

Dbl Review

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Deafblind International was formerly known as the International Association for the Education of Deafblind People. Dbl Review is published twice yearly, the two editions are dated January and July. The editor will be pleased to receive articles, news items, letters, notices of books and information on forthcoming events, such as conferences and courses, concerning deafblind children, young adults and older people. Photographs are welcome.

All written material should be in the English language and may be edited before publication. It should be sent for publication to arrive by the date below.

Opinions expressed in articles are those of the author and should not be understood as representing the view of Dbl.

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Cover: Dbl celebrates 40 years

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A message from the President

Dear Friends and Colleagues,

Our last Management Committee meeting was in Copenhagen in this past February. It was great to meet as a strengthened committee with Dennis Lolli looking at increasing our diversity and representation and Henriette Hermann-Olesen as our Networks Coordinator.

It was really helpful to meet with the scientific and planning committees for the European Dbl conference being scheduled for 5th–8th Sept 2017 in Aalborg. Everybody is working really hard to make the conference a success with the planning of presentations, submissions of abstracts and all the practical organisation of venues already being considered.

The ManCom was also beginning to plan for the full Board and AGM in Orlando in August. ICEVI and the World Blind Union are hosting the 2nd of their Joint General Assemblies so we are looking forward to joining our partners and colleagues at the much larger event. We hope that will make it easier for Board members to attend. We are aware that travel and time are so precious nowadays we really need to make the most of every meeting.

Dmitry Polikanov and our Russian colleagues have done a fantastic job in producing the Dbl Review in Russian. Really great achievement.

Our wonderful secretariat will get the Board and AGM details to you and we look forward to meeting everyone in August.

As ever the Dbl Review is packed full of interesting articles and it's such a joy when new ideas emerge. One of our jobs is to ensure that there is 'space' for innovative thinking so I'm grateful to Stan for the huge amount of work that goes into the organising and editing of the Review and of course the wonderful contributions. Happy reading!

With Best Wishes
Gill Morbey
President

Editorial

Welcome to the 57th Edition of Dbl Review. When I took on the assignment of becoming the Dbl Review Editor twelve issues ago, I envisioned that there would be editions built around particular themes. Much like the fact that deafblindness is such an individualized disability, the conclusion I have reached is that each edition is incredibly individualized covering a wide spectrum of topics. This edition is definitely no different, with something for everyone – the scientist, the educator, those wishing

information on practical solutions working with individuals with special needs and, of course, those professionals involved with the numerous Networks.

Susan Bruce presents several more Action Research articles in the ever growing important deafblindness research field. For educators, readers should check a review of the Deafblind Education program in the USA presented by researchers from Illinois University. Dr. Ineke Haakma has suggested an important theme in education through another feature article titled 'Motivation to Learn'. Coming up with appropriate strategies for teachers to stimulate student motivation is essential for good education. For students with congenital as well as students with acquired deafblindness, teachers play an important role in stimulating their students' motivation to learn.

Regarding articles presenting 'practical solutions', take a close look at the lead article by Joëlle Minvielle titled 'Learning and communicating through movement'. This article was translated from French and submitted by Jacques Souriau to introduce the Feldenkraï's method used by Ms Minvielle who worked with congenitally deafblind children (in this particular article with children with CHARGE Syndrome) in the National Resource Centre in Poitiers, France. Jacques believes that this practical method would be of interest to international readers.

Another practical solution has been developed by a Canadian Behavioural Therapist, Corene Jonat titled 'Increasing Wellbeing for a Deafblind Person with Obsessive Compulsive Disorder'. The article traces her methodology developed to assist intervenors to increase the individual's well being. The key to success, according to Ms Jonat, is that intervenors provide consistency, structure and routine during all interactions; offering re-direction when required and engaging in alternate positive sensory experiences.

Who would have considered providing families with trained surrogate volunteers to care for and educate deafblind children during the regular family's 'Break' period? The Russian Deaf-Blind Support Foundation "Con-nection" and its newly established subsidiary, the Deaf-Blind Family Association, recently launched a support program called 'Break for Families'. Check that article from Russia in the interesting Country Reports section. As usual, this edition is packed with other numerous other interesting country and Network reports.

Conferences continue to be an integral part of Dbl activities. We are just over one year away from the 9th Dbl European Conference (Touch of Closeness) scheduled for September 2017 in Aalborg Denmark. Check their website this autumn for the call for papers and registration.

In the conference section of the magazine, Jacques Souriau provides another article summarizing the Touch Conference held in Paris in March 2016 titled: 'Touch to learn, Touch to communicate'.

Other upcoming conferences this year include the Australian National Conference and the conference in Groningen Netherlands titled: 'Communication in the context of congenital deafblindness' commemorating the 10th Anniversary Masters of Deafblindness and Communication Course cosponsored by Groningen University and the Dbl Communication Network.

Lastly, this year Dbl is celebrating forty years as an organization whose members have been dedicated to improving the lives of individuals with the unique disability of deafblindness. Dbl or as it was once known as IAEDB, was officially formed in the summer of 1976, during a conference of professionals in North Rocks, Australia. My home organization, the Canadian Deafblind Association, which celebrated its 40-year anniversary in 2015, has a close connection to that event. We sponsored John McInnes and Jacquelyn Treffry who were mentors to our fledgling organization to attend this important conference. John was elected Vice-President at that conference and was elected President at a conference in Poitiers, France in 1987. IAEDB/Dbl can be proud of its many achievements; evolving from being strictly a professional driven organization focusing on education and organizing conferences into a mature, broad based professional organization representing programs and services for thousands of people with deafblindness around the globe.

Respectively,
Stan Munroe, July 2016

Vice Presidents' Messages

Bernadette M. Kappen reports:

It is hard to believe that this is the 40th Anniversary of Deafblind International (Dbl). Our vibrant organization started out with a few individuals who wanted to get together to share ideas. It was a time when there was not very much written about the medical, educational and social needs of children and adults with deafblindness. The motivation for sharing continues to be the backbone of Dbl. Each event brings together professionals who freely share their knowledge and ideas with the goal of improving the quality of life for the individuals they work with. Dbl has evolved along with social media. We now have a chance to communicate through Facebook and the website connects Dbl to the world. The Networks offer an opportunity for people to share common ideas and support each other. This is an important part of the structure of Dbl and I encourage members to join a Network and share what is happening in your program as well as learning from others. A strong Network is a true community of learners and a wonderful way to continue to grow as a professional.

The talent in the field of deafblindness is outstanding and this is seen at every conference and event. I hope you will look at the criteria for the Dbl Awards and consider nominating one of your colleagues for an award at the European Dbl Conference in Aalborg in 2017.

Please celebrate the 40th Anniversary and spread the word about Dbl.

Bernadette M. Kappen
(bkappen@nyise.org)

Frank Kat reports:

Dear colleagues and friends,

Deafblind International is on the move; we are full steam ahead still after forty years. We have all worked hard for this and it is certainly something to be proud of. A good example of what we can achieve is the visit I received from Caireen Sutherland this week. Caireen is conducting a 'Fellowship Research Tour'. This tour is not an Olympics Tour nor the Tour de France; its Caireen's 'Tour de DbI information technology'. Caireen is touring care and educational institutions throughout interviewing colleagues to learn about the current use of Information Technology used in these various facilities. The results of her research will undoubtedly present us with some practical recommendations for DbI. This is a wonderful initiative and I sincerely hope that she will be sharing its outcome with us in the DbI Review and at the DbI European Conference in Denmark next year. Another good example of 'full steam ahead' is the International Congress planned for 24–25 June 2016 in Heiligenbronn, Germany. This congress is specifically aimed at deafblindness and specific educational theory. The increasing volume of work in this field in Eastern Europe and in Russia shows that the sharing of knowledge and experience are taken seriously there. Some of our DbI member organizations, including Kentalis and the German Deafblind Consortium, are participating. For more information, check out the website:

http://www.stiftung-st-franziskus.de/index.php?id=466&no_cache=1.

This summer, the energy will start flowing again in August when the Board meets in Orlando, Florida, where we hope to exchange ideas for our strategic planning decisions. Also we need to keep in mind the diversity that we wish to achieve in the organization. As well we will discuss further how IT can support our work, facilitating knowledge sharing and getting in touch with each other.

Here's to 40 years of learning together, sharing knowledge, improving service and support for deafblind people; Great learning, Great sharing, Great fun!

Frank Kat
(F.Kat@kentalis.nl)

Learning and Communicating through Movement

Joëlle Minvielle

The purpose of this article is to share the outcome of a learning experience involving children with CHARGE syndrome. We would like to show that these children have competencies that are ready to emerge if the conditions that allow them to express themselves are within their reach. Actually, in contrast with a medical diagnosis that

could end up stigmatising certain types of behaviour, it is possible that through body movements these individuals can channel their expressions in intentional and meaningful ways. By addressing the child holistically and in a playful way, we can give the child the possibility to feel that he plays an active role when engaged in communicative activity. Our point of view is based on the Feldenkraï's method (1985) that uses movement as the opening to a developmental process.

A) The History of the Feldenkraï's philosophy

Feldenkraï's (1993) developed his method through his knowledge of physics, anatomy, neuropsychology and psychology; yet he was mainly focused on trying to understand, through observation, the dynamics of human movement. The difficulty explaining the principles of the Feldenkraï's method relates to the fact that the method is systemic, not linear. According to Berthoz (2009), while one can look at how the body works by focusing on separate elements that are apparently autonomous (e.g.'s, motor functions, vision, hearing and touch), in the end, everything works together holistically.

In his learning method, Feldenkraï's states that the relations between movement and thought constitute the basis for the conditions that steer our behaviours. When the efficiency and the efficacy of our movements improve, our intentions and acts become clearer. Our body experiences are witnesses to our brain functioning (Varela, 1996).

These conditions evolve as we engage totally in our experiences. These experiences constitute the fabric with which our lives are recorded and integrated by our brains through our sensory-motor system. The Feldenkraï's approach suggests initially that our habits hinder our development and well-being. By contrast, according to Feldenkraï's (1985), through constructing in the mind the image of particular movements (e.g., standing up or raising a glass) one will create new neural connections. In practice, the point is to become 'conscious' through the movement of what one is doing and to try out various possibilities to discover more efficient and coordinated movements.

If the brain is damaged or dysfunctional, the areas of the brain that control the sensorial and motor processes are under-utilized, which weakens brain functioning to a point where the capacity to perceive minute differences disappears. According to Feldenkraï's, it is possible to restore these functions through conscious movements when developed enough to recapture the capacity of the brain's processing ability.

B) CHARGE Syndrome

Drawing on the many observations I realised with children and youngsters with CHARGE syndrome, I could identify a number of constant developmental characteristics inherent with this syndrome.

One typical characteristic is their posture; the individual intensity of which is related to the sensory deprivation affecting each individual. The various postures are expressed according to each individual's perception of their upright position, balance, awareness of space, and body movements. Their postures may also be

affected in instances of respiratory deficiencies affecting their breathing functions. With proper support for those at the early emergence of difficult postures, the posture can be improved to assist with breathing and swallowing. In other instances, I have noticed that the posture of some children is such that they are unaware that they can put their weight on the ground and feel gravity to give them a sense of security.

Some of these children can develop particular ways to take control of their disability. For some it depends on the measures they use to protect themselves as well as understand their individual situation.

Through using the Feldenkraï's perspective it is possible for the practitioner to appreciate how a child with CHARGE views themselves and their relationship in the world. In other words, a Feldenkraï's practitioner should be able to read these individuals' behaviours and discover what internal resources the child uses to cope with their environment. Also an essential aspect of this approach is to appreciate that learning for these individuals comes from within and that their achievements are based upon developing trust and familiarization with people and other individuals in their surroundings.

One of our ambitions as a practitioner is to help these children acquire self-awareness and help them understand the symptoms of their condition. For them to realise their desires and build-up their self-confidence requires an absolute capacity for us to listen to them. During an interaction, it is necessary by reading their expressions and cues, to understand who the child is and where each child is in his/her own development in order to help them.

These observations and interactions with these children open the way to a co-constructed dialogue (Souriau & Minvielle, 1999). The content of this interaction comes to light progressively through the permissions, the answers, the questionings and the interpretations of the emerging movements of the child.

C) An example of an interaction session

We consider each session with these children as a unique moment where it is necessary to reinvent the approach, including the entry to communication, the forms of proximity that are allowed, and the information to be passed on through our exchanges of movements. The following part is a descriptive narrative of a particular session with a child whom we shall call "C".

