

DbI REVIEW

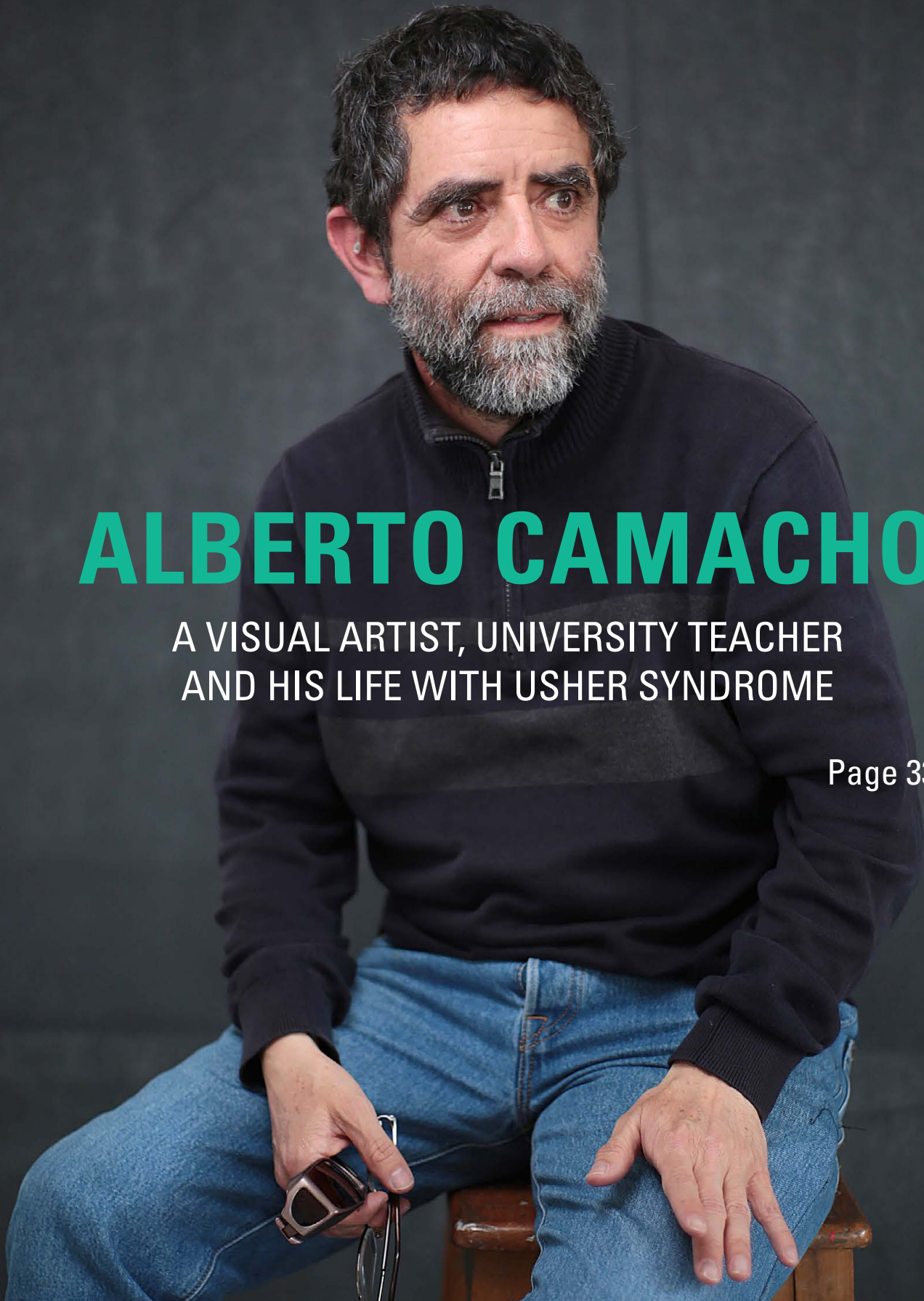
THE MAGAZINE
OF DEAFBLIND
INTERNATIONAL



ALBERTO CAMACHO

A VISUAL ARTIST, UNIVERSITY TEACHER
AND HIS LIFE WITH USHER SYNDROME

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leave no one behind!

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We are DBI... leave no one behind!



Just a 1,5 year to go till the DBI World conference in Canada. But before that - in the spring of next year, we are proud to announce that DBI will hold, for the first time, International Africa Conference. We are making good progress on our strategic goals – we established numerous international collaborations - for example with WFBD, ICEVI, IDDC, WHO. These partnerships will help us to make more impact, raise awareness and help us to get deafblindness recognised as a distinct disability. But there are other great examples as well, we participated (our Technology Network) in the second global consultation for the WHO- UNICEF report on Assistive Technology. And I'm sure you noticed the activity of the Communication Committee. They created a flow of news, sharing updates, ambassadors and lately

our first newsletter. All these activities were initiated during a difficult time. Last year we entered an educational crisis the world had never seen before. The corona pandemic put the whole world on its back. The effect on education and participation is enormous. We all know what struggle the deafblind community had to face. Participation in the community activities with “social distance”, like in education, general care or daily activities. Children with deafblindness are statistically less likely to be in school than children without disabilities. That is why I'm looking forward to the ICEVI / DBI /WFBD meeting to explore and discuss the creation of a global education campaign for children and young people with deafblindness. This is what we do together at DBI, hope to see you soon!

FRANK KAT

PRESIDENT OF
DEAFBLIND
INTERNATIONAL

International Day of The Deafblind People, from Home: Closer than Ever

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The last year and a half have been irremediably marked due the COVID-19 pandemic, that has affected all the world. Nevertheless, the collective of deafblind people has noticed that the isolation they usually used to suffer has severely become more intensive with this situation.

In Spain, it was instituted the quarantine, that was later extended to almost four months. Four months during which the people should not leave their homes, unless they have to carry out essential activities and, in doing this, they have to keep the interpersonal distance of 1.5 metres – 2 metres, wear a mask and avoid touching their surroundings as far as possible.

But what about the individuals who are deafblind? How do they go out without touching the surroundings when it is their union with the world? How do they communicate if, again, they need the touch to do it? How do those people, who need reading lips of an interlocutor, communicate when a piece of fabric/cloth covers them? How can they respect the established interpersonal safety distance if they can neither see nor hear the others?

All these questions concerning how the individuals who are deafblind, the professional teams and the entities which work with deafblindness in Spain, have handled this period, were discussed during the celebration on the International Day of the Deafblind People 2021.

It's a celebration that, in Spain, is traditionally organised by FASOCIDE, FOAPS and APASCIDE on an annual basis as an opportunity for an unknown collective such as this one to approach to bodies/authorities, media and the society in general.

Usually it is an on-site activity, which is held with the participation of three entities, many deafblind people, authorities of the disability area of the Ministry of Health and other areas or bodies related to the collective. An event that brings people together, an event that, during the worst moment of the pandemic, was unfeasible. Therefore, it could not be celebrated in 2020 and that is why it was not on-site in 2021, but it was considered necessary to do it. In the adjusted way, to commemorate and share precisely such adaptive capacity that the collective and its professionals have shown, and keep demonstrating it at such difficult times.

An online event, held under the banner/motto Pandemic and Deafblindness: We Keep Breaking Down Barriers, was interpreted into Spanish sign language, and everybody could freely access it through YouTube.

The speeches/interventions were made by the presidents of three organising entities: Francisco Trigueros for FASOCIDE, Andrés Ramos for FOAPS and Dolores Romero for APASCIDE. As well as by the Director of Disability Policies

of the Spanish Ministry of Health, Consumption and Social Welfare, Jesús Martín, and the Vice-President of Social Services and Participation of ONCE, Imelda Fernández. All this was coordinated by Rosana Rodrigo, a deafblind woman representative of the Accessibility Committee of FASOCIDE.

However, the main characters/protagonists of this event, once again, were the deafblind individuals from different places of Spain. They shared in first person their experiences during the pandemic from very different situations and personal conditions.

Cristina González started, a deafblind young woman from Andalusia, Dietetics and Nutrition student, who explained how the pandemic caught her in the middle of the course and complicated her participation in the exams very much, as they were made in online environments and she did not have a deafblind interpreter.

Then, Candelaria Luis, a deafblind activist woman from Canarias, complained about how new technologies, which allowed the society in general to access to the communication, information and even formation and work, were not accessible to every kind of deafblindness. Furthermore, she remarked that this was an example of the existence of a group - of individuals who are deafblind - that during this social crisis hasn't been taken into account.

In addition, she complained about how inaccessible was the official information on the pandemic evolution, either through media or the Spanish Government, and that they were able to access this information only thanks to the association of the deafblind people of their zone.

Later, Sergio García, a young man with an additional physical disability, shared his experience as a student when he was left without a mediator due to the pandemic and thus saw a gap in his training until he found a new deafblind interpreter. He appealed to the bodies, asking not to ignore the collective, denouncing the fact that neither the collective nor its professionals were given priority when it came to establishing the vaccination calendar for special groups. He also claimed the need for support in order to have more deafblind interpreters and communication mediators, saying as follows, "without them

we are nothing, just buoys floating adrift in a hushed and dark sea".

Raquel Alba, worker at ONCE's Technical Unit for Deafblindness, explained how her work changed with the start of pandemic and isolation, incorporation of new tools for teleworking, which she considers to be positive as a new learning and opportunity.

Finally, Dolores Franco and José Luis Garrido made a joint intervention from APASCIDE's Santa Angela de la Cruz Centre.

Dolores explained how she used to carry out many activities with APASCIDE and ASOCIDE, but with the start of pandemic she felt very lonely, and the mediators provided her with materials, books, they were asking how she felt. Furthermore, at the end of the isolation period they visited her, all with the aim of keeping working from home.

José Luis specially noted that, as a member of a day care centre, he can see his fellows of 24 hours-residence only when they pass each other in the corridor, being separated by prevention plastics, so he misses being able to hug and talk to them very much.

To close the event, the leaders of three organising entities shared the carried out good practices, and the president of FASOCIDE, Francisco Trigueros, took the opportunity to thank and highlight the involvement, dedication and adaptation of the professional deafblind interpreters during the pandemic period, aimed to ensure that the individuals who are deafblind were not left unattended. They achieved this by doing interpretation by video-calls, face-to-face interpreting (in essential cases) at home, at hospitals and health care centres. They also carried out tasks that were not part of their daily work, for example: shopping, garbage removal, etc.

Different entities highlighted how many of their workers ended up infected due to their great involvement and how, with all of this, it was possible to avoid the outbreak to other workers or deafblind people, containing the infection.

A part of this event's novelty - an availability to join it online - made it possible to organise the participation and follow the event for many deafblind people and future professionals in the sector from different parts of the country.

An International Project about Deafblindness in Development: International Universities and Non-Profit Organizations are Carrying Out a Broad Study That Will Develop Specific ICF Core Sets for Deafblindness

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Deafblind International is carrying out an international study, led by the European Deafblind Network, that wants to provide a standardized description of functioning for the wide range of combinations of hearing and vision loss causing deafblindness, independently of the medical cause or level of personal autonomy of a deafblind individual. This would provide a scientific basis for the assessment of functional status, goal setting, treatment planning and monitoring of the evolutions, as well as measurement of the outcome. Besides this main objective, the project also aims to contribute to raise awareness on deafblindness inside the medical community worldwide.

The few data available estimates that only in the EU there could be as many as 3 million deafblind people, according to Deafblindindicators.eu, a project developed by the European Deafblind Network. Although this condition is highly incapacitating,

deafblindness is one of the most rarely diagnosed conditions in medical practice. Normally, a person who is potentially deaf and blind, goes through a long process of clinical evaluation commonly executed in two separate processes: one for the vision loss,

and one for the hearing loss, not having any medical scale intended to put both inputs together. As a consequence, deafblind people have to be certified following non-standard indicators generating subjective or incomplete results with a huge impact on the further intervention and assistive plan.

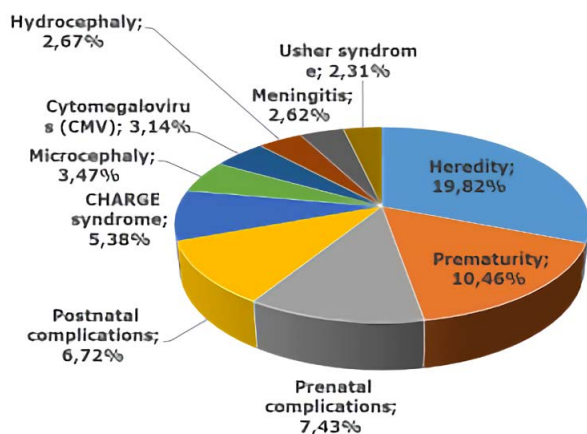


Chart 1: Top ten etiologies meaning 65 percent of USA Deafblind Census O-21 y.o. Graphic is the author's own creation based on the data provided by the census. [1]

In this context, the development of an international standard following the International Classification of Functioning, Disability and Health (ICF), the framework of WHO aimed to measure health and disability on the individual level and population, that this study proposes, seems necessary and convenient. The project considers 4 themes or working groups:

References

1. Killoran, J. (2007). *The National Deaf-Blind Child Count: 1998 - 2005 in Review*. National Technical Assistance Consortium. Monmouth, OR.

- **Empirical Multicenter Study (EMS).** Identification of the most common problems experienced by the target group of individuals by applying the ICF checklist.
- **Systematic Literature Review (SLR).** Summarizing the international scientific literature on the particular health condition, health condition group or healthcare context.
- **Qualitative Study (QS).** Reflects the view of persons living with deafblindness. The acquired ones by themselves, the congenital by their parents.
- **Expert's Survey (ES).** An Internet-based study addressed to gather opinions of experts on aspects of functioning and environmental factors that are relevant for individuals who are deafblind. A Delphi study may also be conducted.

The results from these groups will be evaluated by an international consensus conference in parallel with the global Dbl conference. Also, the results of this conference will be handed to the World Health Organization for their worldwide incorporation to the International Classification of Functioning, Disability and Health. The project is already in development by a team of 20 experts from 18 different countries representing 7 world regions. The Systematic Literature Review and the Qualitative Study will be carried out simultaneously in 2021.

Peru Promotes Training of Interpreter Guides for Individuals who are Deafblind

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Since its constitution in 2009, Sense International Peru has promoted the recognition of deafblindness as a unique and specific disability.

On May 2, 2010, Law No. 29524 was published, recognizing deafblindness as a unique disability and establishing provisions for the care of individuals who are deafblind. The approval of the law was the result of an advocacy effort led by Sense International Peru, which drew up a first draft that was enriched with contributions from civil society organizations dealing with deafblindness and which was then presented to the Special Commission on Disability of the Congress of the Republic.

On June 16, 2011, Supreme Decree No. 006-2011-MIMDES was published, regulating Law No. 29524 and establishing, among other things, that public and private entities for public use are obliged to provide the interpreter guide service for individuals who are deafblind free of charge. To achieve this, it was determined that the Ministry of Education should validate alternative communication systems for individuals who are deafblind and approve complementary standards for the training of interpreter

guides. It also stated that the National Council of Persons with Disabilities (CONADIS), should create a register of interpreter guides as a sub-register of the National Register of Persons with Disabilities.

