A message from the President

Dear Friends and colleagues,

I know many of you will have attended the Network of Americas conference held this past April. It was fantastic that the conference was dedicated to Professor Jan Van Dijk, definitely one of the most important and much loved people in our field. Huge thanks must go to Perkins School for the Blind, Marianne Riggio, the scientific committee and everyone involved. Sadly, I wasn’t there; it must be the first DbI conference I have missed in so many years and was sad not to have been able to attend. I am delighted to congratulate Carolyn Monaco for being awarded the Anne Sullivan Medal for excellence in the field of deafblindness. I am equally pleased for all the other Award recipients and great to see their dedication and hard work recognised. Generally, I haven’t been travelling much but the DbI Management Committee and Board are still very much in touch and working hard. Our three priorities of diversity, technology and knowledge remain at the heart of what we do. We are looking forward to the WFBB conference in June and the Young Researchers conference in Russia in October. I know Able Australia and the Scientific Committee are working hard on the DbI World conference in 2019.

As ever, our huge thanks must go to Stan and CDBA for the wonderful work on this Review; Able Australia and Gary Daly for the massive amount of Secretariat work and Maria Brons who is taking forward Frank’s work as treasurer. Our deafblind community is important and it’s a privilege to be part of it.

With Best Wishes
Gill Morbery President

Our three priorities of diversity, technology and knowledge remain at the heart of what we do.”

8
DbI Review
July 2018

General Articles

Advocating for the right of Education for the Learners with Deafblindness and Multiple Disabilities in Egypt

What Inclusion Means to Us? Parents’ and Caregivers’ Perspectives in the Indian Context

Empowerment of Children with Dual Sensory Loss

A new Era for Perkins International Latin America and the Caribbean

Impact of Perkins’ Website as a resource for Families and Professionals in Latin America and the Caribbean

An Emergency Intervenor Services Program (EISP)

An Analysis of the Social return on Investment (SROI) for the Lego del Fio d’oro

How to Plan a Holistic Rehabilitation Process

Overview of the First DbI Network of the Americas Conference

The 1st International Young Researchers Conference on Deafblindness

Able Australia Welcomes the World to The Gold Coast for the 17th World Conference on Deafblindness

Country News
Burkina Faso, Canada, Egypt, Germany, Guatemala, Russia, Switzerland

Network News
APA, Communication, CHARGE, Outdoor, Research, Usher, Youth

DbI International Membership and News
Board membership 2015–2019
Secretariat news
DbI sponsorship guidelines
DbI Strategic Plan
Officers and Corporate membership listings

Contents
A message from the President Page 2
Editorial and contents Page 3
Vice President’s messages Page 4

Welcome to the 61st and Summer 2018 Edition of DbI Review.
One of DbI’s key focus areas is Diversity. Without asking for articles specifically about diversity, articles keep arriving from far corners of the world to satisfy that focus. The diversity of articles is not just about originating from so many regions but also about the diverse assortment of subject matter and its ideas and programs. This edition is no exception with the diversity of material and the diversity of locations from which the papers originate. This edition features writers with specialized articles from: Egypt, India, Denmark, Guatemala, Russia, Italy, Canada, Burkina Faso and Switzerland. In addition, several articles appear from Perkins International Latin America and the Caribbean co-written by authors from Brazil, Argentina and Mexico. The edition begins with an article written by Amal Azzat from Cairo Egypt titled: “Advocating for the right of education for the learners with deafblindness and multiple disabilities in Egypt”. Amal Azzat’s determined advocacy to get the Government of Egypt to provide educational services for children with multiple disabilities is remarkable. She is truly a hero.

The article from Sense International titled: “What Inclusion means to us”, is an eye-opening expose of what inclusion in India means for individuals with deafblindness, their parents and caregivers with respect to education, health care, employment, etc. The narratives from caregivers and parents speaks about how persons with deafblindness are denied basic human rights within Indian society. Their struggle for inclusion is an everyday struggle.

Karina Hoebjerre Seiler has an intriguing article entitled: “Empowerment of Children with Dual Sensory Loss”. She described her experience with “narrative coaching” as a means of empowering children with deafblindness to deal with their disability by focusing on their experiences, emotions and reflections about their situation, dreams, issues and future. In addition to these feature articles, this edition follows the magazine’s tradition of presenting brief updates from the following DbI Networks: CHARGE, Communication, Youth, Outdoor, Usher Syndrome, Research and from the newest network, Adapted Physical Activity Network. Have a read about Emma Boswell’s train experience.

(continued on page 8)
The year has gone by so quickly for DbI. In looking back, we have achieved many of the goals that we identified. The area that has seen tremendous growth is the effort to promote diversity. Social media has helped keep us connected to activities happening around the world. So many wonderful projects are offering individuals with deafblindness more access and the ability to participate in daily life.

The recent Network of the Americas Conference brought together people from over 20 different countries. The enthusiasm of the participants and the high quality of the presentations show the growth of DbI as well as the need for sharing information. DbI appreciates the work that the Perkins staff did to host the conference. As we look ahead, the Scientific Planning Committee for the World Conference in 2019 is busy working on the program. The sub-committees for each of the topics: Accessibility, Communication and Technology are identifying speakers for the plenary sessions and will be reviewing the abstracts for the workshops. DbI is excited to be partnering with Able Australia and the local Host Committee is working hard to create a memorable time while at the conference.

Individuals who are deafblind are successful because of the people who support them. In our field we have so many individuals who have made or are making outstanding contributions. On behalf of the Awards Committee, I hope you will consider nominating individuals for the Young Leaders Award, the Distinguished Service Award or the Lifetime Achievement Award. The information on how to nominate an individual is on the DbI website. DbI will present awards at the World Conference in 2019.

Bernadette M. Kappen (B.Kappen@nyise.org)

AdvoCatIng For the Right of Education for the Learners with Deafblindness and Multiple Disabilities in Egypt

Amal Ezzat

I graduated from the Psychology Department of Ain Shams University in 1993 and eventually worked as a psychologist in a hospital for mental health. In 1995 I participated in a training course at the University’s faculty of medicine to study speech therapy and worked at Ain Shams Hospital as a speech therapist for 30 months. I was fortunate because I trained with the greatest professors at the faculty of medicine at Ain Shams hospital at that time.

The challenge of deafblindness

The biggest challenge I faced in my work was in the year 2000 when I worked as a speech therapist in a center for children with cerebral palsy. I was working with a child with deafblindness and multiple disabilities. For the first time I felt like a failure due to my inability to communicate with the child. I became frustrated and started to search for information about deafblindness. I was surprised to discover that there was not any school or organization in Egypt that taught those children. But I did not wait a long time to find my way in the field of deafblindness. Luckily, in 2002, I read an advertisement about a training course on deafblind education in Egypt. It was a cooperative effort between Oslo University and Egypt. This course was the first step on my journey to understanding deafblindness. From that time I became fascinated by working with children with deafblindness and multiple disabilities. The Norwegian experts taught me the Scandinavian method in deafblind education. They emphasized the development of social interaction as a basis for development of communicative expressions.

Lack of resources about deafblindness in Arabic language

The second challenge I met was the lack of information and resources about this disability in the Arabic language. I found only two books and a chapter in a book about deafblindness in the Arabic language. This problem motivated me to introduce the first research in the Arabic language about deafblindness, at a conference at the University of Banha in 2007. I also translated into Arabic booklets titled “Co-creating Communication” by Anna Nafstad and Inger Rodbroe, and other articles about deafblindness and the Callier Azusa scale. In addition, I finished my thesis for a Master’s Degree in 2010 which was the first such thesis about deafblindness in the Arabic language in Egypt. This opened the door for more studies in the field of deafblindness. With

1 www.asu.edu
2 University of Banha
3 These booklets were produced by DbI’s Communication Network
4 The Callier-Azusa Scale designed to aid in the assessment of deaf-blind and multi-handicapped children in the areas of motor development, https://www.utdallas.edu/calliercenter/evaluation-and-treatment/azusa-scale
The Educational Rights of those with Multiple Disabilities

What is after social interaction?
The question I always wondered about was what follows social interaction? Will we continue to play with the children or do we teach them like their peers? How do we encourage them to get out of their comfort zone to face the real life?

These questions motivated me to read more about deafblind and multiple disabilities education and eventually enrolled in training courses online from Perkins School for the Blind. I was very impressed with Perkins and I dreamed someday of participating in their Educational Leadership Program (ELP). I was eventually accepted to take this course beginning in 2016. While I was happy to achieve this dream at the same time it was another challenge to leave my three children in Egypt to be away in the USA for such a long period.

Advocating for the right of education
After working with children with deafblindness and multiple disabilities and their families now for eight years, I was surprised that the law here in Egypt prohibits any child with more than one disability from attending school. I could not imagine that we could deprive any child of his or her right to an education. I discovered that the lives of all those children are tied one way or another to legislation. So, I suggested to the families that we needed to take the initiative to meet the Egyptian Ministry of Education officials to advocate for these children’s right to education. The families of deafblind and multiply disabled children chose me to represent them in discussions with Ministry officials. We started our way in advocacy in 2010 when I went to the Ministry of Education to convince the officials about this issue. I showed them some pictures of the children in various activities and explained how we communicate with them and emphasized the need to train teachers and open classes for these individuals. While these officials were convinced about this issue, they indicated that they needed to take this proposal to the Education Minister. It was three years before anything developed. I happened to meet the Minister at a conference and asked him why the Ministry of Education prevents children with deafblindness and multiple disabilities from their rights to an education. The Minister promised to try to find a solution for those children.

After one week the Minister invited me and several specialists in special education to meet to discuss the project for deafblind and multiple disabilities education. This was the happiest day of my life because we had won the first round. Finally, we were able to move forward the right for these children in Egypt to get an education.

I had established the Hope City Foundation (HCF) in 2014 as the first step towards implementing this project. But not too fast there were delays. The Minister was changed along with other officials in the Ministry. With every change I had to convince the new officials to continue in the project. Some were convinced; others did not care. At this time, I received the acceptance to travel on a scholarship to Perkins for the ELP course.

More Inspiration
While at Perkins School for the Blind in Boston, USA I was inspired by the story of John Dix Fisher when he went to Paris to discuss the idea about the Perkins School. I wished I would have been able to deliver the same idea in Egypt and start a school model for students with deafblindness and multiple disabilities. It was at Perkins that I found the answers for all the questions I was thinking about “what is after social interaction?”. I knew that we should prepare these multiply disabled children for transition from childhood to adulthood to allow them to be productive members in their community. Without a doubt, they should have equal opportunities to work, live and love. I learned new strategies in teaching children with these disabilities. I was so happy to find the missing link in their education that I was looking for. When I returned to Egypt in 2015, I started in the Hope City Foundation a small school model similar to the Perkins model.

The influence of advocacy
In the Hope City Foundation (HCF) we believe that education is the key to all for sustainable development. We are doing our best to ensure that every child in Egypt has their right to a free and appropriate public education in locations close to his/her home.

In 2015 we presented an initiative called “Your Right to Learn” to the Egyptian Ministry of Education, recommending that four classes were required for children with dual sensory impairment and multiple disabilities. The Minister approved this!

In August 2016, we trained 14 teachers from the Ministry of Education in Hope City Foundation, about the strategies for teaching learners with deafblindness or multiple disabilities and visual impairment. The training consisted of 60 hours of theoretical training followed by 72 hours of practical training. We also prepared the first curriculum for teacher training in Egypt which was approved by the Ministry of Education. We also opened the door between the Ministry of education and Perkins School for the Blind to train teachers through the curriculum of Perkins International. In addition, we encouraged teachers to study in the Perkins Educational Leadership Program to increase the number of qualified teachers. Our advocacy work continues to influence the government and NGO’s in

my colleagues we started to introduce lectures and training courses to train teachers and parents about the principals of deafblind education. I should note that the number of studies in deafblindness in Egypt as well as deafblindness awareness has increased since that time.

The magic of social interaction
I am very passionate about the Van Dijk approach as well as the booklets “Co-creating Communication”. They highlight the role of social interaction in communication development.

Social interaction works like magic in improving communication with children with deafblindness and multiple disabilities. It is the cornerstone for the development of the child.

The child’s motivation to communicate emerges from the positive experiences through togetherness. Many researches confirm that when the child securely attaches to their caregiver, he/she has a secure base which provides the motivation to explore their world around them helping them to develop communication.

We are doing our best to ensure that every child in Egypt has their right to a free and appropriate public education in locations close to his/her home.

“Social interaction works like magic in improving communication with children with deafblindness and multiple disabilities.”

1 www.perkinslearning.org/dr-jan-van-dijk-child-guided-assessment

6 John Dix Fisher first considered the idea of a school for blind children based upon his visits to Paris at the National Institute for the Blind and was inspired to create such a school in Boston. (https://en.wikipedia.org/wiki/Perkins_School_for_the_Blind)
The Educational Rights of those with Multiple Disabilities

For more information, contact Amal Ezzat (amalezzat@yahoo.com), Speech and Language Pathologist/Special Education Consultant, Hope City Foundation (https://b-m.facebook.com/Hope-City-Foundation-HCF)

Editor’s note:

a) Two weeks before the teacher training was to begin in August 2016, the author was diagnosed with cancer, which she suggested was the biggest challenge in her life and testing her courage. She proceeded with the 15-day training program despite her physician’s advice. The author said: I discovered that I am strong and needed to complete my dream and fight my health later. I decided to give the training to the teachers at its designated time, since I want to ensure these children have their rights to an education.

b) The author attended the Network of the Americas Conference and had a workshop presentation titled: Developing Early Language Skills of Children with Deafblindness and Multiple Disabilities through Social Play.

What Inclusion Means to Us?

Parents’ and Caregivers’ Perspectives in the Indian Context

Ms. Smriti Dhingra
Manager Research
Sense International India

Mr. Deepak Krishna Sharma
Assistant Manager, Networks
Sense International India

“Inclusion refers to the opportunity for persons with disabilities to participate fully in all the educational, employment, consumer, recreational, community and domestic activities that typify everyday society.” (Tilstone & Rose, 2003)

Introduction

In general, there exists different views of how an inclusive society functions and has room for diversity. Inclusion in India is not specifically defined in the recent Rights of Persons with Disabilities (RPWD) Act, 2016. However, the principles of United Nations Conventions on the Rights of Persons with Disabilities (UNCRPD) supports inclusion in the areas of education; skill development and employment; social security; health rehabilitation and recreation.

The idea of inclusion continues in society because the meaning of it has been significantly framed in various international, national and local level contexts. Sense International India, in its desire to understand the perspectives of parents of Persons with Deafblindness (PwDb) with respect to ‘Inclusion’, conducted a small session with thirty-five parents and caregivers from twenty-two states of India. This session was conducted during a National Meeting for Parents and Educators of persons with deafblindness (PwDb) and Adults with Deafblindness (AwDb), where the objective was to understand the idea of inclusion in various settings and what it means for them. This article highlights the discussions during that session, where parents felt that inclusion means to them: education, employment, participation in society, health and rehabilitation services.

Inclusion in Education

WHO and the World Bank’s World report on Disability (2011) writes “if children with disabilities (CwD) are denied the opportunity to participate, then it will lead to isolation, decreased autonomy and lower quality of life. UNICEF’s ‘The state of the world’s children 2013: Children with disabilities’ writes, “Education is the gateway to full participation in society”. These two international organizations focus upon education as the primary concern where inclusion of CwD is highly important. Similar views were expressed during this session by the parents and caregivers of PwDb, about the need for inclusion primarily at elementary and secondary school levels and secondarily during higher education.

Editor’s Message (continued from page 3)

Once again, the Country Reports feature interesting submissions from: Burkina Faso, Canada, Egypt, Switzerland, Germany and Russia. They are all a great read. Conferences continue to be an integral activity of DbI. The First Network of the Americas Conference, hosted by Perkins School for the Blind, held in Hyannis (Cape Cod, USA) this past April was an outstanding success, as indicated by the summary article outlining the conference’s activities.

By publication time, we will be just weeks away from the First Young Researchers Conference scheduled for Moscow Russia in early October 2018. Also, we are just a year away from the 17th World DbI Conference hosted by Able Australia and located in Gold Coast Australia.

In closing, I want to extend my deep thanks again to the many collaborators who submit articles to support this valuable publication.

 Respectively, 
Stan Munroe, 
July 2018

1. www.perkins.org/international/academy

2. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC54519007


4. www.senseindia.org/


EDITORS’ MESSAGE

Once again, the Country Reports feature interesting submissions from: Burkina Faso, Canada, Egypt, Switzerland, Germany and Russia. They are all a great read. Conferences continue to be an integral activity of DbI. The First Network of the Americas Conference, hosted by Perkins School for the Blind, held in Hyannis (Cape Cod, USA) this past April was an outstanding success, as indicated by the summary article outlining the conference’s activities.

By publication time, we will be just weeks away from the First Young Researchers Conference scheduled for Moscow Russia in early October 2018. Also, we are just a year away from the 17th World DbI Conference hosted by Able Australia and located in Gold Coast Australia.

In closing, I want to extend my deep thanks again to the many collaborators who submit articles to support this valuable publication.

Respectively, 
Stan Munroe, 
July 2018
What Inclusion Means to Us?

Compulsory Education Act (RTE-2009). This was later amended to include Children with Special Needs (CwSN).

The experience of parents of PwDb paints quite a different picture. When these parents approached their local schools, they were denied admission explaining that because of the students’ disability, teachers were not ready to take responsibility for them. These individuals were considered a burden for a regular classroom setting due to lack of trained human resources and school infrastructure. Further, teachers suggested the children should be enrolled in special schools or a resource centre run under Sarva Shiksha Abhiyan (SSA) i.e Education for All, a Government of India initiative. It is important to note that these resource centres are located far from the residences.

For higher education, government mandates three percent of positions reserved for students with disabilities (SwD) in government institutions. According to the National Centre for Promotion of Employment of Disabled People (NCPEDP) in its 2015 survey on ‘Status of Disability in Higher Education’, only 0.56 percent seats are occupied in over 150 higher education institutions across the country. This clearly draws an image that SwD tend to drop out of school during their initial level of education, a similar concern shared by the parents of PwDb. Parents believe that deafblindness, being a complex disability and not identified in the census, lacks proper awareness. This leads to poor access to educational services and technological advancements limiting the ability of PwDb to achieve a higher education.

To the best of Sense International India’s knowledge, only ten persons with deafblindness in India have attained or are currently pursuing graduate level or higher education. This scenario reflects the status of higher education for PwDb and their exclusion from mainstream education institutions.

Inclusion in Employment

Employment was another area of concern where parents felt PwDb are excluded. According to parents and caregivers, inclusion also means employment and the reality is that the employment sector is not inclusive for PwDb. The RPWD Act, 2016 provides that four percent of positions in government jobs be reserved for PwDb, which includes one percent of employment for persons with multiple disabilities including PwDb.

Also, private sector employers are provided incentives by the government to employ PwDb. It is observed that the job requirements for employing a PwD is quite specific; employers expect these candidates to have these usable skills. For example, a candidate must be able to multi-task, travel without any inhibitions and have computer software related skills. Employers are often not keen to invest in facilities and technology which would make the office environment accessible and disability friendly.