First we need to be there to listen and often imitate (Decety, 2002) the child in its posture ('acture', Feldenkraï's would call it); and sometimes, if nothing happens, move closer and then move away in order to trigger his/her attention. Following this, wait for her reaction in order to respect the way he feels and how she perceives this closeness. So the 'dance' can begin, with a dialogue building up, based upon rocking; sitting side by side – towards the left and towards the right; waiting for an answer which consists in taking turns in getting closer or going away. Together we establish a movement of shifting the weight from one hip to the other; controlling this until the point that we can go from one side to the other. In this lesson, I used deflated balloons the pressure of which, when placed under her arms, gives an idea of breath, flow and back and forth movements. I try then to put my left hand behind

her back and, by surrounding them that way, to hold my hand on the balloon against her left-hand side. By slight variations in the rocking, I managed to modify the orientation of the rocking which opened towards the back and the left and then turned around back to the right. This change of plan allowed the opening of the ribs while organising the space in a back-front orientation. Then, through discovering the third plan of flexion-extension of the body, the spine gets organized in a downward then upward direction. "C" liked these variations a lot. Through these changes, consisting of movements of rotation, flexion-extension and tilting of the chest, our relation to space (and to all the possibilities allowed in our sitting position) developed smoothly.

After returning to our original position we changed position with "C" was now lying on her back, providing an opportunity to see if, in a different position, our conversation could continue. In order to connect with the previous situation, I kept using the soft balloons entrusting her to keep them.

I tried to make her feel a movement of force through her body by crossing her right leg and placing a weight on her right foot in order to go up as far as possible. After a few repetitions, not only had she understood the mechanism of this movement but she began to turn her head toward the left and to stretch out her left hand upward. To catch her gaze and give more existence or sense to this position of the arm, I made a soft balloon roll all over her arm, from her left shoulder up to her hand. "C" took the balloon in her hand, folded her arm while pushing back the balloon to her left shoulder; then extended her left hand in the same position. This looked like a request to start game over, which I accepted immediately. "C" repeated this several times, smiling at the discovery of the game. Then, when she decided to stop, we moved on. Surprisingly, these decisions and initiatives gave evidence of her intelligence and capacity to understand her bodily situations.

Then we changed from the rocking movements that "C" had made earlier while in a sitting position now to side to side rolling movements while lying on her back. She had understood the game and pleasantly took initiative to repeat it. She was completely relaxed after this experience which had provided her enough space to learn, play and set up reference points for her security. This child, who does not use a spoken language to express herself, obviously has body communication capabilities which she must necessarily learn to decode.

D) Important experiences and fundamentals

For these individuals to develop their self-awareness in relation to their spatial environment requires developing a personal understanding of their various body movements. Developing access to this personal knowledge rests essentially on their understanding of the fundamentals of various body movements, body orientation, balance and skeletal-muscle forces. Let's examine these fundamentals.

1. Orientation

Here, orientation, in the context of visual impairments (Bullinger & Jouen, 1983), relates to the whole body. Looking at a child, through their chest and face orientation

and trying progressively to build up this face to face interaction, help him/her to understand their vertebral axis orientation (Paillard, 1971).

Understanding this axis allows for the understanding of up and down; right and left sides. We can turn around to feel what is behind and what is in front. The experience of flexible movements, rotation and tilt allow for the construction of a spatial reference system. Through movement, this system is explored, felt and gradually absorbed to be reused.

This is how one learns their position.

2. Leaning points

When we allow the child to put weight to the ground, we offer him/her a stable connection to the ground. These leaning or pressure points inform about the possibility of realizing a directed action. He/she can also put their weight on a support to modify the trajectory of their movement.

The leaning (or pressure) points may include the feet only, a combination of the feet and hands (which is not easy), the back, the head, the knees and the elbows, the shoulders and the hips. The consciousness of these leaning points makes it possible to feel where we touch and where we make a contact with the ground to begin an action. Moving from one leaning point to another helps to organize more fluid and simpler movements.

3. Transmission and pushes

The transmission of force through our skeletal bones allows for detection of bodily sensations. When a push from the feet is passed to the legs through the joints towards the pelvis, the spine and the head, a sense of direction is given to the child. In this way the child feels their body is connected. To stand is to feel the body in relation to gravity and its leaning points (feet, pelvis, hands, head, back, etc.). It is of the utmost importance for a human being to feel the ground; a human being is designed to be in a standing position.

The transmission of the force from one joint to another makes it possible to initiate body movements (Bullinger, 1994; Cohen, 1993) which may be specifically organised to react in a survival situation or to a change in the environment.

Cohen (1993) describes six gravitational patterns: the spinal push from the head to the coccyx (and return); the counterpart push from the two feet to the two hands (and return) and the ipsilateral push from the hand to the foot on the same side (and return). These pushes give directions of force through our bones and constitute the first reference for our 'personal kinesphere', that is the construction of the references of our body in connection with the space and the directions towards which we go and act.

E) The actions we use: pushes, resistance, compression, searching for movement through torsions and rotations

The question is how to help these children build dynamics in their body to make them feel and organize the logistics of movement. Pushing actions and their sub-

categories (pressing, throwing, resisting, holding, releasing) are examples of exercise choices used when reacting to external demands.

Through co-constructing these actions, the body can be engaged in various games. Through games, it is possible to create many opportunities for the child to communicate, exchange information, practice stopping and starting, etc. All of the body actions involved with stretching, turning, reversing, etc. enhance the variety of body postures. These physical experiences create a multitude of feelings and emotions which provides these children with a greater perspective of adaptability when they experience unpredictable events.

These actions create direct connections for the child with a particular object or with a wider environment. The result is the development of a sense of continuity, a history, a memory, a presence in the world.

These notions can also be found in more complex actions, for example, when we put a child face downward on a big balloon and he/she gradually understands how to push on his/her feet. The child then manages to make the balloon roll with the body changing orientation eventually ending up in an upside down posture. Then, we teach how to put their hands on the ground to protect oneself, anticipating that the hand pushing will start a movement in the reverse direction. The next step will be to find some contact with their feet which can be transformed into a support from which a force can be transmitted. All these stages, which look so simple, are far from easy for these children with CHARGE. All these learning experiences together help these children develop their relationship to the world.

Daily life challenges can also improve the way these children feel their body. For instance, the complex action of 'climbing upstairs' by getting support from their feet and from the hand on the bannister, involves a transmission of force through their legs within which the axis of their bones must be organized to become aligned.

These experiences are proposed in the context of the action and also through varying situations where we can insist on this specific transmission of the push to support their weight. For example, climbing on blocks with various heights, which required pushing with different forces; climbing on and getting down forward and backwards, makes possible experimenting with the landing on the foot and flexing the knee; climbing face forwards or on the side etc. These variations in the game are more enriching than simply the quantity of repetitions. After such experiences, we noticed that the alignment of the legs of the children become noticeably better; the knees find an improved alignment instead of colliding with each during walking. This results in a lot of changes in the posture of the child, better functional walking and improved awareness of spatial relationship.

F) The effects of the movements

Through all these neuro-motor experiences, we try to identify the aspects of the child's development which have not been explored enough. We try to go back to the point where the child stopped the explorations that were necessary to improve their functions; we try to make him/her repeat situations that can help them to perform these functions better. Some children may stop their development because of so many obstacles generated by their disability, or because they had no interest to do

otherwise. I define this situation as a conflict between the developmental difficulties of the child versus the real-life physical and social environment within which they are being shaped.

Conclusion

These children enjoy movements as long as they are able to master them in a context of trust. As they 'play the game' it is not unusual to perceive them feeling the kinaesthetic information running inside them. In our approach we do not work on the weak functional parts of the child but rather on the body as whole in order to make the child implement them in efficient and effective ways.

The Feldenkrais-type bodily experiences should be offered to these children as early as possible, either in an educational or home setting, to give the children a chance to feel their bodies, organise their actions, learn nuances and control, and to build up points of reference that make them feel more secure in their environment.

We cannot insist enough on how important it is for the child to create a unified perception of himself to access his/her own feelings and to take initiatives. This is entirely possible through their experiencing a wide array of movements and supporting their progressive organization into memory.

The meetings with these children are unique; they are based on their specific needs and on what they show of their skills. Through the experience of movement, they can progressively make sense of these skills.

Editors Note:

This article, originally written in French by Joëlle Minvielle (joelle.minvielle9@orange.fr), was translated into English by Jacques Souriau (jacques.souriau@gmail.com). Jacques is a former President of Dbl (1991–1995) and a current member of the Dbl Communication Network.

Translator Jacques Souriau's note:

Joëlle Minvielle was a former Professor of Dance at the the University of Poitiers. Her interest in the role that movement plays in developing an understanding of one's body in relationship to their environment, led her to develop a deep knowledge and expertise in the Feldenkrais method. As a former Director of the School for Deafblind Children in Poitiers – France and of the National Resource Center, I had the privilege to see how Joëlle worked with congenitally deafblind children using her method to assess and develop their body potential. This article represents an introduction to her experience which I believed was worth sharing with those who are in contact with congenitally deafblind children.

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On an Approach to Evaluation of an Accessible Level of Symbolization in the Context of Communication Performed by Children with Visual and Hearing Impairment and Developmental Disorders

Alina Kholhlova and Irina Moiseeva

The necessity to communicate is one of the basic needs of a human being. A child needs communication from birth on, and the early years of the childhood are very important in terms of the formation of a relationship not only to relatives but also to the whole outside world. The communication process makes it possible to exchange information, to show the attitude to someone or something, to reach mutual understanding with other people or sometimes to affect a counterpart or a situation. Not all the children with special needs have the same way and the same terms of language and speech development. Thus, it is the aim of educators and psychologists to define the possible means and the appropriate level.

The following article describes a possible approach to the evaluation of the communication tools of children with visual and hearing impairment combined with multiple developmental disorders.

The method is designed for examining children with complex and multiple developmental disorders, including those with combined vision and hearing disorders.

It is advantageous to use the 'named approach' in order to evaluate the level of language development of children who are not using any developed form of a conventional spoken or sign language, especially in the cases when the others have problems in evaluating what phrases and to what extent a child is capable of understanding. The surrounding adults (parents, educators) are usually in a possible way evaluating the accessible way of symbolization during the communication process and contemplation of a child. However in the context of working with children having multiple developmental disorders the expectations applied to a child may be often either too high, or too low. For this reason, we are suggesting a standardized evaluation procedure to assess the development level of symbols that a child can understand. This procedure may be used for primary diagnostics as well as for the dynamic tracking of the development of language skills during the learning process.

This version of the method can be used for working with children who are able to see forms and subjects. The target group by age includes school children. Hence, the aim of the method is to assess the level of symbolization accessible for the examined child. The results of such diagnostics can be used in order to organize the learning process as well as communication and to choose the accessible ways of presenting the material and coding any information.

The stimulus material of the approach has been chosen according to the symbol system of the gestural code (M. Skelly as in Wide, R.), according to which the initial level of the symbolization represents a real subject (demonstration of any item becomes a permanent sign for the beginning of a corresponding event, for example: a cap is a symbol for a walk), whereas the highest level of the symbolization is a definition of the language, i.e., a word.

The stimulus material includes 15 real subjects, 5 pieces of clothing, 5 pieces of dinnerware and 5 school items as well as the photographs of these subjects, the realistic colorful drawings and the outline drawings. Apart from that there are identification plates with the names of those items and the photographs of the gestural equivalents on these plates.

The approach presentation procedure is as follows:

- 1.** The psychologist or the educator is showing to the child (one by one) pieces of clothing, asking "What is it?" (orally, using a sign, using a questioning facial expression) or is contemplating the child's reaction. Further, depending on the child's response, the procedure can be carried on in two different ways.
- 2.** If the child names the items using a word or a sign, one can proceed to the next group of subjects. In a case when the child defines all of the items using language (signs, words), the examining procedure can either be finished. But it can be also offered to the child to choose written indications of the items on the plates, as an additional task to assess the reading skills of the child. In any case this response of the child allows to conclude that the following communication can be carried out by means of language – using words or signs.