As part of the advocacy work for the proper implementation of Law No. 29524 and its regulations approved by Supreme Decree No. 006-2011-MIMDES, Sense International Peru held exchanges and meetings with the Director of Special Primary Education at the Ministry of Education and the President of the National Council of Persons with Disabilities (CONADIS).

The Directorate of Special Primary Education at the Ministry of Education set up a working group in charge of contributing to and agreeing on the proposals of alternative communication systems for individuals who are deafblind. The working group was led by Sense International Peru and the results were delivered after 6 months of work and meetings.

On August 28, 2012, Ministerial Resolution No. 325-2012-ED was published, validating the alternative communication systems for individuals who are deafblind identified by the working group set up under Ministerial Resolution No. 0636-2011-ED. The following alternative communication systems were identified:

- Finger Spelling System: Visual and Tactile;
- Block Alphabet;
- Visual Sign Language;
- Tactile Sign Language;
- Adapted Oral Language or Amplified Speech;
- Lip Reading; and
- Tadoma system.

The President of the National Council of Persons with Disabilities (CONADIS) approved Presidential Resolution No. 020-2017-CONADIS/PRE which sets out the new Regulation of the National Register of Persons with Disabilities and establishes, in Chapter VII, the Register of Interpreter Guides for Individuals who are Deafblind.

The requirements and profile for the training of interpreter guides for individuals who are deafblind have been reviewed, analysed, discussed and agreed upon in various meetings, working groups and sector commissions under the Ministry of Education since 2011. Sense International Peru participated in all the working tables and commissions and/or consulted with the Association of the Deafblind of Peru (ASOCIP), the Association of United Deafblind of Peru (ASCUP), the Association of Friends of the Deafblind, Deaf and Blind (AMISSORCI), the Association of Interpreters and Sign Language Interpreters

of Peru (ASISEP), and Special Primary Education Centres (CEBEs) – principally CEBE EFATA, CEBE La Inmaculada and CEBE San Francisco de Asís.

On July 7, 2021, after 10 years of sustained advocacy work with the Ministry of Education, the Director of Special Primary Education at the Ministry of Education informed Sense International Peru about the approval of the requirements, profile and competencies for the training of interpreter guides for individuals who are deafblind, and their publication in the National Catalogue of Training Opportunities provided by the Directorate of Higher Technological, Artistic and Technical-Productive Education at the Ministry of Education.

This publication allows any institution and/or higher education school to offer the Interpreter Guide for Individuals who are Deafblind Study Programme which, consisting of 2250 hours and 120 academic credits, results in the training level of Technical Professional in Guide Interpretation for Individuals who are Deafblind. A technical Bachelor's degree is obtained that, according to Law No. 30512 (Law of Institutes and Schools of Higher Education and the Public Career of their Teachers), can be recognised as a higher academic degree.

From now on, new advocacy and collaborative work processes will be aimed towards establishing the accreditation system of non-formal interpreter guides; also, for higher education institutes and/or schools to carry out situational analyses on the demand for the service of interpreter guides to generate new training processes. Despite significant progress, the road is still long for the consolidation of this advance in the realization of the rights of individuals who are deafblind.

The World Made of Silentness and Fog

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If you listen to silence attentively, it will start listening to you with the same attention.

An altered quotation by Nietzsche perfectly fits this anthology, which coupled the image of the author and silence, the condition (together with the darkness, echo of abyss) within which the individuals who are deafblind live.

I – Silence is a part of the international project In the Language of Silence, called upon to pay attention to the individuals who are deafblind, conceptualize the topic of deafblindness in literary texts, and, finally, provide a platform for the people having vision and hearing loss, whose texts are published on website/anthology pages on equal terms with the authors without sensory challenges.

The idea of the project came up on the sideline of a writing competition for individuals who are deafblind Co-creativity, which was held in 2019 for the first time. One of the nominations, Works on Individuals who are Deafblind/Deafblindness, was addressing outwards the community and designed for all interested people, instead of addressing inwards the community. However, the received works were fading among the texts of deafblind people, who the competition was focused on. It's no coincidence that the foreword of the collection Vigilant Heart, issued on the back of it, contained the phrase of the critic Olga Balla, "On some level, we've got the statements of

representatives of another vision facing us. And consequently, inevitably – of partly another (just partly!) understanding of life"¹.

These statements brought us to a new aim: to look behind the veil of silence and darkness through getting familiar with the world perception of individuals who are deafblind, and as a consequence, to understand Another Person better. And, finally, to show how we, individuals without sensory challenges, understand individuals who are deafblind and their being in a form of the text (thus, in a form of the statement, accessible to Them).

It all started from an idea – a desire to (start) speaking about deafblindness in a new style, in terms of art. From realizing how it is important to get through to everyone: the individuals who are deafblind are the same as we are. They are among us, and the accident – loss of hearing and vision – may occur to anyone.

That is how we came to the project In the Language of Silence, concurrently keeping in mind the thought of inclusion and (its important component) global available space. But how can we reach it, if the individuals who are deafblind (and, in general, all people with <un>limited abilities) remain invisible to society?

In the project presentation I wrote, "Just a while ago the individuals who are deafblind couldn't attend theaters and museums, the public transport was unavailable to them, practically none of them

¹ Balla O. (2019). The Main You Cannot See with Eyes. Vigilant Heart. M.: LitGOST, p. 6-7.

had rehabilitation equipment. Frequently, the maximum they could reckon on were glasses or an acoustic aid. In the USSR, they used to be considered uneducable people for a long time¹. A paradox (is that really a paradox?): now there are P.h.D.s and doctors of science², actors, artists, and writers among them.

The project was launched in February 2020 in Yekaterinburg, in the museum Literary Life of Urals of XX Century, it started with the presentation of the collection Vigilant Heart (it was important to push off exactly with the texts of deafblind people: Tatyana Kiryanova, a deafblind individual, has also attended the event, she was both reading and signing³), excursion into the history of rehabilitation of people with hearing and vision loss. And, finally, with reading the texts of Sergei Ivkin, Anna Lukashenok, Viacheslav Sementsul, and others – who the literary collection of the project started from. The event was organized by Iuliia Podlubnova, who noticed documented (and that's important!) nature of many texts of deafblind people⁴ in the article "From Different Niches of Reality", and who later wrote a poem for the project; in the hall there was also Aleksei Salnikov, who gave a review to the anthology in blurb-e on a cover (could the author of Petrov's Flu suppose so at that time?!), "It's very good that such a big number of distinguished authors took part in such a needed book. <...> ...we can hope that among the readers there won't be just those who read with the eyes, but also those, who feel the texts with their hands. After all, modern technologies have enlarged human abilities related to the access to a wide variety of information..."

The technology, which made the online world of texts available to the hands of individuals who are deafblind, concerns the Braille displays. Reading with their help is similar to reading relief pages of Braille books, but a keyboard is performed in one line, and

filled with six-spot components. The project page with the first cumulated texts (Olga Bragina from Kiev, Andrei Tavrov, and Valerii Ledenyev from Moscow, and others joined those from Yekaterinburg), an article on bi-sensory loss and deafblindness in literature, appeared online on the International Day of the Deafblind People – on June 27, 2020. And it was regularly updated (in average, once in two weeks, 31 times in total) until the summer of 2021. Here is the link: <https://so-edinenie.org/proekt-na-yazike-tishini>

In quantitative terms, In the Language of Silence, and consequently, the anthology I – Silence represents 124 authors (poets, prosaists, essayists) and 12 translators; and as some translators have written something for the anthology themselves, its authorial composition comprises 131 persons. They represent 20 countries: Australia, Belarus, Brazil, Great Britain, Germany, Denmark, Israel, Spain, Kazakhstan, Canada, Latvia, Moldova, Poland, Russia, Serbia, Slovakia, USA, Ukraine, Sweden, and Japan. And they live in 50 different towns and cities.

And they are all under the same cover.

Apart from Aleksei Salnikov's review, this cover contains the words of Liudmila Ilitskaya, who mentioned the project's importance, "Since birth a person gets to the world, full of sounds and colours. And most part of the human race doesn't even think about what the world of a person with vision and hearing loss is like. Is that a downsized world? Yes, it undoubtedly is. But this downsized world is abundant in its own way: sometimes the things, which those who don't have vision and hearing challenges scarcely catch, unfold to the people with vision and hearing loss. That's exactly the thing that the poems, gathered in this collection, declare."

The poems (but not only them: prose and essay as well) are written especially for the

1 <https://so-edinenie.org/proekt-na-yazike-tishini>

2 This means also the first swallow O.I. Skorokhodova (1911-1982), and recently passed away S.A. Sirotkin (1949-2021), and now living A.V. Suvorov (born in 1953). The younger generation is upcoming too – Nikolay Kuznetsov was enrolled in the postgraduate training program of Saint Petersburg State University under the program of Jurisprudence in Saint Petersburg in August 2021.

3 One mark on inapprehension: Tatyana Kiryanova has been a singer in a territorial office of the All Russia Association of the Blind for a long time. When she started losing the hearing rapidly, she was asked to leave the stage, the association of the blind merely could satisfy the needs of a person with vision and hearing loss. And then Tatyana sank into depression – all the way to thinking of suicide. And she came back to life only after getting into the association of the deafblind.

4 Podlubnova Yu. (2021). From Different Niches of Reality. Acquired Light. M.: LitGOST, p. 6.

book, or found in archives, as the one by Vladimir Aristov on a deafblind sculptor,

Is sculpture the art of blind and deaf?
That's what I thought of
after watching the works of my friend.
The fabulous light mimics –
those subtle emotions in face
which form tiny waves and pass
after notably light touching
of fingers.

The story, which seems unbelievable (we quoted the fragment of a large poem, written in the 80-ies and now retraced), has real embodiments. A totally deafblind sculptor Aleksandr Silyanov (wasn't he the one who became a prototype?) creates busts of animals and people owing to the memory of hands. Once he went to a horse-breeding farm in order to explore a horse's head in a tactile way, and then sculpted it. None of the descriptions, neither handed from one person to another, nor retrieved from the Internet – could give required information. Silyanov's palms became his eyes.

That's not the only retraced text in the anthology, one more is To a Certain Degree Palimpsest by Maria Galina, "Young trees has already learnt how to speak / The ABC of creak, rustle and bustle is clear to them <...> Touching each other discreetly in an earthly half darkness / Having trust in a palm, and a face, and the shapes of a body / Relying on the fingertips – night reliable vision."

The world of nature and a human is welded tightly – everything influences everything, the life is an intercommunicated vessel, and something that happens to a human (here: deafblindness), may be found in nature as well (see, for example, a poem by Marianna Kianovskaya in translation of Natalya Belchenko). A reverse process also exists: a touch of cold and rain causes goose-pimples (see the text by Daria Belkevich), which remind Braille dots.

The anthology contains a lot of important texts, and it's impossible to tell about all of them. Practically each of them hides a story. Natalia Beskhebnaya creates The ABC for the Deafblind, based on the statements of the individuals who are deafblind on what surrounds them/happens in their lives,

A Flight

I love flying on an airplane. At first it goes slowly, then faster and even faster, then very fast, and then it takes off the ground. That's the moment I love very-very much. When the airplane takes off, it stops whirring, the noise becomes more quiet. Just a moment and I'm in the sky.

Leo Butnaru stands out the analogy: if the blind Homer and the deaf Beethoven were genius, then a person who is deafblind may appear extremely genius. Anna Halberstadt tells a story of Helen Keller and Anne Sullivan, whose feelings turn out to be stronger than a disease, "It seems that the gift of speech and love / has dissipated darkness of deafblindness." Valeriya Grechina turns to the life of the deafblind Alena Kapustyan, to that episode, when the girl thought of the suicide¹. Sasha Moroz shifts the words of the deafblind Irina Povolotskaya², retrieved from the movie Word on a Palm, into a poetic text,

Every person with vision loss has its own type of blindness.
It can be black, when there is nothing at all.
And it can be black, but with flashes, and fireworks, pieces of light,
But that light is the false one.
And there is blindness with some images too
Yet they are the false ones as well.
The blindness means a human can't perceive the world that's real.

Andrei Cherkasov has represented an experiment of Ideogram, in course of which he asked people having hearing and vision

1 When I was 13 years old, I was even thinking of the suicide, but then something stopped me (see: <https://www.mk.ru/social/2021/05/11/neobychnaya-istoriya-devushki-aleny-mama-rasskazala-pro-ego-tatuirovki-i-ya-vlyubilas.html>)

2 The anthology also contains the texts of Alen Kapustyan (essay) and Irina Povolotskaya (poems and essay).

loss to perform a haiku by Marina Khagen in a sign language, combining the signs of each of them (they had light-emitting diodes, fixed to their fingers) in one frame. In the text *Vowels on the Fingertips*, Lida Iusupova builds on the movie *The Land of Silentness and Darkness*, retelling the plot in a foreword, which appeared to be even larger than the poem itself, especially for the people having hearing and vision loss...

The project was getting more and more friends with each update. The poet and translator Anna Orlitskaya has found two deafblind authors from Brazil (Alex Garcia) and Spain (Agusti Vila), and then wrote a poem on deafblindness herself. The poet Zuzana Kuglerova has engaged over 20 Slovak poets (!) – four of them got in the anthology: Janka Biskupičová, Dana Kováčová, Anton Pižurný, and Marek Sopko (all of them in the translation of Sofya Alempievich, who added the Serbian poet Maria Vranic as well). An employee of the Con-nection fund, the journalist Natalia Pervova, has found and translated the text of the Swedish Torbjörn Svensson, who is deafblind and who wrote a blistering letter to the Usher's syndrome (Mister Usher), that took away his vision and hearing. The translator and translologist Lena Baybikova has found the verses of the Japanese deafblind professor Satoshi Fukushima, written in two languages for reporting at the international conference of Helen Keller as far back as 2001...

Moreover, the fragments from memoirs of Aleksandr Suvorov, a well-known deafblind person, participant of Zagorsky Experiment¹, were published in the book for the first time,

Once, I got lost in a sylvan park, I lost the right turning. I started to ask bypassers for help. First I stopped one woman, who was staring at a plate, where it was written, that I am a deafblind individual and the one can talk to me using a combining alphabet – relief-dotted and visual. The woman had calloused, broad hands with short and poorly bending fingers. She was spreading the blindness and deafness of soul, and also some sheep's and cow's dullness. She never understood

neither the instructions given on an alphabet plate nor my oral request to show the turning to the forest pond, repeated multiple times. It all ended with her going her own way and almost taking away the alphabet plate as a souvenir. I noticed two more very dark silhouettes, appeared to be the same inapprehensive, but the hands of these ones I didn't hold.

