

DbI REVIEW

THE MAGAZINE
OF DEAFBLIND
INTERNATIONAL



CONNECT to ACT

and Weave Globally!



A Joint Message from the Presidents
of Deafblind International (DbI) and
the World Federation of the Deafblind
(WFDB)

Page: 3

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

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

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

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

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

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

A Dbl membership offers a threefold benefit:

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

“We rise by lifting others.”
Robert Ingersoll

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

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

A MESSAGE FROM THE PRESIDENTS

Connect To Act and Weave Globally!

➔ 3

NEWS

Core Values

➔ 5

News from the Network Coordinator

➔ 6

Dbi Research Network News

➔ 7

Dbi Communication Network News

➔ 8

Deafblind Education Network News

➔ 9

News from the Acquired Deafblindness Network (ADBN)

➔ 10

News from the Dbi CHARGE Network

➔ 12

News from the Anne Sullivan Foundation, Ireland

➔ 14

ANNOUNCEMENTS

We are Happy to Present the 18th Dbi International World Conference Proceedings

➔ 16

Yarn Bombing

➔ 16

Are You the New Co-Network Coordinator Dbi Needs?

➔ 17

ARTICLES

Coping with Usher. Development of a Manual and Training Program for Professionals Who Provide Psychosocial Support to Parents and Their Children with Usher Syndrome

➔ 18

Evaluating the Quality of Educational Programs for Learners Who are Deafblind

➔ 22

Launch of the National Model of Educational Services for Learners with Deafblindness and Multiple Disabilities in the Dominican Republic

➔ 27

Beyond Deafblindness: Ahimsa at the Forefront of Special and Inclusive Education

➔ 31

Objects as Communication Symbols for Students with Visual Impairments and Additional Disabilities

➔ 36

SIXTEM TO BRAILLE

Toys to learn Braille

➔ 42

■ CONTENTS

My Tactile Way: Revealing Tactile Potentials to Create New Possibilities. A Case Study

➔ 48

EXCHANGE OF EXPERIENCE

The Red-and-White Canes

➔ 52

A Parent's Perspective

➔ 55

Cross-Cultural Project on Deafblindness: an ERASMUS+ Project

➔ 58

The Power of Mentorship Programs

➔ 62

Sensory Integration and Musical Therapy in Education Children with Deafblindness

➔ 63

Implementations for Children Who are Deafblind Demonstrated in Renovated Building

➔ 66

Four Days of Activities in a Forest

➔ 69

Deafblind Spring Chow! – “Sharing a Meal, Sharing a Community”

➔ 71

Describe the Beauty of Your Native Shore to Me

➔ 74

Facilitating Participation in Research – an Intervenor's Perspective

➔ 77

INTERVIEW

The Key Point is to Avoid Shrinking into Yourself and Getting Out of Touch with the World!

➔ 79

NETWORKS AND NETWORK LEADERS

➔ 83



Deafblind
International DbI



Connect To Act and Weave Globally!

Deafblind International (DbI) AND The World Federation of the Deafblind (WFDB) are all about connecting to make a significant change for the rights and the quality of life of persons with deaf-blindness. Together, we invite everyone concerned and involved to join us and help maximize our positive impact: persons living with deafblindness, family members, friends, professionals, re-searchers, service providers, government officials - anyone, with and without deafblindness, who wants to contribute.

The global situation of persons living with deafblindness is not acceptable. This reality made evident in WFDB's Global Reports and through additional data collected in DbI's Global Education Campaign.

It is outrageous that persons with deafblindness are still excluded in many places and situations, and that deafblindness is still not universally recognized as a unique, distinct and very diverse condition.

To change this, we must all work together, complementing and learning from each other. Together, we are much stronger.

SANJA TARCZAY

WFDB PRESIDENT

MIRKO BAUR

PRESIDENT OF
DEAFBLIND
INTERNATIONAL

■ A MESSAGE FROM THE PRESIDENTS

This extends well beyond WFDB and Dbl. We need to build and develop networks, include every-one interested, any ally and any supporter who shares our purpose. We need to convince that this is about including everyone, excluding none, that inclusion and participation of persons with deaf-blindness makes life for all better: More divers, more equitable, more inclusive.

Networking means communicating, means lots and lots of soft skills. In a way, we are all weaving a very colourful and also very delicate fabric. We do that literally, during Dbl's yarnbombing events and we do that socially in our respective contexts every single day, with every new encounter.

WFDB and Dbl have recently committed to working in much closer collaboration to

achieve these goals. We have adopted a new Memorandum of Understanding (MoU). Amongst others, we have agreed to engage in joint efforts of research promotion, campaigning releases, policy development, and conferences, forming joint committees, working groups and project teams. Further-more, we are open to inviting representatives to join these committees, working groups, and project teams from either WFDB or Dbl, if appropriate and funding is available.

The new MoU is our fundament to walk the talk in our presidential roles. Additionally, we are equally passionate about making a meaningful impact together. Join us on this journey: You are indeed very welcome!



Sanja Tarczay
WFDB President



Mirko Baur
President Dbl

News from the Network Coordinator

TREES VAN NUNEN

DBI NETWORK COORDINATOR

T.VANNUNEN@KENTALIS.NL



In a world where connection is more important than ever, the Dbi networks are a great example of this. As a network coordinator, I was so proud during the Dbi World Conference in Ottawa. Almost all network leaders and their representatives presented their networks during a plenary session. In addition, a large number of networks organized during the conference a gathering to meet existing and new members of their network. Finally, the pre-conferences of the Usher network and the Communication network were very well attended.

Since my last update, I'm glad to introduce to you officially our 17th network: Deafblind Education Network (DEN). They are already active on social media and are planning their first activities.

The increasing number of networks also means an increase in work for the network coordinator. Dbi ManCom and the Board have therefore also responded to my request to look for a second, co-net-

work coordinator. Elsewhere in this Dbi Review you will find an expression of interest. If you are interested in this position submit your completed Expression of Interest before May 31.

Over the past year, the network leaders have met again every 3 months during our network meetings online. It remains interesting to hear from each network that the number of members has increased again and we learn from each other when it comes to organizing activities or the possibilities of technical gadgets. Also each network has put together a committee consisting of at least 3 people: the network leader, a representative and someone responsible for social media. This allows responsibilities to be better distributed and makes a network less vulnerable.

Most networks are active as never before and I would like to thank all network leaders and their members for their tireless efforts to share their knowledge around the world.

Dbl Research Network News

The Dbl Research Network held a call for applications in 2023 to support five research projects. The 500 Euro awards are intended to cover costs related to the involvement of individuals with lived experience of deafblindness to be able to participate in research activities. Allowable expenses include participant payment, interpreter and communication expenses, or travel to/from research participation. To avoid conflicts of interest, all applications were evaluated by three reviewers that were not part of any application. The successful teams of the 2023 funding round are:

Brazil: Elemregina Moraes Eminergideo, Iury Moraes Eminergideo & Sheyla Macedo de Sousa;

Title: The School Identity Project: From Floor Plan to Digital Accessibility

International: Walter Wittich (Canada), Leda Kamenopoulou (UK), Peter Simcock (UK), Serge Maynard (Canada), Cloe Rodrigue (Canada), Atul Jaiswal (Canada/India), Natalina Martiniello (Canada), Maria Kett (UK), Liz Duncan (UK), Katerina Bezerianou (Greece), Akhil S. Paul (India), Jennifer Robbins (Canada), Renu Minhas (Canada), Ismael K. Byaruhanga (Republic of the Congo), Mirko Baur (Switzerland), Samuel Valencia (Colombia) & Diane Bell (UK);

Title: Growing up & Being Deafblind: Analyzing comparative case studies from the Global South and North to illuminate enablers that lead towards the achievement of

the UN Sustainable Development Goals

International: Meredith Prain (Australia), Leda Kamenopoulou (UK), Natasha Layton, (Australia) & Mary Maragia (Kenya);

Title: Exploring the outcomes of using the My Assistive Technology Outcomes Framework (MyATOF) in 4 countries in Africa

International: Walter Wittich (Canada), Sarah Granberg (Sweden), Mahadeo Sukhai (Canada), Atul Jaiswal (India/Canada), Serge Maynard (Canada), Cloe Rodrigue (Canada), Sherry Grabowski (Canada), Sonja Van de Molengraft (Netherlands), Mirko Baur (Switzerland), Ricard Lopez (Spain), Renu Minhas (Canada), Jennifer Robbins (Canada);

Title: Development of a Core Set for Deafblindness using the International Classification of Functioning, Disability and Health – Phase 4: The Clinical Assessment study

Democratic Republic of the Congo: Kamonyo Botanyi, Jonas Tuombe, Agizo Josue, Bulabula Kalonda & Shabana Florention;

Title: Research on Autonomy of young Deafblind of the Democratic Republic of the Congo through Education

Funding will be granted to each team upon receipt of an approved human research ethics application. Congratulations to all! We look forward to reading more about the results of these studies in the coming year.

Your Dbl Research Network Team.

WALTER WITTICH

ATUL JAISWAL

UNIVERSITÉ DE MONTRÉAL, CANADA

SASKIA DAMEN

UNIVERSITY OF GRONINGEN & ROYAL KENTALIS, THE NETHERLANDS

MEREDITH PRAIN

ABLE AUSTRALIA, AUSTRALIA

CAROLIN GRAVEL

UNIVERSITY OF COLOGNE, GERMANY

DbI Communication Network News

SASKIA DAMEN

UNIVERSITY OF GRONINGEN, GRONINGEN, THE NETHERLANDS
ROYAL KENTALIS, UTRECHT, THE NETHERLANDS

MEREDITH PRAIN

ABLE AUSTRALIA, MELBOURNE, AUSTRALIA

HELLE BLUELUND

CENTER FOR DEAFBLINDNESS OR HEARING LOSS, AALBORG, DENMARK

STEVE ROSE

VISION AUSTRALIA, MELBOURNE, AUSTRALIA

The DbI Communication network committee has been preparing a new webinar series. The first webinar the network organised was on Early Intervention and was held in April 2021. This webinar had over 100 participants from all over the world. In November 2022 the DbI communication network hosted the webinar series 'from emergencing gestures to tactile sign language'. Another webinar, on tactile communication and different hand positions, was held in 2023. Recordings of these webinars can be found on our networkpage on the DbI website, see [Communication Network Webinars - Deafblind International](#).

In our newest webinar series, hosted on April 17/18 2024, Liliaston Liston shares her parent perspective on supporting and advocating for her deafblind son. She shares some of her early experiences as a mother to a child with

deafblindness, how she was able to equip herself to recognise her son's communicative and cognitive potential and how he coped and explored the world. She will discuss what worked well and how she empowered herself to give him the best life possible, identifying professionals who were able to help and collaborate to develop a positive experience.

The network is also organizing a webinar series for network members in the second half of the year of 2024. The purpose of this webinar series is to discuss a case and share experiences and expertise among DbI Communication network members. We hope to meet you in one of our webinar series. Visit our facebook page for the latest information [DbI Communication Network | Facebook](#).

The DbI Communication Network Committee.

Deafblind Education Network News



Fig. 1.

Greetings from Dbl's newest network. In 2023, Anders Martin Rundh set out to start this network, which was accepted during the Dbl World Conference in Ottawa, Canada. We had our first meeting at the conference (Fig. 1) with 15 attendees from around the world. The aim of the network is to become a dynamic, strong and long-lasting network, where participants exchange knowledge with teaching in the field of deafblindness. It is also important to the DEN that we support each other as educators through connecting through social media and webinars we hope to hold in the future. In addition, we will strive to be inclusive, with members representing every continent, and to also align our discussion topics with the set Dbl themes. We look forward to engaging with the "Let Me In" Campaign in 2025! Watch this space....

The DEN has a Facebook page which was set up in 2023 that currently has 200 members (at writing). To access it and join the page as a member, search "Deafblind Education Network." We also encourage Dbl members to register to join the DEN via the Deafblind International website.

Since the first meeting in Canada, we have held two Board meetings via Microsoft Teams. We have discussed the goals of the network, how we will be structured, and what we would like to offer members as far as topical discussions, coffee hours, or speakers and webinars.

We plan to meet every other month on Teams as well as anytime there is an opportunity to meet face-to-face during conferences.

MEMBERS OF THE BOARD OF DEN:

ANDERS MARTIN RUNDH

DENMARK (CHAIR)

DEIRDRE LEECH

IRELAND (CO-CHAIR)

MEAGHAN BRESSER

CANADA

YONI VAN DER LINDEN

NETHERLANDS

GUNTHER MEYER-REINHARD

GERMANY

KRISTIN CARLSON

USA

News from the Acquired Deafblindness Network (ADBN)

FEMKE KRIJGER
LIZ DUNCAN
PETER SIMCOCK



It's curiosity, exploration, and a genuine interest to connect with one another that binds the members of the Dbl Acquired Deafblindness Network (ADBN), which now has over 400 participating members. Focused on the

specific challenges and needs of people living with acquired deafblindness, we share personal as well as professional experiences, latest research, and other information of interest, like upcoming events, publications and awards

being granted in the field of acquired deafblindness.

In short, our network aims to connect, celebrate, and grow. We believe that if we are willing to open up to the many perspectives that shape our network, it will inspire us, our work, and our lives. Our aim is to acknowledge the body of work that is undertaken by so many in the field of acquired deafblindness and to invite questions and answers to help us grow and move forward.

There are several channels of communication through which our ADBN members can connect, including **ADBNews**, a newsletter sent out every two months in English, Spanish and French, and the ADBN Facebook group, where members can share ideas, news, and information, within a safe space.

ADBN also hosts a series of webinars, in which experts in the field have presented on a range of topics. These include best practice in social care for adults with acquired deafblindness (Jackie Kidd), existential care for, and the experiences of, older people with late life acquired deafblindness/dual sensory impairment (Dr Daniel Prause and Dr Moira Dunsmore), the development of an ICF Core Set for deafblindness (Assoc. Prof. Walter Wittich), and the experiences of both an artist and a researcher living with Usher Syndrome (Prof. Alberto Camacho and Dr Annmaree Watharow). The theme for this year's webinar series is '**Beyond**

Existence: Exploring and Living Life'. This series started in January with an excellent presentation by Dr Ismael Byaruhanga about his work with families with Usher Syndrome in the Democratic Republic of the Congo. Reflecting the words of Helen Keller, that life is either a daring adventure or nothing at all, the second webinar in the series was a fascinating presentation about the brave new world of artificial intelligence (AI) and its use by acquired deafblind people, expertly delivered by ADBN member Carolina Cohoon and her colleagues Jeremy Marks and Mike Ingram. We now look forward to the other webinars in this series: an introduction to the use of social haptic communication to enable acquired deafblind people's involvement in hobbies (Dr Riitta Lahtinen and Russ Palmer PhD h.c.) and parenting and acquired deafblindness (Dr Ann-Sofie Sundqvist and Angela Priestly). The recordings of our webinars can be found on our recently launched YouTube Channel, **ADBNow**.

All of our work is made possible by many active network members, who help us make ADBN as inclusive as possible. We are also very grateful for the support ADBN receives from Network Coordinator Trees van Nunen-Schrauwen, Dbl Social Media Pioneer Graciela Ferioli, and Deafblind UK.

If you wish to join our network, you are most welcome. For further details on how to join, please visit our website [here](#).

News from the Dbl CHARGE Network



ANNE SCHOONE

CO-CHAIR
DEAFBLIND
INTERNATIONAL
CHARGE NETWORK

A.SCHOONE@KENTALIS.NL

Since the World Conference in Ottawa, the Dbl CHARGE Network has gone through a number of developments that we would like to share with you!

CHARGE Syndrome is the most common cause of congenital deafblindness worldwide and a true multi-sensory impairment. As it is a rare syndrome, it is very important to share information, experience and expertise on a global scale.

The Dbl CHARGE Network is an interdisciplinary network composed of individuals with CHARGE syndrome, family members, professionals (such as teachers, intervenors, educators, therapists and doctors) and researchers.

The CHARGE Network has always been a rather active network, organizing some very successful pre conferences and publications in the past. Our main future goal is to continue being an active Dbl Network and to connect people involved with CHARGE syndrome worldwide.

During the Ottawa conference, we organized a hybrid network meeting. We were very pleased to welcome a lot of people interested in the network, in person as well as online. One of our goals for this meeting was to form a new organizing committee or task group to get our network going. Besides that, we discussed some topics of interest that could use some attention in our network.

At this moment, I'm really happy that this resulted in a newly formed organizing committee for our network. The CHARGE network committee consists of Andrea Wanka (chair), Allison Mail, Heather Colson-Osborne, Jerry Petroff, Lourdes Quintana Baez, Veena Ramrakhiani and myself (co-chair).

Sharing information and connecting people with CHARGE syndrome, families, professionals, re-searchers and other organizations is our primary goal to work on.

One way to reach this goal is our newsletter that we share several times throughout the year. This newsletter is also being translated to Spanish, to expand the group of members we can reach. Sharing CHARGE related events and launches are an important part of the newsletter. We'd like to cooperate with other Dbl networks as well, for example with the Communication Network and the Ibero Latin America network. Besides the newsletter, we also have a WhatsApp group to exchange information regarding CHARGE syndrome.

For 2024, we are planning some online events. We will start with a webinar on June 26 2024. We are planning to host the webinar two times (most likely at 10.00 CET

and 20.00 CET), so please save the date in your agenda if you are interested.

In autumn, we are planning online case discussions in groups.

More details about these events will be shared in our newsletter.

We are excited to welcome new members every month. If you are not a member yet, but are in-terested in the Dbl CHARGE Network, you can become a member here:

[Become a Member – Deafblind International](#)

Whether you have CHARGE syndrome yourself, are a family member or work with children or adults with CHARGE, you are welcome to join. We believe that sharing knowledge and experiences in this field is critical to improve our understanding of CHARGE syndrome.

For more information, or if you have any questions regarding the network, please contact Anne Schoone, on behalf of the Dbl CHARGE Network: A.Schoone@kentalis.nl

News from the Anne Sullivan Foundation, Ireland

DEIRDRE LEECH

OUTREACH SERVICES MANAGER, ANNE SULLIVAN FOUNDATION, IRELAND

OUTREACH@ANNESULLIVAN.IE



Fig. 1. (L to R): Members of the Anne Sullivan Foundation Outreach Team standing at a recent Service Development Meeting: Matt Tuohy, Deirdre Leech, Sorcha Nallen, Kirsty Grant, and Grace Kelly-Hartnett (CEO)

Greetings from Ireland! We continue to work with individuals who are deafblind of all ages around the country through our Outreach Programme as well as the adults our residential Centre in Dublin.

In addition to our work directly with clients, their families and support staff/teachers, we have received funding to engage in some interesting projects in the past few months. One grant we were awarded was inspired by and based on the research done by Dr. Lilli Nielsen to create active learning equipment for children in our Outreach Service. We have had equipment made for children aged 0-4 who have been identified

as having dual sensory loss such as “little rooms,” tactile blankets, sensory hoops and slant boards. It has been exciting to reach out to families who are now using this equipment to help their child develop their skills.

Our Assistive Technology Library is continuing to support the deafblind community in Ireland. We are excited to continue developing this service and promote the independence of our clients. The area of assistive technology is ever changing so we are keen to link up with anyone who has a similar service in their country or organisation.

We run an online course in deafblindness for professionals and families in Ireland throughout the year and had a huge response to our recent Winter Webinar Series of online topical sessions.

We hosted a CHARGE Family Day in September 2023 with 10 families living in Ireland attending—many of whom had not met in person since our last event in 2019. It was a great

day of fun which offered a chance for parents to connect about their childrens' common medical, therapeutic and educational needs.

We would also love to connect with other countries who have experience in the area of advocacy as we work towards recognition of deafblindness. Get in touch with us at outreach@annesullivan.ie

We are Happy to Present the 18th Dbi International World Conference Proceedings

Dbi
INTERNATIONAL

Deafblind International Dbi is pleased to present the Virtual Proceedings Document of the 18th International World Conference, Ottawa, Canada (July 2023). Held in Ottawa, Canada, this event brought together leading experts, researchers, practitioners, and advocates in the field of deafblindness from around the globe. Thirteen selected post-conference papers represent a small cross-section of this international conference's many presentations, posters and plenary sessions. A

varied group of individuals with deafblindness, family members, practitioners, and research scholars sent papers for the proceedings. The materials were edited and prepared by an international team of experts. They are now available on the Dbi website.

You can download and read the articles using the link <https://www.deafblindinternational.org/we-are-happy-to-present-the-18th-dbi-international-world-conference-proceedings/>

Yarn Bombing

Dbi
INTERNATIONAL

We invite you to join us again in June 2024 for a movement that will build awareness about deafblindness on a global scale.

In June 2023, over 30 installations were created in Dbi's third yarn bombing initiative, with colourful, tactile displays on fences, pillars, bicycles, and community spaces around the world!

Yarn bombing, which is sometimes known as 'knitfiti', is a form of street art where yarn that is knit, crochet, or wrapped, adorns an object in a public space. It is thought to have originated in the United States in 2005.

