Deafblind
International DbI

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PROCEEDINGS
18th DbI INTERNATIONAL WORLD CONFERENCE

Lived Experiences, Evidence-Based Practices and Research

GLOBAL
CONNECTIONS
18th International World Conference
July 22-28, 2023 Ottawa, Canada

The future in our hands Le futur est entre nos mains

CONNEXIONS
MONDIALES
18ième conférence mondiale internationale
22-28 juillet 2023 Ottawa, Canada

PROCEEDINGS
18th DbI INTERNATIONAL WORLD CONFERENCE

Lived Experiences, Evidence-Based Practices and Research

2024

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Lived Experiences

INTRODUCTION

Deafblind International DbI is pleased to present this Virtual Proceedings Document of the 18th International World Conference, Ottawa, Canada (July 2023). These thirteen selected post-conference papers represent a small cross section of the many presentations, posters and plenary sessions that were offered at this international conference. Written papers were elicited from those who presented at the conference. A varied group of individuals with deafblindness, family members, practitioners and research scholars sent in papers for the proceedings.

The Emerging Scientific Committee members conducted the independent peer review and a subset of papers were identified for inclusion into the Conference Proceedings. A subgroup of the Conference Scientific Committee (18th DbI International World Conference) reviewed and refined selected submissions to prepare them for publication. The final group of papers provide insight into the unique experiences of individuals with deafblindness; highlight examples of programs and practices; and offer research findings that respect deafblind culture and understandings.

As a result, these proceedings are presented to illuminate the variety of realities, challenges, and progress made by individuals with deafblindness and those that support them. These proceedings are intended to be a selective peer-reviewed collection and are copyright protected.

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KEYNOTE PAPER AND CONFERENCE OPENING

The Next Big Thing in Deafblindness Research: Where Does the Field Go from Here?

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Abstract

The past decades have brought tremendous progress in the field of deafblindness research. The translation of this research into practice has allowed for remarkable advances in education, communication, service provision, technology, and policy. These, in turn, have resulted in clear improvements of functioning, independence and quality of life of persons of all ages living with deafblindness and their allies. However, new needs and priorities continue to emerge, especially when individuals living with deafblindness are included in the co-creation process; therefore, the time is right to reflect on the diverse work being conducted in deafblindness research, and how a common framework can center these efforts. This is an overview of the currently ongoing international collaborative effort on the development of a Core Set for deafblindness, using the World Health Organization's International Classification of Functioning, Disability, and Health.

Given the recent emergence in popularity and access to artificial intelligence, it is now possible to consult with a Chatbot with Generative Pre-trained Transformer ability (ChatGPT) on the question: What is the next big thing in deafblindness research? Interestingly, the level of insight in the response is quite surprising. The main topics that ChatGPT provided were technology, rehabilitation, early intervention, genetics, education, and mental health. Using the AI software Perplexity, the suggested priorities were the development

of new technology and innovative communication methods, as well as focus on the Protactile movement. With increased exploration of current trends in deafblindness research, it becomes clear that the next big thing needs to be able to recognize the diversity of the type of work being conducted. Some of us study definitions and terminology, screening and assessment techniques, others focus on genetics and medical treatments. Others again are rooting their work in literacy development and communication, education, employment, or retirement. Overall, quality of life is a central goal, and accessibility and assistive technology play an important role in supporting these efforts. Above all, policies, services, and procedures need to expand for researchers to be able to conduct their work.

To recognize these diverse interests, a framework is required to connect the work while accommodating different interests. The World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF) can accomplish exactly this goal (World Health Organization, 2001). Officially, the ICF is the WHO's framework for measuring health and disability at both individual and population levels; however, it is also as a way of thinking, a way of conceptualizing the idea of health that can express functioning by using a bio-psycho-social perspective. The ICF (see Figure 1) considers the interaction of impairments in body functions and structures, as well as activity limitations and participation restrictions caused by any given health condition (in our case deafblindness), and how these are influenced by environmental and personal barriers and facilitators. To apply the ICF, a coding system is available that provides over 1,400 defined terms to describe any aspect of this framework (Tate & Perdices, 2008). Given this vast number, reduced and context-specific sets of codes – the Core Sets – exist that can be applied to a particular health condition. Core Sets can be general, abbreviated, or specific to children and youth. For hearing loss, such Core Sets already exist (Danermark et al., 2013) and for vision impairment, they are currently under development (Billiet et al., 2021). Therefore, the time is ideal for the development of Core Sets specific to deafblindness – and this project is currently underway with the support of many organizations around the planet.

The process of developing a Core Set is highly regulated by the WHO (Selb et al., 2015), and a research team based in Canada has published a detailed account of the process that is currently being followed (Paramasivam et al., 2021). All institutional review board ethics approvals have been obtained, and every effort is being made to have representation on the team as well as within the data sets across all six WHO regions: Africa, the Americas, South-East Asia, Europe, the Eastern Mediterranean, and the Western Pacific. The results of our systematic literature review, as well as the outcomes of the expert survey, will be published before the end of 2023 (Jaiswal et al., under revision; Paramasivam et al., in press). The qualitative interviews with persons with lived experience, parents, and informal care providers are currently ongoing, and data collection of the multi-center clinical study was planned to commence in November of 2023. The International Consensus Conference that will decide on the codes to be included in the recommended Core Sets is planned for summer/fall 2024.

In the effort to promote the process of developing Core Sets for deafblindness, an important question remains: Why do we need such Core Sets? The answer has multiple layers, given that Core Sets can influence many different aspects of visibility and recognition, as well as service and policy development. Individuals that are in a position of power to make decisions about health care access and delivery, or insurance coverage, for example, cannot be expected to be experts on all health conditions that fall within their responsibility. Therefore, they can turn to standardized information that is sanctioned by internationally recognised organizations, such as the WHO. The same applies for ministries, funding agencies, non-for-profit organizations, health and social service providers, and researchers. Specifically, the process of developing Core Sets allows all stakeholders to identify and compare priorities as they are expressed in the perspective of persons with lived experience, experts in the field, and in research priorities that have been pursued so far. As a result, researchers can identify priority domains that have not yet been explored but need to be urgently addressed.

A systematic review has indicated that the most common standardized measures that have been used in deafblindness research to date have focused on depression, cognition, and instrumental activities of daily living (Paramasivam et al., in press). When comparing the outcomes of this review with the priorities that were identified in the expert survey, the data indicated that both perspectives agreed with regard to activities and participation: interpersonal interactions and relationships (code d7), as well as communication (code d3) were the most frequently mentioned and measured items. On the contrary, while the literature review indicated that the focus of studying environmental barriers and facilitators rests on technology (code e1) and human-made changes to the environment (code e2), most experts pointed at supports and relationships (code e3) as the most important environmental factor (Wittich et al., 2023). As more data are collected, the team is able to work on comparisons of these priorities with the perspectives of persons living with deafblindness. The hope is to be able to highlight where gaps exist in existing knowledge that are particularly of interest to persons with lived experience.

A key concept that crystallized during the process of conducting this series of studies on the development of the Core Sets for deafblindness is the international collaboration that makes projects of this type possible. Deafblindness remains a relatively low-incidence and low-prevalence disability (Bright et al., 2023), and often does not draw the attention and resources that are necessary to fully allow individuals living with deafblindness to realize their full potential. However, globally, there is tremendous overlap among the needs, concerns, and questions. Therefore, vigilance is essential, collaboration is vital, and the definition of research and rehabilitation priorities in deafblindness remains important (Wittich et al., 2016). Such an approach will allow researchers to harmonize efforts, avoid redundancy, and show strength and commitment to move progress in deafblindness research forward, ultimately improving all aspects of life for persons living with deafblindness.

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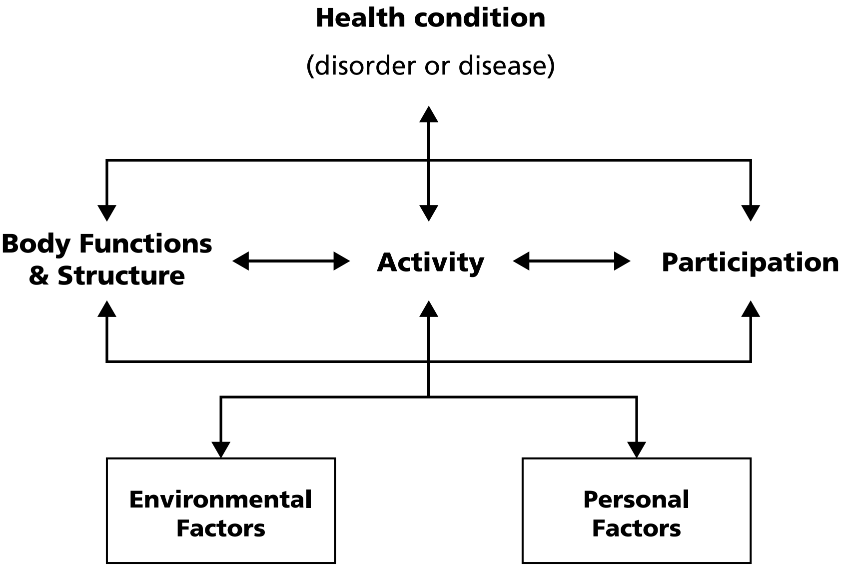

Figure 1. Schematic overview of the World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF).

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PROFESSIONAL PAPERS AND RESEARCH

Social-Haptic Communication, Hospital-Haptices in Health Care Settings

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Photo credits: Riitta Lahtinen

Hospital-Based haptices is one part of social-haptic communication (SHC). They are part of nursing practice as their role is to provide information to patients as to what is happening or how to respond by their own movements. Haptices are chosen according to individual needs and the use of haptices can be agreed to by the patient and nurses in advance. During a SHC field-research study, 12 most common haptices used by patients with dual-sensory impairment in hospital settings were identified. These haptices were analysed by their origins and etymology and by which haptemes (grammar of touch) were applied. These chosen 12 haptices have six different functional categories: professional role, measurements, length of treatment, emotions, movements, and confirmations. The most common haptemes were location, pressure, movements, speed, duration, and handshape.

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Introduction

Touch is used in a natural way during treatment of patients in many different health care settings. For patients who are dual-sensory impaired and deafblind, social-haptic communication (SHC) is a natural method of receiving information when visual and auditory communication is not possible. Lahtinen's research in the 1990s identified social-haptic communication and currently the sub-groups also include hospital-haptices (Lahtinen, 2008). Hospital-haptices are used across people with congenital and acquired deafblindness, who use either spoken or sign language or other communication methods.

The use of touch within the hospital setting has been researched across a variety of patient groups for decades. Examples include how nurses touch patients, how touch is used to reduce pain, and how patients feel if they are being touched in intimate areas of their body (Rosqvist 2003, Routasalo 1997). Patients with dual sensory impairment who are receiving treatment or have gone through an operation, may be physically unstable and therefore, not capable or in a position to use either an interpreter or hearing aid devices. Haptices may offer a means to receive instructions or to become familiar with their new surroundings if they are being transferred to the intensive care unit.

Studying Hospital-Haptices

Hospital-haptices, touch messages onto the body, have been studied with deafblind people and hospital staff during treatment procedures such as cataract operations and medical examinations, and in recovery and isolation rooms. Hospital-haptices can help communication during various nursing functions because the haptices give information about the upcoming procedure, or how the patient should react during the treatment. Those who use hospital-haptices need to know how to adapt to different circumstances and situations. If the medical staff and the patient have agreed on the use of haptices in advance, they can be useful for both the nurse and the deafblind patient. (Lahtinen et al., 2016)

Many professionals can use haptices during the hospital stay, including as nurses, caregivers, interpreters and assistants. Most often, however, the family members provide information on haptices, along with the deafblind individuals themselves. Usually these short, practical and describing messages are haptiered onto the hand or arm, but also on other body areas, such as the leg, shoulder, and head, in particular to indicate that one is not allowed to move during treatment.

Nursing, Touch, and Haptices

Touch may be the only possible method used by nurses for certain types of treatments or interventions such as checking the pulse, taking a temperature, washing, dressing, or going to the toilet, taking a blood sample, or treating and dressing wounds. However, effective communication is critical for effective patient care. However, this communication can be hindered for many reasons including when the patient cannot hear or see well. The specialised hospital haptices used in the care or hospital environment were born from this need to give information in advance to the patient about upcoming procedures. (Palmer, 2015)

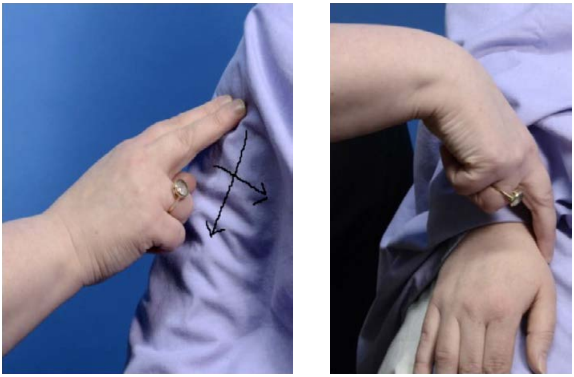
Haptices form a hierarchical system that can be compared to speech or sign language. As in speech or sign language, haptices consist of grammatical elements, known as haptemes. The hospital-haptices are part of social-haptic communication, which, according to Lahtinen (2008), can be classified into functional categories, such as emotions, music, relaxation, or space. Each subgroup has its own lexicon. Hospital-haptices are one of the subgroups.