Then I stopped two people. I dealt with one of them; the second man (or woman) seemed to me a vertical blur (actually, I could see people wearing black during the daytime, but late in life I stopped noticing people around me at all, unless they were holding my hand). This man's hands were very cozy, dry, warm, kind of not soft, not rough, but creasy. The man was definitely educated and creative: he puzzled out my alphabet plate in less than a minute, started writing on my palm, accompanied me to the needed turning, and was clearly ready to help me further, but I thanked him and told, that I would figure it out myself. Moving away from them by the path they showed me, I felt them standing and following – guarding me – with their eyes. The warm feeling to this man and his fellow (who apparently was a woman) is still vivid in me, although many years have passed. It's a pity, I scrupled to make a real acquaintance with them, maybe we would be friends now...

And also a totally deafblind Vladimir Elfimov told about how he lost vision, falling into – as he says – “blindish” period. Ilya Kaminsky (in translation of Tatyana Retivova) and Yaroslav Pichugin dug the readers in the world of deaf people (by the way, the book *Deaf Republic* by Kaminsky was acknowledged as the book of the year according to *Washington Post*, *The Guardian*, *The Telegraph*, *New York Times Book Review*, etc.). Moreover... (but we have to stop at some point)...

The project texts were published not only on the website, but in the Russian and Ukrainian periodicals as well. In autumn 2020 the magazine *Paradigma* published a series of materials, dedicated to deafblindness with the

¹ The memoirs were issued in the end of 2021: Suvorov A.V. (2021). *Experiment as Long as Life*. M.: LitGOST, 240 p.

verses of Olga Bragina, Valery Ledenyev, Sofia Kamill, Darina Gladun, Irina Povolotskaya, Lida Yusupova, and also an essay by Anna Gruver (in anthology it is represented in translation of Kseniia Chikunova), etc.¹

In autumn 2021, when the anthology was sent to the printing office, two more selections came around: the one in art digest Soloneba² and another one in magazine Diskurs³.

I - Silence became the first anthology of texts on deafblindness in the world (thanks to its unique concept, in May 2021 it obtained bronze of the Silver Mercury award). In the foreword Aleksandr Markov, DLitt, noticed,

“Reading this anthology isn’t an easy task, that is not a theme-based anthology in an habitual sense of different approaches to one subject. Rather the opposite, it is an indication that the subject appeared to be close to us...”⁴ And it comes laden with – I will add – a social message, not only the literary one. When we read *The House, Where...* by Mariam Petrosyan, we see common children in the book’s characters above all, not the people with disabilities. We’d really appreciate, if the attitude to individuals who are deafblind were the same – on equal terms, except perhaps it would exhibit more empathy and patience.

1 Special series: <https://prdg.me/ru/project-deafblind>.
Essay: <https://prdg.me/ru/jak-my-vpiznajemo-odne-odnogo>

2 <http://soloneba.com/i-am-silence/>

3 <https://discours.io/expo/literature/poetry/deaf-blindness>

4 Markov A. (2021). Deafblindness as the Culture of Existence Itself. I - Silence. Deafblindness in the Texts of Modern Authors: Anthology. M.: UGAR, p. 14.

The Relevance of the DASH-3 and Vineland-3 Assessment Instruments for Children and Adults who are Deafblind

This is the fifth article in a series about the assessment of children and/or adults who are deafblind. We will discuss two formal assessment instruments, the Developmental Assessment for Individuals with Severe Disabilities, Third Edition (DASH-3; Dykes & Mruzek, 2012) and the Vineland Adaptive Behavior Scales, Third Edition (Vineland-3; Sparrow, Cicchetti, & Saulnier, 2016). We will begin with sharing the areas of learning assessed by these instruments, providing more details on assessment of communication and language. Administration procedures will also be discussed. It may be helpful to review the guidelines for selecting formal assessment instruments, presented in the fourth article in this series (Bruce, & Bianco, 2021). It is important to recognize that no single formal assessment instrument can give an accurate and complete picture of the knowledge and skills of any learner who is deafblind. Each instrument must be evaluated for items that are biased culturally, linguistically, visually, auditorily, and experientially. Thus, it is critical to use more than one assessment instrument and/or to pair them with structured informal assessments, such as the van Dijk approach to assessment, discussed in the third article in this series (see Bruce, Nelson, & Francis, 2020).

Developmental Assessment for Individuals with Severe Disabilities, Third Edition (DASH-3)

The DASH-3 (Dykes, & Mruzek, 2012) is a formal, criterion-referenced, developmental assessment instrument intended for use with individuals with severe and

multiple disabilities, with a developmental age of up to 8 years. However, when assessing older students or adults, teams should not rely only on developmental



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tools. Other approaches, such as adaptive behavior instruments, functional outcomes approaches, and person-centered approaches will bring other perspectives about what the learner knows and should be working toward. The DASH-3 (Dykes, & Mruzek) assessment package includes five scales measuring development in different learning domains, an examiner manual, a sheet to summarize findings, a priority intervention worksheet that can be used as an initial step for planning instruction, and a record sheet to document student progress.

The DASH-3 (Dykes, & Mruzek, 2012) assesses an individual in five areas: social-emotional, language, sensory-motor, activities of daily living, and basic academics. The social-emotional scale features 180 items measuring awareness of self and others, expression of

feelings, responses to other's emotions, and social skills. The language section (discussed below in more details) includes 180 items on non-symbolic skills, expressive language, and receptive language. The sensory motor area addresses reflexes (15 items), gross motor development (217 items), sensory (38 items), and hand skills (99 items). The daily living skills section addresses feeding (90 items), dressing (51 items), toileting (23 items), home routines (32 items), and travel and safety (27 items). The basic academics section addresses pre-academics (147 items), numerical reasoning (55 items), and reading (45 items). The large number of items in the DASH-3 (Dykes & Mruzek) is one of its relative strengths. Instruments with more items capture smaller increments of development and may be a better guide as to what to teach next.

Communication

The DASH-3 (Dykes, & Mruzek, 2012) scale of language measures both receptive and expressive communication and language skills, including several aspects of communication that are central to the deafblind experience. The assessment begins by measuring non-verbal communication, whether it is gesturing or signaling one's emotions. Following directions, initiating request, and use of context-appropriate phrases and grammatically correct utterances are more advanced

examples of communication measured by the DASH-3 (Dykes, & Mruzek). Lastly, the pitch, quality and fluency of one's spoken voice are also taken into consideration. For individuals who are deafblind, it is important that all relevant forms/modes of communication are measured. The large number of DASH-3 items measuring communication across forms allows the team to capture a holistic view of the learner's communication strengths and needs.

Procedures

The DASH-3 (Dykes, & Mruzek, 2012) allows for flexible means to collect information on student performance, which is essential for accurate assessment of learners who are deafblind. The assessment process may include observed data (including day-to-day observation data), interview data, and reported data. There are five clearly defined scoring levels for the DASH-3 (Dykes, & Mruzek): task resistance, full assistance, partial assistance, minimal assistance, and

independent performance. Thus, the DASH-3 (Dykes, & Mruzek) captures partial performance and performance with different levels of prompting. Although this instrument provides information on calculating basal, ceiling, and developmental age scores, teams will want to focus on what the child has achieved and which of the partially performed or not yet performed items will be worthwhile for the child to learn.

Vineland Adaptive Behavior Scales, Third Edition (Vineland-3)

The Vineland Adaptive Behavior Scales, Third Edition (Vineland-3; Sparrow, Cicchetti,

& Salunier, 2016) is a formal assessment instrument intended for use with individuals

with a variety of disabilities, ages 0-90 years. As the name states, it measures adaptive behaviors which are skills we use in everyday activities. Adaptive skills are practical skills that tend to improve with age, so adaptive instruments are often part of the repertoire of assessment instruments used with older students and adults. This instrument includes different forms of input from teachers or parents, as well as an interview format. It has well defined norming groups, although there is no special norming group for individuals who are deafblind. Thus, careful consideration of the items and thoughtful interpretation of scores is warranted.

The Vineland-3 (Sparrow, Cicchetti, & Salunier, 2016) assesses an individual in three required domains of learning: communication, daily living skills, and social skills and relationships. Two additional domains are

optional to assess: motor skills and maladaptive behaviors. We don't include the number of items within each domain because this differs in the teacher form, parent form, and interview. The daily living skills domain has items divided into three areas: personal, domestic, and community. The personal section includes items on dressing, eating and personal hygiene. The domestic section addresses performance of typical household tasks. The community items assess money handling, telephone use, computer skills, and job skills. The social skills and relationships scale assesses interpersonal relationships, play and leisure, and coping skills (such as demonstrating responsibility). The first optional section, on motor skills, measures both gross and fine motor skills. The second optional section, on maladaptive behavior, addresses both internalizing and externalizing behaviors.

Communication

The Vineland-3 (Sparrow, Cicchetti, & Salunier, 2016) addresses receptive communication, expressive communication, and written communication. Additionally, items are labeled "A-J" to correspond to a category of skills. Examples of these categories include following directions (basic and complex), comprehension of questions, and comprehension of nonverbal communication.

The included items consider understanding gestures, paying attention, naming objects, size of vocabulary, nature of sentence structures expressed, and basic reading and writing skills, and other relevant skills in communication, language, and literacy. Some of these items are relevant for many learners who are deafblind.

Procedures

Assessment procedures include the use of forms provided for teachers and parents/caregivers to complete, and the option of a face-to-face interview. The forms are available in Spanish, and they are available online as well. A conversational style of interview is suggested, with directions provided about how to measure items through a conversational approach. The interview option includes more items than appear on either the teacher or parent forms separately. Scoring is 0-2, depending on the level of independence in demonstrating each particular skill; lack of knowledge; or no opportunity to perform the skills. As mentioned earlier, one of the interesting features of the Vineland-3 (Sparrow, Cicchetti, & Salunier, 2016) interview format

is that each item is coded with a letter representing a particular category. Thus, one can easily determine patterns of responses within a particular category, such as all items related to responding to others within the communication domain. However, one of the drawbacks of this assessment instrument is that there is a limited number of items (often 30-40) in each domain. Thus, there is more distance in development between one item and the next one, making it more difficult to use it as a precise guide for teaching. Still, since many adult agencies use adaptive behavior instruments when assessing adults, it is helpful to be familiar with adaptive behavior instruments. Such instruments may also provide the team with ideas for teaching youth or adults of transition age.

Conclusion

The purpose of assessment is to build a clear picture of what the learner can currently do across environments, as a basis for making decisions about future instruction. This will require the use of multiple assessment approaches and assessment instruments that offer the opportunity for individuals across environments to give input. Team members have the responsibility to be knowledgeable about the available

assessment instruments, their strengths, weaknesses, and biases (including the reliance of test items on vision and hearing). Assessment of learners who are deafblind must also include assessments that are sensitive to the environments in which they learn. Comprehensive team assessments of learners who are deafblind are the foundation of meaningful individualized and personalized instruction.

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Reference Objects: Paths to Literacy

The term “reference objects” applies to objects that have special meanings related to them. Reference objects can be used systematically and symbolically to favor communication and understanding of environmental situations (McLarty, 1997).

Reference objects can be whole or partial and serve to represent different categories of meaning. They can be easily handled and have an obvious perceptual relation with what they represent, in other words, with their referents (Trief, Bruce, & Cascella, 2010).

These objects serve to anticipate certain situations and can be used through an instructional sequence that occurs in a relatively simple and unstructured way: a spoon can be used to represent eating. To a certain extent, the simplicity that constitutes the use of these objects highlights two questions: how can one thing represent another? And how to offer conditions for someone to understand this meaning?

One of the most interesting aspects in the use of reference objects lies in the distance between the word, the object and the thing it represents. Distancing, in the conception of Werner and Kaplan (1988 apud Bruce, 2005), refers to a complex and gradual process that includes the separation of oneself from the others (physical and psychological) and the separation of objects from their representations. The key components that structure the symbolic representation are the following: the sender of the message, the recipient, the object to be represented and its representation. This process is essential for developing communication and understanding symbols.



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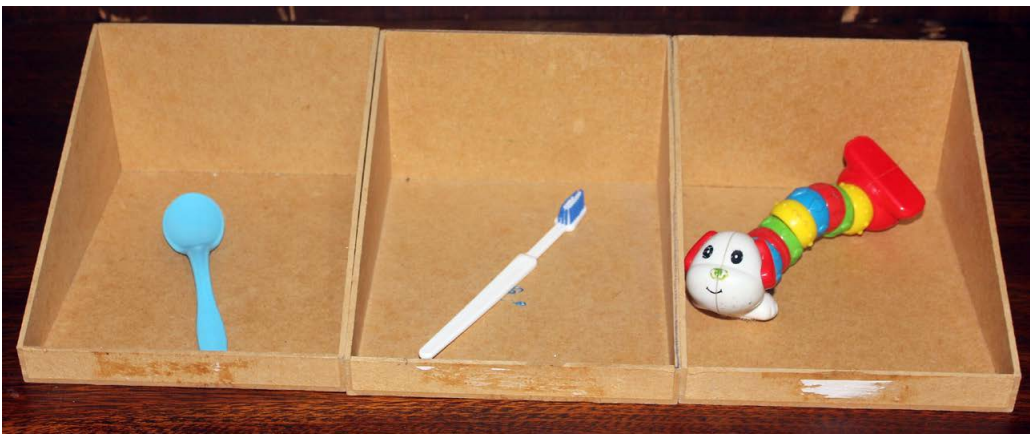


Fig. 1. Instructional sequence for using reference objects.

As children understand the meaning of symbols, they are able to establish increasing distance between themselves and their communication partners, between themselves and the object to be represented.

Figure 1 exemplifies the use of three reference objects within a routine through an instructional sequence: a spoon to represent eating, a toothbrush to represent brushing teeth, and a toy to represent playing.

Thinking about children with multiple disabilities and vision loss, who may have blindness or low vision associated with other disabilities, it is important to provide conditions for them to understand the functionality and meaning of these objects in their daily lives. Furthermore, this instructional sequence must provide a child with the conditions allowing to understand the beginning and the end of activities in a concrete way. Removing the object from inside the box indicates the “beginning”. Carrying out the activity refers to “doing” and storing the object in a basket or bag represents “the end”. According to MacFarland (2000), instructional sequences involve forms of instruction that facilitate children’s responses in their natural environments and are based on: goals that are functional for the children’s needs; encouraging skill development; setting goals that the child is expected to achieve; and assessment of the child’s progress.

But how can one thing be used to represent another one? In a certain sense, this question may seem simple, but its answer deserves attention. The word “spoon” does not contain food and does not make the person eat when uttered. According to Park (1997), one of the great aspects that involves the use of reference objects lies in the distance between the word, the object, and the referent. Children with multiple disabilities and vision loss often struggle to gain an understanding of symbols and this is a prerequisite for language development. Without understanding the symbolism, the child feels trapped in the present moment and cannot communicate about objects and people that are not part of their current context (Bruce, 2005). Talking about something or someone which or who is not present involves

understanding their existence from the idea promoted by the word that represents them. Werner and Kaplan (1964) comment that distancing is a gradual process that involves separation from oneself and the others, separation from objects and separation from objects and their representation.