By coming together to yarn bomb objects in as many cities and countries as possible in June, we strive **to foster connections and unite a community** with individuals, service and advocacy groups in the field, Dbi members and partners, and the wider global public.

Regardless of whether your country, region, or organization celebrates deafblind awareness as a month, a week, or day, our combined efforts will **create a stronger and united voice**.

Learn how to you can get involved in this year's global Yarn Bombing Initiative here: <https://www.deafblindinternational.org/yarn-bombing/>

Are You the New Co-Network Coordinator Dbi Needs?

Networks have a central role within Dbi: it's all about connecting people and sharing knowledge. As the number of Dbi's Networks have grown, we have identified a need to add a Co-Network Coordinator role to the team.

The Co-Network Coordinator will have a supporting and complimentary role to the current Dbi Network Coordinator. The Co-Network Coordinator underlines the importance of the value of the Dbi Networks and will be knowledgeable of the Dbi Guidelines concerning Networks.

The Co-Network Coordinator responsibilities include:

- working closely with the Network Coordinator
- complementing the work of the Network Coordinator: for example taking part in sub-committees of the ComCom (Communication Committee) or playing an active role in the field of social media concerning the networks
- replacing the Network Coordinator in case of emergencies
- getting to know the Network Leaders and following the activities of the Networks

Because the position of a Co-Network Coordinator is new within Dbi, you will start with monthly consultations with the Network Coordinator to gain insight into the role and responsibilities and to coordinate which qualities can be used for the various tasks in order to achieve a good division of work.

In this role you can expect to spend approximately 3 hours per month on Network-related volunteer work.

If you are interested in this exciting new role, please submit your completed Expression of Interest form via email to the Dbi Secretariat at dbi-secretariat@sensity.ca no later than **May 31, 2024**. The Expression of Interest Form can be found here: <https://www.deafblindinternational.org/are-you-the-new-co-network-coordinator-dbi-needs/>

Dbi
INTERNATIONAL

Coping with Usher. Development of a Manual and Training Program for Professionals Who Provide Psychosocial Support to Parents and Their Children with Usher Syndrome

SASKIA DAMEN
ELINE HEPPE
VERA KNAPEN

Coping with Usher syndrome and its associated progressive deafblindness is considered a complicated task. Serious psychological and social consequences of Usher syndrome have been described, such as stress, depression, and social isolation (Dean et al., 2017). These consequences imply a need for psychosocial support.

While the impact of Usher syndrome is well described for adolescents and adults with this condition, the impact on their parents and other family members is less well described. Kyzar et al. (2016) revealed that deafblindness in general can have a negative impact on family quality of life, but adequate family support and a good parent-professionals relationship can improve this quality. This is in line with Correa-Torres and Bowen' (2016)

finding that support of parents and siblings of children with deafblindness improved their ability to cope with this disability.

However, family support is not very often provided to parents with a child with Usher syndrome as described in a recent Dutch study (Damen et al., 2022). To our knowledge, no evidence-based intervention for psychosocial support of families with a family

member with Usher syndrome currently exists.

This study described in this report was conducted in the Netherlands with the aim of developing and evaluating a manual and training program for professionals who provide psychosocial support to families with a

Method

Ethical approval for this study was granted by the Department of Pedagogical and Educational Sciences of the University of Groningen in the Netherlands. All participants or their legal representatives gave written informed consent. The research

Research phase

To gain insight into the support needs and experiences of individuals with Usher syndrome and their parents, the following methods were used: a) a literature study, b) interviews, c) focus group sessions, d) survey. To gain insight in existing methods and interventions for providing psychosocial support, the following methods were used: e) an inventory, and f) expert meetings.

A. Literature study

In April 2019, a literature search was carried out in ERIC and PsychInfo by Special Needs Education students under the supervision of the first author. A total of 12 scientific peer-reviewed English-written articles were selected for further analysis as they focused on support needs of individuals with Usher syndrome or deafblindness. The included papers presented nine studies that involved individuals with Usher syndrome.

B. Interviews

Eleven parents of ten children with Usher syndrome Type 1 or 2, aged between four and 21, participated in semi-structured interviews conducted by professionals. Anonymized transcripts of the interviews were coded thematically by students under supervision of the first author.

child with Usher syndrome. In order to tailor the manual and training program to the specific support needs of the parents and their children with Usher syndrome, and to make use of existing lived and professional experience, multiple research methods were applied.

project consisted of three phases: 1) research phase, 2) intervention development phase, and 3) pilot study. Below, we briefly describe the methodology used in each phase, and then the results and conclusion of the study.

C. Focus group sessions

Three focus group sessions were organized: one for individuals with Usher syndrome aged between 18 and 30 (N=6), one for individuals with Usher syndrome aged 30 and older (N= 8) and one for parents of children with Usher syndrome (N=10). Participants of focus group 1 had Usher Type 1 or 2. In focus group 2 and 3 all Usher syndrome types were represented. Anonymized transcripts of the sessions were coded thematically by two researchers and two experts-with-lived- experience.

D. Survey

A total of 39 participants completed the survey. Of these, 23 had Usher syndrome (18 with Type 2; five with Type 1) and 16 were parents. Their children (aged 7 months – 19 years) were diagnosed with Usher syndrome: one with Type 1, twelve with Type 2 and one with Type 3.

E. Inventory

Of the five participating care organizations, one contact person was responsible for conducting the inventory within their own organization. The inventory was organized to establish an overview of methods and interventions for psychosocial support used among the different organisations, and sub-

sequently to explore the usability of these methods and interventions.

F. Expert meetings

Two expert meetings were held with nine experts: one meeting to agree on terminology

Intervention development phase

The results gathered from the research phase were used to develop a manual and training program for professionals who provide psychosocial support to families with a child with Usher syndrome. The manual covers various topics and includes an overview of relevant methods,

Pilot-study

Five families with a child with Usher syndrome participated in the pilot-study (three families with a child between 0-8 years, two with a child between 8-18 years, and one with a child between 12-18 years). They had received psychosocial support from a professional who used the manu-

Results and conclusion

The results of the literature review, the interviews, focus group sessions, and survey revealed that families with a child with Usher have needs for support in: 1) obtaining information about the syndrome, 2) learning to cope with the syndrome in daily life, 3) developing a positive outlook for the future, and 4) dealing with the consequences of the syndrome emotionally and socially. These needs arise as early as directly after receiving the diagnosis, but may also arise later in the child's life. Both the literature and empirical studies demonstrate the importance of peer support for families (meeting other families with lived-experience) and the need to facilitate such support. Crucial to positive experiences with professional support appeared to be the way support was provided by professionals. Participants described the importance of empathy and patience, of equal cooperation between the professional and parents, and the importance of specialized knowledge of and experience in supporting families with a child with Usher syndrome. Participants also described the

and definitions of psychosocial support for families with a family member with Usher syndrome; one meeting for deciding which of the listed methods or interventions could be used and, if, what should be developed to guide professionals.

interventions, and resources. The training program consists of a two-hour workshop in using the manual, two interprofessional collaboration sessions, and on-demand consultation sessions with experts-with-lived-experience over a six month period.

al and had attended the training program. Both the parents of the participating families and the professionals completed an evaluation questionnaire. Additionally the professionals were interviewed about their experiences with the manual and training program.

importance of support that is tailored to the needs of families and family-centered support.

The research phase revealed that many respondents with Usher syndrome and parents with a child with Usher syndrome never received psychosocial support in coping with the syndrome. Respondents who did receive support mainly received information and knowledge about the syndrome. Furthermore, professionals from five care organizations agreed that psychosocial support is a type of support that is appropriate for supporting individuals with Usher and their families as it provides a combination of information and knowledge, coping strategies, and emotional support. Professionals indicated that specific psychosocial support methods for Usher syndrome are lacking, but identified Dutch psychosocial programs and materials for other populations (e.g. deaf and hard-of-hearing children) that can be used as a basis for developing a manual and training program for professionals.

They also identified several key themes that were described in the manual.

The results of the pilot study showed that families rated the psychosocial support with a 7.4 (SD=1.59), and the professional who used the manual and had received the training program with an 8.1 (SD=1.46) on a scale between 0 and 10. They rated the effectiveness of the psychosocial support as moderate (2.8 on a scale from 0 to 5). Five of the ten families reported positive changes as a result of the psychosocial support: for example, the family was less stressed, worried less about the future, and felt they had been given tools to cope with the syndrome. Professionals were generally positive about the manual and training program. Of the training program, professionals rated the interprofessional collaboration as the most valuable component. However, some professionals expressed a need for additional training and a more concrete manual (e.g., with assignments and exercises). Most

had consulted an experienced colleague for additional support that was not part of the training program.

Based on these studies, we conclude that psychosocial support is appropriate to support families with a child with Usher syndrome. However, this type of support makes specific demands on the professional's attitude, knowledge, and skills. Providing a manual and 2-hour training seemed to enhance professionals' skills and knowledge to some extent, but not yet enough. In future research, a more comprehensive training program and manual should be developed and examined for effectiveness. Especially since evidence-based psychosocial support for families with a child with Usher syndrome is still lacking. Such a project is currently being conducted in the Netherlands within a nationwide research program called Deelkracht together with Royal Kentalis and the University of Groningen.

References

- Correa-Torres, S.M, Bowen, S.K. (2016). Recognizing the Needs of Families of Children and Youth Who Are Deafblind. *Am Ann Deaf*. 161(4):454-461. doi: 10.1353/aad.2016.0037. PMID: 27818401.
- Damen, S., Van Zadelhoff, I., & Tijsseling, C. (2022). Experiences of families involving a parent with progressive deafblindness. *British Journal of Visual Impairment*, 41(2), 212-230. <https://doi.org/10.1177/O2646196211059751>
- Dean, G., Orford, A., Staines, R., McGee, A., & Smith, K. J. (2017). Psychosocial well-being and health-related quality of life in a UK population with Usher syndrome. *BMJ open*, 7(1), e013261.
- Kyzar, K., Brady, S., Summers, J., Haines, S., Turnbull, A. (2016). Services and Supports, Partnership, and Family Quality of Life: Focus on Deaf-Blindness. *Exceptional Children*. 83. 10.1177/OO14402916655432.

Evaluating the Quality of Educational Programs for Learners Who are Deafblind

SUSAN BRUCE

BOSTON COLLEGE

CHRISTOPHER BRUM

SAN DIEGO STATE UNIVERSITY

LENA SPEAR

CAMPUS SCHOOL AT BOSTON COLLEGE

Introduction

This is the ninth and final article in a series addressing the assessment of children and adolescents who are deafblind. Comprehensive assessment goes beyond assessment of the learner to include assessment of educational program quality. In this article, program refers to what is provided to each learner in the school or other educational setting. We will discuss the following components of quality programs for children and

youth who are deafblind: (1) professional preparation and staffing patterns; (2) the curriculum and implementation of evidence-based practices; (3) quality of professional and student interactions; (4) environment, materials, and assistive technology; (5) the yearly individualized education plan and monitoring student progress; and (6) the role of collaboration in program quality.

Professional Preparation and Staffing Patterns

The quality of an educational program is integrally connected to the preservice and inservice preparation of its personnel, including teachers, interveners, paraprofessionals, and therapists. Learners who are deafblind especially require well-prepared professionals because much of what they learn must be directly taught in near space. The Council for Exceptional Children (CEC) is one source of professional standards for teachers and interveners (<https://exceptionalchildren.org/standards/specialty-sets-specific-practice-areas>). The teacher standards in deafblindness address ethical practices, individual learning needs, social-emotional growth, assessment, curriculum, effective instruction, and team collaboration. [\[tsbvi.edu/statewide-resources/professional-development/online-learning\]\(https://tsbvi.edu/statewide-resources/professional-development/online-learning\)](https://www.</p>
</div>
<div data-bbox=)

Ensuring that professional standards are met by teachers and interveners is the foundation for high quality educational programs.

Due to the shortage of preservice preparation programs in deafblindness, there is a continued need for inservice professional development (Nelson, et al., 2022). Resources include Open Hands, Open Access (OHOA): Deaf-Blind Intervener Modules (<https://www.nationaldb.org/products/modules/ohoa/>), a resource aligned with CEC standards. Online learning opportunities are available through Perkins School for the Blind (<https://www.perkins.org/course-topic/multiple-disabilities->

[deafblindness/](#), Helen Keller Services (<https://www.helenkeller.org/professional-training/>), Texas School for the Blind and Visually Impaired (<https://www.tsbvi.edu/statewide-resources/professional-development/online-learning>), and state and regional deaf-blind projects in the U.S.

In addition to ensuring the hire and retention of qualified personnel, the school or district must also ensure appropriate professional to student ratios. There should be enough

staff to ensure active engagement in activities, high levels of responsiveness to student communication, and ample opportunities for each student to demonstrate what they know. Professional services provided by therapists and other specialists should meet the needs of each child and allow sufficient time for consultation and collaboration. Each team serving a child who is deaf-blind should include at least one professional who has expertise in deafblindness (Parker, et al., 2011)

The Curriculum and Implementation of Evidence-Based Practices

Guidelines for effective programming for children and youth with other disabilities may shape effective programming for children who are deafblind. Browder et al. (2020) suggest the following elements for evaluation of programming for students with moderate and severe disabilities: promotion of inclusive practices, evidence-based instruction, access to the general curriculum, teaching academic skills, teaching functional skills, supporting self-determination, positive behavior supports, collaborative teaming, and home-school collaboration. Children who are deafblind require instruction in the expanded core curriculum which addresses nine curricular areas: assistive technology, career education, compensatory skills (such as organization skills), independent living skills, orientation and mobility, recreating and leisure, self-determination, sensory efficiency, and social interaction skills (<https://www.tsbvi.edu/programs/ecc>).

The implementation of evidence-based practices has been positively linked to achievement for students with disabilities (McLeskey et al., 2017). The Collaboration for Effective

Educator Development, Accountability, and Reform, most often referred to as the CEEDAR Center, has published documents on evidence-based practices that can be located at (<https://ceedar.education.ufl.edu/innovation-configurations/>). These practices are discussed in documents called Innovation Configurations. The Innovation Configuration on Sensory Disabilities (Ferrell, et al., 2014) includes a section specific to practices in deafblindness (pp. 205-219). https://ceedar.education.ufl.edu/wp-content/uploads/2014/09/IC-4_FINAL_03-30-15.pdf An evaluation rubric appears in the appendix of this Innovation Configuration. This is intended for use when engaging in planning or evaluating preservice personnel preparation programs for teachers, but it can also be used when planning inservice professional development. Additionally, McLeskey, et al. (2017) developed an Innovation Configuration focused on High-Leverage practices in special education that provides a research synthesis of evidence-based practices to support children with disabilities in the areas of assessment, collaboration, instruction, and behavior/social-emotional development.

Quality of Professional and Student Interactions

The importance of high-quality professional and student interactions cannot be over-emphasized. Sundqvist et al. (2022) presents a useful review of intervention research on interactions and communication. Multiple studies by Janssen et al., and Damen et al. (including Janssen et al., 2010; Damen, et al., 2020) provide guidance about how to cre-

ate high quality interactions with children who are deafblind. These researchers and their teams have demonstrated that communication partners can improve their skills through modeling and coaching. The following resource may be used in self-evaluation and in planning for improved interactions (Rodriguez-Gil & Brown, 2023):

<https://cadeafblind.org/wp-content/uploads/2023/10/Fact-Sheet-A-Self-Evaluation-Guide-for-Assessing-the->

[Quality-of-Your-Interactions-with-a-Student-who-is-Deafblind-.pdf](#)

Environments, Materials, and Assistive Technologies

Quality programming includes consideration of each environment within the school or other educational setting, as well as the materials used within activities, and the application of assistive technologies, including adaptive equipment. Environments should be assessed for their accessibility and for the quality of engagement afforded. Ecological inventories and analyses support the identification of relevant activities, the development of task analyses, and recognition of the impact of the physical and social characteristics of each environment on the individual (Butler & Bruce, 2022). Taylor et al. (2006) developed a classroom observation instrument to support program evaluation <https://documents.nationaldb.org/products/coi-2006>.

Within each environment, the materials must be accessible and pleasing. Sufficient time for tactile exploration paired with meaningful communication will be needed.

Learners who are deafblind require a range of assistive technologies (AT), including high tech devices such as personal alert-vibrating systems for the phone and low tech supports such as tactile daily schedules, and communication boards (Parker et al., 2011). Teams may need to apply a planning framework such as SETT (which considers the student, environment, task, and tools) to plan appropriate AT for each learner (Hartmann & Weismer, 2016). Ease of use across environments is an important AT consideration.

Yearly Individualized Plan and Monitoring Student Progress

Some countries have yearly plans for each student. In the U.S. it is the Individualized Education Plan (IEP). The IEP includes assessment results, learning goals, accommodations, and the staffing plan. The document, *IEP Quality Indicators for Students with Deafblindness* (<https://txdeafblindproject.org/wp-content/uploads/2022/07/IEP-Indicators.pdf>; Texas Deafblind Outreach, 2009) provides guidance for IEP development in 10 areas: etiology, access to information, social issues, communication, calendar system, behavior, orientation and mobility,

related and supplemental services, transition planning, and team processes.

Program quality can also be viewed from the lens of student achievement. Implementation of evidence-based practices (those with research evidence) and promising practices (those that are well-established in practice literature) will support student achievement. Instruction of children who are deafblind should emphasize communication and language instruction (Parker et al., 2011). The child's progress must be monitored, with results shared with the family.

Role of Collaboration in Program Quality

The complex strengths and needs of students who are deafblind are often addressed by large educational teams. Rodriguez-Gil (2009) provides detailed information about team member roles, including the roles of specialist teachers, therapists, the Certified Orientation and Mobility Specialist, and intervener, which can support teams in role clarification. Effective teams will have members

with deafblind specific knowledge and skills, collaborative processes to develop and monitor educational plans, and a supportive leader who ensures sufficient time and resources for collaboration (Hartmann, 2020). Due to the scarcity of deafblind specific professional preparation programs, parents bring not only knowledge of their child, but may also be the most knowledgeable team mem-

ber about deafblindness (McKittrik, 2022). It may be necessary to also invite outside consultants, with expertise in educational programming for learners who are deafblind, to support team efforts. Grisham-Brown et al (2018) proposed that such consultations include classroom and home visits, identifi-

cation of team priorities, planning interventions, identification of resources, and follow-up coaching. Role clarification may also be needed due to the size of the collaborative teams and the lack of knowledge about some specializations.

Conclusion

While high quality educational programs are important for all children, they are critical for children who are deafblind due to reduced opportunities for observational and incidental learning. Program evaluation includes an examination of staff preparation, staffing patterns, curricula, professional implementation of evidence-based and promising practices, quality of professional

and student interactions, required assistive technologies across environments and activities, each child's yearly education plan, progress monitoring, and effective collaboration. The ideas presented in this article may support program self-evaluation by educational teams or evaluations conducted by consultants.

References

- Browder, D., M., Spooner, F., Courtade, G. R. (2020). *Teaching students with moderate and severe disabilities*. Second edition. The Guilford Press.
- Butler, R., & Bruce, S. M. (2022). Ecological assessment and individuals who are deafblind. *Dbi Review*, 68, 43-45.
- Council for Exceptional Children (2020). Initial and advanced specialty sets. <https://exceptionalchildren.org/standards/specialty-sets-specific-practice-areas>
- Damen, S., Prain, M., & Martens, M. (2020). Video-feedback interventions for individuals with congenital deafblindness. *Journal of Deafblind Studies on Communication*, 6, 5-44.
- Ferrell, K. A., Bruce, S., & Luckner, J. L. (2014). *Evidence-based practices for students with sensory impairments*. (Document No. IC-4). University of Florida, Collaboration for Effective Educator, Development, Accountability and Reform Center (CEEDAR Center). <http://cedar.education.ufl.edu/tools/innovation-configurations/>.
- Grisham-Brown, J., Degirmenci, H. D., Snyder, D., & Luiselli, T. E. (2018). Improving practices for learners with deaf-blindness: A consultation and Coaching model. *TEACHING Exceptional Children*, 50, 263-271.
- Hartmann, E. S. (2020). From fragmented practice to rich professional learning: The collaborative work of teachers of learners with deafblindness. *Frontiers in Education*, 5, 1-9.
- Hartmann, E. & Weismer, P. (2016). Technology implementation and curriculum engagement for children and youth who are deafblind. *American Annals of the Deaf*, 161(4), 462-473.
- Janssen, M. J., Riksen-Walraven, J. M., van Dijk, J., & Ruijsenaars, W. A. J. J. M. (2010). Interaction coaching with mothers of children with congenital deaf-blindness at home: Applying the diagnostic intervention model. *Journal of Visual Impairment & Blindness*, 104, 15-29.

ARTICLES

McKittrick, L. L. (2022). Parents of children who are deafblind face challenges in fostering collaboration within the individualized education program teams. *British Journal of Visual Impairment*, 09, 26461962211271.

McLeskey, J., Barringer, M-D., Billingsley, B., Brownell, M., Jackson, D., Kennedy, M., Lewis, T., Maheady, L., Rodriguez, J., Scheeler, M. C., Winn, J., & Ziegler, D. (2017, January). *High-leverage practices in special education*. Arlington, VA: Council for Exceptional Children & CEEDAR Center.