Hospital-Haptices During a Pilot Study

This pilot study explores SHC and haptices with patients who have given consent and are recognised with sensory impairment. The pilot study data was collected in various health care settings and evaluated in different functional situations (cataract surgery, recovery, etc.). Patients who use spoken language but are not able to use their hearing aid devices found the haptices particularly useful.

The data consists of 12 different haptices which were used by some dual-sensory impaired people during the pilot study. The haptices form six different functional categories. They are professional role identification, confirmation (feedback), emotions, procedures and measurements, treatment duration, and movement instructions (Lahtinen et al., 2016), as described below:

Professional Role Identification

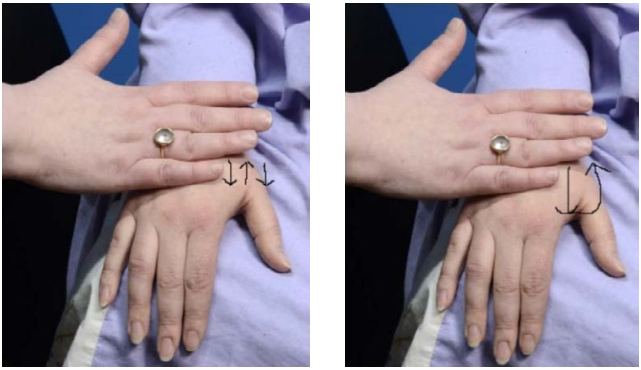


nurse **doctor**

Figure 1. NURSE and DOCTOR haptices on the arm and hand.

When a professional enters a patient’s room, they must state who they are. It is important for a deafblind patient to know who entered next to him/her into their personal area. A NURSE or DOCTOR can identify themselves using haptices (Figure 1).

Confirmation (Feedback)



yes **no**

Figure 2. YES and NO haptices on the hand and arm.

When a deafblind person is using spoken language, the nurse or doctor can answer by giving YES or NO haptices onto the hand or arm (Figure 2). These are usually basic confirmations that simply a yes or no answer.

Expressing Feeling or Emotions

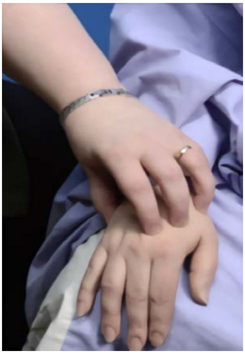


Figure 3. "HURTING" haptic onto the arm.

A patient's condition is assessed in a variety of ways, including observation or direct inquiry. In the case of evaluating if the patient is or will experience pain / discomfort,the HURTING haptic can be used. (Figure 3 shows how we can share "HURTING" -information. This way, the patient has advance notice, knows to prepare for the pain, and avoids anxiety.

Procedures and Measurements

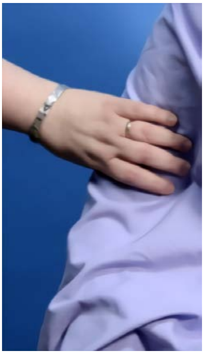
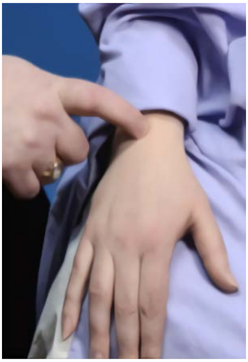


Figure 4. BLOOD PRESSURE haptic on the arm.

When a nurse needs to measure a patient's blood pressure or perform other health-related measurements or tests, the appropriate haptices should be used. Figure 4 demonstrates the BLOOD PRESSURE haptic .

Treatment Duration



time

Figure 5. TIME haptic on the wrist.

Sometimes during an operation or a procedure there is a specific moment for something that requires extra attention. In that case it is very important to communicate what the individual can expect. about that moment. Picture 5 shows the way to convey that it is TIME to for that moment requiring extra care. This also needs to be explained in advance of the operation or procedure to be functional. The TIME haptic is produced by tapping the area where a wristwatch would be worn 3 to 4 times.

Movement Instructions

wait, no movement

Picture 6. WAIT, NO MOVEMENT haptic on the wrist and arm.

This category includes movement instructions for the patient, including instruction not to move. Picture 6 shows the ”WAIT, NO MOVEMENT” haptic. When this haptic is used, the deafblind patient will know to not move as long as they feel the hand pressing down.

Results

The most common haptemes in the data were location, pressure, movement, speed, duration and handshape. The most frequent locations for the haptices were the arm and hand. Usually, the intensity of touch was normal or heavy. The movements used were haptiered slowly in a calm motion. The longest durations were for the STOP and NO MOVEMENT haptices. Handshape variations ranged from a flat hand to one finger and a grip.

Conclusion

Since hospital-haptics are not yet in general use, talking about them and instructing the individual nurse or doctor performing the procedure is vital. However, observational data suggests that many nurses already use haptices, often unconsciously. A deafblind person can instruct hospital staff how to use haptices in a structured manner. They may even want to produce a special folder for hospital visits, which includes some pictures of hospital-haptices as lexicon.

The nurses' feedback in the pilot study was encouraging; haptices can be used with different patient groups in various units. These include the operation theatre, during surgery and tests, the intensive care unit, and the recovery room. It is not only deafblind people who can benefit from the use of haptices, but also other patients who have language and other communication problems, such as patients with visual impairment, autism, intellectual disability, people with memory problems, and those in the terminal phase. Haptices can be used to provide predictive information about future procedures. Now social-haptic communication has spread worldwide.

Medical treatments are often mentally stressful, so the use of haptices gives a feeling of being cared for and being noticed. The need for touch is individual and touch is to be used with respect.

“When someone touches my upper arm I know that my blood pressure is being taken. When I feel a heavy, stationary touch that indicates I have to stay still.”

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Music, Vibration, and Touch

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Music is for all, not just for people with normal hearing and vision. Often music is associated with sound patterns, but there are also visual patterns in playing music and watching music being played. The most important feature of music, however, is the vibrations surrounding and rocking us - at least at a concert. It is the musical vibrations that create the atmosphere, the vibe, and the feel of the venue, and that is why we enjoy live performances. A vibrosensoric experience is the essence of all music.

You can enjoy music and the vibrations at home as well, when pre-recorded music is played through a hi-fi system or a portable loudspeaker or if someone in the family plays an instrument and you can touch the instrument so that you can feel it vibrating. Most often a light touch relays the vibrations better than a heavy one. Some vibrations are easier to feel, others take time and practice to notice. Usually the lower the vibration, the easier it is to notice. You can also feel the air vibrating to the music in an enclosed space.

With pre-recorded music, in addition to touching the loudspeakers, you can also experiment touching the table the loudspeaker is on or feel the vibrations through the wooden floor in the room. Music is everywhere, in the way we talk, sign, walk, or wave. Music is rhythm, a combination of rhythms and a pattern of vibrations.

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Introduction

How does a deafblind person experience music through touch? This can be done in various ways: this we refer to as vibrosensoric experience (Palmer & Ojala, 2016). If one goes to a live concert, the experiences one feels from the musical vibrations and general atmosphere of the venue may be perceived in different ways (Palmer et al., 2017). One can also play pre-recorded music, either through a dedicated hi-fi system with speakers or a tablet with a wireless speaker - or headphones. Some deafblind people may prefer to use either non-technical methods of feeling the tones and vibrations of the music being played and/or using various hearing devices, hearing aids, cochlear implants or specialised aids. This paper identifies these different methods and explores how a deafblind person can get a holistic experience of music.

Basic Concepts

Music is made of tones and vibrations, which in itself include other elements, such as rhythm, melody, harmonies and texture. Basic physical measurements show that music travels through different media such as air and water. In a concert hall-type acoustic environment, a sound being played will travel through the air and bounce off the walls in a specified manner which is experienced by the audience as the "feel" of the particular hall (Beranek, 1979). If a deafblind person attends a concert, they may be affected by the whole experience of entering the building and feeling the environment; they may feel the hubbub of people talking, the general chatter, and people's anticipation - especially if it is a famous singer or a performing band - or the world-famous BBC Proms.

When one goes to the seat in the auditorium and sits down with a friend or an interpreter, the atmosphere and the excitement before the concert starts is already tangible. For example, when going to a concert with your favourite band, you can feel the emotions building up inside you as you recognise your favourite songs and realise that the band is actually there. Similarly, sometimes, you can feel the vibrations from the electronic pop music through the structures; metal handrails, seats, even the floor in the venue. The vibrations can be unbelievably strong - and though the sounds are not loud or sharp, they are enhanced and feel strong and discernible when felt through the structures. Sometimes you can even feel the vibrations flowing through you. On various occasions, the music has been so powerful that people have started to dance on their seats, and one certainly does feel included as part of the audience and the concert when joining in the dance! However, to enable sharing this experience, you can also benefit from musical haptics, for example to know which instruments are being played or when people around you either join in the sing-along or get up and dance in the aisles (Palmer, et al, 2012). Haptics are touch messages from one person's hands to another person's body (Lahtinen, 2008).

A vibrosensoric approach refers to a holistic experience of feeling the musical vibrations and hearing some of the musical sounds through either the hearing devices or the vibrotactile aids one uses (Palmer & Ojala, 2016). Those individuals who do not wear hearing aid devices rely on vibrational body experience and the visual aspects of music.

Visual Aspects of Music

Traditionally, music has been considered an acoustic phenomenon, but it also includes visual aspects, often disregarded in connection to music research. These are the patterns of music that weave their own patterns and paint visual displays of music. There are the synchronised movements of an orchestra, the movement patterns of the players, the movements of the conductor in a concert. They may be accompanied by swatches of colour where the orchestra dresses in black and the soloists in contrast wear a more striking colour palette. The scene is set quite differently in an opera or musical theatre performance where the movements and actions of the musicians tell the story along with the acoustic music (Lahtinen, Palmer & Ojala, 2012; Palmer et al, 2012).

When using haptics, you might want to book the seats at the end of the row so that you can stand on the side of the auditorium as this allows you more flexibility to enjoy the performances in even more immersive ways if desired. Some individuals will be quite content having haptics produced only on their upper arm or back of the hand while others may want to be more adventurous.

Sometimes it might be possible to visit the rehearsals of the orchestra and check the vibrational patterns of the venue in advance. This would allow the deafblind individual to choose the best possible seating position from the vibrational aspects of the venue.

Applications

Vibrations from the Instruments

It may be that one of your family members plays an instrument. In that case you might ask for permission to touch the instrument while they are playing it. You might want to explore the best place to touch the instrument so that playing is still natural. To give a few examples: a piano has a keyboard where the player's hands dance and push the keys in a certain order to produce the music. It would be inappropriate to touch the piano near the keys, but it is acceptable to touch the top of the piano, which is more convenient than crouching down to touch the base of the piano, where the vibrations may be stronger. A guitar player strums or plucks the strings with one hand and at the same time presses down the strings on the neck of the guitar so that it produces the music. The vibrations from a guitar may be stronger on the body of the guitar but it is more convenient to touch the headstock of the guitar, where you can feel the vibrations and do not hinder the playing experience. The player can show you where to touch the instrument.

Sometimes a wooden floor relays the vibrations to the feet of the listeners. This is the case in particular with loudspeakers or instruments that are standing on the floor, such as a double bass or a cello. Interestingly, a cello has a pointed metal support and the vibrations from it are strong enough to be carried on by the floor. Wooden raised structures called music floors are used in music therapy to allow the clients to stand, sit, or lie on them to enjoy the music (Palmer & Ojala, 2022). Should the music venue have such a feature, it would be a great asset for accessibility. Most often the music floor is used with electrically amplified or pre-recorded music.

Feeling Vibrations

Vibrations from the instrument can be felt either directly, as noted in previous paragraph, or by using everyday objects to enhance the vibrations. Luckily some individuals have been thinking outside-the-box and found out that wooden kitchen utensils made of juniper or pine are very good at transmitting vibrations. However, some muscle tension is required to hold the utensil in place if the player plays very expressively and sways during the performance.

