

Reflections on the 18th World DbI Conference in Ottawa

Sarah Bradley:
I Shoot Events at the 18th
Deafblind International World
Conference.

Page 9

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 PRESIDENT

→ 3

NEWS

Presentation of the New Board Members

→ 5

Farewell from the Outgoing Dbl Board Member

→ 7

Reflections on the 18th World Dbl Conference in Ottawa

→ 9

The Short Videos of the Deafblind People at the Dbl Conference in Ottawa

→ 12

ARTICLES

Person Centered Planning and Learners Who are Deafblind

→ 13

Identification of the Visual and Acoustic Perception Specifics in Children with Severe Complex Disabilities: Case Study

→ 18

Open Eye Tracker Application Designed for People with Multiple Disabilities and Visual Impairment

→ 24

SIXTEM – a Code for Entering Alphanumeric Characters on a Numeric or Dedicated Keypad

→ 27

Haptic Communication to Facilitate Braille Instruction for Deafblind Adults

→ 32

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

→ 36

EXCHANGE OF EXPERIENCE

One Hundred – Marathon 2023

→ 40

INTERVIEW

Interview with Tatiana Basilova

→ 42

NETWORKS AND NETWORK LEADERS

→ 45

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.



A Message from the President

MIRKO BAUR

PRESIDENT OF
DEAFBLIND
INTERNATIONAL

Dear Dbi members, dear readers,

The last few weeks I have been on the road for our Global Education Campaign. The ICEVI East Asia Conference in Yogyakarta, Indonesia, and the 1st ICEVI Africa Conference in Nairobi, Kenya, offered both wonderful opportunities to talk about deafblindness and Dbi, to present the campaign,

to meet wonderful people and projects and to work on sustainable networks. Not long after our own fantastic World Conference in Ottawa, Canada, I experienced again how important conferences are to create awareness for deafblindness as a unique and distinct

A MESSAGE FROM THE PRESIDENT

disability and how important personal encounters are.

Of course, we do work a lot online with virtual meetings. That works well, is much more affordable than traveling and is certainly better for the climate. However, Dbl connects to act. We want to be THE point of connection in deafblindness worldwide to maximize positive impact with and for all those concerned and involved. And that needs personal presence and personal relationships. We are what we are because we are family, or better, family members in touch – and not on distance.

That is our culture. Cultivating, growing and developing it, means to exchange, to learn from each other, to collaborate openly, to go again and again into dialogue and thrive through our diversity. On this way we need all of you, every single one. The challenges are, as we know, huge.

According to the 2nd World Report of our most important partner, the World Federation of the Deafblind, based on quantitative data across 36 countries for children with deafblindness, aged 2 to 17 years, just 14% of them are enrolled in education. Only 20% are developmentally on track and just 49% are registered at birth.

So, our Global Education Campaign is indeed most important. It calls for the immediate respect of the right to education of ALL children with deafblindness with focus on Africa, Asia and Latin America. Working bottom-up and top-down, this campaign relies

on global, regional and national networks. The volunteer journeys to Yogyakarta and Nairobi added enormously to them, for example in creating a first, emerging network in deafblindness in Indonesia, in getting us in contact with SEAMEO SEN, the organization of the Southeast Asian Ministers of Education, in gaining new individual members throughout Africa, new important contacts in Burkina Faso, Ghana, Rwanda, the Republic of the Congo and Somalia, and in the area of technology.

Work like that would never be possible without friendships based on our passion for the field and without great teamwork. I am indeed happy to write you that this new Dbl term from 2023 to 2027, has started just like that. Dbl is not about money and not about positions, it is about connecting to act. That is very much the feeling in the new Management Committee and in the new Board, in the bigger Communication Committee and the equally growing Fundraising Committee.

CONNECT TO ACT that means all of you and all of our partners. Allow me, nevertheless, to introduce you specifically to our two new Vice-Presidents: Mary Maragia from Kenya and Meredith Prain from Australia. As the “3 Ms” in Dbl’s management team we will be your “tour guides” in this new term – and therefore very much in dialogue with you. Watch out for a first online chat invitation on our social media in the coming days.

Stay involved and in touch. Terima kasih, Asanta Sana, thank you and grazie mille!



Your Dbl President, Mirko Baur

Presentation of the New Board Members

Akhil Paul

Founder Director, Sense International India.



Akhil has played a pivotal role in making deafblind people a known entity in India. Equipped with degrees in Science, Law, Social Work and Diploma in Multiple Disabilities from Perkins School for the Blind (USA), from 1989, Akhil worked with National Association for the Blind (India) for 7 years in reaching out to rural blind through Community Based Rehabilitation.

In 1997, he took up the challenge of developing services for deafblind when not even handful of people knew what deafblindness was and nurtured the movement to the extent that today, from one service in 1997 to in more than 60 in 24 states in India as well as in Nepal, Bangladesh, Sri Lanka, Malaysia.

Today Sense India has transformed lives of more than 85,000 deafblind people and ensuring their rightful inclusion in our society. Under Akhil's leadership, Sense India has created networks of teachers, deafblind adults, and their families. He has succeeded

in creating a dedicated team to ensure that deafblind people are 'seen & heard'. It is the persistent efforts under his active stewardship that 'deafblindness' has been recognized as a unique category of disability under the Rights of Persons with Disabilities Act-2016.

- Board Member of 'Deafblind International', a global umbrella organisation looking into the education of deafblind.
- Founder Member of the National Trust for welfare of People with Autism, Cerebral palsy, Mental retardation and Multiple disabilities set up by Act of Law by Government of India.

Sherry Grabowski

Vice President CNIB Deafblind Community Services,

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I have worked in the field of deaf, blind and deafblindness for 33 years. Initially I started working with Canadian Hearing Services, where I learned a lot about deafness and hard of hearing and

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DIRECTOR, SENSE
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INDIA

SHERRY GRABOWSKI

VICE PRESIDENT
CNIB DEAFBLIND
COMMUNITY
SERVICES

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DEPUTY DIRECTOR
AND ADVISOR,
NKCDB

the services that were needed in Northern Ontario, Canada. We started French interpreter services for the francophone deaf and hired a LSQ interpreter. We also established a life skills and literacy program and an employment program.

I then moved on to The Canadian National Institute for the Blind and started to learn a lot about blindness. With the experience with both sensory losses, I was so pleased to be selected as the Vice President of CNIB Deafblind Community Services.

I am currently on the Deafblind Network of Ontario Board. I am also very involved in other partnerships and collaborations with other organizations throughout Canada.

I have a sincere interest in this field as I see the difference services such as Intervenor and literacy services can have in one's life. I am so fortunate to be working with such talented people both within our organization and within other organizations in Ontario and around the world.

Caroline Lindström

Deputy Director and advisor, Nkcdb, caroline.lindstrom@nkcdb.se



My name is Caroline Lindström and I work as Deputy Director and advisor at

the The National Knowledge Center for Deafblindness in Sweden, Nkcdb (www.nk-cdb.se). Nkcdb is a comprehensive national resource that provides specific expertise so that all authorities, services and concerned parties on different levels can meet the varying needs of people with deafblindness and their families

and relatives. Since 2003, Nkcdb's activities have been financed by government grants under the Mo Gård Foundation, and since 2013, Nkcdb get assignments from the National Board of Health and Welfare. Before I began my employment at Nkcdb I worked at Mo Gård in Sweden for several years (www.mogard.se).

I have worked in the field of deafblindness for over twenty years, focused on communication and congenital deafblindness. I have a M.A in upper secondary education, a M.A in Special Education Needs and a MSc in Communication and Deafblindness. I am also a member of the Nordic network on tactile language. Several years ago I started learning sign language and at that time I became a caregiver to people with congenital deafblindness. Through my work I was introduced to tactile communication and since then I have strived to develop knowledge and make a difference for people with deafblindness and their communication rights. I have had the privileged to learn from people with deafblindness during the years. They have thought me about diversity, possibilities, equal rights and tactile communication. During the years I have worked alot with guidance, support and education for staff within Mo Gård's organization.

Farewell from the Outgoing Dbl Board Member

Marleen is a Professor Emeritus of Educational Psychology, specialized in Congenital and Acquired Deafblindness at the University of Groningen in the Netherlands. Following her master's degree in Special Education (University of Utrecht) and a PhD in Developmental Psychology focused on Harmonious Interactions in children with deafblindness (Radboud University Nijmegen), she has worked since 2008 as a professor in Educational Psychology in Groningen. Before that time, she worked as a teacher of students with congenital deafblindness for 7 years and after that, she combined educational research and practice in different educational jobs at Royal Kentalis. Her research is focused on communication intervention studies in people with deafblindness. She has published over 40 articles in international peer-reviewed journals. She is former Editor in Chief of the journal *Deafblind Studies on Communication*, former curriculum coordinator of the Master Pedagogical Sciences Communication and Deafblindness, former chair of the Deafblind International Communication Network, former advisor to Kentalis Deafblindness Centre of Excellence, and she is still active for the University of Groningen Institute for Deafblindness in editing books for Oxford University Press and Groningen University Press. In 2019 she received the royal decoration Knight of the Order of the Dutch Lion for her lifetime research into deafblindness and communication with people who have been deafblind since birth. On July 27th 2023, she received the Deafblind International Lifetime Achievement Award at the Dbl World Conference in Ottawa, Canada, in recognition of her significant and sustained contribution to individuals who are deafblind and the international field of deafblindness.

MARLEEN JANSSEN

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Experiences and Reflections with Deafblind International

"The circle is completed" as they say in our country, the Netherlands. That was what I thought during the recent Deafblind International World Conference in Ottawa Canada. And that was not only because I received this incredible Life Time Achievement Award for my work and contribution

to people who are deafblind. No that was already during the two-days Preconference of the Communication Network, when I saw my successors, Saskia Damen (NL), Meredith Prain (AUS) and Helle Selling Buelund (DK) with on-line support of Steve Rose (UK) present and organize this won-

derful event. During the main conference I was impressed by the dynamic and transparent way how all presentations and meetings went.

I even met colleagues from my first Dbl Worldconference which was in 1984 in New York, in the Roosevelt Hotel, almost 40 years ago. In that time I was a teacher at the Rafael school in Sint-Michielsgestel and together with Bernadette van den Tillaart, who lives and worked now already for over twenty years in the US, we memorized that we as teachers shared a room there in the Roosevelt Hotel and that we learned the most from content presentations. In that time presentations about school buildings and the management of deafblind programs were more emphasized than it is now. We were proud that we as teachers could present about our daily work, and that we were stimulated to do that by Jan van Dijk, who was and is our inspirer forever.