As these children evolve in the use of symbols, they establish a growing distance between themselves and their communication partners, between themselves and the object to be represented and between the object and its representation. This process is essential to the development of communication. After all, when children understand the meaning of the symbol they are able to communicate about a referent – person or object – that is not part of their current context (Werner, & Kaplan, 1964).

When children acquire an understanding of “me” and “other”, they are able to perceive themselves as individuals separated from the others and, consequently, are able to establish distance. The process of realizing that you are separate from the others is called individuation. Jan van Dijk (1983) emphasizes that all representations must start first in the child’s body, first he or she must understand that they are separate from the others, and then other representations must be initiated.

This entire process favors the acquisition of receptive and expressive language, because as children perceive the meaning of reference objects, they receive and understand information through touch and can use these objects to express their interests, needs and feelings. Objects can be placed loosely or nailed to cards. When nailed to cards they become tangible symbols. According to Trief, Bruce, and Cascella (2010), loose objects and tangible symbols require little use of memory and representation capacity, which makes them suitable to favor the receptive and expressive communication of children with multiple visual sensory disabilities who communicate at a pre-symbolic level.

For this reason, loose objects and tangible symbols promote the literacy of these children. Nelson and Bruce (2019) point out that traditional or conventional literacy is

usually defined as reading and writing, but actually it is a developmental stage that begins before traditional reading and writing. It is a growing process that includes tactile experiences, incidental learning of letters

associated with words and concrete elements. Then, in figure 2, there is a suggestion of concrete material that uses letters, words written in ink and Braille, and concrete items.



Fig. 2. Letters, words, and concrete objects.

The use of these cards can be done through a relatively simple instructional sequence. The teacher offers the reference object to be tactually explored by a child and tells the name of this object. The teacher and the child focus attention on this object in order to perceive its attributes. Then the teacher asks the child to repeat the name of the object and waits for their response, which can be a word, a sound, a gesture or a facial expression. After the child expresses their understanding of the meaning of the reference object, the adult offers them the wooden and Braille letter to be tactually explored and relates it to the object. This activity involves

instruction tip and time delay, as the teacher must present the options to be explored, give verbal instruction and a tactile model, and wait for the child's response.

Other objects, other letters and other words can be used to be explored by the children. Park (1997) emphasizes the importance of considering the size of objects, their placement and their means of access so that the children with multiple sensory challenges can associate an entire object, a letter, and a word. The feeling created by a real mace is certainly more significant than the one created by a miniature mace. Thumbnails are

only useful if the child can use vision to make the association between the thumbnail, the letter and the word (Park, 1997).

Borrowing Nelson and Bruce's (2019) considerations, this article also reveals that literacy is a very broad process, based on a rich range of experiences that involves many practical learning opportunities. All children

benefit from stimulating environments, rich in meaningful literacy experiences, both at home and at school. Thus, it is hoped that these cards serve as suggestions for other teachers and professionals to offer tactile opportunities that favor the learning of concepts and facilitate literacy for children with multiple disabilities and vision loss.

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Perkins Quality Indicators Research: Leadership and Innovation in the Educational Experience

In Latin America, Perkins School for the Blind is measuring the impact of our training and coaching in teacher behavior and child learning outcomes in schools of Argentina, Brazil, and Mexico. A fundamental part of this research is the revision of the Perkins Quality Indicators (PQI), an instrument for evaluating and promoting improvements in the quality and practice of education for children with vision loss and multiple disabilities.

This article aims to share some initial findings of this research, especially the role of innovation and leadership in quality accessible education.

Program Evaluation of Perkins Programs in Latin America

Evaluation of education programs in Latin America has improved in the last 30 years owing to the dissemination of results, a methodological development, the interaction with the research field, and the participation in international evaluations. According to Martinic (2010), this advancement

became possible thanks to a greater awareness of the value of the information that can be obtained through program evaluation. Quality data allows for a better understanding of challenges and achievements and therefore improves educational processes and results. This improvement



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has been particularly noteworthy in the participation in standardized evaluations (Ravela et al., 2008). In the case of special education, however, evaluation is influenced by the medical perspective of disability, which centers the evaluations on the person, not the context. Concepts of disability, diagnoses, and typologies, often guide educational interventions towards rehabilitation. Undoubtedly, the medical approach has contributed significantly to the evaluation processes; nevertheless, social changes in educational settings and the evolution of concepts related to disabilities and education, make it necessary to review the idea behind evaluation, its implementation, and the use of results.

New approaches consider evaluation as an ongoing process where participation is continuous, and dialogue among experts, teachers and the education community is essential. In this sense, evaluation is presented as a critical and learning activity. According to Álvarez Méndez (2005), “you evaluate to learn, you learn from and with the evaluation.” This entails reflecting upon the objectives of the evaluation and translating the results into knowledge that can help us make decisions and change strategy when necessary. From this perspective, Perkins LA recognizes that evaluation is not an activity that yields absolute certainty. Perkins aims to develop a process that provides reflection to decide on changes, adjustments and well thought out decisions in search of good practice.

In 2010, Perkins developed the Perkins Quality Indicators (PQI) to assess and accelerate progress in improving the quality of education for children with multiple disabilities. The PQI contain the following: a tool designed to assess education programs for children with vision loss and multiple disabilities; a complement to Perkins mentoring, training, and support; a metric to document education program quality improvement over time (Riggio et al., 2010). Work continued and resulted in the second revision of the PQI in 2019, and today, in this third revision, Perkins is refining a tool that is sensitive to different educational contexts, as proposed by Marchesi (2021),

aware of the inequality, poverty, diversity and emerging movements that fight for inclusion and that give identity in the Latin American context. For this, a process is initiated to incorporate local points of view, combine quantitative and qualitative methodologies to detect and deepen the understanding of the environment, and have a general idea of the common aspects that can be measured.

The goal is to improve the information needed to help decision making and, thus, enhance the innovation and leadership of schools, measured by quality parameters valued by Perkins, which are as follows:

- Practices that promote the students’ autonomy;
- Collaborative work;
- Communication considered as the work philosophy and the methodological strategy;
- Inclusive education.

As a second step, the revision identifies different levels of achievement based on two aspects, which are: 1) The scope of the quality practices observed in the school, 2) Autonomy and initiative to assume new practices and institutionalize them. These levels are as follows:

- Focal: the practice is enacted by one person or in some aspect;
- Expanding: the practice is enacted on a discontinuous but recurring basis by several people in different scenarios;
- Transversal: the practice is enacted in a systematic and regular manner at different school levels;
- Institutional policy: documented innovative practices, involving all areas and members of the school;
- Innovative culture: ongoing innovative actions in pursuit of educational excellence impacting the others.

The intersection between the parameters examined by Perkins and the levels of

achievement allows the evaluator to see where school professionals are on their development

path, and the degree of response achieved by the instrument in diverse contexts.

Leadership and Innovation as Quality Parameters to Measure Change

In Latin America, the refinement of PQI is based on the practical application of the PQI to measure improvement of education quality in 9 schools in Argentina, Brazil, and Mexico. Early PQI data shows that two elements drive the transformation of school teams into agents of change: leadership and innovation.

Innovation is the incorporation of something new into an existing reality according to Mohr (2003). The cultural identity of an educational organization is modified and strengthened or associated in this new context. This transformation is seen through changes in policy design, work dynamics, and the implementation of clear communication strategies and inclusion principles. Innovation doesn't mean that every program follows the same path; rather they improve within their own organizational structures and realities. They reflect upon their actions, considering diversity and local social transformations. Leadership is transformational for Amelinckx, & Verhaeghe (2004); it is the practice that combines considering the context and ensuring certain conditions in order to reach specific goals. It is a permanent change

factor (innovative culture) that incorporates participants' different levels of engagement developing the capacity to grow impact and productivity.

We find that leadership and innovation are essential qualities necessary to generate systemic change and continuous growth at school. These key attributes help ensure the growth of schools beyond the Perkins partnership, as they are able to evaluate and monitor their own processes and generate change, without the need for external forces to drive them. We continue to observe that leadership and innovation grow jointly; one influences the other. It usually starts with one person or a small group of people interested in contributing toward the change at school, and then these same individuals begin to influence and train the others. Beyond the knowledge and experience gained in their field, they still believe there is much to learn and there are important changes to be incorporated. In the process, the systematization of new experiences makes the change sustainable, able to impact the educational practice in the classrooms, and at the level of planning, to issue official documents and influence other programs.

The Future of Program Evaluation in Latin America

Innovation and leadership have become for us a quality parameter for model programs and also fundamental principles for the elaboration and application of the evaluation tool. The indicators must therefore provide feedback on the various realities identified and the different ways of expressing the programs' capacity for leadership and innovation.

Perkins is consolidating a tool to evaluate programs that serve the population with multiple disabilities or deafblindness through internal validation, analyzing and testing of PQI. This is an effort to contribute to the improvement of educational practices in the region and to develop programs in the world of continuous transformation taking into account leadership and innovation, which ultimately will result in better opportunities for the children.

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Descriptive Study of 2 Populations from 0 to 5 Years Old of the City of Córdoba (Southern and Northern Areas)

with Emphasis on the Implementation of Intervention Strategies Associated with the Current Situation of Early Childhood

Introduction

In Argentina, more than 10 thousand babies out of 755 thousand born ones die before reaching the age of 5. Approximately 9 thousand die before reaching the age of 1 year and, among them, around 6 thousand die during their first month of life (Aulicino, C. et al., 2015).

After the first year of life, the environmental context in which the child develops and the basic care he or she receives are the most important aspects in relation to mortality. Some of the main causes of death for children between 1 and 4 years old are external: domestic accidents and exposure to various kinds of violence, followed by diseases of the respiratory system and parasitic diseases. (López, Konterllnik, Duer, Urosevich, Fundación Arcor, 2012).

The data on multidimensional child poverty obtained from the Multiple Indicator Cluster Survey (MICS) 2011/12 shows that poverty affects 30.1% of girls and boys in Argentina (UNICEF, 2016). The National Nutrition and Health Survey (2007), carried out by the Ministry of Health of the Nation, revealed that 3.8% of Argentine children between 6 months and 5 years old suffer from chronic malnutrition (a process characterized by lack of calorie and protein intake which results in depletion of body energy reserves (ENNyS, Ministry of Health, 2007 in UNICEF Argentina). These health conditions, derived from unfavorable social contexts, don't only mark the possibility of "living or not", but in case of absence of the adequate and timely intervention they also determine, at this stage, future conditions.

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Theoretical Constructions

The concepts of childhood, family and education have changed over time, crossed by the evolution of culture and society. Currently, the subject contextualization is demanded from the perspective of the appearance of problems of plurality of circumstances and situations' peculiarities as a factor under investigation.

It is for this reason that, when working with children, it is essential to update knowledge and new perspectives on childhood, as well as on current conceptualizations of family, school, and society. It is necessary to improve access to caregiving and educational services as well as to promote the enhancement of professionals' skills oriented to the early detection of significant and multiple disabilities, vision loss and deafblindness in

Methodology

To achieve the proposed objective, emphasis is placed on the description of what is observed. The improvements, proposed on the basis of the research, carry positive impact on the integral development of childhood in the community in which the children live.

According to the themes and objectives, which the research shall work on, a qualitative and quantitative study will be combined, and the cross section analysis will be carried out.

As for the quantitative one, we will apply a questionnaire of closed and open questions (Educometer). It is intended to measure and evaluate the educational opportunities of girls and boys within the given territory.

The main indicator used for measuring the level of community development is taking

newborn babies, ensure awareness of the need and the benefit of early intervention, which doesn't support only the child, but also the family.

If the health and education services work together, as a team, they can provide quality services that guarantee children's rights.

In relation to the above, the main objective of this research work is to characterize the current state of early childhood development from an integral point of view in two areas (one in the north and another one in the south) of the City of Córdoba, Argentina, in order to be able to design intervention strategies that will cover the educational and health needs of the studied population, effectively and efficiently.

care of children. It is carried out through four dimensions:

- Significant conditions of the socio-economic context;
- Significant conditions of the infrastructure and local social capital;
- The educational situation of the formal sector, non-formal education;
- Other social and local policies, favouring the children.

The focus population groups of this research study are boys and girls from 0 to 5 years old and their families, living in the southern and northern areas of the city of Córdoba, Argentina.

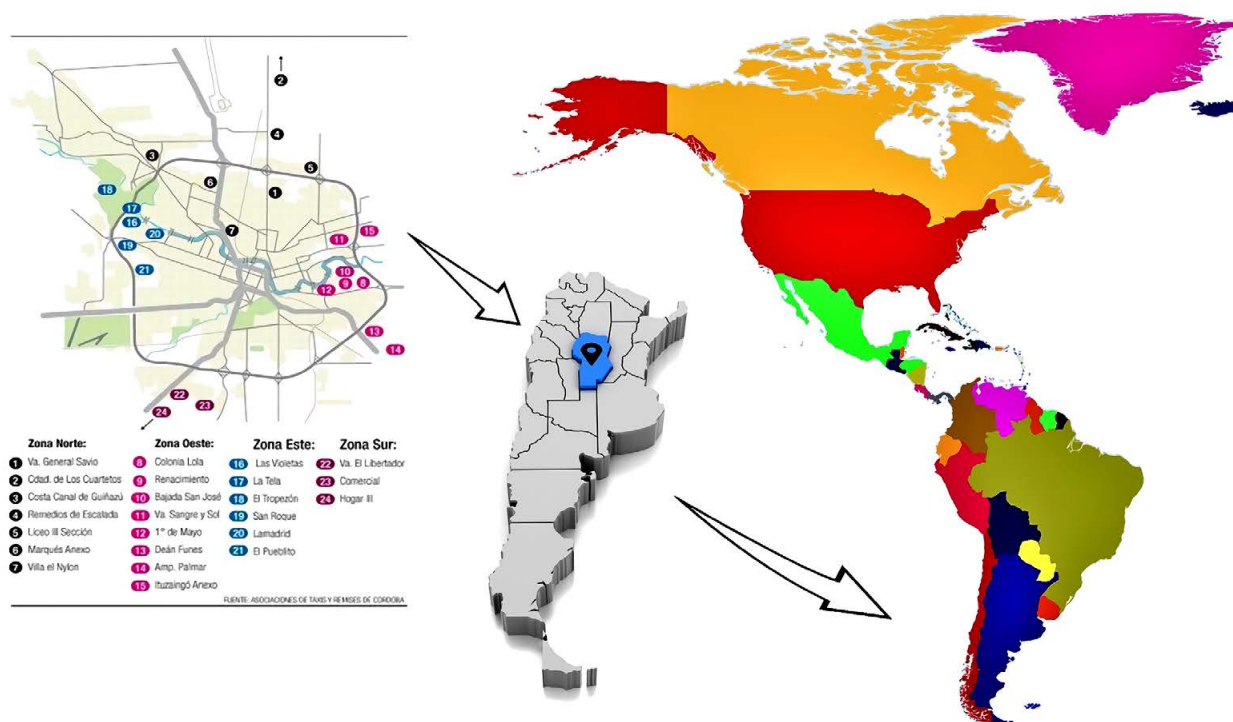


Fig.1 Critical area of the City of Córdoba, Argentina. Geographical location: southern and northern areas of the City of Córdoba, Argentina.