In such cases, the person either loses the job opportunity or if employed, doesn’t receive enough opportunities to grow while in an inaccessible work environment. This situation only qualifies exceptional PwDb’s or persons with a single disability to attain employment. In these situations, the PwDb are left behind as they require extra support for communication and accessibility in the work-setting.

Another concern is when PwDb’s drop out of school without attaining a higher education. Their only feasible opportunity is now vocational training and self-employment. Vocational Rehabilitation Centres, now known as National Career Service Centres for Differently Abled (NCSCDA)

mynacareers.com/tag/national-careers-service-centre-for-differently-abled/ and the Sense International India initiative located far from their residences.

This discussion resulted in the initiation of a research project titled: ‘Inclusive Education for Students with Deafblindness’ under the direction of Sarva Shiksha Abhiyan. This research project has as its objectives: preparation of an inclusive education plan, capacity building and awareness workshops for school teachers and other stakeholders in the government schools of Gujarath and Jharkhand.

Inclusion in Employment

Employment was another area of concern where parents felt PwDb are excluded. According to parents and caregivers, inclusion also means employment and the reality is that the employment sector is not inclusive for PwDb. The RPWD Act, 2016 provides that four percent of positions in government jobs be reserved for PwDb, which includes one percent of employment for persons with multiple disabilities including PwDb.

Also, private sector employers are provided incentives by the government to employ PwDb. It is observed that the job requirements for employing a PwD is quite specific; employers expect these candidates to have these usable skills. For example, a candidate must be able to multi-task, travel without any inhibitions and have computer software related skills. Employers are often not keen to invest in facilities and technology which would make the office environment accessible and disability friendly.

In such cases, the person either loses the job opportunity or if employed, doesn’t receive enough opportunities to grow while in an inaccessible work environment. This situation only qualifies exceptional PwDb’s or persons with a single disability to attain employment. In these situations, the PwDb are left behind as they require extra support for communication and accessibility in the work-setting.

Another concern is when PwDb’s drop out of school without attaining a higher education. Their only feasible opportunity is now vocational training and self-employment. Vocational Rehabilitation Centres, now known as National Career Service Centres for Differently Abled (NCSCDA),

have been established to provide vocational training to PwDb. It has been observed by parents and the Sense International India team members that the job skill provision is based as per market demands. These job trades are only made available with adaptation for persons with a single disability (a person with visual impairment or with a hearing impairment), thus excluding PwDb from these opportunities.

Recently as the market for vocationally trained youth with or without disabilities has expanded, the Ministry of Labour and Employment has made provisions for jobs through the National Career Service Portal (NCSCP)

for youth with or without a disability. This portal has opened the job market where employers prefer to recruit a person without disability or having a single disability and able to multi-task with efficiency, quickly learn skills and not demand a specialised work environment. This again has resulted in exclusion of PwDb from employment. As the last resort, parents now are exploring self-employment avenues, which requires investment and capacity building for the family of the PwDb.

To address the need for vocational training and self-employment, Sense International India team brought synergy to the NCSCDA ecosystem through awareness and capacity building for professionals associated with vocational rehabilitation for the employment needs of PwDb. As a result, three AwDb persons are now receiving vocational training in Kolkata and Patna.

Sense International India has also focussed on self-employment where they created the capacity for PwDb to be involved in various trades. They have provided 83 AwDb persons with financial support to set up their own Income Generation Activity (IGA) to earn their livelihood.

### Inclusion in Health and Rehabilitation Services

Article 47 of the Indian Constitution explains the mandate to improve nutrition and provide for a public health system. While various flagship health policies/programmes were initiated, there was no access to services for PwDs. This has now been changed with the adoption of the National Health Policy’s 12th Five Year Plan which has provided an inclusive approach towards healthcare.

Despite these provisions, parents of CwDb still face challenges and discrimination in accessing the health care system. For example, discriminatory and insensitive remarks are made by medical professionals about a child’s disability. Often treatment is not provided to PwDb specific to their needs because they lack understanding about communicating with them. This insensitive approach towards the PwDb does not only exclude them from health services but further causes their overall discrimination in the society.
What Inclusion Means to Us?

Provided by Sense International India

John, adult with deafblindness at his canteen at National Association for the Blind, Delhi. The canteen was initiated through income generation support provided by Sense India.

Another serious concern which parents emphasized was intrusion into their privacy while accessing these services. In one incident, an AwDb person accompanied by her parent to the hospital for a medical check-up, the doctor did not request the parent to step out or seek consent from AwDb person to allow the parent to stay. Experiences like these portray the approach of medical institutions where PwDb are not consulted as they are often considered to be childlike. The concept of consent and dissemination of information and communication is often neglected in health institutions.

In another conversation, it was observed that PwDb are not informed about their sexual and reproductive health. There exists a notion where PwDb are not considered sexual beings; as a result, the information about their own body and sexual and reproductive health is not shared with them. This leads to a situation where decisions about their health are taken on their behalf without any consent and communication.

Understanding this neglected situation, Sense International India started organizing training sessions to provide a comprehensive sexual and reproductive health education program. These trainings conducted with AwDb highlighted a huge gap in exclusion for PwDb in the area of sexual and reproductive health.

Sense International India has improved the knowledge capacity for 99 AwDb by providing information about body and body processes and other information about sexual and reproductive health. Before these trainings were initiated, the parents and caregivers were first questioned about the need for these trainings as well as the content. There was initial reluctance to send their children for these trainings. Often when they attended the trainings with their children, they did not properly communicate the information to them. Eventually this changed after training. Parents observed that their children were better understanding their bodily changes and becoming more confident about managing their body independently, requiring less support. As a result, there was a greater demand for similar training.

Regarding health care for this disabled population, there exists a range of accessibility barriers. These include: lack of awareness about their location; the healthcare infrastructure likely may be inaccessible; personal assistance would likely be unavailable; the services unaffordable; and especially a dearth of professionals who understand deafblindness and the ways to communicate with them. Other examples to highlight the inaccessibility of health and health products for PwDb include the lack of availability of such products as: sanitary napkins; condoms and other contraceptives; pregnancy test kits; medications, etc. Furthermore, every time these individuals may need to access these products, they generally need to seek the support of another person, which increases their dependency as well as intruding into their privacy.

The lack of rehabilitation services is also a source of worry for this population, as well as the availability and quality of technical aids and appliances. Sometimes the aids and appliances they receive are unsuitable or do not function. PwDb’s demand a system where they could receive customized devices at an affordable cost with trained professionals available to provide support and counselling.

These experiences described by PwDb individuals themselves, stress the need for inclusion in health and rehabilitation services. A mechanism must be developed where services are made available in reasonable time and health professionals are trained to be aware of people with these disabilities.

Inclusion in Society – Holistic Approach

Parents and caregivers associated with Sense India belongs to different cultures and class systems. Expectations for their inclusion in society will only be fulfilled through systemic and policy changes. A change in society, through a holistic approach, is required where provisions are made such that no PwDb is left behind in their engagement with society. During the exchange of thoughts about exclusion from society, parents explained how their children are being excluded from the playground, even family ceremonies in their own family settings, including their children’s birthday parties. They understand that inclusion in the society and other services is their children’s constitutional right, but as they shared their stories, they underlined the harsh truths of the society in which they live. They furthermore demanded attitudinal change in every aspect. While these experiences painted a heart-wrenching picture for us at Sense International India, it reinforced our resolve that we are all responsible for making society a better place to live for everyone.

The following are a few comments made by parents demonstrating the lack of inclusion:

- Parent from Madhya Pradesh, “People stare at my daughter whenever she goes to play in the park”.
- Parent from New Delhi, “Swings in the play areas are not made accessible as per the child’s need hence I cannot leave my child alone”.
- Parent from Jharkhand, “Nobody showed up to my son’s birthday party from the neighbourhood”.
- Parent from Orissa, “Parents from the neighbourhood think that my child will harm their children, therefore, they instruct their children not to play with my child. My only question is: don’t other children fight with each other during play?”
- Parent from Mumbai, “During family ceremonies, I am indirectly asked not to bring my child along because she is deafblind.”

Parents from West Bengal, “I had never thought about my son’s marriage. One day he expressed the desire to get married but my extended family vehemently opposed the idea.

Conclusion

These narratives of caregivers and parents speak about how PwDb are denied basic human rights in our present society. This struggle for inclusion is an everyday struggle where intervention in policies and an attitudinal change in Indian society is necessary. Yes, there are systemic changes where current government Acts and Policies have increased opportunities in various sectors and services for PwDb’s; but at the same time it is very important to observe how many of these reserved seats are actually occupied by these individuals. These discussions not only represent the systemic gap but also highlight the reality of our non-inclusive attitudes. The change cannot be brought by taking a micro to macro level approach or vice-versa. The approach must be both ways together because we are already many decades behind in bringing systemic and attitudinal changes in comparison to other developmental concerns.

References


All photographs by Sense International India
Empowerment of Children with Dual Sensory Loss

Karina Hoejbjerg Seiler, Consultant for children with deafblindness, Centre for Deafblindness and Hearing Loss, Aalborg, Denmark

Throughout my working life I have been concerned about just how creative a consulting conversation with a child could be, for it to be as meaningful as possible. Inspired by narrative coaching, my perspective has recently become focused on empowering their living conditions and externalizing challenging problems. I found that my counselling can be even more applicable and effective, if I focus on the child’s experiences, emotions and reflections on their reality, dreams, issues and future...

The Centre for Deafblindness and Hearing Loss provides national counselling for children, families, pedagogic staff, social workers, habilitation workers and educational facilities for children (0-18 years of age) with acquired and congenital deafblindness.

I am a consultant for a group of children and youngsters, primarily those with acquired deafblindness, living in the area of the Danish capital Copenhagen. Given the fact that my task is to guide these children to live meaningful and acceptable lives despite their sensory loss, I constantly try to improve my approach in each case. Previously I have been very focused on supporting each individual primarily by using various technical aids and asking such questions as: “how are you doing right now?”; “how can I, or someone else, help you?” Generally, my approach for each child is first to estimate their degree of hearing and vision loss, then suggest various solutions to the family members, teachers etc., based on my assessment of each individual’s situation.

Inspired by a course in narrative coaching (based on systems theory) I decided to change my way of counselling by doing something different. I started trying methods and techniques inspired from narrative coaching... using examples such as externalization and outside witness methods. My question guide was inspired from Karl Tomm’s externalizing circle-questions. Instead of asking, “Is physical education/gymnastics difficult? Why?”, I would try to open up my line of questions and ask; “what are the challenges with physical ed/gymnastics? What do these challenges do to trouble you? How do manage to get through anyway? These strengths – can you bring them with you into your other areas in life, where you will meet other challenges?”

After a period of time, I realized that the center of my counselling should focus on: how each child should empower themselves to cope with the lifelong consequences of their dual sensory loss and help them appreciate that the person is not the problem but their disability is and they must learn to cope. The latest research from Swedish Scientist Moa Wahlqvist about people living with Usher syndrome has shown that children and young adults living with dual sensory loss are highly designated to deal with psychiatric issues later in their adult lives.

Based on my interviews with young adults living with dual sensory loss (and supported by information from experienced colleagues), she suggested that the reason for the many psychiatric challenges these individuals face, have their foundation in childhood. Therefore, it is a priority to focus on the child – to support them to cope as a person with deafblindness. As pedagogic consultants, my colleagues and I follow each child closely throughout their development. We need to be aware of the importance of empowering these children by guiding them to develop personal coping strategies that provide them with a clear understanding of their complicated situation.

In Denmark we have a national counselling for deafblindness and hearing loss. Based on her interviews with people living with Usher syndrome? How much is the Usher syndrome bothering you today when going to the movies with friends? etc. These conversations also help to reassure the child’s inherent strengths and allows them to understand and deal with their lifetime sensory losses. Consequently, the individual should be better able to handle difficult changes throughout their lives whether it be going to an unknown place, moving to a new home, starting education, changing jobs, etc. Practicing small changes with success, will provide the child an opportunity to gain inner strength for dealing with larger changes throughout their life.

1 The Centre for Deafblindness and Hearing Loss (www.cdh.rn.dk) is a small corporate member of DbI
2 Narrative Coaching allows one to uncover, understand, and change what truly drives human behavior through the process of listening to and understanding (narrativecoach.com/program)
3 Karl Tomm 1992, Canadian psychiatrist & family systems therapist.
4 https://www.researchgate.net/profile/Moa_Wahlqvist
In using the narrative and systems theory of thinking, my aim is to capture the essence of each child’s concerns. Actually, I create a drawing as a summary of our conversation. Each drawing serves as an ‘outsider witness’ of what the child’s finds important which I then document in my working journal. My aim is to co-create the drawing with the child during the conversation that we have, whether it is at their home or at school.

Recently my colleagues and I have started a teen-group for 4 girls with different levels of dual sensory loss. Our goal is to facilitate a process for the girls to draw something important or useful aspects of their lives. Examples include ‘what/which things are our helpers, and who/which things are troubling’. Listening to each other is an important key in narrative conversation. Danish philosopher Ole Fogh Kirkeby states: “I only understand what I say, when I hear it from others”. In Danish we have the ‘effect of the mirror’, meaning that I know myself better in meaningful connections and relations to significant others.

Members of our teen-group will be witnesses to important thoughts and emotional expressions from each other, and hopefully they will understand themselves better, and be better able to cope, using their inner resources, with life’s changes. The points of the individual drawings will become significant in future counseling with the child’s parents, teachers, pedagogic staff etc., since they provide this network information on exactly what makes sense for the child! What could be more important…? Much more work needs to be done. I hope to meet European and International colleagues for co-creating workshops & conferences to share information and experiences about; how to be more significant as a guest in the lives of people living with dual sensory loss.

For more information, contact Karina Hoejbjerre Seiler by email at k.seiler@rn.dk

---

**In using the narrative and systems theory of thinking, my aim is to capture the essence of each child’s concerns.**

---

Plenary presenter Maurice Belote

Plenary presenter Ed Bosso
The Keynote Speaker of the Conference was Dr. Anthony Lake, Past Executive Director of UNICEF. In his presentation titled “It’s About Ability: From Inspiration to ‘Of Course’,” Dr. Lake urged leaders in the deafblind community to advocate for lasting change by influencing not only lawmakers but citizens as well. “Our progress will depend upon legal and regulatory reform – and translating that reform into everyday practical action,” he said. “But also, and perhaps more difficult, it will require changing public attitudes around the world.”

Plenary Sessions
The conference featured three Plenary Sessions with the following themes: Family Partnerships; To be Included – What does it mean? and Measuring Success. Each Plenary session included a plenary speaker followed by a plenary panel discussion.

The Three Plenary Speakers were: Ed Bosso (Perkins Superintendent), George Stern (Vice President, DeafBlind Citizens in Action and Maurice Belote (Project Coordinator for California Deafblind Services). The titles of their presentations were as follows: “Simplicity: The Other Side of Complexity” (Ed Bosso); “The Inclusive Mindset” (George Stern), and “Happiness and the Search for the Essence of Success” (Maurice Belote.) The titles of the three associated plenary panel sessions were in the same order: Perspectives on Family Partnerships; Perspectives on Inclusion and Perspectives on Success.

Workshops, Poster Sessions and Focus Groups
Over the four-day program, over 90 workshop sessions were organized, 11 posters were displayed, and 3 focus group discussions were held.

Reflections and Future Directions
The daily events of the conference concluded with the final topic: Reflections and Future Direction, featuring Robbie Blaha and Chris Russell. Robbie, a long-standing expert in deafblindness from the Texas School for the Blind and Visually Impaired, reflected on the conference and deafblind services in the USA; while Chris represented the new blood in deafblind services and spoke about what he viewed as the future direction for services in the USA.

Conference Closing
The conference concluded with the evening Awards Banquet featuring an address from Ambassador Aubrey Webson (formerly from Perkins School for the Blind), titled: Leaving No Child Behind. Perkins handed out their prestigious Ann Sullivan Macy award to several individuals; while DbI presented awards for Distinguished Service and Life Time Achievement in the field of deafblindness.

The 1st International Young Researchers Conference on Deafblindness is a new and big event for most talented students, graduate students and young scientists from Europe, Asia, America and Russia who are interested in problem of visual and hearing impairments.

The MAIN GOAL OF THE CONFERENCE is the exchange of experience between young specialists in deafblindness and the creation of an international network on which depends the future of the science and practical assistance to persons with deafblindness.

TIME AND PLACE
Moscow on 9–11th of October

Services FREE for participants
- Registration fee
- Coffee breaks, lunches, welcome cocktail, farewell banquet
- Night Moscow city-tour

Conditions
- We invite young specialists (at the age up to 35 years) already having experience of scientific and practical work, as well as students who are just starting their way in the field of studying deafblindness.
- We are waiting for the presentation of big and small researches and practical reports in the field of physiology, medicine, social work, psychology and education.
- Possible forms of participation: without presentation, presentation – master class (20 minutes), short message (5 minutes), poster presentation.

Registration
- The registration fee is not required for participation.
- During the conference the participants will be provided with free food (coffee break, lunch, welcome cocktail, farewell banquet).
- Registration is available on the website http://so-edinenie.org/conf-youth/en/
- For more information, please, contact the organizers j.mayorova@so-edinenie.org
- Travel-coordinator (hotels, visa support) k.yaritskaya@so-edinenie.org

Prepared by Stan Munroe

Organizers: The Russian Deafblind Support Foundation “Con-nection” (www.so-edinenie.org)
ABLE AUSTRALIA WELCOMES THE WORLD TO THE GOLD COAST FOR THE 17th World Conference on Deafblindness
August 12–16, 2019

Hosted by Able Australia1 the 17th Deafblind International World Conference 2019 will be held on the Gold Coast, Queensland Australia2, August 12–16, 2019. The conference will take place at the Surfers Paradise Marriott Resort & Spa3. The Scientific Committee4 has selected as the conference theme: “Sharing the Knowledge to ACT: Accessibility, Communication, Technology. Now is your time to ACT!” Each day of the conference will feature one of these three themes (ACT).

To commemorate this conference, the logo design includes the acronym ACT in black and white font, with the words ‘Accessibility, Communication and Technology’ in smaller font at the bottom. The boomerang represents Australia and acknowledges Able Australia, the host organization.

Conference attendees, including individuals who are deafblind, families, academics and professionals are encouraged to attend the conference. A variety of perspectives including research and best practices in deafblindness within the themes will be shared throughout the conference period. The period of Early Bird Registration will be December 01, 2018 through February 28, 2019.

1  www.ableaustralia.org.au
2  https://www.destinationgoldcoast.com
3  www.marriott.com
4  The Conference planning committee includes representatives from Australia, Argentina, Canada, Denmark, India, Japan and USA

CALL FOR PAPERS NOW OPEN
Call for papers open until August 31, 2018.
17th Deafblind International World Conference
www.dbiaustralia2019.com.au

The Scientific Committee is seeking presentations that align with the conference theme: Accessiblity, Communication and Technology. All applicants interested in presenting at the conference should prepare their presentations to meet accessibility requirements for a fully inclusive experience for all participants.