In my case, I presented about the Use of Objects of Reference with my first deafblind student. She was 10 years at that time and she was completely blind and completely deaf with additional disabilities because of Congenital Rubella Syndrome. She did not know the difference between night and day. In the five years that followed and that I was her full-time teacher she learned a lexicon of 900 concepts, and also 2-3 word sentences, through natural gestures, referential objects, and fingerspelling in the hand. Those communication methods were known for a long time because of Helen Keller, a famous American deafblind woman who became deafblind at 19 months and who received a lifelong education from Ann Sullivan and others. But how exactly do you use those methods by first building up a good relation-

ship and good contact with somebody who is born deafblind, that was my biggest question at that time. It took me up till now to find some answers.

And how glad I was to have been a member of DeafBlind International all those years. Because I found many answers together with my international colleagues. That is what Dbl was and is for me: networking, meeting colleagues and discuss and exchange information about communication, learning, development and well-being of persons who are deafblind.

What inspired me the most during all those years, is working with international colleagues of Dbl. It felt more like a family, my 'deafblind family'. And that is what I hear from many colleagues, wherever they come from. I met colleagues from many countries all over the globe, also because of the master program in Groningen, (Africa, Japan, New Zealand, Australia, Jordan, Turkey, Greece, Germany, Canada, Switzerland, UK, Nordic countries and they all feel the same. Especially working with colleagues, of the former Dbl Communication Network, for over 30 years, who I want to name here once again Anne Nafstad, Inger rodbroe, Ton Visser, Jacques Souriau, Marlene Daelman, Paul Hart and Flemming Ask Larsen brought me not only a lot of knowledge but also unforgettable shared memories. Between work, there was always time for socializing, unexpected visits because a daughter-in-law had to give birth in a hospital, nice dinners, and above all good company and inspiring discussions.

This was also true of the many enjoyable meetings with international colleagues on the Dbl Board. Because we are working for the same goal.

Reflections on the 18th World Dbl Conference in Ottawa

I Shoot Events at the 18th Deafblind International World Conference

I had the pleasure and the honor of “shooting” the Deafblind International World Conference in Ottawa, Canada. I have photographed many large conferences, but this one really touched me.

When “shooting” events my goal is to capture the overall event including guests in posed, candid & engaging shots in a photo-journalistic manner. Telling the story of the event through my photos.

My first interaction with the delegates was at a social evening. I

did my usual thing: posed group shots; candid shots of people laughing and enjoying themselves; photographing speakers as well as the entertainment. It didn't take me long to realize this was going to be a different conference.

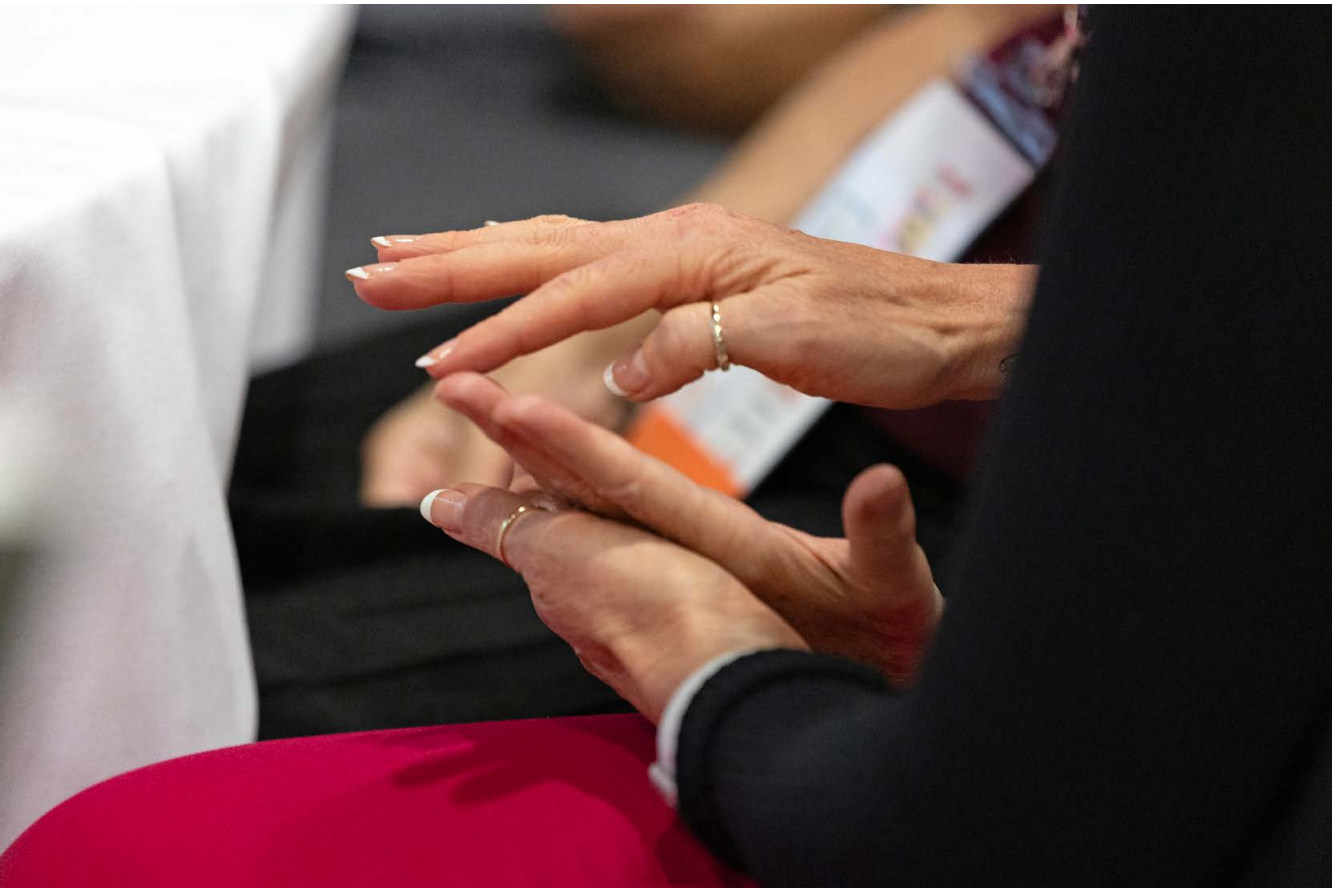


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Over the next few days, I witnessed the incredible bond between individuals with deafblindness (interesting to note that MS Word underlines this as a spelling mistake!) and their translators. I was absolutely mesmerized. I watched 2 people with deafblindness engaged in a conversation together using tactile signing (something I have never heard of – google it!). There was another very inspiring lady with deafblindness in a wheelchair who had one intervenor tactile signing while another touched her back in various ways to communicate what was happening in the room; whether it be laughter or applause.

My photography style quickly changed to include capturing that bond by focusing on the hands.

By day 5 I felt like a part of this very tight, loving, supportive community. In fact, I was very emotional knowing it was coming to an end. I have a newfound awareness of the deaf, the blind, but especially the deafblind.

With much love,

Sarah the photographer who is 5'3 with dark blonde hair and green eyes.

Special shoutout to Bettyanne Sherrer from CanPlan Event & Conference Services for introducing me to this inspiring community.

The Short Videos of the Deafblind People at the Dbl Conference in Ottawa

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Deafblind Victoria (DBV) attended the recent Dbl conference to give a poster presentation about how deafblind people run the organization.

At the conference we met many other wonderful deafblind people from around the world. We made 10 short videos with some of them, and published the videos on the DBV website - www.deafblindvictoria.com

All the videos are subtitled and have a transcript in the description panel.

The deafblind people in the videos are:

- Michelle, Trudy and Andrew, Deafblind Victoria (Australia).
- Raquel Alba Martin, ONCE (Spain).
- Sunil Abbas, SEDB (India).
- Divya Goel, DBCA (USA).
- Ryan Ollis from Canada.
- Liz Duncan, Deafblind UK.
- Anindya "Bapin" Bhattacharyya, Helen Keller National Centre (USA).
- Eliza Jane McEwin from Sydney (Australia).
- Penny Bennett, Canada.
- Alisha Purkiss, Canada.
- Chey Mclarin, Canada.

Person Centered Planning and Learners Who are Deafblind

This is the eighth article in a series about assessment of learners who are deafblind. This article addresses the person-centered planning approach (PCP), a style of assessment and planning that maintains a focus on the strengths and desired outcomes of the individual with a disability. PCP is a collaborative structured process where an individual who is deafblind and their support system (i.e., family members, peers, friends, teachers, therapists, etc.) co-construct a shared vision for the individual's future and their life in the community. The PCP approach features a conversational process that is highly inclusive of the individual who is deafblind, seeking to bring out their ideas and hopes for the future. During the meeting, the individual's assets (strengths, interests, goals), needs (medical needs, support services, housing requirements), and preferences (recreation, relationships, social activities) are identified and discussed in relation to their desired outcomes and a written plan is developed. For example, if independent living and supported employment are goals for the individual's future, the team will consider various ways to accomplish these goals by identifying the necessary supports, establishing a timeline, monitoring progress, and making adjustments to the plan as needed.

During the PCP process, the individual who is deafblind should

have a voice in deciding some of the people invited to participate. Careful consideration must be paid to the communication strengths and needs of the learner who is deafblind, such as the need for certified sign language interpreters. Peers and family members assist the team to know more about how the individual participates in contexts outside of school or work settings. A facilitator supports rich conversation during the meeting, often encouraging others to share their ideas. A recorder may also be present to either write or draw out ideas expressed by those attending the meeting. Team problem solving is also part of the PCP meeting, with an emphasis on breaking down barriers that currently are blocking the individual's participation. Sometimes this involves the creation of maps, such as a map of places the individual currently participates in or would like to participate in. No matter which specific PCP approach is used, attention is paid to the individual's desired outcomes and the identification of resources to support their achievement (Root, et al., 2020). Person-centered planning approaches include the McGill Action Planning System (Vandercook, et al., 1989; Planning Alternative Tomorrows with Hope (PATH; Pearpoint, et al., 1993), and Personal Futures Planning for transition age youth and adults (Mount & Zwernick, 1990), discussed below.