A balloon can also be used to enhance the vibrations. The sensitivity and the type of vibrations that can be felt differs according to how one holds the balloon: holding it by the fingertips renders the middle and higher sounds with the finer patterns, while holding it by the palms relays the bass and the rhythmic elements better.

Vibrotactile Aids

Some individuals use so-called vibrotactile aids that are developed for speech perception. However, they also relay other sounds, including music. Most often vibrotactile aids are used in addition to other methods mentioned in this article. Sadly, there is currently no further development or maintenance programmes for the end-user products.

Musical Haptics

Social-haptic communication is a hierarchical system of touch messages (haptics) and grammar (haptemes) that are used for a variety of purposes across a wide spectrum of experiences. Basic musical haptices follow the acoustic events, such as rhythm in the simplest form while a more complex use of haptices also follows melodies, harmonies, texture, and intensity variations in the music, as well as visual components of the performance, including shapes and sizes, dance and movements, and surprising visual effects, such as fireworks or laser shows.

Conclusions

Social-haptic communication during the process of interpreting music, vibrations, and sometimes also visual arts has been identified as a useful tool to allow a deafblind individual to enjoy a performance holistically, in real-time.

Enhancing tones and vibrations produced during a musical performance with some of the techniques mentioned in this article can be used to become more sensitive and responsive to the vibratory information from music. If the individual has acquired deafblindness, the information received through vibrations and touch can replace some or all of the auditory and/or visual information. This is referred to as switching of senses (Lahtinen & Palmer, 2005; Palmer et al., 2017).

Music is everywhere, in the way we talk, sign, walk, or wave. Music is rhythm, a combination of rhythms, and a pattern of vibrations.

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If You Can See It, You Can Support It – Recognising Tactile Language

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Abstract

Providing the right conditions for people with congenital deafblindness to develop language is a complex task. It can be difficult for parents or professionals to notice expressions based on a bodily-tactile modality. To overcome these barriers the Nordic Network on Tactile Language aims to develop knowledge regarding tactile language and tactile language development. The network has published a book called *If you can see it, you can support it. A book on tactile language* (Creutz et al., 2019, English version published 2019), which contains different perspectives on tactile language as well as a model to be used as a framework and an analytic tool. This article is based on the book and describes how language in a bodily-tactile modality emerges and is expressed, and how this natural language can be recognised and supported by the non-deafblind communication partner.

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Statement and Significance of Need

As early as 2009, the Nordic Welfare Centre initiated collaboration in the Nordic countries on the topic of tactile language for people with congenital deafblindness (CDB). Despite the fact that individuals with CDB are exposed to tactile sign language, only a small acquire a tactile sign language (Dammeyer & Ask Larsen, 2016).

The collaboration led to the Nordic Network on Tactile Language being formed in 2014. The purpose of the network is to identify key points in tactile language so that we can gain a better understanding of how people with CDB use bodily-tactile modality to express themselves.

A challenge many people with CDB face is the risks of misunderstanding and no recognition of their communicative agency as their communicative expressions, to an untrained eye, can be difficult to read. In the field of deafblindness we speak about the *low readability* of expressions. It is well known that low readability creates a risk of isolation. If more communication partners get the opportunity to recognise bodily-tactile expressions as language, we contribute to increased readability and thus minimize the risk of experiencing isolation.

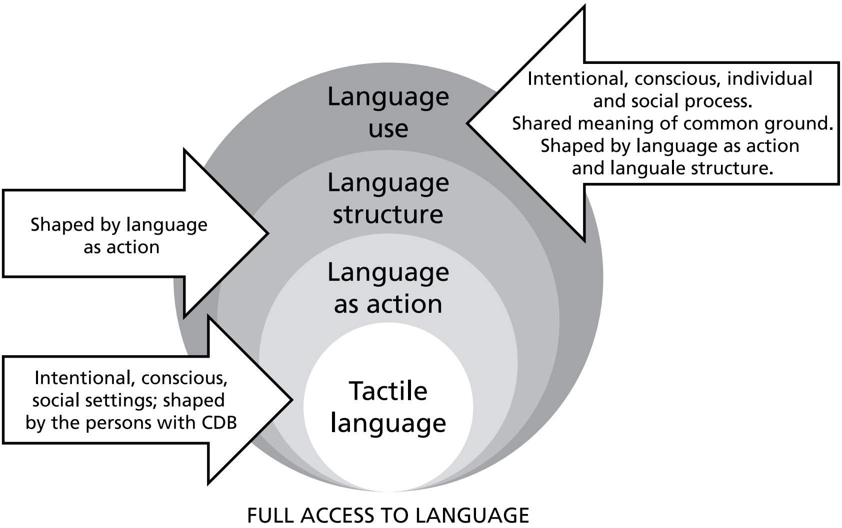
In 2019, The Nordic Network on Tactile Language published a book called *If you can see it, you can support it*. *A book on tactile language* (Creutz et al., 2019). The book consists of 19 chapters describing different perspectives on tactile language. The aim of the book is to increase the readability of expressions as well as to increase partner competence and contribute to the development of tactile language. This article is based on the book and highlights some of the basic concepts in understanding language development for people with CDB.

Theoretical Description

In the Nordic Network on Tactile Language, our starting point is the understanding that all people want to share their feelings, thoughts, and experiences with others. The basic assumption is that all people have an innate ability to engage in communication with others. Tactile language emerges in complex interactions between two or more communication partners as the partners are active in using different strategies to create meaning together (Nafstad & Rödbroe, 2015).

People with CDB use their bodily engagement in the world as the basis for understanding and realization. They need to sense the world before they can act in it. Their bodily engagement in the world will shape the structure of their language since it will be based on a bodily-tactile modality (Forsgren et al, 2018). Their actions and linguistic structure will affect how they use language and create meaning in interactions with others (see Figure 1).

Figure 1. Full Access to Language



(Credit: Ivanova, N. Powerpoint presentation. Copenhagen 2022).

According to the Nordic Network on Tactile Language, tactile language is defined as:

- An early language in the making.
- A language used by people with CDB,
- An authentic, natural language, from within.
- A language based on the bodily engagement in the world.
- A language that involves the tactile, kinesthetics, and proprioceptive senses.

To support the development of tactile language together with persons with CDB we use the figurative expression "To put on the language glasses", meaning that the communication partner must learn to perceive the person's expressions as an utterance that has potential of language (Creutz et al., 2019; Ivanova, 2019b). When we put on our language glasses and give bodily-tactile expressions a linguistic value, we can communicate with people with CDB in a linguistic manner.

What Can it Mean to "Put On The Language Glasses?"

- Seeing different linguistic categories that the person is using to form an utterance. (Forsgren, 2019).
- Awareness of a combination of several modalities that the person is using to form an utterance. (Brede, 2019a; Brede, 2019b; Foote, 2019; Costain, 2019; Buelund Selling, 2019; Tuomi & Lahtinen, 2019; Dammeyer & Ask Larsen, 2016).
- Awareness of how the person is using his/her signing space to form an utterance (own positions, other persons, objects, space) (Costain, 2019; Buelund Selling, 2019)
- Awareness of syntax from a bodily engagement in the world (Brede, 2019a; Brede, 2019b; Buelund Selling, 2019)

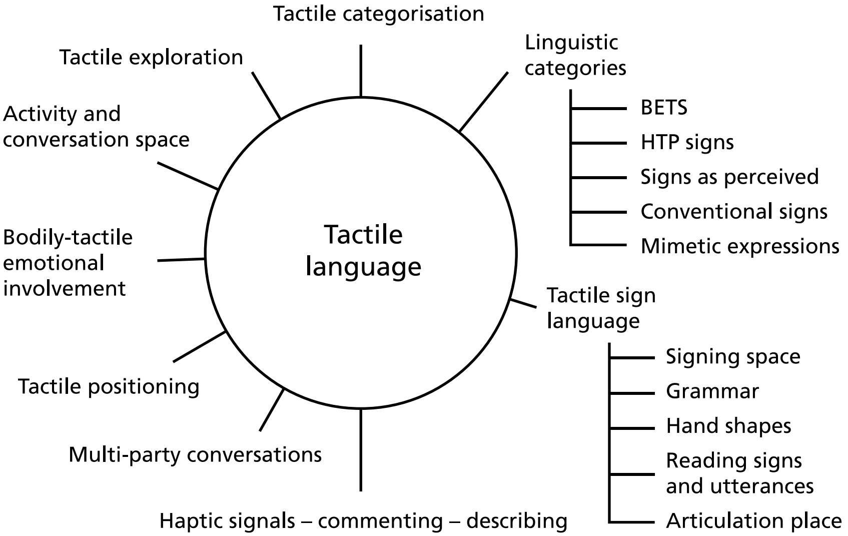
How Can We Support Tactile Language and Easily "Put On Our Language Glasses"?

The Nordic Network on Tactile Language has published a circle model in the book *If you can see it, you can support it: A book on tactile language*, called "The Tactile Circle Model" (Näslund & Kastrup Pedersen, 2019) (see Figure 2).

The circle model provides a framework to help us to keep track of all the different elements that are in play when we talk about a tactile language. The tactile circle model is also an analytic tool that can be used together with video analysis to find key points of tactile language, seek the potential, and understand how to support the development of this early language.

By using the circle model as an analytic model, we discovered that we could use our knowledge about the basic parameters of sign language (e.g., location, handshape, movements) to recognize structure in expressions and thereby give them linguistic value (Dammeyer et al., 2015; Ivanova, 2019b). When we add a linguistic value to expressions, we see them as part of an utterance, and we can help people with CDB to sustain and elaborate their language use.

Figure 2. The Tactile Circle Model



Conclusions and Recommendations

Throughout the years we have used the circle model in a lot of different settings of video analysis. We have investigated how language in a bodily-tactile modality emerges and expressed, and how this natural language is recognised and supported by the non-deafblind communication partner. Some of the common features found in the different analysis are:

- People with CDB sense and experience something and then they want to share it.
- Their language is multi-modal (bodily-tactile, visual, auditive).

- They combine different linguistic categories in one utterance or action (e.g., BETs (Bodily Emotional Traces), HTP (Heightened Tactile Perception)-signs, comparisons, pointing-gestures and, mimetic signs).

- Their utterance is often part of a whole scenario, and they can create their own narrative about something that happened.

- They use muscle and joint tension to emphasize the emotional experience.

- The most significant impression is expressed first.

- Even though the person with CDB uses some conventional signs, they tend to use their bodily-tactile language repertoire when something is very important to them.

Video analysis provides us with good examples of scaffolding methods used to help develop tactile language and shared understanding. These methods are commonly known within the field of deafblindness (Souriau et al., 2008; Sundqvist et al., 2022) and include the following:

- Being sensorily accessible to the person with CDB.

- Making language sensory accessible for both parties.

- Providing time and space for breaks/pause and reflection.

- Tactile and multimodal reciprocity and imitation to let the child know that we know what he knows.

- Tactile repetition and re-cycling with variation.

- Tactile preparation: co-construction, re-co-construction, and joint processing

- Switching between conversation and activity space to wrap language around the activity.

- Using active and lively communicating hands and different hand positions to support turn-taking.

- Bodily emotional involvement to reinforce and sustain the shared experience.

- Elaborating the story by adding new elements from the shared scenario.
- Blending language modalities by introducing the cultural sign(s) or word(s) to the bodily-tactile utterance.

Experiences show that when the communication partner does their best to meet the person with CDB on their terms, putting on their language glasses and adding linguistic value to bodily-tactile expressions, language will emerge. As the book suggests, if you can see it, you can support it.

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Technology, Learning and Independence Among Adults Who Become DeafBlind

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Introduction

According to the World Federation of the DeafBlind (WFDB, 2023), people with deafblindness face barriers in all areas of life due to challenges in communication and lack of access to assistive technology (WFDB, 2023). In India, an estimated 500,000 individuals are living with deafblindness (0.04% of the general population) (Sense International (India), 2020-2021). There is little information on the participation of adults with deafblindness in everyday life, nor the major barriers to and facilitators of their access. In 2020, the Society for the Empowerment of the DeafBlind (SEDB) conducted the first conference of the DeafBlind by the DeafBlind in India, providing an opportunity to address this question. Across all respondents and all areas of life, technology emerged as an important enabler, along with interpreter support (SEDB), 2020). This paper focuses on the topic of technology access and learning among adults who are deafblind.

This research is part of a larger survey, "Status and Opportunities for Promoting the Use of Assistive Technologies and Content for Persons with Disabilities in India" (Surendran, et al, 2022), conducted by Saksham Trust and The Federation of Indian Chambers of Commerce & Industry (FICCI), India. The study was approved by an ethics commit-

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tee. Focus group leaders were given the freedom to adapt the questions and methodology of data gathering to accommodate the needs and special requirements of their group. Chetana Charitable Trust (Chetana Trust) led the study of the deafblind community in India by conducting in-depth interviews based on and extending beyond the survey questions and consolidating the data received. Through interviews, this study explores the contrasting experiences and perspectives of individuals who acquire deafblindness regarding the availability and access to Assistive Technology (AT) and training support.