For further information, please contact: Roxanna Spruyt-Rocks, Scientific Committee Chair at dbi2019info@deafblindontario.com

The Scientific Committee will confirm presenters in early December 2018.

CONFERENCE INFORMATION
www.dbiaustralia2019.com.au

Conference dates: 12 – 16 August 2019
Registrations open: 1 December 2018 – 28 February 2019
Dbi network workshops/meetings: 11 August 2019
Venue: Surfers Paradise Marriott Resort & Spa
158 Ferny Ave, Surfers Paradise QLD 4217

Follow us on Facebook:
www.facebook.com/ableaus
www.twitter.com/AbleAus

Burkina Faso

Education Beyond a Thorn-Ridden Path

Bambaro Olivia is 11 years old. She was born deaf in Garango in the East-Central region of Burkina Faso. When she was 7, she suffered a trauma in the eye, this trauma left a scar in the cornea. She had now become visually impaired as well, leaving her deafblind. At that time her parents and people around her thought that she would not benefit from going to school. She was kept at home.

Olivia comes from a low-income family where her father is a farmer and her mother a housewife. She is the second born of four children. Her family’s financial circumstances and her disability meant that her parents came to the conclusion that Olivia would not benefit from going to school and that they could not afford to send her to a special school. This situation is not unusual in Burkina Faso. Many children with disabilities are not supported to go to school by their families or communities. Not all teachers are aware of the country’s policy for all children to have equitable access to education. This situation is changing; more teachers are being trained in inclusive education. However, life was hard for Olivia living with deafblindness in her rural community. She was often left alone at home with very little communication between her and her family. There seemed to be no way to change her situation. The other children of her age were not very interested in her because of her deafblindness. She was seen as different. She was marginalized, unhappy, and was seen as a burden on her parents because she was not independent. She was totally reliant on others to support her every day existence.

In 2013 a community-based inclusive development (CBID) team came across Olivia in Garango. This programme is an implementation partner for CBM’s Inclusive Education project. After her identification she was referred for eye health care. During medical examination by an ophthalmologist, the corneal scar in the one eye was found to be irreparable. The second eye was diagnosed as having low vision, so she could use this vision to find her way around and to learn in school.

Her hearing was also assessed. She was diagnosed with a sensorineural hearing loss, leaving her profoundly deaf. No amplification aids were available. She and her family were provided with lessons in signed communication.

Despite the support of the CBID team with eye medicines, her parents were still pessimistic and reluctant to send her to school. The CBID team worked hard to convince Olivia’s parents to send her to school. Following these discussions Olivia was enrolled in the Bougla Ladenbourg School in Galindo. This is a state school supported by amongst others, Centre Saint Martin e.V. (Germany), who has supported inclusive education activities at the school for several years.

The staff at the Bougla Ladenbourg School are trained in Inclusive Education techniques. All children are used to seeing and being in class with children having different needs and strengths. They are used to diversity.

The inclusive ethos of the school means that signed communication is accepted as an important way for communicating with children who are deaf. Since Olivia’s admission to primary school, her life has changed for the better. Schooling with deaf and hearing children has been positive for her. She can communicate in sign language with her classmates and her teacher.

Olivia is now in the CP2 Class (second year of primary school). She does find some aspects of school learning challenging due to the years

11 August 2019

The Conference in Australia

Country News

Burkina Faso
Burkina Faso continued

The Development of a Deafblind Team: A Collaborative Partnership to Meet Complex Student Needs

Surrey School District1 has developed a unique approach to support their population of students with deafblindness, one that is contingent on the collaboration of a diverse group of professionals. Surrey School District is located in British Columbia (BC), Canada. It is the largest school district in the province with more than 70,000 students, and is extremely diverse. Surrey is currently home to 13 students, kindergarten through grade 12, who are identified as deafblind. They are very different with respect to age, strengths, and needs, as well as where they live within the district.

A key support for students who are deafblind in BC is the Provincial Outreach Program for Students with Deafblindness (POPDB)2. POPDB has teacher consultants that support students and their school districts all around the province. For the past 12 years, Surrey has had one primary consultant – Michele Kohut-Jones. Prior to establishment of the team, there were frequent changes with respect to school district partners, school-based staff and district leadership. Every year Kohut-Jones had to effectively “start over”, a huge frustration considering that she was not even an employee of Surrey District! The district recognized the need for a cohesive educational program, however, each team member was very different and had a limited understanding of each other’s roles. At the same time, key people were often missing from the planning table, and documentation systems were virtually non-existent. Independent Educational Plans (IEPs) were written with no understanding of deafblindness and contained goals that were unrealistic. Independent educational programs were ill-equipped to create meaningful materials such as calendar systems.

During September 2014, Director of Instruction Michelle Schmidt adopted the portfolios for students who are Deafblind or hearing impaired and blind/visually impaired. Soon after, Schmidt realized that educational programs were not being developed from the perspective of dual sensory impairment. With this in mind, a proposal was submitted to the Board of Education to attend the Deafblind International Conference in Romania during May 2015.

Consequently, Schmidt returned home with an intense desire to do more and with a better sense of the possibilities. Specifically, Schmidt thought to create a Deafblind team, to develop consistency and to utilize the expertise of POPDB to build district capacity.

A key role in the team would be an Integration Support Teacher with a special focus on Deafblindness. Tanya Margison was offered the then part-time position in fall 2015 and eventually becoming the case manager for all the students who were deafblind. Under Kohut-Jones and Margison, Tanya learned about the unique needs of students with deafblindness. Now a full-time position, Margison plays a huge role as the case manager, in addition to conducting assessments, supporting the classroom teacher and school team, modeling interventions, facilitating transitions, organizing itinerant supports and community outings, and being the first contact point for parents, school staff, and members of outside agencies.

In fall of 2015 there was another role specifically designated for the deafblind students, that of the District Deafblind Intervenor. Rachel Kavanagh received her Deafblind Intervenor training at George Brown College1 in Toronto, Ontario, Canada. Kavanagh’s role is multi-faceted requiring a flexible approach in supporting the educational assistants (EA) and school teams, working and building relationships with students, documenting in various forms, and making materials established by the team. It is a unique role in the deafblind world and it continues to evolve as the team and student needs evolve.

In addition to the above members, the primary team currently includes a Teacher of the Deaf and Hard of Hearing (Annie Lembauer), a Teacher of students with visual impairments (Kendra Anderson), and a Speech and Language Pathologist with a specialization in Alternative and Augmentative Communication (Ann-Maree Foxe). Two physiotherapists and two occupational therapists serve on the team as well.

1 This article was presented at the First Network of the Americas Conference, April 2016, 2018
2 https://www.surreyschools.ca
3 popdb.sd38.bc.ca

FIGURE 1 Interaction of the Deafblind Team Legend:
- TDHH – Teacher of Deaf and Hard of Hearing
- TVI – Teacher of Blind/Visually Impaired
- OT – Occupational Therapist
- PT – Physical Therapist
- AACSLP – Augmentative Communication Speech and Language Pathologist
- POPDB – Provincial Outreach Program for Deafblind
- District Intervenor

“...The development of the Deafblind Team in Surrey School District has been a dynamic process and every variation will experience success as long as the students who are deafblind are kept at the centre...”

Originally written in French by Valerie Ouedraogo and translated by Sian Tesni (Sian.Tesni@cbm.org), Senior Advisor for Education Technical Unit CBM International

therapists are also part of the team. Additional professionals join each student’s team as needed, such as nursing support. Overall the benefits have been far reaching, for students, school teams, families and team members themselves. Some of the projects we’ve been able to work on include: providing deafblind simulations, creating brochures, developing a literacy program, and piloting an assessment with the Provincial Resource Centre for the Visually Impaired (PRCVI) using the Transdisciplinary Play-Based Assessment1 and Jan van Dijk’s domains2.

Team members have been able to network outside of Surrey District at conferences and professional development days. The district has been supportive of staff who want Braille and American Sign Language training, as well as taking courses through POPDB who offers a Deafblind Intervention Certificate Program. These are all in addition to the many meetings and day-to-day support that the team provides. The Deafblind team takes an inclusive, student centred, strength-based, holistic approach that recognizes diversity, as well as the need for collaboration, mutual respect, equal participation, accountability, and continuity. Team members benefit as we work smarter, not harder. The team creates a sense of community, reducing feelings of isolation as well as providing opportunities for reflective practice. Collectively there is an increase in professionals’ knowledge and skills, and together we have a greater appreciation of student strengths and capacities. The benefits to students are multi-dimensional. As student needs, wants, and cultural context are acknowledged, it impacts the supports that they receive. Goals reflect each students’ uniqueness, and learning demonstrates that students feel understood. When there is increased capacity at the school level among those who work with the students on a daily basis, the students are more comfortable. We have also noted that parents have become much more involved with decision making and as a result, what we do at school more easily transfers to home.

In everything, there are always challenges and growing pains to overcome. All professionals have had to adjust their styles to allow for a more team focused approach. We have had to learn a balance between respecting where our professions differ and trusting each other in those areas of overlap. Efficient communication is another challenge as we all visit the students during the week, and often have notes or updates that need to be shared. To date, we shift between sending emails, phoning, and creating running documents on our district portal. Another challenge that we have had to adjust to is that of answering a question from the school which may require consultation with the team first. The benefits of the team far outweigh the challenges – which are almost entirely related to personal relationships. Dependent on the school which we work with, we may require consultation with the team first. The benefits of the team far outweigh the challenges – which are almost entirely related to personal relationships. Dependent on the school which we work with, we may require consultation with the team first.

The development of the Deafblind Team in Surrey School District has been a dynamic process and every variation will experience success as long as the students who are deafblind are kept at the centre.

For additional information, contact Michelle Schmidt PhD, Director of Instruction, Surrey School District (schmidt_m@surreyschools.com)

1 www.products.brookepublishing.com
2 www.perkinselearning.org/dj-van-dijk-child-guided-assessment

Country News

Dual sensory loss in older Canadians: First insights from the Canadian Longitudinal Study of Aging

Anni Hämäläinen, Paul Mick, M. Kathleen Pichora-Fuller, Walter Wittich

With life expectancy steadily increasing and the baby boomer generation reaching retirement age, the number of senior citizens is on the rise3. One consequence of this increase is that more people find themselves adjusting to newly acquired sensory challenges in their advanced years, as both vision and hearing tend to decline with age. As a result, acquired dual sensory loss is becoming an increasingly important public health concern and a research priority.

The consequences of combined vision and hearing impairments range from minor reductions in ability to perform daily activities to major challenges participating in social activities, and even an increased risk of depression and dementia. People with mild visual or hearing loss can often compensate for an impairment in one sense by relying more on information acquired via the other sense. They may also need to harness more of their brain capacity to interpret the visual or auditory information that comes from the world to their brains. However, when both senses have deteriorated, or cognitive function declines simultaneously (e.g., due to dementia or mild cognitive impairment), the ability to compensate for sensory loss plummets. As a result, many studies have found that dual sensory loss (loss of both vision and hearing function) can have much more severe consequences for quality of life and independence than either hearing or vision alone4 and hearing impairment as average pure-tone air conduction threshold greater than 25 dB (500–4000 Hz, better ear). For society to prepare to accommodate and care for older adults with dual sensory loss (and often many other co-occurring chronic health concerns), it is critical that we determine just how many people are at risk for or currently suffer from dual sensory loss, and whether there are modifiable lifestyle and health concerns that could be addressed to prevent or slow the progression of dual sensory loss in older adults.

Epidemiologists can identify factors that could influence the risk of progression of dual sensory loss by collecting information on sensory function as well as details on various aspects of lifestyle and health in large numbers of people. Statistical methods are then used to determine which of those factors differ between people who have developed dual sensory loss and those who have not. We are examining dual sensory loss in 30,000 Canadians aged 45–85 years, who are participating in the comprehensive, ongoing Canadian Longitudinal Study of Aging (CLSA, https://www.clsa-elcv.ca/). This study is the largest undertaking in Canada to understand the biological, psychological and social aspects of aging. The first wave of data collection was completed in year 2015, and the study is set to run for a total of 20 years. In addition to answering numerous questions about their background, lifestyle, environment and health, study participants complete a number of cognitive tasks and undergo vision and hearing testing. Our aim is to use data from the CLSA to examine longitudinal changes in hearing, vision, health, and many other aspects of aging.

Country News

Canada continued

24 • DbI Review • Jul 2018

Canada continued

2018 • DbI Review • 25
Scaling up from the data set for the 30,000 people who are participating in the CLSA, we have estimated that there are currently upwards of 130,000 older people in Canada who have measurable dual sensory loss. The person being tested can see at a distance of 20 feet or 6 meters what a normally sighted person can see at 32 feet (10 meters). As predicted, we found that dual sensory loss was more common in older participants: a diagnosis of both hearing and vision loss increased from less than 1% in the 45–49 year-age group to 24% in the 80–85 year-age group (Figure 1). However, when we asked participants to evaluate their own vision and hearing ability (from “excellent” to “poor”), only about 1% of the youngest age group (45–49 years old) and 3% of the oldest age group (80–85 years old) reported that their vision and hearing were “fair” or “poor”. Thus, even though almost a quarter of this oldest age group were found to have dual sensory loss based on audiometry and visual acuity tests, fewer older people reported having sensory problems. This suggests that unless the impairments have noticeably severe consequences on people’s lives, most do not self-report dual sensory impairment that may be detected using tests of hearing and vision. This finding is important because other health problems may be worsened or complicated by sensory impairment even if the person does not notice a problem with their sensory function. For example, our preliminary results suggest worse cognitive function (executive function and short-term memory) in participants with dual sensory loss than in those with only hearing or vision loss or no sensory impairment. Strikingly, objectively measured sensory loss (using audiometry and vision acuity tests) is a substantially better predictor of cognitive decline than self-reported sensory loss.

It is obvious from our results that sensory impairments and other chronic health issues are far from usual conditions in the older adults. Some women and men maintain excellent sensory function until old age. In examining factors other than age, we found that dual sensory loss was more common in men than women, in groups with a lower education and income level, and in people reporting lifestyle risk factors such as smoking, obesity, and unhealthy nutritional habits, as well as those with diabetes or cardiovascular disease. The significance of these lifestyle risk factors suggests a possibility that age-related dual sensory impairment could be attenuated or even prevented with lifestyle adjustments. Encouraging people to adopt healthier habits also aligns with best practices for lowering the risk of heart disease, diabetes, and dementia among other aging-associated diseases. Thus, strategies that may reduce the risk of hearing and vision loss fit well in a more general approach to promote overall healthy aging.

Acknowledgments: This work was done in collaboration with the CCNA team 17, particularly Natalie Phillips (Department of Psychology, Concordia University) and Dawn Guthrie (Department of Kinesiology and Physical Education, Wilfred Laurier University). Funding was provided by CIHR (grant LSA 94/47) and the Canada Foundation for Innovation. The CLSA is led by Drs. Parminder Raina, Christino Wolfson and Susan Kirkland. The preliminary findings reported here are based on analyses of the CLSA Baseline Comprehensive Dataset version 3.2.

For more information, contact anni.hamalainen@umontreal.ca

Authors: Anni Hämäläinen and Walter Wittich1 are affiliated with the School of Optometry, University of Montreal Paul Mick is affiliated with the Faculty of Medicine, University of British Columbia and M. Kathleen Pichora-Fuller is affiliated with the Department of Psychology, University of Toronto.

References

1 Walter Wittich is Leader of the DbI Research Network

FIGURE 1: Age-specific proportions of people with hearing, vision, and dual sensory loss in participants of the Canadian Longitudinal Study of Aging, based on audiometry and visual acuity measures.
Education of Learners with Deafblindness and Multiple Disabilities at Hope City Foundation, Egypt

Education = Life

Hope City Foundation is a non-profit organization established in 2014. We provide comprehensive educational services for persons from birth to adulthood with visual or hearing impairment with or without additional disabilities, deafblindness and those with multiple disabilities. We provide technical assistance and trainings for teachers, specialists, researchers and families.

MISSION:
Achieving quality of life, independence, inclusion and social participation for persons with deafblindness, visual impairment or hearing impairment with or without additional disabilities and those with multiple disabilities.

VISION:
Enable persons with these disabilities to obtain their right to appropriate education and provide them with the quality educational and rehabilitation services to achieve their independence, employment, production and participation effectively in society.

Hope City Foundation provides comprehensive educational services to children and youth with sensory disabilities (with or without additional disabilities) from birth to 22 years old. Every child has an individual Educational program using the calendar system to recognize their schedule. Our Program offers several curriculum options using Montessori Method frameworks, including practical life, sensory life, language, math, science, social studies and art. We have four classes as follows:

1. Early Intervention
For babies from birth to four years old. We invite parents to attend with their baby to learn all about their child. In this stage we help our children to explore and discover through social play.

2. Preschool
For children ages four through eight. We focus on behavior management, self-care skills such as toileting, eating, washing and dressing, sensory integration, motor skills, cognitive skills, early language and communication.

3. Early Academic
For children ages from six to twelve. We focus on development of social and behavior skills, independent living skills, communication and language, cognitive skills, early academic skills, physical education, religion, music, art, and play skills.

4. Vocational
For youth from twelve through to young adults up to twenty-two. We incorporate expanded core curriculum areas to encourage our students to be independent; preparing them to find a job to become productive members in the community. We focus on functional academic skills, daily living skills, language and communication, food preparation, manufacturing of accessories and handmade carpets, packing, housekeeping, shopping, arts and crafts, orientation and mobility, and music.

EDUCATIONAL SYSTEMS
Hope City provides quality educational services for children and young adults with multiple disabilities, visual impairment, hearing impairment or deafblindness (MD/DB) through several systems:

School model system
(Full day): educational services are offered through individual and group sessions. It has been created as a school model to prepare the learners to easily move into regular classes and get them used to the regular daily school system.

Individual sessions: Many individual sessions are offered for children who cannot attend the full-day program. The sessions are offered in several areas: speech therapy, academic skills, occupational therapy, auditory verbal therapy, visual habilitation, Braille, Sign Language, orientation & mobility. Physical Education, Art & crafts, Music, Vocational Habilitation, computer and technology.

Assessment department: Assessment services are provided in the area of psychological assessment, developmental assessment, communication & language assessment, academic skills assessment, OT assessment, behavioral assessment, functional visual assessment, functional auditory assessment, assistive technology assessment.

Training and Consulting Department: The aim of this department is to provide consultation and support to families through family training and community based rehabilitation programs. The plan is to increase the number of high quality specialists in the field of Deafblindness/multi-disability education.

The Department of Research and Scientific Cooperation:
This department is concerned with the undertaking of scientific research initiatives that contribute to the development of educational and rehabilitation services. Staff will participate in local and international conferences, assist researchers by providing human resources, organizing conferences, cooperating with local & international institutions and universities.

COMMUNITY SERVICE

• Hope City is doing its best to ensure that every child in Egypt has the right of quality education. We struggled to enable Learners with DB/MD to get their right in education through the initiative “Your right to learn”

• We introduced the first training course in Egypt for teachers of the Ministry of Education

• We prepared the first Egyptian curriculum to train the teachers in education for students with DB/MD.
Country News

**Egypt continued**

It was approved by the Professional Academy of Teachers in the Ministry of Education.