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McGill Action Planning System

The McGill Action Planning System (MAPS) is a PCP model for use with school-age children who are deafblind (figure 1). The structure is similar to PCP described above, with the MAPS process resulting in a visual representation of the process that details the individual's history, dreams, fears, individuality, and needs, as well as a tangible action plan (NJCIE, 2012). Research into the MAPS process has indicated improvements in family-professional partnerships, as well as improvements in self-advocacy and self-determination for the individual with disabilities (Haines et al., 2018). During the MAPS process, a facilitator is selected to support the conversation by framing discussion around these questions:

- What is the individual's history?
- What is your dream for the individual?
- What is your nightmare?
- Who is the individual (Provide descriptive words)
- What are the individual's strengths, gifts and abilities?
- What are the individual's needs?
- What would the individual's ideal day at school like and what must be done to make it happen?

(Vandercook, et al., 1989)

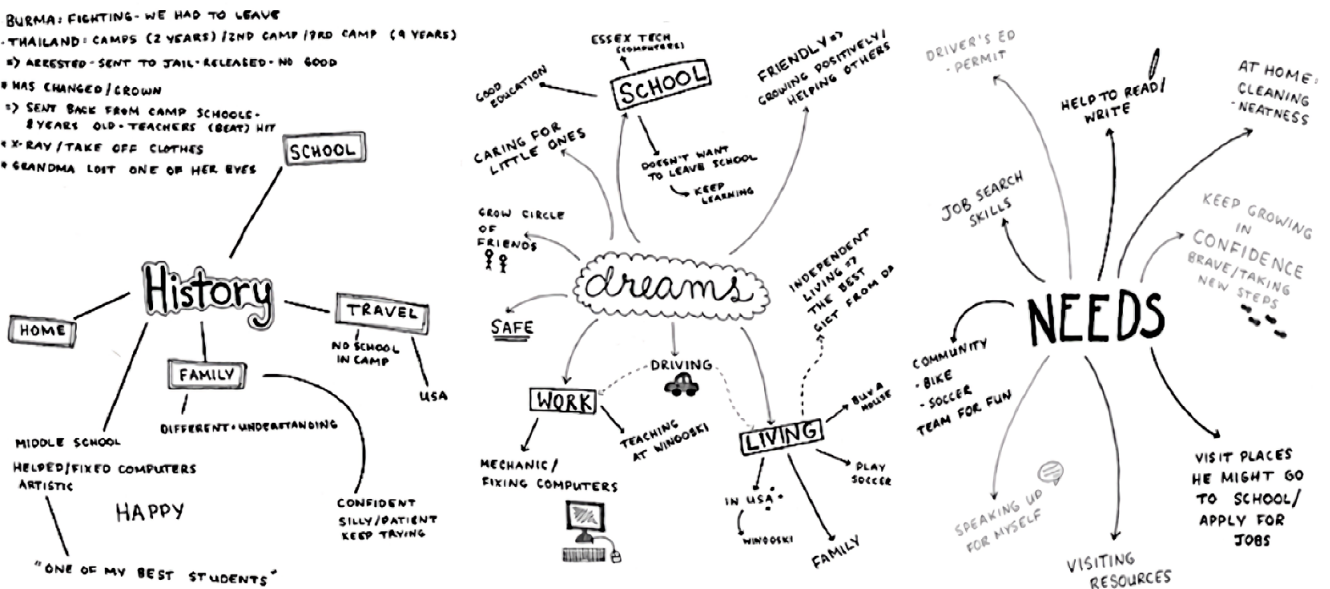


Figure 1. Example of MAPS (Haines et al., 2018).

Family members or someone assigned to do the graphics will create maps to depict input from the family and other stakeholders. MAPS is unique for its focus on history and nightmares. It can be helpful to know how a family thinks about their child's history, which can also be referred to as their "story." Perhaps the team will draw a historical map of their child that only shows key medical events or highlight other elements related to their culture, values, and experiences that have influenced or impacted the individual's development (Haines et al., 2018). Similarly, for their nightmares or fears, the individual and their family

describe areas of distress, worry, or concern so that potential barriers can be identified and addressed. Knowing a family's fears can help professionals to develop programming that will make those nightmares less likely to occur. **Planning Alternative Tomorrows with Hope**

Planning Alternative Tomorrows with Hope (PATH) is a person centered planning model that emphasizes the strengths of the individual who is deafblind, desired outcomes, and supports required to achieve those outcomes (Pipi, 2010). The PATH approach follows a specific sequence of steps, beginning with identification of the dream, identification of a goal

to be achieved in a year, defining the current status relative to the goal, identification of people to support the individual with a disability to achieve their goal and to address barriers, and establishing action steps to support achievement of the goal (Pearpoint, O'Brien, & Forest, 1993). The annual goal established in the PATH

process aligns well with the yearly individualized plans conducted in school and adult settings in some countries. Like other PCP approaches, the PATH process is facilitated by the individual's supporters and results in the development of graphic display (figure 2).

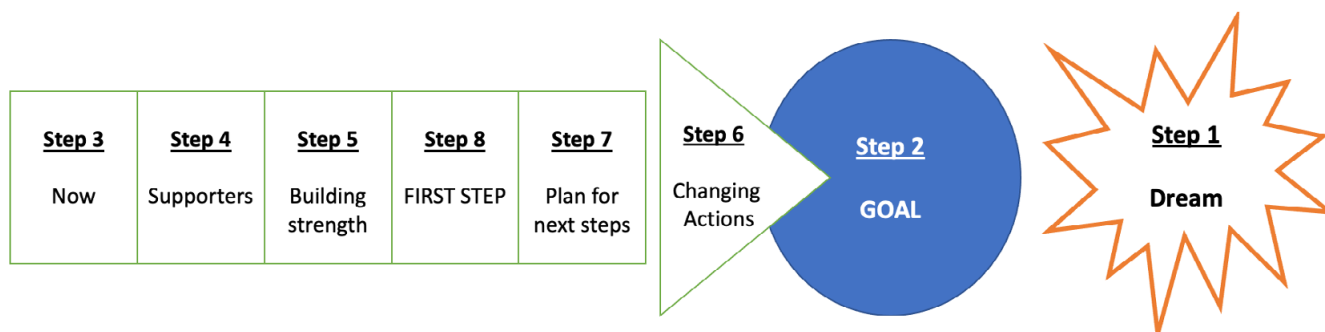


Figure 2. Steps in the PATH process

Personal Futures Planning

Personal Futures Planning (PFP) is a PCP that is focused on transition age youth and should address educational, vocational, residential, and community interests and needs. Similar to the other PCP structures described earlier, PFP is centered around the individual who is deafblind and their family, advocates, community members, agency staff, and anyone else who would like to see the individual turn their dreams into realities. The process focuses on the individual's strengths and encourages participants to tell stories about the individual as a means to provide a comprehensive description of the individual as a framework

for establishing actionable steps to achieve short- and long-term goals (Moss & Wiley, 1995). The key components of the PFP process include: (1) Planning the process, identifying key stakeholders, and arranging the meeting; (2) Telling stories about the individual to build a personal profile with a description of their life, preferences, desires, opportunities, and challenges; (3) Dreaming together to build a plan for the individual's future that includes small actionable-steps to make the dream a reality; and, (4) Consistent meetings over time to share accomplishments, review progress, and revise the plan as needed.

After the PCP Meeting

A positive impact from PCP can only be achieved if there are follow-up procedures in place. This may include Action Plans that state the various responsibilities of team members and the dates for these responsibilities to be achieved. If the individual is school-age, the PCP meeting should occur before the yearly meeting for that person. This will ensure that the findings from the PCP translate into

goals and objectives and shared responsibility by professionals on the team. Thus, the PCP should involve more than a single meeting. Additional conversations should occur about the team's progress in supporting the desired outcomes for the individual who is deafblind, and provide opportunities to make revisions to the plan as needed. An example of a PCP action plan is below (Table 1).

Table 1: Example of MAPS Action Plan

MAPS ACTION PLAN [DATE]

The vision for Blake is to: participate with peers in all classes and progress to the next grade.

List of Strengths:

Artistic, Creative
 Detailed orientated in artwork
 Very musical (self-taught guitar)
 Kind, accepting of others
 Good writer
 Very poetic - way with words
 Good with technology
 Expressive language is very good

List of Needs:

Finish assignments on time
 Listen and following directions
 Accessing transportation
 Develop more friendships
 Learn to organize work
 Ask questions when not understanding

Action Items: (what needs to be done)

Action Dates

Action Team

Start	Completed
Aug. 20	
Sep. 8	
Sep. 4	
Sep. 1	
Sep. 1	Sep. 15
Sep. 1	Sep. 15

1. Teach organization skills

SPED Teacher;
Counselor

2. Teach to use graphic organizers for essay reports and writing

Gen. Ed. Teacher;
SPED teacher

3. Provide tutoring with multiplication and division

Gen. Ed. Teacher;
SPED teacher

4. Teach self-management skills for task completion

SPED teacher;
instructional aide

5. Develop a system to obtain help from a teacher, peer, or instructional aide.

SPED teacher

6. Help select and join an after school club

Gen. Ed. Teacher;
Parent

Notes:

Dates for follow-ups: 2 weeks after meeting; 3 months after meeting; 6 months after meeting.

Adapted from: Wells & Sheehay (2012)

Resources

1. Video: What is Person-Centered Planning? Timothy Carey. <https://www.youtube.com/watch?v=ECcH5SR4KzM>
2. Document: Person-Centered Planning. National Parent Center on Transition and Employment. <https://www.pacer.org/transition/learning-center/independent-community-living/person-centered.asp>
3. Video: Person-Centered Transition Planning. Perkins School for the Blind. <https://www.perkins.org/resource/person-centered-transition-planning/>
4. Video: What is a PATH: Person Centered Planning-Visioning/Inclusive Solutions <https://www.youtube.com/watch?v=7XpWfgbR1ns>
5. Website: Person Centered Planning Staff Resources: [https://acl.gov/programs/consumer-control/person-centered-plan-ning#:~:text=Person%2Dcentered%20planning%20\(PCP\),person%20who%20receives%20the%20support](https://acl.gov/programs/consumer-control/person-centered-plan-ning#:~:text=Person%2Dcentered%20planning%20(PCP),person%20who%20receives%20the%20support)

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Identification of the Visual and Acoustic Perception Specifics in Children with Severe Complex Disabilities: Case Study

Keywords

Functional vision, functional hearing, deafblindness, severe complex disabilities, functional evaluation.

Funding

International Foundation of Applied Disability Research (FIRAH) funds the reported study.

Acknowledgments

The authors are grateful all parents raising children with severe complex disabilities who participate in the research project.

Introduction

This article will discuss the interim results of the project “Identification of Perceptual characteristics and individualized educational programs for children with deafblindness and other severe complex disabilities”.