If the child does not name the items, the person conducting the experiment should offer to the child one of the following actions, each in turn: 1) taking an item and doing something to it (not in order to assess the level of the development of subject-related skills but in order to be sure that the child recognized the item). 2) picking photographs for the items in every group. 3) picking realistic pictures for the items in every group. 4) picking outline drawings for the items. 5) pointing to an item after a sign description made by the diagnostician. 6) choosing a plate with a written word for each item.

A protocol for the results has been elaborated. Evaluation of the protocol enables one to find out at which level and extent of the symbolic description of the subjects allows a child to act in a most successful way and at what maximum symbolization level this child can achieve. According to these results it is possible to give recommendations to the teachers and family members related to the use of alternative (or language-based) means of communication in order to make contact with the child during the educational process.

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Sensory Engagement: Increasing Wellbeing for a Person who is Deafblind with an Obsessive Compulsive Disorder

Corene Jonat

Sensory Engagement can be key to increasing our wellbeing; developing cognitive function, social interaction, communication and exploration. Studies have shown that we rely heavily on our multiple senses to process and gain information about our world and relationships. Engaging multiple senses can develop more ways for information to be triggered and retrieved from our brains' learning centre. Low levels of wellbeing can be costly to an individual's health, social interactions and daily life. Developing sensory engagement can be an important positive psychological element used to enhance a person's sense of motivation and purpose in life. Without it, health, both physical and psychological are at risk of deteriorating.

As a deafblindness consultant, accessing supports needed to reduce the risk of health deterioration and implement changes to enhance well being was developed for Andrew. Andrew is a 49-year old male with congenital deafblindness, diagnosed with obsessive compulsive disorder and anxiety, residing at The Lions McInnes House¹, a group home located in Brantford (Ontario, Canada) for persons with deafblindness. Andrew's obsessive compulsive behaviors of dressing and undressing could last for hours, resulting in receiving minimal opportunities to engage in other ways in and out of his home. This created challenges interacting and engaging with his environment and people, as well as poor eating habits when he had gone long periods of time without food. He often appeared agitated and sad, having little interest in his days.

Upon awakening in the morning when prompted to get dressed, Andrew would comply but then immediately undress and lay back down on his bed for increasingly long periods of time. Dressing and undressing could last anywhere from 3–6 hours. He was stuck getting started with his day and not able to participate in activities or outings with staff due to these challenges. Andrew also had difficulty with staff shift changes and interacting with multiple intervenors that he did not have any consistency with; trying to reset his day when someone new came on, thinking it was time for bed and wanting to go to sleep.

Analysis and documentation determined that Andrew repeated these challenging behaviors consistently on a daily basis which had been increasing over the last few years. His repetitive dressing and undressing and difficulty with multiple intervenors, appeared to bring on confusion and anxiety where laying back down on his bed, minimally clothed, gave him some relief from his long periods of obsessive compulsive behaviours. He would even miss eating breakfast and lunch only to initiate eating his first meal in the late afternoon or binge eating. Andrew slept during the night, yet would also sleep during the day; his internal clock appeared to be

misaligned needing to build trust, through structure, consistency and routine to develop his psychological, physical, environmental and social experiences. Andrew continued to have challenges engaging, exploring, communicating and gaining information about his environment, relationships and ability to express himself. He was not developing the security needed to engage in his world other than through the repetitive behaviours that increased his anxiety and now posed as a risk to deteriorating his health.

A sensory support program was developed for Andrew that encouraged the development of trust and security through sensory communication and information using sensory integration and engagement to develop wellbeing. Sensory information enters our brain at every moment of the day from every part of our body. The central nervous system uses this sensory input to produce awareness, perception, knowledge, body posture, movements, thoughts and emotions. Andrew's ability to sense and gain information from, olfactory (smell), gustatory (taste), auditory (feel sound vibrations), visual (possible light and dark shadows), vestibular (movement), proprioceptive (position his body) were addressed through this plan. When initiating Andrew's sensory support plan, consistency and adherence was very important to successfully implement success long term, therefore Andrew was given direct focus with one to one intervenor attention, to include 4–6 intervenors that shared shifts in service to Andrew over a period of 6 weeks. Following this period, he would return to working with all other intervenors to initiate his plan as well. He required an initial focus from a team of intervenors that had specific training to provide the consistency needed, offering calm non-judgmental interactions and to utilize a detailed daily schedule.

Andrew's sensory engagement plan consisted of the following: sensory cues to establish his morning and night timeframe using smell and sound vibrations. A scent diffuser and CD used morning and night indicating stimulating smells (lemon, lime, orange) and stimulating sound vibrations (jazz, classical) for waking up and relaxing smells (lavender, sandalwood, rose) and relaxing sound vibrations (guitar, harp) when going to sleep. Adherence to his previous sensory diet prescribed by an occupational therapist was reestablished, using brushes and textures to help his body adjust to waking. In addition, change to the texture and height of his mattress in the morning was employed to reduce his interest in lying back down and further communicate that there are other activities to explore and engage in.

Three meals a day were promoted with small snacks in between to encourage his body to regulate itself and stay alert. After every main meal Andrew was given a concrete cue to go out of his apartment and take part in a community outing or an activity to increase sensory stimulation and promote proprioceptive and vestibular movement and body awareness. All outings and activities were established to engage all of Andrew's senses and to connect and build relationships with his intervenor, himself and his experience. intervenor interaction invited and guided Andrew into engaging in sensory activities they were already participating in to motivate, build trust and connection. Andrew was always given choice, and offered alternatives when interacted with.

Receiving information is important to wanting to explore and experience your world. Sensory engagement initiates the brain to carry impulses or information through the nervous system to the body, motivating a person to want to know more. Specific sensory experiences were created for Andrew to provide this and included a sensory bin (ideas to encourage taste, touch, music, movement exercise), art activities (examples: lemon scented marble printmaking, cinnamon ginger painting, drumming art) and outings (examples: flower gardens, butterfly conservatories, animal experiences). These were planned and developed to give Andrew the opportunity to share his experiences and explore them with his intervenor. He was never left to explore alone but to share with his intervenor. Forming connections with others ultimately gave him the courage to gain and search out for more information on his own.

After the first 2 weeks of implementing the sensory support program, Andrew started to show success in building trust through sensory engagement with structure, routine and consistency. Documentation showed that he physically had more endurance, was more active and energetic, and took part in going for walks and outings, going to places he had not been to in years, such as, bowling, going to his favorite restaurant, and having the interest to help prepare his dinner with his intervenor. Psychologically he was happier, less anxious and more relaxed and did not resort to lying back down in his bed and sleeping during the day. He now would sit in his living room with his other room mates. Andrew was smiling, laughing and responsive, interacting with his Intervenors with who he had built supportive relationships and enjoyed taking part in new activities. intervenors used sensory experiences, activities and outings to help him gain information about his world. Every day we communicate with, and receive information from our environment and relationships. From everything around us – the weather, other people's voices, touches, facial expressions, music, alarm clocks, television, etc. The information and communication we receive enables us to anticipate our next move, whether to wear a coat or not, if someone is pleased with us, how much time we have left to sleep and so on. We get this visually and auditorily at all times, allowing us to feel connected and purposeful. With dual hearing and vision loss, Andrew did not have the ability to pick up on those communication messages, and was unable to anticipate what was going on around him, what things meant, and mostly what was going to happen to him. He may have perceived that it was safer to stay in his room on a daily basis and lay on his bed because it was familiar and nothing else was of interest. Presenting new information at this stage was always unsuccessful because he lacked trust and motivation.

Andrew gained trust by experiencing and feeling acceptance, security and safety when sharing and receiving new information through his senses. In utilizing consistency, routine and structure by inviting the exploration of new information through sensory engagement, Andrew continues to increase his self-esteem, self-worth and build healthy connections to his environment and relationships, further strengthening his interest to learn, grow and feel purposeful.

Andrew continues to have successful days interested in gaining information from his environment, relationships and experiences. He takes part in nature walks exploring

his property, stores and restaurants in his area, touching the grass, leaves, trees, flowers and leaves, forming friendships with his intervenors, creating sensory art explorations and engaging in new experiences like going to the Science Centre² for the day and exploring all the exhibits. Andrew can have some challenging days where he requests his bed or will repeat dressing and undressing, but it does not last long. All intervenors remain united in providing consistency, structure and routine in how they interact with Andrew, communicating and offering re-direction to engage in alternate positive sensory experiences, increasing his well being.

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¹ The Lions McInnes House is a small corporate member of Dbl.

² <https://www.ontariosciencecentre.ca>

Expressive Sensory Activities and Outings

Sensory Engagement IDEAS

Expressive Sensory Activities and Outings to be shared with and explored together

Sensory Activities:

1. Cinnamon, clove drawings
2. Textured ribbons glued to canvas
3. Shaving cream/acrylic prints
4. Clay sculptures w/ buttons
5. Textured fabric collages w/ glue
6. Paintings on wood with applied gel water beads placed into wet paint
7. Nature collage with sticks, leaves, pines cones ect on canvas boards
8. Lavender paintings
9. Finger painting with a variety of textures: whipped cream, pudding, jello, shaving cream on papers
10. Sand play – not just sand use macaroni, popcorn, oatmeal, rice, dried beans and do collages with then afterward
11. Water and paint art using spray bottles, brushes, sponges on canvas
12. Scented paper collages: tear paper and glue to wood.
13. Painting to music using acrylics and brushes on canvas
14. Balloon prints. Blow up small sized balloons and use to dip in paint and create a painting on paper or canvas
15. Paint inside a heart with paint mixed with sand, use your finger (latex gloves optional)
16. Scribble drawings w/multiple lines and colours using scented markers on paper to music
17. Paint a large rock or multiple small rocks with scented paints

18. Paint with ice coloured with food dye. Hold with fingers and let melt on water colour paper as you move them around
19. Collect leaves and create a leaf collage with glue
20. Yarn art: Wrap multiple colours of yarn around a canvas to a textured art piece
21. Apple prints w/paint on paper
22. Potato prints with ink on paper
23. Create stepping stones with plaster and colourful jewel beads
24. Bubble wrap prints: cover with paint on top of bubble wrap press papers on top and pull off to create prints

Sensory Outings:

1. Museums (touch, movement)
2. Community music concerts (sound vibrations)
3. Mall walk (movement, textures)
4. Green house, garden centres (smell, textures)
5. Flower shops (smell, textures)
6. Chocolate/candy stores (smell)
7. Bath and body stores (smell)
8. Bulk barn (smell spices)
9. Music stores, instruments (sound vibrations, touch)
10. Sensory rooms (sound vibrations, textures)
11. Toys stores, stuffed animals (textures)
12. Fabric Stores (textures)
13. Parks (Texture, Smell)
14. Art galleries (texture)
15. Coffee shops (taste)
16. Restaurants (taste)
17. Animal farms (Textures)
18. Grocery stores (Touch, smell)
19. Beaches (Touch, Smell,)
20. Nature walks (touch, smell, sound vibrations)

Expressive Sensory Activities

SOFT TEXTURES

Foam and Feathers

SOFT TEXTURES OF FOAM AND FEATHERS, CREATING LAVENDER SCENTED ACRYLIC PRINTS ON PAPER

Foam Prints

Supplies:

1. Can of shaving cream

2. Thick paper or water colour paper
3. 2 colours acrylic paint
4. Metal or wood ruler
5. stir stick, feathers, lavender oil
6. Square tin pan to hold paper

Directions:

1. Spray out square shape of shaving cream on pan and fill in.
2. Drop two colours of acrylic paint and drops of lavender oil on shaving cream, stir colours and oil lightly with stir stick.
3. Lay paper on top and press into shaving cream. Remove paper from shaving cream and scrap off excess shaving cream. using ruler.

Notes:

1. Hold ruler firmly on paper when scrapping off excess shaving cream to reveal paint designs absorbed on paper.
2. Dollar store has acrylic paints in squeeze bottles that allow you to drop onto surface of shaving cream.

ESSENTIAL OILS

Scent Art: Create Scented Art with Cotton Balls

STIMULATING: Anise, Spearmint, Rosemary, Peppermint, Tea tree, Chili, Dill, Eucalyptus

CALMING: Basil, Pine, Cedar, Ginger, Lavender, Vanilla, Balsam fir

UPLIFTING: Orange, Cinnamon, Grapefruit, Lime

Scent art

Supplies:

1. Canvas
2. Bag of cotton balls
3. Multiple stimulating, calming or uplifting essential oils
4. White Glue

Directions:

1. Choose to do either a Stimulating, calming or uplifting scented art. Choose 1–2 oils for your art.
2. Fill two bowls with cotton balls and drop oils onto cotton balls.
3. Fill another bowl with white glue and pick up scented cotton ball one by one and dip into glue and glue onto canvas.