Multiple disabilities and deafblindness. Perkins School for the Blind.

<https://www.perkins.org/course-topic/multiple-disabilities-deafblindness/>

Nelson, C., Bruce, S., & Barnhill, B. A. (2022). Future directions in the field of deafblindness. In C. Guardino & J. E. Cannon, & P. V. Paul (Eds.). *Deaf and hard of hearing learners with disabilities: Foundations, strategies, and resources* (pp. 162-192). New York: Routledge Press.

Online learning. Texas School for the Blind and Visually Impaired.

<https://www.tsbvi.edu/statewide-resources/professional-development/online-learning>

Open hands, Open Access (OHOA) Deafblind intervener learning modules.

<https://www.nationaldb.org/products/modules/ohoa/>

Parker, A. T., McGinnity, B. L., & Bruce, S. M. (2011). *Educational programming for students who are deafblind: Position statement*. Council for Exceptional Children, Division on Visual Impairment.

Rodriguez-Gil (2009). The roles and responsibilities of team members for a student who is deafblind. *reSources*, 14(3), 1-6. California Deaf-Blind Services.

Rodriguez-Gil, G. & Brown, D. (2023). *A self-evaluation guide for assessing the quality of your interactions with a student who is deaf-blind. Fact Sheet*. California Deaf-Blind Services.

<https://cadeafblind.org/wp-content/uploads/2023/10/Fact-Sheet-A-Self-Evaluation-Guide-for-Assessing-the-Quality-of-Your-Interactions-with-a-Student-who-is-Deafblind-.pdf>

Sundqvist, A-S., Wahlqvist, M., Anderzén-Carlson A., & Olsson, E. (2022). Interventions for children with deafblindness-An integrative review. *Child Care Health Development*, 49, 407-430.

Taylor, E., Stremel, K., & Steele, N. (2006). Classroom observation instrument for educational environments serving students with deaf-blindness.

Texas Deafblind Outreach (2009, March). *IEP Quality indicators for students with deafblindness*. Texas Deafblind Project.

https://txdeafblindproject.org/wpcontent/uploads/2022/07/IEP_Indicatoars.pdf

The learning center. Helen Keller National Center.

<https://www.helenkeller.org/professional-training/>

What is the expanded core curriculum? Texas School for the Blind and Visually Impaired.

<https://www.tsbvi.edu/programs/ecc>

Launch of the National Model of Educational Services for Learners with Deafblindness and Multiple Disabilities in the Dominican Republic

Great news from the Dominican Republic. On March 15th Ancell Scheker Mendoza, Vice minister of National Technical Pedagogical Services, and Lucía Vásquez Espínola, General Director of Special Education of the Ministry of Education (MINERD) officially launched the “National Inclusive Educational Model for Students who are Deafblind and with Multiple Disabilities in the Dominican Republic”¹. The first model of its kind in Latin America and the Caribbean. This is a nation-wide, innovative policy that will transform the access and quality of education of children and youth with disabilities throughout the whole country, especially the more than 40,000 who are deafblind or have multiple disabilities (DB/MDVI)², opening new opportunities for them and their families.

Since 2022, MINERD, Foundation ONCE for Latin America (FOAL) and Perkins School for the Blind (Perkins), with the participation of organizations of people with disabilities as well as their families,

joined efforts to design a model with the goal of inclusion and equity for students with DB/MDVI so they can receive a quality and accessible education.

¹ See the launch in <https://www.youtube.com/watch?v=t8OD5lQbl10>.

² Estimations based on WFDB (2023) and Paul et al. (2021)



GLORIA RODRÍGUEZ-GIL

DIRECTOR LATIN AMERICA AND THE CARIBBEAN, INTERNATIONAL PROGRAMS PERKINS SCHOOL FOR THE BLIND, UNITED STATES OF AMERICA,

GLORIA.RODRIGUEZ@PERKINS.ORG



ALVARO DIAZ

DIRECTOR OF RESEARCH, INTERNATIONAL PROGRAMS PERKINS SCHOOL FOR THE BLIND, ARGENTINA

ALVARO.DIAZ@PERKINS.ORG



Fig. 3. Group of personnel from the MINERD Special Education Department, National Resource Center “Olga Estrella”, FOAL and Perkins

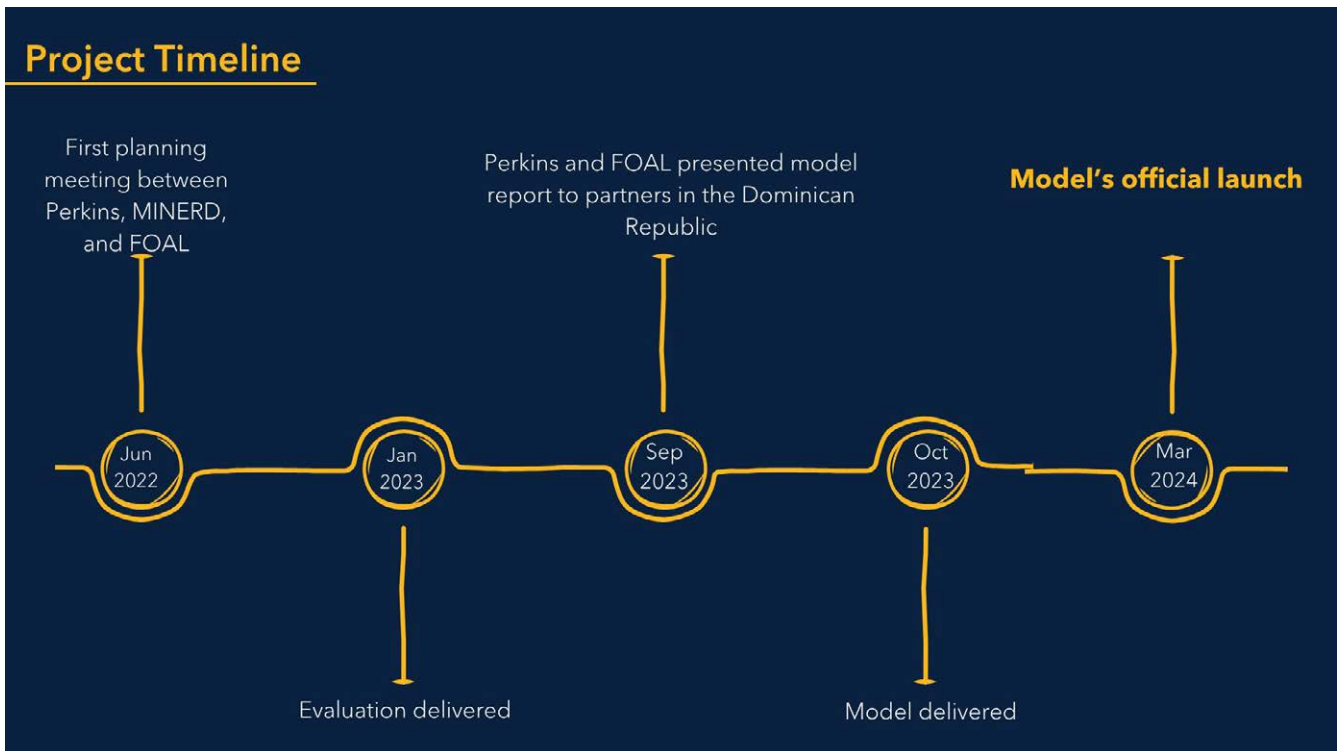


Fig. 4. Model project timeline graphic from June 2022 to March 2024

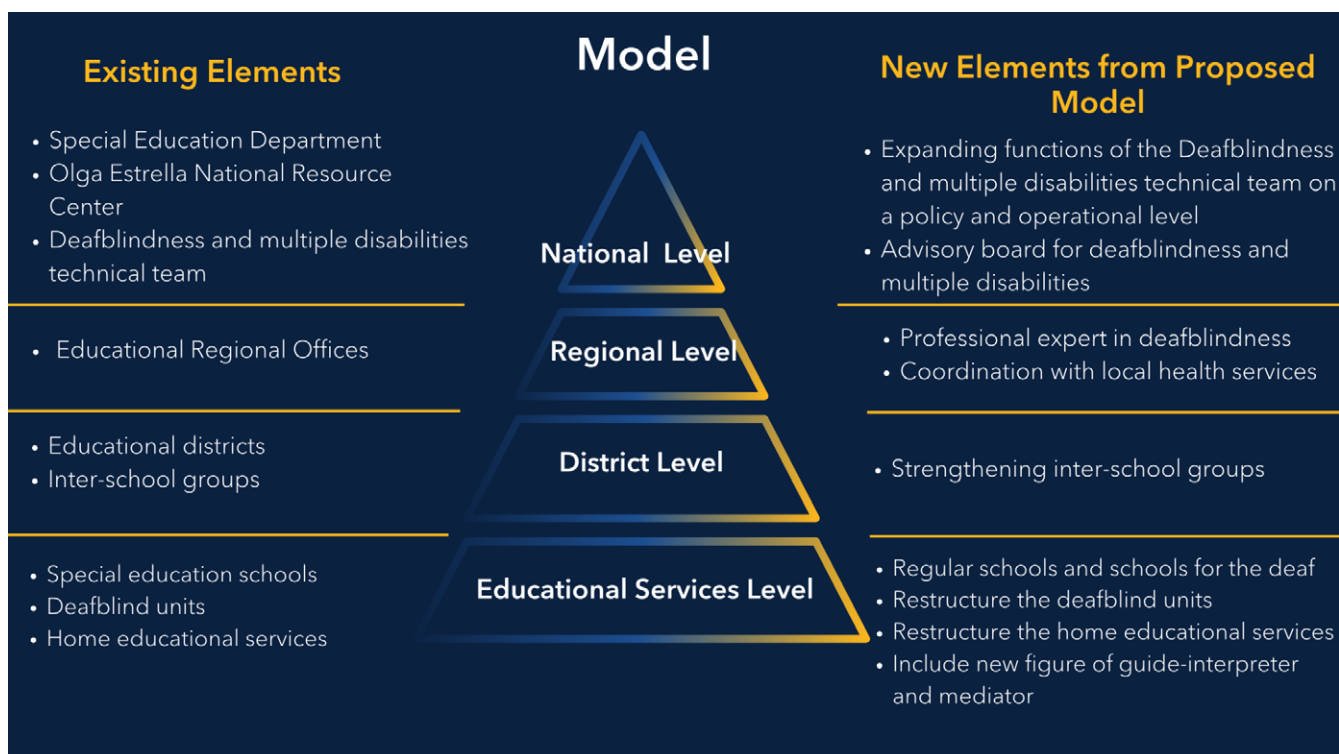


Fig. 5. Visual Representation of Existing and Added Components

To tackle this challenge, three development phases were established. The first phase involved an evaluation of educational services (Fundación Once para América Latina [FOAL] and Perkins School for the Blind [Perkins], 2023). The second phase involved the development of the model of services which included orientations for a definition of deafblindness (FOAL & Perkins, 2023) aiming to establish a national consensus regarding its recognition as a distinct disability and for identifying within the population. Early identification of deafblindness will help allocate resources and services more efficiently to provide people with deafblindness with the support they need. Finally, the third phase involved a proposal for technical training necessary to implement the model (FOAL & Perkins, 2023). Below is the timeline outlining the phases of the project leading up to the launch of the model.

Fully integrated within the international human rights framework, this policy will contribute to SDG4¹ ensuring accessible, inclusive, and quality education, and SDG10 reducing inequality, increasing social participation, and decreasing discrimination.

¹ See <https://sdgs.un.org/goals>.

Also collaboration between public and private organizations will contribute to SDG17. Additionally, the model addresses eight of the nine actions proposed by the United Nations (2019).

The model was built upon the interaction of six principles so that systemic transformation can happen. Its foundation is rooted in a rights-based approach, recognizing the government's responsibility to ensure inclusive education for all. This initiative highlights the importance of collaboration among professionals, families, and communities to address the needs of students with DB/MDVI. Furthermore, it underscores the need for leadership in educational institutions to address challenges, as well as the importance of continuously adapting the educational system to meet the changing needs of learners. Quality education is emphasized, with data-driven management as a means for continuous improvement of educational processes.

The model builds upon the existing MINERD structure, aiming to coordinate and enhance services where needed, considering national,

regional, district, and educational program levels. Some of the new features incorporated are: At the national level, the expansion of the national technical team to focus on two different tasks, namely public policy and the operation of the model; establishing a national advisory group. At the regional level, ensuring the inclusion of a specialist on DB/MDVI and the coordination with local services for the identification and procurement of medical evaluation. Strengthening inter-school groups at the district level is deemed crucial for knowledge and experience sharing. Additionally, the model supports inclusion in regular and special schools, as well as the restructuring of the specialized deafblind units and home-educational services, and the incorporation of interveners or guide-interpreter.

Despite the recent official launch, several components have already been established

in the preceding months. Five educational regions have been selected to participate in a pilot program with training sessions conducted to teachers and professionals. Learners with DB have already started to be identified within schools. MINERD has started an awareness campaign on DB/MDVI. An advisory board composed of government and civil society organizations has been convened to collaborate with the development of the education of learners with DB/MDVI. Their first task will be working on the national definition of deafblindness.

Education is much more than just going to school, but school is a privileged place of education. However, inclusion that is not of quality is not real inclusion. Through this policy the Dominican Republic is showing the world that the country is committed to demonstrating that every child can learn.

References

1. Fundación Once para América Latina and Perkins School for the Blind (2023). *Todos Los Niños, Niñas y Jóvenes Pueden Aprender: Evaluación de los servicios educativos para la población con sordoceguera y discapacidad visual con otras discapacidades añadidas en República Dominicana*.
<https://perkinsglobalcommunity.org/lac/wp-content/uploads/2024/03/Informe-Republica-Dominicana.pdf>
2. Fundación Once para América Latina and Perkins School for the Blind (2023). *Todos los Niños, Niñas y Jóvenes Pueden Aprender: Propuesta Proyecto de Servicios Educativos Para Niños, Niñas, y Jóvenes con Sordoceguera en República Dominicana Aplicable a Estudiantes con Discapacidad Visual y Otras Discapacidades Añadidas*.
<https://perkinsglobalcommunity.org/lac/wp-content/uploads/2024/03/MODELO-EDUCATIVO-REPUBLICA-DOMINICANA-1-1.pdf>
3. Paul, S., Rafal, M., & Houtenville, A. (2021). *Annual Disability Statistics Compendium*.
[https://disabilitycompendium.org/sites/default/files/user-uploads/Events/2022ReleaseYear/2021 Annual Disability Statistics Compendium WEB.pdf](https://disabilitycompendium.org/sites/default/files/user-uploads/Events/2022ReleaseYear/2021%20Annual%20Disability%20Statistics%20Compendium%20WEB.pdf)
4. United Nations Department of Economic and Social Affairs (2019). *Disability and Development Report: Realizing the Sustainable Development Goals by, for and with Persons with Disabilities*.
<https://social.un.org/publications/UN-Flagship-Report-Disability-Final.pdf>
5. World Federation of the Deafblind (2023). *Second Global Report: Good Practices and Recommendations for the Inclusion of Persons with Deafblindness*.
https://wfdb.eu/wp-content/uploads/2023/03/ENG_WFDB-2nd-Global-Report_-FINAL-V6.pdf

Beyond Deafblindness: Ahimsa at the Forefront of Special and Inclusive Education

Introduction

Deafblindness significantly challenges communication, mobility, and social interaction, necessitating specialized educational strategies to overcome isolation and promote inclusion, autonomy, and dignity. In Brazil, the educational institution Ahimsa has been outstanding in the field of Special Education since 1991, in São Paulo, as a pioneering philanthropic entity focused on the qualification of individuals with deafblindness and multiple sensory disabilities (Araóz & Costa, 2008).

The Importance of Special Education for Inclusion

At the educational crossroads, Special Education is characterized by its focus on the unique needs of learners, thereby facilitating their comprehensive development, while Inclusive Education seeks to transform the school environment into a territory that celebrates and values diversity, fostering co-learning among students regardless of their differences. Specialized Educational Assistance (SEA) operates at the intersection of these approaches, effecting a smooth transition from specialized education to inclusive learning environments,

Adopting innovative pedagogical practices, educational, care, and health professionals foster the independence of their students, respecting their singularities and driving a learning paradigm that contributes to quality of life. Against this backdrop, this study investigates the impact of these practices on the lives of students, analyzing the pedagogical evolution of the institution, the methodologies implemented, and the social, educational, and individual transformations promoted.

demonstrating that special and inclusive education, far from being divergent, are complementary and cohesive in the pursuit of a welcoming and enriching educational system for all (Sartoretto & Bersch, 2010; Pletsch, 2014).

This operational duality, however, requires a systemic commitment to inclusion that permeates all layers of educational management, from public policy formulation to teacher training and community interaction. The challenge of establishing genuinely inclusive spaces demands

ANDRESSA FRANÇA

FEDERAL
UNIVERSITY OF
SÃO CARLOS, SÃO
CARLOS, SÃO
PAULO, BRAZIL

ANDRESSAF@ESTUDANTE.UFSCAR.BR

MARIA DA PIEDADE RESENDE DA COSTA

FEDERAL
UNIVERSITY OF
SÃO CARLOS, SÃO
CARLOS, SÃO
PAULO, BRAZIL

PIEDADE@UFSCAR.BR

consistent investments in resources and teacher training, as well as ongoing critique of the pedagogical methodologies employed. Reflecting on SEA practices should be viewed as an iterative and reflective process that enhances educational practice,

Method

Building on this premise, this study employed document analysis, as outlined by Gil (2008) and Prodanov & Freitas (2013), examining three primary documents: two detailing the history and foundation of Ahimsa and its Political Pedagogical Project (PPP), complemented by a public image collection available on one of the school's social media platforms.

History and Foundation: The Legacy of Ahimsa in Special and Inclusive Education

Ahimsa emerges as a milestone in Special Education in Brazil since its foundation, incorporating the Sanskrit principle of non-violence into its name and practices. Within its educational spectrum, the school offers a curriculum adapted from early childhood education through the 5th grade of elementary school, complemented by extracurricular activities and specialized services aimed at enriching the learning process. Concurrently, in the realm of social assistance, it implements programs focused on family support and advances in health services provision, particularly in physiotherapeutic treatments and making spaces available for research and innovative procedures, highlighting its efforts to become a specialized reference center (Muller, 2006; Ahimsa, 2002, 2023, 2024).

Grounded in the World Health Organization's International Classification of Functioning, Disability, and Health (ICF) (2001), the institution adopts a pedagogy distinct from conventional teaching, focusing on functional-

emphasizing that inclusion goes beyond the concept of physical accessibility and becomes a collective journey of learning, pedagogical renewal, and reimagining the social role of education (Bosco, Mesquita & Maia, 2010).

The analysis spanned a broad spectrum of information, from the evolution of the institution and its infrastructure to educational practices and community engagement, offering new insights into the challenges and advancements of Ahimsa in promoting specialized education aimed at inclusion.

ity and social participation, in line with the National Common Curricular Base (BNCC) (Brazil, 2016) and the São Paulo Curriculum (São Paulo, 2019). This is evident in early childhood education with activities engaging body and mind, and in the initial grades of elementary education, where an interdisciplinary methodology fosters the integration of knowledge with students' experiences.

Furthermore, the school promotes awareness and training for professionals and families, conducting ongoing training and establishing strategic partnerships with governmental bodies and academic institutions, for example, to assist in the transition of students to regular education. This effort to embrace diversity and strengthen ties with families and the local community underscores the institution's role as a vector of academic, social, and personal development, preparing its students for active and autonomous participation in society (Ahimsa, 2023, 2024).

The Ahimsa Political Pedagogical Project in Light of Brazilian Educational Norms

The Ahimsa Political Pedagogical Project (PPP) should reflect the directives of the prevailing national educational policies, artic-

ulating the individualization of learning and curricular flexibility, in line with the National Common Curricular Base - BNCC (Brazil, 2016)

and the specific guidelines of the São Paulo Curriculum (São Paulo, 2019). The connection between the PPP and these legal benchmarks reveals the need for revisions towards a more incisive methodological congruence.

The BNCC, focusing on special education from an inclusive perspective, suggests curricular flexibility and adaptation as strategies to meet the specific educational needs of students. The São Paulo Curriculum adopts this viewpoint, proposing guidelines that favor inclusion and respect for diversity. With the intention of harmonizing its practices with these normative documents, Ahimsa's PPP presents an overview of its pedagogical approach, teaching methodologies, target audience, and strategies for inclusion and accessibility (Brasil, 2016; São Paulo, 2019).

The PPP underscores the importance of adapting the curriculum to student needs, yet it requires detailed documentation and explicit pedagogical justifications for the curricular adaptations made and their motivations, strengthening the alignment with educational policies. There is also recognition of the need for continuous professional development. However, to enrich the guidelines governing training in inclusive practices and adapted teaching methodologies, a documentary record of teacher preparation aligned with the present challenges in educating students with deafblindness and multiple disabilities is needed.