The aim of this research project is to summarize and generalize parental experience, professional and scientific knowledge in order to develop structured protocols for identifying visual and auditory perceptual possibilities in children

with deafblindness and others severe complex disabilities.

Identification is based on behavioral reactions and enables parents and professionals to describe in detail the child's abilities profile to modify the environment and training programs on the appropriate way.

The background of the study was:

- Evolution of the etiology of sensory impairments (Guthrie, et al., 2009; Lueck & Dutton, 2015; Moore et al. 2018; Basilova, 2011; Meliksetyan et al., 2018).
- Attention of the professional and scientific community to complex and multiple disabilities (Chabrol & Desguerre, 2020; Guidetti & Tourette, 2018; Lombardi, 2019; Nelson et al., 2009).
- Individualization of approaches to the education of children with special needs (Ask Larsen et al., 2014).
- Functional model of disability, particularly deafblindness (Ask Larsen et al., 2014; Guidetti & Tourette, 2018; Johansen, 2018; Bendixen et al., 2020).
- Recognizing the value of functional assessment of sensory functions (Nelson et al., 2009; Ask Larsen et al., 2014; Johansen, 2018; Bendixen et al., 2020).

The hypotheses of the study are as follows:

Methods

The project has developed the instruments of assessment, which include a questionnaire for parents on the symptoms of their child's peripheral and central visual and hearing impairments as well as 3 protocols of observation during free and organized activities, aimed at identifying the functional characteristics of child's hearing and vision.

Analysis of the completed questionnaires and observation protocols allows us to de-

1. The structured and detailed analysis of children's behavior during free and organized activities enables a reliable assessment of the significant specifics of their auditory and visual perception without strict reference to medical diagnoses.
2. The results of the proposed evaluation model can become an effective base for the creation or modification of individual educational programs.

The study, carried out in France and Russia, involves 25 children aged between 0 and 7. They may have different degrees of visual and hearing impairments, different levels of cognitive and language skills.

We suppose that functional assessment of individual perceptual characteristics is particularly important for two groups of children.

The first group includes cases where hearing and visual impairments are not diagnosed in the context of severe intellectual, motor or autistic disorders, or where these impairments are supposed, but it is difficult to clarify their degree and specificity. The second group includes cases where deafness, blindness or deafblindness has been considered and the child's usual behavior corresponds to these states, but under certain conditions, the child seems able to respond to visual and/or acoustic stimuli.

scribe 11 characteristics of functional vision and 6 characteristics of functional hearing. These parameters were selected as significant as a result of a literature review and a summary of the working groups which included the parents and the professionals from France and Russia.

In the following, we illustrate the description of some of these parameters and the recommendations made based on its results with a case study.

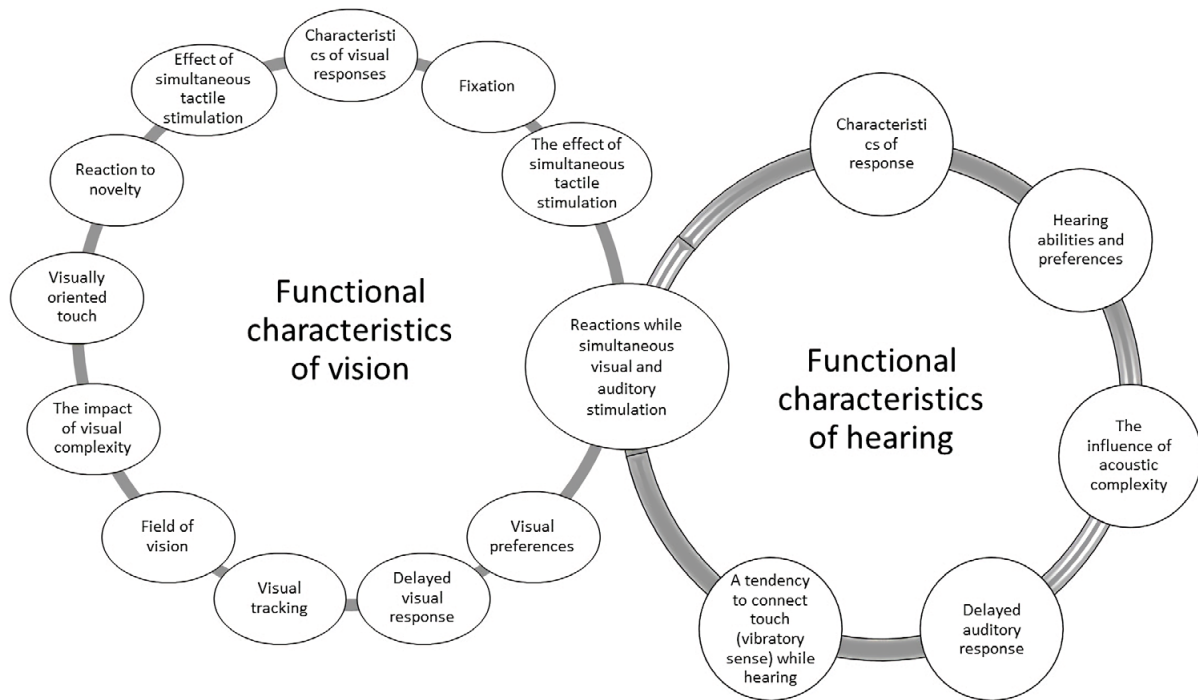


Fig. 1: The characteristics of functional vision and functional hearing

Case study: Jules

Jules (the name is changed) is a little boy aged 5 years old who has been diagnosed with blindness and tetraparesis as a result of being born prematurely. Medical examinations cannot measure his visual acuity, and his parents cannot understand what and how their son sees. According to medical data, he has no hearing impairment.

Jules is interested in objects and people, and shows a high level of activity, curiosity and drive. He always reacts happily when we approach him, and prefers the dynamic activities with adults to passive solitude. Jules interacts with others through vocalizations and expressive emotional reactions (laugh, smiles, and body movements). He likes physical contact and tries to touch his interlocutor with

his hands. He uses his right hand more effectively than his left. He almost never brings his hands together. He can reach out for a person or an object, but does not find them immediately, due to motor and visual problems. Eye movements are also difficult. He often rolls his eyes when making efforts, and it is difficult to synchronize both eyes to fix and follow an object. Jules puts almost all objects to his mouth or throws them to hear a sound. Sometimes, before throwing or taking an object to his mouth, he brings it to his eyes.

During the assessment, Jules demonstrated significant specificities in some parameters of his visual perception. Their descriptions as well as our propositions and recommendations follow just below.

Characteristics of visual responses

Jules does not always react to visual stimuli, and it is not always clear to others what he looks at or sees something. His visual reactions are most remarkable if an object or a person is directly in front of his face, at a distance of 10 to 20 cm. When he sees an object, he starts trying to grasp it with his hands.

In this regard, it makes sense to show Jules objects close to his face and wait for his reaction. The clearest indication that the boy has seen the object or the person is the attempt to take it with hands. It could be also useful to show him all the objects of his daily life before to use them: spoon, pampers, teeth brush, toys etc.

Fixation

Jules can sometimes fix almost directly on an object or person, sometimes he turns his head to the right and move his eyes to the left, or looks “sideways”, with his head tilted slightly downwards.

Delay in the visual response

Jules reacts to visual stimuli with a remarkable delay. It takes him a few seconds to detect them. Jules reacts to a person’s face with the longest delay (8 seconds). He prefers familiar faces to unfamiliar ones. It is important to notice that the visual response

We have to keep in mind that if Jules does not look directly, it does not mean he cannot see the object or is not interested in it. You need to give him the opportunity to “adjust” his gaze, as it is comfortable for him.

time decreases, if Jules is already expecting to see something.

It is necessary to take into account the time Jules needs to see an object and fix on it. This means that when we show him something, we have to wait a few seconds.

Visually oriented touch

Jules tries to grasp the object he sees with his hand, but with some delay, (it usually takes him some seconds to reach out his hand after detecting the object). He does not find the object immediately, but searches for some time in the air.

We propose not to give the toys in his hands immediately. It is better first to ask Jules to look at them and to give him enough time to find the object on his own.

The effect of simultaneous tactile stimulation

When Jules has a tactile sensation, he tries to find its origin with his eyes.

It means that we can use touch to attract visual attention.

Visual tracking

Jules can follow a little the movement of an object in different directions, but he does not do it each time, and only for very short periods. Tracking is possible if he first fixes on a stationary object close to his face. Sometimes he follows more or less well, but most often with a delay and in fits and starts. He follows best the luminous, shiny, black-and-white, red or yellow objects. He moves his gaze mostly from the centre to

the right, sometimes from the centre up and down and rarely often to the left.

Since visual response time decreases when Jules expects to be shown something, it is a good idea to organize regular visual training for 5 to 10 minutes: show him bright or shiny objects and images in front of his face, moving them slowly 5 to 7 centimetres to the right, left, up and down.

The impact of visual complexity

On a complex background (i.e. multicolour or with many details), he cannot remark objects.

several toys at once, do not use multicolour surfaces, etc. We should create the environment with a monochrome background and a contrasting objects or images.

That is why for now it is better to avoid visually complex situations: do not play with

Characteristics of responses to the acoustic stimuli

Jules responds well to the acoustic stimulation. He hears the loud and quite sounds at the significant distance, but he has no habit to look for their sources. He demonstrates usually the reaction of orientation and reacts emotionally. Only if the source of sound

is very close, he can turn his head in its direction.

Since sounds are very interesting and motivating for Jules, it makes sense to do exercises to find the sources of sounds. First start very close to his head and gradually move away the sounding objects.

Reactions while simultaneous visual and auditory stimulation

Jules does not usually look while he listens. For example, he stops looking at an object if it we tap on it and starts listening to the sounds.

However, his visual attention can be attracted by sound. For example, we can tap an object that we show him in front of his face and then stop. In this way, the sound helps Jules to find the object with his eyes. It also makes sense to attract his visual attention with

the verbal instruction “Look”, but then stop talking and wait until he responds visually.

The family and professionals accompanying Jules received the results and recommendations some months ago, and are followed them to the best of their possibilities. At present, the ophthalmologist notes the emergence of fixation and “conscious visual behaviour”.

Conclusion

Functional assessment of visual and auditory perceptual characteristics not only allows a better understanding of the child, but also describes useful conditions to develop his/her abilities.

Appropriate visual and acoustic stimulation not only helps to improve the perception, but at the same time paves the ways for the development of other functions.

For families, it helps to involve the child in meaningful interactions with close people and to modify the home environment. It helps to improve orientation and independence. For professionals, the structured functional assessment significantly reduces the time to understand children’s perceptual abilities and the effective ways of providing information that can be extremely important in interactions with a child.