Expected Impact of the Project

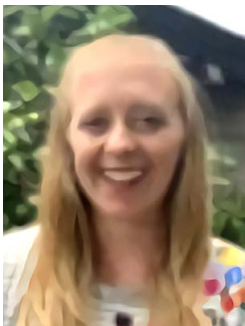
The work of this research team aims to contribute in showing the impact of the lack of awareness of early childhood caregiving and how it affects early childhood development, based on the analysis of the data collected and in contrast with new questions of the research project, and how the said data determines the development of public policies according to the reality in early childhood.

Likewise, as an applied science, it aims to contribute to the social and educational development of a particular group of population, from the formation of human capital, contributing to its well-being and addressing problems that require a global approach, in order to document this process of impact on the quality of education.

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The Inspiration We All Need



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When families learn about their child's deafblind diagnosis, their biggest concern often surrounds the success of their child's life. Parents always want the best for their child, but many parents assume their child's future to be bleak when they are told that he or she won't have vision or different hearing levels. Thankfully, I have met many phenomenal deafblind adults. I inform parents that there are deafblind adults who are successful, independent, and truly exceptional. Drew Hunthausen is one of these people. I met him at my former job, and Drew became my friend instantly. After termination of our joint sessions we continued to text, meet up for coffee, and go for walks with my daughter tagging along. Drew is an extraordinary person who keeps his goals high, he is passionate about his hobbies, and he is the type of friend we all need. When we met for the first time, Drew was wearing a triathlon shirt. When I asked about his shirt, Drew told me all about his biggest passion, racing in triathlons. Drew has no vision and wears hearing aids to assist with hearing others. When Drew was 11 years old he had bacterial meningitis and after being in coma for three months, he woke up without vision and with lower hearing levels. Drew was a boy who loved to play sports and go to school and church and truly couldn't believe that it had happened to him. With the help of his family, his church, and his community, Drew adapted to this new way of being and became the amazing person he is today. But don't take my word for it, let's read what Drew says about it all.

Kayla: Tell me the story of how you became a member of the deafblind community.

Drew: I am 35 now but when I was 11 and a half, I was diagnosed with bacterial meningitis (BM) out of the blue. I was a very healthy child. But I got a fever and fell into a coma. I have been in a coma for 3 months. After ten day of coma the doctor told my parents, I most likely wouldn't have made it. My kidneys were failing and if I did survive, I would be brain dead/a vegetable. Not too long after I started coming around, my body started figuring it out. At this time, there weren't a lot of treatments for BM and it wasn't something they had done before. They did whatever they could to save my life. When I started to wake up, coming out of a coma was a process. It took about a month. I was awake and didn't understand my circumstances. I was visualizing my bedroom but couldn't understand where I was. I was frustrated with people because they were trying to tell me what was going on. I was verbally violent and cursing, which wasn't something I normally did. When I finally realized what had happened, I was in a wheelchair with my dad. He brought me around to touch things in my hospital room and that's when reality set in. When I touched the elevator button, reality hit me. And it was hard. I was then homeschooled during my 7th grade year. Being back to campus was awesome but at the same time tough, emotionally. Everything was within reach, but I still couldn't do what I wanted. Unless my friends sought me out, I would be alone, I couldn't seek them out. There was a lot of isolation. Isolation became a theme for my whole life. Keeping friends became more of an effort. But new people can help you learn new things and it gets better. It was a choice I had to make. I brought all the hurt and anger on to myself. Your body can bounce back. Mind and body.

Kayla: Who was the first person to encourage you to continue in sports? What was it like?

Drew: It wasn't just one person. People closest to me, my family, my dad. He was my little league coach and he is a physical therapist. He is also a big part of the encouragement to keep me going. That anything is possible.



Kayla: What sports or activities did you play before and after getting bacterial meningitis?

Drew: Before, I was in little league, soccer, golf, and roller hockey. I've tried kicking a soccer ball, but it is not fun not knowing where it goes. I also used to go to the driving range. But I transitioned into the new sports: swimming, biking, triathlons, and snow skiing.

It was interesting to see how much muscle memory played a part in relearning sports.

Kayla: What was the transition like going back into sports?

Drew: It was tough. I was homeschooled in 7th grade and went back to school in 8th grade. It was definitely a transition and it was definitely challenging. I was in the mainstream classroom, the teacher had an FM system, and I had a one-on-one aide. I was back on my feet but I was still very weak. The body is incredible. About 5-6 months or a year after, I started eating better. I had problems with my stomach and I couldn't eat, once I could I gained 45 pounds. I was huge! In 8th grade I was keeping to the Atkins diet and lost all this weight, and the diet made me exercising again. I got some muscles back. I discovered swimming again. I went on a family vacation to Palm Springs to see my grandparents, and my sister encouraged me to swim in the pool. I kept swimming back and

forth. I started cycling as well. No one can do it alone, it takes a village, family, friends, and some people you would never have known otherwise. I then swam in the swim team in high school and then in 2016 I got into triathlons for the Challenged Athletes Foundation.



Kayla: What is your biggest passion now?

Drew: My biggest passion is definitely getting out there and being the best I can be and to help others. I see myself as a motivational and inspirational speaker. [A big passion] for me is doing triathlons and doing sports, I do it because I love it. I am doing this bike ride in three weeks, where I am biking for three days straight. I start in Santa Barbara and

end in San Diego. I met someone who has been giving me rides to the San Diego practices and he is an amputee and he has been so inspired by all of the other challenged athletes, and now he inspires me!

Kayla: If you talked to someone with a recent diagnosis of deafblindness, what would you tell them?

Drew: I think the biggest advice is something that sounds simple, not to give up. There is so much that is possible. I remember when I came home from the hospital, I was lying in my bed feeling totally helpless, yelling at God and asking what I was supposed to do with my life then. And just looking back at all the people and opportunities that God had put in front of me, I can tell that anything is possible. It's definitely challenging but keep moving forward.

Kayla: And lastly, who inspires you?

Drew: I have had so many people who have inspired me throughout the years in different ways. For sure, my parents have been huge inspirations in my life. My dad is a very positive person who was always encouraging me and picking me up emotionally and physically, and in so many different ways. He gave me the message not to give up and to keep moving forward. When I came home from the hospital, it was a huge blessing to have my mom, who is an audiologist, and who had that expertise at my fingertips, along with the encouragement. These two people are definitely my main inspiration.

Alberto Camacho – a Visual Artist, University Teacher and His Life with Usher Syndrome



This interview shows some experiences of the Colombian art teacher, named Alberto Camacho, who is a visual artist and university teacher, living with Usher syndrome. The interview is carried out by his colleague Luis Carrillo, a university art teacher.

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Interviewer: Tell us when the disorder started.

Alberto: My hearing loss started when I was seven years old, I didn't know what could happen to me. I just noticed a slow and progressive loss. I was confusing similar words' sounds and the school homeworks or couldn't get full sentences. More than ten years after I got the RP. I found out having night vision difficulties as well as peripheral vision loss. It is as you look through a funnel, a tunnel or even a shotgun barrel. You see the center and the peripheric of the "funnel", everything else is just gloomy.

When I started my high school, I adopted empirical methods to do my school and social tasks. As an example, lip reading or resources to orientate myself in the school space in a way that I was able to get a panoramic cover of spaces I had to move on.

When I started fine arts at the Colombian National University, after a basic course it was divided in four disciplinary branches: painting, sculpture, graven, and ceramic; my father gave me good hearing aids that allowed me approach social interaction in an unknown environment, those helped me with the bass tones at the same time that I was losing the treble ones.

This loss was solved when I got the cochlear implant, not long ago. After it, slowly I was becoming able to recognize sounds. Even in the year of pandemic, I hear again the warble of birds, hear the rain, crickets at night and some other sounds that I totally forgot decades ago or have been ignoring.

Interviewer: What motivated you to study a visual art career having this growing disability at this moment?

Alberto: Since I was a child, I wanted to be an artist. I was always receiving my parents' support and affection, offering me motivational words since I did my first draws. Through them I recognized and appropriated the scenes with enthusiasm, that also allowed me to communicate with others with the shapes language.

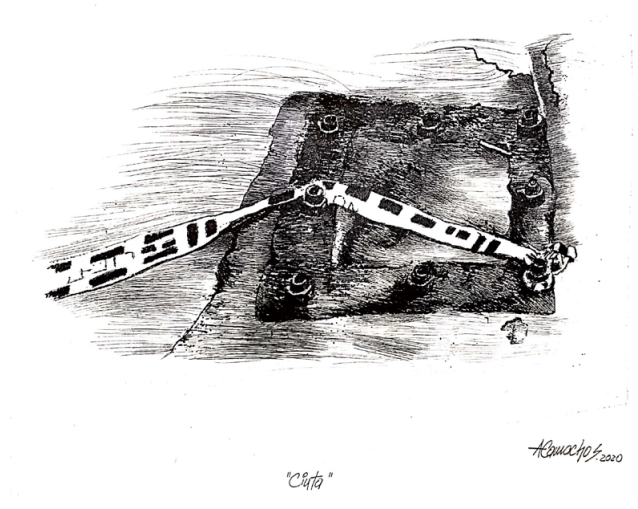
When I assumed the challenge of studying fine arts my RP was not advancing. When I got the diagnosis, I did not assume it as an impairment impeding me to go forward and continue my studies. Of course, I had difficult moments when I had to meet the requirements of university tasks. For example, chromatic confusion, poor visibility in dark classes' environment. It also influenced the academic production techniques, such as using high contrast in my drawing expressions to perceive those better.

I think that the best strategy that I developed those years was the continued feedback in the work appreciation, an aspect that I've been keeping all my life. When I ask,

I am able to complete the information I require to appreciate an art or artistic work.

Interviewer: Taking in consideration the Usher conditions, what do you feel as a creator and artist today?

Alberto: I think that my current artistic practice is the result of a long learning process and of the strategies, aimed to perceive the world, the result of some kind of survival strategy, which doesn't allow me to be defeated by the syndrome. The creative work that I do consider natural during the day-time, non-shining superficies, contrast and particular order to access the working materials. My current plastic artwork starts on reflections around the question on what can I see and how to translate it in a plastic manner? Questions that are consolidated into issues such as the constant photophobia, plans confusion, my moving into a city where I have to live, the tactile perception, are all present in the No Shadows project.



Interviewer: Which are the conditions that make you opt to be a visual art teacher, and which are related to the disorder?

Alberto: Broaden the dialogs to avoid the siege. One of the aspects that defined my academic work concerns the fact that I could avoid that the Usher would slowly isolate me. Accessing the academy, the dialog became broader, interactions and creative interests propitiated thanks to diverse cultures and people that energized the university life.

Then, if we talk about the inclusion challenge, my university work nurtured by constant

learning of fluctuant conditions, a challenge that I wanted to assume, of course with some failures and mistakes. And it was also nurtured by the institution where I work.

Designing of my esthetic concerns. My academic work lets me design the esthetic concerns in the form of a proposal dialog with the university students, and through them I am able to recognize the feedback that allows me to contrast, review and direct those concerns.

Interviewer: What is the teaching practice such as air print like accounting your condition?

Alberto: The art print is an artist expression in which the material print has a style, it is different to painting that requires the perception and color nuances and expression, that are foreign to me, as an artist affected by Usher.

I came to it for practical reasons when I lost certain colors perception and started to confuse them, for that reason it is easier for me to manage images through the art print and a monochromatic use. For that reason, the black ink sketch engraving allows me trust and contrast manipulation. However, I did not want to keep using the traditional techniques, otherwise based on the basic knowledge to achieve other lands derived

from this, for example to multiply the image with other resources, and this is how I focus my art print at university classes. To teach the techniques, it took me a long time to memorize the workshop space, its illumination and the place where the students sit, and where the equipment is.

Interviewer: Which contributions to teaching can you present after years of having the disability condition and being a teacher?

Alberto: According to the national laws, the persons with disabilities shall have a guarantee of the full legal capacity, as well as access to reasonable accommodations, but our society is still far from fully complying. For that reason, in my professional exercise, I assume the principles of the laws such as the inherent dignity of a person with disabilities as a human being. The right of the person to self-determination, primacy of the will and persons' preferences that have to be identified, eliminating obstacles and barriers that make impossible to access the services and rights. The observation of an equal treatment for everyone without discrimination for any reason, looking for removal of the obstacles and barriers that generate inequalities. Anyway, my contributions correspond to the words of the sociologist Orlando Fals Borda, who says, "We act with our heart, but also use the head and when we mix both, we are feeling-thinking".

Interview with Mireia Mendoza, Deafblind Model

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Interviewer: What kind of deafblindness do you have?

Mireia: I have Usher syndrome type 1. I was born with profound deafness and by 10 years old the early signs of retinitis pigmentosa appeared. Currently, I have residual functional vision and I use a cochlear implant.

Interviewer: In your daily life, where do you feel you find more barriers or which are the worst for you?

Mireia: At night, I am afraid when I get about with the red-white cane to take the bus, for example. More accessibility in the world is needed.

Interviewer: What have you studied?

Mireia: I made an intermediate level training cycle of aesthetics and apart from that I have taken computer courses, sign language courses and other things. I have also taken a specific course on administration and management at the State Public Employment Service (SEPE). However, I have not got a job in anything related to what I have studied.

Interviewer: How long have you been working as a model?

Mireia: Actually, I have not been so long, I started in 2019, in February, when I walked the catwalk at Milan Fashion Week.

Interviewer: How did this opportunity arise?

Mireia: The designer Elvira Shipitsina said she wanted a deafblind person for her fashion show, it was proposed to me and I accepted. It was about a collection named I See and my dress was red, because of the red-white cane of the deafblind people. That was my first show at Milan Fashion Week.

Later, in May 2019, I went to Mallorca and met the designer called María Lafuente, and there she proposed that I would walk for her in July of that year at Madrid Fashion Week.

I also modelled with her for the same catwalk in January 2020 and recently, in September 2021.

Interviewer: When did you realise that you wanted to be a model?

Mireia: Since I was a child I wanted to work as a model or in the fashion world in general. Then, with the experience of Milan I realised that I was capable, that even being deafblind I could do it.

Interviewer: What else do you do in the fashion world?

Mireia: I created my personal project named MM Deafblind Model to raise awareness of deafblindness in the fashion world. Some of its objectives concern giving lectures about deafblindness, making collaborations, working with different photographers in order to let them know about deafblindness, going to high schools, schools, etc.

This is a non-profit project, but it aims to strive in order to get an accessible and inclusive world.

Interviewer: Which barriers have you found in your career because of your disability?

Mireia: At the moment of the catwalk, the spotlights can dazzle me and, obviously, the communication has barriers because they do not know sign language. This can be avoided if I go with my mediator, of course.

Interviewer: Have you worked in this field with other people with disabilities?

Mireia: No, but I would like to walk with people with other disabilities.