Notes:

1. You can either purchase white or coloured cotton balls or die them yourself with food colouring and let them dry over night.

2. Cover all surfaces with plastic cloth.

String textures

Spaghetti

ENGAGE WITH DIFFERENT TEXTURES, TAPE, and RAW SPAGHETTI
CREATING SPAGHETTI COLLAGE PAINTINGS ON CANVAS

Spaghetti Art

Supplies:

1. Dollar store canvas
2. Masking tape
3. Long spaghetti
4. Acrylic paint colour
5. Stir stick, feathers, lavender oil
6. Square tin pan to hold paper

Directions:

1. Apply 4–9 long strands of masking tape to hang over edges of canvas.
2. Paint over top of tape with acrylic paint.
3. Pull up tape to reveal design and add stick long.

Notes:

1. Create any design you like with the masking tape on the canvas as you will paint over the tape and then lift it up to reveal your design.

Aromas

Spices

ENGAGE IN ART USING CINNAMON AND GINGER CREATING HERB/SPICE
PAINTINGS WITH ACRYLIC PAINTS ON CANVAS

Spice Art

Supplies:

1. Canvas
2. Various spices, cinnamon and ginger
3. Squeeze White Glue bottle
4. Large foil tin pan

Directions:

1. Squeeze out glue in different shapes on canvas.
2. Sprinkle cinnamon all over glue to stick. Empty excess in pan.

3. Repeat layer of glue and cinnamon to make free form designs on your canvas.

Notes:

1. Tin pans (used for roasts) are from dollar store . They will hold any spillage from the spices to reduce mess. Cover all surfaces with a plastic table cloth as well.

Education for Students with Deafblindness in the United States

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Students with deafblindness often enter classrooms with many diverse and very unique needs as well as a variety of multiple disabilities. As a result, accurate prevalence data for individuals who are deafblind in the United States (US) is difficult to determine. According to Miles (2008), the struggle to classify children (aged birth to 22 years) as deafblind produces only estimates.

The National Center on Deaf-Blindness (NCDB)¹ released its most current Child Count of Children and Youth who are Deaf-Blind in October, 2015. The NCDB produces the longest running registry of children who are deafblind in the US. The census reported that nearly 90% of the children included in the count have additional disabilities, stating that the number of children with deafblindness was 9,384 (The National Center on Deaf-Blindness, 2015). A noteworthy difference existed between the recent NCDB numbers and the population of children with deafblindness reported by the Office of Special Education Programs – US Department of Education² (2008) indicated that 1,539 children (aged 3–21) were identified as deafblind. The difference in numbers could be due to the fact that most organizations report their children/students with deafblindness under alternate disability categories (i.e., developmentally delayed, multiply disabled, visually impaired, or hearing impaired) (NCDB, 2015). Additionally, there exist many misunderstandings related to deafblindness. The lack of identification and misunderstanding of deafblindness have been consistent over time, resulting in grave concerns and often result in a lack or delay of appropriate intervention and/or educational placement (Malloy & Killoran, 2007; Mueller, 2006).

Educational Placement

For educational purposes in the US, an individual is identified as deafblind when their educational needs require substantial adaptations and modifications to their educational program due to the communication and developmental delays produced by the combination of the loss of both hearing and vision (Larsen & Damen, 2014). While an educational diagnosis of deafblindness is possible in the US, children are often given a primary label that is not deafblindness. The National Center on Deaf-Blindness specified that in 2014 only 17% of children with deafblindness (ages 6–22) qualified for educational services under category of deafblind while many

students (35%) were reported in the primary disability category of multiple disabilities. Because of the wide variability of primary disability labels and the lack of educational personnel who are trained in deafblindness in the US, these students are often served by the teacher who has a license which corresponds to the child's primary education label (The National Center on Deaf-Blindness, 2015) as: teachers licenced in severe disabilities, teachers of the deaf and hard of hearing (TODs), teachers licensed in low vision and blindness (TVIs) or teachers with a certificate in general special education (The National Center on Deaf-Blindness, 2014). However, in order to provide appropriate services to children with deafblindness, it is imperative that teachers be trained in instructional strategies and interventions, individualized supports specific to deafblindness as well as intervener services. Furthermore, due to the great heterogeneity of this population of learners, a diversity of educational placements is required to meet their varied needs (Ferrell, Bruce, & Luckner, 2014). In the US, students who are deafblind receive instruction in general education classrooms, self-contained classrooms, resource classrooms, separate schools, residential facilities, homebound hospitals and private schools (The National Center on Deaf-Blindness, 2015). Additionally, in the US, only nine university teacher preparation programs offer coursework in deafblindness (Hall, 2003) and only two states offer a teaching endorsement in deafblindness – Illinois and Utah (A. Parker, personal communication, November, 2, 2015). With so few teacher preparation programs as well as the scarcity of states providing teacher certification in deafblindness, it is imperative that the shortage of teachers in this area also be addressed (McLetchie & MacFarland, 1995; Zambone & Huebner, 1992).

Case Example Including Recommendations

Classroom Makeup

This authentic case example describes a self-contained classroom for deaf/hard of hearing students taught by a Teacher of the Deaf (TOD) with five students (ages 4–7) with multiple learning needs. Four of the five students in this classroom have a form of vision loss with one having an educational label of deafblindness (although all four meet the federal definition of deafblindness). The table describes these four students. The classroom was supported by other adults including one TOD and three paraprofessionals, as well as intermittent related service providers (e.g. speech language pathologist, occupational therapist, nurse, teacher consultant of students with visual impairment (TCVI), orientation & mobility specialist and deafblindness consultant).

| Student | Diagnoses/Characteristics | Strengths | Needs |
|------------------|---|--|--|
| Student 1 | Deaf, Visual Acuity 20/200, Motor Delays, Cognitive Impairment, Seizure Disorder, peroxisome biogenesis disorder (Zellweger Syndrome ³) | Seeks social interaction from adults, loves music, compliant for most work tasks | Very few spontaneous signs/words (approximately 10 signs), gross and fine motor tasks, functional skills |
| Student 2 | Deaf, Visual Acuity 20/600 in Left Eye and 20/200 in Right Eye, Behavioral Disorder | Age-appropriate dramatic play, enjoys being read to, will pull communication partner to wants/needs, imitates most signs, some spontaneous signing (30 signs) | Transitions, participation in structured tasks, increased vocabulary and sentence structure, learning to use field of vision more consistently, pre-academics |
| Student 3 | Deaf, Suspected Autism or Behavioral Disorder, Visual Acuity 20/200 | Appropriate participation in preferred activities, fine motor tasks, will pull communication partner to wants/needs, imitates most signs, some spontaneous sign (20 signs) | Transitions to non-preferred tasks, sensory integration, physical aggression, increased vocabulary and sentence structure, tolerating glasses and hearing aids for extended period of time |
| Student 4 | Deafblind (Light Perception only) | Enjoys and seeks out environmental exploration, desire for 1:1 work with frequent reinforcement, enjoys sensory activities | Orienting to her environment, transitions throughout her day, increased awareness and completion of typical tasks during day (school routine), increased communication initiations |

The classroom was located in a round open-concept wing where there were three walls separating the classroom from the adjacent classrooms. A partial fourth wall was constructed from filing cabinets and other classroom materials to create a barrier and door opening. The TOD utilized a sound field system within the classroom to mitigate acoustic concerns. The classroom contained traditional age-appropriate materials (e.g. puzzles, play centers, alphabet/number signage), adaptive equipment/materials (e.g. Rifton⁴ special needs chairs, feeding equipment, oral thickener), and an area designated for students to “cool down” after behavioral tantrum, however, it was open and did not have designated areas for different activities or instruction. The TOD used tape and tables as environmental supports to separate the learning spaces.

Classroom Instruction

Instructional time consisted of small group activities at the table, circle time, one-on-one, and centers. The TOD was in her first year of teaching and had received traditional deaf education training with no additional training related to deafblindness or additional disabilities outside of deafness. She used various workbox tasks during one-on-one time with some of the students. Students responded inconsistently to small group and individualized instruction, often times trying to leave the instructional area when the TOD’s attention was not individualized specifically to them. The paraprofessionals were proficient at redirecting the students, however redirection was consistently needed for the students to stay in the instructional area. Minimal use of reinforcement was observed in the environment. Even though the TOD planned age-appropriate, meaningful activities, the students did not appear to gain the intended instructional targets due to low language levels, high levels of aberrant or inappropriate behavior exhibited by the students, and vision loss.

Recommendations

Given the unique classroom and intense needs of the students in the classroom, recommendations were made for the areas of behavior, instructional strategies, and sensory needs. These recommendations are grounded in behavioral theory and several are evidence-based practices from the field of autism (Wong, et al., 2014) or the field of severe disabilities. Additionally, child-guided techniques from the field of deafblindness were considered and embedded in recommendations in order to encourage staff to establish trusting relationships with and respect the learners who were deafblind.

Behavior

When students have limited language, they are sure to engage in behavior to get wants and needs met. In fact, there is a negative relationship between communication and behavior levels (Barker, et al., 2009; Dominick, Davis, Lainhart, Tager-Flusberg, & Folstein, 2007). Additionally, students with deafblindness who have decreased communication skills may use behaviors considered to be aberrant

to express themselves. Many of the recommendations made for this classroom revolved around the use of reinforcement. Following a preference assessment for each student, effective reinforcers can be selected to increase desired student behavior and increase trusting relationships with the staff. The schedule of reinforcement was also critical to discuss with staff. In order for a student to learn a new skill, it is vital for reinforcement to occur on an immediate and consistent basis. In this case, it was important for staff to know that they must start with a 1:1 reinforcement schedule (e.g., the Premack principle⁵ or “If-Then” contingency; you must do one difficult task before you get your preferred item or activity, also providing the learner a clear ending to the activity) and then increase demand in order for the student to gain reinforcement. We emphasized that attending to the amount of reinforcement needed for each activity/each day and remaining flexible with demand based on how the student is doing would allow the staff and students to change their schedule as needed and in turn, ensure student success with tasks (errorless learning).

It was also recommended that each student have a Functional Behavior Assessment (FBA)⁶ to determine the function of aberrant behaviors in the classroom. By determining whether a behavior (e.g., running out of the classroom) served the communicative function of attention seeking, task avoidance or escape, gaining a desired item, or sensory seeking is critical to intervention selection. By determining the function of the aberrant behavior, the staff could select an intervention that gave the student access to the same function through a more socially-acceptable behavior. Furthermore, understanding the function of the behavior would allow staff to teach the students alternative ways to communicate in order to increase both receptive and expressive communication.

Classroom staff were instructed to tie communication training to all tasks and routines throughout the school day. Students should be taught to appropriately request breaks and desired items in an appropriate way rather than using aberrant behavior. Teaching students to use communication rather than tantrum or physical behavior can be accomplished through a strong system of prompting and reinforcement and should be used with all students consistently throughout the day. Visual and tactile schedules were instituted in order to aid in bringing order and predictability to the students’ classroom/world and to allow them to have a sense of control over their environment. The staff was instructed to create routines which could be followed throughout the school day so that the students schedule would be predictable. For example: Prior to the beginning of each school day, the icons were placed on each student’s schedule in order of occurrence. Then, at the start of each activity, the students would remove the icon or object, take it to the area indicated, place the icon/object in the square with their color code. As students completed each activity throughout the day, they removed the picture and placed it into a “finished” area at the bottom of their individual schedule. Finally, at the end of the day, staff would remove any remaining icons/pictures.

Lastly, recommendations were made related to the prompting hierarchy. In order for students to succeed at a task, they may require prompting. A most-to-least strategy (Machalicek, O’Reilly, Beretvas, Sigafoos, & Lancioni, 2007) is typically used when a

student is first learning a skill; the first trial is prompted with the most intrusive prompt (full physical assistance) appropriate to accomplish the skill successfully. The first trial is followed by subsequent lesser intrusive prompts (partial physical assistance). The less-prompted, successful trial is then reinforced. A least-to-most strategy is typically used when a student has shown, in the past, an ability to accomplish successfully a task (e.g., usually 80% or more of trials). No matter which strategy is used, it is critical to remember to fade prompts as quickly as is possible. Finally, remember to differentially reinforce those responses that require less prompting (“What is ABA Therapy?”)