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CHIARA FILIPPINI

Open Eye Tracker Application Designed for People with Multiple Disabilities and Visual Impairment

FONDAZIONE LEGA
DEL FILO D'ORO
ONLUS, OSIMO,
ITALY



**LORENZO
PERGOLINI**



PAOLO DE CECCO

Introduction

The Open Eye Tracker Application (OpEye 2, <https://opeye2.splet.arnes.si>) project seeks to provide an open application that facilitates and adapts the use of commercially available eye-tracking systems to the specific needs of people with multiple disabilities and visual impairment (MDVI) and deafblindness (DB). This was, in fact, specially developed without including any auditory feedback. Currently, eye-tracker devices can be used to control a computer system. Such devices, however, are intended for those who do not have particular needs. The application will assist the target audience in increasing their use of computer systems. Furthermore, advancements in the assessment of eye movements with infrared eye trackers will give the possibility to obtain quantitative parameters of oculomotor and visual function.

The presented project is part of the European Union's Erasmus+ program and involved the collaboration of for major international centers: "Lega Del Filo D'oro", "Center IRIS Ljubljana" experts in the field of VI and DB; "Centre pour le développement des compétences relatives à la vue" and "Aspaym Castilla y León" experts in developing applications and adjusting the eye-tracking solutions to the specific needs.

Open Eye Tracker Application

The application allows the target audience to train and evaluate their visual skills by completing several exercises that require visual tracking, searching and detecting different objects. These exercises are divided into three main categories: “Smooth pursuit” (to evaluate pursuit skills), “Visual Field” and “Saccades”. Each contains a sequence of exercises with different levels of difficulty.

The “Smooth Pursuit” attempts to evaluate a person’s functional vision, and it provides training in basic visual skills. The activities

differ in terms of background details and the speed of the object on the screen. In the settings menu, different colors/contrasts can be selected as well as the shape, size and direction of the target. The application allows to record the total time in seconds, the user has/has not stared at the target and the direction chosen in the configuration. The target in the final exercise of this category also randomly changes shape (triangle, rectangle, circle) and the user has to count the number of times the shape of the object has changed.

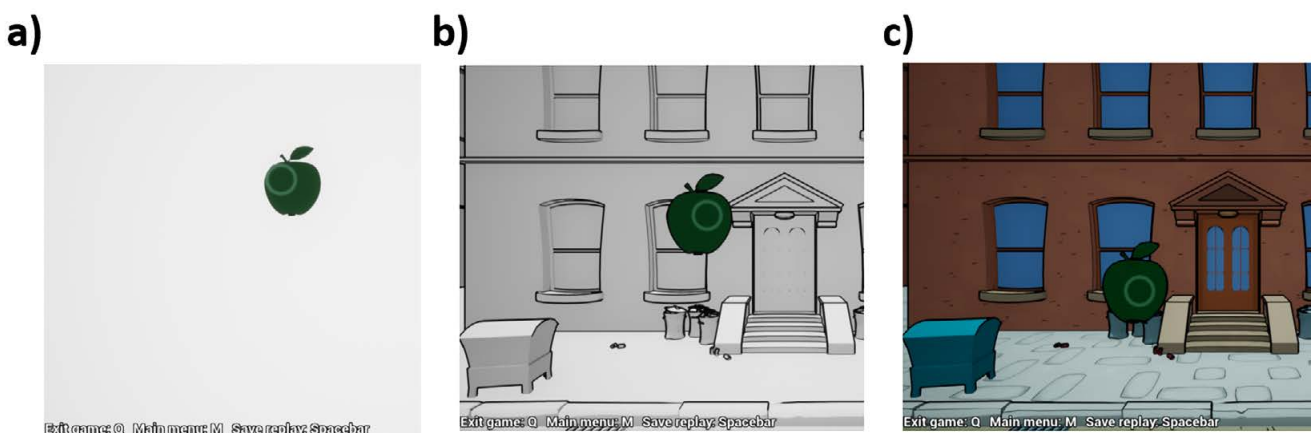


Fig1. Smooth Pursuit task with a) no background detail b) background containing details of the same colors c) background containing colored details.

The “Visual Field” helps to evaluate the extent of the central vision field and detect possible scotomas. In the exercise, just after the user focused on the central target on the screen, a peripheral target appears and as soon as the user has looked at it, it disappears, then the user needs to focus again on the central target. In the second exercise, the peripheral target slowly moves to-

wards the central target and as soon as the user detects it, it disappears. The size of the peripheral target as well as the different colors and contrast can be selected by the professional. The application allows the recording of the time in seconds that the user took to find the peripheral target, and a graph displaying an approximation of the central visual field.

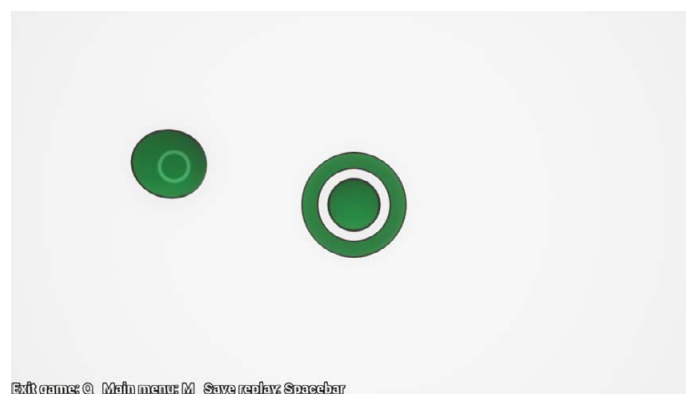


Fig2. Visual field task with peripheral static target.

The “Saccades” category tries to assess the precision and speed of focusing on the target while eye shifting. Here, different exercises require the user to shift his gaze from one spot to another. In one exercise, for example, there are two circles in the center of the screen, one of which has a ring around it. The user must glance at the circle on which the ring should appear in order to shift the ring from one circle to the other. Or, in another

exercise, two fish will appear in the pond. The goal is to watch the fish, so they won't escape the pond. With shifting gaze on both of the fish, they stay in the pond until the end of the game; and so on. The application allows to record the number of times the saccade movement was too short or too far, as well as the amount of precise saccade movements. The contrast, size and distance between targets can be chosen by the professional.

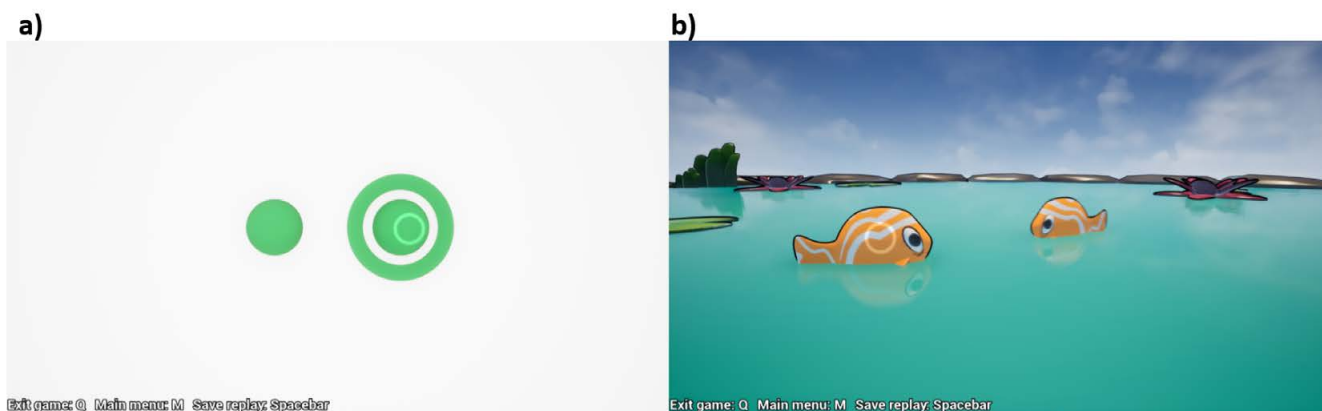


Fig3 Saccades task a) exercise with the two circles in the center of the screen, and the ring to be passed alternatively around one of them; b) exercise with the two fish in the pond that must not be let out of the pond.

In addition, the “Saccades” category includes exercise in which the user must focus on moving an object on the screen through the gaze. Such as for instance the “Frog” exercise in which a frog appears on the upper left part of the screen on the first water lily. The goal is to assist the frog in reaching the end of the water lily trail, which is located in the lower right corner of the screen. The user must focus on the frog in order for it to hop on the next water lily. Another example is the “Words” exercise, in which, a line of stars appears on the screen. The first star that the user must look at is highlighted in a distinct colour. When the gaze shifts to the highlight-

ed star, the secret letter is revealed and the next star is illuminated. Following the reveal of the entire word, another line of stars appears below (up to 3 lines). Finally, there are exercises in which the goal is to find objects in two different settings. A market and a wardrobe setting. On the market, vegetables and fruits need to be found, whilst on the wardrobe different pieces of clothing are to be found. The object to be found is displayed on the screen, at the beginning. The software records the max and min time in seconds the user took to find the object, whilst in the previous exercises it records the max and min time the users took to focus on the frog or to reveal letters.

Conclusion

The project's idea is to employ a commercially available eye-tracking technology and develop a specific application for the MDVI and DB target audience to quantitatively assess and train their visual function as well as to facilitate their access to computer systems. The application was also created without audio feedback, to further meet the needs of DB users. This program provides the pro-

fessional with instant feedback on the users' functional vision. In addition, the application recordings are stored and can be compared to previous training sessions. This enables the professional to make a more properly assess and monitor the progress of users. The application is freely available at <https://github.com/Opeye-erasmus/OPEYE2>.

SIXTEM – a Code for Entering Alphanumeric Characters on a Numeric or Dedicated Keypad

Entered on a standard or dedicated numeric keypad, it associates 2 symbols among 6 allowing the composition of usual alphanumeric characters.

Being based on handwriting (**SIX** symboles pour la Transcription de l'**E**criture **M**anuscrite), it is easy to remember.

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- It only takes a few hours to learn;
- A code-assisted learning method has been developed and validated by the engineers having vision loss;
- It can be a step in learning the 6-dot Braille code;
- Project has been under development since 1978 with **ENSERG, Center IMC, UJF, Grenoble** and **Ile d'Abeau IUTs**;
- Prototype for the individuals having disabilities awarded at the ADI MICRO 80 competition, 4th Achievement Prize (ENSERG, Center IMC).

Preliminaries

The SIXTEM keyboard has six keys, but two keystrokes are required for each character.