The assessment process in special education requires a meticulous description of the evaluative methods, in harmony with normative guidelines. The PPP mentions functional assessment and authentic valuation, but detailing the assessment methods and how they align with the directives of the BNCC and the São Paulo Curriculum would rein-

force the integrity of the assessment process (Ahimsa, 2024).

The school-family partnership is an essential vector in inclusive education, highlighted both in governmental directives and in Ahimsa's PPP. Intensifying this interaction with detailed operational descriptions could also improve synergy with legal requirements, promoting more effective collaboration and holistic development of students, as well as fostering continuous feedback mechanisms between the school and families.

The transition to adult life and entry into the job market represent critical end goals emphasized by the BNCC and the São Paulo Curriculum. Planning activities that integrate life skills and professional competencies would contribute to a more comprehensive education for the students. Community engagement and support for the autonomy of deafblind students and those with multiple disabilities are aspects that should be explicit in the PPP, not just as institutional philosophy, but as concrete practices, systematized in specific programs and projects, serving as a model for other institutions (Ahimsa, 2024).

Aligning the PPP with current legislation is a dynamic process, necessitating periodic updates to reflect changes in educational practices and student needs. This document should be seen as a living instrument, a reflection of the educational aspirations of the institution, which adapts and improves continuously in response to its pedagogical context. It represents a serious commitment to the education of people with deafblindness and multiple disabilities and can progress further in fulfilling its educational mission. Dedication to a reflective and informed pedagogical practice solidifies its role as a benchmark in special education.

Challenges and Opportunities: The Reality of Striving for Excellence in Special Education

In its pursuit of excellence in special education, Ahimsa encounters challenges such as limited financial resources and the need for appropriate physical spaces, essential for expanding and enhancing its services. Operating in rented facilities, the institution faces limitations

that impact the full development of educational and therapeutic activities. Figure 1 illustrates the congested reception area, highlighting the urgency for more extensive infrastructure to facilitate mobility and accommodation of students, particularly those using wheelchairs.



Fig. 1. Institution's reception during student arrival and departure times

To mitigate these adversities, Ahimsa adopts innovative and sustainable initiatives, such as offering courses and workshops, creatively reusing recyclable materials in educational projects, and producing and selling handmade and food items crafted by students, showcased in the compilation of figure 2. These strategies not only generate additional resources for the institution but also promote inclusion, environmental awareness, and the development of practical and entrepreneurial skills among students. Despite financial and structural hurdles, Ahimsa stands out for its innovative educational approach and commitment to continuous quality improvement in teaching, revealing the institution's resilience and its capability to provide a conducive learning environment for its students (Ahimsa, 2023, 2024).



Fig. 2. Sequence of images from bread-making with active participation of Ahimsa students.

Conclusions

Ahimsa's journey in educating deafblind individuals and those with multiple disabilities in Brazil underscores its role as a cornerstone of pedagogical innovation and inclusion, despite facing financial and infrastructural challenges. By implementing Individualized Education Plans and fostering ongoing teacher training, Ahimsa ensures educational practices that honor student uniqueness and promote meaningful learning experiences. However, the scarcity of resources and lack of adequate spaces highlight the necessity for financial support and infrastructure investments to expand its services.

Overcoming these obstacles requires the involvement of the government, civil society, and strategic partnerships that provide financial support, promote the training of specialized professionals, and encourage research into new adapted educational technologies. Ahimsa's dedication to specialized education inspires the adoption of coordinated strategies to create a more inclusive educational eco-system, emphasizing the need for collective action to ensure the full and autonomous development of all students.

References

- Ahimsa – Associação Educacional para Múltipla Deficiência. (2002). *Histórico Final Ahimsa*. São Paulo, Brasil.
- Ahimsa – Associação Educacional para Múltipla Deficiência. (2023). *Histórico Ahimsa 2023*. São Paulo, Brasil.
- Ahimsa – Associação Educacional para Múltipla Deficiência. (2024). *PPP Ahimsa 2024*. São Paulo, Brasil.
- Aráoz, S. M. M., & Costa, M. P. R. (2008). Aspectos biopsicossociais na surdocegueira. *Revista Brasileira de Educação Especial*, 14(1), 21-34.
- Bosco, I. C. M. G., Mesquita, S. R. S. H., & Maia, S. R. (2010). *A Educação Especial na Perspectiva da Inclusão Escolar: Surdocegueira e Deficiência Múltipla*. Ministério da Educação, Secretaria de Educação Especial, Universidade Federal do Ceará.
Retrieved from <https://gedh-uerj.pro.br/wp-content/uploads/tainacan-items/14699/30349/2010 MEC Seesp Surdocegueira Deficiencia Multipla completo.pdf>
- Brasil. Ministério da Educação. (2016). *Base Nacional Comum Curricular (BNCC)* [PDF].
Re-trieved from <http://basenacionalcomum.mec.gov.br>
- Gil, A. C. (2008). *Métodos e técnicas de pesquisa social*. (6ª ed.). Editora Atlas.
- Muller, J.-M. (2006). Por uma educação para a não-violência. *Dialogia*, 5, 25-36.
Retrieved from <https://uninove.emnuvens.com.br/dialogia/article/download/884/757>
- Organização Mundial da Saúde. (2001). *Classificação Internacional de Funcionalidade, Incapacidade e Saúde (CIF)* [International Classification of Functioning, Disability and Health (ICF)].
Retrieved from <https://icd.who.int/dev11/l-icf/en>
- Pletsch, M. D. (2014). Educação especial e inclusão escolar: Políticas, práticas curriculares e processos de ensino e aprendizagem. *Poíesis Pedagógica*, 12(1), 7-26.
- Prodanov, C. C., & Freitas, E. C. de. (2013). *Metodologia do trabalho científico: Métodos e técnicas da pesquisa e do trabalho acadêmico* (2ª ed.). Editora Feevale.
- São Paulo. Secretaria da Educação. (2019). *Currículo Paulista* [PDF].
Retrieved from <http://curriculopaulista.educacao.sp.gov.br>
- Sartoretto, M. L., & Bersch, R. de C. R. (2010). *A educação especial na perspectiva da inclusão escolar: Recursos pedagógicos acessíveis e comunicação aumentativa e alternativa*. (1ª ed.) Ministério da Educação, Secretaria de Educação Especial.
Retrieved from <https://repositorio.ufc.br/handle/riufc/43218>

Objects as Communication Symbols for Students with Visual Impairments and Additional Disabilities

**FLAVIA DANIELA
DOS SANTOS
MOREIRA**

PROFESSOR
OF THE
POSTGRADUATE
PROGRAM IN
TEACHING VISUAL
IMPAIRMENT AT
THE BENJAMIN
CONSTANT
INSTITUTE/
PPGEDV-IBC – RIO
DE JANEIRO –
BRAZIL

[FLAVIAMOREIRA@
IBC.GOV.BR](mailto:FLAVIAMOREIRA@IBC.GOV.BR)

Abstract:

Reference objects serve to represent different concepts and support receptive and expressive communication. The need for cognitive closure refers to the desire to obtain answers that avoid doubts and ambiguities. Given this, the question arises: can reference objects promote communicative skills in students with multiple visual sensory disabilities at home? How to implement cognitive closure activities/strategies through remote teaching? Objectives: to verify whether participants started to communicate more, whether they made choices using reference objects, whether they used them to represent their routine with or without help from their mothers; implement cognitive closure activities/strategies, through remote teaching, offering concrete opportunities to represent the beginning and end of the service. Method: qualitative and quantitative research starting in April and ending in September 2021. Participants: three students, aged 10, 11 and 12. Location: institutional Google Meet. Results: although difficulties arose in implementing the use of reference objects in the domestic environment by mothers, the results revealed that their use favored communication, making choices and allowing students to represent the beginning and end of care in a concrete way. Considerations: in both remote and in-person teaching, it is essential that students are able to understand that things begin and end through concrete representations.

Keywords:

Need for Cognitive Closure. Remote Teaching. Choice Opportunities.

Introduction

Students with visual impairment and additional disabilities are part of a very heterogeneous group, in which visual impairment is the common element.

It is important to explain that visual impairment and additional disabilities involve visual impairment, blindness or low vision, associated with other disabilities. Additional disabilities often may include intellectual disability, physical disability, cerebral palsy, pervasive developmental disorders (stereotypies, impairment in social interaction and communication skills), neurological disorders, or poor health (Chen, 1995).

Many of these students may have complex communication needs. According to the Department of Communities, Disability Services and Seniors (2018), people with complex communication needs do not have all the communication skills to meet their needs. In some cases this condition is temporary, in others it is permanent.

Also according to the Department of Communities, Disability Services and Seniors (2018), some of these people, although they do not use speech to communicate, are able to communicate through other modalities, such as natural gestures. Other people can speak, but it is difficult for others to understand. There are also those who cannot understand what others say.

Students with visual impairment and additional disabilities and complex communication needs have limited access to information. This reduces their motivation to explore, initiate interactions, and actively participate in everyday activities (Chen, 1995). Corbeil and Normand-Guerette (2012) explain that in many cases, they manifest behaviors with communicative intentions to express emotions, preferences or irritation. The look, the smile, facial expressions, shouts, vocal emissions, sighs, tension and even silence are ways that allow the student to communicate with others.

Parents, guardians and teachers must, therefore, identify and decode these student behaviors and attitudes and accept that ev-

erything can be communication. Corbeil and Normand-Guerette (2012) mention that it is not possible to be sure about the student's communicative intention and the understanding of the message by other people.

A viable way to promote the receptive and expressive communication of these students is the use of reference objects. Okelford (1993) explains that reference objects are any objects that receive special meanings related to them. They can be whole objects or in part to refer to people, places, other objects, actions, foods or feelings. They are concrete ways to support conversational interactions and language development. They can even represent a student's daily routine and, contrary to popular belief, reference objects do not replace or impede oral language, but supplement the functions of speech (Okelford, 1993).

As mentioned previously, many students with visual impairments and additional disabilities have difficulty accessing information. It is common for things to appear and disappear before them without them realizing whether they started or ended. Determining the beginning and end in a concrete way is one of the ways to avoid uncertainty and ambiguity and meet the need for cognitive closure.

According to Webster and Kruglanski (1994), the need for cognitive closure is defined as the desire to obtain a definitive answer to a question, as opposed to uncertainty, ambiguity and confusion. This need for closure varies along a continuum. Webster and Kruglanski (1994) point out that some people feel a strong need for cognitive closure, while others avoid it at all costs and this depends on situational factors and individual differences.

For students with visual impairments and additional disabilities, it is very important to determine the beginning and end of school activities or individualized assistance, in order to avoid uncertainty and confusion. However, at the time of the COVID-19 pandemic (1), uncertainty was inevitable. Due to the high transmissibility and global spread of this virus, social distancing was imposed, the

use of masks became part of people's clothing and social inequalities became even more pronounced. Fear and uncertainty were common sensations.

Many adults, elderly people and children around the world have had their routines changed. If the COVID-19 pandemic caused disorganization and ambiguity for everyone, it is believed that this also negatively affected the lives of students with visual impairments and additional disabilities who, from one moment to the next, had their in-person attendance and classes interrupted.

Instead of the in-person modality, emergency remote teaching was implemented, in which the curriculum, planning and class dynamics needed to be urgently restructured with the intention of mitigating the negative impact of the pandemic on learning (Behar, 2020).

Given all these considerations, the following question was raised: can reference objects promote communicative skills in students with visual impairments and additional disabilities? How to implement cognitive closure

Method

This study is an integral part of a large Post-Doctoral research in Education of the Post-Graduate Program in Education at the State University of Rio de Janeiro. It lasted two years (2020 to 2022), was sent to the Ethics and Research Committee and received an Approved opinion under protocol number 4,211,598.

The method of this study is quantitative and qualitative in nature. According to Knechtel (2014), qualitative research values proximity to participants with the intention of highlighting their essence, socially constructed from reality. Quantitative research, on the other hand, is based on the quantification of data and variables and is opposed to ambiguity.

Three students participated in the research. Amanda was 10 years old at the time of the research, blind and diagnosed with autism. Isadora, 11 years old, low vision, cerebral palsy, severe motor disability, other conditions under investigation. Patrícia, 12 years old,

activities/strategies through remote teaching for these students?

These research questions raised the following objectives: Verify whether the students participating in this research began to communicate more, whether they made choices through the use of reference objects, whether they used objects that represented their daily routine with or without the help of their mothers. And implement cognitive closure activities/strategies, through remote teaching, offering concrete opportunities to represent the beginning and end of care in a concrete way.

This study is considered to be of great importance for Special Education, notably for students with visual impairments and additional disabilities and complex communication needs, for families and teachers as it uncovers topics that are little researched on the national scene and for presenting concrete options that they expand receptive and expressive communication and offer concrete means of representing the beginning and end of activities.

wheelchair-bound, blind and with diagnosis under investigation. These students do not communicate through speech and have complex communication needs.

The data was collected through filming via Google Meet Institutional and had two stages called: a) stage 1: baseline, data collected under natural contingencies; b) stage 2: intervention, data collected after the mothers received the objects and boards in the mail. The following were considered: 1) use of reference objects from the daily routine board to encourage communication, make choices and represent actions of the domestic routine; 2) cognitive closure activities/strategies using objects to represent the beginning and end of remote care. Expected target behaviors: 1) that the student used the objects to make choices alone or with the help of her mother; 2) use the object to represent the beginning and end of the service, taking it out of the basket to start and placing it inside the basket to finish.

Materials



Figure 1. Amanda's board. Source: Material prepared by the researcher.



Figure 2. Isadora's board. Source: Material prepared by the researcher.



Figure 3. Patrícia's board. Source: Material prepared by the researcher.

Results

The data from the baseline and intervention videos were analyzed qualitatively to highlight the evolution and number of times the students used their routine boards with reference objects and made choices. In the baseline phase, student Amanda had not yet received the objects and the board in the mail, so in the baseline she still did not use this material. The data revealed that Amanda used the objects 14 times with physical help from her mother and used them alone, only

This researcher created three boards with objects to represent the three students' domestic routine. The objects that represented the service and the recipients of the end result were chosen in each participant's home, following the instructions given by the researcher remotely.

The following instruments were used to collect data: a) filming, b) Protocol for Identification of Communicative, Functional and Interactional Skills adapted from the Child-Guided Assessment, developed by Jan Van Dijk (Nelson, van Dijk, McDonnell, & Thompson 2002). This research was scheduled to take place in person, but due to the risks posed by COVID-19 and the prolongation of this pandemic, the research was restructured to a remote mode to preserve everyone's health and safety. After contacting the families and explaining the objectives of the research, the researcher sent the Free and Informed Consent Terms by post, along with the boards and objects. The families signed it, photographed it and sent the images via WhatsApp to the researcher. Baseline and intervention data were analyzed using the Video Analysis Protocol for Student Target Behaviors, which was developed by this researcher to analyze the number/amount of occurrence of these target behaviors: number of times the student used the objects alone and with the help of her mother; number of times the student made choices alone and with the help of her mother. All videos were transcribed in full by this researcher.

once, with verbal support from her mother. Rowland (2009) explains that receptive communication corresponds to the ways in which the student receives and interprets information, while expressive communication refers to the ways in which the student expresses their needs, interests and emotions. The use of boards with reference objects favored both receptive and expressive communication, since it is a resource that offers information through touch.

Regarding student Isadora's performance using the reference objects, the data revealed that in the baseline phase, Isadora had not yet received the board with the objects in the mail, so she was not yet using them in her daily routine. During the intervention, Isadora used the objects six times with physical support from her mother and used them alone with verbal support from her mother once. Although reference objects are not standardized resources, their use must occur in a structured and systematic way by students with multiple visual sensory disabilities, as they serve to support communication and represent different concepts (McLarty, 1997).

Considerations

The results showed that the use of boards with reference objects, in times of the COVID-19 pandemic, favored communicative skills, provided a certain comfort when organizing routines and offered conditions for the three students to represent the beginning and end of the services. in remote teaching in a concrete way.

The effectiveness of routines only occurs when carried out on regular days and times, with the same objects and, preferably, with the support and encouragement of the same person (McLarty, 1997).

Another important aspect was the creation of opportunities to choose between two objects as a way of valuing the preferences of the three participating students.

Cognitive closure activities/strategies were particularly challenging to implement remotely, but brought beneficial results. In the case of students Amanda and Isadora, who used the same objects to represent the be-

During the baseline phase, Patrícia had not yet received the board with the objects in the mail, so she still did not use objects to represent her domestic routine. The data revealed that during the intervention Patrícia used the objects on her board six times with help and physical support from her mother, but did not use them once alone. Although Patrícia's mother received information about the concept of reference objects and the importance of using them systematically, the objects on Patrícia's board were changed several times, making it very difficult for her to relate them to her activities routine.

ginning and end of remote learning services, the results showed that they were able to use their objects once with the support and verbal encouragement of their mothers. The same did not happen with Patrícia, who had different objects throughout this research. Webster and Kruglanski (1994) are eloquent in mentioning that cognitive closure activities/strategies must be carried out consistently so that students are able to realize that things begin and end.

Therefore, it can be inferred that both in remote and in-person teaching, students with multiple visual sensory disabilities need opportunities to express their preferences and understand that things begin and end and not just appear and disappear like magic and without explanation.

Given the relevance of the themes presented here, it is believed that this study should be disseminated to encourage the practice of other teachers, professionals and families.

References

Behar, P. A. (2020). O Ensino Remoto Emergencial e a Educação a Distância. *Jornal da Universidade*. Porto Alegre, RS: Universidade Federal do Rio Grande do Sul. Disponível em: <https://www.ufrgs.br/coronavirus/base/artigo-o-ensino-remoto-emergencial-e-a-educacao-a-distancia/> Acesso em: 12/06/2023.

Chen, D. (1995). Who are young children whose multiple disabilities include visual impairment? In: Chen, D., & Dote-Kwan, J. *Starting points: instructional practices for young children*

whose multiple disabilities include visual impairment. Los Angeles, CA: Blind Childrens Center.

Corbeil, T., & Normand-Guerette, D. (2012). Analyse de pratique assistée vidéo pour l'enseignement aux élèves polyhandicapés. *Revue Francophone de La Deficience Intellectuelle*, 23, 13-21.

Knechtel, M. R. (2014). Metodologia da pesquisa em educação: uma abordagem teórico-prática dialogada. Curitiba, PR: Intersaberes.

Mclarty, M. (1997). Putting objects of reference in context. *European Journal of Special Needs Education*, 12(1), 12-20. DOI:10.1080/O885625970120102

Nelson, C., van Dijk, J., McDonnell, A. P., & Thompson, K. (2002). A framework for understanding young children with severe multiple disabilities. In: *Research to Practice for Persons with Severe Disabilities*, 27(2), 97-110. Doi: 10.2511/rpsd.27.2.97

Ockelford, A. *Objects of reference: promoting communication skills and concept development with visually impaired children who have other disabilities*. London, UK: Royal National Institute for the Blind, 1993.

Rowland, C. (2009). *Assessing communication and Learning in young children who are deaf-blind or who have multiple disabilities*. Portland, Oregon: Design to Learn Projects/Oregon Health & Science University.

Webster, D. M., & Kruglanski, A. W. (1994). Diferenças individuais na necessidade de fechamento cognitivo. *Journal of Personality and Social Psychology*, 67(6), 1049-1062.

Doi: <https://doi.org/10.1037/0022-3514.67.6.1049>

Notes:

(1) According to the Ministry of Health website, COVID-19 is a severe acute respiratory infection, with very high transmissibility and global dissemination, caused by the coronavirus SARS-CoV-2. For more, visit the website: <https://www.gov.br/saude/pt-br/coronavirus/o-que-e-o-coronavirus#:~:text=A%20Covid%2D19%20%C3%A9%20uma,transmissibilidade%20e%20de%20distribui%C3%A7%C3%A3o%20global>.

Toys to Learn Braille

JEAN-PIERRE BACHY

PEDIATRICIAN,
DESIGNER OF THE
SIXTEM CODE,
FORMER CHILD
NEUROLOGY
CONSULTANT,
CHUGA CHILD
GUIDANCE

JEANPIERREBACHY@GMAIL.COM

Acknowledgements

We thank A. Eberhard of the Grenoble Institute of Applied Mathematics, all the students and their teachers of the UJF1 of Grenoble who helped develop the SIXTEM project. The project was financially supported by the Rotary Club, the Lion's Club and the students' host institutions at Grenoble and Ile d' Abeau IUTs.

Summary

Applications of the SIXTEM code have been developed since the creation of the device intended for the individuals having disabilities. Obtaining 4th prize at the French National Micro 1980 of the National Informatics Agency (ADI) competition was the origin of the SIXTEM project in which many students of the University Joseph Fourier of Grenoble participated with the help of their teachers, the Rotary Club and the Grenoble Lion's Club.

The reluctance of institutes for the individuals who are blind to test the code, which they no longer considered useful due to the technological aids that were appearing at the time, encouraged us to entrust the development of the project to students. Their work has been published on the ResearchGate platform and is on open access.