Methods

The research was conducted in the midst of the restrictions that arose during the pandemic. Chetana Trust reached out to the leaders of SEDB to plan the research. The participant pool was restricted, as those selected needed to have access to either a smartphone or computer with internet connection and access to a deaf or hearing partner who could help interpret our questions to the participant. One SEDB leader reached out to the community to explain the research and invite their participation. Before he reached out, the first interview was conducted with him, through a combination of online interview and dialogue on WhatsApp (messaging app) so that he would completely understand the scope of the research and represent it correctly to the participants. The research team included one deafblind leader from SEDB and three members of Chetana Trust, one of whom was a tactile interpreter.

Participants

11 people participated in the survey, but one was dropped due to difficulty in getting a high-quality interview. The majority (60%) identified themselves as being basic level users of technology, with the remainder identifying as being advanced (20%) or mid-level users (20%).

The study included seven male participants and three female participants ranging in age from 18 to 43 years. Five interviews were held online; two were online followed with WhatsApp messages ; one was conducted on WhatsApp alone; and two were face to face. Nine of the ten participants were born deaf and lost vision later in life. Of these, three lost vision while still school age. The remaining participant was born blind and lost hearing progressively post school age.

Data Collection & Analysis

The survey tool developed by Saksham and FICCI was modified based on discussion with the research team, which included the SEDB leader. This served as the interview guide and ensured that common, basic information was gathered across all participants. Interviews lasted for an average of one and a half hours. The interview team included one or two members of the research team and the interpreter who signed the questions and voiced the responses. The person who was sitting with the participant mirrored the signs to pass on the question to the participant. Since they were usually people living with the person at that time, they could confirm and add to the points being made during the interview. Notes were taken in real time, and also by watching the recorded video and sharing the transcription with the rest of the team for reconfirmation. Any remaining questions were clarified by text or with short follow up video calls.Technology adoption timelines were created from each interview and main themes were identified and recorded.

The survey information was summarized to provide basic information about the participants, including the assistive devices they used and the ways in which they were used in different areas of life. The interviews were analysed across two broad questions: acquisition of devices and learning to use devices. Pseudonyms have been used to protect the privacy of the participants.

Results

Survey Results

All the participants used English as their main language for reading and writing; one used a combination of English and regional language. 40% use e-text only, 20% use Braille only, 10% use Braille and e-text, and 30% use e-text and large print.

Most participants identified their mobile smart phone as their most preferred device. 80% said that they bought the phone with their own money and 20% said that they received it through a non-government organization or a government scheme.

All the people in the group used technology for communicating with their friends, teachers, and peers. 90% used technology for reading and writing and 80% used it to search the internet for information and reading material.

40% mentioned that they learnt to use the smart phone from family members and peers, 30% said that they were completely self-taught, 20% said that they learnt it from their peers, and 10% said that they learnt it formally from a teacher.

Interview Analysis

The two recurring themes in access to AT were obtaining devices and the need to modify existing AT to meet their specific needs. Under learning AT, the deaf-blind trainer's role in supporting acceptance of device and learning usage was a strong, recurrent theme.

Assistive Technology

Obtaining AT

All participants spoke of their difficulties in obtaining assistive devices. Although government schemes do exist, the participants were largely unaware of them and did not know where to go or what would be required to access the schemes.

For those who attended a special school, basic devices, like a cane or slate and stylus, were obtained and distributed by the schools. However, being a student in a special school did not guarantee access to basic devices. For example, Anchal, who has low vision, lost her hearing at age 6 or 7 and was enrolled in a school for the deaf. While she was supported to take classes at school, it took three years before she received a hearing aid. For those who lost vision or hearing post school years, the situation was even worse. They did not learn about available assistive devices or, when they did, they had no way to purchase them. *"A big problem in India is that we all have to go get devices ourselves. Most DeafBlind do not earn a good salary and most are left unemployed or self employed. So how? How will they buy devices? There needs to be more places in India where AT train-*

ing can be provided along with the device for the participant to use life long." - Rohit

Modifying AT

Participants spoke of "last mile" problems with existing technology or finding technology that met their needs as a deafblind individual. Sandeep speaks about how his decreasing vision made it difficult to see alerting and safety devices like his doorbell light or CCTV camera. He described in detail how he found fixes. Hari, who has excellent literacy skills, researched exhaustively to find solutions as his vision deteriorated. He says, *"Some of the latest technology available is only present in more expensive devices or are limited to only certain countries. More coordination needs to be made with tech companies to produce more diverse products from features already available for the disabled."*

Learning AT

Particularly with the smartphone, many participants talked of teaching themselves. Manoj's mother speaks about her son's love and use of technology, *"The phone and tablet - he just taught himself. I myself don't know how he types or how he learnt to do different things like change his WhatsApp profile picture!"* However, our observation during the interviews revealed their limited usage and the need for training to understand the full value of the technology to enable greater participation.

However, many participants, including Manoj, spoke of resisting new technology, especially when vision was lost later in life, forcing them to learn Braille and cane use.

Acceptance, Learning & Deafblind Trainer Role

Being a student was a benefit, especially in receiving basic training in language and literacy. Arthi, who had low vision and hearing loss at age six, had early exposure to Braille, sign language, and technology, making it easier for her to learn and use devices actively as she grew older and lost more visual capacity. *"I learnt the computer from class one in my school. Later I learnt from a DeafBlind friend how to use keyboard shortcuts and the refreshable Braille display."*

However, even among those who attended schools where there were professionals to teach these skills, having useful residual vision or hearing was often a deterrent to learning skills like sign language, Braille, or mobility. Anchal, a participant, spoke of avoiding Braille as a child. Her teacher said that she struggled to learn this skill until she met a deafblind adult who was a fluent Braille reader. Among those who lost hearing or vision later in life, it was interacting with a deafblind adult that motivated them to put their efforts into learning Braille or sign language.

Sita was 34 when she joined a center for the deafblind. She dropped out of school at 12. She had never used any assistive device until that point. At the center, she was offered instruction in Braille, but initially refused. It was her deafblind colleagues who helped change her mind *"Prithvi and Dinesh insisted that I learn and so they taught me. I began using the keypad mobile the same year and later that year, I bought a smart phone. I learnt how to use it without any issue. Both Prithvi and Dinesh taught me how to use it. I learnt how to use the phone to keep in touch with my family."*

Deafblind trainers were uniquely positioned to help the learner accept new ways of learning and overcome their hesitations. They could also respond to the learner's current situation, offering solutions to everyday difficulties and challenges, drawing from their own experiences.

Conclusion

Addressing the specific needs of this population requires increased awareness among all stakeholders - including policy makers, improved accessibility to AT, and tailored support systems. Encouraging a solid sensory exposure and training as children, and introducing multiple modes of communication and literacy, will help those who lose a second sense as adults.

We found that early exposure to technology and education builds literacy and eases the adoption of technology solutions when there is change in sensory capacity later in life. Exposure to a range of technology while growing up, allows the user to develop confidence and a self-perception as a successful user of technology.

As seen in the survey, most participants had not undergone formal training in using their assistive devices. While many did learn from their peers or taught themselves, they also often used devices with less efficiency and knew less about available features. Deafblind trainers are very effective in addressing the challenges of learning faced by adults who become deafblind, as well as their hesitancy to adopt new technology.

Summary

In India, deafblindness is not recognized as a specific category of persons with disabilities in the Rights of Persons with Disabilities Act 2016. Instead, deafblindness is grouped under the category of Multiple Disabilities. This has resulted in a lack of data specific to deafblind people in the country, which in turn results in lack of policies and programs that ensure participation and effective inclusion. It has also perpetuated the misconception that it is adequate to extend existing services for the deaf and the blind to persons with deafblindness. This has adversely impacted the full and effective participation of this population. A supportive ecosystem is vital for the active participation of the deafblind in the community and active measures should be set in place for better awareness and services to the adult deafblind population in India.

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Relational Aspects of Creating Accessible and Successful Meetings, Lived Experience Observations

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Much is made – and correctly so – of assistive technology and infrastructure accessibility when planning and conducting meetings. This article emphasises the relational aspects of meeting accessibility that foster inclusion of people with disability, especially those with single or dual sensory impairment and other communication disability. Further, the article is written from the perspectives of a meeting organiser, a participant/attendee, and a speaker who has lived experience of deafblindness-dual sensory impairment. The word "meeting" is used here to refer to conferences, meetings, lectures, presentations, educational events, etc.

One way of breaking down accessibility barriers is to include people with lived experience of disability in the planning and delivery of meetings and content. People with lived experience bring a practical perspective and an intimate knowledge of the kinds of barriers people with disability face in accessing, participating in, and contributing to meetings. Organisers of meetings should encourage people with disability to lead, chair, and present at meetings. That way we will "grow" the transmission of knowledge around accessibility needs and increase the visibility in society of people who live with disability and their/our capabilities.

Good meeting etiquette is essential and should be universal. Good etiquette helps ensure that all attendees feel included and able to contribute as wanted, regardless of whether they are joining in person or remotely. The chairs, organisers, and presenters should be provided with explicit guidelines for accessibility and be able to enforce rules outlined below to foster inclusion, transmission of content and respectful turn taking.

Key considerations when organising and conducting meetings include:

- Acquiring specific knowledge (ASK) of accessibility needs of attendees and speakers by asking individuals if and what they need to access the event and content.

- Being open to learning new ways of doing, sharing, and telling as a means for improved accessibility. Meeting platforms are constantly evolving so seeking key information from those with lived experience and information technology expertise is critical.

- Not assuming you are "fully accessible" as there is no such thing within the vast heterogeneity of disability and some accommodations for one disability type may, in fact, decrease accessibility for another e.g., bright lighting for some with low vision versus the need for dim lighting for those with contrast sensitivity.

- Recognising that many with disability don't identify and/or disclose as such, so even if no one communicates they have accessibility needs, some basic accessibility should be provided. Captioning is a good example as this helps many, including those who have left their reading glasses behind or have poor audio in hybrid meetings.

- Booking a larger room. Some speakers and participants with disability may bring interpreters, communication guides, support workers, accessibility assistants, or service animals with them. Space needs to be made available to include these aides.

- Being respectful: Ask about accessibility in the registration form and give people a real person to contact who is informed and able to enact accessibility provisions.

- Responding to accessibility enquiries promptly. This shows you value the query and are respectful of the fact that people living with disability are constantly asking for assistance to be included. Make it easier.

- Allowing time before the meeting for conversion of documents or presentation materials to alternative formats so that participants/attendees can use their own devices with their preferred accessibility settings.

- Positioning of speakers so that they can be lip read. This is important for in-person, virtual, and hybrid meetings. Speakers should avoid standing in front of windows and blinds should be down to avoid glare. Captioning is essential, especially if the speaker’s face is not clearly visible.
- Explaining the accessibility features of the meeting platform and the meeting venue at the meeting start.
- Advising at the beginning of a meeting how speakers will manage question and answer time (if relevant).
- Introducing all chairs, speakers, and panel members at the outset and then again, each time they speak or comment.
- Describing all visual content: graphics, pictures, photos, art works, graphs, tables, etc. is a must. Reading slide titles and describing content when you advance to the next slide.
- Indicating page numbers when screen sharing a distributed document, so participants with low vision can follow along on their device with their own assistive software.
- Slowing down. There may be live captioners or interpreters who need to capture your words and image descriptions. People speed up when nervous so if this is you, make a note every now and then to slow down. When timing/writing your presentation don’t cram too much in verbally or visually.
- Pausing when asking questions to ensure the interpreters and the audience have time to process, relay or read, feel, or see the question. Allow extra time for question responses as some participants will take longer if using an assistive speech device or having information relayed.
- Introducing all speakers, contributors, panelists, and those asking questions, each time they contribute, e.g., say “Alex here” or “Riley from the University of Smith,” so that those using AI, auto transcription, and/or interpreters know who is speaking. AI transcription, such as Otter, can differentiate between different voices but many others, such as Siri, can’t.

- Turn taking needs to be respectful and moderated by the chair or the speaker. If more than one person is talking, interpreters, captioning, and transcribing cannot provide accurate content. Enforcing turn taking and either introducing each new speaker by name or asking speakers to identify themselves makes the interpretation or transcript more meaningful.

- Using obvious cues for turn taking, like raised hands and verbal confirmation. Hybrid meetings may involve the hands-up function or chat box.

- Repeating or paraphrasing questions that have been asked so that all members can hear, and so the questions can be included in the captions and conversations.

- Reading aloud the questions in the chat if you are responding to them.orga

- Planning breaks during longer meetings for everyone to refresh and regroup. Interpreting is kinetic work and living with disability and working out what is going on is hard work too.