Fig 1. Standard numeric keypad with dedicated keys

Six keys form a graphic sign of a representative form, which means that the juxtaposition of two signs resulting from the typing of two keys of a character gives a text easy to decode.

The keys shown are those of a standard numeric keypad.

We successively press the keys that will give the representative form of the letter. For example, if

we press "1" for the vertical line and "2" for the right loop, that will give



Fig 2. Association of the vertical line and right loop symbols represents the character "b" which is **the lowercase letter "b"**

"5" for the left loop and "4" for the small vertical (or horizontal or dot) line gives



Fig 3. Association of the small vertical line and the left loop represents the character "a" which is **the lowercase letter "a"**

To write "SIXTEM", for example, we press the keys "5" and "2", then "4" and "3", "5" and "2", "2" and "5", "4" and "1", "4" and "5", "6" and "6".

What can be written in SIXTEM alphabet:

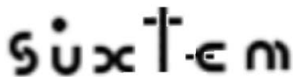


Fig4. The word "SIXTEM" in SIXTEM. The first symbol is partially covered by the second

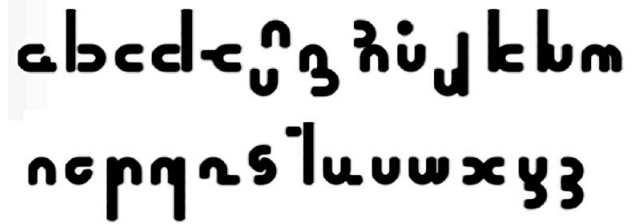


Fig 5. SIXTEM alphabet

SIXTEM code (partial).

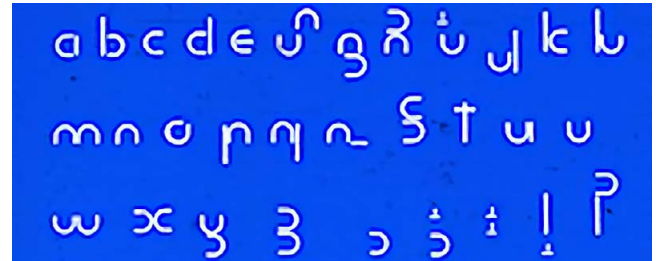


Fig 6. Combining six symbols to represent handwriting

The symbols are arranged on a numeric keypad accompanied by useful function keys for rapid writing.

The 1st symbol is red. The 2nd is green.

- Alphabet -

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- 6tem Keyboard -

Representation of the 6 symbols of the 6tem code

- : Representation of the 6 symbols of the 6tem code
- : Press one key, then another
- : Double press the same key
- : Press one key and then the key space

Opposite repetition : Generates the symmetrical symbol

Repetition of the same symbol

Simple space

Space within the text

Delete the last character

Fig 7. Use of the SIXTEM keyboard with repetition and function keys

Orange lines represent the memory vectorization of keystrokes.

The repetition and opposite repetition keys for the previously pressed symbol are intended to avoid releasing a key for the 2nd press.

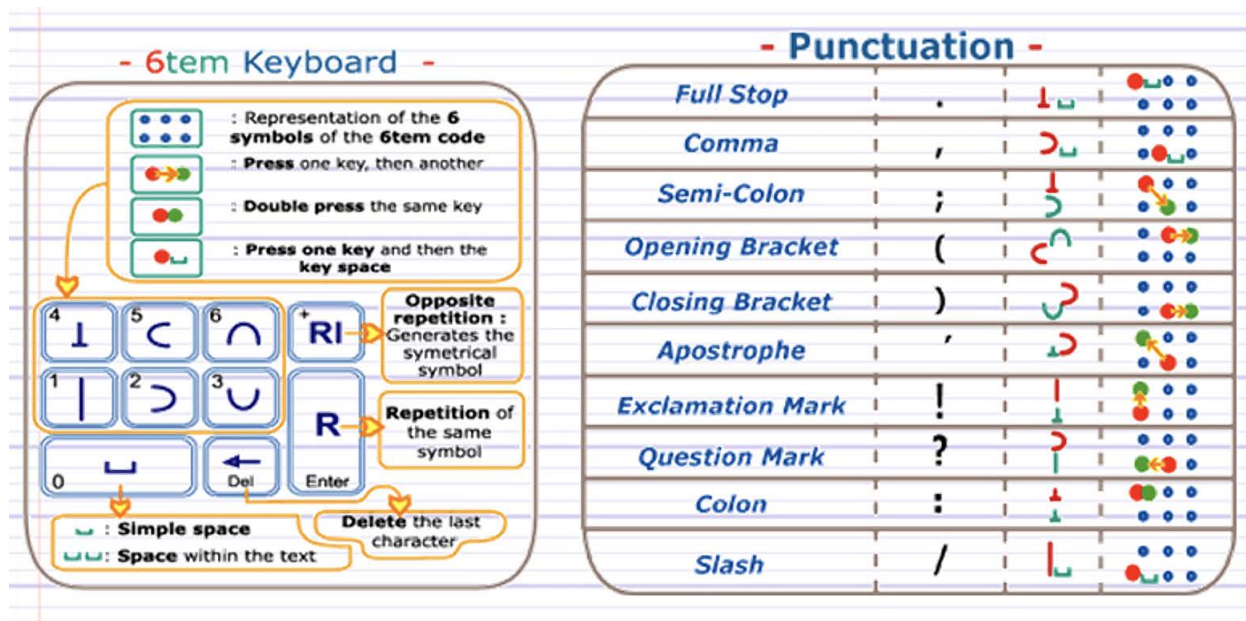


Fig 8. Punctuation for simple texts

Learning to write with one hand can be a step towards accessing Braille by replacing the SIXTEM cell with a classic Braille cell, using the same loop learning system developed for the SIXTEM code.

The simplified SIXTEM alphabet may be sufficient for e-mail or text messaging for those who haven't mastered the use of the keyboard, but as it uses only one hand, it can be used to learn Braille which has been adopted by the individuals having vision loss and which offers incomparable material and psychological environment, even if it is difficult to access. This development of assisted learning in loop was requested by two engineers having vision loss who validated the tactile reading of the SIXTEM code, but with a Braille keyboard rather than a SIXTEM one.

Studies have shown that few individuals having vision loss acquired in adulthood have taken up learning Braille, even though it offers them entry into a community and interesting integration possibilities.

The deliberate simplicity of the SIXTEM code, based on the form of the manustrite script

of Latin characters, makes for an easy transition between the handwritten character and its SIXTEM code. The learning loop can develop a rapidly acquired conditioned reflex, reinforced by the implementation of sequences recorded on the system. Since the code is an input code on a numeric keyboard, any adaptation is possible, and in particular auditory or tactile reading by means of adapted cells.

Writing SIXTEM on the numeric keypad is easy and can be learnt in a few hours even without a strike control system, but reading is difficult because it uses 6 dots like Braille.

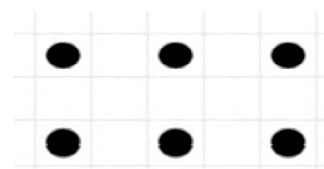


Fig 9. SIXTEM cell with six dots driven by electromagnets

Below: a b c d e f g h on the SIXTEM cell with six solenoid-operated pins under the left fingers.



Fig 10. a, b ,c, d ,e ,f ,g ,h

The square corresponds to the 1st symbol struck, the round – to the 2nd.

There is no character which composition requires memorization of presses.

After testing the system, two engineers having vision loss validated the method, but criticized its passive-reading nature.

A static display with active reading is conceivable, but its implementation is complex.

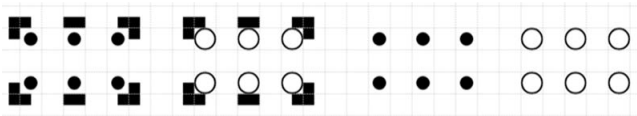


Fig 11. Cell with six dots driven by concentric electromagnets

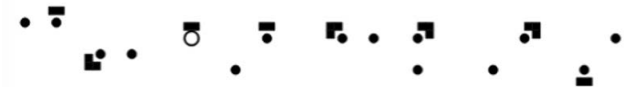


Fig 12. The 1st keystroke is identified by its position on the keyboard, the 2nd – by its position relative to the 1st

In practice, it's just as difficult to read as Braille, which is much more complete.

Examples

Simulation on a 7-segment display.

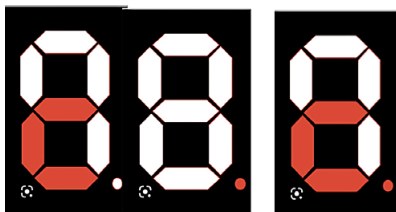


Fig 15. Composition of the letter “a” with a left loop and the DP

The 1st keystroke shows the left loop, the 2nd – the Data Point. The “a” character is then displayed permanently on the 7-segment display.

Hence the search for static finger reading like Braille on a 7-segment + DP display.

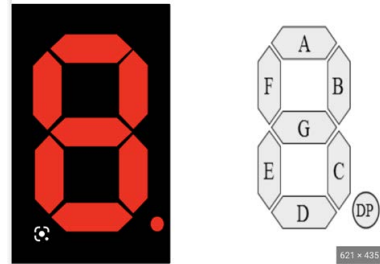


Fig 13. 7-segment display + DP

We took the needs and experience of the individuals having disabilities as a starting point and designed a modified display that was less elegant but more affordable in terms of learning for the individuals having vision loss acquired in adulthood.

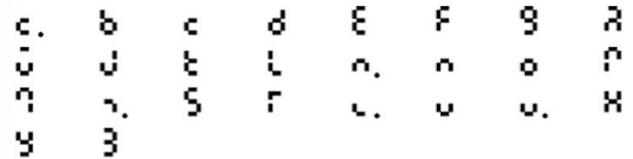


Fig 14. 7-segment display code + DP

The 1st keystroke shows the vertical line, the 2nd – the right loop. The “b” character is then displayed.



Fig 16. Composition of the letter “b” with the vertical line and the right loop displayed permanently on the 7-segment display

For the relief mechanical implementation only very low-cost components are used.

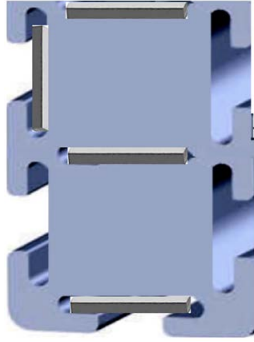


Fig 17. Aluminum profile with mobile segments

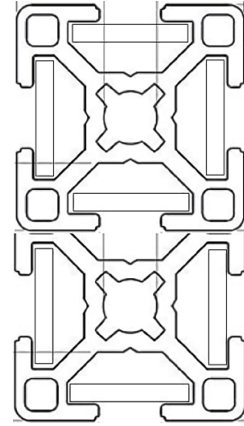


Fig 18. Structure

Aluminum profile with mobile segments driven by electromagnets controlled by Arduino.