An article introducing SIXTEM to the individuals who are deafblind was published in DBI Review but there was again a reluctance to learn a code, even if it is easy to learn, because it competed with a tactile adaptation of the American Sign language (ASL) and tactile languages which are very popular with the individuals who are deafblind because they are user-friendly and taught by very involved people.

The advantage offered by SIXTEM is its outlet for Braille, computer systems and the low cost of its implementation for disadvantaged countries.

We will only present the least expensive system since it can be built by any careful DIYer. The principle of SIXTEM code is the composition of all alphabet characters and punctuation by the association of 2 symbols, chosen from six, which represent the shape of a desired letter.

The symbols are represented on four faces of a half-cube which can rotate and tilt around its horizontal axis to allow the display of six symbols. The second half-cube without a symbol allows you to insert a space in the composition of a letter if necessary or a space between 2 words in the composition of a text.

The set of two half-cubes form a cube with designations in Braille located in the center of the cube's base having six removable pins representing dots.

To compose a word or text, all you need is a set of engraved half-cubes accompanied by a few half-cubes that are empty but available for a particular use.

We propose the second transcoding system based on a cube which faces include the symbols or characters of different alphabets: Braille, SIXTEM or Latin.

Introduction

Approved by UNESCO in the 1950s, Braille has been adapted to 133 languages and given rise to special Braille codes for music, science, and mathematical notation.

With the growing awareness of accessibility for the individuals having disabilities, these relief dots are everywhere: road signs, elevator buttons, new bank notes and even medicine packaging. The problem is that only a tiny fraction of the individuals who are blind read Braille today. In the United States, less than 10% (about 60,000 individuals) of approximately 8 million individuals who are blind use it regularly. This is a significant decline from the 1960s, when more than half of the country's blind population used to read Braille. (1)

If you hadn't learnt Braille as a child, the prospect of learning to read this code might seem daunting, as it requires six to nine months of intensive study and memorization. With advanced speech synthesis technologies and smartphone applications, experts fear that Braille will become a dead language.

Alternatives to the Braille code have been proposed, such as the ELIA system (1), which has been criticized by Braille supporters despite its ease of learning tested by 200,000 users.

Andrew Chepaitis, its criticized designer, responds: "We respect their opposition and criticism of our work. This is an area where a lot is at stake. People's independence, education, literacy and ability to work may be affected by our work".

For our part, we are convinced of the importance of Braille and its sustainability, but we are also concerned by the fact that 90% of the population likely to benefit from it does not have access to it for educational or economic reasons.

Hence, the reasons for our research are as follows: ease of learning, gateway to Braille,

low manufacturing cost, scalability, link with computer systems at the origin of the development of the code in 1978, and its possibilities of extension.

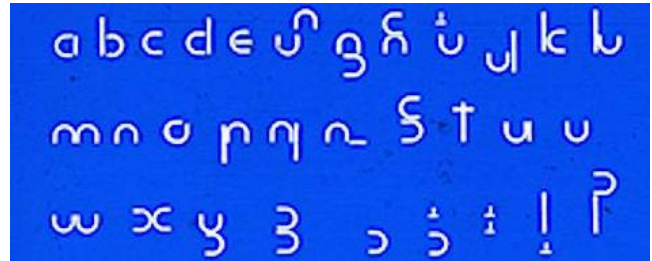


Fig. 1. Reminder of the simplified SIXTEM alphabet (2).

Key "1": Vertical line

Key "4": Small vertical or horizontal line or point

Keys "5, 2, 6, 3": left loop, right loop, upper loop, down loop



Fig. 2. Dedicated keys of the numeric keyboard (4).

The keyboard below offers six symbols on six pins allowing to write the alphabet like in a Braille cell.



Fig. 3. The original representation of the SIXTEM alphabet.

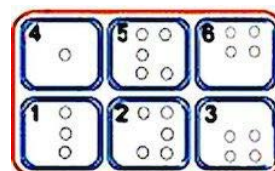


Fig. 4. Dedicated buttons with Braille type pins.

In previous studies we made a simulation on a magnetic board.

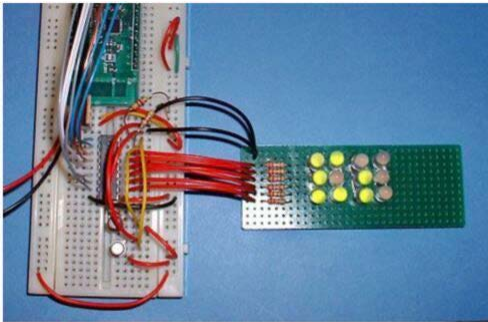


Fig. 5. The symbols are well recognizable on two 8-dot Braille cells but we have chosen the classic Braille with a 6-dot cell

The content of our programmed work on a microkit has been archived on the WayBaxkMacine.

Below, a display of an “a” on two contiguous LED arrays. (3)

Control of 2 LED arrays
By JeeP the Monday 24 May 2010 at 16h50



We use the multiplex program to write an "a" on the 2 matrices.
Loop oriented to the left (<) on the first 3x2 matrix and small bar (horizontal or vertical) on the second 3x2 matrix.
Instead of having to recognize 26 configurations for the restricted Braille alphabet on a 6-pin matrix, we have to recognize 6 configuratons on 2 6-pin matrices.

Fig. 6. Character “a” displayed on 2 Braille cells

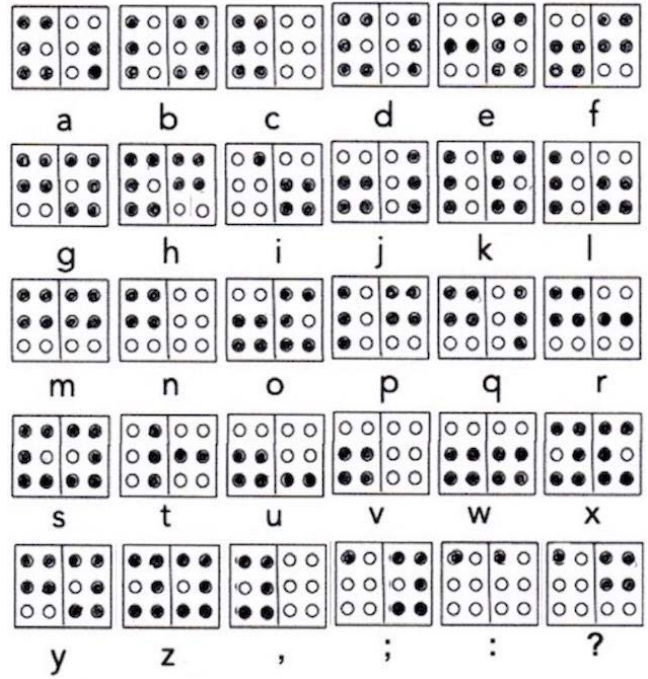
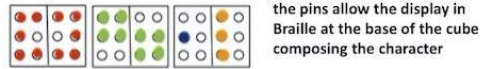
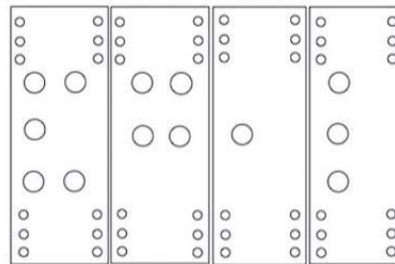


Fig. 7. Alphabet composition

the 6 sixtem symbols



Loop left, right, high, low, point, high bar



Rotating or reversing a box allows to offer 6 symbols for 4 faces.

Space

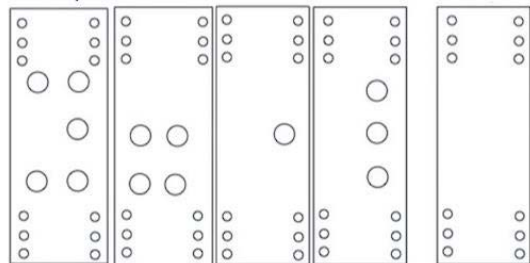


Fig. 8. Half-cubes showing symbols on four faces.

Six symbols can be represented on four sides of a half-cube by rotating or reversing the half-cube along its horizontal axis.

By combining two half-cubes, you can compose entire Braille alphabet.

Its 6-dot designation is in the center of the base. The pins are inserted into small holes and are removable. The cubes can then be put together to form words. Two empty half-cubes can be used to make the space between two words.

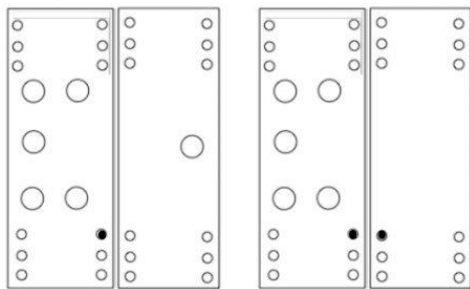


Fig. 9. Braille designation for “a” and “c” at the bottom of half-cubes (“1” pressed for “a”; “1” and “6” pressed for “c”). The half-cubes can rotate and tilt along their horizontal axes.

The pins are mobile (steel-headed nails, for example) and are put in their place when the character is composed.

A small cylindrical magnet attached at the bottom of the hole can hold the pins. Braille reading is then performed on the basis of the cubes threaded on an axis in place. Extraction can be done with a large magnet.

Alphabet braille (présentation traditionnelle)									

Fig. 10. Braille character chart.

We consider 3 ranges: from “A” to “L”, from “K” to “T” and from “U” to “Z”.

Configuration of the pins in the 1st range is repeated in the following ranges.

The 2nd range, from “K” to “T”, has one more pin: pin “3”.

The 3rd range also has one more pin: pin “6”.

“W” is an exception added because “W” did not exist in the time of Braille (point “3” is missing).

We admired this invention of a 16-year-old student and we sought to make the connection with the SIXTEM code. But given that the bases for developing the codes were completely different, there was no reason to connect them.

The use of Information Technologies solves the problem of transcoding but it is only accessible to a minority and we are oriented towards a wider audience.

We first needed support for transcoding that accepted 3 codes: Braille, SIXTEM, and Latin.

Therefore, we moved from a 2D representation to a 3D one.

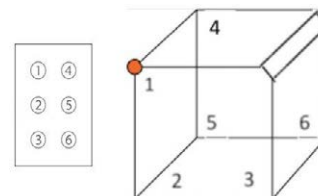


Fig. 11. 3D representation of the Braille cell

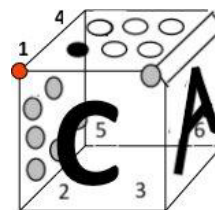


Fig. 12. The transcoding cube

This allows you to introduce the correspondence between the codes.

The beveled edge “7-8” is the reference of the cube.

SIXTEM TO BRAILLE

Six corners out of eight carry the Braille code (here in red for “A”).

The side with a Braille character is therefore unfolded and the corners have a specific marking (for example, a headed nail in a hole).

On the top side, the Braille character is common.

- The 1st SIXTEM code symbol is shown on the left side, the 2nd – on the right side.
- The Latin character is engraved on the front side.
- For those who have good tactile sensitivity, two symbols can be displayed on the rear side (two sets of six dots readable with two forefingers).

The 3D representation clearly visualizes the symmetries and defines the subranges from “A” to “E”, from “F” to “I”, from “K” to “O”, from “P” to “T”, and from “U” to “Z”.

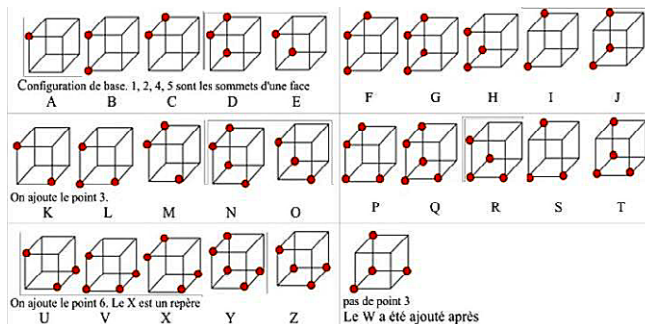


Fig. 13. Repetitive configurations of the faces “1”, “2”, “5”, and “6”. “K” to “T” have an extra dot “3”. “U” to “Z” have an extra dot “4” with the exception of “W”



Fig. 14. The association of two symbols reproduces the shape of a character (“4”, “5”).

The Ricoré medallion



Fig. 15. “By the fingers and eyes” on a capsule that comes with a Ricoré box.

An aluminum disk is embossed with a flat punch to write a text. The disc becomes a medallion.

The display of a 4-dot vertical line, small horizontal and vertical lines and a single dot facilitates tactile reading. They are programmed on an 8-dot Braille reader for reading SIXTEM code.

Magnefic Simulation

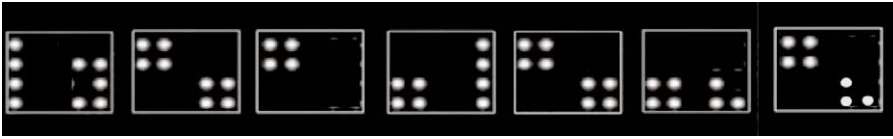


Fig. 16. “Bonjour” in SIXTEM.

Conclusion

We offer two complementary learning methods:

- The first is particularly economical since it only uses two elements, one of which is empty, but involves putting the Braille designation corresponding to the compound character. It allows you to write words and small messages by composing the characters as needed.
- The second method implies a prepared printing block which makes the correspondence between the codes but it is more elaborate and therefore more expensive.

These two methods are games and aren't considered as educational methods compared to the lessons having been structured for two centuries...

They were inspired by reflections of the psychologist Jean Piaget.

“Intelligence is what you use when you don't know what to do: when neither innateness nor learning have prepared you for a particular situation”.

“Playing is a job you have being a child”.

Children learn to learn.

References

1. ALIA <https://www.behance.net/blog/this-is-what-truly-inclusive-design-looks-like-today>
2. SIXTEM Badge https://www.researchgate.net/publication/345493282_Projet_Badge_Sixtem
3. WayBackArchive <https://web.archive.org/web/20120614175304/http://aweb2u.free.fr/dotclear/index.php?category/CPUStick-StickOS>
4. SIXTEM – a Code for Entering Alphanumeric Characters on a Numeric or Dedicated Keypad https://www.researchgate.net/publication/375558633_SIXTEM_-_a_Code_for_Entering_Alphanumeric_Characters_on_a_Numeric_or_Dedicated_Keypad
5. Pinguin game https://www.researchgate.net/publication/376073227_Pingouin_game_for_deafblind
6. CubiSIXTEM https://www.researchgate.net/publication/377385018_CubiSIXTEM

My Tactile Way: Revealing Tactile Potentials to Create New Possibilities. A Case Study

ESTHER KELLER

E.KELLER@
KENTALIS.NL

LISA MONEN

L.MONEN@
KENTALIS.NL

Introduction

This article describes a case study in which we assessed the tactile potentials and preferences, and stimulated the active communication skills of Peter, a young man with congenital deafblindness (CDB).

Case description

Peter is a 25-year-old man with CDB because of a chromosome abnormality. Peter is completely blind and has some residual hearing. He has a cognitive delay, motor impairment and a poorly developed vestibular sense. He has very fluctuating arousal levels. His caregivers use speech in daily interaction with him. Peter understands familiar words and short sentences. Peter himself can't speak. He uses body language and signals to communicate actively. He can take someone's hand and start a movement with it, which stands for certain songs. When singing these songs, interaction partners make these movements together with Peter's hands and on his body.

His caregivers wanted to know how they could stimulate Peter's active communication skills and

asked the authors of this case study, a communication coach and a speech and language therapist, for advice. We hypothesized that he could benefit from using the bodily-tactile modality in communication, as for people with deafblindness, there is a high risk that the processing of information is fragmented or limited. Especially if the functional use of residual vision and hearing is not supported by the bodily-tactile sense. Individuals who are deafblind benefit from interventions compensating for their limitations in hearing and vision, as well as from an environment that allows them to make the best use of their bodily-tactile senses (Nicholas, Johannessen & van Nunen, 2019). For a person with CDB the bodily-tactile modality is the primarily communicative access to the world (Dammeyer, et al., 2015).

Methodology

With this hypothesis in mind, we started our assessment. Our questions were:

- What are Peter’s tactile preferences and possibilities?
- What are Peter’s working memory potentials in the bodily-tactile modality?
- How can we stimulate Peter’s active communication skills in the bodily-tactile modality?

To answer these questions, we used two different instruments. To find out Peter’s tactile preferences and possibilities, we used the Tactual Profile MDVI (TP-MDVI). TP-MDVI is developed for persons who have Multiple Disabilities and are Visual Impaired (MDVI). The instrument has been outlined as ‘structured observation’ (Withagen, et al., 2017). We used it in a dynamic way, as a starting

point for stimulation and training of tactile functioning.

To reveal Peter’s working memory potentials in the bodily-tactile modality, we used the Tactile Working Memory Scale (TWMS). The TWMS has been developed with the aim of enabling the identification and promotion of working memory in the bodily-tactile modality in individuals with CDB. It is a dynamic assessment instrument and focuses on the working memory processing part. The TWMS appoints two key intervention strategies that are necessary to enhance tactile working memory: optimizing the physical and social environment and mediating learning strategies within a bodily-tactile modality. There are three major groups of learning strategies: perceptual, social cognitive and cognitive strategies (Nicholas, Johannessen & van Nunen, 2019).

Procedure

First, the TP-MDVI was used. Second, the TWMS was scored for the first time. Based on the results of both instruments, the TWMS

learning strategies were selected. After applying the learning strategies, the TWMS was scored again to measure progress.

First results

Results TP-MDVI

The TP-MDVI revealed that Peter needs communication partners to consider the following:

- Provide a steady, secure base.
- Use feet and legs for tactile contact. His hands are sensitive.
- Wait for Peter’s initiative.
- Don’t interrupt, stay available.
- Be predictable, use routines.
- Use firm touch.
- Be aware of his sequential perception.
- o Touch versus hearing
- o Using objects during interaction is difficult. Be aware of his arousal level.

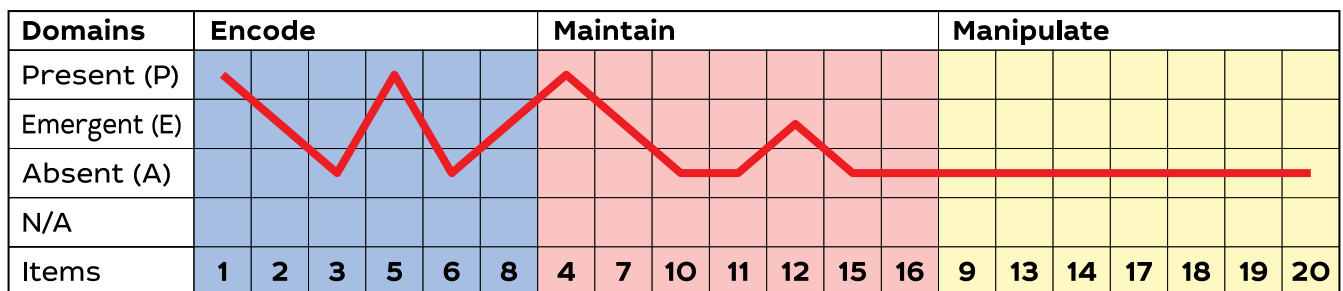


Figure 1. Pre-intervention profile TWMS

Pre-intervention Profile TWMS

The pre-intervention profile (figure 1) shows for example that Peter’s tactile sustained

Selection learning strategies

To select the learning strategies to stimulate Peter’s tactile working memory and active communication skills, we used the TWMS pre-intervention profile and the results from TP- MDVI. The TP-MDVI results were used to optimize the physical and social environment for Peter.

For Peter we selected social cognitive and cognitive strategies. These strategies focus on (tactile) interaction, which can be challenging for Peter sometimes.

Applying learning strategies

The strategies were applied during individual interaction moments between Peter and a familiar caregiver. In these moments the interaction partner created the right conditions for Peter to learn, using the learning strategies.

The interaction partner fostered a sense of togetherness by being physical close. She continually held tactile contact with Peter by sitting against each other or holding her hand against his leg/foot. She allowed him processing time and affirmed his signals tactilely. She provided scaffolding by using a clear routine, consisting of the same person, room and sequence of actions. The retrieval cue strategy was applied by creating a ‘frame’.

attention during interaction is developing. Peter can focus tactilely on an object or his interaction partner, but not at the same time.

Selected social cognitive strategies:

- Stimulating reciprocity and turn-taking.
 - Affirming signals.
 - Allowing sufficient processing time.
 - Fostering a sense of togetherness.
 - Providing scaffolding during interaction.
- Selected cognitive strategy:

- Retrieval cue strategy

When Peter touched his foot with his hand, the interaction partner chose to affirm this by starting to massage this foot. After that, she held her hand against it. A few minutes later, Peter touched his foot again and the interaction partner started the massage again. This repeated several times, also in the following weeks.

The ‘frame’ from the retrieval cue strategy helped Peter to remember the signal. The body position of Peter was important, his right leg needed to be on his left knee to be able to touch his foot himself. His shoes were always off. By maintaining contact with Peter’s foot with her hand, the interaction partner drew attention towards his foot to remember the signal.

