attitude to life. We began texting each other. In a year, he came to visit me at my house. And a year after we got married.

In 2008, a misfortune happened to me, I didn't succeed to become a mother. I sank into depression. I got a Chihuahua dog and didn't want to see anybody else. That's when my girlfriends decided that I expressly needed a computer with a refreshable Braille display. They found Vladimir Kallistov who helped buy it.

How do you appear to yourself? What traits are the main ones?

I always wanted to be beautiful. I was reading about Angelique, Catherine... You might remember fashion for the books about superwomen of those times. I didn't want to be a super one, but I often felt bitterness thinking of appearance. Since childhood, mother has

been convincing me that in appearance I was and would always remain a mouse...

I remember myself quietly suffering from it until the age of about 30. Later, when I began to come out more, I started receiving compliments. And even more of them when I began to be active in social networks. And now I have no complexes related to appearance. I understood, that first of all much depends personally on me, on how I present myself. Secondly, and substantially, if one evaluates you critically, it doesn't mean at all that all the others will see you the same.

I even started to be loyal to the photos, which is rare for the individuals having vision loss. It is pleasant when a burst of positive energy follows after you upload a photo.

And talking of something but appearance... I'm a very complicate person, but not a boring one for sure.

Community Stands for “Let’s Do It” Instead of “Give Me”

MARIA ZIMINA

The Interregional Benevolent Non-Governmental Organization which is called Community of Families of the Individuals who are Deafblind (hereinafter referred to as “Community”) was established in 2015 with the idea of uniting the parents of the children who are deafblind, that live in different regions of Russia.

Today the Community consists of over 250 parents from over 40 regions.



Group photo of community members

Main objective of Community activities is making relatives of the individuals who are deafblind active, especially, their parents. It is necessary to make more parents get involved into active work related to improvement of life quality of the individuals who are deafblind.

Nowadays, many people talk of necessity to search for new forms of social interaction.

Uniting parents for eagerly sought projects implementation is a new form of social problems solution that has already demonstrated its efficiency.

Social projects of non-commercial organizations make it possible to develop new work technologies and fill in blanks in rendering governmental social services.

If this is not the case, grownup children with sensory impairments will be able only to stay at home and walk around the yard with a white cane. Parents desire more for their children and they are ready to participate in their lives not only within their apartments. One of the ways to do it is to get united and create a new reality.

Wings that prevent from falling



Anastasia Begunova

"Mums are like buttons, everything is held together thanks to them," says the phrase that people like to send each other in messaging apps on holidays substituting the wish for the reality in a certain way. In fact, what can be held together by a regular mother? Almost the same as by a regular father and any sane concerned person.

But mums-buttons really exist and much is held together by them. Both uniting other mothers and implementation of important projects.

In Novgorod region, it is Anastasia Begunova, Regional Department Manager and Project Coordinator of Everyone Can Study.

Sasha, Nastya's daughter, also can study. Even though the school was standing against it at first. Sasha has visual and hearing impairment and other disorders. Although the education system likes the word "inclusion", for now it doesn't completely realize what to do with such children. A large school was afraid of little Sasha. No, they didn't reject to enroll her, but an offer to study at home and

Community activities are of project nature and they are carried out in 4 focal areas:

- Helping parents to organize the process of child's education;
- Organization of caregiving and support;
- Occupational guidance and organization of activities;
- Supporting parents (in terms of psychological, legal, consultative, informational support as well as social project management support).

not to attend classes sounded imperative. Shut yourself up from the world in the apartment, fence yourself off from school life (and probably from the life in general) with the diagnosis – Begunovs family certainly wasn't willing to agree with it. Sasha didn't want only to study, but also to communicate and make friends. For Sasha, school was a place, where she could feel herself needed.

Then Nastya suggested a ready strategy. The child studies at home, but comes to school to attend some classes, and the school hires a teacher with the qualification of visual impairment specialist and audiologist.

And Sasha began studying.

Nastya, in its turn, began teaching other mothers, who were still choosing a school and needed advice.

"Community is a big family, where everyone can help each other," she says. "Seeing your fellows, friends, you become happier and it empowers you. You feel support and realize that it isn't for nothing."