Interviewer: Do you think the fashion world has changed to some extent since you have been in it?

Mireia: I do think it has changed, but I am not the only model with disability, since there are also people with other disabilities in the fashion world.

Interviewer: What is the relationship with people without disabilities that work in your area like? What is communication like?

Mireia: As they don't know sign language, the communication in the fashion world is more difficult because of my communication system. If I am with my mediator I can interact on equal terms.

It is true that sometimes other models may feel awkward about starting the conversation with me, because they see me signing and they think, "How can I do it if I do not know it?". So yes, it is true that we talk less than usual.

Interviewer: What are your hobbies?

Mireia: I like watching movies, walking, meeting friends, going shopping...

Interviewer: You have been working as a coupon seller, since when? What has it meant to you to take up this job?

Mireia: Yes, I started in November 2020. The truth is that I am excited because I wanted to work and I like this job because of the contact with customers and because of the company ONCE, which works with many people having disabilities.

I had been looking for a job for 2 years and I could not find anything. I submitted CVs to

different places and as soon as they saw "with a disability" they were throwing my CVs away.

I also tried to get ready for competitive exams, but I had to give it up because it is very hard and it was affecting my vision.

Before this job I worked as a cashier for 3 years in Carrefour and one Christmas season in Kiabi.

Interviewer: What strategy do you use to clear the communication barrier with your customers?

Mireia: I look for resources, now with masks it is more complicated to understand them, sometimes they pull down their masks for a second to tell me what they want, but we usually rely on visuals, I ask them what they want and they point it out to me.

My cochlear implant, which I got at the age of 4, and the speech therapy work also help me.

Interviewer: How do you combine your job as a coupon seller and the one as a model?

Mireia: ONCE usually gives me permission to adapt it in a way that does not affect either of two jobs. For example, I usually work in the mornings, but last week I had to go to the fashion show in Madrid. So I was selling in the morning, then I travelled to Madrid to do the show in the evening and on Saturday I went back home, but instead of selling in the morning I was doing it in the afternoon.

Interviewer: What encouraged you to lead the associative movement of deafblind people in the Balearic Islands?

Mireia: I realized that deafblind people in Balearic Islands were withdrawn into themselves and I wanted to mobilize them. As there was no ASOCIDE in Balearics, I wanted to encourage them to create the association and to organize meetings and activities.

Therefore, I keep encouraging them to join in and participate.

Interviewer: What are the difficulties that you have found in the process of creation of the association?

Mireia: The difficulty concerned the fact that it has coincided with the pandemic and this has slowed everything down. Besides, it is true that any doubt we have, we ask FASOCIDE and they help us.

Interviewer: What positive experiences do you take of all this process?

Mireia: The positive part concerned contacting the deafblind people and asking to sign up. The desire to have everything ready and to be able to announce that we have already created it, to spread it and to start working a lot.

Interviewer: How is your communication with the rest of the deafblind people of your community?

Mireia: I communicate in sign language at a distance, in tactile and oral language, for the rest I use the guide-interpreting resource, but I do really like to learn fingerspelling. Recently, I made a course of Spanish sign language at B1 level in order to learn and improve my communication, for example.

Interviewer: Why do you think that ASOCIDE Balears is important for the deafblind people who live in Balearic Islands?

Mireia: Because of the need for communication, for expressing emotions, and also for receiving help at the time of doing some management activities and for organising activities.

Interviewer: What ideas do you have for the future development of the association?

Mireia: I would like to be able to organise sign language courses for those deafblind people who need it. Work on getting ready for the future loss or worsening of any of the senses. And organise socio-cultural activities, of course.

Interviewer: Finally, what would you say to deafblind people in general and to young people in particular?

Mireia: I would tell all of them, that they shall not be afraid, they shall keep their spirits up because they have the capacity, different capacities, yes, but so many things can be done freely.

I would also like to encourage, specially, young deafblind people from the Balearic Islands to participate more, as I was the only participant from the area at the last meeting organised by the Youth Section of FASOCIDE.

Going to Hospital in the Time of Covid-19? Read This Now

Going to hospital for a person and/or patient who is deafblind can be a risky business. There is evidence, that before the Covid-19 pandemic patients with disability were subject to mistreatment and discrimination (National Disability Services, 2014) and those who are deafblind experienced high rates of “not knowing what was going on” and unacceptable rates of neglect, abuse and poor experiences (Watharow, 2021; Takahashi, 2019; Sense UK, 2001; Ellis, Keenan, & Hodges, 2015).

Negative experiences for any patient are known to be linked to poorer health and wellbeing outcomes (Sutherland et al., 2017). Models of exemplary patient care – including informed consent, shared decision making and patient centred care – all depend on shared power and communication between patients and healthcare providers (Berry et al., 2017; Walton, 2006; Heath, 2018).

As there is such diversity in the conditions of deafblindness (residual levels of vision and/or hearing), not everyone has access to shared languages, interpreters, assistive devices and technologies to promote successful communication exchanges.

Specifically, the individuals who are deafblind have reported profoundly poor experiences without access to understanding professionals, support networks, interpreters when needed and wanted, adequate time spent on explanations and discussion, and the use of assistive technologies. Patients

who received communication support when and wherever needed were far fewer but reported positive experiences (Watharow, 2021). One individual who is deafblind said, “The health system should look after us”. Yet it is obvious that much work is needed to improve awareness of the needs of the individuals who are deafblind at all levels of healthcare institutions, as well as practical strategies informing that the individual patient needs to “know what is going on”.

And then a global pandemic of Covid-19 came along. Hospitals have become fortresses aimed at keeping coronavirus and its variants out, alongside trying to keep health resources from burning out (humans) and running out (oxygen, ventilators, and ICU beds). The survivalist strategies of eliminating visitors and “unnecessary” social support services and universal mask wearing (often in conjunction with clear face shields) have combined to isolate those with communication disabilities.

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Specifically, many individuals with some residual hearing who previously coped well have become newly disabled as they can no longer lipread or use facial cues, or hear the muffled voices of staff explaining tests, results, treatments, operations or discharge plans. In the face of such additional hurdles, what can patients, families, caregivers and assistants do for disaster-proof patients who are deafblind when going to hospitals?

The following suggestions are not exhaustive, but I am opening the conversation here knowing that this global community can add and advise something from their own experiences and practices. It is acknowledged that access to much of what is discussed now is not available widely or freely in many countries and cultures. Access to good healthcare – whilst enshrined by the United Nations in the Charter of the Rights of People with Disability (United Nations, 2006) – remains an ongoing and vast work-in-progress.

Harnessing our own capabilities to do what we can to protect ourselves from adversity when we are patients in hospital is vital. Being prepared for hospital (especially for unexpected, unplanned or emergency admissions) involves some organisation in the short term and taking a long view on maintaining good health and wellbeing. Firstly, paying attention to our general health such as healthy lifestyles and preventative care is important. In this time of Covid-19, not getting infected is crucial because of the higher risk of serious illness and even death for people living with disability. We have to follow public health orders and stay home when necessary. Everyone who lives and/or works with us needs to learn infection control procedures and follow them. Wash the hands frequently and take care to cough in our elbows. Get Covid-19 tests if we have symptoms. Keep masks at home and in cars and handbags so one is always within reach. The evidence is that social distancing, mask wearing and hand hygiene help reduce infection risk and spread. Not getting infected keeps you out of hospital.

Another important measure to keep us out of hospital is vaccination, which has been

proven to reduce severe illness, admission to ICU and death. We need to be vaccinated as well as our caregivers and our communities.

The Covid-19 pandemic hasn't stopped us being sent to hospital with other illnesses and injuries. If you know ahead of time you must go to hospital, have preliminary discussions with your doctor, interpreter, family and caregivers about what is likely to happen and when. Knowing what happens in hospitals is vital – that routines such as being woken up in the middle of the night for blood pressure checks is normal; they are alarming if unexpected. Talk through everything that is likely to happen so that you have some idea of what is going on some of the time at least. Next, begin collecting all your important information: personal, health insurance, social security numbers, medical information (allergies, medications); and keep it on smartphones. Doctors have a lot of trouble working out what you're taking if all you can say is "the little round tablets". Other important information to include (in paper and in app form) are Covid-19 vaccine passports/certificates, documents relating to your wishes for end-of-life care, enduring guardianship, documents about your future health and lifestyle decisions, and power of attorney for payment authority.

After adding your social and medical information, you shall consider adding details on your daily care routines as well as the use and care of the assistive devices and equipment you use. Since multiple disabilities are common amongst individuals who are deafblind – 25 to 75% according to the World Federation of the Deafblind (2018) – this will be very different for each person.

Next, keep all this important information in one place. Some suggestions include keeping it in a specially marked bag with a tactile symbol in the fridge (Lahtinen, Palmer, & Tuomaala, 2016), in a bedside table or on a hall table. If the paramedics are taking you to hospital, tell them about this information and where to find it.

Another way to manage the wider variety of information and documents is related to a care passport. This can be in the form of an

electronic folder on a smart device, an app or paper-based. Since vaccination programs have begun, you should also keep your Covid-19 vaccination record, your exemption documents if any, and your latest Covid-19 test results with your going-to-hospital documents. Some hospitals will refuse to admit you for some procedures if these are missing, or make you take another test. Either way, a hold up in providing the correct documents might mean a delay in getting admitted and treated.

Building your own going-to-hospital kit is a good way to be better prepared. This includes all the information and documents mentioned, with the addition of individual extras we need to keep us safer, comfortable and in touch. There are non-documents that need to come to hospital with us as well. They could be hearing aid batteries, denture glue and cleaners, recharging devices, smart tablets or assistive devices. But we cannot assume that staff knows how to work with these things, so copies of instructions, or links to product information are also important to be included. Laminated manual deafblind alphabet sheets are handy for those that sign. The manual alphabet is easy for staff to learn, and many patients have the alphabet pinned above their bed. This can be helpful in the absence of an interpreter to give us some idea of what is going on, such as needles and x-rays.

Some other potentially useful items to include in going-to-hospital preparation kits are wristbands to alert all staff wherever you go in hospital that you have communication needs; with a clear "I AM DEAFBLIND" or 'I AM VISION IMPAIRED'. Patients have reported high satisfaction and usefulness of these cheap to produce and simple bands (Watharow, 2019). They are also useful in other situations such as airport security, shops and even when being arrested by police.

Sometimes old ways are good ways. If you have sufficient residual vision, use pen and paper to communicate with the staff. If you are non-verbal but can write, you can then at least communicate your concerns/symptoms/questions to the staff. There are small personal whiteboards that can be obtained

from office supply stores or two-dollar shops that are used to help communication along in the same way as pen and paper. The note function on smartphones and tablets can be also utilised, with the added advantage of speech-to-text if the health worker has an accent or personal protective equipment makes it difficult to hear.

Flash cards on paper, in Braille or as an app can be really handy for all patients who find themselves unable to understand what is going on. One example I have used is CardMedic, but you can also make your own personal cards. Screenshot them onto smart devices or emboss with Braille so that staff can hand you the relevant card, i.e., "injection" or "x-ray". If you have some idea of what is going on, you will feel less anxious (Watharow, 2021).

Health haptics are touch signals aimed to convey information quickly (Lahtinen, 2008; Lahtinen, Palmer, & Tuomaala, 2016). Their use is not limited to people and/or individuals who are deafblind but also to older people, those with deafness or who are hard of hearing, older people who have hearing loss – which affects 66 percent of people over 60 (House of Representative Standing Committee on Health, Aged Care and Sport, 2017) – and those living with intellectual disability. Have signals in the chart and written forms (laminated if able), have them in your going-to-hospital kit and show the staff – tape to your bedside for easy reference. Keep it simple (20 or fewer), we suggest: emergency, doctor, nurse, needle, blood pressure, pain, tablets, happy, okay and sad (Lahtinen, 2008; Lahtinen, Palmer, & Tuomaala, 2016).

We also need to use the technological capability we have for speech-to-text or Braille, for screenshots of important information, for apps and folders of important information. Another recent innovation is pocket voice amplifiers. They connect and amplify smartphones, tablets and televisions, and can be bought from hearing support services or online. There are disposable covers so that doctors, nurses, clinics and hospitals can purchase and use them for any patient who is hard of hearing, has forgotten their

hearing aids or has enough residual hearing to benefit. They cost around 360 - 400 AUD. They help many people to hear important conversations when in hospital.

Good in-person support also matters. Gathering all this information will likely require assistance. So, all the support workers, families, caregivers and professionals reading this, please help us be better prepared for the new challenges of going to hospital. Gather documents, set up folders and links, show us how to use assistive functions on our tech devices and in every conversation keep reminding staff that we need to get information and be communicated with and mobilise safely in hospital.

Lived experience matters and is being increasingly recognised as a necessary part of research, monitoring patient experiences and healthcare. Attain representation wherever you can: in hospital patient experience committees or as lived experience representatives at Health Ministry level. Talk about how accessibility matters – that for all people living with disability, good care and communication is a human right, and that it is achievable. Tell of the problems, give them ideas regarding solutions for the issues our communities are experiencing. Lived experience is being increasingly recognised as essential for co-creating research, policies and practices that impact the lives of people living with disability, especially in public health settings (Bergths et al., 2016).

And if you do end up in hospital and have no access to your caregiver, keep asking nurse unit managers and hospital administrators to allow a caregiver to stay or come regularly to aid communication and support. Families and caregivers can call daily, visit when allowed and also ask to read the information contained in hospital kits, passports

and files. Ask for nurse navigators, discharge planners, patient experience advocates – whatever specialists are there, and whatever they are called.

We can empower and support each other to query, question and complain about mistreatment and bad experiences. If we don't add our voices wherever we can, it will be as if the problems of poor care and communication in hospitals don't exist.

Some negative hospital experiences can be reduced by the steps we, patients, take for better preparation and support of communication in hospitals. This does mean that, as it often happens, the burden of educating health professionals and supporting communication falls on the individuals who are deafblind and not on the institution which they belong to. But until there is greater inclusion and participation of people living with disability in all levels of society, and full access to information, communication, orientation and mobility support is embedded in practice (not just as policy and legal protections) at all levels of healthcare institutions, we must persist. Preparation is the key: thinking about what might be needed in hospital ahead of time and gathering as many resources as possible to support us during a hospital stay are contributions we can and should be making.

Good care and communication require much more than these patient contributions to generate better health and wellbeing outcomes. We will need to ensure that our voices, signs and lived experiences are heard. We are complicated but we are not difficult. Continuing this conversation and sharing experiences, solutions, strategies and hacks is critical. Email me annmaree.watharow@syd.edu.au to add your voices and ideas. We need you.

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Wohntrainingsgruppe: A Self-Determined, Shared Living Model Project in Germany for Young Adults with Deafblindness



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The transition from school towards independent living is a huge step in life for any young adult. This life event is much more complicated for young deafblind adults. Due to the lack of accessible residential facilities, as well as communication difficulties, these young people have a harder time to take the leap and live on their own. The life skills of young deafblind adults are often insufficient to take such a drastic step. Furthermore, there are fewer role models for peer support.