- Mandating rest breaks for interpreters and ensuring that change-overs are able to proceed without content being missed. Don't end the meeting before the interpreters have finished relaying.

- Empowering participants to ask other participants (or the host) to adjust their cameras to make faces visible, turn on captions, and ensure that everyone is actively included. Participants need to be able to ask that a speaker slows down if going too fast. Interpreters, communication guides, and support and accessibility assistants may be part of a participant's, a speaker's, or an organiser's team and also should be empowered to ask speakers to slow down.

- Sharing all meeting files with attendees/participants. Slides, transcripts of videos, etc. should be sent to the organiser ahead of time and made available to participants with disability and their supports.

- Seeking post-meeting feedback in accessible ways and including explicit questions on access success – or not. Specifically ask about accessibility. Check in, if appropriate, with speakers/participants with disabilities to ask "how did we do?"

- Responding to criticism with grace: What may seem a small matter to you may compromise someone else's engagement. We can always do better.

Conclusion

Accessibility in meetings, events, and conferences is a basic human right. People with disabilities have the right to access information and participate in the way(s) that work for them. All of us, whether organiser, speaker, or participant can do much to include everyone who wishes to participate. By putting in the extra effort to prioritise relational accessibility and practising good meeting etiquette, we are creating a welcoming environment for everyone and setting the stage for successful sharing and engaging learning.

Ageing with an 'Invisible' Disability: Dual Sensory Impairment in Australia

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Abstract

The combination of vision and hearing impairment or loss, known as Dual Sensory Impairment (DSI), is a unique and complex challenge for older adults, with a growing body of international research identifying a range of impacts that limit everyday function, independence and quality of life. In Australia, caring responsibilities predominantly fall to family members, often with limited external support. The caring dyad (family carer and family member with DSI) experience shared barriers to social participation, which compromises access to health care and social support networks. This brief paper provides an analysis of qualitative narratives collected through intensive face to face interviews with family carers

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(n=8) of older adults with DSI. This research was undertaken at the University of Sydney with ethical approval granted through the Human Research Ethics Committee (HREC), The University of Sydney, NSW, Australia (HREC 2014/897). This paper highlights the lived experience of DSI from the family carer perspective.

Discussion

Informal caring in Australia is integral to meeting health and social needs of the Australian population, with increasing attention directed to the impacts of caring and carers' needs (Eagar et al., 2007; Shu et al., 2019); the physically and mentally arduous nature of caring is noted, with concern that demand will increasingly outstrip supply (Deloitte Access Economics, 2020). In Australia, caring responsibilities predominantly fall to family members, often with limited external support, and this reflects the experience of individuals with DSI. The impacts of DSI have been typically explored from the individual perspective of the impaired person or their partner/caregiver; however, this approach does not take into account the reciprocal microsocial processes at a dyadic level that may help explain the shared social experiences relevant to DSI.

Previous publications (see Dunsmore et al., 2020) highlight the *effort* of caring in a DSI context. The data shows that while family carers (FC) recognised their family members' need for care, their ability to recognise DSI as the source of these caring needs was often undermined by the additional health and social needs of their ageing parent or spouse. Limited understanding of DSI by family carers in this study meant that DSI occupied a lower rank on the hierarchy of health needs for both parties. In Australia, poor acknowledgement of DSI and normalisation of DSI in micro-, meso- and macrosocial contexts limits recognition and understanding of the effort involved in caring for those with DSI. Carers, therefore, receive little of the credit and public empathy often afforded to those caring for someone with a more "visible" disability.

Invisibility was a key theme in family carers' narratives in this study; caring in this context was social, often intangible, and difficult to articulate to others. Indeed, many carers themselves did not recognise their caring role despite the need for them to navigate their family members' physical and social environment, to act as their "eyes and ears." These experiences reflect the invisible and largely unrecognised social work of family carers.

This study identifies the adaptation of family carers to a new and non-traditional social caring role, a process involving negotiating of a new role, and adaptation to new ways of caring. This study recognises the skill and nuanced support required to *live with* DSI and identifies the need for new ways of caring. 'Conscious Caring' evolved as a concept through carers' insights and descriptions of the intangible social experiences which they felt were poorly understood at the microsocial level and relatively 'lost' in a structural framework that 'normalises' the disabling impact of DSI in older adults. To this end, 'Conscious Caring' is a model of care under development that seeks to integrate care networks, both formal and informal. This model views FCs as central to both creating social opportunities and reducing social effort for their family member with DSI, enabling them to participate in a meaningful way. The concept of conscious caring has two interrelated aspects: first, insight into the unique skills required to care for someone with DSI, and second, the self-care required for FCs to meet the demands of their caring role while maintaining their own identity within the dyad.

Conscious caring for others includes four key interrelated aspects: empathic understanding; engagement in social networks; enabling a safe space; and social facilitation and protection. Conscious caring represents the bridging link between these microsocial features of caring within the dyad (at an individual level) and the mesosocial (community support) networks that serve to both limit and facilitate social engagement. The intense work of caring limits the capacity of carers to contextualise DSI at anything other than this individualised level or to understand the broader systemic forces that shape their experiences. Developing integrated models of both formal and informal support, providing strategies to improve interpersonal communication (such as social haptics), and supporting health care professionals through micro credentialing education will enhance primary care support for those with DSI and support Australian policy aimed at 'ageing in place'.

The second interrelated aspect of conscious caring is caring for self. Family carers experienced significant challenges in maintaining their own social independence and identity. These challenges included, for instance, shrinking social networks and barriers to their own social participation, and leaving little time to adapt to their ongoing changed circumstances as a carer, with resulting social isolation. Family carers described a combination of both active and passive transitioning to new caring roles. For some, the ability to adopt different ways of caring that might have supported their own needs in this transition was more limited, and often 'passive'. In contrast, those with external support networks had enhanced capacity to actively participate and engage beyond their caring role. Building these external support networks is critical to maintaining social engagement for the dyad.

Summary Statement

In summary, this research explored the experiences of FCs in the context of DSI, finding that FCs shared similar experiences of social isolation, social effort, and identity transition. Data suggests that informal caring is prevalent in the older DSI population, and that FCs misunderstand and minimise the social effects of DSI. Identification, targeted support, and education of informal carers is important to improving outcomes. This study identifies a new model of care, 'Conscious Caring', that aims to integrate care networks (formal and informal), support the development of communication strategies for both family carer and person with DSI, and increase recognition of DSI in older individuals at a community and primary care level. Improving health literacy of DSI in older populations and addressing gaps in primary care partnerships may contribute to more integrated policy and service responses to support both those with DSI *and* their family carers.

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How Interveners Learn the Knowledge and Skills Required to Support Students Who Are DeafBlind in School Settings

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Abstract

An intervener is a person who has been trained to provide one to one support for a deafblind person. The purpose of this study was to determine how training, education, and experience lead to an intervener's ability to support their student in school settings. This qualitative study provides much needed empirical guidance for training interveners.

Introduction

Prior to this study (Kennedy, 2021), there was no empirical evidence to guide how interveners are trained. The results support current practice and illuminate the importance of reflection to elevate learning.

Methods

This study was informed by a social constructivist theoretical perspective, which values learning through experience and was conducted using a constructivist grounded theory methodology. Having been in the field since 1991, and training interveners since 2012, it would be impossible to separate myself from what I have come to know. Charmaz (2014) explains that researchers should be able to embrace previous knowledge and experience, cocreating meaning with their participants.

Population and Sample

The population for this study was interveners who are currently supporting a deafblind student in a school setting within the United States. The purposive sample included sixteen interveners with either a national credential from the National Resource Center for Paraeducators, Interveners, and Related Service Providers, or a national certificate from the Paraprofessional Resource and Research Center. Participants were recruited using an e-flyer disseminated through State DeafBlind Projects and the two aforementioned organizations. The participants were trained using higher education coursework, structured in-person workshops, the Open Hands Open Access (OHOA) intervener learning modules, or a combination of these options. Participants work in educational settings including: general education, special education classrooms, and state schools for the deaf or the blind. Participants support students having a variety of etiologies, support needs, and academic abilities, who vary in age, modes of communication, and level of language fluency. Given the small number of interveners in the U.S. who have national-level qualifications, further detail has been withheld to protect confidentiality.

Data Collection

The initial interview protocol was pilot tested with three interveners who were not included in the study. The initial protocol was revised prior to initiating the study so the questions better captured the trajectory of learning that occurs as interveners work with deafblind students. Initial interviews lasted 45-60 minutes, serving to both develop rapport and collect data. The second interview was also 45-60 minutes, allowing for member checking of the initial concepts and further data collection. Participants were asked for photos of materials they use while at work, such as schedule systems, experience books, and adapted materials. Reviewing photos and discussing them with participants provided insights into support provided for their student, who taught them to create or adapt the material, and possible collaboration with team members, with the secondary benefit of providing talking points and helping build rapport.

A web meeting platform was used to conduct interviews and an application designed to record and transcribe spoken words was used to capture data. Because the transcripts were produced using voice to text, I listened to the recordings, editing each one as part of the initial data analysis. To maintain confidentiality, I assigned unisex pseudonyms and used gender neutral pronouns. The data was immediately analyzed to find concepts and inform subsequent interviews. As is typical with constructivist grounded theory studies, the interview protocol evolved, becoming more focused on certain data points and helping to avoid collecting unnecessary data.

Analysis of the Data

Data was immediately coded and sorted to find and develop concepts using constant comparison. As the analyzation proceeded, the data was condensed by organizing the codes into concepts. Adhering to procedures recommended by Charmaz (2014), extant theory was not explored until later in the analyzation process.

The analysis of the data collected during the initial interviews resulted in some clear concepts and the second interview protocol was subsequently changed to include questions about strategies for reflection on practice. Data collection for this study continued until the simultaneous analysis of the data indicated saturation had been reached. The changes made to the second interview protocol allowed for the collection of data that reinforced the emerging theoretical code. No anomalies were found in the data so no additional recruitment or interviews with original participants were necessary. Data analysis resulted in an emerging theory of practice.

Trustworthiness

An audit trail was created by journaling and memo writing throughout the data collection and analysis processes. As recommended by Charmaz (2014), the memos were a key strategy to ensure that I did not allow my own knowledge and experience to overshadow my participants' responses. My knowledge and experience proved to be assets in identifying salient codes and helping to recognize theoretical plausibility. I was transparent about my background and current roles with all participants, which contributed to trustworthiness and positioned myself within the study. It is possible that name recognition as someone who helped to develop the Open Hands Open Access (OHOA) modules, is a State Deafblind Project director, and is the director of an intervener training program contributed to being able to recruit sixteen interveners for this study.

Once the theoretical level of analysis was reached, I recorded a short video summarizing what I had found. I sent a link to the video to all participants with a short survey to facilitate a response. Fifteen of the participants responded to this request and they all agreed with my analysis. The use of member checking was important given my subjectivities about intervener training.

Results

All sixteen participants started their intervener training program at some point after their first day working as an intervener, which is typical in the U.S. There were three distinct themes that became clear in early data analysis. The first, *learning by doing*, stands to reason given that interveners begin working prior to receiving training. "Blake" described being an intervener as a, "learn as you go profession" and continued that, *"nothing is black and white, nothing is right or wrong. You just learn as you go."* Most of the participants expressed being overwhelmed as they tried to determine how to meet the complex needs of the deafblind student. "Lee" stated that supporting a deafblind student felt, "natural," but confessed that "I had no idea what I was doing," when they began working as an intervener. Two participants with previous experience working as ASL interpreters, one who had worked with deafblind adults, stated that being an intervener was, "totally different than anything they had done" in their role as an interpreter. "Drew" commented on how different working as an intervener is, being available and doing things with the student, compared to working as a paraprofessional, "jumping in and doing something [for the student]." Concepts found in the data that are included under *learning by doing* include *observing their student, observing others with their student, making mistakes, using trial and error, having a "bag of tricks"* (a collection of ideas for adaptations and supports).

The second theme, *being trained*, also makes sense. All participants emphasized the need for interveners to receive training and all had received training based on established knowledge and skill competencies for interveners. Dana explained that prior to completing training, "I'd been shortchanging my student … pacing … processing time… [training] is important for the intervener, but more so for the student because they are missing out on so much more if the person working with them doesn't know." Concepts within this theme include: *learning while doing* and *training while working* (on the job training for immediate application of learning), *training with an intervener* (observation of, mentoring from), *learning from simulations, having a coach* (feedback on practice), *completing a portfolio* (a collection of photos, videos, and written reflections on practice to demonstrate skill competencies), *accessing professional development* (post earning their qualification).