Sensory Needs

Since many of the students exhibited obvious sensory processing and modulation dysfunction (evidenced by both vision issues and physical behavior such as galloping, jumping, and constant need for gross motor movement), it was imperative that their program also take into consideration their unique sensory needs. We proposed working closely with an Occupational Therapist who had knowledge in the area of sensory dysfunction in order to enhance a strong behavior- and communication-based program. Furthermore, given the students’ self-regulation deficits, we strongly recommended that students be provided with a visual break card to utilize when needed to help facilitate self-regulation. To teach this skill, staff were trained to use a visualized social story in conjunction with repetition. Sensory needs (including over stimulation) are primary causes of unappreciated behaviors.

Instructional Strategies

After the staff were trained in basic behavioral interventions, it was critical that recommendations be made regarding instructional strategies. Once the students were motivated to access instruction, it was important that the staff had strategies to increase skills. We recommended that staff provide a five to 10 second wait period after making requests of the students. The use of time delay has been proven to increase student independence, decrease reliance on prompting, and increase desired skills (Fleury, 2013). Further, time delay can be used to address a variety of skills including “social, communication, behavior, joint attention, play, cognitive, school-readiness, academic, motor, and adaptive skills” (Fleury, 2013, p. 99). Additionally, staff were recommended to provide instruction through a multi-sensory approach. For example, when asking what a student wants (e.g., drink), we instructed staff to pair the verbalization with the actual items (e.g., hold up a cup). Allowing students to have a concrete referent will likely increase understanding and accuracy. Moreover, the item used may serve a representational communication function for the child, allowing the communication partner opportunities to improve communication.

It was important in this classroom that we especially emphasize use of strategies that not only addressed the deafness/hearing loss but also addressed the vision loss. The TOD and support staff needed instruction in use of contrast (e.g., SMART board, light boxes, visual schedules, and classroom materials), magnification, and tactile supports. While the use of sign language was used for some students in the

classroom, much of our training focused in on assessing and considering field of vision for each of the students and the impact upon their ability to visually access the sign language input.

Conclusion

In order for children with deafblindness to receive appropriate adaptations and modifications to their learning programs, teachers and staff must receive appropriate training. This may occur through university coursework, professional development, conferences, and/or consultation services as provided in the case example. While the strategies recommended for this classroom were tailored to fit specific students, they were created using evidence based practices which have been established as useful with a variety of learners. As researchers and practitioners seek to identify interventions which meet individual student needs, we suggest looking to adjacent fields for direction in addition to using accepted practices in the field of deafblindness. Finally, crafting a suitable educational program for learners with deafblindness is one which requires a team member who understands the unique learning needs of this population and is able to discern the appropriateness of practices from adjacent fields in order to ascertain the applicability to the individual child's learning needs.

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¹ <https://nationaldeafblindness.org>

² www2.ed.gov/about/offices/list/osep

³ www.ninds.nih.gov

⁴ www.rifton.com/products/special-needs-chairs/rifton-activity-chairs

⁵ The Premack principle of reinforcement which states that an opportunity to engage in more probable behaviors (or activities) will reinforce less probable behaviors (or activities).

www.springerreference.com/docs/html/chapterdeafblindnessid/344414.html

⁶ cecp.air.org/fba

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Motivation to learn in students with deafblindness

Dr. Ineke Haakma

Students with deafblindness are a unique group within the education system. Having sensory loss influences the motivation to learn (McInnes & Treffry, 1982). In my PhD research, I tried to gain insight into the motivational processes for students with congenital and acquired deafblindness. In this article, I will briefly discuss my research. I would like to start by explaining the concept of motivation.

Students' motivation

Motivation is important in education. Motivated learning leads to better performance and more thorough information processing. Children are by nature intrinsically motivated to learn. They are born with natural curiosity and want to explore their environment and learn new interesting things. People in their social environment can either foster or diminish students' natural intrinsic motivation. In the educational setting, the teacher plays a crucial role in stimulating children's intrinsic motivation to learn. Self-Determination Theory (Deci & Ryan, 2000) describes how teachers can positively influence student motivation. This theory states that teachers need to pay attention to the psychological needs of students: their need for competence, autonomy, and relatedness.

Competence refers to being confident, in other words, having the feeling that one is capable of acquiring interesting, new abilities, and being successful in performing tasks. Autonomy refers to the feeling of freedom and having the opportunity to act on one's own initiative, the feeling of making one's own choices and expressing one's own ideas. Relatedness refers to the experience of safety, care, and positive contact with others.

Previous research has explored these psychological needs and the teacher's role in satisfying these needs in students without disabilities. Research on motivational

processes in students with sensory loss is lacking, however. The aim of my PhD research was to make an initial attempt to fill this gap in the research.

Students with deafblindness

Congenital deafblindness

Sensory loss influences the motivation to learn and the learning process itself. For example, children without sensory loss learn by exploration, imitation, and observation. Children who are born deafblind are only aware of objects and people within reach. Exploring the environment can hardly be motivating, if you don't know what there is to explore. Therefore, many children with congenital deafblindness show decreased responsiveness, stereotypical behavior, learned helplessness, and fewer possible ways to communicate (Chen & Haney, 1995; Hersch, 2013; Sall & Marr, 1999; Marks, 1998). Some children are only able to communicate through direct contact, for instance, by means of tactile sign language. Therefore, there are often only a small number of people in the child's environment who the child can communicate with. Having congenital deafblindness hinders the likelihood of learning by observation and imitation, and social interactions. These are all crucial aspects of a student's motivation to learn.

Acquired deafblindness

Students with acquired deafblindness face challenges that differ from those of students with congenital deafblindness. Since these children often have already learned a language and since comorbidity¹ (such as intellectual disabilities) is less often the case, these students are usually capable of being educated pretty much as students without sensory loss. However, the fact of becoming deaf and blind has an enormous impact on a person. It requires an enormous amount of energy and adaptability. Suffering sensory loss has a tremendous impact on someone's life and motivation to learn. Take, for instance, the fact that a student might have to adjust or even relinquish his or her dreams for the future, for instance, for a profession he or she had in mind (Ellis & Hodges, 2013).

The teacher's role

As has been mentioned, the needs for competence, autonomy, and relatedness play an important role in students' motivation to learn and engagement in the learning process. Research on Self-Determination Theory has shown that teachers can satisfy these needs by providing structure, autonomy support and involvement, respectively. When students experience support for these needs, this will have a positive effect on their motivation to learn. In my PhD research, I have explored whether and how teachers satisfy the psychological needs of students with congenital and acquired deafblindness, and whether this has, in turn, influenced their motivation. The results showed that students' motivation is generally high when teachers provide need support, suggesting that need-supporting teacher behavior does indeed influence student motivation. In general, teachers provide more structure than autonomy support and involvement.

Structure

Teachers can foster students' need for competence by providing structure. Providing structure means being clear about what is expected of the student, providing realistic challenges, and providing constructive feedback on what the students are doing. This is also the case for teachers of students with sensory loss, although the teacher needs to carefully adjust this to the individual student. When providing structure, the teacher also needs to take into account the physical classroom environment, for instance, appropriate lighting and acoustics. A poorly arranged classroom can be very demotivating for students. It is also important to adapt the learning material to the individual student. Is large print or Braille text necessary? Are subtitles needed while watching a movie?

Autonomy support

Teachers can support student autonomy by providing opportunities to explore and by offering choices. Sometimes teachers are overly protective towards their students. They do things for the students, which the students are perfectly capable of doing on their own. This negatively influences a student's autonomy. It is better to let students' do as much as possible by themselves, even though the student might make a mistake or take more time (at first). Underestimating a student with sensory loss also diminishes their autonomy. Learning tasks/goals that are too easy are demotivating. Why would you do your best to perform a task that is very easy for you to do?

Involvement

Teachers can support a student's need for relatedness by being involved; showing interest in the student, providing care, and seeing things from the student's perspective. Trust, responsiveness, and communication are important aspects. Children with congenital deafblindness often have an individual and unique way of communicating. The teacher needs to know the student thoroughly in order to know what the student means exactly. It is important for the teacher to be able to recognize the student's communicative utterances and know how to react to them appropriately. Not responding or responding incorrectly can be demotivating. For students with acquired deafblindness, adapted communication is also important. Students with acquired deafblindness are often included in mainstream educational settings, or settings for students with either visual or auditory loss. An extra element, which might make this more difficult, is that class sizes are often larger, so a teacher has to focus on all the other students in addition to the student with sensory loss.

Recommendations for practice

Motivation to learn is an important theme in education. Coming up with appropriate strategies for teachers to stimulate student motivation is essential for good education. For students with congenital as well as students with acquired deafblindness, teachers play an important role in stimulating their students' motivation to learn. Teachers need to be sensitive, and possess the right knowledge and skills in order to understand these students and to adjust to them in the best

way possible (Janssen, Riksen-Walraven, & Van Dijk, 2002). My recommendation for practice would be to pay more attention to need-supportive teaching in the professionalization of teachers. The provision of autonomy support deserves particular attention, given that the teachers in this study focused least on this aspect of need-supportive teaching.

This research was funded by Royal Dutch Kentalis² and supervised by Prof. Dr. Marleen Janssen and Prof. Dr. Alexander Minnaert.

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¹ Comorbidity is the presence of more than one distinct condition in an individual (Valderas et al., 2009).

² Kentalis is a large corporate member of Dbl (www.kentalis.nl)

³ www.rug.nl

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Identifying the Problem and Forming a Research Question

Article #2 – Action Research in Deafblindness Series

Brent Stutzman and Susan M. Bruce

This is the second article in the action research in deafblindness series written by members of the Action Research Work Group of the Deafblind International (DbI) Research Network. The previous installation in this series introduced action research and presented a brief overview of different types of action research. To help ground the work of practitioners, this piece will describe two stages (that are often iterative) within the action research process: identifying the problem and forming the research question. Essential elements of each stage will be accompanied by practical examples to tie theory to practice.

Identifying the Problem

Practitioners may not know where to begin the process of identifying a problem. The use of inquiry, acts of investigation to discover information, is an invaluable asset for beginning to recognize problems in the classroom. This can include using a reflective journal, reviewing student data, taking classroom notes, or critically analyzing the curriculum. Cochran-Smith and Lytle (2009) write about inquiry as stance, positioning the teacher as learner and challenging practitioners to find productive tensions in daily practice. The reflective practitioner can utilize inquiry across contexts to discover potential areas of tension that can be addressed through action research.

In the context of action research, it is important to frame tensions not as sources of stress but instead as opportunities for learning. Behavioral challenges, learned helplessness, low communication skills, selecting instructional goals, and authentic choice making may all be areas of tension when working with learners who are deafblind. Practitioners are encouraged to think critically about the areas of tension that they are engaged with daily. From within these tensions, practitioners can begin to identify the problem(s) to be researched. Pine and Bruce (2010) recommend

using one's interests to guide in selecting the research problem. This approach ensures that the practitioner will be enthusiastic about conducting the research. The identification of tensions and the guidance of practitioner interest will help in finding a research problem. The problem must also have some essential components for good research to occur. Hendricks (2009) frames the problem in terms of actions and outcomes. "Actions" refer to the steps that can be taken to make researching the problem possible. "Outcomes" are the effects that will be measured. Broad, general problems (such as, "My student isn't learning .") may not have any clear actions to make research possible or outcomes that are indicative of meaningful effects. It is better to have a concise problem that leads to specific actions and outcomes.

The process may look like this: A practitioner is interested in improving a student's choice making. After taking notes for a week, it appears that choice making opportunities are inconsistently presented. The problem is narrowed down to using personalized, concrete representations when offering leisure options. Initial actions might be to develop a consistent schedule with leisure time included, create the concrete representations for different activities, and track what choices are made as well as student behaviors following the selection. The outcome could possibly be that the student makes authentic choices for leisure activities, realized as selecting an activity and engaging in the activity for five minutes without protest or request to change activities.