Kira, Yulia Miroshnichenko's daughter, is going to school next year. Yulia is a Manager of the Regional Department of the Community of Families of the Individuals who are Deafblind in Saint Petersburg. In this city, there are more special needs schools than in many other towns and cities. But if the choice will be still complicated, the Community will help with both information and simple warm support.

There are many of us, and each of us has specific experience in medicine, education, and child and family's life organization. I know that any question arises, I will always find who write to or call in order to resolve it. I'm very glad to be acquainted

with our wonderful mothers. Every meeting with them, whether it is online or offline, gives me strength and new knowledge. The Community is the wings that prevent from falling.

Two-parts T-shirt



Liudmila Archvadze

"I've learnt of the Time Out project thanks to the Community," tells Liudmila Archvadze. "I'd like it to be developing in our city, in Moscow. And I'll be happy, if it happens with my participation. I was a mother of a child who was deafblind and I understand how important it is... Time Out and little Daniel missed each other by a small period of time. A year ago the parents of the children with special needs received an availability to take a breath, entrusting their child to an experienced special nurse. Three years ago Liudmila's son passed away.

Daniel was born with multiple complex disorders. He couldn't neither hear, nor see or swallow. During the first weeks of the life he was living at the intensive care unit and Liudmila was living in hell. The doctors of the maternity hospital were offering her to file surrender of child without mincing their words. But Liudmila saw that the baby was reacting to her and needed her.

She promised herself to stop crying, took Daniel home, and a regular, full of concerns life of a mother and her near and dear baby started.

Although, it's wasn't that regular. For example, Daniel had gastrostomy tube. And when he, like any self-respecting baby, was asking to eat during the walk, it was an extra credit question. How can you "get connected" to gastrostomy tube without getting the child undressed? This you can't learn neither at a school for expecting mothers nor at designer courses. And Liudmila decided to become a designer herself. To make clothes for the children with special needs. A cut-out on a tummy for the children having gastrostomy tube. Zips under the armpits for those having ICP (so it would be easier to put spastic arms in). Two-parts T-shirts for those who are bedridden.

"The Community enables to tell," says Liudmila. "Not only of my tailor's shop. For example, it enables to tell of clothes that the government gives out with e-certificates. Of how one can get it. An in general, of how to get something you have rights to... The Community encourages the ideas of new projects. And the parents get acquainted with what we and our partners do.

How can one avoid getting into a trap of ready solution



Elizaveta Zimina

The story of Elizaveta Zimina from Orenburg also implies the fact that if you want to do something well, do it by yourself.

Everyone has heard a phrase, "I've got 2 news for you. One is good and another is bad, which one should I start with?" Liza smiles. "The bad news is that your child has special needs. He will grow up, but he'll re-

main a child in an adult's body. And what is the good news? The good news is that you aren't alone..."

Liza got a feeling of not being alone in 2018. At that time, she got acquainted with the Community.

Vanya, Liza's son, was 6 years old. He couldn't see well, had hearing loss, and loved enrichment activities and books. But it turned out that there were only 2 tactile books in the whole Orenburg. They were kept at the children's library. And even those didn't fit for little children having vision loss. They were too hard for perception. It meant, that she should have made a book for Vanya and other children with sensory impairment by herself...

By education Elizaveta is an artist, and it helped working at a book, in which she had to mix different materials and texture. And consultations of speech pathologist helped make the book useful and accessible to the children having multiple complex developmental disorders.

Yulia Kremneva, executive director of the Community of Families of the Individuals who are Deafblind, says,

What do we need to get united for?



Tatyana Selezen

In Volgograd, the driving force of the Community is Tatyana Selezen. One can easier imagine this fair-haired lady at some party, but not at a social project planning meeting. Nevertheless, exactly she was the one who helped Volgograd families with special needs understand, that a person can invent something on their own, but it's better to implement it together.

Maybe, one day, textbooks on social management will contain a chapter on a trap of ready solution. Human nature makes us search for a ready solution, having faced a problem. And sometimes we even find it. If we need a book, we go to the library... You get sick, then go to a doctor. Is it time to send a child to school? Let's look for a remedial class. But ready solutions don't imply personalized approach. Most likely, some standard set of activities will be carried out, a person will receive a service... and will be, mildly speaking, at a stand. Indeed, the problem hasn't been solved! There is almost no place for engagement in the system. That's why some of us took another road. If we don't have convenient options, we develop them by ourselves, and they meet our needs to the greatest possible extent.