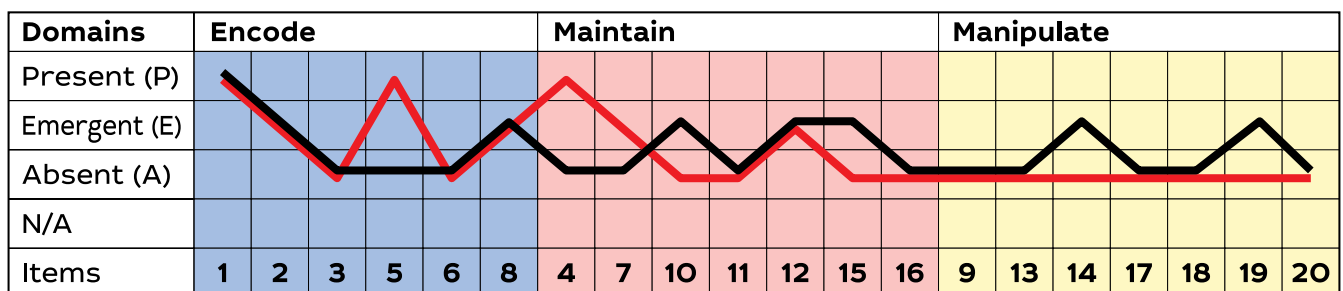


Figure 2. Post-intervention profile TWMS

Results

While using the same 'frame', Peter touched his foot to get a massage in various interaction moments.

Post-intervention profile

Figure 2 shows the pre-intervention profile (red line) and the post-intervention profile (black line) of the TWMS.

The pre-intervention profile is based on interaction moments where Peter used ob-

jects. The post-intervention profile is based on interaction moments where no objects were used. This is why some of the items scored 'P' or 'E' in the pre-intervention profile and 'A' in the post-intervention profile.

After applying the learning strategies Peter shows progress on 'Social Working Memory: mutual & joint attention', 'Sustained Attention: interaction-time', 'Attentional Switching' and 'Attentional Manipulation: maintenance cognitive strategies'.

Conclusion

We concluded that Peter's tactile working memory skills and active communication skills developed, after applying learning strategies in the bodily-tactile modality. Before, Peter communicated actively by body language, signals and using hands of the inter-

action partner to start a movement. During this study, Peter started using a new signal to communicate actively, using his own hand.

The combined use of the TP-MDVI and the TWMS was valuable in creating optimal conditions for bodily-tactile contact with Peter.

How to continue?

We would like to continue expanding Peter's tactile world. The next step would be to inform other caregivers about the possibilities

of applying learning strategies and creating pleasant interaction moments during everyday situations.

References

- Dammeyer, J., Nielsen, A., Strum, E., Hendra, O., & Eiríksdóttir, V. (2015). *A case study of Tactile Language and its Possible Structure: A tentative Outline to Study Tactile Language Systems among children with Congenital Deafblindness*. *Commun Disord Deaf Stud Hearing*, 2015, 3:2, pp. 1-7.
- Nicholas, J. T., Johannessen, A. M., & van Nunen, T. (2019). *Tactile Working Memory Scale – A Professional Manual*. Nordic Welfare Centre.
- Withagen, A., Blok, A., Huls, W., Jacobs, I., de Lange, M., Schening, N. & Zwijgers, M. (2017). *Tactual Profile MDVI*. Royal Visio.

The Red-and-White Canes



YANNIS PANAIRLIS

'ILIOTROPIO'
(='SUNFLOWER')
NATIONAL
DEAFBLIND
ASSOCIATION,
GREECE

YANNIS.PAN@HOTMAIL.COM

[I gave this speech, originally titled 'Living with Usher Syndrome', on July 1st 2023 in Athens, as part of the 'Disability and Cinematography' seminar organised by the Student Cultural Society of the University of Athens]

My name is Yannis, I am thirty five and I work as an architect. I was born and raised in Drama (North Greece). Age eighteen, I moved to nearby Thessaloniki where I spent my undergraduate years and then moved again, this time to London where I stayed for nearly a decade. Nowadays, I live and work in Athens. During the last seventeen years I have shared living with Usher Syndrome (type 2A) and today I'd like to speak to you about this *living-together* state of being.

Usher syndrome is a genetic chronic disease which falls into the broad spectrum of deaf-blindness. To be more specific, I suffer from a syndrome type that comes with two sorts of impairments: firstly, a congenital severe hearing impairment which in most cases remains stable throughout the course of life, and secondly, a visual impairment called *retinitis pigmentosa* which leads to the gradual degeneration of the retina cells. The latter entails a slow and stepwise visual loss, which begins from the peripheral areas of the eye and moves on towards the central parts of it.

The diagnosis of the disease happened in two different phases. I don't recall the first diagnosis and its impact, as I was three years old. During the very first years of my life, prior to that first diagnosis, my hearing impairment was mis-understood by my family as a

childish sign of an inward-looking aloofness. Slightly later on, the fact that I was late in developing speech -which by the way once it appeared it came with an articulation disorder- worried my parents who tried to understand 'what-is-wrong-with-him'. By then, I was old enough to patiently co-operate during the medical procedures that my father initially put me through as he happened to be an ENT doctor. The medical test results indicated that I suffered from an incurable form of *sensorineural hearing impairment*. At the beginning, this was a shock to my family; they felt fear, sadness and an inescapable sense of uncertainty and worry regarding my future. You need to take into account that I was raised in a rural area during the nineties, in a small conservative town where disability means stigma, not to mention my family in which other disabled family members suffered, and still do, the consequences of an outer 'cruel' world. Almost immediately, I became a hearing aid user; which I still am today. I tirelessly attended speech therapy sessions to get rid of the lisp I had in most of the alphabet sounds. Maybe in this way I would manage to achieve school readiness and start school as any other 'abled' child. And so it happened. My academic years (primary/secondary schools & university) passed by with no significant setbacks. The immense love and solidarity I received from my family,

teachers, friends and classmates has been the most precious possession I keep still today.

At university when I was about twenty years old, I started noticing a slight difficulty in perceiving moving objects, especially when they moved fast. Example given, I can recall a time where I was standing in the middle of a football pitch and how hard it was to know where the ball was. Or I remember instances where I was stumbling over lower pieces of furniture while walking in unfamiliar narrow areas. At first I thought that all this was happening because my short-sightedness or perhaps my astigmatism had increased. I arranged an appointment at an eye clinic in Thessaloniki. The diagnosis was simple and direct: *retinitis pigmentosa*; a condition I had never heard of up until that moment, a name that took me a while to even pronounce properly. During that visit, while the eye doctor was describing to us –my mother and I– the unpleasant prognosis, a medical student who was present observed that I used hearing aids. She apologised, left the room and before I knew it she came back with a thick book. Her book told her, the initial diagnosis was incomplete. Long story short, she concluded that I suffered from Usher syndrome, one that they, same as the majority of medical specialists I have met since that day, have never encountered in (a) person.

This second shock, almost twenty years after the first one when I was three, was equally significant – the only difference between the two is that this second one I can recall. At least the first time there was a promising magic solution –the hearing aids–, now *what? What can I do? What will happen? How is it going to be?* The feeling of fearful helplessness due to a hard-to-digest prognosis was the first step of an unprecedented ladder that I was forced to ascend. I quit my university studies for a brief period of time as the only way to absorb the heat of that first numbness. At the same time, I was privileged enough to start psychotherapy to help me manage the negative feelings and the anxiety that started to emerge. Apart from dealing with Usher syndrome, this decision had a much wider beneficial impact on me. Day by day, and because of my personality, I managed to develop a fragile balance between myself and my loved

ones –family, friends, partners etc– when it came to Usher syndrome. Such a condition was not easy not only for me, but of course for the people too that love and surround me. Staying informed, from a medical point of view, and being open about my disability allowed me –an ongoing ‘battle’– to manage this situation that was so abruptly introduced to my life. It took me ages to reconcile, to integrate Usher into myself. Year by year, the quiet world of my childhood and adolescence blends smoothly with the dark, dimly-lit world of my adulthood. During this process, my body and mind are developing adjustment mechanisms which I was unaware of; the rest of sensory organs, orientation, spatial perception, memory, imagination are now way more sensitive than before. Another unexpected and positive turn of events, as part of that process, I’ve recently developed an in-depth relationship with literature and fiction writing. Creating fictional spaces can perhaps become my way of *hearing* and *seeing* clearly.

Around ten years ago, when I left Greece and moved to the UK, I became acquainted with the British national health service. I informed them of my condition and they immediately initiated the relevant medical protocol. I underwent various medical tests –genetic test included– which confirmed the Usher diagnosis, all provided free of charge. Additionally, an official medical document called *Certificate of Visual Impairment* was granted, a document which rendered me entitled for a number of welfare benefits. Thereafter and every eighteen months, I pay a visit to the *Moorfields Eye Hospital* in London for routine check-ups. In addition, following a request by the research department of this specialist hospital, I have participated in a five-year long study collecting medical data on an annual basis from patients with Usher syndrome. The aim of this study is to get a better understanding and potentially develop a cure for some of the deafblind diseases.

Living with Usher syndrome is definitely a painful relationship. Deaf-blindness is ubiquitous in every aspect of my everyday life. That hardship is not only due to the impact of being impaired, but also due to the fact that Usher syndrome –at least in my current state– is an *invisible disability*, meaning a disability that is

not expected or suspected by the non-disabled people. As an example, I can make use of you, the members of the audience, right now, in front of me. If you were able to momentarily forget the subject of my speech and everything I have told you so far, you would have assumed that I'd be able to see you, similarly to you seeing me – a fact that is not true. This lecture hall is poorly lit, therefore I can't count heads, I can't locate you, I can't observe your physical appearance – a fact that you can't tell from my appearance or my behaviour. I don't blame you, probably I'd act and assume the same, our culture is primarily a visual culture which tends to exclude everything that is not visible.

Let me come back to the topic of how I manage my everyday life. I'd like to mention two points. Firstly, due to the slow progress of my disease, all practical changes that gradually take place happen on a moment-by-moment basis. I am privileged enough to have this slight buffer zone every time to adjust to how my Usher progresses without having to go through abrupt or sudden changes. For sure, some of my lifestyle preferences are different today than before, but I don't interpret this as a form of social isolation. Secondly, another lifestyle difference I can observe, compared to a few years ago, is that I constantly organise every little aspect of my personal life, e.g. I am walking around only when there is enough daylight as my vision is stronger during the day, or I am always being accompanied in unfamiliar contexts like a concert hall, a theatre, a bar etc. In order to achieve this, I am trying to stand above my inhibitions and ask for help -from people I do or don't know- I describe to them what's going on and what sort of assistance I need. Year by year, I avoid putting myself into circumstances that can be awkward or dangerous, though having lost the quality of a spontaneous everyday life. No big deal, one has to find new ways to make sure they don't end up socially isolated, a trap that constantly looms over disabled people.

As my speech is coming to an end, I would like to mention the concept of *future*. I am not referring to my own personal future. I am more interested in the future of the world of the disabled people and the discussions that are

to be had in relation to the ways in which we can move forward. I'd like to share two points. The first one concerns the need for all disabled people -and the people that are close to them- to join their respective organisations, societies, associations etc. Since I came back to Greece two years ago, I met the '*Sunflower*' *National Deafblind Association* and many of its members –a few of them here with us today-. I became aware of the challenges the deafblind people are dealing with nowadays in Greece, I was informed that there is no clear definition for deaf-blindness within the local law system / welfare state, which considers that deaf-blind people are suffering from two distinctive impairments –visual and hearing- and not from one dual condition. On the other hand, I became aware of all these wonderful efforts and actions that the '*Sunflower*' *Association* has achieved with limited resources since its foundation in 1992, largely actions related to the creation of educational and re-establishment facilities for deafblind children and adults. '*Sunflower*' also taught me that deaf-blind people should use red-and-white canes and not the white ones used by blind people, a practice that pretty much no one is aware of. In conclusion, stronger disability associations lead to enhanced arguments for more inclusive urban environments and public means of transport, towards a society that all of its members have equal rights to work, free time and self-fulfillment, towards a future where non-disabled people are better-informed on the various aspects and challenges disabled people are facing. No collective right was won by individual action.

The second and last thought I'd like to share with you today is about approaching disability with a sense of openness. I am afraid that being open about disability should be initiated by disabled people ourselves – at least by the ones who are able to do so. It is very important for us to feel open, to speak our minds to the people that surround us, to inform them about the challenges that suppress us. That way non-disabled people's lack of knowledge will eventually be ruled out. I believe that this is the only way our diversity will transform into a norm. After all, we are all different and everyone needs to realise that disability concerns us all. Therefore, if I chose to end my speech with one word, that would be openness.

A Parent's Perspective

My 26 year old son lives with Congenital Deafblindness (Cdb). The day he was born, doctors said I didn't have to take him home from hospital if I didn't want to. We haven't looked back since. As is common for children with Cdb, my son was referred to many support services. By his first birthday, I was exhausted. We had a stream of professionals coming to the house and many hospital appointments. I had been plunged into an unknown world of disability and no longer had control over my daily life. My initial feelings of shock, fear, and bewilderment at having a disabled child became mixed with relief, hope and optimism at the help that was offered but it was also overwhelming.

I was told my son had Cdb when he was 18 months. I heard the word but had no idea what it meant. No one explained and I didn't ask. Why not? I was exhausted physically and emotionally; I didn't know what I didn't know, and I assumed if there was anything I needed to know, I would be told. How wrong I was!

Years later I discovered the information that my son had Cdb was not included in the paperwork that followed him through school. As a result, his Cdb was not considered by therapists or teachers. Also, assessments did not allow for his Cdb: he was perceived as failing to achieve in all areas. My son was judged against norms of a sighted/hearing world. Professionals told me repeatedly what my son was never going to do: I was told he wasn't going to survive his first year; nor the following winter; he was never going to walk and his cognitive ability and potential were underestimated. My son was not listened to. His communicative actions and gestures were interpreted as "behaviour", and he was labelled as having "challenging behaviour".

I knew instinctively that my son was not supported appropriately

but in discussions with professionals I was not taken seriously despite being told "You know your son best". This was because I was "just" Mum; family knowledge has very low status (Breemer, R, 2023); I did not have the language of professionals so was seen as an outsider, not one of the inner circle with something worthwhile and useful to say; as my knowledge and ability to express myself in professional terms grew, I was then seen as a threat. Rather than opening the door to co-operative constructive discussion, my input and questioning won me a reputation for being uncooperative, difficult and a problem parent. Meanwhile, my son was adrift in a world that didn't understand him.

In 2015 I went to a DBI Conference in Romania. I met people living with Deafblindness (Db) who were interacting using tactile communication; they were active communicators, with agency, participating fully in the conference itself, and in the shared, joyful, exciting experience of all who had come from round the globe. It was the start of understanding my son's world.

LILIAS M. LISTON

MOTHER OF
PERSON LIVING
WITH CDB

[LILIAS.LISTON@
GMAIL.COM](mailto:LILIAS.LISTON@GMAIL.COM)

Looking back, what did I need to know to support my son as a person with CDb?

I needed to:

- understand and accept that my son wasn't "odd" or a "funny little thing", phrases I heard from professionals, but that he had a "unique disability" (Rødbroe & Janssen, 2006);
- know what CDb was, the consequences, and that people with Db have "access to the world within an arm's length" (Lundqvist, Klefstad & Seljeseth, 2013);
- understand the importance and function of other senses for a child with CDb and

crucially, the vital importance of touch. Without touch my son was alone, marooned on an island of isolation;

- understand my son's perspective on the world;
- know how to use my knowledge to make my actions and communications meaningful; I needed to meet my son in his world, not to try to drag him into mine;

The professionals around my son also needed to understand exactly the same things.

On reflection, what would I say to professionals?

See children with CDb as people with potential.

Take parents seriously. They really are the experts on their child.

Treat parents with respect.

Take nothing for granted.

Look past the "public face" and take the perspective of the parent.

Make no assumptions.

Treat parents as genuinely equal partners and work with them in true collaboration.

If a parent questions, welcome it with cooperation not judgement.

Receive every morsel of information from parents as a gift to be valued, cherished, explored and as a vital piece of the key that will help unlock that child's world.

What would I say to other parents?

Dare to challenge. The professionals in their real or imagined white coats are just people. They don't know everything.

Dare to ask questions. Why? When? Who? What? Where? There's no such thing as a stupid question.

Trust your instincts. If it doesn't seem right, then it probably isn't.

Demand explanation and clarification. If something isn't clear, ask again.

Demand training, information, knowledge. It's your right to be given the skills to communicate effectively with your child and to enable and empower them as they go out into the world.

You are truly the expert on your child.

Believe in what your child is telling you.

Believe in yourself!!!!

Kofi Annan, former secretary-general of the United Nations, said

"Knowledge is power. Information is liberating. Education is the premiss of progress, in every society, in every family" (1997, UN Press Release)

As families of children with CDb strive to meet their children in their world, the gift of knowledge, information and education will empower them in the face of opposition and adversity.

For professionals, the knowledge that families can bring will educate and inform, thus enriching their expertise and practice as they support people with CDb.

Working together families and professionals in the field of CDb will become empowered to unlock the door of bodily tactile

communication and cast light into an otherwise dark world of potential isolation and loneliness.

References

Annan, K (1997) Press Release SG/SM/6268

<https://press.un.org/en/1997/1997O623.sgsm6268.html>

van den Breemer, R. (2023). Presentation, DBI Conference, Ottawa

Lundqvist, E. K., Klefstad, L., & Seljeseth, T. (2013). *Feel my language* (L. Zachø Trans.).

University Hospital of North Norway, Regional Centre for People with Deafblindness:

doi: www.unn.no

Rødbrøe, I., & Janssen, M. (2006). *Communication and congenital deafblindness 1 congenital deafblindness and the core principles of intervention*. St. Michielsgestel, The Netherlands: VCDBF/Viataal.

Cross-Cultural Project on Deafblindness: an ERASMUS+ Project

MARJANA KENDA

DEAFBLIND ASSOCIATION OF SLOVENIA DLAN, LJUBLJANA, SLOVENIA

MARJANA.DLAN@GMAIL.COM

LASSE WINTHER WEHNER

CENTRE FOR SENSORY LOSS, THE NORTH DENMARK REGION, AALBORG, DENMARK

LASSE.WEHNER@RN.DK

RASMUS HOUGAARD PEDERSEN

CENTRE FOR SENSORY LOSS, THE NORTH DENMARK REGION, AALBORG, DENMARK

RASMUS.PEDERSEN@RN.DK

A project across borders

To keep developing knowledge on deafblindness and deafblind practice, it is essential with cooperation between specialized organisations working in the field. Often cooperation happens between organisations in the same geographical area with a uniform view on deafblind practice. These collaborations are important; however, much can be learned by collaborating with organisations that might not share a similar practice. The perspectives of another organisation have the potential to act as a mirror in which you can look towards your own practice. In this article we will describe a recently finished collaboration project – ‘Cross-Cultural

Theme days and visits

The theme days addressed several issues. The first theme day in Slovenia titled *“Deafblindness Among Us”* covered the situation for support and care for people with deafblindness in both Denmark and Slovenia and focused on tactile communication and the co-creation of meaning for people with deafblindness. The second theme day in Denmark – *“Human Rights and the Identification of Deafblindness”* – focused on the status of human rights in Slovenia and Denmark, about the devel-

opment of a functional assessment tool for identifying deafblindness, and on how to create a sense of community and unity for people with deafblindness. The last theme day held at the deafblind organization Dodir in Croatia with the title *“Bridging the Gap”* focused on good practices and recommendations for the inclusion of persons with deafblindness as well as on empowerment in relation to both congenital and acquired deafblindness.

- Theme days and visits in Slovenia, Denmark, and Croatia
- Publications in English and Slovene
- Attendances at the Nordic Conference on Deafblindness and the DBI World Conference

We will dive into these activities in the following.

With our theme days we wanted to not only raise awareness about deafblindness but also to bridge the gap between deafblindness and equal participation. We wanted to empower the word deafblindness and focus on all the ways people with deafblindness can contribute to society. People with deafblindness also participated. Among others, Hanne Ottesen from the Danish Deafblind Association had the opportunity to share her experiences – an invaluable knowledge.

Being in a hybrid format, the theme days reached out to students, persons with deafblindness and professionals working in the deafblind field across Europe – from Greece in the South to Sweden in the North.

Hosting a theme day in Zagreb by chance enabled us to visit Mali Dom – a public institution that provides services to children and young adults with severe disabilities. The visit was made possible by the regional director for Europe and Eurasia at Perkins International Darija Udovičić Mahmuljin, who provided a valuable insight into their practices and approaches. An initiative like this was not mentioned in the original project description but emerged as a possibility along the way.