Forming a Research Question

After the practitioner has identified the problem, it must be translated into a researchable question. The question should reflect the priorities of the practitioner, especially the type of knowledge desired as an outcome. A question that can be answered with a "yes" or "no" does not give a lot of meaningful information. Forming a question using what, why, or how may lead to research that uncovers relationships, discovers explanations, reveals classroom dynamics, or provides new reasons for observed behavior (Pine & Bruce, 2010). The formation of the question in this way will help practitioners to be able to better address the identified problem. Like the problem, a research question should be specific. This specificity may inform the actions needed to address the problem, focusing the practitioner on how to make improvements in teaching that will benefit the student (Pine, 2009). If there is interest in a student's communication skills, what context(s) will be investigated? What forms of communication? What communicative functions? The inclusion of more specific details will, ultimately, help to produce knowledge that guides instruction and improves student outcomes.

For the question to be researchable, it must also be testable and observable. A question such as, "What form of communication is best?", is probably outside the realm of testability, and doesn't consider the complexity of different contexts and individual needs. Instead, a question that investigates the changes in frequency of communicative acts during a new type of instruction will have a distinctly testable element: The type of instruction is something that we can change to test how it influences the frequency of communicative acts. By defining communicative acts,

the question also becomes observable. Practitioners can observe communication and record those observations in the form of quantitative and qualitative data. Some questions that are testable and observable may be outside of the scope of practitioners in terms of time and resources. In this sense, it is necessary to find a research question that fits practitioner interest, will lead to practical knowledge to benefit students, and is within the scope of implementation. At first, it may feel difficult to articulate good questions, so practice making connections to problems and writing down the relevant question.

Here are some examples:

- How do my students respond to increased opportunities for choice making during leisure time?
- What types of instruction am I using to increase student engagement during literacy lessons?
- How can we increase parental involvement in a student's IEP meeting?
- What strategies will increase my students' level of participation?

Lastly, Pine (2009) also recommends that practitioners take ownership of the question. It should contain "I", "my", "we", or "our" to reflect the investment of those involved in the research. Practitioners should consider their place in the research not shy away from their personal investment in the process. Action research may produce knowledge that supports practitioners in practice, and this begins by accepting our place in the identification of problems and the formation of research questions.

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Country News

Africa

Notes from a meeting of the AFDB Board, August 10, 2015

AFDB Board members from Malawi, Uganda, South Africa, Cote d'Ivoire, Kenya, Zambia and Congo Brazzaville met in Lilongwe, Malawi, on August 10, 2015 to discuss several important issues as follows:

The role of the AFDB Board; Definitions regarding DeafBlindness; the Organization's Legal Status; Achievements since 2009 and long term Action Plan.

Role of the Board

The major role was identified as Developing Policies and Procedures.

Recommended policies included: Defining and Classifying DeafBlindness;

Guidelines for Interpreter Guides: Policy for languages and media of communication;

Procedures for Memberships; Identifying country DeafBlind contacts.

Legal Status

The plan is for AFDB to be registered in Malawi as an International Non-Governmental Organization. A Secretariat and Bank account will follow once there is a Legal status.

DeafBlindness Definitions

The Board decided on the following definition of DeafBlindness:

- DeafBlindness is a unique disability that requires unique interventions.
- DeafBlindness is a single disability; not a dual disability as outlined in the AFDB Constitution.
- The Board should write DeafBlindness (with capital D on Deaf and capital B in Blind) and develop definitions in individual vernacular languages.

The Board decided there be four categories of DeafBlindness:

- Individuals who are totally Blind and partially Deaf
- Individuals who are totally Deaf and partially Blind
- Individuals who are totally Deaf and totally Blind
- Individuals who are partially Deaf and partially Blind

Achievements

The achievements since 2009 of the AFDB Board are organized in three categories:

1. Provided a collective voice for people with DeafBlindness in Africa through attendance at such meetings as:

- World Federation of the Deafblind; African Disability Forum;
- Kenya Declaration of the 2015 Millennium Development Goals; African Women with Disabilities; the African Decade (Kenya, 2008);
- Conference on Social Protection (2009); African Union for the Blind General Assembly in Morocco (2008 & 2009)

2. Empowered members to speak for themselves by:

- Identifying national DeafBlind member from Mozambique, Zimbabwe, Namibia, Somalia, Eritrea, Cameroon, Ruanda, Chad, Egypt, Algeria;
- Appointing regional representatives to coordinate the activities of DeafBlindness in Africa.

3. Strengthened the AFDB Board and its members by:

- Registering the organization in Uganda; Developing a constitution; organizing two General Assemblies; organizing regular meetings; training of Board members; fundraising; developing a AFDB strategic plan; developing partnerships, etc.

Achieving success for our Board continues to be challenged by (but not limited to) the following issues: the lack of financial resources; small national membership numbers; lack of awareness by national governments and other stakeholders about deafblindness being a unique disability; gender imbalance making it difficult to bring women into leadership positions in some countries; linguistic issues; lack of communication technology; absence of legal registration in many countries; absence of a functional secretariat and personnel.

AFDB Board Action Plan 2016–2019

Recognizing the continuous challenges, the Board intends to keep working on these issues and at the same time has identified some major initiatives over the next several years indicated as follows:

- Seek observer status in the African Union
- Seek representation in various political and economic agencies in Africa
- Establish a regional representation for North Africa
- Finalize AFDB registration in Malawi
- Achieve consular status
- Establish a Secretariat
- Ensure attendance and participation of meetings of such African networks where AFDB is represented ie WFDB
- Increase the visibility of the African DeafBlindness agenda in national, regional, continental and international forums
- Sensitize African governments about DeafBlindness and the activities of AFDB
- Establish a website in English and French

- Strengthen National memberships including women participation
- Review the constitution and remove inconsistencies
- Other plans include: seeking volunteers; conducting further Board trainings; organizing annual meetings, etc

For more information about AFDB, contact Ezekiel Kumwenda (ezeikielkumwenda@gmail.com)

Report Submitted to President African Deafblind Association regarding the AFDB Interpretive Guide Training Program

During the AFDB Annual General Meeting (AGM) in Johannesburg, South Africa (SA) in 2014, it was reported that the majority of interpreter guides had no training in service delivery for their Deaf-Blind (DB) clients. This has created challenges for these individuals because of their inaccessibility to information leading to their lack of satisfactory participation in society. This lack of interpreter guide training furthermore contributes to much misunderstanding about the needs of their deafblind clients, among other issues.

As a corrective measure, the AFDB President (Ezekiel Kumwenda) agreed that introductory training for all Deaf-Blind Interpreter Guides was urgent. Consequently, a four-day introductory Interpretive Guide Training Program was organized to be held in Lilongwe, Malawi, August 10–13, 2015.

The overall goal of the training programme was to provide training about the main aspects of Deafblind interpreter guiding for the purpose of improving services for individuals with deafblindness. The objectives stated were: to sensitize the interpretive guides about the complicated needs of their DeafBlind clients; as well as and providing guidance for the interpreter guides to reflect upon the nature and success of the services that they provide.

The training course was delivered by Natasha Parkins-Maliko, a South African Sign Language (SASL) Interpreter and Tutor at the University of the Witwatersrand Language School¹, who specializes in communication access for Deaf and DeafBlind persons. The facilitator presented concepts and definitions in the following topics: Definitions and Overview of DeafBlindness; Understanding the Perspective of DeafBlind People; Identifying Communication Methods; The Role and Functions of the interpreter; Foundations of Sighted Guide Techniques; Haptic Communications; Describing the Visual Environment; Ethical Decision Making.

The ten participants in the course were the interpreter guides for the DeafBlind board members represented the following African countries: Malawi, Uganda, South Africa, Cote d'Ivoire, Kenya, Zambia and Congo Brazzaville.

Course Evaluation

Questionnaires were completed by the participants to obtain information on the status of DeafBlind interpreting in their representative African countries.

Three-quarters of the respondents indicated that they were not employed full time but work largely on a volunteer basis. Those who are paid, work in an office as an administrator and did not work as an interpreter guide. This discussion reflects the dire situation in African countries with DeafBlind clients not being able to afford the services of a full time interpreter guide.

Further data from the questionnaires indicated that most DeafBlind interpreters do not have adequate experience in service delivery to their clients. The respondents also indicated a low job satisfaction among their group due to their inability to have a feeling of success in delivering accurate relevant assistance to their clients. As a consequence, the DeafBlind client's successful access to information and participation in society is directly affected by the ability of their interpreter guide. Clients were also asked to rate their level of access to interpreter guides in their respective countries. Based on their responses it is most evident that DeafBlind clients have minimal or a complete lack of access to interpreter guides in the countries represented in this training session.

While the feedback from the participants indicated that the training objectives were met, the respondents felt a need for a more in-depth training.

Course participants were also informed about The World Association of Sign Language Interpreters (WASLI)², an international forum for all Sign Language interpreters including of DeafBlind interpreter guides. None of respondents were aware of the existence of WASLI and its aims and objectives. This indicates a need to link National DeafBlind interpreter guides to a global platform to motivate and mobilize them to deliver professional service for DeafBlind clients through the support of WASLI. Participants were informed that they can register as individual members of WASLI to gain support in their work through information, training, learning exchanges and relevant advocacy initiatives.

Participants had the following recommendations:

Availability of accredited training for DeafBlind interpreter guides leading to proper qualifications; support DeafBlind interpreter guides to find employment; request for the AFDB Board to produce guidelines for good working conditions for DeafBlind interpreter guides; suggest that AFDB sign an MOU with WASLI Africa and support the registration of DeafBlind interpreter guides as individual members of the organization.

For more information, contact Ezekiel Kumwenda (ezekielkumwenda@gmail.com)

¹ www.witslanguageschool.com

² Wasli.org

CDBA Ontario opens an apartment complex for adults with deafblindness

A new \$3-million apartment complex, two years in the planning stage, officially opened on June 10, 2015, in Paris, Ontario, (107 km west of Toronto) providing adult individuals with deafblindness accommodation and a measure of independence many have never experienced. The new complex consists of four-three bedroom units, two-two bedroom units and two-one bedroom units as well as an upstairs apartment where families of residents will be welcome to stay. This residential complex project completes another phase of the ambitious plans of the Canadian Deafblind Association Ontario Chapter¹, which opened its 1343 square-meter Resource Centre of Excellence² three years ago in the former Sacred Heart School building.

With a beaming smile prior to her move in, Julia Seed, accompanied by Heather Arsenault, her Intervenor for the past 13 years, runs her hands along the kitchen cupboards and bathroom tiles in her bright new apartment, taking in the location and texture of each fixture. "Excited" she said when asked how she feels about her new apartment. Julia is one of 20 adult deafblind individuals, ranging in age from 18 to 50, from Brantford Ontario and other parts of southwestern Ontario who moved into the new apartment complex. The complex is located adjacent to the Canadian Deafblind Association Ontario Chapter offices and resource centre. For some of the individuals this is the first time that have lived away from their families.

Because of the proximity of the W. Ross Macdonald School for Visually Impaired and Deafblind³, located in Brantford, Ontario, there is higher than average population of individuals who are deafblind in the area. Some of the residents are in fact graduates of the school program.

The Association's Executive Director, Cathy Proll, explained that this apartment development stemmed from a housing study conducted by CDBA-Ontario Chapter several years ago that determined many deafblind people were living in homes that weren't safe for them. In addition, they were inaccessible, had inadequate lighting, and were also unaffordable. CDBA needed to look at a different model of housing since it is difficult to adapt existing housing to suit the needs of people who are deafblind.

"One of the things we really had to pay attention to was contrast," Cathy said. Appliances need to contrast cupboards and doors from doorframes to help the low-vision residents distinguish between different objects and surfaces". "Lighting is really important and being able to manage it. Some people need really bright light, some dimmer.

The new apartments are completely accessible with design features to make getting around easier for tenants. Tiles, fixtures, and paint colours were all chosen to provide a high level of contrast for those who have some limited vision. There are also varied textures on tiles and other surfaces to help them navigate. Some of the apartments are equipped with lifts. Depending on their needs, residents will have Intervenor with them for all or part of the day and night.

The Canadian Deafblind Association Ontario Chapter employs about 300 Intervenor, who work all over the province of Ontario and who serve about 70 adults and 80 to 100 children throughout Ontario. In addition to the CDBA apartment residents, other individuals with deafblindness travel to the Paris location to spend time at the Resource Centre, the only one of its kind in Canada. The centre features a Snoezelen⁴ room, a music room and a multi-purpose space for activities. The new apartment complex connects by pathway to the Resource Centre, being almost an extension of (tenants') living rooms, according to Cathy.