The third theme, *feeling supported in their practice*, speaks to the need for interveners to feel respected as part of the educational team and the need to have one or more people with whom they can brainstorm, celebrate, and vent frustrations. One participant had worked with two teams, first on one that was inclusive and supportive, and later with a team that made them feel isolated and alone. They confessed, "if it had been reversed, I probably would have left the field." Included in this theme are: having a supportive team, *having access to one or more interveners, flying solo* (an envivo code coined by "Alex" for, "not having people to bounce ideas off of"), and *having a mentor*.

"Drew" was the first participant to discuss the use of video outside of the requirements for completing a portfolio for a national-level qualification. "I watched a video from three years [ago] of a meltdown happening … and the student kept going like this [gestures] … I was like … 'the student has been communicating with me this whole time' … since that time, I video all the time … to watch back and [see] if there is something I missed." My response was, "video is an amazing tool for self-reflection." The exchange caused me to add questions about forms of reflection to the second interview protocol. The second round of interviews solidified the initial concepts and resulted in a new theme, *reflecting on practice*. Most of the participants did not realize that they were engaging in reflective practices, but readily admitted to practices like: *making notes about their day, journaling about their work, talking with other team members, or occasionally watching videos of themselves* [supporting their student]. "Casey" described being thoughtful about their practice, considering what had worked and what had not been effective. Lee reaches out to specific people to discuss what they have noticed through trial and error to get ideas on how to better support their student. "Robin" recalled revisiting their portfolio, "I remember when I would do it that way … but the way I do it now is so much better."

Conclusions

The literature review conducted prior to this study was purposefully limited as suggested by Charmaz (2014). As I analyzed data and concepts began to develop, a review of the literature helped to reach and develop thinking at the theoretical level. I avoided research on how teachers and other professionals on the team learn because, in the U.S., many people conflate the role of the intervener with the separate roles of others on the educational team. Jasper (2013) developed a model that explains how people learn from experience, the Experience Reflection Action (ERA) Cycle: the experience occurs, a period of reflection follows, and then action is taken based on what was learned from the reflection. The ERA Cycle helps to explain how interveners in this study learned to support deafblind students.

To gain a better understanding of the impact of reflecting on practice, it is helpful to consider Mezirow's (1990) Transformative Learning Theory. Mezirow (1990) states that when a person realizes that what they believed to know no longer makes sense, they experience a "distorting dilemma." When a person becomes critically aware of their practice, transformative learning can occur (Mezirow, 1990). Completing the portfolio process requires prospective interveners (in the U.S.) to examine their practice competency by competency, potentially causing a "distorting dilemma," elevating learning to a transformative level.

Summary Statement

This study provides guidance for people who train, hire, and work with interveners through an emerging theory that reflection on practice leads to transformative learning. It is crucial that interveners receive training that includes rigorous reflection on practice to advance their learning to help ensure that they are well equipped to provide support for deafblind people.

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Hand in Hand – A Project to Develop Professional Competencies in the Field of Deafblindness at the Institution Nikolauspflege,Germany

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Abstract

In 2021, the Stiftung Nikolauspflege (Germany) was funded to develop professional competences in deafblindness.The target group included children and young adults with deafblindness as well as employees of the Nikolauspflege. The sub-objectives were to develop a qualification program for employees, to identify deafblindness in children with complex disabilities, to build up a network, and public relations. In addition to offering sign language courses, acquiring basic materials and literature, and introducing employees to the use of assistive devices, the focus over the past two years has been on developing a qualification program for employees. A total of eleven national and international experts will give lectures focused on different aspects of deafblind education. Individual modules of the program were evaluated by master and bachelor students. The evaluation of the first module is already completed and shows positive results.

The Project "Hand in Hand"

The Stiftung Nikolauspflege is a leading center for blindness, visual impairment, and multiple disabilities in the south of Germany. For 160 years, people of all ages (from early childhood to adult residential living) have been educated, encouraged, advised, and accompanied. Deafblindness was recognized as an independent disability in Germany in 2017. Since then, the perception of the dual-sensory disability changed. It is now clear that people with deafblindness need specific support and advice in order to be able to develop their potential. As has become increasingly evident in recent years, there are people with deafblindness at the Nikolauspflege. For this reason, the Nikolauspflege sees in itself the responsibility for building up and sustainably establishing the professional competencies of deafblindness in the facility (main objective). The Project "Hand in Hand" is one of four projects that the Nikolauspflege has launched for this purpose in recent years. From 2021 to 2024 the project is sponsored by the Aktion Mensch (Foundation) and the Lipoid Stiftung (Foundation). The target group included children and young adults with deafblindness as well as employees of the Nikolauspflege (early childhood and school age). The sub-objectives of the project were:

- (1) to identify deafblindness in children with complex disabilities,
- (2) to qualify employees and
- (3) to set up a medical and therapeutic network, as well as public relations.

With regard to the first sub-objective, the identification of deafblindness in children with complex disabilities, the IKI-TAU, a screening and assessment tool to assess the functional vision and functional hearing of people with complex disabilities will be used. Currently, this tool is in development at the Heidelberg University of Education. The employees of the Nikolauspflege will then be trained in so that they can use the tool in practice. The second sub-goal, the qualification of employees in the field of deafblindness, aims to be achieved, among other things, through sign language courses and a training program.

The third sub-goal relates to establishing contact with doctors, pediatric-audiologists, hearing aid acousticians, speech therapists, and similar professions, as well as participating in congresses, conferences, and committees, and publishing the project progress in journals.

In the last two years, the focus has been on the qualification of employees. First, basic purchases were made. These included the purchase of basic literature, test kits for hearing aids, materials for self-experience under simulation (soundproof headphones and obscured glasses), as well as access to a digital sign dictionary for all employees.

Employees were then trained in usage of assistive devices (e. g. hearing aids) and in the handling of the test kid for hearing aids.

Further, classes in German Sign Language were offered. As part of this process, the sign language system and vocabulary used at the Nikolauspflege were unified across the educational areas of early childhood, school age, and adult education. With access to the digital dictionary via the sign language app "Kestner," (new) signs can now be used easily in everyday situations (Figure 1). In addition, all employees have access to a database of sign language images to support the teaching of songs or lesson content. Further, the "sign of the week" was established (Figure 2): each week a new sign is introduced to the employees, teachers, and students.

Figure 1. Usage of signs and sign app with a student.

Figure 2. "Sign of the week" HOT

Another important step was the development and implementation of a special qualification program in which employees acquire knowledge of skills specific to deafblindness. Based on an assessment of demand at the beginning of the project, a curriculum was developed. The aim of the curriculum is to define the transfer of knowledge (content and skills to be acquired) and to ensure sustainability beyond the duration of the project.

In seven modules, the participants acquire both theoretical and practical knowledge about deafblindness. The transfer of the acquired knowledge into practical everyday life is considered to be particularly relevant. A total of eleven national and international experts presented lectures focused on different aspects of deafblind education, which included:

- Introduction to Deafblindness (definition, group of people, prevalence & causes)
- Specifics of Development (concept knowledge & construction of the world)
- Syndromes
- Communication (contact & social interaction, conventional and unconventional forms of communication)
- Video Analysis
- Working with the Tactile Working Memory Scale
- Educational & Pediatric Audiology
- Didactics
- Adult Education

Most of the training content included self-experience exercises. In total 29 employees took part. The participants' educational backgrounds and fields of work are highly heterogeneous and, therefore, interdisciplinary: Teachers of special needs education as well as nurses, occupational and physical therapists, and educators in kindergarten or in residential living took part in the training.

Individual program modules were evaluated by master and bachelor students. The results have shown that nearly all of the participants had had contact with a person with deafblindness in the past. Only a few currently have no contact with a person with deafblindness. The majority of the participants identified their contacts to people with congenital deafblindness who have residual hearing and vision.

The feedback on the choice of content, implementation, and organization, as well as the increase in knowledge, was consistently positive. The further examination of video material and the practical relevance were mentioned as suggestions for improvement. In addition, time management and the use of technology can be improved. These points of constructive critique will be included in the planning and implementation of the next modules.

For the following and final year of the project, the focus will be on the successful completion of the qualification program and the establishment of the medical-therapeutic network. In addition, a support network for families with children with deafblindness is to be developed. The aim to identify children with deafblindness is also being pursued. Employees in early intervention, kindergarten, and school were trained in how to use the hearing assessment portion of the screening and assessment tool, IKI-TAU. In order to establish the expertise in the facility in the long term beyond the project, the trained employees are expected to serve as multipliers in their respective areas.

Summary

People with deafblindness need specific support adapted to their individual circumstances in order to develop their potential. Developing appropriate expertise is the responsibility of those who work with people with deafblindness. In this sense, the Nikolauspflege takes on its responsibility by establishing, among other things, the project "Hand in Hand". As envisaged in the conception of the project, the qualification of employees is of great importance. Expertise can only be spread with qualified employees. As expected, training content requires careful planning, close to the practical context. Through the development and implementation of the qualification program, the employees should learn to empathize with the perception of a person with deafblindness and develop ideas on how they can support and accompany the person in their everyday work. In their role as multipliers, they are also responsible for sharing their knowledge with colleagues and providing support in everyday life. In addition, employees have the opportunity to expand their skills in sign language and thus expand access to language for their students.

The project will continue for another year to achieve the remaining goals, such as networking and public relations and training the employees on how to identify children with deafblindness.

The Nikolauspflege is looking forward to another successful year of developing professional competencies in the field of deafblindness.

Every Child Can Learn: The Model Program Approach for Enhancing Education of Children and Youth with Visual Impairments, Including Those with Deafblindness

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Abstract

Perkins School for the Blind's Model Program Approach is based on 200 years of experience working collaboratively with children, parents, educators, healthcare professionals, community organizations, and governments across 97 countries. We do not build schools – we build capacity. Our approach focuses on building local partnerships to foster transformative, meaningful, and lasting change. This paper describes Perkins' core strategy of model programs and its exemplary growth in Mexico and Armenia, elevating educational opportunities for children and youth with multiple disabilities and deafblindness. This concept takes into account unique characteristics of each program, cultural contexts, and societal issues. Through collaboration with local governments, schools, families, and universities, Model programs emerge as

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exemplary teaching sites driving systemic change. The impact is measured through the Perkins Quality Improvement process to evaluate and improve learning environments for children with disabilities. This proven model contributes significantly to the field of education of children with multiple disabilities and deafblindness and inclusive education for all children.

Introduction

Perkins School for the Blind is dedicated to empowering children with visual impairments and multiple disabilities, including those with deafblindness. We firmly believe that every child can learn, including 240 million children with disabilities around the world - many of whom are out of school - and that they can thrive as valued members of their families, schools, and communities. Our approach is dynamic, enabling us to meet children where they are, be it in schools, residential facilities, community programs, or their homes. Through flexible partnerships and best practices for inclusive education, we strive to accommodate each country’s unique economic, cultural, and educational context.

Our Strategy: Model Programs

Our core strategy centers around developing communities of model programs. Model programs are local programs with the potential to become exemplary in their communities. Perkins provides specialized technical support, planning, coaching, and mentoring to these programs. Over time, selected model programs become teaching sites for nearby programs, expanding the adoption of best practices in a ripple effect that reaches more children.

Every child can learn. But most education systems lack the readiness to make learning accessible to all children. Through our model program approach, we set new standards for what is possible for children with multiple disabilities and deafblindness. The model program approach is a transformational process that takes into account the unique characteristics of the programs and their contexts, as well as the current community, cultural, and societal issues. It involves collaboration with local governments, teachers, families, community organizations and universities. As model programs evolve, Perkins’ support evolves as well, to guide collaboration with government agencies and improve national standards. This practical support, at both programmatic and policy levels, drives systemic change. This approach empowers local partners to take ownership of the process, ensuring sustainability and scalability.

Illustrating the above - in 2019 Pekins in Latin America began the model program strategy by partnering with governments: Mexico, Brazil and Argentina, .We started with three schools in each country. Now, only four years later, we are in 48 schools and plan to be in 71 by 2025.

Through this collaboration, we've learned that becoming a Model Program is an ongoing journey involving the community and society. Perkins defines a model school as:

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

Impact Measurement: Perkins Quality Improvement Process and Indicators

Our impact is measured through the Perkins Quality Improvement process, which identifies educational best practices for children with disabilities. The model program development process is based on the use of evidence for decision-making, using a standard set of quality indicators in order to evaluate the existing quality of learning and teaching, establish a baseline and goals for improvement, and implement a training and mentoring plan for teachers, administrators and parents to help children with disabilities learn- ideally in an inclusive environment.

The Perkins Quality Indicators (PQI) tool covers nine key evaluation categories, each containing a number of indicators, in total 70 indicators. These categories include Building Community/Inclusive Culture, Program Planning and Classroom Organization, Learning Environment and Materials, Communication and Social Relationships, Child Assessment and Progress Monitoring, Curriculum and Instruction, Family Support, Administration and Support, and Governmental Collaborations. The PQI tool provides a comprehensive framework to ensure that educational services address the needs of children with disabilities while being adaptable to different cultural, contextual, and programmatic settings. Perkins' global benchmarking metric has a standard core so it can be implemented in diverse educational settings around the world.