So did a short internship at the Centre for Sensory Loss in Aalborg, Denmark for

Marjana (one of the coauthors of this article) from the Deafblind Association of Slovenia DLAN. During her visit she got to know the organization, different living units for children and adults with congenital deafblindness and the department for children with deafblindness in school and kindergarten for children with different impairments. She did a short internship in a residential unit for the youngest children with congenital deafblindness. Being able to be part of the residential unit enabled her to gain an insight into the approaches, work methods and guidelines followed by pedagogues who support children with deafblindness and other professionals. It was observed how in their work they take the child's wishes into consideration, give them power and control, and try to motivate the child in various ways to achieve a certain goal. The staff carefully strengthen and stimulate the residual senses in a calming way that is very beneficial. In all of this, they derive exclusively from the needs of each child. During the internship she also experienced therapy with horses and water therapy. This opportunity to visit one of the largest centres for people with congenital deafblindness was extremely valuable and she was able to learn from some of the best in the field of deafblindness and gain inspiration and motivation for future work.



EXCHANGE OF EXPERIENCE

Publications

Publications were also a vital part of the project and consists of several booklets that were translated into English and Slovene

The booklets are originally a Danish series on deafblindness aimed at professionals, people with lived experience and relatives but is also useful in introducing deafblindness to students and people with no previous knowledge on deafblindness.

Four different booklets have been translated into English and three of them into Slovene:

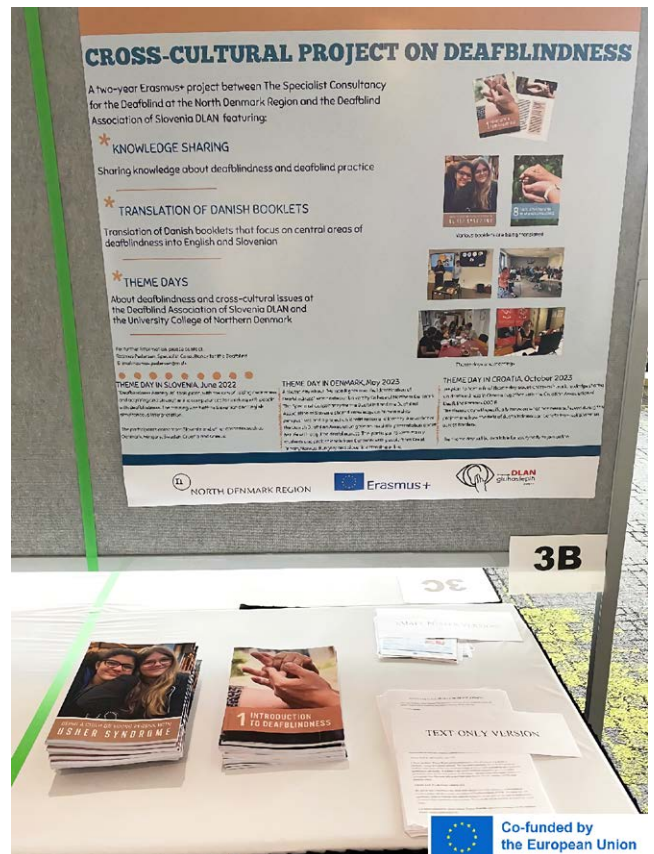
- Introduction to Deafblindness
- Being a Child or Young Person with Usher Syndrome
- Tactile Communication for People with Congenital Deafblindness
- Mobility, Guiding Technique and Congenital Deafblindness (English only)



To acquire the booklets in English, please contact lasse.wehner@rn.dk or rasmus.pedersen@rn.dk. The first limited print run is free of charge, except for postage and an administration fee.

Conferences

During the Nordic Conference on Deafblindness 2022 in Tampere, Finland and the Dbl World Conference 2023 in Ottawa, Canada we presented some of the perspectives of this project, hopefully inspiring others to reflect on how organisations working in the field of deafblindness can gain from similar collaborations and projects.



Bridging perspectives on deafblindness

To us, the Erasmus+ programme/project has been extremely valuable and proved an important opportunity for learning, growth, development, connection and mutual strengthening. It gave us an opportunity to learn from experts in the field of deafblindness, and thus develop the profession in Slovenia and Denmark respectively. Projects like these serve as an upgrade to our current knowledge and practical experience and moreover not only strengthen

professional approaches in working with people with deafblindness, but also further in-depth professional cooperation between the participating countries. This opportunity only came to be because of the funds given by the Erasmus+. Thus, we recommend EU-readers to explore the options of Erasmus+ – it might be easier than you think.

Please, do not hesitate to contact us, if you want to know more about the project or have other requests.

The Power of Mentorship Programs

SAMANTHA GASPAR

SENSITY COMMUNICATIONS & EVENTS COORDINATOR

SGASPAR@SENSITY.CA

Sensity Deafblind and Sensory Support Network of Canada, based in Paris, Ontario, Canada, has a rich history spanning over 30 years of dedicated service. We offer various services for people who are deafblind or experiencing sensory loss, along with Intervenor training programs and consultation services.

At Sensity, we pride ourselves on our strong introductory training program for our staff. At the same time, we are always looking for ways to improve our training. One of the strategies that we implemented over the past year is mentorship. With this article, we are sharing the results of that strategy.

Workplace mentorship, defined as a “learning partnership between employees” to exchange information and insights about a profession, is not a new concept. Historically, individuals have learned from those more experienced than themselves. At Sensity, we have created mentorship roles within our Training team to focus on this concept, supporting intervenors to apply the theory they learn in training in practical situations.

At the heart of our training philosophy is the principle of “Do With, Not For,” often referred to as the Intervenor Motto within the deafblind field. This principle calls attention to involving individuals who are deafblind in all aspects of their lives, essential for effective intervenor services. Although many intervenors join the field with a desire to assist others,

their goodhearted intentions to help individuals who are deafblind can unconsciously result in doing tasks for them, which limits opportunity for independence.

Mentorship shines when it focuses on the “Do With, Not For” approach. Our mentors, chosen for their ability to empower individuals who are deafblind, guide intervenors to apply their training to meet unique needs. Mentoring, boosts skills, understanding, and confidence among intervenors, regardless of their tenure. By emphasizing “Do With, Not For,” mentors breathe life into this principle. New intervenors appreciate the guidance as they apply their training, and even experienced staff feel refreshed by getting back to basics.

By providing mentorship and enhancing staff support skills, we empower both intervenors and individuals receiving services to pursue what matters most to them, aligning with our organizational purpose:

“Your Journey. Our Supports. Endless Possibilities.”

For more information on our Mentorship program, visit our website www.sensity.ca or contact training@sensity.ca.

Sensory Integration and Musical Therapy in Education Children with Deafblindness

In September 2021, a class for the children having multiple disabilities and children with deafblindness, was framed on the basis of the State Autonomous General Education Institution Nizhny Novgorod Regional Special Needs Boarding School for the Children who are Blind and Children Having Vision Loss. The children attend school on a full-time basis (6 hours a day). Currently, the class comprises 5 children of different ages who study there permanently.

Special attention is paid to every-day-living skills development: effective communication, spatial reasoning and mobility, social and domestic skills, challenging behavior intervention.

The children's schedule includes sensory integration lessons that represent a special feature of organizing activities in the class. These lessons are crucial for the children having developmental disabilities. They are oriented to assist in building missing skills that were not developed in sensitive periods under various circumstances. Reduction of sensitivity to stimuli or, on the contrary, satiation of sensory impoverishment help recover the balance as well as stop exerting effort and energy on protecting oneself from environmental exposure which imply faster and more active and harmonious development. Besides, the sensory integration approach may de-



FEDOTOVA ALENA

HEAD OF
RESOURCE
EDUCATION
CENTER FOR
CHILDREN
WITH MULTIPLE
DISABILITIES



**CHERNYAEVA
EVGENIYA**

MUSICAL TEACHER
AND MUSICAL
THERAPIST



**MITROFANOVA
ANNA**

SPECIALIST
ON SENSORY
INTEGRATION



**BELYAKOVA
EKATERINA**

SPECIAL
EDUCATION
TEACHER

[RESKABINET@
YANDEX.RU](mailto:RESKABINET@YANDEX.RU)

EXCHANGE OF EXPERIENCE

velop ability of proper emotional response in different situations, shape personal agency and improve the level of social integration. The more a child is conscious of their body scheme and feelings and the easier it is for them to perceive various characteristics of the environment, the more they are ready to study and communicate in both the class and society in general. Another important aspect of the sensory integration lessons is an opportunity to organize regular group lessons in the future, as an ability to perceive and feel is common for all people notwithstanding their sex, age, condition and developmental disabilities. Thus, the one can always find things in common, choose accessible and understandable options of sensory activity which will help expand and significantly improve interaction of children among themselves, share social behavior experience with them and acquaint with different elements of cultural heritage.

One more schedule feature is that the music lessons are held in a way unusual for a school.

We use music as a treatment tool. Inspiring and carrying away with cheerful rhythms and beautiful melodies, it has therapeutic effect on an individual. An individual doesn't perceive sounds only with the ears, but with the entire body. That is why it is effective in working with the children having multiple complex developmental disorder. Music impacts brain function as well as biological functions (breathing, warming, etc.). Elementary dances, jiggling to the live singing of a teacher motivate even the most complicated children to move. Music provokes a huge emotional response, relieves body tension. Being engaged actively or passively in music activities, a child becomes a co-creator of their own changes. The voice (singing), simple musical instruments (percussion, wind and string ones) are used at music therapy lessons. The lessons help stimulate developmental processes, balance physical and emotional condition, develop communication skills, improve self-adjustment.

We can form an opinion about effectiveness of studies based on the performance – children demonstrate dynamics of development.

Misha, 12 years old. Stage 5 retinopathy of prematurity (total blindness), severe hearing loss. Light physical disorders. Misha had a cochlear implant surgery on one ear but wasn't wearing the aid.

Before entering our class Misha hadn't attended any institutions and hadn't studied anywhere. He used to communicate with the others only by means of emotional response to their activities.



Figure 1. Sensory integration lesson

Main achievements:

- We have managed to get the boy used to wear the aid and now he wears it all day long that lets us continue working on hearing perception development;
- With the help of tangible symbols Misha has learnt the system of alternative communication (now his calendar includes over eight symbols meaning a specific activity), he has also learnt four tactile signs. We have also managed to normalize child's day regimen;
- Misha has learnt to wear a T-shirt, trousers and socks independently; he has learnt to wear and take off shoes as well as to spoon the food out.

Petr, 15 years old.

Stage 5 retinopathy of prematurity (total blindness), severe hearing loss, light motor impairment. Petr has been wearing super powerful hearing aids for about five years. Petr doesn't use oral communication. We use tactile sign language and special calendars composed of tangible symbols as a mean of communication.



Figure 2. Music therapy lesson

Before entering our class Petr had studied at a boarding school for the children having hearing loss located in a town different from the one where his parents lived.

Main Petr's achievement in our class:

- Hearing perception improvement: the boy has started reacting to adults' speech better, he can follow oral instructions accessible to him (understands about 200 words aurally);
- Passive and active sign vocabulary extension: Petr can communicate about his wishes by means of signs quite freely; he can show what hurts, make short phrases; he can ask questions "What is it?", "What are we going to do?", "What will be next?"; he can answer the questions and tell about an object "What it is" and "What object it is";
- Petr has learnt several fingerspelling words, which means that a word is expressed letter by letter;
- We are also teaching Braille to Petr: he has learnt to sort out enlarged letters; he can choose a specific letter from several letters;

- Petr has improved self-service skills: he has learnt to fasten even small buttons, to use scissors and a knife safely;
- He can sort out the objects as well as classify them (clothes, utensils, personal hygiene products, etc.);
- He learnt to distinguish objects by their properties (size, hardness, temperature, form, texture), count out a specified number of objects;
- He started using a long white cane for walking in the street properly.



Figure 3. The classroom

The one who plays the leading role in organizing education process in the class is a teacher – a specialist having a degree in the education for children with visual loss who has passed special training and is experienced in working with the children who are deafblind. Tutors – specialists that also have a field-specific degree in education or psychology, work under the guidance of this teacher.

A personal tutor spends with a child most of time, gives one-to-one lessons, accompanies a child at group lessons and during carrying out of the elements of the routine. Implementation of such a form of education would be impossible without full-time tutors, because the children who are deafblind require constant intense support in all types of activities.

Implementations for Children Who Are Deafblind Demonstrated in Renovated Building



**ASAKO
KAWAHARA**

[KAWAHARA-36@
NISE.GO.JP](mailto:KAWAHARA-36@NISE.GO.JP)

ATSUSHI KATO

**MICHIMASA
OZAWA**

YASUHIRO AIDA

THE AFFILIATION
OF THE AUTHORS:
NATIONAL
INSTITUTE OF
SPECIAL NEEDS
EDUCATION,
MULTIPLE
DISABILITIES
UNIT, YOKOSUKA
AND HIGASHI-
HIROSHIMA, JAPAN

Introduction

The National Institute of Special Needs Education in Japan has transformed the building, called “Research Unit for Natural Living Environment (Photo 1),” into a space for learning about deafblindness and considering education for children with deafblindness. This structure has several rooms, including a kitchen and bathroom, each of which

demonstrates adaptations for the lives of children with deafblindness. By actually using and operating the exhibits, children with deafblindness, their families, and teachers can collaborate on what can be incorporated into their daily lives and education. This paper discusses the entrance, kitchen, sensory playroom, study room, and teacher training room.



Photo 1.

(1) Entrance

At the entrance, visitors are given earplugs and clear files (or eye masks), and they can tour while experiencing a simulation of deafblindness. The clear file is a simple way to experi-

ence difficulty seeing, such as the cloudy condition (of course, we emphasize that these do not fully represent the state of deafblindness and that simulated experiences have limitations).



Photo 2.

(2) Kitchen

In the kitchen, we demonstrate environmental preparation for the independence of children with deafblindness. For example, we show tactile and simple clues, such as bubble wrap on the handle of the refrigerator. Also, on the table, we prepared dishes and other items (Photo

2). Furthermore, you can learn various cooking techniques from inexpensive products available. We want to think together about the independent lives of children with deafblindness from various perspectives, including vision, hearing, cognitive, and motor function.

(3) Sensory playroom



Photo 3.

In this room, we demonstrate ways for children with deafblindness to play while experiencing various sensations throughout their whole body. We value the opportunity to experience various sensations such as touch, smell, sound, and color alongside children with deafblindness and the people involved. From standard plays like sheet swings and safe fans, we have a wide range of different sizes and tactile balls, as well as light-based tools, etc. We hang various objects on the wall, allowing you to accidentally touch sensations you would not normally touch (Photo 3). Additionally, when you look up at the ceiling, you can see that the light is covered. This is because, for children who frequently lie down and move, direct light enters the eyes, making them appear dazzling or making other objects difficult to see.

(4) study room

In this room, we simulate the learning environment of children who are deafblind and demonstrate ideas for

teaching materials, teaching tools, and instruction. For example, we propose using color to allow you to access

EXCHANGE OF EXPERIENCE

your own luggage storage, chairs, and belongings independently. As shown in Photo 4, if a child prefers red, place a red sticker on the chair. If fluorescent green is easily visible to another child, place a green sheet on the luggage storage (Photo 4). Also, on the desk, we display a variety of teaching materials, including a calendar box and tactile teaching materials. Using these tools, we can consider methods of communication that are understandable to children, whether verbal or non-verbal. Furthermore, we value the ability to gradually expand the time frame in which we can gain perspective, from one hour to one day, and then to one week. Aside from that, we emphasize the importance of promoting autonomy, such as choosing for oneself, doing what one enjoys, and negotiating what one does not want to do.



Photo 4.

(5) Teacher training room



Photo 5.

This room is used by those who work with deafblind children, particularly teachers, to understand and discuss deafblindness. In this renewal, we upgraded ICT equipment such as iPads and laptops to consider the use of ICT equipment for children with deafblindness.

Future prospects

Future work will focus on improving the exhibits. We intend to invite children with deafblindness and their families to this building. Based on their experience, we intend to create more practical exhibits. Also, because there is a limit to what we can learn about

Acknowledgements

This work is supported by the Fast Retailing Foundation. Also, the renewed teacher

Following the renewal, it is primarily used as a training facility for visitors and teachers. We provide basic information about deafblindness before allowing visitors to experience a simple simulation of it. Even visitors who are unfamiliar with deafblindness can learn firsthand about the difficulties that children with deafblindness face and consider what they can do. Furthermore, with the advancement of ICT equipment, even if the deafblind child lives in a remote location, such as on an island or a mountain, training can be conducted online from this building. For example, we ask teachers to record the typical classroom situation, and we monitor the children's situation from this building. Then, we can imagine the child's visibility and hearing together and consider how to make adjustments, not only discussing the situation together but also utilizing the resources in the building, (Photo 5).

deafblind children through exhibits alone, we will collect information such as videos, books, and articles with practical examples. We work with external organizations and stakeholders to support children with deafblindness, teachers, and families across the country.

training room is supported by MORIMURA HOUMEIKAI FOUNDATION.

Four Days of Activities in a Forest

RUMA
CHATTERJEE



Figure 1.

“SENSE AND FEEL NATURE” is the theme when teachers and members of *Kolkata Society for Empowerment of the Differently Abled (KSEDA)* were thinking of having a nature study and adventure camp for its students with deafblindness and multiple disabilities. After so much debates regarding utilization of fund for this purpose, the desire had won and quickly a group of 7 campers between the age group of 9 and 16 years was finalized; it was an inclusive camp with 2 children without any disability and 5 were with deafblindness and multiple disabilities, and of them, only 3 were females and 5 males. Escorts were selected from teachers and parents. Two members of the organization looked into the logistics. Management was much relieved when Indian Mountaineering Foundation East Zone Committee (IMF EZC) managed to get the Matha Forest Complex, Purulia district in

West Bengal, free of cost from the Forest Department of West Bengal, India for four days, March 1-4, 2023. Thus, the team of 17 persons from KSEDA and 5 persons including Camp Commandant and instructors assembled at Howrah Station on 1st march early morning to board the to reach the camp zone on the same day.

The days were wonderfully planned with activities and feeling of freshness amidst nature. Familiarisation with trees, flowers, and fruits was held in the forest with practical experience of knowing by touch. They also learned about the usages of these by the forest tribal people. Tying knots and holding rope with two hands above for a rope walk was shown to them. Each camper did this exercise, starting with fear and ultimately ending jubilantly. There was another activity of Burmah bridge navigation.

EXCHANGE OF EXPERIENCE

Two parallel ropes were tied with another one in a zigzag pattern and one had to walk through this zigzag rope. It was a challenging one for the campers and took some time for each of them to feel and understand the cumbersome rope passage through which they had to move. With minimum support, they completed the task. Another event was climbing the spider net. Only one camper could climb to the top, and others also achieved according to their abilities. Instructors were cautious enough so that no one got frightened and left the game. The river crossing was another event of holding the rope in two hands and moving on by using a pulley.



Figure 2.

Boulder climbing, small rock climbing, and rappelling down using a harness was shown another day. Each one practiced those and experienced the thrill of climbing boulder/small rock using the technique of “three-point climbing”. Rappelling down was an exciting one for them.

A long trek of 5 km from the campsite to the nearby village using the forest trail was an enduring practice for all; each felt the pain of raising his / her foot one foot high to reach a safe place. Some felt the need to shed much extra weight to become physically fit. This trek for three hours with short breaks, was enjoyable to all the camp-

ers and the escorts. In such a break, the trainers showed them *palash* (*butea monosperma*), Flame of Forest trees with flowers blooming and spreading in the ground; the campers felt the petals by touching them. The trekking exercise was a test of endurance with feeling and sensing the change of narrow pathway and keeping body balance. Although escorts were holding campers' hands, most of the escorts were also experiencing this uphill trek for the first time. The whole team came back safely.



Figure 3.

Most enjoyable was the campfire. Each person of this camp showed their talents by telling stories, singing, reciting, drum beating, and a short skit showing the bounties of nature and need for its preservation. At the end, a sumptuous meal was laid down for all; it is generally called “barakhana”.

These four days passed so fast with full of excitement. We felt that the short camp routine provided joy not only to the students but to their parents also. Most of them bear the challenges of providing education / training according to the need and abilities of their son and daughter which leave little scope for their own enjoyments. In such a short time, these parents came closer and developed a bonding, unknown to them earlier. While going back to their own home, all were feeling to have this enjoyment in forest again in next winter.

Deafblind Spring Chow! – “Sharing a Meal, Sharing a Community”

Acknowledgements

Special thanks to the Deafblind Programme, Community Services from the Singapore Association for the Deaf and National Council of Social Services for supporting this event.

At noon on Saturday, 2 March 2024, the SAdeaf Deafblind community made their way to Fusion Spoon, located in Botanic Gardens, ready for quality time with each other, enjoying shared food, laughter, and connection. The aroma of local dishes, such as fried rice and spring rolls, accompanied the gentle hum of conversation that day as patrons from the general public joined in after their morning walk.