The project is underway thanks to a student.



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Haptic Communication to Facilitate Braille Instruction for Deafblind Adults



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Introduction

This article describes a research study conducted by the Helen Keller National Center for Deaf Blind Youths and Adults (HKNC) on the effects of using Haptic communication during braille instruction with DeafBlind adults in a rehabilitation setting. Haptics, as described in this paper, is a standardized system of providing visual, environmental, and social information via touch signals on the body (Raanes & Berge, 2016). Typically, a provider, presents Haptic signals to the receiver, using specific hand shapes combined with pressure on the deafblind person’s “places of articulation” such

as the back, arm, leg, hand or foot (HKNC, 2018). It is important to note that Haptics is not synonymous with Protactile (PT). Haptics and Protactile may be similar in that they

are both forms of touch systems, however, there are vastly different in their origins, philosophies, touch signals, and strategies (Protactile Language Interpreting, 2022).

Literature Review

Spearheaded by Deafblind leader Trine Næss, the term Haptics was coined in Norway to describe common touch signals used collectively by the Deafblind community in the 1990's (Bjørge et al., 2015; Næss, 2002). In 1991, the concept of social-haptic communication was documented during the 10th Deafblind International (DbI) World Conference in Örebro, Sweden (Palmer & Lahtinen, 1994). The first research article to mention social-haptic communication was the "Proceedings of the 3rd International Association for the Education

of the Deafblind (DbI) European Conference in Potsdam, 1993" (Palmer & Lahtinen, 1994, p.1). From there, an organization called Hapti-Co was developed to further the training of Haptic communication which resulted in the book, *Haptisk Kommunikasjon* (Øverås et al., 2013). HKNC learned of Haptics and collaborated with Hapti-Co to create a modified American Edition to share with Deafblind community members, providers, interpreters, and other professionals in the United States (Bjørge, 2015).

Methodology

This qualitative study used a case study approach to collect and analyze data over a six-month period. Participants were six Deafblind adults attending the rehabilitation training program at the Helen Keller National Center for Deafblind Youths and Adults in New York. This purposeful sample of participants allowed for the study to explore the effects of Haptics on those who were (a) legally Deafblind, (b) over the age of 18, and (c) engaged in braille training. Data was collected using student records, student interviews, instructor observations, and observations from video recorded braille lessons using Haptics. All the participants received direct communication from their instructor via visual or tactile ASL. The instructor described the Haptic signals to the student by presenting the signal and explaining what the signal meant. A typical lesson would begin with the student sitting down next to or across from the instructor, with a sheet of braille letters, contractions, or sentences. The student would read the braille, communicate what they were reading to the instructor in ASL and receive Haptics and/or ASL feedback from the instructor. Exit interviews were also conducted for four of the six participants that covered much of the same ground as the post-lesson interviews but with an expansion

on their overall experience with using Haptics during braille instruction.

Table 1.

Demographics	Number of Participants (N=6)
Gender	
Male	3
Female	3
Race/Ethnicity	
Black	1
White	5
Previous Haptics	
Yes	3
No	3
Primary Language	
Tactile ASL	5
Visual ASL	1
Braille Skill Level	
Beginner	4
Intermediate	2

Findings

Haptics during braille instruction appeared to enhance learning, communication, and rapport. This research also revealed the impact of instructor knowledge and skill in Haptics, instructor body placement, variance in signal preferences amongst students, and the need

for open communication in modifying signals as needed. This section will discuss the themes that emerged across six case study participants over a six-month period. Please note that participants' names have been changed to protect their anonymity.

Potential for Enhanced Learning, Communication, and Rapport

All the participants said they appreciated the use of Haptic signals and found them useful in both learning and social contexts. Participants agreed that using Haptic signals was helpful for elements related to learning such as efficiency, focus, level of frustration, and encouragement. One braille student shared that she was able to communicate and read simultaneously as she was able to read braille with one hand, sign what she was reading with the other hand, and then respond to Haptic feedback by her instructor at the same time. Other participants shared the following remarks.

"I didn't have to communicate through tactile sign language...I could focus on the braille." -Barry

"Braille is hard! [Haptics] can make it easier for when you make a mistake." -Sara

"[When the teacher lets me know that they are leaving the room or that they are laughing] ...That's important for me to be aware of the teacher. It soothes me...I can't hear you laughing, so it's nice to use the 'laughing' haptic when you laugh. It lets me know you're excited...I really liked when you were telling me 'yes' and tapped my arm very energetically because it meant you were happy that I got it right." - Adele

Using Haptics related to social cues during instruction also had additional benefits for students, such as establishing a rapport with the teacher. Barry said, "I loved [Haptics for social cues]! If I was having a hard time reading the braille and finally figured out a word, and [the teacher] used 'smiling', Haptic it was very encouraging." Video observations, also showed Adele animated, enthused, and engaged in the braille lesson while using Haptics.

Importance of Student Choice: Personal Preferences, Frequency, Modifications, and New Signals

Some personal preferences and modifications that students made during instruction included the instructor sitting on a specific side next to them, presenting some signals on the arm and others on the shoulder, varying degrees of pressure, using a twisting motion rather than pressure, combining use of visual/tactile cues, and slowing down:

"In the beginning, when learning the braille alphabet, maybe [use] haptics on the back to show the braille cell like a picture. Once you learn A to Z, then on the upper arm." -Barry

It was important for students and instructors to discuss student preferences at the start of instruction and to check in periodically. When first starting braille instruction with the use of Haptics, some students preferred to have signals presented frequently, especially signals conveying encouragement, but as students grew more confident frequent signals were almost distracting and they preferred signals only as correction. Certain signals were more difficult to understand than others, but there was also the option to modify signals. For example, the "braille cell" signal seemed hard to interpret for most students. Some students came up with their own ways to modify the signal to make it more understandable such as giving the braille cell signal after a "question mark" signal was provided or presented with more pressure, as well as repeating more than once on the shoulder or back. Participants also had personal preferences for which signals work best for them, how frequently to

present them, and how to provide them so that they are understandable. Adele shared:

“All the haptics are very helpful. I can’t see facial expressions. If I get lost, I don’t want to take my hands off the page. Haptics make it easier. Less distracting, and it’s more immediate [feedback]...the leveling (signal) made it more smooth—You didn’t have to move my hand.”

Instructor Skill & Experience

It became evident that as an instructor grew more familiar with the Haptic signals being used, and comfortable enough to adapt signals based on student preferences, Haptics was more easily incorporated into the lesson and students were more responsive to their use. As an example, the instructors for Adele and Barry were both experienced with Haptics and used signals frequently, incorporating lots of “encouragement” using Haptics such as “yes, correct” and “smiling”. They both sat alongside the student and kept constant contact with a light hand on the arm that the student was using to sign, where they also presented Haptic signals. During Avery and

There was also fluidity in the use of Haptic signals. Students and instructors worked together to create and make modifications to suit their individual needs. For instance, modifying the “leveling” signal to give feedback about interpreting dots within a braille cell, creating a signal for “mirror image” braille letters, and using more pressure with hard to distinguish Haptic signals.

Sara’s lessons, and for the first lesson with Ronald, the instructor, who was less experienced with Haptics, sat across from them and had to lean across the table to give Haptic signals. When the instructor presented Haptic signals, the students sometimes startled because the instructor was reaching across the table and the signal surprised them. Over time the instructor incorporated feedback on Haptics use from others and became more confident. By the last few lessons with Ronald the instructor was sitting next to him, giving constant contact, and more feedback. The exchange seemed more comfortable, and Ronald seemed more focused on his braille work.

Discussion and Implications for Practice

This study has found positive implications for using Haptics during braille instruction for Deafblind adults. The findings indicate that the use of Haptics enhanced learning, communication, and rapport within this research sample of six participants. This qualitative research also discovered the impact of instructor knowledge and skill in Haptics, instructor body placement, variance in signal preferences amongst students, and the need for open communication to modify signals as needed.

With Haptics proving to be a useful tool in braille instruction, it could potentially be applied to other areas of learning within rehabilitation settings. Additionally, these findings support a need for professional development around Haptics for service providers. Future research is needed to better understand the efficiency of Haptics across instructional settings such as orientation and mobility, employment training, assistive technology, independent living skills, and more.

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

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Acknowledgement

This article was produced as part of the Australian Research Council funded Linkage Project “*Deafblind communication: Building professional competencies*” partnering with Able Australia and the National Accreditation Authority for Translators and Interpreters.

We wish to acknowledge the support of the wider project team in the collection and evaluation of data, and for their valuable input to the contents of this article:

Dr Meredith Bartlett, Ms Eleanore Hunter, Dr Shimako Iwasaki, Dr Howard Manns, Dr Meredith Prain, Mr Dennis Witcombe

Introduction

The first global report of the World Federation for the Deafblind notes that access to “a professional interpreter-guide service can be the key to accessing other services and fundamental rights, such as education, employment, health-care, culture and recreation” for deafblind people (2018, p. 5). Yet access to such services is far from universal. Partly this is a funding issue, but the second global report

of the World Federation for the Deafblind (2023) also foregrounds that the issue is compounded by a lack of training and certification programs for professionals working with deafblind clients in much of the world.

A challenge in establishing training programs is ascertaining what skills should be covered and what models of delivery might work

best. In this article we report key findings from a global survey of professionals working with deafblind people (Willoughby et al., 2023). Our research aimed to provide a bet-

Methodology

In order to ensure global reach, our survey was distributed in five languages: English, Chinese, French, Japanese and Spanish. The questionnaires were distributed through a variety of electronic channels, including Facebook post by key deafblindness service providers/ networks, newsletters and direct emails to our contacts. The survey was open from July-October 2021.

We received 324 completed responses from professionals working with deafblind clients

Results

Preservice training

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

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

ter understanding of the training landscape internationally, including respondents' experience with pre-service training, professional development and barriers to training.

across 36 countries. Australia (27%) Japan (23%) and Canada (10%) were the most represented countries. Just under half (46%) of our respondents worked solely or mainly as interpreters, 23% as support workers and 30% in mixed or other roles. Respondents were generally well educated: just over half (52%) held a bachelor degree or higher. Many were also highly experienced: over half of the interpreters but only 31% of support workers had been working in the field for more than 10 years.