A Proven Model: Project Pixan in Mexico

Pixan is an ancient Mayan word describing the power that gives life to every human being, regardless of his or her ability. Project Pixan is proof of the effectiveness of the Model Program Approach in improving educational opportunities for children with deafblindness, multiple disabilities and visual impairments. The project focuses on applying the Perkins Quality Improvement process to public special education schools in Mexico.

In 2019, Project Pixan began with 3 schools in Yucatan, Morelos, and Aguascalientes. Through collaboration with State Secretaries of Education, educators, and parents, the project aims to increase access to quality education for children with disabilities. By 2025, Project Pixan plans to have improved conditions in 41 public schools throughout 13 states and by 2030 we will be reaching 71 schools. The growth is incremental, with the addition of new schools every year, ensuring a sustained impact and expanded support.

Project Pixan also represents collaboration with a Strategic Working Group - Grupo Izamal. The group, comprising representatives from 29 public and private organizations, mother leaders, and adults with visual disabilities and deafblindness, plays a pivotal role in influencing curriculum in teacher training programs, impacting practices in schools, promoting family-school collaboration and coordinating health and education services.

Additionally, partnerships with public universities such as - Universidad Autonoma de México and Universidad Autónoma de Yucatán have contributed to delivering specialized training and conducting research on the intersection of modern Mayan culture with mothers and children with disabilities. Furthermore, with the Yucatán State Secretary of Education, Perkins has created an Adaptive Design Center to build and provide custom-made accessible equipment to support educational goals of children with disabilities.

Armenia: Focus on Inclusion

Perkins' impact in Armenia is evident in its commitment to meeting children where they are, whether at home, orphanages or schools. Work in Armenia began in orphanages, providing knowledge and support for their transformation through introducing community-based activities and services to prevent further institutionalization. Perkins' support of the establishment of inclusive day care programs provided more options for parents to further decrease institutionalization rates. When Armenia's inclusive policy led to all mainstream schools becoming inclusive schools and special schools transforming into Support Centers, Perkins collaborated actively with the government through Republican Support Centers: the main governmental resource organization responsible for implementing inclusive practice in all schools in the country.

Through close collaboration and our Perkins Quality Improvement process inclusive schools, orphanages, and Regional support centers become Model Programs, modeling best practices and creating a ripple effect of inclusion and quality improvement.

By fostering collaboration among Model programs, Perkins cultivates a network of devoted teachers and professionals. Alongside this, our close partnership with the Pedagogical University provides additional knowledge resources, empowering regional leaders to implement inclusive practices effectively. Collaboration with the University has extended to the enhancement of their curriculum, ensuring that future educators are equipped to provide appropriate education for children with multiple disabilities and deafblindness. In this competition approach, inclusive education is fostered by establishing local collaborations for national impact, always keeping the wellbeing of every child at the heart of education.

Conclusion

Perkins School for the Blind's Model Program Approach has proven to be a powerful strategy for improving education and support for children with disabilities in large countries and small, around the world. Local partnerships drive systemic change and create a ripple effect. Focus on quality improvement and collaboration with governments fosters a significant contribution to the field of multiple disabilities, deafblindness and inclusive education. In the future, new collaborations to expand the Perkins Model Program Approach to more children, teachers, families and geographies can unlock new opportunities for every child to learn and belong.

Research on Description of People and Portraits: Implications for the Deafblind Community

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Introduction

Early in 2022, the Helen Keller National Center (HKNC) and the University of Hawai'i at Manoa (UHM) collaborated on a research project that conducted five focus groups and two interviews with blind, low vision, and deafblind individuals on the topic of AD. The aim of this study was to examine preferred characteristics of AD related to various media contexts, specifically characteristics in the areas of race/ethnicity, disability, gender, and age. These sessions were conducted to learn firsthand what blind, low vision, and deafblind people value most in the delivery of AD.

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Methods

Of the 15 participants, ten were deafblind and five were blind or low vision. The researchers also conducted a pilot study with three blind and two deafblind individuals to test and refine the research questions. Participants for the full study were recruited through postings on listservs catering to blind, low vision, and deafblind individuals. Participants were asked to complete an initial screening and demographic survey before being assigned to a focus group or individual interview. Individual interviews were conducted with participants who faced technology or communication barriers to participating in a focus group over Zoom.

The focus groups and interviews were conducted by the primary author, who is deafblind, with support from a research assistant during 90-minute focus groups on Zoom. Additionally, one interview was conducted via Zoom and one via telephone. American Sign Language (ASL) interpreters were provided for participants whose first language was ASL. Participants were asked guiding questions about their preferences for the description of people and portraits across different contexts and specifically in relation to markers of identity such as race/ethnicity, gender, age, and disability. All of the focus groups and the interviews that were conducted on Zoom were transcribed for thematic analysis. Peer-review was performed by two researchers who coded the transcripts independently and then compared codes. These were then given to the wider team for additional peer review. The full team also met regularly to discuss the development of coding and themes.

Results

Five major themes emerged: 1) Importance of facial expression; 2) Age of onset and AD; 3) Describing directly from the visual source; 4) Integration of sound and sight to create a "whole picture"; and 5) Taking an educated guess. Other findings included the importance of context around AD, self-identification of the person being described, and the AD user's general acceptance of real-world limitations. For the purposes of this paper, the themes that most aligned with the deafblind participants in this study are highlighted; additional themes shared by blind, low vision, and deafblind participants are available in a separate paper (Conway et al., 2023). Note that participants' names have been changed to protect their identity.

Importance of Facial Expression

Deafblind participants who communicate via American Sign Language (ASL) stressed the importance of facial expression in aiding in their understanding of visual information about a person. Deafblind participant Anita shared, "I'm always more interested in the person's facial expressions than I am interested in their attire." Charles agreed and added that,

> "We cannot hear the tone of the voice when it goes up and down. But the facial expression, you know, or from the audio description that you might receive about a person [includes] their emotions and what they're experiencing."

As tone of voice was not accessible to those who were born Deaf, maintaining eye contact and looking at the speaker's face was a good way to learn about their state of well-being, intent, and more. Later in life, with reduced visual fields, getting access to this information through AD was expressed as essential to understanding the emotion behind a portrait or person. Another participant, Bruce, explained the strategy of using haptics, as a tactual representation on his arm or back, to help him understand the emotional context of the conversation as he was born with vision and this information was meaningful to him.

Age of Onset and Audio Description

Being blind, low vision, or deafblind from birth versus later onset can affect the desired content of AD such as the description of color. Those who never experienced color may have no need for this description, whereas others who have seen and understand color may find great meaning in this addition to the description. Charles shared:

> "I really like a basic description of colors. I think that's good enough for me…I've tried with somebody who's fully deafblind, we've had a conversation about it. And they told me that they were born blind, and they said they have no concept of black and white at all people who are born with sight and they lose their vision down the road, they tend to love color. It really means a lot to them."

In sum, understanding the age of onset and communicating AD preferences can help to improve the quality of AD for that individual on a personalized basis. In general, it seems that those who do like information about color prefer a basic and brief description, without using fancy terms like maroon or periwinkle, sticking with simple words like dark red or blue seems to work best.

Describing Directly from the Visual Source

In the context of portraits, this can mean describing the painting itself instead of reading the description from a nearby plaque that provides the details of the artist, medium, etc. Essentially starting from the big picture and then focusing on smaller details such as the scene, thematic points, action, emotion, and then possibly color. One deafblind participant shared:

> "I get the big picture first, what the picture is about. And then it goes down to the details of what's actually in the picture and what the point of the picture is. So, if you know, you go straight to the face, I won't know exactly what's happening, in the portrait with a picture. So, I think that the overall theme needs to be established first."

Others agreed that moving from general to specific allowed them to envision the scene better. Using the visual source was preferred over a text or spoken description by a tour guide as rich visual elements could be lost in translation. This can include the perceived emotion or feeling that the artist might leave up to individual interpretation.

Integration of Sound and Sight to Create a "Whole Picture"

With many of the deafblind participants being born Deaf, additional auditory cues, such as the mood of a room at a social function (i.e., glasses clinking, people laughing, etc.) should be added to the audio description to provide the "whole picture". Deafblind participants also emphasized the importance of including auditory information, such as tone of voice, accent, or background noise along with visual information to describe people in film, live performances, and other live situations such as social events. Within this group, AD has been provided in visual or tactile ASL with some also using haptic communication or ProTactile to offer as much information as possible to create an equivalent experience. Also, as the term audio description can be perceived as audio-centric, deafblind community members often use the term, “environmental facilitation” or EF to indicate someone that provides auditory, visual, and social information via ASL or other means.

Taking an Educated Guess

One interesting difference between the blind/low vision and deafblind participants regarding describing sensitive topics such as perceived gender identity, age, disability, and race was that the blind/low vision group preferred to use the person’s self-identified description (i.e., transgender, Hispanic, etc.) or none at all, erring on the side of caution when making assumptions. Whereas there were a few deafblind participants that would prefer an educated guess in order to provide a comprehensive description. The important note here was to use verbiage like, “it seems that … or I am not sure, but she appears to be in her mid-thirties…” One theory is that a person who is deafblind may not have access to additional auditory cues, such as a soft feminine voice or accent to provide additional clues incidentally. Although not all of the participants were in agreement, some said that at a social event, things like race and gender would not change how they interacted with the person and was therefore not relevant. While another participant preferred an educated guess rather than the visual description of a “caramel” skin tone that keeps them wondering about a perceived identity at a diversity event where this information could be relevant. Yet, there was also an understanding by some that if this information was not requested or relevant to the context of the situation, then it could be left out altogether.

Conclusion

Takeaways for describers are to engage in on-going communication around AD preferences as it relates to what information is most meaningful to the AD user based on their age of onset, level of vision/hearing, and other priorities across contexts and settings. This can include the amount of information as well as the process for describing race, gender, disability, or other associations that the AD user may find relevant. After an event, debriefing and gaining feedback from the AD user is also encouraged to improve the quality of individualized AD.

Summary

This paper discussed findings from a series of focus groups and interviews conducted with 15 participants who identified as blind, low vision, or deafblind on their preferences for the description of portraits and people via audio description (AD). Thematic analysis of the transcripts led to the following themes: 1) Importance of facial expression; 2) Age of onset and AD; 3) Describing directly from the visual source; 4) Integration of sound and sight to create a "whole picture"; and 5) Taking an educated guess. These results are in line with previous research that suggests there is no "one size fits all" approach to AD (Hutchinson et al., 2020; Naraine et al., 2018). The findings of this study lay a foundation for further research on representations of diversity in audio description.

Author Note

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LIVED EXPERIENCES

Bringing Experience to Life, Research, and Education

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Lived Experience

Lived experience refers to the people who have firsthand experiences of disability and its related challenges – legal, medical, social, and personal (Byrne et al., 2015). This includes knowledge and expertise about their own impairments, disability related challenges, and experiences of microaggression, discrimination, marginalisation, disadvantage, and oppression. What this means is that we (those of us with lived experience) are expert-knowers and we know the most about what it is like to experience disability. Lived experience research and lived experience-led research values these storytelling insights.

Epistemic Justice

For any research about any aspects of our lives, our culture, our needs, our priorities and the services that both support and fail us, it is not enough for researchers to 'observe' us, they must ask us. They should involve us. We are the ones with the most knowledge.

Researchers must engage and develop what British philosopher Miranda Fricker calls 'testimonial sensibility' where researchers immerse themselves into the worlds and lives and hear countless testimonies so as to become 'perceptually aware' (Fricker 2007). This creates challenges of accessibility, of reach, of culture, of communication. Without attention to these challenges, any research and whatever services or policies and protections are created and maintained, won't be inclusive, relevant to community priorities, or trustworthy. Despite having lived experience, we don't know it all, so testimonial sensibility and immersion is still necessary: We each hold but slivers of the whole. If we neglect testimonial sensibility, fail to provide accessibility, and neglect to seek out hidden voices, we commit testimonial injustice. Testimonial injustice – the wrongdoings of knowledge building – is part of Fricker's framework on epistemic injustice.

Australian society has yet to declare deafblindness-dual sensory impairment (DBDSI) a distinct disability. We have yet to come to grips with the growing and significant number of older people with DBDSI. Few are asking them for their stories and what they need, their priorities, what support works and what doesn't. Where is the society for older people who don't see or hear very well? Without this information, policy makers, professionals, and practitioners run the real risk of spending money on supports that don't work or aren't wanted.