In 2017, the Foundation participated with the Arab Council for Childhood and Development in the preparation of the conceptual framework for assistive technology to include Arabic children with disabilities in education.

**RESEARCH AND PRESENTATIONS**

Hope City Foundation (HCF) is interested in scientific research to raise awareness and improve the educational services for persons with DB/MD. HCF has undertaken several research programs and made presentations at scientific conferences. In April 2018, HCF participated in the DbI Network of Americas conference, Hyannis Massachusetts, USA, with a presentation entitled “Developing early language skills of children with deafblindness and multiple disabilities through social play”. The relationship between social interaction, attention and early language skills has been identified.

The research addressed the importance of starting with developing the feeling of security with the child to develop language. The child first needs to have a secure basis for exploring the world. The research clarified that motivation emerges from positive experiences with togetherness. The communication partner should begin with the child’s preference to co-create communication. The partner must observe the child’s natural expressions and respond to them as if they are expressing communication. This research confirms that social play helps the child to express his emotion, improve his skills and hence his quality of life.

In July 2016 we made a presentation at the Seventh Scientific Conference of the Faculty of Education, Banha University, Egypt. The title of the presentation was “Adaptation and modification of the Montessori method for children with special challenges; autism, cerebral palsy, dual and multiple disabilities”. In November 2016 we participated in the First Conference of the Hearing and Speech Institute, Cairo, Egypt, with a presentation entitled “Auditory training for deafblind children with Cochlear Implants”.

We are also interested in assistive technology. We made a presentation titled “Using iPads to create communication opportunities for children with cortical visual impairment” at the 5th National Congress of the Egyptian Society of Phoniatrics and Logopedics, Faculty of Medicine, Mansoura university, Egypt, March 2015. In addition, we participated by a presentation titled “Language development in children with autism spectrum disorder and visual impairment” in the 4th Annual National Congress of the Egyptian Society of Phoniatrics and Logopedics, Faculty of Medicine, Ain Shams university, Cairo, Egypt, March 2014.

For more information, contact Amal Ezat (amalezzat@yahoo.com), Hope City Foundation (https://www.facebook.com/Hope-City-Foundation-HCF), Hope City Foundation (https://www.espl-egypt.org).

Country News

**Completion of a Three Year International Project Concerning Communication and Deafblindness Ends with an Expert Conference**

Ewald Graf

About 100 professionals attended an international conference at Stiftung St. Franziskus Heiligenbronn in the Black Forest on 2nd February 2018. The conference marked the completion of the three-year international project “EQaT”, which was attended by 100 professionals from the deafblind and deafblindness advocacy organizations. The goal of the project was to develop a qualification course to develop competent communication partners for persons with congenital deafblindness within the German-speaking area.

The results of the three-year project were presented to the participants at the international expert conference. The members of panel discussion, from left: Dr. Andrea Wanaka (Project Leader, Stiftung St. Franziskus Heiligenbronn); Professor Dr. Peter Martin (Seguin-Klinik Kehl-Kor); Professor Dr. Karin Terforth (University of Education, Heidelberg); Ministerialrat Sinke Amsussen (Ministry of Education and Cultural Affairs, Baden-Wuerttemberg); Dr. Maria Bruns (Royal Dutch Kentalis) and Barbara Latzelsberger (Austrian Relief Organization for Deafblind and Profoundly Hearing and Visually Impaired Persons (OHTB)).

The results of the three-year project were presented to the participants at the international expert conference. The members of panel discussion, from left: Dr. Andrea Wanaka (Project Leader, Stiftung St. Franziskus Heiligenbronn); Professor Dr. Peter Martin (Seguin-Klinik Kehl-Kor); Professor Dr. Karin Terforth (University of Education, Heidelberg); Ministerialrat Sinke Amsussen (Ministry of Education and Cultural Affairs, Baden-Wuerttemberg); Dr. Maria Bruns (Royal Dutch Kentalis) and Barbara Latzelsberger (Austrian Relief Organization for Deafblind and Profoundly Hearing and Visually Impaired Persons (OHTB)).

The members of panel discussion, from left: Dr. Andrea Wanaka (Project Leader, Stiftung St. Franziskus Heiligenbronn); Professor Dr. Peter Martin (Seguin-Klinik Kehl-Kor); Professor Dr. Karin Terforth (University of Education, Heidelberg); Ministerialrat Sinke Amsussen (Ministry of Education and Cultural Affairs, Baden-Wuerttemberg); Dr. Maria Bruns (Royal Dutch Kentalis) and Barbara Latzelsberger (Austrian Relief Organization for Deafblind and Profoundly Hearing and Visually Impaired Persons (OHTB)).

The members of panel discussion, from left: Dr. Andrea Wanaka (Project Leader, Stiftung St. Franziskus Heiligenbronn); Professor Dr. Peter Martin (Seguin-Klinik Kehl-Kor); Professor Dr. Karin Terforth (University of Education, Heidelberg); Ministerialrat Sinke Amsussen (Ministry of Education and Cultural Affairs, Baden-Wuerttemberg); Dr. Maria Bruns (Royal Dutch Kentalis) and Barbara Latzelsberger (Austrian Relief Organization for Deafblind and Profoundly Hearing and Visually Impaired Persons (OHTB)).

The members of panel discussion, from left: Dr. Andrea Wanaka (Project Leader, Stiftung St. Franziskus Heiligenbronn); Professor Dr. Peter Martin (Seguin-Klinik Kehl-Kor); Professor Dr. Karin Terforth (University of Education, Heidelberg); Ministerialrat Sinke Amsussen (Ministry of Education and Cultural Affairs, Baden-Wuerttemberg); Dr. Maria Bruns (Royal Dutch Kentalis) and Barbara Latzelsberger (Austrian Relief Organization for Deafblind and Profoundly Hearing and Visually Impaired Persons (OHTB)).

The members of panel discussion, from left: Dr. Andrea Wanaka (Project Leader, Stiftung St. Franziskus Heiligenbronn); Professor Dr. Peter Martin (Seguin-Klinik Kehl-Kor); Professor Dr. Karin Terforth (University of Education, Heidelberg); Ministerialrat Sinke Amsussen (Ministry of Education and Cultural Affairs, Baden-Wuerttemberg); Dr. Maria Bruns (Royal Dutch Kentalis) and Barbara Latzelsberger (Austrian Relief Organization for Deafblind and Profoundly Hearing and Visually Impaired Persons (OHTB)).

The members of panel discussion, from left: Dr. Andrea Wanaka (Project Leader, Stiftung St. Franziskus Heiligenbronn); Professor Dr. Peter Martin (Seguin-Klinik Kehl-Kor); Professor Dr. Karin Terforth (University of Education, Heidelberg); Ministerialrat Sinke Amsussen (Ministry of Education and Cultural Affairs, Baden-Wuerttemberg); Dr. Maria Bruns (Royal Dutch Kentalis) and Barbara Latzelsberger (Austrian Relief Organization for Deafblind and Profoundly Hearing and Visually Impaired Persons (OHTB)).

The members of panel discussion, from left: Dr. Andrea Wanaka (Project Leader, Stiftung St. Franziskus Heiligenbronn); Professor Dr. Peter Martin (Seguin-Klinik Kehl-Kor); Professor Dr. Karin Terforth (University of Education, Heidelberg); Ministerialrat Sinke Amsussen (Ministry of Education and Cultural Affairs, Baden-Wuerttemberg); Dr. Maria Bruns (Royal Dutch Kentalis) and Barbara Latzelsberger (Austrian Relief Organization for Deafblind and Profoundly Hearing and Visually Impaired Persons (OHTB)).

The members of panel discussion, from left: Dr. Andrea Wanaka (Project Leader, Stiftung St. Franziskus Heiligenbronn); Professor Dr. Peter Martin (Seguin-Klinik Kehl-Kor); Professor Dr. Karin Terforth (University of Education, Heidelberg); Ministerialrat Sinke Amsussen (Ministry of Education and Cultural Affairs, Baden-Wuerttemberg); Dr. Maria Bruns (Royal Dutch Kentalis) and Barbara Latzelsberger (Austrian Relief Organization for Deafblind and Profoundly Hearing and Visually Impaired Persons (OHTB)).

The members of panel discussion, from left: Dr. Andrea Wanaka (Project Leader, Stiftung St. Franziskus Heiligenbronn); Professor Dr. Peter Martin (Seguin-Klinik Kehl-Kor); Professor Dr. Karin Terforth (University of Education, Heidelberg); Ministerialrat Sinke Amsussen (Ministry of Education and Cultural Affairs, Baden-Wuerttemberg); Dr. Maria Bruns (Royal Dutch Kentalis) and Barbara Latzelsberger (Austrian Relief Organization for Deafblind and Profoundly Hearing and Visually Impaired Persons (OHTB)).

The members of panel discussion, from left: Dr. Andrea Wanaka (Project Leader, Stiftung St. Franziskus Heiligenbronn); Professor Dr. Peter Martin (Seguin-Klinik Kehl-Kor); Professor Dr. Karin Terforth (University of Education, Heidelberg); Ministerialrat Sinke Amsussen (Ministry of Education and Cultural Affairs, Baden-Wuerttemberg); Dr. Maria Bruns (Royal Dutch Kentalis) and Barbara Latzelsberger (Austrian Relief Organization for Deafblind and Profoundly Hearing and Visually Impaired Persons (OHTB)).

The members of panel discussion, from left: Dr. Andrea Wanaka (Project Leader, Stiftung St. Franziskus Heiligenbronn); Professor Dr. Peter Martin (Seguin-Klinik Kehl-Kor); Professor Dr. Karin Terforth (University of Education, Heidelberg); Ministerialrat Sinke Amsussen (Ministry of Education and Cultural Affairs, Baden-Wuerttemberg); Dr. Maria Bruns (Royal Dutch Kentalis) and Barbara Latzelsberger (Austrian Relief Organization for Deafblind and Profoundly Hearing and Visually Impaired Persons (OHTB)).

The members of panel discussion, from left: Dr. Andrea Wanaka (Project Leader, Stiftung St. Franziskus Heiligenbronn); Professor Dr. Peter Martin (Seguin-Klinik Kehl-Kor); Professor Dr. Karin Terforth (University of Education, Heidelberg); Ministerialrat Sinke Amsussen (Ministry of Education and Cultural Affairs, Baden-Wuerttemberg); Dr. Maria Bruns (Royal Dutch Kentalis) and Barbara Latzelsberger (Austrian Relief Organization for Deafblind and Profoundly Hearing and Visually Impaired Persons (OHTB)).
Development of a Professional Training Course for Staff Working in the Deafblind Field in Europe

Persons with deafblindness are highly dependent on others to assist with their communication and mobility needs because of the significant impact that arises from their visual and hearing impairment.

It has now become widely recognized that only competent communication partners, those who are trained and prepared to engage in complex communication processes, can provide the appropriate assistance to persons with deafblindness throughout their lives. It has become obvious in the field of deafblindness that there is a very real need for a broad and innovative training program for staff in this field to work with these individuals. Because of the absence of appropriate training courses, staff representing a network of organizations and institutions recently collaborated to develop a Staff Training Program (Mitarbeiter_innen Schulungs Programm) designed to establish qualifications and competencies for individuals working in the field of deafblindness. The goal of this pedagogical program is to facilitate an improvement to the quality of life of persons with deafblindness.

Training goal: The intention of this staff training program is that participants will expand their current level of competency in the field of deafblindness to become expert competent communication partners to assist persons with congenital deafblindness or persons with difficult communication to further develop their communication abilities.

When participants complete their training course as competent communication partners, they should be able to use their newly acquired skills in their daily practice to provide ‘emotionally stable and cognitively fruitful’ communication for communication challenged individuals. The Staff Training Program was developed based on the four booklets titled ‘Communication and Congenital Deafblindness’ produced by the DbI Communication Network and the new reference book ‘Communication Relations’ written by Inger Rodbroe. The training course is designed for all staff members who work with deafblind individuals of all ages. The methods of teaching are based on contemporary methodologies, using the latest findings from adult education and neurophysiology, with the use of video analysis as a central working tool.

For further information please contact Ann-Kathrin Bihler: Ann-Kathrin.Bihler@stiftung-st-franziskus.de

“The methods of teaching are based on contemporary methodologies, using the latest findings from adult education and neurophysiology, with the use of video analysis as a central working tool. ”

1 Rijsuniversiteit Groningen, Netherlands (www.rug.nl); Royal Stichting Kentalins, Netherlands (www.kentalins.nl); DTW Hannover Germany (www.taubblindenzentrum.de); Blindeinstitutsstiftung Würzburg Germany (https://www.blindeninstitut.de); Oberlinhaus Potsdam, Germany (www.oberlinhaus.de/startseite); Stiftung St. Franziskus Heiligenbronn Germany (www.stiftung-st-franziskus.de); ÖHTB Wien Austria (www.oehlb.at); Tarne Langnau a.A. Switzerland (www.tarne.ch)

2 Inger Rodbroe is one of the authors of DbI Communication Network booklets.

The participants of the project at their final meeting in Heiligenbronn conference in Heiligenbronn. Among the participants were professionals from the institutions involved in the project, as well as professionals from other institutions and public authorities.

The project leaders Andrea Wanka and Barbara Latzelsberger, and representatives from the EQuaT project working groups outlined the contents of the training program. During workshops, staff from Stiftung St. Franziskus presented insights into the diverse aspects of communication related to persons with deafblindness. This included such aspects as the use of objects of reference, interactions with peer groups, the meaning of bodily-emotional traces, etc. Through panel discussions, representatives from the Ministry of Education and Cultural Affairs (Baden-Wuerttemberg), the University of Education (Heidelberg), Epilepsy Center (Kehl-Kork) and Royal Dutch Kentalins (Netherlands) gave positive feedback to the project leaders. They praised their “training model” and encouraged them to spread the course widely.

Two relevant reference books about to be published concerning deafblindness pedagogics were presented by their authors: Inger Rodbroe from Denmark and translator Ulrike Broy-Schwenk introduced ‘Communicative Relations’. Elisa Keesen from Stiftung St. Franziskus Heiligenbronn presented her book, Angeborene Taubblindheit und die Konstruktion der Welt (‘Congenital Deafblindness and the Construction of the World’). Both books will be published by Edition Benthem. The ideas and topics presented at this conference met with a very positive and inspirational response from the participants. The chair of Blindeninstitutsstiftung Würzburg, Johannes Spielmann, thanked Roland Flaig, the head of the Services for the Disabled, for his strong commitment to the international transfer of knowledge. He was ceremoniously presented with a medal of honor and an apple tree to be planted in Heiligenbronn. Just like networking, the tree will bear rich fruit!

Looking back on this second successful EU deafblindness project, Roland Flaig suggested that: “in order to successfully complete an ambitious project, first of all one needs a great challenge, followed by visionary ideas and a strategy for their realization. Following that of course is the will for positive results with the obligation to fulfill them.”

The article was translated by Mrs. Ulrike Broy-Schwenk.

For further information, contact: ann-katrin.bihler@stiftung-st-franziskus.de
Continued Growth: An Impact Evaluation of FUNDAL

Álvaro Diaz

For Perkins International’s (PI) Latin America and Caribbean Region¹, 2017 was a special year. For the first time, an evaluation of the impact that our actions have on the children and young people with disabilities we work for, was planned for one of our most beloved programs: FUNDAL² (short for Guatemalan Alex Foundation for Children with Deafblindness, after its acronym in Spanish – Fundación Guatemalteca para niños con sordoceguera Alex). During a period of seven months, the PI Monitoring, Evaluation, and Learning team prepared the evaluation tools to be applied. Interviews, observations, reports, and quantitative data were thoroughly organized and systematically analyzed. Findings and conclusions were shared with FUNDAL’s board and staff.

The project was intended to share with a broader audience the main findings that the impact evaluation shed light on.

The Project

Perkins International’s Expanding Model Education Services in Latin America project is a four-year, multi-country, multi-partner initiative being implemented between 2014 and 2018, developed in alliance with Lavelle Fund for the Blind³. FUNDAL is one of the main organizations this project works with.

FUNDAL first opened its doors in 1997 after the son of Hellen de Bonilla, founder of FUNDAL, was turned away from school because he had multiple disabilities. She reached out to Perkins School for the Blind, visited one of our partners in Argentina, and returned to Guatemala inspired to start her own program. Over the next 20 years, FUNDAL sought and received grants and technical assistance from Perkins to strengthen its programs.

With Lavelle Fund for the Blind joining the partnership in 2010, FUNDAL has become the model education program that it is today, with schools in 3 locations – Guatemala City, Huehuetenango, and Quetzaltenango – that serve children with multiple disabilities and their families. It is the only resource on deafblindness and multiple disabilities education officially recognized by the Guatemala Ministry of Education. In recent years, the organization has emerged as a regional leader providing technical advice to peer organizations and governments in countries such as El Salvador, Honduras, and México.

Impact Evaluation (IE)

An IE is an assessment of the intended and unintended changes produced by an action, project, program, and/or policy intervention. IEs are mainly conducted for lesson-learning, decision-making, and accountability. FUNDAL’s IE was guided in order to know what progress FUNDAL was making towards reaching its output and outcome targets, what impact its activities were producing, and how FUNDAL could be positioned for continued growth in the future.

Mixed methods were used to inform the evaluation. Quantitative data was primarily gathered from project documents with subsequent verification from FUNDAL while qualitative data was gathered through interviews and conversations with key informants. Perkins visited FUNDAL and inclusive school programs to conduct observations and interview key informants. Distance interviews were conducted with FUNDAL’s partners located in México, El Salvador, and Honduras. Data was coded, categorized, and analyzed using a tool that Perkins designed to determine impact at organization, beneficiary, and/or systems levels.

Key Findings

Perkins found that FUNDAL’s activities have had a high level of impact on children with disabilities and their families.

FUNDAL has, in the last 3 years:
- Reached 11,117 children and 30,540 parents
- Trained 4,723 teachers
- Advised 138 organizations
- Can increase their impact by integrating their work with other organizations
- May enhance the production of adaptive materials and...
Russia

Living Paintings / Anima Chroma – Art, Dance and Theater in an Inclusive Performance

The Inclusion Theatre Company of Russia launched the first showing of its latest production ‘Living Paintings / Anima Chroma’ at the Cultural Forum in St Petersburg in late 2017, followed by its second performance in Moscow in January 2018. Living Paintings/ Anima Chroma is a play about paintings and how people with and without eyesight perceive them. The Inclusion Theatre Company is a centre for the development of professional inclusive theatre in Russia, bringing together artists and directors of leading drama theatres and its own inclusive troupe. It is a part of Inclusion Arts Centre which also includes Inclusion.School and Inclusion.Laboratory. Inclusion Theatre Company projects use various forms of theatre to enable actors with different abilities to reach the highest levels of artistry. Since the first staging of Touch-Ables (2015), Inclusion Theatre has produced six productions. Touch-Ables was created to raise social awareness about Deafblind people in Russia. Three further plays were co-created with three leading drama schools in Russia to explore different forms of theatre with inclusive opportunities: Marriage by Gogol, Seagull by Chekhov and Carmen by Mérimée. The productions were all brilliant examples of how high quality performance erases any limits and stereotypes, uniting actors with various abilities in breath-taking, hilarious, unforgettable plays. The search for best practices and how to apply them in Russian inclusive theatre resulted in creating the sensory performance ‘Four Winds’ as a part of accessibility programme with the British director Tim Webb. The Living Paintings/ Anima Chroma performance involves four deafblind actors who work together with three professional actors. It combines modern dance and animation by Oscar-winning artist Alexander Petrov. The actors express in their dance, the actions of the creation of seven paintings from the Hermitage art collection in St Petersburg. Actors in the performance represent the colors that come to life under the artist’s brush, turning them into artistic images. This is the first time in the world that all three components – art, dance and theater – work together, with the deafblind actors indistinguishable from their professional colleagues.