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

Professional development experience

Around half of our respondents had less than 15 hours of professional development in this area across their entire careers. This speaks to a dearth of training in the area, which was confirmed from responses to subsequent questions. The most common training that people had accessed was deafblind awareness training (accessed by around 80% of respondents) and guiding deafblind people (accessed by over 65% of respondents). Between 40-60% of respondents had attended a short training in visual frame signing, introduction to tactile signing and haptics, while less than 30% had any training at all in protactile or specialised aspects of tactile signing (e.g. use of space, use of pronouns). Respondents were, however, extremely enthusiastic about the trainings that they had been able to attend, reporting average satisfaction ratings of 4.2-4.6 out of 5 for the vast majority of trainings that we asked about. They also gave average scores above 4 on the same scale when asked their interest in receiving more training in these areas.

Barriers to training

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

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

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

making it difficult to attend (both to cover the costs of the training and the income foregone in not working that day).

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

Conclusion

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

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

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One Hundred – Marathon 2023

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NETWORK FOR THE
FAMILIES OF THE
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June 27, the International Day of Deafblindness, marked the start of online walking marathon for the children and adults having multiple complex developmental disorders ONE HUNDRED 2023.

Marathon motto: Be a part of the team! Always! Anywhere!

The marathon has been organized by the Community for the Families of the Individuals, Interregional Charity Non-Governmental Organization who are Deafblind with

support of the Con-nection Fund. The authors of The One Hundred project are international organizations working with the children having multiple complex developmental disorders: Perkins school for the Blind (USA) and PAVIC (Philippines).



Photo 1. Marathon participants of the teams from Saint Petersburg and Nizhniy Novgorod

- 54 applications were filed;
- 13 teams were formed and the participants' age of 4 of them is 18+;
- The applications were received from 22 Russian cities and towns from Kaliningrad to Surgut (including Moscow, Saint Petersburg, Nizhniy Novgorod, Kazan, Surgut, Velikiy Novgorod, Yekaterinburg, Smolensk, Piatigorsk);
- The youngest marathon participant is 2 years old, the oldest one is 67 years old.

Each team, consisting of 4 participants and their accompanying persons, had to cover the total distance of 100 km each day in the course of 10 days. But the participants appeared to be strong in spirit and to have excellent physical ability, covering much longer distance every day. According to the marathon results, from June 27 to July 6 the teams walked 3339 km that is equal to the distance between Saint Petersburg and Istanbul. Some of marathoners personally passed over 100 km!



Photo 2. Kira Miroshnichenko, a marathon participant

In the course of all 10 days the teams were accompanied by almost hundred fans who passed about 2000 km.

The marathon main objective was to attract attention to the benefits of walking as it unnoticeably disappears from our lives. But a person of any age feels the need of movement. Insufficient motor activity affects both physical and mental health. In particular, walking is good for children! In motion, a child perceives the world and develops. Besides, the marathon helps to form in children the ability to work in a team, overcome difficulties, obtain communication skills, set aims and achieve them.

Upon marathon completion, we can declare achievement of all objectives. Each participant coped with the task, got positive emotions and new physical skills, and expressed willingness to take part in the marathon next year!

Here is one of numerous received feedbacks:

Anna Khanipova, the town of Verkhnyaya Pyshma,

I can't believe that the marathon came to the end!

It was very interesting to get to know the participants. On the day of meeting them I had a feeling of acquiring new friends. On the day of introducing cities and towns a wish of visiting them appeared in me. And above all, it was exciting to test my own forces. In these 10 days Kostya achieved several victories. First of all, 33.07 km were passed. Secondly, he overcame the fear of sand for good. Now Kostya happily walks on it, takes it in the hands, pours it from one place to another. And today he has achieved the 3rd victory. Today Kostya has played with colorful ribbons fluttering at the beach entrance.

We'll participate next year with the greatest pleasure!

Interview with Tatiana Basilova¹



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QUESTIONS BY
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Tatiana Basilova, The Professor of the chair of Special Education and Rehabilitation for the Physically Impaired Individuals, the faculty of Clinical Psychology and Special Education, and Professor Emeritus of the Moscow State Psychology and Pedagogy University

How did you start working with the individuals who are deafblind? What is the brightest remembrance from those times when you had first got to know individuals who are deafblind?

I first saw young individuals who are deafblind when they were preparing for entrance exams at the Moscow State University in 1971. I heard Aleksandr Mescheriakov's story about them. At those times, I was a second to last year student of the psychological faculty at the Moscow University. I was surprised by the fact of existence of the people who are deafblind because I had never heard of anything similar before. Exactly due to this shock I called in for working a few hours a week as a second-part-of-the-day teacher in an experimental group of the individuals who are deafblind at the Institute of Speech Pathology. I was assigned to walk with 2 visually impaired girls having hearing loss. Having started working there I met 4 future learners who were deafblind, their teachers and employees of deafblind teaching laboratory, including Olga Skorokhodova (Olga Skorokhodova is a woman who is deafblind, researcher in the field of deafblindness and a teacher).

Sometimes, I had to replace her secretary fallen ill and help her at home. And one of the brightest impressions of those times is that before I would leave, she used to ask me not to forget to switch off the light in all the rooms of her flat. And going away, I was leaving her in total darkness.

What experience and approaches do you implement working with the students interested in the issues of deafblindness, and what results in this area are you proud of most of all?

I started working as a teacher in 1995 at one of Moscow higher education institutions, where I was teaching a course of the Psychology of the Individuals Having Hearing Loss. By that time, I had been combining my main research activities at the Institute of Speech Pathology with a job of an applied psychologist at a school for the individuals having hearing loss and additional disabilities. A little later I was invited to the Moscow State Psycho-Pedagogical University to teach a course of Teaching Individuals who are Deafblind, and then I became a full professor of that university. Of course, I include inter-

¹ This year celebrated the centenary of Aleksandr Mescheriakov, one of the 1st specialists and teachers who were studying deafblindness in Russia. Tatiana was one of Aleksandr Mescheriakov's students.

esting stories about the individuals who are deafblind familiar to me from the books and personal experience, as well as video clips, almost to all the disciplines. For several years already, my colleague at the chair is professor Aleksandr Suvorov who is deafblind.

And if we pass to the most meaningful for me results in work with the individuals who are deafblind, these are my students that successfully work in this area and that are the authors of very interesting and needed papers. Some of the textbooks contain my chapters on teaching the individuals who are deafblind. I am the compiler and co-author of 2 guidelines: on particularities of life of adult individuals who are deafblind in a metropolis and on psychological support of the children with multiple complex disorders in their families. The last textbook for which I had written several chapters was issued in 2019. It was fully dedicated to teaching the individuals who are deafblind and it was called Teaching the Individuals who are Deafblind. My book, History of Teaching the Individuals who are Deafblind in Russia was translated into English and Japanese, and from time to time I receive feedbacks from different countries of the world that make me feel proud. Experience of international cooperation in the area of deafblindness, participation at DBI European and international conferences, was of great importance for me. And I'm trying to encourage my learners to keep track of the experience of researchers from different countries.

Is your current job related to the research of sensory impairment? What main topics of the research would you single out?

My current job is teaching a few disciplines, mostly related to the sensory and complex impairments, at the university, and also, I'm a research advisor for bachelors, students, graduates and candidates. In the area of psychology of the individuals having hearing loss, I would particularly outline dissertations of such my candidates as Alina Khokhlova, Intellectual Development of the Children Having Hearing Loss and Originating from the Families with the Parents Having Hearing Loss and Having No Sensory Challenges, Yulia. Zamaletdinova, Developmental Age

in the Structure of Self-Awareness of the Children Having Hearing Loss and Having No Sensory Challenges in the Age of 6–8 Years Old. Moreover, one of the 1st dissertations in the area of psychological studying of severe multiple complex disorders was written by E. Samarina in the topic of Social and Labour Abilitation of the Learners Having Severe Intellectual Disabilities in the Setting of a Boarding School. And now, Mariia Vetrova, who is, I guess, my last candidate, finishes research on diagnostic studying of the children with multiple complex disorders. A few years ago, I organized and had been managing the sole in our country Master's program that was called precisely Psychological and Pedagogical Support of the Individuals who are Deafblind and Having Severe Multiple Complex Disorders. And I am proud of the graduates that had passed this training. I guess, the most interesting dissertations in the area of deafblindness, written under my guidance, are The Use of Modern Information Technologies for Socialization of the Individuals Having Acquired Deafblindness by Evgeniia Lagunina and Effect of Participation in Dramatic Art Activities on Speech and Personal Development of the Individuals who are Deafblind by Pavel Mazaev. Among the graduates' researches dedicated to the multiple complex disorders, I'd like to outline N. Karpova's dissertation entitled Particularities of the Development of Self-Awareness in the Young Children Having Severe Multiple Complex Disorders.

Are you planning to make any publication on the topic of deafblindness in the foreseeable future?

Now I'm finishing working on a chapter for a multi-author monograph addressed to the modern researches in the area of multiple complex disorders. My chapter will be entitled From Deafblindness to Multiple Complex Disorders. This year celebrated Aleksandr Mescheriakov's centenary and 60-year-anniversary of Sergiev-Passad Orphanage for the Individuals who are Deafblind that now bears the name of Mescheriakov's Family Centre. I'm planning to write an article dedicated to these events, but for now nothing works out.

Tatiana, your employee tenure is 50 years. Let me make sure I've got it right, have the individuals who are deafblind been under your magnifying glass one way or the other all this time? During this time, what changes took place in the scientific approach to this topic and in public perception of this issue?

In the course of all years of my professional activities, research issues related to deafblindness have been composing my main academic interest and the most part of my 50 works are written on this topic. Over my long professional life, I see how the causes of deafblindness are changing. Keller's classic deafblindness is becoming rarer, but severe multiple complex disorders including sensory disorders are becoming more frequent. Deafblindness doesn't frighten common people anymore and hardly anyone is surprised

at the individuals who are deafblind successfully studying at the universities.

How do you see the future of working on the topic of deafblindness in Russia?

I believe that a lot has been made in the area of psycho-pedagogical support of the children having complex sensory impairment and in the area of training specialists to work with them. The main focus should shift to a later vision and hearing loss. More and more people experience difficulties with vision and hearing in adulthood and, especially, at the great age. For now, the extent of helping these people at the national level is very low. It's clear, that the number of young individuals with military injuries, and with deafblindness as well, is increasing. At the moment, the need of psycho-pedagogical and psychotherapeutic support to my fellow countrymen is felt acutely.

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