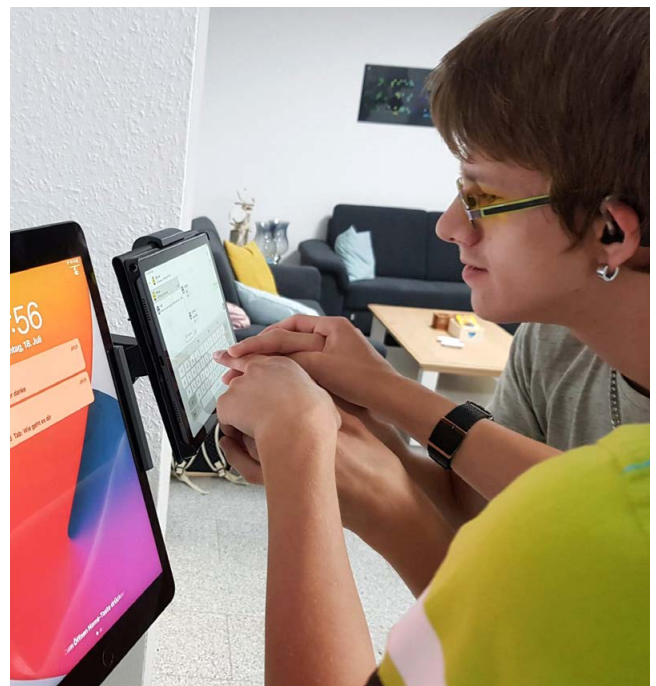


An inpatient-residential facility might not be necessary for everyone. However, an outpatient-serviced apartment can be too demanding or not appropriate. In this case, the Wohntrainingsgruppe offers exactly the right intermediate step. To help these young people, the Deutsches Taubblindenwerk (German Deafblind Association) has undertaken a model project. The goal is to enable young deafblind adults to experience shared living. Hereby, they learn practical life skills, which are necessary for living on their own and to build confidence. Any deafblind adult who does not need or want to live in a full-inpatient residential home, shouldn't have to do it.

A new life phase has begun for five young adults in Hanover. As residents of the Wohntrainingsgruppe, they will live together in a shared apartment. This will enable them to lead a more independent and self-determined life. The aim of this flat-share project is on the acquisition of necessary everyday skills. These include shopping, meal preparation, and laundry care. According to our observations, these skills can be better learnt and taught in a shared living setting than in an inpatient-residential home. In this setting, the housemates have higher security, as well as reliability of care and companionship from

their trusted caregivers and themselves. They do not have to master living on their own. Nevertheless, they have the opportunity to experience a realistic living environment.

The Wohntrainingsgruppe is located in a bungalow, which is around 170 square meters in size and has been built for residents with dual sensory loss in mind. It is located within walking distance from the main building of the Deutsches Taubblindenwerk in Hanover. Each of five residents have their own room and share two bathrooms, a kitchen, and a common room. In addition, the facility offers a utility room and a large garden. To ensure that the adults feel like they are at home and find their way around their new four walls, many tactile markers were included in the layout in advance. For example, the design of the rooms is geared to the specific needs of people with hearing loss. Special dimmable lighting technology, strong contrasts in the interior design and tactile floor markings provide orientation and offer assistance. The Wohntrainingsgruppe's technology is also up-to-date and serves individual requirements. A digital communication corner with video phones, tablets and smartphones make it easy to connect with each other. It is possible to contact the support staff using video phones at all times. The caregivers visit the group several times a day and provide help in everyday life and necessities.



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The Wohntrainingsgruppe is based on the guiding principles of the UN Convention on the Rights of Persons with Disabilities (CRPD). These guidelines include the pursuit of individual autonomy including the freedom to make one's own choices and full and effective participation in society. The Wohntrainingsgruppe tries to make these CRPD's guiding principles tangible for its young deafblind residents.

The concept is already a success. The residents complement and support each other in everyday life according to their individual abilities. Together, they experience the advantages and challenges of living together in a shared space. They cook, eat, do laundry and pursue leisure activities as a peer group together. Without this experience, these adults would not be as independent as they are now.

Project Overview: Guide to Tactile Communication Methods

Project partners:

- **CRESAM;**
- **Erika Gonnord:** Designer for ESAT establishment and work assistance service at Image Arts Graphiques, Angouleme;
- **Julia Fraud:** Illustrator and Graphic Designer, specialized in scientific communication.

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Project Overview: Guide to Tactile Communication Methods

Over the course of our experience, we have discovered that the tactual modality is generally adapted to the individuals who are deafblind since it relies on a sense that is available.

We wish to present these tactile communication modalities through practical and pedagogical sheets on the subject.

Genesis of the Project

One year ago, we discovered tactile dactylology or fingerspelling (in particular, in the Netherlands), i.e. dactylology adapted to the tactile communication modality. This modality is very suitable for the individuals who are deafblind because it relies on an available sense.

It is not easy to understand dactylology through the tactile modality, even when the one is used to communicate in tactile sign language. The tactual perception of the difference between a “D” and a “G” or an “H” is not instantaneous. The person with dual sensory loss

needs to be more active in tactile exploration rather than simply remain in reception mode.

As we identified these difficulties in discernment, we adapted the so called classical dactylology for tactile reception.

In order to disseminate this new initiative, we hired an illustrator to translate the 26 hand patterns into images. We then circulated this illustrated board in course of our training and awareness sessions throughout France.

In the course of our interactions with professionals, we realized

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that we needed to work on all other tactile communication methods and design other educational sheets.

What Does This Guide Consist of?

The project is an ambitious one and includes 10 thematic sheets. Our goal is to bring together the emerging practices from various parts of the world and to make this knowledge accessible.

We have noted that deafblindness and the specificities with regard to communication overwhelm or sometimes even discourage individuals. These sheets have therefore been designed so that people could practically use these tools and establish a well-meaning and adapted communication with the person with dual sensory loss.

We asked our team to participate in order to leverage the specific skills and knowledge of professionals at CRESAM (National Center Resources for Deafblind Persons) to benefit from different perspectives and to establish

This is when the tactile dactylology project evolved into the Guide to Tactile Communication Methods.

a more accurate and comprehensive approach.

We also worked with other partners for the illustrations and the graphic design. The idea is to present a lasting educational and communication tool.

We have completed the design of the booklet and its 10 thematic sheets: Tactile Communication, Tactile French Sign Language Dactylology, Tactile Dactylology, Print on Palm and Fictive Writing, Lorm Method Haptic Communication, Braille and Hand Braille Non-Coded Communication. The sheets are [available on CRESAM 's website](#). This guide can also evolve to accommodate new emerging communication methods. We have thus planned to design a sheet on the Protactile Method in 2021.

Engaging People Who are Deafblind and Their Families During the Pandemic

The onset of the pandemic kick-started the de-railed and deserted national networks of people who are deafblind, their parents and special educators into a flourishing online community.

Ever since the pandemic broke out, people around the world have been forced to switch their lives online. For people who are deafblind, it was a mammoth transition where they were left alone to find the answers themselves. It led to more isolation when the touch was banned globally to reduce risk

of being infected by the deadly COVID-19 virus. The only way the people who are deafblind used to communicate was shunned by the world. Children who are deafblind had to be taught by their parents rather than their teachers. It was the “Big Adjustment” for people who are deafblind.

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How Sense India Engaged with People Who are Deafblind Online

Sense International India has been working with people who are deafblind since 1997 across the vast nation to support people who are deafblind and their families in India. Sense India has been able to reach out to about 80000+ people who are deafblind and their families. We had to shift our work from physical to online and at the same time had to ensure that more participation of people who are deafblind and their families would be done, and that it would be more effective. We started engaging our national level networks of people who are deafblind and their parents in online meaningful discussions.

Sense India supports three National Networks, they are as

follows: Abhi-Prerna (which means “to motivate”), a network of special second-part-of-the-day teachers for children who are deafblind; Prayaas (which means “to try”), a network of family members and caregivers for people who are deafblind; and Udaan (which means “to fly”), a network of adults who are deafblind. Simply saying, the motivation from the second-part-of-the-day teachers makes parents try harder and so their children who are deafblind can fly. We slowly started on WhatsApp groups in which families of children who are deafblind started engaging and discussed the issues they faced in supporting their children who are deafblind at length.

Creating an Online Platform for the Networks

In a country like India, issues become manifold depending on where you are, what language you speak, which culture you belong to and if you have access to technology. All these factors intermingle and all we have to do is to solve them like peeling an onion. While shifting our Network activities online we took challenges head-on. This practice gradually developed into Prayaas Online Activity Coordination Group (POACG), a national network of families of persons who are deafblind. Within its frames, the active parents from local networks across India came together and discussed proper certification for people who are deafblind, issues related to the online education, injustice faced by people who are deafblind across the world, issues related to the children who are deafblind and who have multi-sensory loss during the pandemic and took the lead in training and advocacy.

We did the same with the national networks of adults who are deafblind and created the Udaan Online Activity Coordination Group (UOACG). Within its frames, we brought young adults who are deafblind to a virtual platform, which, to be honest, was not an easy task. Apart from language and communication barriers, there was an issue of Internet connectivity and availability of proper digital devices to be able to attend these regular meetings. Another challenge

Making a Digital Collective of People Who are Deafblind and Their Caregivers

We have been using these meetings to guide parents on legal benefits like guardianships, training them in sign language to support other children who are deafblind and discuss vocational activities. For people who are deafblind, we have managed to utilize these platforms to make them more active in advocacy and prepare them to participate in state, national and international platforms. On the other side, active parents became mentors and guides to other parents' groups through online discussions and meetings.

was to attract their interest to attend the meetings at the initial days.

Most people who are deafblind have severe communication issues and so we had to reach out to their caregivers and educators to ensure total communication. We also needed to ensure accessibility of all the network members, for which we engaged interns and volunteers who supported us in live transcription during the meetings. Our aim was to secure communication for people who are deafblind so that they could understand and give their active and meaningful participation.

To practice active involvement and participation, we received support of active parents and educators who provided translation support during the call. Our objective was to ensure connecting with people who are deafblind, their family members, and caregivers. Through these meetings we could record their concerns and challenges related to education, access to proper healthcare support during the pandemic, getting disability pension, loss of employment and business during pandemic. We also worked towards enhancing their capacity by discussing all current affairs in the disability sector. We guided families and people who are deafblind to understand their rights, take lead in advocacy and look for solutions within their own communities at local levels.

The groups' solidarity was growing, they took initiatives to celebrate the good days together and advocate for issues that should not have happened first. For example, on Helen Keller Day, the Udaan network's members decided to have their own way of celebrating and paying tribute to Helen Keller by posting the same WhatsApp status designed by them which marked deafblindness as their strength and pride and a promise to take forward the legacy of Helen Keller.

During one of these online calls, members of Udaan network were informed about Becca Meyers, a three-time gold winning Paralympic

swimmer who is deafblind, quitting the US team over not being allowed a personal care assistance (PCA) due to Covid-19 restrictions. Members of the Udaan network were quite taken aback by this occasion and they signed a joint statement to voice against this injustice. This joint statement was submitted to the International Paralympic Committee with 80 signatures of adults who are deafblind and who endorsed this statement.

We also utilized these online discussions to prepare members to lead at side events organized by Sense International India at UN COSP13 (13th session of the United Nations Conference of State Parties), UN COSP14 (14th session of the United Nations Conference of State Parties), UN ECOSOC (United Nations Economic and Social Council), etc. During these events members from Udaan and Prayaas shared their opinions

and recommendations and were visible at international events.

We are happy to share that by this moment we have held about 40 discussions with the national network of families and 26 discussions with the national network of people who are deafblind. It has now become a part of our lives where we meet at a designated time for a fixed amount of time and encourage others in their circle to be active advocates for people who are deafblind.

Through these online discussions with adults who are deafblind and their family members, we were able to ensure Nothing About Us, Without Us. Facing all challenges, we brought all their voices together and now we have new leaders in our national network who are taking forward advocacy initiatives and guiding other young adults who are deafblind for the same.

A Step Forward in the Communication of People Who are Deafblind: the DACTYLS System

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The communication systems used by people who are deafblind are very heterogeneous and diverse, due to the different characteristics and personal backgrounds of each individual. Some individuals who are deafblind use speech as their usual system of communication in their daily lives. But when their vision and hearing start to deteriorate significantly, they need to learn a new system, often a tactile manual alphabet, to transmit messages through touch instead of spoken language.

However, the tactile manual alphabets have several disadvantages:

1. Speed of communicating through manual alphabets is slower than through speech, and it might lead to a time gap between the transmission of the oral message and the tactile reception, shortened messages, loss of information, and misinterpretations .
2. A deafblind person is forced to make a larger effort in his mind to try to guess and find out the missing information to complement the incomplete message, which may make them feel psychologically and physically exhausted and cause loss of concentration and misunderstandings.
3. Communication through manual alphabets doesn't allow the simultaneous transmission of the message together with the visual and/or auditory elements of the environment that facilitate an individual who is deafblind to get a general picture of the situation and a coherent and contextualized understanding of the messages.

For this reason, almost 30 years ago Daniel Álvarez, a person with acquired deafblindness from Spain (who was the Head of the ONCE Deafblind Unit for many years), together with his guide-interpreter tried to improve their communication through the Spanish Manual Alphabet by including

some elements that could make their exchanges faster, more effective and inclusive. That is how they created a new communication system: Dactyls.

Dactyls is a tactile system of communication, alternative to speech. It comprises the use of the following components:

- The Spanish Tactile Manual Alphabet to fingerspell a part of the message on the deafblind individuals' palm, having the same structure (word order) as the oral language does;
- The tactile signs to substitute the spelling of some words or expressions. Some of them are taken from the Spanish Sign Language and adapted to be perceived through touch, while the others have been created by the users. They are mostly performed on the palm, but some of them are performed on the fingers, the back of the hand, wrist, arm and even the shoulder of the person who is deafblind;
- Other resources such as pointing, drawing on the palm, using the palm as a map, short messages;
- Grammatical rules of use that regulate its functioning.

That way Dactyls allows us a) to transmit and exchange messages and information; b) to provide the individual who is deafblind with visual and auditory information from the surroundings that complement the message, such as elements from the nonverbal communication, vocal qualities, emotions, physiological reactions, vocalisations, silence, facial expressions, etc.; and c) to transmit messages and information from the environment while walking, and guarantee safety.

The name Dactyls comes from the abbreviation of three Spanish words: "dact" (from "Dactilológico", "Manual Alphabet" in Spanish), "y" (from "Y", "and" in Spanish), and "ls" (from "Lengua de Signos", "Sign Language" in Spanish).

Dactyls offers several benefits over other tactile communication systems, they are as follows:

- Higher speed in the transmission of messages;
- Transmitting complementary information from the environment which facilitates the contextualization of messages;
- Transmitting elements from nonverbal communication;
- Anticipating information about imminent situations;
- Providing short and fast warnings to assure safety when moving around;
- Transmitting messages privately and discreetly.