For more information, contact Natalia Sokolova (n.sokolova@so-edinenie.org), Head of Public Relations and Fundraising, Deaf-Blind Support Foundation ‘Con-sent’.

A New Association of Persons with Hearing and Vision Impairment was Recently Established in Moscow

The Association of Persons with Hearing and Vision Impairment was established in Moscow Russia, February 20, 2018. This new association was named “Con-sent”. Two hundred delegates, including deafblind people, members of their families, representatives of Russian public organization that support them, including the Deaf-blind Support Foundation ‘Con-sent’, took part in the initial congress.

Previously there was no unified organization for people with hearing and vision impairment in Russia. This unprecedented event will serve to unite not only deafblind people themselves, but also their relatives and friends. The intent is that the Association members will determine the direction and development of the new organization themselves. They intend to work actively by creating a dialogue with local authorities throughout the Russian regions, asserting their rights to initiate and implement social projects aimed at improving their quality of life as people with deafblindness. It is equally important that their family members and friends provide support in the process. The Association was established to coordinate all the projects related to deafblind people throughout all the regions of Russia and provide a means for information exchange among each other. As well it will provide an opportunity for deafblind people themselves to establish control over the implementation of programs serving their needs.

This Association intends to improve interaction with the Russian state to protect the rights of deafblind people. A major part of the work of the association will also be to raise public awareness about the problems these disabled individuals face.

For more information, contact contact Natalia Sokolova (n.sokolova@so-edinenie.org), Head of Public Relations and Fundraising, Deaf-Blind Support Foundation ‘Con-sent’.

1 For more information, check out: www.nationaltheatre.org.uk/sitess/default/files/rtv-press_release.pdf
2 See DbI Review Edition 58, January 2017
3 https://en.wikipedia.org/wiki/Marriage_(play)
4 https://www.imdb.com/name/nm0678154/
5 https://en.wikipedia.org/wiki/Carmen_(novella)
6 https://en.wikipedia.org/wiki/Mérimée
7 https://www.imdb.com/name/nm1022697
8 hermitage--www.hermitagemuseum.org
9 https://www.imdb.com/title/tt0122607/
10 https://www.enb.org.uk/news/enb9181/

1 For more information, check out: www.nationaltheatre.org.uk/sites/default/files/rtv-press_release.pdf
2 See DbI Review Edition 58, January 2017
3 https://en.wikipedia.org/wiki/Marriage_(play)
4 https://www.imdb.com/name/nm0678154/
5 https://en.wikipedia.org/wiki/Carmen_(novella)
6 https://www.imdb.com/name/nm1022697
7 https://www.imdb.com/name/nm0678154/
8 hermitage--www.hermitagemuseum.org
9 https://www.imdb.com/title/tt0122607/
10 https://www.enb.org.uk/news/enb9181/
Learning New Signs Despite a Hearing and Visual Impairment

A Pilot course run by SNABBLIND using special teaching methods

Language is always changing. New words are constantly being invented and we speak differently today from how we did just a few years ago. Of course, these new concepts also make their way into sign language. Many users of sign language who have a hearing and a visual impairment find it difficult to learn new signs because of their limited vision. A course run by the advice centres for hearing and visually impaired and deafblind people allows them to learn new signs by using teaching methods specially adapted to their needs.

In order to be able to follow other people or interpreters who are signing, you need to know, for example, how Instagram, Bitcoin and vegan are signed. The names of new Swiss Federal Councillors and of well-known people such as Roger Federer also have to be learned. Sign language experts who have themselves deaf decide which terms or sign names best suit these people. The group of experts meets regularly to define new signs, which are then included in the public sign lexicon and passed on to interpreters.

The difficulty that hearing and visually impaired people have in learning new signs relates to being able to see them. For example, if the person has a restricted field of vision, the signing area must be reduced in size (visual frame signing). Mouthing and facial expressions also form part of sign language, but people with poor visual acuity cannot see them clearly. They also find it difficult to distinguish between the letters of the finger alphabet. For these reasons, tactile signing helps them to recognise the shape of the hands, the position on the body and the movement.

As a result, in 2017 the SNABBLIND advice centres for hearing and visually impaired and deafblind people came up with the idea of offering its clients a course to ensure that they do not miss out on new signs. The pilot project took place in Zurich and could be run in other regions if there is a demand for it.

The teaching methods were developed by a person with a hearing and visual impairment, a sign language expert/instructor and a rehab specialist. The first requirement for the success of the course was to adapt the speed at which the signs were demonstrated to the participants. If you have a hearing and visual impairment, everything takes longer. We describe this different time requirement as “deafblind time”. In order to prevent the participants from being dazzled and to increase the contrast, everyone, including the course attendees, had to wear plain dark clothing up to the chin. The lighting had to be adjusted so that it was glare-free and the signing took place against a black background.

In addition, the instruction was in small groups (a maximum of six participants), which ensured that the course attendees were the correct distance away from the instructor. Each participant was also accompanied by a deaf support person who could sign very well themselves.

Because the finger alphabet can be difficult to understand, the words that were being taught were sent to the smartphones of the participants during the course in an ongoing group chat. This ensured that the word was displayed in the font size and contrast that allowed each individual to read it.

The central part of the course involved demonstrating and reproducing the signs. The instructor first showed the hand shapes, then the position on the body or in space and after this the movement. She showed the sign from the front and from the side, which made the movement easier to see, even if the participant no longer had 3D vision. Each participant’s support person repeated the sign in tactile form, if necessary, to enable the participant to understand the sign properly.

To allow a group discussion to take place, the instructor repeated what the participants said, which gave everyone the best possible view of the person who was signing.

On the first day of the course, we learned a lot of things that we could apply during the subsequent days. In the group discussions, people changed seats. The person signing had to come to the front so that everyone could see what was being said. This did not work well and therefore we switched to the “parroting” system. Discussions within the peer group are important and must not be neglected. The support person had to sit closer to the participant than we had first thought. Only two of the six participants see well enough to be able to sit in the second row. On the next course day we will try out a new approach. The trainer will sit on an office chair with castors and will move from one participant to the next to demonstrate the new sign herself in accurate tactile form. If the participants’ sight deteriorates further, we will divide them into two groups.

The course has been enjoyable, but it requires full concentration from everyone. However, the break is not just to give people a chance to relax, but also to enable them to talk to their peers.

Mäde Martha Müller SZB/SNAB (mueller@szb.ch)

Text also available in German and French.

1 Swiss National Association of and for the Blind (http://www.szb.ch/en/) is a small corporate member of DbI.
2 https://signsuisse.sgb-fss.ch/de/
Adapted Physical Activity (APA) Network

We understand that the APA network is the youngest of the networks within the DbI. We received the official approval during the European Conference, held in Aalborg, Denmark, September 2017. We are proud to have achieved this and will do our utmost to live up to the standards and guidelines of DbI. The way that we want this network to be dynamic is that each new member will introduce themselves to the group. We call for new theory, different practices and themes of discussions to benefit each participant, and for the benefit of the deafblind society. To create an open discussion at all times in our network, we have created a closed Facebook group carrying the name of ‘DbI & APA’. It is a closed group, because we like the members to introduce themselves in approximately 100 words. Then all members can see who participated and who might be of assistance, be it a similar school or a school in the same geographical area. Everybody within the field of deafblindness and adapted physical activity is welcome to join.

Within the next year, we hope to take part in the following conferences:

- www.pcn.net/fagkonference-2018
- We hope to host the first international network meeting at: www.ableaustralia.org.au/news-events/events/17th-deafblind-international-world-conference-2019

We hope you will be inspired to join the network and hopefully meet us at these conferences.

If you want to participate in the DbI & APA Network, please contact us as follows: Mads Kopperholdt (Mads.kopperholdt@fm.dk) or Anders M. Rundh (anmaru@fm.dk)

CHARGE Network

We are planning a preconference on August 11th, 2019, in advance of the next world conference in Australia. If you are interested in attending or in giving a presentation, sharing a video, etc. please contact me.

A CHARGE conference is taking place in France in September 2018.

Communication Network

Marleen Janssen reports:

A new and larger DbI Communication Network is almost here. The last year has been one of transition for our network. The following represents the main developments that have taken place in our network since September 2017.

Network meeting Communication Network at the Aalborg Conference

We organized a Network Meeting at the Aalborg conference in September 2017. There we started with a new format. The Nordic Network on Communicative Relations held a magnificent presentation. The core of their content was a video analysis about an interesting case of complex communication. The presenters plan to write a report about their presentation for the next issue of DbI Review. Anni Lise Ellefson from Norway will be in charge of that.

Following that presentation we had a discussion about how to develop the larger DbI Communication Network in the future. The following ideas were suggested:

- Share knowledge on Communication from different countries and different places all over the world. We can plan fixed moments to have contact with the network, not only at conferences but also in between. This can be done if we have a platform but also in between. This can be done if we have a platform.
- Video conferencing all over the world. We can plan fixed moments to have contact with the network, not only at conferences but also in between. This can be done if we have a platform.
- Open the Communication Network for individual members; not only for professionals but also for people with deafblindness and parents.
- Start a web page connected to the DbI website (may be also a Facebook page). We hope that many members will join and we’ll have an expanded network in the near future.

Communication Network

For more information please contact Corinne Boutet (corinne.boutet@cresam.org).

Dr. Andrea Wanka

Chair DbI CHARGE Network

As first concrete steps we agreed upon: a) making a mailing list, b) setting up a Webpage connected to the DbI website, c) plan concrete meetings with concrete topics. If subgroups want to make a report for DbI Review they can send their report first to the chair of the network. These reports will then be used for the Network report that is send to the information officer of DbI.
I hope you have some patience with our network plans, but soon we will be open for everybody who is interested.

I hope you have some patience with our network plans, but soon we will be open for everybody who is interested.

REPORTS FROM THE SMALLER NETWORK GROUPS

Groningen Group – Study group on Congenital Deafblindness and Diversity in Communication by Paul Hart

At the 2017 DbI conference in Denmark, the new DbI Communication Network was launched. Initially it will be co-ordinated by Marleen Janssen from the University of Groningen. There are many exciting developments in communication taking place all across the world, in relation to both congenital and acquired deafblindness. The DbI Communication Network aims to provide a meeting place for all those developments so that various groups can all learn from one another. It is hoped that the umbrella DbI Communication Network will comprise of many smaller groups who will consider specific aspects of communication – these groups may work autonomously or from time to time they may work together on ideas. And that is where the real value of the DbI Network in how these groups all share ideas with each other so that we can really push forward our thinking about authentic communication. Some of these groups are likely to come together at DbI World Conferences or regional conferences as part of the larger DbI Communication Network to offer pre-conferences and network days. Indeed, like any DbI networks, the Communication Network may host an entire conference on communication. All of this is for network members to decide.

Most of you will know that this new larger Communication Network has grown out of the original DbI Communication Network, which originally started as a European Working Group on Communication. This group will continue and become one of the groups that are members of the larger network. It will be known as the Study Group on Congenital Deafblindness and Diversity in Communication or the Groningen Group, because that is where most meetings of the group take place and where much of its current work is focused. The members of this group (Marleen Janssen, Marlene Daelman, Jacques Souriau, Anne Nafstad, Paul Hart and Flemming Ask-Larsen) are almost all connected to the Masters course in Communication and Congenital Deafblindness delivered by the University of Groningen in The Netherlands, under the direction of Professor Janssen.

There are already various elements that are connected to this overall program organized by the Groningen Group:

• Delivery of the Master’s course each year, with many exciting theses by students (mostly relating to congenital deafblindness but some theses have directly involved people with acquired deafblindness and has everyone to learn new insights into the diversity of human communication)
• An active Alumni network of alumni and current students of the Masters and was also open for staff and students of the University of Groningen in the field of deafblindness
• The seminar was organized for alumni and current students of the Masters and was also open for staff and students of the University of Groningen in the field of deafblindness
• The seminar was organized for alumni and current students of the Masters and was also open for staff and students of the University of Groningen in the field of deafblindness
• The seminar was organized for alumni and current students of the Masters and was also open for staff and students of the University of Groningen in the field of deafblindness

After the lecture, a case study was presented by Annika Johanssen, consultant deafblindness from Statped Norway. Annika presented a video in which an individual with deafblindness learned the linguistic concept of a tree as a result of bodily-tactile rehearsal strategies, linguistic input and reminiscing. In the afternoon, Saskia Damen, researcher at the University of Groningen, held a presentation on competencies of communication partners. In the presentation she showed research findings with regard to effective ways to support communication partners and discussed implications for research and practice. After this presentation, participants worked in small groups to analyze videos, using concepts that were presented in the lectures.

On Wednesday 15th of March an alumni seminar was held. Here it was discussed which activities are relevant for the network and how to keep in touch. This resulted in the start of a face book group. Any alumni can join the Alumni Group by Jonathan Reid. Also, it was decided to already plan the next alumni seminar on September 26 and 27, 2018. The seminar was in connection with the graduation day of the students of the Masters of Communication and Deafblindness in Groningen. This will enable the attendees of the seminar to hear the presentations of the masters projects. The topics for next seminar are ‘partner competencies’ and ‘the role of art’. The seminar will be open for alumni and other professionals interested.

For more information please contact the alumni network: alumninetworkcdb@gmail.com
Walter Wittich reports:

The DbI Research Network is moving into its fourth year of existence, and we continue to grow and expand. As of May 2018, we now have 110 members on our e-mail contact list. Saskia Damen and Flemming Ask Larsen continue to maintain the Deafblind International Research Network Facebook Group (www.facebook.com/groups/158743377516989/), which currently has 202 members and growing. Come look us up and join in the conversation! Christine Lehane continues to maintain our Deafblind International Research Network LinkedIn group (www.linkedin.com/groups/8339092/), which currently has 57 members.

The Action Research Working Group, led by Susan Bruce, continues to promote collaborative opportunities, and you can learn more about her efforts on our Research Network web page. Additional initiatives are always welcome, so please get in touch with any of the members of the DbI Research Network, in case you have an idea you would like to share. The network members have begun to organize the research activities that are planned to be part of the next DbI International conference in Gold Coast, Australia, in August of 2019, which will likely include: a Pre-Conference Research Workshop, a Research Network Session and a Research Forum as part of the conference itself. This will be an opportunity to re-visit the research priorities that were discussed by attendees at the recent 9th European Deafblindness conference in Aalborg, Denmark, where Saskia Damen and Flemming Ask Larsen hosted the Research Network session.

Until then, if you have any ideas for us, or other requests for research-specific information, we look forward to hearing from you, and please feel free to check out the networking opportunities on our web page and contact us with your interests and thoughts.

Walter Wittich (walter.wittich@umontreal.com) on behalf of the DbI Research Network Team.

The Nordic Welfare Centre (https://nordicwelfare.org/en/about-us/) is a small corporate member of DbI.

---

DbI Outdoor Network

Joe Gibson reports:

This has been a quiet period for the Outdoor Network. Here in northern Europe we have come through a long winter and are beginning our summer activities. The planning for this year’s Outdoor Week is well under way. This year’s event will be held in Semøødalen in Norway with the details as follows.

**DbI Outdoor Network Outdoor Week, 2018**

**DATES**
Week 38 17th–21st September 2018

**LOCATION**
Johnsgård Tourist Centre, Semøødalen, Norway
http://www.johnsgard.no

**PRICE**
4000 NOK per person, includes four nights accommodation, food and activities

**ACTIVITIES**
Activities will include, fishing, canoeing, outdoor cooking, making traditional food (butter and flat bread), frisbee golf and hill walking

**CONTACT**
Reidar Martin Steigen reidarms@online.no

This past May the Nordic Welfare Centre ran a course on Meaningful Activities focused on outdoor activities. As a result of this event, the Outdoor Network now has many new members. There are now currently over 140 people on the mailing list and over 150 on the Facebook page. The address for the Facebook page is: https://www.facebook.com/groups/771554296237459/ and can be searched for as: Outdoor Network, Deafblind International.
Usher Network

Emma Boswell reports:

The Usher Network members are making plans for another exciting Usher Network Pre-conference in Australia next Summer 2019. More details to follow in the next edition of DbI Review. If anyone would like to be on the mailing list, please do contact Emma to be added to the list.

In the meantime we are thrilled to welcome Alana Roy as a new member of the Usher Network. Alana Roy is a registered Psychologist, Mental Health Social Worker, Counsellor, Advocate, Teacher and PhD candidate specialising in Deafblind research methodology. She is completing a Diploma in Auslan. Alana is passionate about working with trauma, suicide prevention, disabilities, mental health and wellbeing for children, youth, families and adults. Alana can be reached at: alana@thesignsoflife.com.au

As part of my report, I am adding this personal story which happened on the train.

Have attitudes towards disabled people within society (UK) REALLY changed in the last few decades?

I was returning from a meeting in Birmingham recently when I had an ‘exchange’ with a lady on the train. The lady was travelling with her three children (and lots of luggage) and she reacted angrily to my request to move seats. We were all boarding at Birmingham, the lady was in front of me as we piled onto the train. Unfortunately, as I got through the doors and found my way to my reserved seat at the front of the coach, the lady and her three children were already sitting there. I was standing to the side of the table, in the aisle, with my guide dog, Bella by my side and my interpreter behind me. She reacted rudely when asked if we could sit down.

There were two people in front of me but they decided to walk away quietly as the woman angrily picked up her bags and pushchair and her bewildered children. As you know there is limited space on trains, Bella and I had to lean to the side to let her past, she stormed around swearing saying she should have been put down (we were in the corridor of the coach, the lady and her three children left the carriage with an air of anger. We sat down and the interpreter told me exactly what she had said. The two women who were behind us in the queue to get on the train sat down next to us, they were shocked too as they had heard the lady’s comments, and to add insult to injury as one of their relatives are deaf!

I felt strangely calm and not bothered by her comment, but I had to tell myself that I am proud of my achievements and love the life that I am leading so I did not feel any bitterness towards her. Perhaps another person with Usher in my shoes may have reacted differently – perhaps they would have got upset or other emotions may have risen? Is this hate crime? Should I have reported it?

I decided to leave it and get on with my journey, but it got me thinking. One thing that hit me is has society really changed its attitude towards disabled people, especially in the last few years. Sometimes it feels like things are going backwards in terms of attitude, especially with the benefit scrounger rhetoric1, benefit sanctions, ATW1 caps and problems with PIP payments and appeals2. There is also anecdotal evidence that there is a marked rise in disability hate crime and it can’t be a coincidence that these things are happening in parallel.