What this tells us is that older people with DBDSI are invisible. This is not just a testimonial injustice of an unheard story but also a hermeneutical injustice (Fricker 2007). Hermeneutical is an uncommonly used word for the lack of awareness of the name and meaning of an experience. Many older people cannot name and therefore cannot communicate their experience of dual sensory impairment. Furthermore, no one is asking them; therefore, they are not able to improve their circumstances. Fricker calls this a situated hermeneutical inequality: This means older people's social situation is such that a collective hermeneutical gap or profound lack of awareness, prevents them from making sense of their lived experiences.

This hermeneutic lack of awareness is seen in the way older people refer to their significant sensory losses as just a normal part of getting old. These experiences are so common and yet so invisible. The failure to seek and make visible the lived experience stories of older age and sensory loss, these hermeneutic and testimonial injustices, belongs to society, its researchers, policy makers, social care providers, and legislators. Lived experiences need to be seen, heard, and felt. We will look later at how we can make lived experience more of a consideration in research and policy.

My Lived Experience

I have Usher syndrome, as do a few other members of my family. Deaf at birth, I got the Usher diagnosis in my twenties after several years in a hermeneutic wasteland of worsening sight but no recognition by any health professional. But now I had a name and way too much information about all the bad stuff that was going to happen. The medical librarian got me a copy of a landmark paper by Vernon (1968). He wrote of blindness, psychosis, cognitive decline, institutionalisation. This terrified me. I didn't understand how disability was 'managed' in the past, I didn't understand this wouldn't happen to me. I didn't know any others with Usher until my brother was diagnosed after me. We just said to each other: Yep. Rubbish stuff. Let's ignore it. I just kept working in health care until moving into research more recently. It has taken me many years to make sense of my own experiences because professional awareness of DBDSI was so low and there wasn't a social care presence for decades until the advent in 2013 of Australia's National Disability Insurance Scheme (NDIS), the principal form of support for people with permanent, severe disability who enter the scheme before 65 years of age. This means most people, especially older Australians, are not under its auspices. This creates serious inequities. This is why recognition as a unique and distinct disability is so critical. And why people with lived experience are campaigning for this.

As a person with DBDSI, I have many identities and roles in life. These layer my lived experiences in strange and complicated ways. We live with DBDSI but that's not all we do. We are often busy being and doing other things. If society were better organised and less oppressive, we would be busier still and more productive. We are enormously capable when adequately supported. I am a carer as well as cared for; I am a parent with a disability and an adult child of parents with dual sensory impairment; I am a service user and a service provider; a participant in research and a leader of research.

As service users, we have epistemic insights from our experiences that should be informing everything about us: the protections, policies, and practices. I know this from my lived experience research.

Disability is a big business in Australia, worth 34 billion dollars a year and growing. But we don't have a grasp on our workforce: it's casualised, disordered and the market force favours unskilled, lower paid workers. And for service providers and workers that support people with complex communication and other needs, multiple disability, and intersectionality, the current market and model just isn't working. I can say this from lived experience. And this lived experience is informing the review of the NDIS that is currently underway.

Low expectations hamper people living with disability getting plans and supports that meet their goals and aspirations. My planner said 'let's get you someone to help shower you, walk you round the block, and chat with you for a bit. And would you like me to look for a daycare or club with others like you?' I replied that I thought that was what going to work at university was – daycare with people like myself. It is also frustrating that unlike the UK, where it is recognised that people with DBDSI need specialised support, in Australia I don't get extra funds to pay for this specialised support, such as training in tactile messaging, sighted guide, social haptics, and technological assistance at a university level. I've been lucky and privileged to have creative people as my accessibility assistants, I wouldn't be here without them, I would have very limited work outputs without them, no book, no presentations, no research, no lifelong learning, no important internet shopping. How do I know about all this? From my lived experience.

I also know from my lived experience-led research that people with DBDSI are subject to significant care and communication failures in hospitals. My research revealed that no one got an accessible to them consent form (Watharow 2023). Some of the other results include:

- I am cared about = 11%
- I am treated as a human being = 17%
- I understand what professionals say = 11%
- I experience high-quality and safe clinical care = 22%
- I have confidence in the professionals treating me = 22%
- I am treated equally no matter who I am = 22%
- My hospital puts the need of patients first = 6%
- My feedback is welcomed and acted upon = 6%

This is a damning report card into the performance of hospitals for patients with DBDSI. We know this because we asked the expert-knowers, giving them choice and control over creating safe narrative spaces, providing trusted interpreters where needed, and developing testimonial sensibilities. It is crucial and epistemically just that all patients are given inclusive ways to share their experiences of care and carelessness in hospitals (Calvert et al 2022, Watharow 2023).

Unwanted Lived Experiences

Oppression and discrimination are alive and unwanted experiences of disability layer and complicate life. Recently, I decided to measure how much, how often. I started keeping a diary of enabling events and disabling ones. After one week I had so many of the latter, I thought that must be a one off, a spike in incidents, so I continued collecting experiences for another week and found lots of them again. It crystallised for me, that when other people are dismissive of the 'severity' of a microaggression at work or during a meeting which is inaccessible, they are failing to understand that happens on top of the bank refusing to assist you, or the health service refusing to provide accessible forms, or the bus driver saying the ubiquitous, ableist 'you don't LOOK disabled.' All these layers are thick and sticky and often invisible, we need to be asked about them in safe ways and share these experiences with researchers with testimonial sensibilities or lived experience.

Inclusion of Lived Experience in Research:

A roadmap to a better evidence base to inform protections, policies, and practices would include.

1. Recognition of DBDSI as distinct disability.
2. Co-production for all research about disability: Include people with disability at all stages of the research process.
3. Accessibility for all: Grant applications must be made accessible, as most are not.
4. Meeting etiquette: We all know that all research and policy making involves interminable, long meetings. We need etiquette to include people with disability, manage turn taking and maximise information, inclusion, and contribution by those with lived experiences.
5. Remuneration: Pay for the expert-knowledge of people with disability.
6. Authorship: Include all the knowledge builders as authors where possible.
7. Grow experience: Provide opportunities for those with lived experience to tell their stories, participate in the production of research, get skills. Lifelong learning for all.
8. Budget for increased time and accessibility provisions.

9. Share experiences about the challenges and adjustments to methodologies when conducting research by lived experience researchers and with people with disability.
10. Ensure research outputs translate into a socially just, epistemically truthful benefit for communities and individuals.
11. Embrace scholar activism (Paradies 2018).

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Teen Years With Usher syndrome:
Living It My Own Way!

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Introduction

The main objective of this article is to describe the journey of a 16-year-old girl, Laurie, who has Usher syndrome and a language disorder.

From a young age, Laurie has faced personal, academic and professional challenges. Her involvement and perseverance are illustrated by concrete examples. These testify to her investment and her positive attitude, both with the rehabilitation team and at school.

Laurie is learning adapted, which requires her to use technology to have access to information and to maintain communications as her vision will eventually deteriorate. Allowing teens and parents, as well as their rehabilitation team, to acknowledge different experiences lived-in real-life situations and how interventions can help in coping with difficulties that occur along the way.

Laurie's motivation is to communicate that it is possible, even with deafness and visual and language impairments, to live fully, do many things, and get through tough times.

Laurie’s childhood Journey

My parents discovered that I was deaf when I was 7 months old. I didn’t react much to the noises in my environment.

My hearing was assessed and I had my first cochlear implant when I was 17 months old. From 1.5 to 5 years old, I went to the IRDPQ stimulation center (Institute of Rehabilitation in Physical Impairment of Quebec) and also to a family daycare.

Then Chantal, my speech therapist, suggested the Oralist School to my parents - it’s a private school for Deaf children. This is where I started school.

I developed my language and it was discovered that I had a visual problem at the age of seven.

Communication and Language Development

When I was little, I wanted to communicate. I learned some signs, but I didn’t say a lot of words. I really wanted to talk.

Inclusion in different activities

Before going to day camp, I was an energetic and self-confident child and I had always felt welcome; at daycare, at school, with my family.

At day camp, I wanted to make friends, but children made fun of me and called me ugly names like: monster because of my implants. I didn’t understand everything they said, but I saw their expression and the way they spoke to me and I felt rejected.

At that time, it was difficult to express myself well and to tell my mother what I was going through. I lacked the words to express my emotions. I did not want to go back to day camp anymore. I repeated it several times, day after day. Finally, my parents agreed that I would stay at home during the summer with my brother. I improved my autonomy, to keep busy during the day, to cook a little and to do tasks like the dishes. I became more responsible and my parents gained trust in me. Afterwards, I no longer felt like leaving the house or wanting to meet people, or do family activities, even if my parents suggested it. I did not want to be bothered anymore.

My Second Cochlear Implant

I got my second implant when I was 5 years old. I had issues with that one: tinnitus, tickling; it was really unpleasant. I didn't really use it until about age 13. At that time, it was difficult for me to speak clearly and the audiologist had to program the implant by watching my reactions, my facial expressions, and the blinking of my eyes to see if I was comfortable. It hasn't been easy.

When I was able to express myself better, there was a reprogramming of my implant. I was now able to tell if the sound was too loud, too weak, disturbing, or if it was comfortable. I could tell if I had a pain or tickle in my head. Moreover, the programming possibilities of the implant were better than when I was 5 years old.

With my second implant, which I wear now, I hear better on both sides, it's easier. I have to speak lower to hear my voice correctly. I listen to the TV quieter and it's better for my parents' ears! I can also connect on Bluetooth to a TV listening system and to my smartphone.

Vision Loss

When I lost more vision, I saw less and it was darker, I had more difficult times. At school, I was stressed because I was facing more difficulties and I wanted to succeed in doing the work. I had more problems, like in sports, and I lost self-confidence. I felt that my difference was more obvious. When I arrived home from school, I was tired and I was often angry. I often stayed alone in my room.

And indeed, it was hard. At school, I remained in a fairly good mood, even coping with the stress. But at home, I was more depressed. In the same period, I was entering adolescence. I was offered help and went to the psychologist and doctor for stress medication.

I couldn't manage to lower my anger on my own. I didn't feel good because anger is not like me, it's not in my personality, I was reacting to my loss of vision. I tried to improve this, but I needed support to make it happen.

With the psychologist, I worked step by step. I wanted to regain self-confidence. First, we worked on anger management, then I developed stress management tools. Afterwards, we worked on sadness and depression. It seems to me that after that period, I was better able to understand quickly. I feel that I have opened up and I that I now process information better.

After my vision loss, the rehab team suggested to me to discover Braille. I wasn't so sure at first, but I accepted. I really enjoyed learning how Braille works. I also learned some basics to write using a Braille keyboard.

I know that I will be able to continue to learn and that with Braille and screen readers with speech synthesis I will be able to continue to have access to the computer and do a lot of things, even if I see less.

Getting to Know Myself Better and Gaining Confidence

At the time when my vision went down and in the following months, I spoke about my visual difficulties at school. Teachers and students were informed. It was difficult to make teachers and young people my age understand what I was going through and how stressed I was. Since I was experiencing difficulties, a meeting with the rehab teams was organized.

My teachers were surprised, they did not expect such significant impacts and had not felt how much my vision was affected.

My friends were also impressed by what I was going through, especially in the ball game. My childhood friend tried a 3-4 meter shot with me. She managed to catch the ball but when she took off the simulation glasses, she saw that it was not that far!

After the meetings, the other students were more supportive and tried to help me more. The teachers also knew what to do better to help me.

Talking About It Without Feeling Embarrassed

I started talking about my vision and hearing problems to several new people. I was lucky enough to be able to do it in a fun and relaxed context, at my father's family and work parties. Now, when I have personal experiences, like for example at the beautician or if someone notices my cane, I am able to explain my situation and how

I see, how I manage, and how they can help someone who is visually impaired. I know I can help other people and that is why I am sharing my experience with people.

Going to School with Some Adaptations

I am now in my third year of Québec's version of high school. I got help at school from the rehab team and I have always been working hard.

I participated in several projects at school, which helped me to make a lot of progress.

Even when I was unaware of it, people were working things out to adapt to my environment at school.

Family Life and Personal Interests

From the moment I was little and up to today, I have done a lot of activities and tried a lot of things. I want to experiment, discover and have fun.

Student Job

Last winter, I started working as a clerk in a grocery store. I learn a lot and meet new people. I like that a lot. I managed to find this job thanks to my grandmother and because this place was open for social integration.

My Future...

Soon, I will change schools, to continue to learn and prepare for my future. I began seeking advice from an orientation counselor to learn about the possibilities and the trainings and jobs that I could do later. I want to know myself better, to consider my strengths and limitations, and make interesting choices for my future. It is a challenge for me, as for most young people my age!

Conclusion

To sum up, I want to remind everyone that even with visual, auditory, and language difficulties, you need to have confidence and keep trying lots of things. We are capable!