Since Dactyls was created, other Spanish people who are deafblind started to use it. Considering the fact that in those times there were no teaching/learning materials available, new users learned it by word of mouth which meant that people were customizing the system by adapting it to their own needs and including their own new signs. This situation made it difficult to broaden the use of Dactyls within the deafblind community.

Therefore, ONCE (Spanish National Organization of the Blind), under its Deafblind Unit's coordination, in collaboration with FASOCIDE (Federation of Associations of Deafblind People of Spain) and thanks to a consensus with the deafblind users, has carried out the task of standardization and systematization of the system. As a result, the first set of 750 signs has been determined, the rules of use have been established, and the further creation or incorporation of new signs have been regulated, so that all potential users have it at their disposal: individuals who are deafblind, guide-interpreters, intervenors, family members and general public.

As a result of all this work, the ONCE's Center of Technology for the Blind and Innovation (<https://cti.once.es>) and the ONCE's Deafblind Unit in collaboration with the Complutense University of Madrid have developed the Dactyls Apps available for free download in

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Spanish both on App Store [Dactyls en App Store \(apple.com\)](#) and Google Play, [Dactyls - Aplicaciones en Google Play](#) as well as a web page www.dactyls.es

This material, which is also accessible for people with vision loss, contains several tools that allow an individual to get to know all the elements of the system: a search engine, a total of 9000 videos of 750 signs (including a front and a side view and different play-back options), an informative card for each sign, the video of each letter of the manual alphabet and a detailed explanation of the elements, resources and rules that form the system.



The sign of Dactyls

For more information or if you have questions about Dactyls, please feel free to contact us at uts@once.es

Using Yarn Bombing to Build Awareness and Fostering Global Connection in June 2021

In June 2021, 21 countries around the world came together during June's Deafblind Awareness Month to raise awareness using a large-scale tactile art project called Yarn Bombing. Communication Ambassadors in coordination with and as a part of the Deafblind International's (Dbi) Communication Committee (or ComCom, as it is widely known) worked with individuals, service and advocacy groups in the field, Dbi members and partners, and their community connections around the world to create and join knitted or crocheted yarn squares before wrapping them around local structures.

Pictures of these colourful, textured art installations in the cities and towns around the world were captured across media stories and social media channels throughout the month of June. They demonstrated how different groups could foster connections using a few simple materials – yarn and knitting needles or crochet hooks – to increase awareness and knowledge of deafblindness as a distinct disability and to influence appropriate services for the individuals who are deafblind.

To help them get started, ComCom sent all Communication Ambassadors a toolkit with recommendations on how to plan their yarn bombing

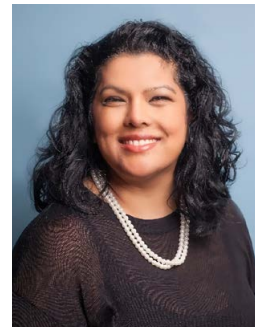
activities. These recommendations included the following: choosing the yarn bombing location, securing permits and permissions, sourcing yarn, and suggestions for communication and promotion. To help spreading the information about these installations throughout the world, all participants were encouraged to use specific hashtags to share and tag their social media messages (#DeafblindAwareness, #YB2021, #YarnBombingForDeafblindAwareness and #TactileArt). Communication Ambassadors also received monthly updates with tips on how to promote their efforts to create a maximum impact.



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EXCHANGE OF EXPERIENCE



In just a few months, Dbi networks/colleagues were able to draw on a spirit of unity and raise awareness about deafblindness in Argentina, Australia, Brazil, Canada, Cyprus, El Salvador, England, France, Germany, Greece, Guatemala, India, Ireland, Italy, Japan, Mexico, the Netherlands, Norway, Switzerland, USA, and Venezuela.

The ambassadors reported that despite the challenges created by pandemic restrictions, yarn bombing helped them engage

with their local communities, garner media coverage, facilitated interactions with national, regional and local elected officials and offered a wonderful opportunity to focus on the positive.

Dbi Ambassadors are excited to announce that they will be joining again in a spirit of unity and are eagerly planning to raise awareness in June 2022. Get out your knitting needles, crochet hooks and your balls of yarn and stay tuned for more details!

Lived Experience of Individuals Who are Deafblind on Use of the Tactile Body Immersion (TBI) Chair, ImmersX at DeafBlind Ontario Services

Acknowledgement

The authors would like to thank the study participants, the users of the ImmersX chair, and their intervenors, for their time and valuable contributions to this research study.

Vibro-acoustic technology uses sound to produce mechanical vibrations that are administered to the body. These sound frequencies are inserted through speakers and transducers that are placed within mattresses, mats, chairs and other soft furniture to provide the user with both an auditory and physiological experience (Boy-Brewer, 2003). The benefits of this technology include anxiety relief, pain management, symptom reduction, and general health improvement.

Certain sound frequencies have been found to be successful in delivering therapeutic benefits and have shown that the collaboration of vibrations and music may be

more beneficial than using either element independently (Boyd-Brewer, 2003). The research has found that the use of vibrotactile stimuli through sensory simulation technology is successful in dispatching emotional information when a person is experiencing music (Good et al., 2014). Tempos in music vibrate at different frequencies inducing various emotional responses. Palmer et al., 2017, discovered similar findings in their research, stating that when vibrational sensitivity is incorporated into music therapy, it can be useful for individuals with dual sensory impairments (DSI) by relieving stress, increasing confidence and improving general well-being.

The ImmersX Chair is a tactile body immersion (TBI) chair that activates your tactile senses, creates a profound sense of immersion for those who are experiencing it and, which is essential,

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it is converting the physical power of sound into a dynamic sensory experience. Tactile body immersion was developed at Ryerson University, Toronto in their SMART lab. It was designed as a tool to help deaf people feel sound ([ImmersX TBI - Posts | Facebook](#)).

Methodology

In February-March 2021, the study used a mixed method approach, traditional/data driven. The methods were traditional owing to the use of observation, and data driven owing to analyzing behavioural outcomes. The methods of observation included as follows: visual, auditory, recorded notes, and video clips of the users, taken while they were using the chairs. The approach is focused on understanding the nature of the ImmersX chair experience by the users through the collection of secondary data from intervenors. The data was then shared with researchers in order to complete data analysis.

The study participants who are deafblind integrated the use of the ImmersX Chair into their daily schedule for a period of eight weeks at a minimum of once per week. The intervenors recorded and shared their personal observations of the users' experience prior, during and after using the chair through the log notes. The intervenors also recorded short video clips of the users' reactions and experiences during the use of the chair. This included various expressions such as joy, smiling and other additional movements that indicated enjoyment. The videos were recorded at least twice, once at the first or second introductory session of the chair, and one more time towards the end of two months. This was done in order to visually observe the difference in experiences over time. The footage captured specific significant and observable moments that reflected one or more themes: mood and behaviour, engagement and communication and the impact on music enjoyment.

The sample group consisted of six individuals who were deafblind and who had varying

The objective of the study was to collect qualitative information on the use and effects of music and recreational activity through the vibro-acoustic technology of the ImmersX chair from the individuals who are deafblind.

degrees of vision and hearing loss, as well as methods of communications. All participants had no difficulties with balance, had good upper body strength and were not prone to motion sickness. These conditions were required in order to ensure the safety of the participants and for proper use of the chair. The individuals had regular access to the ImmersX chair as a weekly scheduled activity, and a dedicated intervenor to work with them as they used the chair. The consent of both the intervenors and the parents of the individuals who are deafblind was obtained prior to their involvement in the case study.

All of the data required for this study was collected through intervenors, who are professionally trained to act as the "eyes" and "ears" for individuals who are deafblind through the sense of touch. The intervenors played a major role in facilitating the exchange of information and assisted the communication for users of the ImmersX chair. Their role also included facilitating the activity by setting up the people they support in the chair, monitoring participants while they were using the chair, assessing participants and making adjustments to the music or chair position and recording their observations.

The data was analysed thematically, whereby the observations collected from log notes and videos were categorized into three predetermined themes. Data was also categorized according to the date in order to make comparisons between each participant's initial reactions to the use of the chair versus their reactions to the use of the chair towards the end of the study.

The findings of the study included an analysis of each theme.

Theme 1: Mood and Behaviour

The theme of mood and behaviour considered how participants responded to the use of the ImmersX chair by observing their physical responses. These physical responses included, as follows: body language, gestures, body movement, posture (if the participant was relaxed or stiff), and facial expressions (if the participant was smiling, laughing, having a mask-like or unmeaning expression, or emotionally present and filled with interest). Observations also included recording of reduction of the undesired behaviour (if the participant demonstrated a reduction in typical outbursts of anger or frustration), anxiety, or an increase in positive mood and relaxation, if any.

Overall, participants displayed positive physical responses while using the chair. Participants' responses to chair use varied depending on what they were watching. While watching movies, Participant 1 was calm and relaxed, they also displayed a reduction in hitting their chin and chest during chair use, even though they displayed little expression. Participant 2 consistently demonstrated a relaxed posture while engaged with the chair and made positive

head gestures and vocalizations while listening to music. Participant 2 also frequently changed postures from leaning forward and then back when loud sounds occurred while listening to music, and while watching television shows and movies. Participant 3 showed enjoyment through laughing when engaged in watching their favourite shows. Participant 5 also displayed a positive mood and was more energized when music was playing as they used the chair. Participant 6 showed an improved mood by smiling from time to time as they were engaged during the chair activity and displayed calm demeanor while they were in both the upright and the reclined chair positions. While most users were more emotionally present when they were listening to or watching their own preferred and familiar music, music videos, television shows, or movies, Participant 4 did not show any increased interest or engagement with the chair activity. Participant 4 displayed a tactile approach when beginning the activity, the participant needed to feel the chair before sitting on it and did not express any enjoyment before, during, or after the activity.

Theme 2: Engagement and Communication

The second theme focused on observing improved concentration, motivation and participation in daily activities related to the use of the chair. This included observing if there was an increase or change in the participants' confidence, as well as their reactions and approaches to accomplish daily tasks. Additionally, observing if there was an increase in choice making in communication, where the chair was used as a motivator and participants used physical cues and sign language to indicate that they wanted to use the chair, and an increase in concentration, attentiveness, engagement and enthusiasm during activities.

Participant 1 was less engaged during the use of the chair when listening to rock and roll music, this was indicated by the participant tapping on the iPad, looking around the room and being unable to focus. But the participant

became calm, relaxed, and engaged while listening to classical music with high contrast animation and nursery rhymes. Participant 1 became increasingly engaged with chair use as they used it more frequently due to the participant's desire to take the iPad from intervenors and make their way to the chair to begin the activity. Participants 1 and 2 shared a dislike for using headphones while in the chair. However, Participant 2 remained consistently engaged in chair use for the entire study while using different forms of entertainment including music, movies, and television shows. Participant 5 showed improved engagement and tolerance in the use of the chair. At the beginning, the participant endured only 15 minutes of chair use, but later increased their level of use to 45 minutes, displaying energized body movements including movement of their hands and feet in tune with the music beat.

Theme 3: Music Enjoyment

The third theme considered the musical choices of the participant and their increased usage of the chair. Participants were able to select their own music preferences or choose from a selection of music provided by the intervenor which included as follows: soft rock, instrumental music, hip hop, pop, meditation, opera, orchestral, or cultural music. Intervenors documented the participant's choice of music (favourite songs, new music, instrumental tracks or specific music playlists). During the observations the intervenors also noted whether the use of the chair became a meaningful and important activity to those supported, by noticing if they were choosing the chair activity more frequently. Over the course of the study, the participants were observed to increase the amount of time that they utilized the chair during sessions.

Participant 1 had preference for classical and opera genres but was not engaged while

rock and roll or country were played. This Participant showed some engagement while music was played during the chair activity, but most of the time of using the chair the Participant was watching TV shows or movies. Participant 2 displayed a preference for popular 90's acoustic songs instead of relaxing music. They demonstrated this by acting more engaged with music that had a rhythmic beat and had visuals that they could see on the iPad. Although Participant 2 enjoyed listening to music, they preferred watching television shows and movies when using the chair. Participant 3 displayed musical preferences by listening to a variety of genres, they preferred to listen to songs halfway and then switch to another type. Participant 3 showed musical preferences for cartoon theme songs and Beatles music videos which acted as a source of both auditory and visual enjoyment.

Discussion

This is the first study when DeafBlind Ontario Services captures the lived experience of the ImmersX chair in individuals who are deafblind. The findings highlight the impact of the chair on users' activity participation, daily functional ability, mood, behaviour, psychosocial well-being, and their enjoyment of music. The findings in the first theme, Mood and Behaviour, indicate that usage of the chair had a positive effect in reducing undesired behaviour. The chair was also found to induce relaxation in users and generated feelings of interest and excitement prior to and during the use of the chair. The findings from the second theme, Engagement and Communication, indicated the benefit of the chair as a mean of increasing engagement. Over time, usage of the chair became a meaningful activity to exercise choice in communication, as participants began to develop confidence in requesting resources to enhance their experience of the chair, which translated to other day-to-day tasks that the participants engaged in. The third theme, Music Enjoyment, was demonstrated

throughout the study as participants showed enjoyment in being able to express their choice of music. It is important to note the increased usage of the chair which was shown by all participants of the study.

The overall impact of the ImmersX chair has been found to be beneficial to individuals who are deafblind. The vibrotactile stimulation provided by the chair improves the physical, emotional, and psychosocial well-being of users. The range of frequencies and vibrations in music enable those with dual sensory loss to gain and feel the expression of music in a holistic way (Palmer, Skille, Lahtinen, & Ojala, 2017), improving their health and well-being. The thing which attracted particular interest during the case study, is the use of the chair that goes beyond simple listening to music. Participants were able to engage in the chair activity for long durations of time as they watched their favourite movies and television shows. The visual and auditory sensory stimulation, coupled with the vibrations of the chair, had the greatest influence on the chair's users.

Limitations

The limitations of this study included having a small sample group size (six participants), the lack of a standardized assessment tool,

logistical issues, virtual oversight management, restrictions due to stay-at-home orders and the COVID-19 pandemic.

Recommendations

Based on the data analysis, observations and results, the use of the ImmersX Chair is recommended for individuals with sensory loss.

The ongoing usage of the chair may have a positive impact on the health and well-being of individuals who are deafblind.

Conclusion

The use of the chair increases participant's level of engagement in activities, improves communication and increases positive mood and behaviour. The favourable outcomes that the users experienced suggest that the ImmersX chair will be successful in enhancing

the lives of individuals who are deafblind in the long term, thus improving their quality of life. The study would serve as a baseline in building the body of knowledge and practice for wider application of this vibrotactile modality for individuals who are deafblind.

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Being and becoming a member of Dbl

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

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

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

Being an individual member of Dbl means

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

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

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

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

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

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

Mirko Baúr, Strategic Vice-President Dbl, Chair ComCom



Deafblind
International Dbl

DbI Communication Ambassador: Call for Action



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

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

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

What are the responsibilities of a Communication Ambassador:

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

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

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

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