We must remember that we as disabled people have rights and we must support disabled people and deafblind people especially when they may face disability hate crime.

Emma Boswell, Usher Network Leader (emma.boswell@sense.org.uk)

1 https://www.disablednewservice.com
2 https://www.deafmate.com/updates.html

Youth Network Report

Simon Allison reports:

The youth Network (DbIYN) is busy preparing for two events this summer, 2018. In June there will be a group activity held in Zurich, Switzerland. The event is being hosted by TANNE, the Swiss Centre of Competence for the Deafblind. Activities already planned include a cruise on Lake Zurich, Lindt chocolate factory tour, Zurich spa and thermal baths, mountain train trip, Swiss National museum visit and old city tour. The event will also include a mini conference with youth network members discussing their services in their individual countries and future planning for youth network events.

Moving on to July there will be the second part of the Australia / UK Youth Network exchange visit. The visit will take place in Cornwall England and the initial group of young people who went over to Australia in 2015 will be hosting their visitors. The group from Australia will also have the opportunity to take part in a specially arranged visit of the Houses of Parliament in London (UK).

Full details of both these events will be published in the next edition of DbI review.

For more information, contact Simon.allison@sense.org.uk

“The visit will take place in Cornwall England and the initial group of young people who went over to Australia in 2015 will be hosting their visitors.”
A New Era for Perkins International Latin America and the Caribbean

Gloria Rodríguez-Gil, Karina Medina, Marta Elena Ramírez and Ana Lucia Rago

In 2017 Perkins International Latin America and the Caribbean (PI LA&C)1 restructured their regional activity, launched Perkins International Academy (PIA)2 and are organizing strategic meetings and conferences with the purpose of joining efforts with governments and civil society to train 130,000 teachers in 18 countries in LA&C and to 500,000 children and youth with MDVI by 2030. Perkins International (PI)3 is re-aligning their work to meet the UN Sustainable Developmental Goals (SDG’s) or Global Goals for 20304. This re-alignment will focus particularly on Goal No. 4 that seeks to achieve “inclusive and quality education for all”; and more specifically towards target 4C which states: “to substantially increase the supply of qualified teachers”. The intent of the International Academy (PIA) is to satisfy this purpose.

We are taking actions in five directions to reach our goal:

1. Restructuring Latin America and the Caribbean (LA&C)

We have divided the Latin America and the Caribbean (LA&C) into three sub-regions with the intent of locating personnel with deep understanding of the needs and strengths of each region closer to the national key stakeholders and national and international cooperation organizations.

The 3 regions are:

• México, Central America and the Caribbean with the PI Representative Marta Elena Ramirez located in Querétaro, México;
• Brazil with the PI Representative Ana Lucia Rago located in Sao Paulo, Brazil;
• South Cone and Andean Region with the PI Representative Karina Medina located in Córdoba, Argentina.

2. Perkins International Academy

In 2017 PI launched a new global teacher training initiative to address the shortage of trained teachers who could provide appropriate educational services to children and youth with vision loss, additional disabilities including those with deafblindness.

The courses called ‘Education of Learners with Multiple Disabilities and Sensory Loss’ are divided into three levels – Foundations, Advanced, and Program Development. For Perkins with 97 years of international teacher training expertise, this was the first-ever international competency course for teachers working with this specific population.

LA&C is about to begin our sixth training course involving professionals from seven countries. The following testimonies are from professionals who have taken the course from each of the three sub-regions.

• PIA was my first opportunity to receive systematic training in the education of students with multiple disabilities. The opportunity for distance learning, the dynamic presentation of the different topics, the publications and videos offered were important sources of information that I will treasure and to which I will continue to turn to for deeper analysis. (Sonia Beron, Teacher, Rio Cuarto, Argentina)

• It was in 2017 when I was presented with the opportunity to receive certification on multiple-disabilities from Perkins, which I did not hesitate to accept. I discovered with the training that my student Zoe could make achievements despite the challenges that she faced. The most important thing for me was to understand first that Zoe was a whole person and that I needed respond to her needs for her to accomplish something meaningful. (Kimberly, teacher, Guatemala).

• I had the pleasure of being invited to be one of the tutors of Perkins International Academy in Brazil. The launching of PI Academy is a dream come true for the professionals who have already been working in the field of Deafblindness and Multiple Disabilities. This course will enable us (the tutors) to reach other professionals who don’t have this specific training, but still work with this population. (Laura Lebre Monteiro Ancilotto, PIA tutor, Brazil)

3. Establishing Model Programs

With PI Academy, PI intends to create model programs together with various government agencies and NGO’s in each of the regions. There will be educational centers that will provide model educational services; where practitioners will receive training, make observations and practice, and share best practices. These model centers will have strong outreach services to serve the larger community, actively participate with families and create evaluation tools that will further help guide educational planning.

4. Monitoring, Evaluation and Learning (MEL)

PI is increasing its monitoring, evaluation and learning (MEL) capacity by:

• establishing a learning portfolio, developing a comprehensive pre- and post-testing assessment process, as well as a follow-up evaluation for Perkins International Academy;
• performing program, country and regional wide evaluations to help understand the current situation. This is intended to guide PI’s work and that of others as we move forward having more and better trained teachers and consequently an improved the educational service for population we serve.

5. Strategic Meetings and Conferences

PI intends to bring together all the key stakeholders, including government officials from various ministries and secretariats, representatives from universities and local school districts, experts from other disability fields, parent groups and other interested parties who advocate for the rights for the education of children and youth with vision loss and additional disabilities including those with deafblindness.

Our overall purpose is to ensure the continuation and growth of educational opportunities for this population through to and beyond 2030.

Some examples of these activities include:

• Creating a National Forum on Individuals with Multiple Disabilities and Deafblindness in Mexico by coordinating groups from the Mexican Civil Society (COAMEX, ASOMAS, CEMDYS, Comunidad Creer) and Universidad Nacional Autónoma de México (UNAM). Together this resulted in ‘inclusion’ being recognized for the first time by this group in the CRPD Mexico Shadow Report for 20185.

• Participating in The Network of the Americas International Conference (April 2018) organized by PI and DbI (Deafblind International) which brought experts from all the Americas together sharing their expertise and networking in the field of deafblindness.

Organizing the International Conference ‘Utopía y Challenges of Inclusion’ in Córdoba Argentina together with the local government (Dirección de Educación Especial y Hospitalaria de Córdoba) and the public university (Universidad Provincial de Córdoba) Department of Education and Health.

---

1  www.perkins.org/international/latin-america
2  www.perkins.org/international/academy
3  Perkins International (www.perkins.org) is a large corporate member of DbI
4  https://sustainabledevelopment.un.org/menus=1300
Conclusion
The goal of PI-LAC is to train 130,000 teachers in 18 countries of Latin America and the Caribbean to reach 500,000 children and youth with Multiple Disabilities and Visual Impairment (MDVI) by 2030. We can only accomplish this through the commitment of representative governments, along with the support from civil society and various national and international organizations. We want that this population of children and young adults receive quality educational services to provide them the opportunity to have active and engaging lives with their families and communities.

The changes we have already started will evolve as we face the realities of the Region. We need to recognize that the L&AC Region presents widely diverse characteristics, including geography, social structures, and cultural and political institutions, which together will significantly influence the strategies that will be implemented to achieve the proposed goals.

Furthermore, we need to procure the resources with key stakeholders to enable PI to accomplish these objectives despite facing the great challenges. There is no doubt that the world is moving forward with respect to the rights of people with disabilities, if the following are any indication: Convention of the Rights of the Child (1989), The UNESCO Salamanca Statement (1994), the Convention on the Rights of Person with Disabilities (2006) and the Sustainable Development Goals (2016).

Impact of Perkins´ Website as a Resource for Families and Professionals in Latin America and the Caribbean
Paula Rubiolo (paula.rubiolo@perkins.org)
Álvaro Diaz (alvaro.diaz@perkins.org)
Regional Center – Latin America and the Caribbean

Our website www.perkinsla.org was initially launched in 2010. The main goal was to provide a space to share and exchange resources and materials in Spanish and Portuguese about the education of children with multiple disabilities and deafblindness.

We created a special team including a content manager and a programming technician to work with the rest of our personnel to provide program content from throughout the region. As shown in the table below (Changes in the Distribution of Visits), most visitors to our site in 2017 (59.8%) currently are searching for educational resources.

Changes in the Distribution of Visits

<table>
<thead>
<tr>
<th>Year</th>
<th>Information</th>
<th>Education Resources</th>
</tr>
</thead>
<tbody>
<tr>
<td>2014</td>
<td>45,78%</td>
<td>54,22%</td>
</tr>
<tr>
<td>2017</td>
<td>39,80%</td>
<td>60,20%</td>
</tr>
</tbody>
</table>

Source: Google Analytics, March 2018

Significant Changes over time to the Website
Through the years our website has expanded to meet the changing needs of our users; families, professionals and people searching for training in the subject.

- In 2010, we started the website with an initial design that included the most relevant information available at that time.
- In 2013, the website further developed to provide a reader-friendly format, modified to make the information more accessible for readers. The website then including scanned resources from our regional office library.
- In 2014 we developed an online virtual classroom for delivering specialized courses.
- In 2015 a major redesign of the site occurred to make it look similar to the official website of Perkins School for the Blind. In addition, we made the website mobile friendly, linking it to the Perkins website and Twitter account and other sites such as WonderBaby.org.
- A major step occurred in 2016 when we launched Perkins International Academy (PIA) online and began to deliver PIA Certified Courses throughout the region.

Our Visitors
While our online visitors come mainly from Spanish and Portuguese speaking countries in Latin America and the Caribbean, the site also has visitors from other countries around the world. The following table (Visitors by Region) shows the distribution of visitors according to regions. Latin America and the Caribbean for our purposes is divided into 3 sub-regions: Mexico, Central America and the Caribbean; Brazil and the South Cone/Andean Region.

Approximately 60% of the visitors come from the Spanish speaking countries of South America (South Cone and Andean sub region). The others two sub regions, Brazil, and Mexico and Central America, have a much lower participation rate at this time, but this is expected to increase due to the new presence of Perkins Representatives in these sub-regions.

The table (Number and Origin of PI LAC Website Visitors)

Source: Google Analytics, March 2018

Training Opportunities
Webcasts
Because of the increased demand for trainings in the region, we have produced a series of free and easily accessible webcasts for the website featuring different topics of interest.
An Emergency Intervenor Services Program (EISP); an Essential Step Towards Meeting the Needs of the Deafblind Community

Janine Tucker

In 2014, CNIB’s Deafblind Community Services (CNIB DBCS) launched a one-of-a-kind emergency intervenor service in Ontario, Canada. In 2018, the program continues to enhance its ability to dispatch intervenors during a crisis and hopes to collaborate with other intervenor service providers to better meet the needs of the Deafblind community across the province. As we know, when someone who is Deafblind is in a state of emergency, the need for an intervenor is critical.

Prior to 2014 and the implementation of a formal emergency service, CNIB DBCS intervenors responded to emergencies. However, there was often a considerable time delay in getting an intervenor to the scene. Typically, this was precipitated with a great deal of confusion from the perspective of the first responders regarding the accessibility needs of the person, the service provider and contact information. Often, the person who was Deafblind would try to reach one of their regular intervenors or a manager. This attempt wasn’t efficient, especially after-hours and over-the-weekend, and it resulted in significant time delays. In some cases, intervenor service wasn’t provided.

In Ontario, we are fortunate to have the support of the Ministry of Community and Social Services (MCSS)

Going Forward
In 2018, we are planning new changes to the website, including expanding the capacity and making it more practical and useful for users.

Our goal remains unchanged. We want the website to respond to the needs of families, professionals and other people connected to the field of deafblindness and multiple disabilities making it a most useful tool for this population.

Perkins International

These webcasts are presented in Portuguese or Spanish with subtitles in the other respective language.

Current Topics included in the webcasts are:
- Siblings (2016)
- Orientation and Mobility; Social and Educational Inclusion (2015)
- Approaching the reality of deafblindness and multiple disabilities (2016)
- Beyond a dream (non-profit associations); Low vision and multiple disabilities (2016)
- Early Literacy: A Right for All; Adapted designs (2017)

One-topic courses
Some topics related to the education of people with deafblindness and multiple disabilities were developed in a more detailed way.

Eleven courses were developed (between 2014 and 2016) and organized into three major categories: Learning Challenges, Deafblindness and Multiple-Disabilities and Technology and Adaptive Design.

They are listed as follows:

Learning Challenges:
- Teaching strategies for students with disabilities
- Early literacy… an opportunity to access and learn
- Approaching the reality of students with multiple disabilities in the south of Argentina

Deafblindness and Multiple Disabilities:
- What do we know about people with multiple disabilities?
- Visual strategies for children with low vision and multiple disabilities
- Transition to adult life… the challenge of starting earlier!
- Visual strategies for children with low vision and multiple disabilities
- Late departure from school
- Deafblindness and multiple disabilities

Technology and Adaptive Design:
- Technology vs. Disability
- Introduction to adaptive design (workshop)
- Assistive technology in minutes

Individuals from sixteen of the nineteen countries of Latin America have participated in these courses. Those countries not having participants were Bolivia, Cuba and Nicaragua.

The category of Deafblindness and Multiple Disabilities witnessed the most individuals participating in related courses. Courses in the category of Technology and Adaptive Design Deafblindness and Multiple Disabilities had the second most participants.

According to the following graph (Participation in Courses 2014–2017), the highest participation rate according to PI division was South Cone and Andean Region (57.7%), followed by Central America, Mexico and Caribbean Region at 37%, with Brazil participants representing 7 percent.

PI Academy Courses
The certified courses of PERKINS INTERNATIONAL ACADEMY began to be delivered through the website platform, as of 2017.

Two courses were delivered (one in Mexico and the other in Ecuador) which together included more than 50 participants from different countries throughout the region.

Source: Google Analytics, March 2018

Going Forward
In 2018, we are planning new changes to the website, including expanding the capacity and making it more practical and useful for users.

Our goal remains unchanged. We want the website to respond to the needs of families, professionals and other people connected to the field of deafblindness and multiple disabilities making it a most useful tool for this population.

We are waiting for you at: www.perkinsla.org

Paula Rubiolo
Álvaro Diaz

An Emergency Intervenor Services Program (EISP); an Essential Step Towards Meeting the Needs of the Deafblind Community

Janine Tucker

In 2014, CNIB’s Deafblind Community Services (CNIB DBCS) launched a one-of-a-kind emergency intervenor service in Ontario, Canada. In 2018, the program continues to enhance its ability to dispatch intervenors during a crisis and hopes to collaborate with other intervenor service providers to better meet the needs of the Deafblind community across the province. As we know, when someone who is Deafblind is in a state of emergency, the need for an intervenor is critical.

Prior to 2014 and the implementation of a formal emergency service, CNIB DBCS intervenors responded to emergencies. However, there was often a considerable time delay in getting an intervenor to the scene. Typically, this was precipitated with a great deal of confusion from the perspective of the first responders regarding the accessibility needs of the person, the service provider and contact information. Often, the person who was Deafblind would try to reach one of their regular intervenors or a manager. This attempt wasn’t efficient, especially after-hours and over-the-weekend, and it resulted in significant time delays. In some cases, intervenor service wasn’t provided.

In Ontario, we are fortunate to have the support of the Ministry of Community and Social Services (MCSS), which recognizes and respects the rights of people who are Deaf and Deafblind. MCSS funds interpreting services (regular service and after-hour emergency requests) and intervenor services (regular intervenor service for people who live with congenital and acquired Deafblindness, and the CNIB DBCS Emergency Intervenor Services Program). In 2017, 23 transfer payment agencies in Ontario received funding for intervenor services. This is an outstanding level of support compared to other parts of Canada and around the world. Years ago, MCSS established an Intervenor Services Advisory Group (ISAG). Participants include various members of the Deafblind community and representatives from the larger intervenor service providers e.g. CNIB DBCS, Deafblind Ontario Services and the Canadian Deafblind Association – Ontario Chapter. At an ISAG meeting, the need for a formal 24/7 emergency service was identified. So, in 2013, MCSS approached CNIB DBCS and requested a proposal outlining how an emergency intervenor program could work. CNIB DBCS started with an emergency service that would focus on supporting the acquired Deafblind community members who receive services from CNIB DBCS. This reflected MCSS’ view that CNIB DBCS’s clientele were impacted the most by the lack of a formal emergency service. Some of the other agencies had 24/7 intervenor support for their clients (e.g. people living in a group home setting) or other systems in place to support their clients. The first step, which MCSS requested, was to conduct a Needs Assessment to identify the number of people we assist with their geographic locations mapped out, plus the number of intervenors we employed and their geographic locations. This would allow us to analyse whether we had an appropriate number of staff in each region to provide support if an emergency occurred. This helped us identify areas where we could prioritize our recruitment efforts.

1 Canadian National Institute for the Blind (www.cnib.ca) is a small corporate member of DbI
2 https://deafblindservices.ca
3 https://www.mcss.gov.on.ca
4 Deafblind Ontario Services (www.deafblindontario.com) is a large corporate member of DbI
5 Canadian Deafblind Association-Ontario Chapter (www.cdbaontario.com) is a large corporate member of DbI
The second step was to reflect on past experiences. What have the successes and challenges been in responding to emergency intervenor requests in the past? What obstacles does a person who is Deafblind face during an emergency?

The following outlines some of the common issues we considered and the potential solutions to address them:

- lack of awareness within the community at large regarding the needs of people who are Deafblind and the role of an intervenor
- confusion as to a person’s disability; it may be easy to ascertain that someone is Deaf if sign language is being used, or someone is blind if a white cane is being used, but it’s often difficult to determine whether someone is both deaf and blind. This is often realized after much confusion and/or frustration from both parties. This confusion is compounded if a member of the Deafblind community makes the request. People often assume, innocently so, if someone speaks, they must be able to hear. Someone may question why this person would need an intervenor and wonder why they can’t communicate effectively if they use speech.

- Solution: 1. Provide the person who is Deafblind with the decision that someone who can quickly identify them as having Deafblind and indicate how to communicate with them. 2. Ask MCSS to provide training on the use of sign language.

- Solution: 2. Ask MCSS to provide training on the use of sign language to people who can afford MedicaAlert® (both the pendant/bracelet and the membership fee). Once first responders are already accustomed to looking for MedicaAlert pendants, we could have the word “Deafblind” engraved on the pendant and the contact phone number for the EISP.
- first responders typically arrive at the scene of an emergency prior to an intervenor being dispatched and arriving to assist. This is a critical time as first responders need to gather essential information and they are often confused as to how to assist and communicate with the individual who is Deafblind.

- Solution: Create an Emergency Communication Kit which includes various communication aids and the contact information for the Emergency Intervenor Service.

- intervenors who work for CNIB DBCS are not contractually bound to be on-call, and CNIB did not support the idea of staff being placed on-call with this new emergency service. So, how will we ensure intervenors will be willing to take on emergency assignments after-hours and over-weekends?