Elizaveta Zimina says,

The Community helps get united to search for new solutions. It helps understand that even having a child with special needs you can do something for the others... Honestly, I'm afraid anyway. I'm afraid of what will be with our children when they grow up... And as in a cartoon, I suggest to be afraid together! Together we'll be able to implement many different projects for our children.

"The Community gives us a feeling that you can always find support and assistance," mentions Tatyana. "Having such a huge support, one can move forwards confidently."

Tatyana's son, Artemiy, was born premature. He doesn't see and hear well, doesn't walk and speak, but his life is full of events no less than the life of a typically developing child: rehabilitation, new skills, which are small though, but at the same time important and cheery. To receive a new portion of happiness for Artemiy, Tatyana came to the Mother's School. There, she realized that didn't want to be only a mother.

In 2018, Tatyana studied at the Mother's School, and in 2019 already, became a coor-

dinator of this project in Volgograd. Besides, every year she undergoes training at the Leadership School that helps parents implement their ideas, find financing sources and interact with public authorities.

“Just a little while ago I realized my wish to help myself above all...” she confesses. “And when I succeed in it, I have energy to help other families, too. I relearned how to live. To live a new life, a special life. I learnt not to be afraid and to believe in myself.”



Yulia Kremneva

Yulia Kremneva notices,

The Community doesn't stand for “give me”, it stands for “let's do it”. We aren't a charity fund that one can turn to and get money to solve the problem, when for instance, your house was burnt down and you get the same new house built. We are a union. If you want, you can call us even a team that implies partnership and joint participation. And if a fund helps resolve a separate issue, we generate something new and participate in its development. In other words, we build a new house together... The Community includes mothers with different experiences. Mothers, that suddenly started to move in the same direction. And, as the phrase goes, “There is no other way to advance than by taking steps.”

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Being and becoming a member of Dbl

Throughout this brand-new digital Dbl Review you will surely notice: Deafblind International is THE point of connection in deafblindness worldwide.

This is our passion and this is also our vision. To connect more and more and more. And to increase the impact we have for people with deafblindness and their families. Which means for example growing exchange and learning from each other, identifying and promoting best practices, stimulating research in the field or advocating for international awareness and recognition of deafblindness as a unique and distinct disability.

For all of that and more we need YOU as a member. Being or becoming a member: Please help us growing our impact and becoming indeed worldwide THE point of connection.

Being an individual member of Dbl means

- being a part of THE network in deafblindness and in making a difference for people with deafblindness, their families, professionals, researchers and service organizations worldwide
- belonging to the international “Dbl family” and being in touch with members from all parts of the world
- being very much invited to join one of Dbl’s very active thematic networks
- being informed first-hand about news and developments in the field and before anyone else about upcoming possibilities to exchange and learn from each other as in one of Dbl’s conferences
- being able to publish in Dbl’s digital magazine “Dbl Review”
- having member discounts on Dbl’s upcoming merchandise

Being a corporate member of Dbl means means in addition to that

- cooperating with other specialized organizations on an international level for awareness and recognition of deafblindness as a unique and distinct disability, for inclusion, quality services, the needed specialized competence of the professionals, focused research and further improvements in assistive technology
- learning from and with other specialized organizations for your own
- having a chance to be directly involved in Dbl’s management and development as an elected member of the Board and/or of one of its committees
- presenting your organization during Dbl conferences in a booth provided free of charge

Dbl is all about connecting, **individual membership** is therefore **free of charge**.

Corporate members are **the foundation** for the work of Dbl, **also with their financial membership contribution**. That is their pride and that is why they play the key role in Dbl’s direction and management.

If you want to join us as a new member, just go to <https://www.deafblindinternational.org/about-us/become-a-member/> Anyway, being or becoming a member, we are enthusiastic about your power. Together we will boost Dbl’s impact for sure.

Mirko Baúr, Strategic Vice-President Dbl, Chair ComCom



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