Also under construction is a spacious Sensory Garden that will include plants specially selected for their scent and colour, a water feature, a musical bench and a gazebo. Proll hopes that the raised garden beds also will be used by Paris seniors. According to Cathy Proll this residential complex is a non-profit operation, with rents being reduced as the mortgage on the building is paid down. Rents start at \$550 a month but will go down as the CDBA pays down the mortgage on the building. It will keep the units affordable to the residents as they age and transition from Ontario Disability Support Program payments to old age pension, which pays less per month.

Furthermore, we're really emphasizing that this apartment is the place they will call home for many years. This will also give peace of mind for their families to know their loved ones are in safe, supportive housing. One of families biggest fears is 'What will happen to them when I'm gone.'

This article is a compilation of articles appearing in the Brantford Expositor (Feb 05, 2016 – Michele Ruby) and Brant News (Brian Shypula – Feb 10, 2016)

Cathy Proll, Executive Director CDBA Ontario Chapter

¹ CDBA-Ontario is a large corporate member of Dbl (www.cdbaontario.com)

² See Dbl Review Edition 51, July 2013 for article about CDBA-Ontario Resource Centre

³ www.psbnet.ca/eng/schools/wross

⁴ www.snoezelen.info

DeafBlind Ontario Services “Canadian Nonprofit Employer of Choice Award”

DeafBlind Ontario Services¹ has been exploring new ways to meet the unique and specialized needs of our clients as part of the 2015–18 Strategic Plan, “Earlier this year, DeafBlind Ontario Services won the “Nonprofit Employer of Choice Award (NEOC)”². This award recognizes organizations whose people leadership and vision has translated into exemplary talent management practices. This new national program helps participating organizations create positive brand recognition and gain a competitive advantage to attract, engage and retain top talent.

As part of the process, DeafBlind Ontario Services employees were asked to complete a survey with questions in the following categories: compensation and benefits; rewards and recognition; management or employee relations; training and development; career advancement; employee engagement; environment and facilities; leadership; reputation and personal enjoyment.

Based on results from the survey, top scoring items for the organization included: promoting a positive public image; providing a safe/healthy working environment; empowering employees to feel good about the organization's products and services; empowering the employees to feel pride in working at the organization; providing up-to-date technology for employees to do their jobs effectively; and, effectively communicating organizational goals and vision.

An internal Employer of Choice Action Team has been established to assess the data from the benchmarks report and develop a plan for continuous improvement and implementing solutions.

DeafBlind Ontario Services – FOCUS Accreditation

Recently DeafBlind Ontario Services was awarded its second four-year accreditation through FOCUS³. FOCUS brings “an innovative and robust quality improvement and accreditation program that reflects current successful practices and trends in community-based human services” to the organizations they survey.

DeafBlind Ontario Services is committed to long-term sustainability and continuous growth while always striving to evolve. We were the first Ontario organization providing Intervenor Services to be accredited in 2012, and are now the first to be reaccredited!

The process engaged over eighty DeafBlind Ontario Services' employees, Board Members, Community Partners, Funders, Families, and People Using Services – to share their feedback via confidential surveys, interviews and observation.

DeafBlind Ontario Services was applauded for our extraordinary commitment to our clients, demonstrated by the organization's commitment to providing the highest level of services, training, and the promotion of a learning culture and consistency of our service models across the province.

The Accreditation Committee commended DeafBlind Ontario Services on our efforts and committed work to quality improvement. The follow reports highlighted the following key areas of organizational excellence:

- DeafBlind Ontario Services demonstrated that its services are person-directed;
- Leadership within the organization was cited as a strength by many stakeholders, both within and external to the organization;
- DeafBlind Ontario Services has demonstrated, in many ways that it is an organization committed to learning and continuous improvement. Employees are highly trained, skilled and passionate about and committed to their work;
- People using services and other stakeholders expressed great satisfaction with the quality of services provided by DeafBlind Ontario Services!

Undergoing this accreditation process demonstrated DeafBlind Ontario Services' commitment to quality and desire to improve the lives of the people who use our services. It is an achievement that we can all be extremely proud of!

Karen Madho (scgrc@deafblindontario.com)
DeafBlind Ontario Services (www.deafblindontario.com)

¹ Deafblind Ontario Services is a large corporate member of Dbl

² neoc.ca/about/award

³ focusaccreditation.org

Celebrating National Deafblind Awareness Month in Canada

As reported in the January 2016 edition of Dbl Review¹, a Senate of Canada motion was passed in June of 2015 to recognize June as National Deafblind Awareness Month in Canada. Inspired by this historic event, a working group of consumers and organizations supporting people living with deafblindness, gathered across the nation to plan an annual awareness campaign. This initiative marked the first time that a group this size, with representatives from across the country had ever worked together on an initiative of this kind. For a country with six time zones and the largest coastline in the world, this was a significant feat!

The group focused their efforts on building awareness about deafblindness and recognizing the talents and contributions of individuals living with deafblindness in Canada. Leading up to, and during the month of June, they encouraged supporters to spread the word about deafblindness and "*make a wave from coast to coast.*" The logo designed for this initiative can be described as an abstract image of a person with two hands forming two waves. It includes an arc above them and a maple leaf at the end of the arc to the right. The logo symbolizes reaching across Canada, in an abstract sense, with the hands of the person closely mirroring the sign for wave.

Armed with the passion to make a difference and the excitement of a nationally recognized month, the working group began their journey. They created a toolkit with promotional material to help carry out their efforts. The toolkit included key messages and templates to ensure consistency and support communication with key audiences.

National Deafblind Awareness Month events included a Senate reception in early June to help kick off the month attended by Members of Parliament, representatives from the Senate, organizations that provide services to persons who are deafblind and consumers from across Canada in the nations capital.

Other events included lighting up of the CN Tower in Toronto²; festivals celebrating awareness of individuals living with deafblindness (i.e., June fest³ and Intervenor Fest⁴), engagement at community events, attendance at accessibility fairs, displays of art created by individuals living with deafblindness and other events featuring

simulation exercises to help build awareness. At the end of June, the group gathered to assess their efforts and make plans for the year ahead.

At the end of National Deafblind Awareness Month, the working group learned a number of valuable lessons:

1. Teamwork – the mandate of the working group supported the principals of inclusion, consensus building and diversity
2. Plan ahead – to ensure that all participants have the opportunity to share their ideas, leave lots of time to gather feedback from everyone and set clear deadlines for final decisions
3. Decision-making – ensure that each discussion and subsequent decision is inclusive of all perspectives and maintains a respectful tone at all times

Taking on a national initiative with a diverse group of people who have unique talents and perspectives can be a challenge but it is definitely worth the effort. We encourage everyone to spread the word and help build greater understanding about deafblindness where you live.

Karen Madho (scgrc@deafblindontario.com)
DeafBlind Ontario Services⁵ (www.deafblindontario.com)

¹ Dbl Review Edition 56, article on page 43 by DeafBlind Ontario Services

² www.cntower.ca

³ <http://www.junefest.ca/>. JuneFest is an annual event co-hosted by Rotary Cheshire Homes (www.rotarycheshirehomes.org) and the Canadian Helen Keller Centre www.chkc.org

⁴ https://www.facebook.com/permalink.php?story_fbid=1011924585511511&id=107421349295177

⁵ Ontario Services is a large corporate member of Dbl

Ireland

The Anne Sullivan Foundation, Ireland presents: “Celebration of the Senses Month”

The Anne Sullivan Foundation hosted their first National Deafblind Awareness event in 2014. This year, the Deafblind Awareness Day was held on the 25th June, and was one of many events hosted as part of our ‘Celebration of the Senses Month’.

The themes of this year’s Awareness Day, which was held in Rosemont School in Sandyford were a) recognition of deafblindness as a unique disability and b) social Inclusion and community participation. Carol Brill from Dublin, Noreen Power from Cork, Hesline Crawford from Waterford, Gavin Allman from Kilkenny, Russ Palmer from the UK and Riitta Lahtinen from Finland were the six speakers on the day.

There was also a musical performance by Russ Palmer and Juha Sarkkola.

Attendees at the Deafblind Awareness Day were also invited to join in a Movement for Wellbeing class facilitated by Laura Dowdall.

The week before the Awareness Day, the Anne Sullivan Centre¹ celebrated its 20th birthday with an Open Day on the 18th June, on the grounds of the Centre.

Residents, day-users, families, friends, staff and volunteers gathered for a barbeque

and participated in a drumming workshop by Music Together. Residents of the Anne Sullivan Centre also made art and craft items and sold them on the day.

A sponsored Fun Run was organised by the Anne Sullivan Foundation as part of 'Celebration of the Senses' month. This took place on the 4th June and successfully raised much needed awareness and funds that will go towards the provision of supports and services for people who are deafblind in Ireland. Thank you to all our participants and supporters!

Throughout the month of June, staff of the Anne Sullivan Centre and Anne Sullivan Foundation are visiting primary schools to carry out an interactive learning activity to increase young people's awareness of deafblindness. Children were introduced to some aids used by deafblind people and participated in a 'mystery bag' activity, during which, our young participants wore headphones and blindfolds in an attempt to experience challenges faced due to combined sight and hearing loss. They also practiced using a cane and learned about the mobility issues faced by those who are deafblind. We hope to carry out more of this awareness training in the not too distant future.

Finally, on June 26th, the Anne Sullivan Foundation organised a CHARGE Syndrome family day for all those affected by CHARGE syndrome. The event was held in Sandyford Community Centre and was an opportunity for families to meet up and increase their awareness and knowledge.

For more information, contact Heather Colson-Osborne, Anne Sullivan Centre, Stillorgan, Ireland (hcolsonosborne@annesullivancentre.ie)

¹ The Anne Sullivan Centre (www.annesullivan.ie) is a small corporate member of Dbl.

Netherlands

Royal Dutch Visio Reports Success with its New Outdoor Program

Royal Dutch Visio began this past January (2016) to organise monthly outdoor activities for its clients based on the vision of Joe Gibson, Dbl Outdoor Network Leader.

Staff were initially very impressed with the Outdoor Network presentation during the European Conference in Lille in August, 2013. Our interest in an outdoor program was further rekindled as a result of the Outdoor Network presentation during the Dbl World Conference in Bucharest in May of 2015.

As a result, a small group in Visio examined through a number of consultative sessions, how to undertake a number of outdoor activities with our deafblind and intellectually disabled clients. A plan for 2016 was put together and presented to family members and relatives of our clients.

The first activity of our outdoor program was the winter walk. We put on our gloves and caps and went out to experience the January snow. Halfway through this activity, we visited a restaurant for hot chocolate milk. This was all very delightful. Staff received good feedback from clients and all parties involved, generating a positive spirit for us to move forward towards more activities. During the following months our activities included skating, a visit to a farm and hiking. With each activity, the staff and clients got to know and enjoy each other's company better and appreciated the positive value of these activities and its interactions. Furthermore, having family members and volunteers participate strengthened the value of this activity immensely.

We are pleased to report that the results improve with each activity. Although this program is still in its infancy, we can report that Joe Gibson's vision fits well within Royal Dutch Visio.

Amy Mennen
Outdoor Team of Rietwal 30–32
Royal Dutch Visio (www.visio.org)¹
Centre of Expertise for Blind and Partially Sighted People

¹ Royal Dutch Visio is a small corporate member of Dbl (www.visio.org).

Russia

Break for Families: A New Project Launched in Russia

Physical and sensory disabilities and their related problems cause suffering not only for those with disabilities but also for their relatives. Parents often have to be with their deafblind children 24/7, accompanying them everywhere, needing to continually monitor their health and psychological condition. Generally, this responsibility leaves little or no time for their own personal affairs. Many can hardly take a day off work or even take a few hours to see the doctor, go shopping, take in a movie, attend the theater or go on a vacation. Such pressure may lead to family psychological problems, often resulting in their sending their child to a boarding school or in extreme cases, abandoning their children altogether with them ending up in an orphanage.

The Russian Deaf-Blind Support Foundation "Con-nection"¹ and its newly established subsidiary, the Deaf-Blind Family Association, recently launched a support program called "Break". The first sessions of this 'school' to train professional surrogate family members were held in March (2016), the purposes which were to teach these individuals how to care for and educate deafblind children during the regular family's "Break" period.