  - Solution: 1. offer intervenors a higher rate of pay as compensation for going in emergency settings and pay them an additional call-out fee as a way of compensating them for dropping whatever they were doing to respond to the request. This rate of pay would be almost double what they would make during a non-emergency assignment. Note: After a review of the service was conducted in 2015, the idea of staff being on-call was reconsidered but was still seen as an unnecessary expense and an unnecessary responsibility or stress for staff considering the low rate of emergency requests per region/month.

- Solution: 2. provide intervenors with an emergency work kit, so they would be ready to respond to an emergency. MCSS supported the proposal in it’s entirety, so this first step was implementation.

  - A training video was created featuring members of the Deafblind community, paramedics, police and emergency room nurses who were willing to act in the videos.

- EISP brochures and posters were created.

  - Items were created to assist with the identification of a person as being Deafblind, these included:

    - a snap-on cover which fits over or attaches to a person’s health card. This snap-on cover indicates that the person has vision loss and hearing loss and lists the phone number for the CNIB EISP. Even if the person is unconscious, a first responder in attempting to identify the person, would see this information on the person’s health card.

    - communication alert cards; these cards are personalized and state the person’s vision and hearing loss i.e. “I am Deaf and have vision loss” so the communication method the person uses (e.g. “I use tactile American Sign Language and cannot read print”). It also states, “I require an intervenor to facilitate communication. Please contact…”

- MCSS agreed to pay for MedicaAlert membership and pendants. People can contact the coordinator of the EISP to arrange for purchasing a membership and pendant.

- An emergency communication kit was created. This kit contains:

  - a pad of paper with a black marker (only included if the person has residual vision)

  - an emergency communication book – this book uses graphic images which are easy to understand. The first responder simply points to an image (question) they want to ask, and the EISP responds. This book is available in standard size, large print and with braille overlay. The book was created in consultation with paramedics. Therefore, it is user-friendly as the images (questions) are listed in the order a paramedic has been trained to ask them.

  - a visor or hat – this can be used if the person is having difficulty seeing due to glare (e.g. they may be laying down on a stretcher and have lights shining which inhibits their ability to see what people are doing/saying).

  - a key tag – people are encouraged to attach this to their home keys. They can then show anyone the key tag when they want to request an emergency intervenor as the key tag has the name of the program and the contact information.

  - stickers – state that the person has vision loss and hearing loss, the phone number for the EISP and the general helpline for CNIB, if the request in an emergency. These stickers can be used for multiple purposes:

    - business cards with braille

    - brochures in English and French

    - instruction sheets are included to explain each item. People are also encouraged to add items to the kits, i.e. a magnifier, old pair of glasses, list of medications, emergency contact information, non-perishable food, coins, etc.

- MCSS supported the proposed budget, which included the higher rate of pay for intervenors who work emergency assignments. A call-out fee was also supported.

  - Intervenor work kits were created. These kits include:

    - pad of paper and black markers

    - first aid kit with gloves

- b. find contact information for the intervenors to dispatch someone when needed. The call centre was instructed to follow the person’s preference list of intervenors the client felt most comfortable working with, especially in an emergency. CNIB DBCS provided other intervenor options so the call centre had at least three to five names to contact. If none of those intervenors were available or responding, the call centre went through the database to locate other intervenors who lived in the region who were comfortable working with someone using a particular communication method. An interactive map was also added as a resource to locate intervenors in other regions. Intervenors know these hours are paid at the higher rate of pay and not tracked as overtime. Note: Intervenors are not paid to take them out of town, etc.). The call centre would then proceed to the next intervenor. If no intervenor was found, the call centre would contact the project lead for the EISP about next steps.

- The project lead would receive an email notification immediately after a request is received. This notification would then be forwarded to the managers. Also, a detailed report about the request would be sent to the following day, along with any action taken by the project lead who could review and document the information for statistical purposes and would follow up on any issues.
An Emergency Intervenor Program

Successes and ongoing challenges

The Emergency Intervenor Service is responding to an average of eight emergency requests per month. Budgeting for an emergency service is difficult, as emergencies are not predictable or planned. Having said that, over the last four years, we have seen a consistent number of calls coming in. That doesn’t mean these numbers won’t fluctuate, but it helps with anticipating an accurate budget. Also, the number of requests may increase as the clients become more aware of the service and recognize the availability of intervenors is now 24/7 (e.g. people are accustomed to waiting for an intervenor to arrive before dealing with a health issue and may need a reminder that this is no longer necessary as they can contact the EISP anytime).

One of the first emergency calls the program received was a request for an intervenor to assist at a hospital emergency room, as a person who was Deafblind was hit by a vehicle. The EISP was not notified, and therefore, we are not aware of the results of having this formal system in place. This individual was able to show the paramedics their health card, which had the snap-on EISP cover indicating the EISP contact information, and an intervenor was dispatched. The paramedics, upon reading the cover, knew this person had vision loss and hearing loss.

Approximately 50 per cent of CNIB’s DBCS clients have registered for the EISP; around 60 per cent have received their free emergency communication kits, as some feel they don’t need the service. Over the last four years, we have seen a consistent number of calls coming in. That doesn’t mean these numbers won’t fluctuate, but it helps with anticipating an accurate budget. Also, the number of requests may increase as the clients become more aware of the service and recognize the availability of intervenors is now 24/7 (e.g. people are accustomed to waiting for an intervenor to arrive before dealing with a health issue and may need a reminder that this is no longer necessary as they can contact the EISP anytime).

One of the first emergency calls the program received was a request for an intervenor to assist at a hospital emergency room, as a person who was Deafblind was hit by a vehicle. The EISP was not notified, and therefore, we are not aware of the results of having this formal system in place. This individual was able to show the paramedics their health card, which had the snap-on EISP cover indicating the EISP contact information, and an intervenor was dispatched. The paramedics, upon reading the cover, knew this person had vision loss and hearing loss.

Approximately 50 per cent of CNIB’s DBCS clients have registered for the EISP; around 60 per cent have received their free emergency communication kits, as some feel they don’t need the service. Over the last four years, we have seen a consistent number of calls coming in. That doesn’t mean these numbers won’t fluctuate, but it helps with anticipating an accurate budget. Also, the number of requests may increase as the clients become more aware of the service and recognize the availability of intervenors is now 24/7 (e.g. people are accustomed to waiting for an intervenor to arrive before dealing with a health issue and may need a reminder that this is no longer necessary as they can contact the EISP anytime).

One of the first emergency calls the program received was a request for an intervenor to assist at a hospital emergency room, as a person who was Deafblind was hit by a vehicle. The EISP was not notified, and therefore, we are not aware of the results of having this formal system in place. This individual was able to show the paramedics their health card, which had the snap-on EISP cover indicating the EISP contact information, and an intervenor was dispatched. The paramedics, upon reading the cover, knew this person had vision loss and hearing loss.

Approximately 50 per cent of CNIB’s DBCS clients have registered for the EISP; around 60 per cent have received their free emergency communication kits, as some feel they don’t need the service. Over the last four years, we have seen a consistent number of calls coming in. That doesn’t mean these numbers won’t fluctuate, but it helps with anticipating an accurate budget. Also, the number of requests may increase as the clients become more aware of the service and recognize the availability of intervenors is now 24/7 (e.g. people are accustomed to waiting for an intervenor to arrive before dealing with a health issue and may need a reminder that this is no longer necessary as they can contact the EISP anytime).

One of the first emergency calls the program received was a request for an intervenor to assist at a hospital emergency room, as a person who was Deafblind was hit by a vehicle. The EISP was not notified, and therefore, we are not aware of the results of having this formal system in place. This individual was able to show the paramedics their health card, which had the snap-on EISP cover indicating the EISP contact information, and an intervenor was dispatched. The paramedics, upon reading the cover, knew this person had vision loss and hearing loss.

Approximately 50 per cent of CNIB’s DBCS clients have registered for the EISP; around 60 per cent have received their free emergency communication kits, as some feel they don’t need the service. Over the last four years, we have seen a consistent number of calls coming in. That doesn’t mean these numbers won’t fluctuate, but it helps with anticipating an accurate budget. Also, the number of requests may increase as the clients become more aware of the service and recognize the availability of intervenors is now 24/7 (e.g. people are accustomed to waiting for an intervenor to arrive before dealing with a health issue and may need a reminder that this is no longer necessary as they can contact the EISP anytime).
An SRoI Analysis for Lega del Filo d’Oro

For an organization to perform a SRoI analysis, the following steps need to be followed as shown in Figure 1.

**FIGURE 1: A process-based view of the SRoI analysis**

- Setting the stage of the analysis
- Secondary data collection
- Analysis aimed at understanding project specificities
- Defining the boundaries
- Theory of change
- Level of analysis
- Scope of the analysis
- Timeframe
- Mapping and involving relevant stakeholders
- Who is experiencing change by participating in the project
- Selection of the most relevant stakeholder
- Involvement of key informants
- Developing key performance indicators
- List of monetary indicators to value inputs and outcomes
- Casual relationships between inputs, outputs and valuable outcomes
- Intervening factors to control for
- Building social impact value chains
- Data collection and SRoI calculation

A SRoI calculation measures the value of net social benefits created by an organization in relation to their investments together with those from other supporting stakeholders to better achieve the benefits (Figure 2) for its stakeholders.

**FIGURE 2: SRoI Calculation**

- Economic quantification of the differential benefits received by stakeholders as a result of the organisation’s operating model
- Cost of the inputs required for A) the project operations for which the evaluation is made and B) stakeholder’s involvement
- Social Revenues (past, current or expected)
- Capital Invested (or initial investment or total active or total donations received)
- Value both of the investment for project set-up and of the resources for enabling the organization’s ability to pursue its mission
- Operation costs (incurred by the organization and/or stakeholders)
- SROI = (Social Revenues) / (Operation costs)
- Source: Personal elaboration

The result from a SRoI calculation is measured as a ratio of monetized social value. For example, a ratio of 1:3 indicates that an investment of euro 1 delivers 3 euros of social value.

Application of the SRoI methodology to Lega del Filo d’Oro

In accordance with the SRoI principles and methodology, the project identified the primary stakeholder in this process as being the disabled individuals themselves, including their family members, employees, volunteers and the local community in which they all live. Together all the stakeholders can be said to benefit from, and contribute to, the realization of the social mission of the Lega del Filo d’Oro.

The next step was to identify all activities and their impacts, based on in-depth consultation with key participants (e.g., parent association representatives, medical doctors, staff and members of the management team). As a result, social values were developed for each stakeholder category.

The results of the input to output to outcome evaluation shows that the intervention model provided by the Lega del Filo d’Oro, including its’ multidisciplinary evaluation, educational and rehabilitation services, has direct benefits for these multi-disabled individuals and their families. As a result of these services, the individuals are able to demonstrate improved ability to manage their complex disability and experience reduced social isolation through gaining better access to society. The individuals are more able to access a broad level of community services. Furthermore, the lives of their families have also been positively affected by the supports offered by Lega del Filo d’Oro. This includes being able to return to the working lives as well as being better able to partake in personal leisurely activities.

Primary data was collected from a sample of 99 families to provide monetary information based on the areas identified above. Secondary data was collected to quantify and evaluate the impact of the Lega del Filo d’Oro services on employed, volunteers and the local community at large. Types of evaluations included the value of professional training received by employees and volunteers, as well as employment created by the Lega del Filo d’Oro in the Marche Region.

Other impacts evaluated included: an increased level of community volunteering; the value of the knowledge transferred to local institutions and organizations related to the social inclusion of deafblind and multisensory impaired, and the overall increase in the volume of economic activities in the regional area.

**Results of the SRoI analysis**

For every Euro invested in the projects of the Lega del Filo d’Oro by public sector health institutions and donors, the value of the average annual social return, i.e. the change generated in the lives of the beneficiaries and their families, volunteers, employees and the Region of Marche as a whole is equal to 1.93 euros of delivered social value (average annual SRoI ratio 1:1.93). Over the three-year period of the analysis, the Lega del Filo d’Oro has created 17.5 million euros a year in social value, recording a consistent increase of about 15% (from 16,629,605 Euros in 2014 to 18,854,423 Euros in 2016).

In 2016, Lega del Filo d’Oro generated a social value of about 1 million euros for families. This accounted for parents returning to work, becoming themselves more involved in social life, having more financial resources due to reducing the hours of counselling and family therapy they used to pay for, etc.

Finally, Lega del Filo d’Oro has contributed significantly to the economy of the local communities and the surrounding areas in which it operates. On average, 9.3 million euros per year is the value of additional economic activity created by the Lega del Filo d’Oro. This SRoI analysis has demonstrated the possibility for Lega del Filo d’Oro to move away from its emphasis on costs for...
How to Plan a Holistic Rehabilitation Process

THEORETICAL FRAMEWORK

The model was originally developed by Ann-Christin Gullacksen at Malmö University, intended initially for persons with chronic illness and later expanded to be used with persons with a hearing impairment. Over the past ten years, the model has seen increasing use in the field of deafblindness, initially thanks to a Scandinavian research project in 2008-2011. One of the outcomes of the project was the book ‘LIFE ADJUSTMENT AND Combined Visual and Hearing Disability/Deafblindness – an Internal Process over Time’.²

The Danish representative in the project was Anette Rud Jørgensen, who was a deafblindness counsellor at the time. Today she is the manager of the national deafblindness counselling service.

THE LIFE ADJUSTMENT PROCESS

The life adjustment model describes the process people go through when they acquire a sensory impairment, such as deafblindness. The model identifies three stages in the adjustment process:

- Holding on
- Process of exploring
- Rostered in oneself

THREE MODULES = THREE HOUSES

AV House: about hearing and vision and the participants’ own experiences of hearing and vision loss

Energy House: about personal energy, strategies, the use of assistive aids and how to maintain balance in life, for example by means of yoga and mindfulness

Network House: about communication and relationships with family, co-workers, friends and others members of the network

SEPARATE COURSES FOR THE TWO GROUPS. ALTHOUGH THEY HAVE DEAFBLINDNESS IN COMMON, THEIR LIFE SITUATIONS ARE OFTEN QUITE DIFFERENT, DEPENDING ON THEIR LANGUAGE.

PRACTICAL TOOLS AND STRATEGIES

Theses and other studies document the need for a rehabilitation course aimed at giving the participants practical tools and strategies to facilitate their life adjustment process. In 2015, CFD Rådgivning therefore applied for a grant of DKK 2 million from the Danish government fund Satspuljen for a project aimed at developing such a course.

So far, two pilot rehabilitation courses have been held as part of this project – one aimed at persons with deafblindness who use sign language and one aimed at persons with deafblindness who use speech.

The two experienced deafblind counsellors Kirsten Washuus and Else-Maria Jensen, who were in charge of the project, comment on this distinction in terms of target groups:

‘It is crucial for the participants to feel at ease during the courses. To ensure that, we took a cue from the outset that we would establish separate courses for the two groups. Although they have deafblindness in common, their life situations are often quite different, depending on their language.’

They add, ‘Above all, deafblindness is a communication impairment, which means that it takes a very particular focus and careful planning to create the right conditions for communication. It was essential to ensure that the participants could communicate directly with each other within the group. However, despite differences between the two groups, throughout the project we have also found many similarities when it comes to the experience of adjusting to a new life.’

The three general themes were chosen because they were considered essential for a person with deafblindness.

Kirsten Washuus explains: ‘The reason why these particular themes are essential is that together, they cover the entire life situation for a person with deafblindness. The purpose of the project was to develop a holistic approach, and we found that the topics that were included in the three themes allowed us to address the person’s life in full.’

CFD’s deafblind counsellors provide specialized advice and support to persons with acquired deafblindness, that is, persons who develop severe combined hearing and visual impairment during the course of their life. A recently completed project has aimed to develop a coherent and holistic rehabilitation course for this target group. The first in a series of three, this article describes the project’s theoretical framework.
**HOLDING ON**
The initial stage, Holding on, begins when the person first experiences changes in their vision and/or hearing. The initial reaction may include denial of the new situation, as the person instead tries to hold on to what has worked so far, and what they are accustomed to. Towards the end of this stage, there is a growing recognition that life cannot continue exactly as before, and that the future is going to look different than one had imagined. That can lead to an emotional crisis that may continue well into the subsequent stage.

**ROOTED IN ONESELF**
By the time they reach this stage, people have rediscovered the core of their identity and integrated the term of deafblindness into their life situation. They have healed their life and become whole again. Many of the experiences they have made during the process now have to be embraced as a fact of life. They begin to move on, after reshaping their identity and self-image. With regard to rehabilitation, at this stage people often begin to be able to benefit more from technical aids and professional support, for example from interpreters and a dedicated contact person.

**MAINTAINING**
After going through these three stages, people now move on to living with deafblindness. This is not a finite process but a continuous maintenance effort that involves ongoing adjustments over the coming years, as their vision and hearing continue to change. Maintenance includes continued contact with professionals, ongoing use of assistive aids – and adjustments over the coming years, as their vision and hearing continue to change. Maintenance includes continued contact with professionals, ongoing use of assistive aids – and the acquisition of new ones – and a growing awareness of the need to use one’s energy wisely by planning and prioritizing activities.

**KNOWING THE STAGE CAN BE CRUCIAL**
Commenting on the choice of the life adjustment model as the framework for the rehabilitation courses, Kirsten Washuus says,

‘We know that it can be crucial for professionals to know what stage in the overall process the person is at. If we offer deafblindness-specific support or assistive aids at a time when the person is still trying to hold on to or restore what once was, we are going to miss the mark. The kind of rehabilitation course we offer in this project is based on the premise that the person has completed stage one and is thus at a stage where they are motivated to receive support with processing and exploring new strategies for managing everyday life.’

**THE PSYCHOLOGICAL ASPECT IS A CRUCIAL PART OF THE REHABILITATION PROCESS**
Commenting on the choice of the life adjustment model as the framework for the rehabilitation courses, Kirsten Washuus says,

‘We know that it can be crucial for professionals to know what stage in the overall process the person is at. If we offer deafblindness-specific support or assistive aids at a time when the person is still trying to hold on to or restore what once was, we are going to miss the mark. The kind of rehabilitation course we offer in this project is based on the premise that the person has completed stage one and is thus at a stage where they are motivated to receive support with processing and exploring new strategies for managing everyday life.’

**SMART GOALS AND FOUR OBJECTIVES**
The overall goal was that at the conclusion of the project, more than 75% of the participants were to have achieved two goals.

The participants were to have
- initiated new activities in or outside the home
- established new relationships (expanded their network)

For the individual participants, these goals were stated within the framework of the SMART model (see fact box). The outcome was that 80 to 100% of the participants in the courses achieved their SMART goals.
Another four objectives were stated for the participants in the rehabilitation courses.

First, the individual participants should achieve increased insight into their own situation and needs, including a better understanding of their own vision and hearing function and greater awareness of the compound effect of combined vision and hearing loss.

Second, they should find that their ability to process this demanding life adjustment process had been made easier by the exchange of experiences with other course participants and the psychological support.

Third, they should feel better able to engage with the outside world thanks to compensatory techniques and assistive aids that facilitate their communication, access information and wayfinding.