**ANGELES KIARA
LUNA**

THE SINGAPORE
ASSOCIATION FOR
THE DEAF

[KIARA@SADEAF.
ORG.SG](mailto:KIARA@SADEAF.ORG.SG)



Fig. 1. Members of the Deafblind Community waiting for food

EXCHANGE OF EXPERIENCE



Fig. 2. Communication via ProTactile Sign in action



Fig. 3. Spring Chow Deafblind Group Photo

Organised by the Deafblind Programme, the event aimed to provide a welcoming and accessible space for Deafblind individuals to socialise and for families to meet others navigating similar experiences. Volunteers, known as Intervenors, with their array of skills in Deafblind Communication methods, played a crucial role throughout the day. They provided guidance to the restaurant and engaged with everyone through seamless conversations, facilitating only where needed.

What spoke volumes were the smiles on the faces of the Deafblind guests and their families as they enjoyed their dishes, chatted away using braille or speech, and signing with old and new friends! Everyone could

experience the warmth of camaraderie and sense of belonging during the event.

For families, the gathering was a valuable opportunity to connect with others who understand the unique challenges and experiences of being Deafblind and having a Deafblind person in the family. As the event drew to a close, the community said their farewells and exchanged “see you again” sentiments with joy. It was not only about the delicious food but also about the chance to connect, share stories, and build a stronger support network.

The Deafblind Programme staff is thankful to the team of intervenors, communication access experts, and families who made the event possible!

Describe the Beauty of Your Native Shore to Me

**OLGA
KUDRYAVTSEVA**

ASSOCIATION
FOR INDIVIDUALS
HAVING HEARING
AND VISION LOSS
AND SUPPORT
ORGANIZATIONS
CON-SENT

[O.KUDRYAVTSEVA@
SO-EDINENIE.ORG](mailto:O.KUDRYAVTSEVA@SO-EDINENIE.ORG)

One of the missions of the Association for Individuals Having Hearing and Vision Loss and Support Organizations Con-sent implies development of the regional projects attractive for the individuals who are deafblind. The year 2023 marked the implementation of a culture-related and tourist project supported by a subsidy of Chelyabinsk region Governor (South Ural Citizens' Initiative Support Fund).



Figure 1.

Twelve events were organized for Chelyabinsk region residents who are deafblind. These events comprised visiting historical and cultural objects, museums, touristic sites, national parks. The

participants went to Miass *golden* town, Ilmen nature reserve, Zyuratkul national park, Arkaim, Yuzhnouralsk Local History Museum, Zlatoust and Kusa towns, etc.



Figure 2.

Based on results of each trip, a video accompanied by the audio description and translation into the Russian Sign Language was prepared, as well as audio materials allowing to get acquainted with the significant sites of the region. All these materials are in the public domain and may be useful for those individuals having vision loss who are in love with the native shore. The total number of project participants amounts to 251 individuals.

The key event of the project is the Regional Rehabilitation Education and Tourist Forum held in September 2023. Fifty individuals having dual sensory loss were competing in playing adaptive hobby games, shooting an electro-optical rifle, setting up a tent, getting geographical bearings and surmounting the obstacles. In the evenings, intellectual and artistic activities were organized.

We bring to your notice a review of one of the project participants – Aleksandr Chupyshev from Chelyabinsk city:

I was actively involved into Describe the Beauty of Your Native Shore to Me project and had a huge amount of positive emotions! This project gave me an opportunity to visit various towns with remarkable life culture, admire different buildings of refined architecture, get acquainted with museum exhibits and also to get inspired by historical milestones and to be amazed at interesting and unusual monuments. I have visited several town of Chelyabinsk region: Troitsk, Kyshtym, Varna, Miass, Zlatoust and Kusta.

Before each of the trips, we were given 3D-printed pocket-size models of monuments, buildings and parks so that we, being first of all totally blind or totally deafblind, could have an idea of their forms, lines, architecture and cultural value for each particular town. Indeed, it's easier to feel and get an idea of something touching a pocket-size model than wrapping arms about huge and dusty structures.

Each town is famous and valuable in its own way. Troitsk is known for architec-

EXCHANGE OF EXPERIENCE

tural monuments of different epochs, culture and religion structures of two areas of focus, Orthodox faith and Islamism, as well as for pieces of history of various ethnic groups. But the iconic landmark of the town is Dmitrievskaya square named after St. Dmitry Solunsky. The town of Kyshtym amazed with Demidov's estate, fountains and churches' architecture, natural parks, and the atmosphere of old customs of living. The settlement of Varna isn't interesting only thanks to its Bulgarian name, but also thanks to its Varna Local History Museum named after V. Savin displaying exhibits of Varna area history, its inhabitants and heroes who brought fame to this area. The site I would like to single out is the magnificent Church of Nativity of the Blessed Virgin Mary with its refined adornments.

The town of Miass, which name means "*Take it, drink!*" in Bashkir language, is renowned for its famous UralAZ motor-works. I was also impressed by the size and funny idea of the monuments dedicated to compasses, a ruler, a drawing pin and scissors. In this town, there is the Central Local History Museum amazing thanks to its marvelous olden time exhibits. Museum guide wouldn't tell only the history of Miass but would also let you touch different objects that the inhabitants used in household and that helped mine gold in the valley.

The town of Zlatoust, bearing the name of St. Ioann Zlatoust, is located high in the mountains. It has been well said that it is situated in the mining and metallurgical area and it is famous for its plants, such as Bulat, machine-building plant and ironworks. We visited a popular for tourists Krasnaya Gorka suburban settlement. On its territory, there are densely arranged Bazhov park with the characters of Bazhov fairy-tales, Museum of Stones. And the view from the top of Ioann Zlatoust Bell Tower, being a spotlight of this place, takes your breath away. Besides, we should mention the monument to P. Anosov, a talented ironworker.

Kusa is a small town located in 28 km from Zlatoust. It is famous for two plants: the machine-making plant where people used to found cannons, missiles, and sculptures in the days of old; and Precise Technological Stone Plant where people used to make parts of watches and aircraft instruments. A Palace of Culture includes a small Museum and Local History Center where you can get acquainted with various exhibits. During our staying in Kusa, there was a display of Christmas ornaments made of different materials, such as cotton-wool, fiber, wire and plastics.

I believe, that Describe the Beauty of Your Native Shore to Me project instills curiosity, the sense

Facilitating Participation in Research – an Intervenor’s Perspective

In my work as an intervenor, each day brings new opportunities for me and for the individual I support to learn and grow together. My day may involve a visit to a store, grocery shop or include trying out a new sensory activity. Each one of these activities is a chance to learn and enhance communication skills.

Imagine my delight when asked to facilitate communication for an individual I support who will be participating in an important research study, The Development of A Core Set for Deafblindness Using the International Classification of Functioning Disability and Health (ICF), Phase 2: Capturing the lived experiences of individuals with deafblindness.

I was asked to assist Mr. S. I have been his intervenor since 2020 when he joined DeafBlind Ontario Services and therefore, I am quite familiar with his preferences and abilities in terms of communication techniques. I knew that Mr. S had a lot of information to offer this study and I was determined to be an asset to Mr. S’s participation.

One challenge was ensuring he understood the purpose of the study and his own involvement. I used 1-1 time and plain language to make certain that he was fully informed. Once we had this conversation, Mr. S appeared excited and thrilled to be “teaching research-

ers about what it is to be like him and sharing his stories so people can learn.”

The way he felt about this research activity was evident from his joyous vocalizations, his facial expressions, his body language, and his willingness to answer my practice questions. The practice questions were based on a sample set I received from the researchers. The questions were designed to eliminate stage fright and help prepare for the interview process.

Mr. S and I worked together to establish a question and answer format between the two of us that worked well. It allowed him to maximize his comprehension before answering. We were told that the researchers were interested in environmental and personal factors that allowed Mr. S to function and participate in life independently.

Mr. S was asked to share his perspective during an individual

LENORE L. PHILION

CDBIS,
DEAFBLIND
ONTARIO SERVICES,
ONTARIO, CANADA

EXCHANGE OF EXPERIENCE

semi-structured interview with my support as his intervenor. We took the time to rehearse and prepare accordingly.

Each day that I worked with Mr. S leading up to the interview, I would take a little 1-1 time to practice the question and answers with him. I would ask him about himself, about his day, about available stimuli and all sorts of random questions such as, “do you think a giraffe would wear a hat?”

I would ease into some of the questions from the sample set. In time, Mr. S became adept at answering questions - both silly and serious. He became accustomed to being engaged and responsive when in interview mode.

Eventually, the day of the actual interview arrived. Both Mr. S and I were excited and I started getting him ready. Almost immediately we hit a major barrier; Mr. S had a malfunctioning communication device today!

Mr. S and I quickly brainstormed with the help of another intervenor and determined that we could continue nevertheless using Mr. S's nonverbal adaptive communication methods. I needed to paraphrase a lot of the interview questions so that Mr. S could answer them with the communication methods available to him at the time. Our researcher was patient, friendly and adaptable. We proceeded at Mr. S's pace using his best possible ways of receiving and providing information.

Mr. S got through all of the questions and contributed his valuable lived experience to the development of a Core Set for Deafblindness using the International Classification of Functioning Disability and Health. I was proud and pleased to be a part of the process and truly believe it was an invaluable experience for everyone.

Mr. S spent the rest of the evening smiling away. I felt honoured to have assisted him in my role as his intervenor so he could be involved in this vital piece of research about him.

Later on, I was scrolling through the emails and found a new article regarding this exact research project. I used a plain language paraphrase method to convey the message to Mr. S immediately. This was deeply meaningful to both of us as we spent time reflecting on our experience together and respecting the contribution and the impact that Mr. S and other participants had made together with the research team. Mr. S was again smiling and I knew he was pleased.

As Mr. S's intervenor, helping him to share his stories and life experiences in his own way is my duty and my privilege every day. This particular case really helped me to appreciate how much the world needs his input and perspective.

I am truly grateful for the opportunity to support Mr. S and look forward to learning about research in the field of deafblindness.

The Key Point is to Avoid Shrinking into Yourself and Getting Out of Touch with the World!



Figure 1. Vladimir and his wife Elena

Vladimir Elfimov about his childhood with the parents who are deaf, studies at the boarding schools, dangerous work at a plant and acquired family

Vladimir Elfimov is one of the most renowned individuals who are deafblind in Russia. An activist, an essayist and also a communicative and an open-hearted person. It's amazing that he, the one who was born in a family with the parents who are

INTERVIEWED BY

**VLADIMIR
KORKUNOV**

DEAF-BLIND
SUPPORT
FOUNDATION
«CON-NECTION»

[V.KORKUNOV@SO-
EDINENIE.ORG](mailto:V.KORKUNOV@SO-EDINENIE.ORG)

deaf and the one who is completely deafblind now, managed to fulfil his full potential in life: to receive education, to start a family, to bring up wonderful daughters without sensory challenges (he even repairs electronics at home – all by himself!). As far as I'm concerned, behind it, lie extreme self-confidence and rock personality that doesn't let a person give up and have the blues. In this extent, the story of Vladimir Elfimov is a reference for everyone; this is a story of both a person and strength of mind that doesn't only sustain life but allows to shape it in a way that the person needs. Notwithstanding any physical limitations.

Vladimir, you were born in a family with the parents who are deaf. Is your deafblindness genetic, hereditary?

My father isn't only deaf, he also had Usher syndrome. I discovered heredity of this medical condition only at the age of 35 and didn't learn about it from the doctors, but from a report of Mary Gast, Head of English Deafblind Support Organization, at the 1st International Festival of Young Individuals with Disabilities in Moscow in 1992. The festival week opened my eyes to the destiny – mine and others. There, it was the first time when I have seen and met lots of individuals who are deafblind coming not only from Russia but also from the UK, Netherlands and other countries.

I have read that first you learnt the sign language and only after that – Russian. How and, above all, with whom did you study it considering that your parents were communicating through signs?

Russian Sign Language is my first language of communication. I didn't study it on purpose, my family members used to communicate in the Russian Sign Language and I learnt it being a child. It is a common language of exchanging information in a family of the individuals who are deaf and its quality and complexity depend on parent's outlook, sociability and presence of other individuals who are deaf in one's environment. The children who are deaf perceive the world naturally, the same as typically developing children, understand everything in the extent of here and now. On the contrary, being brought up in a family with the parents without hearing loss the

children who are deaf often communicate primitively, they use scanty number of signs and communicate mainly with a forefinger. The Russian Sign Language my parents and I used, was comprehensive and as complex as the maximum of their outlook. They would tell me a lot, explain what they knew and could do, and I used to understand them as much as a child could understand according to the age. From year to year I was learning more meanings of the signs and grammatical structures of the Russian Sign Language and was reacting respectively.

At the age of 7, I entered a boarding school and was considered a smart boy by everybody, including the teachers and high school students. My first teacher, Valentina, perfectly knew the Russian Sign Language and acquainted me with the first Russian letters, first Russian words, which we were referencing to the fingerspelling words and reinforcing with signs. A simple example: what is a ball? It is well-known to all children; a sign of a ball is shown in each family where individuals who are deaf live. At school, we were given a picture of a ball with the Russian inscription "a ball" at the bottom. Below the inscription, there was a picture of three hands showing different finger combinations which were fingerspelling this word. That's how we used to learn the representation and the sense of a word and could communicate it to each other and to a teacher either through fingerspelling or through signs. With time, we were learning the names of objects and animals surrounding us, then we learnt the verbs, adjectives and so on. This is how went

on the extension of Russian vocabulary in combination with fingerspelling and sign language. The lessons of oral communication development also appeared to be important. We were taught to speak correctly and to make phrases. Those who understood better could communicate in Signed Russian, expressing a phrase in sign language based on Russian grammar.

The important fact is that the children who are deaf make first steps in learning Russian Sign Language in their families and then continue improving language in special needs nursery schools and schools for the children who are deaf. That said, to extend Russian vocabulary, nursery school and school focused on fingerspelling. And as fingerspelling is the key mean of interaction between children and adults, it hinders information exchange significantly. Outside lessons, children, in their turn, preferred fast communication in Russian Sign Language. That's when it was improving. And some of the teachers who knew Russian Sign Language were helping us understand the meaning of one or another word, sign or phrase better.

In such environment, the one also learns the culture of the individuals who are deaf, and Russian Sign language was something that was uniting us.

I was very lucky to have parents with little education, talking to me about everything freely, to have the first teacher with fair knowledge of Russian Sign Language, to have passion for reading books... Besides, the teacher managed to develop correct oral communication in me, an individual having congenital hearing loss. It helped me integrate into life notwithstanding the vision challenges...

For a boy having progressive vision loss, is it difficult to study among the children without vision challenges?

The fact that during the first school years I gained respect thanks to my intelligence and complex mind helped me. Moreover, I didn't look like a boy having vision loss, I still had good vision acuity, I was strong in body and played Russian ball game, football and other games freely (unless it was evening tide,

of course). Besides, I loved to read and tell interesting stories, to explain phrase meanings, which was also appreciated a lot... I had no particular problems at the first school. Sure, peers sometimes passed jeers upon me in dark environment. They could twitch at my clothes or beat me underhand and run away. To catch them I had to turn on the light fast and respond to an offender in a language clear to them (sometimes even to fight) or to complain to a teacher. But these are small details. There were other troubles as well. In light of my uneven gait I was released from participating in school events, for example, from dancing at children's matinees and so on. Being afraid of accidents that could happen to me, the teachers deprived me of going on trips to Lenin places or to summer camps, for example... Herewith, it was me who was getting these bonus invitations for the school thanks to studying and winning the contests. The ones who were going to Sochi instead of me were C students... It was hard and unfair but I learnt to accept the situation and remain myself.

Notwithstanding the Usher syndrome you worked at a factory among the individuals without sensory challenges. As far as I understand, an individual who is deafblind has to undertake much more efforts to be as equals?

At those times I was a strong and thick man, that's why I entered the foundry shop of Sibselmash plant without any problems. It was an entire town comprising hundreds of buildings with traveling cranes, narrow-gauge railways, as well as vehicles such as motor trucks and lorries. Of course, it was a job for the individuals without vision challenges. The fact that I had to come to work and go back home in the dark made the things worse. The colleagues having hearing loss used to help me out, sometimes they would arm me from the shop to the checkpoint after which there was public lighting. That blaze of lights guarded me. In the shop it wasn't safe as well. Traveling cranes, carrying containers with metal, were *flying* under my head. Put it shortly, if I had known of this environment in advance, I would have entered the university and found a calmer job. It was very hard for me. Constant psy-

chological tension was dejecting me. The danger was both over the head and under the feet... Luckiness and quick reaction saved me (in light of the vision loss I developed this quick reaction being a child and it let me, for example, ride a bike, play football and even table tennis).

Could you tell us how you met your wife? Considering your sociability, I suppose, it wasn't complicated to find love...

Actually, to find your better part isn't the easiest thing in the world for any person, especially if you have vision loss. Honestly, in my younger days I didn't find it difficult to meet girls, communicate and be on sincere friendly terms with them without any particular hidden agenda. But everything (for me personally and, I believe, for many individuals having Usher syndrome) was breaking down when I was trying to go out with them and communicate in the evening time or night-time. Girls would notice that there was something amiss and start to stay away from me. My dignity was outweighing and I wasn't trying to keep such relations, I was leaving peacefully without any questions, but of course I was taking it hard deep inside. Later on, some of them confessed that they liked me very much but at some point I was getting... too proud of myself in appearance. At the same time, they found embarrassing to force our friendship on. Apparently, God saved me from making a mistake and granted me a real life partner – Elena.

At the age of 26, I was already thinking of a family life, but I wasn't searching for someone actively. I had a bad limp after a terrible car accident. One day, I dreamed of a face of a young girl with a birth-mark on a cheek. It was a very clear *photo*. I woke up but couldn't remember who she was and where I could see her. I have been searching for her a lot among the girls who were deaf

but failed to find her... then I calmed down, it was winter and walking around in pursuit of love was beyond me with my vision.

Once, my friend invited me to visit her friend together, she was afraid of going alone late in winter evening. I agreed, we went, she rang the door, the door opened and... what a miracle, her friend appeared to be the girl from my dream, Elena! I met her at school, when she was a teenager. It turns out, I remembered her while sleeping. Being very surprised with such a coincidence, I wanted to get to know her better and become friends. Though, I was putting it off till May, but then I came to Elena and we talked. We have been going out and communicating for 2 more weeks and I took a chance to ask for her hand. She said yes and we went straight to a Civil Registry Office. Two months after we celebrated a wedding. I was afraid to lose her and that is why (to my surprise) I appeared to be persistent and made an impression. We didn't talk a lot at the boarding school, she was younger than me by 5 years, but that is how everything happened – we have been together for almost 40 years already. I believe, this was God to show me her *photo* in a dream...

What treats did deafblindness develop in you?

Patience and hope for the best. I try to get rid of sad and destructive thoughts as fast as it's possible. Sometimes, I resort to a personal stress-relieving mean – my favourite sweets or a pack of sunflower seeds (*smiling*). I also pray and ask God for more wisdom, humility and love – all of us are in His hands.

What parts of life bring you happiness?

Family, belief, patience, communication and capacity to find a positive aspect in any situation.

Acquired Deafblindness Network (ADBN)

PETER SIMCOCK

peter.simcock@bcu.ac.uk

Vice-leader / representative:

FEMKE KRIJGER, LIZ DUNCAN

Africa Network

MARY MARAGIA

Mary.Maragia@gmail.com

RICHARD MATIVU

richardm@senseint-kenya.org

Vice-leader / representative:

ANTONY NZUKI, MARTIN KIETI

CHARGE network

ANDREA WANKA

wanka@ph-heidelberg.de

Representative network leader 2024

ANNE SCHOONE

a.schoone@kentalis.nl

Communication Network

SASKIA DAMEN

s.damen@rug.nl

Creative Arts Network

IVANA MACOKATIĆ

ivanam@malidom.hr

Vice-leader / representative:

IVANA MACOKATIC, MARTINA CELIZIC

Deafblind Education Network

ANDERS RUNDH

anmaru@rn.dk

Vice-leader / representative:

DEIRDRE LEECH

dleech@annesullivan.ie

European Deafblind Network (EDbN)

RICARD LOPEZ

rlopez@edbn.org

DbI Network coordinator

TREES VAN NUNEN

t.vannunen@kentalis.nl

Family Network

MASSIEL REQUENA DE IRIARTE

massielrdeiriarte@gmail.com

Vice-leader / representative:

AUREA SOZA

Ibero Latin America Network

XIMENA SERPA

ximena.serpa@gmail.com

Vice-leader / representative:

YVETTE GALLEGOS

Network of the Americas

THERESA TANCOCK

theresa@cdbabc.ca

Vice-leader / representative:

CAROLYN MONACO

Outdoor Network

JOE GIBSON

deafblindoutdoors@gmail.com

Vice-leader / representative:

INGRID KORENSTR, MIJKJE WORM

Research Network

WALTER WITTICH

walter.wittich@umontreal.ca

Vice-leader / representative:

MEREDITH PRAIN

Technology network

MIJKJE WORM

mworm@bartimeus.nl

Usher Network

EMMA BOSWELL

Emma.Boswell@sense.org.uk

Youth Network

SIMON ALLISON

simon.allison@sense.org.uk

Vice-leader / representative:

AMANDA CRAYTON

DbI Communication Ambassador: Call for Action



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

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

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

What are the responsibilities of a Communication Ambassador:

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

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

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

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