Fourth, they should acquire coping strategies for managing stress. Deafblindness often makes communication and independent travel very tiring and potentially stressful tasks. Hence, the participants should acquire strategies for how to prioritize their energy and activities.

As one participant put it, ‘I have become very conscious of enjoying those little moments. And I am better at taking care of myself. There’s still a lot of work to do, but I have become very conscious of the benefits of taking a timeout.’

If you would like to learn more about the project, please contact Kirsten W ashuus at kw@cfd.dk.

### PROJECT FACTS

**Project coordination is handled by CFD.**

The project runs from October 2015 through April 2018. It is funded by a grant of just under DKK 2 million from the Danish government fund Satspuljen.

A total of 11 persons with deafblindness took part in the two rehabilitation courses that were included in the project.

The courses were structured as three three-day modules.

### REFERENCES


2. See more (in Danish) in the article ‘Vi bliver ført nye veje...’ at www.cfd.dk.


4. See note 1.
Representing Large Corporate Members

Gillian Morbey
Sense
UK
(Gillian.Morbey@sense.org.uk)

Matthew Wittorff
Senses Australia
AUSTRALIA
(matthew.wittorff@senses.org.au)

Sian Tesni
CBM (Christoffel Blindenmission)
UK
(sian.tesni@cbm.org.uk)

Gloria Rodriguez-Gil
Latin America and the Caribbean
Perkins International
ARGENTINA
(gloria.rodriguez@perkins.org)

David Murray
Deafblind Australia
AUSTRALIA
(david.murray@deafblind.org.au)

Maria Brons
NETHERLANDS
(m.brons@kentalis.nl)

Roland Flaig
German Deafblind Consortium
GERMANY
(roland flaig@stiftung-st-franziskus.de)

Lena Goransson
National Resource Centre for Deafblindness
SWEDEN
(lena.goransson@nkcdb.se)

Roxanna Spruyt-Rocks
DeafBlind Ontario Services CANADA
(ceo@deafblindontario.com)

Representing Small Corporate Members

Carolyn Monaco
Canadian Deafblind Association
CANADA
(carolyn.monaco@sympatico.ca)

Marleen Janssen
University of Groningen
NETHERLANDS
(h.j.m.janssen@rug.nl)

Ricard Lopez
Spanish Federation of Deafblindness (FESOCE)
SPAIN
(flopez@sordoceguera.com;
fesoce@fesoce.org)

Gloria Rodriguez-Gil
Overbrook School for the Blind
USA
(jackie@obs.org)

Jackie Brennan
Perkins International
ARGENTINA
(gloria.rodriguez@perkins.org)

Knut Johansen
Deafblind Australia
AUSTRALIA
(knut.johansen@signo.no)

David Murray
Deafblind Australia
AUSTRALIA
(david.murray@deafblind.org.au)

Koh Poh Kwang
Center for Deafblindness and Hearing Loss
SINGAPORE
(kohpohkwang@lighthouse.edu.sg)

Lars Sobje
Lighthouse School
DENMARK
(lfoejs@rm.dk)

Trish Wetton
Forsight Australia
AUSTRALIA
(trish.wetton@forsight.net.au)

Maria Creutz
Nordic Centre for Welfare and Social Issues
SWEDEN
(maria.creutz@nordicwelfare.org)

Lenah Goransson
National Resource Centre for Deafblindness
SWEDEN
(lena.goransson@nkcdb.se)

Representing DbI Networks

Andrea Wanka
CHARGE Network
Stiftung St. Franziskus, Heiligenbronn
GERMANY
(aw@andrea-wanka.de)

Ricard Lopez
European Deafblind Network
SPAIN
(fecoce@feoce.org)

Emma Boswell
Usher Network
UK
(Emma.Boswell@sense.org.uk)

Trish Wetton
Forsight Australia
AUSTRALIA
(trish.wetton@forsight.net.au)

Maria Creutz
Nordic Centre for Welfare and Social Issues
SWEDEN
(maria.creutz@nordicwelfare.org)

Lenah Goransson
National Resource Centre for Deafblindness
SWEDEN
(lena.goransson@nkcdb.se)

Joe Gibson
Outdoor Network
NORWAY
(deafblindoutdoors@gmail.com)

Simon Allison
Youth Network
UK
(simon.allison@sense.org.uk)

Ricard Lopez
Spanish Federation of Deafblindness (FESOCE)
SPAIN
(flopez@sordoceguera.com;
fesoce@fesoce.org)

Ursula Heinemann
Österreiches Hilfswerk für Taubblinde
AUSTRIA
(ursiheinemann@usa.net)

Bernadette Kappen
The New York Institute for Special Education
USA
(bkappen@nyise.org)

Marie-Jose van den Driessche
Royal Dutch Visio
NETHERLANDS
(Marie-Josevan den Driessche@visio.org)

Mirko Baur
Signo
SWITZERLAND
(mirko.baur@tanne.ch)
It is up to YOU!
Who will Take the Leadership for DBI in the Period 2019 – 2023?

Are you, or someone you know, interested to take on one of these officer’s roles? We are seeking dedicated and passionate persons who can take the lead in the further development of DBI, those who are willing and able to work in close collaboration with families, professionals and persons with deafblindness from around the world.

WHO WILL HAVE A SEAT ON THE BOARD?
By serving on the Board, Corporate members and Networks have a great opportunity to lead DBI into the future, by taking on the responsibility of managing the association.

2018: NOMINATIONS YEAR
The DBI Nominations Committee urge you to have your say and take part in the process towards the election of the future President, Vice-President (2) and Board members of DBI, to be ratified during the Annual General Meeting in the upcoming DBI World Conference in Australia’s Gold Coast, August 12–16, 2019.

The first call for nominations should have reached all members by now, and we hope you take the opportunity to make sure there will be a solid and dedicated leadership within DBI also in the next period.

GUIDELINES FOR NOMINATIONS
When you consider your nominations for President and Vice-Presidents, please have these guidelines in mind:
1. The person you are nominating must be able to be unifying and demonstrate fairness and honesty. The President and Vice-Presidents cannot self-nominate.
2. The nominated person needs to be a good communicator and be able to represent DBI at the highest level.
3. A nominated Vice-President should be willing and able to stand in for the President, if necessary.

The nominees must have the best interests of DBI at heart and approach the work in a positive and honest way.

The Nominations Committee is seeking as wide a representation as possible for the Board. The Board will be composed of a President, 2 Vice-Presidents, the immediate Past-President, and no more than 35 other members. No more than 15 members of the Board can be large corporate members. This means that there will be up to 20 seats available for small corporates and networks. The function time for Board members is 4 years.

2019: ELECTION YEAR
An electronic ballot decides who will be President and Vice-Presidents. When the nominations process is over by the end of November 2018, all members who have the right to cast a vote will receive information on the voting process. This electronic ballot takes place from February to April 2019.

Note that you are required to pay your DBI membership fee for 2019 by March 2019, for your vote to be accepted.

Nominees for President and Vice-President will receive immediate information of the outcome.

Nominated Board members will receive information of the Nominations Committee’s proposal no later than April 2019. The Annual General Meeting appoints the new Board during the World Conference in August 2019.

Any questions concerning nominations – send it to dbinominations@obs.org

THE NOMINATIONS COMMITTEE:
Jackie Brennan, USA (Chair)
Emma Kulombe, Malawi
Ricard Lopez, Spain
Graciela Ferioli, Argentina
Knut Johansen, Norway (ManCom member)

Secretariat News
Since the last DBI Review, DBI ManCom met in April in Hyannis on Cape Cod, USA for our biannual meeting and to attend the DBI Network of the America’s Conference.

As an organization, we continue to work on the Diversity within DBI and have been guided in this initiative by Dennis Lolli and Graciela Ferioli.

The DBI Nominations Committee has been set up after the DBI Board approved the current members which include:
• Jackie Brennan, USA (Chair)
• Emma Kulombe, Malawi
• Ricard Lopez, Spain
• Graciela Ferioli, Argentina
• Knut Johansen, Norway (DBI ManCom member)

The Nominations Committee is active setting up the process for the next elections for DBI Board which will take place in 2019.

Conferences
As DBI Secretariat and the Conference Coordinator of the 17th DBI World Conference 2019 in Australia, I have had the pleasure of speaking at conferences in India, USA, Switzerland and Spain. I had the pleasure of being Chair of the World Federation for the Deafblind (WFDB) General Assembly in Benidorm, Spain. DBI has a Memorandum of Understanding with WFDB and being there gave me the additional opportunity to speak with many DBI organisations, Individual members and people with deafblindness, that all attended the WFDB General Assembly and the 11th Helen Keller World Conference.

Memberships
DBI Treasury and DBI Secretariat have been working with new software packages to better maintain our membership database in a secure format. This has caused some problems with the crossover of software plus we had some issues with the DBI website update. These problems have been focused on and rectified, and we are confident that the membership information is up to date.

Please check that your memberships are current and contact details are up to date. All 2018 membership invoices were sent out in February 2018 but we are still following up with people and organisations that have outstanding memberships due.

You can contact DBI Secretariat at: secretariat@deafblindinternational.org if you require your contact details to be updated or have a membership invoice resent.

Via the Networks on the website: www.deafblindinternational.org/networks.html

Gary Daly, DBI Secretariat
Proudly Hosted by Able Australia
Gary.Daly@ableaustralia.org.au
Barbara started her career working with students with Rubella Syndrome. Little was known about how to teach these children at that time in the early 1970’s. She created a curriculum for these students; always recognizing these students as capable of learning. Her colleagues reported that she was able to capture the personalities of the students she worked with. Her interest and skills in transition, helped prepare the students for life after school.

In her role as Educational Director at Perkins, she provided leadership and support in the development of an educational program that was individualized with the goal of allowing each individual to lead meaningful adult lives. As well, her goal was always to promote a school environment that promoted the principle of dignity for all students.

In addition to her job responsibilities, Barbara was active at the state (Massachusetts), national and international levels. She oversaw the delivery of training and technical assistance to benefit students and their families in several New England states. She was also actively involved for a number of years with DbI as a member of the Board as well as serving on special committees. Barbara gave ‘her all’ to provide the state of the art programs for deafblind individuals. She was also known as someone who led her team to continuously improve; doing this with grace, a positive attitude and a great sense of a humor.

DbI congratulates Barbara Mason for all her contributions, influence and commitments to all people who are deafblind.

As an outstanding educator for 40 years, Barbara Mason has contributed to the lives of many individuals who are deafblind. She began her career as a teaching assistant in the Deafblind Program at Perkins, eventually going on to receive a degree in deafblind education from Boston College.

B arbara has filled many roles throughout her career in Spain as teacher, psychologist, speech therapist and administrator. Though her career, Pilar’s focus was to create a model that would address the needs of individuals who were deafblind throughout her country. She always believed that anyone with deafblindness could realize his/her full potential and have a productive life if the proper resources are provided.

She knew from the beginning that one of the key elements of a quality program for these individuals were well trained professionals. She organized training courses and seminars; partnered with government officials, communication support professionals, and volunteer groups.

Communication, cognition and language were areas that Pilar gained expertise. As part of her work she carried out assessments, developed educational programs and offered guidance to students and their families. Seeing the need for support that the individuals needed, she fostered and created the role of the Intervenor as well as developing competencies needed by the Intervenor.

Outside of ONCE, the organization she worked for, Pilar worked cooperatively to maintain partnerships with other organizations. This included improvements to the Spanish Legislation in support of deafblind people. She also played a fundamental role in the development of the only Residential Center for people with deafblindness in Spain. Pilar has published several articles related to deafblind education.

As a member of the DbI Board for 24 years, Pilar participated in the professionalization of DbI and its growth as an organization. She facilitated the Spanish translation of the DbI Review in order to share knowledge with professionals around the world.

DbI congratulates Pilar Gomez for all her contributions, influence and commitments to all people who are deafblind.
Deafblind International News and Membership

Strategic Plan

Who we are

We are an international not-for-profit membership organization focused on the needs of individuals who are deafblind, their families and the professionals who provide services. We have a constitution and are managed by a volunteer Board from around the globe. We are focused on bringing together individuals and organizations to share information such that they can develop and provide quality services in the regions of the world from which they come.

Our vision

To be the international association which promotes the awareness and knowledge of deafblindness as a unique disability and to influence for appropriate services for people who are deafblind around the world.

Our purpose

To support professionals (such as educators, administrators, researchers, medical specialists, etc.), families and people who are deafblind to raise awareness of deafblindness. Central to our work is to support the sharing of knowledge and the development of services to enable a good quality of life for children and adults of all ages who are deafblind.

Strategic Priorities

June 2015 - August 2019

1. Priority One

Diversity

DbI will become a diverse organisation in all aspects including membership and Board representation.

2. Priority Two

Social Media & Information Technology

DbI will invest in technology and social media to connect with our members and the global community.

3. Priority Three

Share Knowledge

DbI will support our networks to share knowledge and develop partnerships.

Distinguished Service Award

Maria Bove

Maria Bove has spent a 40-year career dedicated to access to and inclusion in education for children who are deafblind. She has served in many roles: teacher, program director, university professor, researcher and international trainer.

Maria is well known in the field for the trainings she has provided to hundreds of people throughout Latin America. Her enthusiasm and high level of energy has motivated so many to become teachers. Her teacher-students have described Maria as “a force with passion” and her classes being life changing for them. Her level of energy would never allow a student to doze off during a class!

Maria believes that all children, no matter their disability, deserve a quality education equal to their non-disabled peers. She not only has had an impact on persons with disabilities but also on the families of those she worked with. She provided family the knowledge and courage to be advocates for their children.

During her career Maria was the lead on several research projects, creating written material for Ministries of Education and for Universities. She was active advocating for the inclusion of students with multiple disabilities and deafblindness into regular schools.

Maria’s warm personality has helped her create collaborative networks between institutions at the national and international level. It was always hard to say no when she presented a proposal for services. Her knowledge, conviction and commitment have changed the lives of many children, young adults and their families in Latin America and the Caribbean.

As well, Maria has participated in numerous DbI conferences; contributing strongly to the field through her presentations and workshops.

DbI is proud to present Maria Bove with the Distinguished Service Award.
Strategic Plan Update

Carolyn Monaco, Strategic Planning Officer

We are now three years into our four-year strategic plan and continue to make progress in all three of our strategic priority areas.

PRIORIT Y # 1 – DIVERSITY

Goal: DbI will create a climate of diversity throughout all aspects of our operation.

Progress Update
• Along with ManCom many members of the Board, our Networks and our Individual members appear to be thinking, writing, saying and doing more with a view to increased diversity of all types.
• The article by Dennis Lolli and Graciela Ferioli in our last edition of DbI Review titled Diversity: Deafblind International’s Strategic Plan Moves Forward and placed prominently on pages 5 to 8 is not only very informative but a great reflection of the DbI philosophy on diversity.
• Many of the tweets Graciela has sent on behalf of DbI have related to our diversity goals by highlighting field related news from places, programs and individuals that otherwise might not be heard from.
• DbI announced that the conference in 2021 will take place in Africa
• Decisions around how our sponsorship funds are distributed have used diversity as part of the criteria
• Representation on the new nominations committee is more diverse
• DbI has facilitated sponsorships of memberships in the organization by making connections between individuals and organizations looking to sponsor with those in need of sponsorship

PRIORIT Y # 2 – SOCIAL MEDIA

Goal: DbI will ascertain the needs and invest in the technology and training required to enhance our ability to share knowledge and to use social media to connect with our members and the global community.

Progress Update
• The hiring of Graciela Ferioli has made a significant difference in DbI’s social media presence
• Not only have her tweets increased the DbI social media presence but so have the retweets of many of our members and followers
• The transition from the previous website to the new one continues and while not without a few challenges we believe all aspects to be working well now

PRIORIT Y # 3 – NETWORKS

Goal: DbI will support our Networks to develop competencies, share specialist knowledge and strengthen connections.

Progress Update
• The DbI CHARGE Network held a full day Pre-conference at the conference in Denmark in September 2017
• A new DbI network called Adapted Physical Activity (APA) was established in the fall of 2017
• Seven of the fourteen Networks contributed to Edition 60 of the Review
• The DbI Network of the Americas hosted a conference in April 2018 along with a membership meeting
• The Youth Network hosted a three-day event in June in Switzerland

DbI Review – Sponsorship Guidelines

Corporate Member Organizations are invited to sponsor future editions of DbI Review. If interested, check out the Guidelines below.

For all levels of sponsorship, DbI reserves the right to not publish submissions that we deem for any other reason to be unsuitable, unlawful, or objectionable, such as but not limited to the content of the material (for example, the usage of inappropriate language), the subject matter, the timeliness or relevance of the material, or reasons related to intellectual property, among others.

Successful Applicants
Successful applicants will be notified no later than one month following their application submission to the publication of the DbI Review they wish to sponsor.

Applicants to accept or decline the sponsorship no later than four and a half months prior to the publication of the DbI Review.

The agreed amount of sponsorship funds will be transferred to the nominated account no later than three months prior to the publication date of the DbI Review they will sponsor.

Funding can only be accepted in Euros and not in any other currency.

The purpose of Deafblind International (DbI) is to bring together professionals, researchers, families, people who are deafblind and administrators to raise awareness of deafblindness. Central to our work is to support the development of services to enable a good quality of life for children and adults who are deafblind of all ages.

One activity that assists in promoting the purpose of DbI is the DbI Review biannual publication. This publication is coordinated and edited by the DbI Information Officer.

The opportunity should be provided to all corporate members and other organizations that support the Mission and Vision of DbI to sponsor the DbI Review. In order to achieve this, sponsorship information should be published in each edition of the DbI Review and also on the website.

Applying for Sponsorship of an Edition of the DbI Review
Applicants requesting sponsorship should have similar social values as DbI and have an interest in the well-being of individuals who are deafblind.

The DbI Management Committee (ManCom) must endorse all sponsorships to the DbI Review. The Secretariat will inform applicants of the outcome of their request for sponsorship following a decision by ManCom. Applications should be received by the DbI Secretariat. The Secretariat will then work with the Information Officer to ensure that the details of the sponsorship commitments by both the sponsor and DbI are followed through.

Sponsorship Levels, Costs and Entitlements of DbI Review

Level 1 Sponsorship = 8000 Euro

There can be only one Level 1 sponsor. If a Level 1 sponsor is approved, then there will be no other levels of sponsorship permitted within that edition. A Level 1 sponsor will have the following entitlements within one edition of DbI Review:
• Exclusive sponsorship rights of that DbI Review
• Name on bottom of front cover of DbI Review
• Supply photograph to be used on front cover of DbI Review
• Have input into the theme for the publication
• Full page advertisement
• 3 articles (related to individuals who are deafblind)

Level 2 Sponsorship = 6000 Euro

There can be only two Level 2 sponsors. A Level 2 sponsor will have the following entitlements to one edition of DbI Review:
• Half page advertisement
• 2 articles (related to individuals who are deafblind)
• 15 x extra copies of DbI Review

Level 3 Sponsorship = 2000 Euro

There are no limits to how many Level 3 sponsors can be approved. A Level 3 sponsor will have the following entitlements to one edition of DbI Review:
• Quarter page advert
• 10 x extra copies of DbI Review

T