This program provides parents of disabled children with 15 days of family support per year (either all at once or split into several periods on the hourly basis) to use the services of a specially trained professional family, to work with their child. During this respite period when the parents can have a rest or take care of their personal business, the child will learn to feel at home in a new environment, communicate with new people, and develop some new impressions of life. Such assistance is intended to help keep the family together, reduce their psychological stress and improve the standard of their lives. The major goal of this project is to prevent the emergence of new orphans.

The educational course comprises 72 hours of seminars and practice, consisting of 6 modules: “Legal and psychological aspects of a child’s short-term accommodation in a hosting family”; “General problems of child’s disability”; “Challenges with raising a child with mental and sensory impairments”; “Practical home based educational methods for a child with multisensory disabilities”; “First aid for children”, “Development of communication techniques for the children with autism, Down’s syndrome etc”.

The first round of courses this past spring involved more than 50 volunteers, who expressed their readiness to become professional surrogate parents. Most of the volunteers themselves belonged to families having several children of their own; some were University students while others were in early retirement. For these individuals it was a good opportunity for them to acquire new skills while earning additional income. All of the volunteers were required to take psychological tests and learn the basics of the appropriate Russian legislation related to disabilities.

Once passing these basic requirements, the individuals were then tested as to their compatibility with the child and child’s family before attempting to take on the hosting.

Each volunteer was required to learn about the classification of various disabilities, their causes, the biological and socio-psychological factors impairing the child’s development, and the standard successful methods used to work with and continue the education of these children. The second round of courses are planned for the autumn and expected to involve approximately the same numbers.

To date, “Break” is a pilot project currently available to 50 families in the Moscow region. Our organization RDBSF plans to eventually expand this program into other regions of Russia. To do so, we are working to include the program into the list of social services provided by the State for the families with disabled children. Having established this program for families of younger children, our next step will be to refine our training methods in order to assist families with deafblind adults who have similar problems as do those with children.

Ksenia Smertina
Deaf-Blind Support Fundation ‘Con-nection’
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Switzerland

“Sense-ful”: Promoting Perception in Spite of Multi-Sensory Impairment

Perception is essential for our existence, our learning and development. For a person with a multi-sensory impairment however, there are very limited possibilities to develop perception. Professional support is needed; but what makes the support competent? The new booklet “Sense-ful” from Tanne, the Swiss Foundation for the Deafblind¹, offers fundamental answers.

Perception and multi-sensory impairment

Nothing exists for us without being perceived: No inner or exterior world; no body or object; no space or time; no significant other and no personal identity. Perception is existential.

Without it there is no experience, no learning and no possibility to make any sense about life. Perception is fundamental for any personal development.

Deafblind children and adults have very limited possibilities of perception. Their well-being, learning and development are at risk without being provided competent support to develop their perceptive resources.

Basic guidelines for competent support

The Tanne, the Swiss Foundation for the Deafblind, offers basic guidelines in its newly released booklet “Sense-ful”, written in German. Based on current research in the field of neurology this booklet introduces those basic principles and techniques that have proven successful in the work of the Tanne, and are essentially relevant approaches in the field of special education.

Especially important to the project team developing “Sense-ful” were such topics as: The Active Learning Approach of Lilli Nielsen (Nielsen, 2001); The Affolter-Approach (Hofer, 2009); Basic Stimulation (Fröhlich, 2008); Basic Communication (Mall, 2008); Montessori Pedagogy (Klein-Landeck & Pütz, 2011; Caspary, 2013); Sensory Integration (Söchting, 2006; Brown, 2008; Brown, 2009) and the publications on the forgotten senses (Brown, 2006; Brown 2007; Brown, 2007; Brown, 2008). During their two-year process, the project working group also dealt with the overlaps and differences in perception, behavior and corresponding educational programs of persons with Autism Spectrum Disorder and multi-sensory impairment.

Making sense about life

The booklet comes along with a DVD illustrating basic principles of competent and effective support using examples from the Tanne. This approach has its foundation in every-day-life through its collaborative approach (or co-creation) based on the dialogue between the professional and multi-sensory impaired learner. During any interaction with the learner, the ability of the professional is crucial to the success of the interaction. The professional must demonstrate competence in their ability to understand the individual such that they can provide different situations and environments as appropriate learning opportunities. That means focusing on what really is important for the learner, what arouses his or her curiosity, interest or exploratory behavior.

The booklet also focuses: On the basics of promoting perception. These are applicable in very different contexts, including daily living situations, during leisure time and more formal educational and therapeutic activities. In all these contexts promoting perception must be very individualized, based strictly upon the real world vision of each learner, their interests, sensory and developmental abilities.

The results will be different for each individual based upon their sensory abilities and depending on the ability of the professional to create a matching opportunity for learning and development. In that way the professional might well experience surprises. For example, one individual with good residual vision might not make their remaining eyesight as their preferred sense but use their tactual sense as their preferred one instead. For another client with very minimal hearing will in fact use their residual hearing as a central part in his or her perception of the world.

Together for more self-efficacy

Perception is a highly complex task for the brain; it involves team work of all the senses. Developing the multi-sensory impaired person's ability to make sense of their world depends upon their developing a belief in their own ability or self-efficacy. Their success is highly dependent on the supporting skills of the professional, their knowledge about perception, its connection to emotions and body identity. And at the root of it all is for the professional to have the proper attitude towards their deafblind – or in fact all – learners.

Very hopefully the booklet "Sense-ful" will help boost the self-efficacy of the professionals in their work providing the support necessary for these multi-sensory impaired individuals. This integrated support takes into account just how existential and fundamental that perception is.

Mirko Baur

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(www.tanne.ch)

¹ www.tanne.ch. The Tanne is a small corporate member of Dbl.

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Now you can learn the Lorm alphabet anytime and anywhere

Anyone who works with deafblind people in Switzerland or Germany knows how easy and practical the Lorm¹ alphabet is. The Swiss National Association of and for the Blind² (SNAB) has developed the “Lern Lormen”³ app in German and French to

help people to learn this form of communication and to practise it on their own on a tablet or smartphone wherever they are.

“I’ve always been interested in languages and, after I retired, I wanted to learn something new and take on a challenge!” For some years, Jürg A. has been a volunteer support person for hearing and visually impaired and deafblind people at the Swiss National Association of and for the Blind (SNAB). He accompanies people on outings, walks, visits to the doctor and holidays and also in other situations. He communicates with the Lorm alphabet when he is out and about with clients, some of whom he has known for a long time. “The Lorm alphabet isn’t difficult and I often make use of it”, Jürg says. As a volunteer support person, he first attended the two Lorm courses offered by the SNAB. They are open to anyone, but it is mainly the volunteers who take part. However, communicating with the Lorm alphabet is like many other skills; if you don’t use it often, you can easily forget it.

This is where the SNAB’s “Lern Lormen” app comes in, because it is designed to help people learn and practise the Lorm alphabet. The app is based on the tried-and-tested principle of groups of letters from the Lorm courses, which allows people to learn the hand-touch alphabet in small steps. This also means that the app is the ideal complement to the training.

The Lorm courses are given by instructors who are themselves hearing and visually impaired or deafblind. They are trained especially by the SNAB and have developed the teaching method with groups of letters. The groups are structured logically and can be learned easily. We would like to thank the self-help associations tactile and GERSAM for the training material that they have made available.

The course participants say that they have limited opportunities to practise the Lorm alphabet and, most importantly, to learn to write it more quickly. That is now possible with “Lern Lormen”. As well as writing words and sentences, they can play a spelling game, because learning and practising should be fun. The app also provides general information about the use of the Lorm alphabet and about deafblindness.

Technical challenge

It took more than a year to develop the app, which is now available in German and French. One particular challenge for the programmer was positioning individual letters correctly on the virtual hand. Signs for letters such as **K** (touching four fingertips together on one point in the palm of the hand) or **R** (light drumming with the fingers on the palm) and the space between words and the full stop at the end of a sentence are very similar.

Jürg A. was one of the first people to test the new app. “I found **R** difficult at first and I also had problems with **ST**. Then I practised again last week and it went much better. Overall I think the app is a very good way of learning the Lorm alphabet and of practising it if you’re a beginner.”

The app has been developed for tablets and smartphones. It is ideal for use on a tablet, because the virtual hand is big enough to make learning and practising as effective as possible.

For more information contact Tina Aeschbach (aeschbach@szb.ch)

More information is available in German and French.
Check out www.szb.ch/lormapp

Photo material you can find on our website:
<http://szb.ch/footer/service/medien/bildergalerie/>

¹ www.deafblind.com/lorm.html

² www.szb.ch. SNAB or SZB is a small corporate member of Dbl

³ www.lorman.com

With the Lormen app we now learn anywhere

The app “learning Lormen” is based on the proven principle of groups of letters from the Lormkursen.

- With the app, learn where the letters are placed on the palm.
- With practice, the letter shape quickly.

Network News

Acquired Deafblindness Network

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Youth Network

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CHARGE Network

Andrea Wanka reports:

The CHARGE Network currently consists of 78 members from 17 countries (Netherlands, Sweden, UK, Japan, USA, Denmark, Malaysia, Finland, Norway, Iceland, Argentina, Germany, Ireland, Australia, France, Italy and Africa).

What do we do? We try to share our thoughts and our questions about CHARGE Syndrome via different media:

- We do have a mailing list.
- Check out our website: <http://chargenetwork.deafblindinternational.org>
- We are on Facebook: <https://www.facebook.com/groups/DbICHARGEnetwork>
- We run a whats app group with a small number of people who share their cell phone number.
- We have an Article Sharing Dropbox where we collect articles related to different topics.

Currently we are collecting “new” contents for the acronym CHARGE with different ideas for associations which come into our minds while thinking about CHARGE, so please feel free to send me your “picture” like the picture you can see as an example.

If you want to become a CHARGE Network member, please contact Andrea Wanka (aw@andrea-wanka.de).

Our Network is planning a Pre-Conference session on September 04, 2017 in advance of the 9th Dbl European Conference planned for Aalborg Denmark, September 05–08, 2017. Among other presentations we are planning, we intend to share some of these acronym pictures.

For more information,
Contact Andrea Wanka
(aw@andrea-wanka.de) and check out
<http://chargenetwork.deafblindinternational.org>

Ricard Lopez reports on:

EDbN's Achievements and Opportunities

Recently the European Deafblind Network has been very focused on several initiatives and projects at the European level. It is time to provide a summary of those most significant.

Moscow Second International Conference on Deafblindness. May, 2016

In Moscow this past May, the Deaf-Blind Support Fund "Con-nection or So-edinenie" organized their second International Conference on Deafblindness. The topic of the conference was "The deafblind in the modern world: overcoming the limits of the possible". The conference was characterized by an active discussion about the barriers that prevent the full development of people with deafblindness and solutions that should be provided.

Over 350 leading Russian and foreign experts in the field of deafblindness and technologies and others interested in the integration of deafblind people from 12 countries attended the conference.

Ricard López, Chair of EDbN participated in the opening ceremony and presented the Catalan Independent Living Program for People with Deafblindness, developed with the support of the Barcelona City Council. There were also meetings with Russian families with the aim of helping them to organize a program of support. There will be soon a working day for families and training volunteers.

The Deaf-Blind Support Fund (So-edinenie) also presented the first Russian edition of the DbI magazine. The magazine will be published once a year and combine the most interesting and useful materials from English editions.

From these lines, we want to congratulate So-edinenie for the great job they have been doing in recent years.

European Disability Forum2 (EDF) Board meeting

Since May 2013 EDbN has been elected as a board member of EDF, which increases our influence and visibility. EDF is the NGO representing 80 million European people with disabilities. EDbN participated in an EDF Board meeting in Amsterdam this past March, 2016.

Representatives of organisations of people with disabilities from all over Europe discussed, among others, the role of municipalities in implementing the UN Convention on the Rights of Persons with Disabilities (UN CRPD)³, the situation of refugees and migrants with disabilities and the upcoming UK referendum on EU membership.

Emmanuelle Grange, Head of the Unit for the Disability and Inclusion of the European Commission, emphasised that de-institutionalisation is a top priority for the European Commission⁴. She also highlighted the importance of the upcoming EU Social Pillar⁵, and the intensity of discussions in Council on the European Accessibility Act⁶.

EDF and its members adopted a resolution calling on the European Institutions to adopt guidelines and provide support to the local and regional authorities on the implementation of the UN CRPD; and to involve people with disabilities and their representative organisations in the process.

Together with Kirsten Lange from the UN Refugee Agency (UNHCR)⁷, EDF's members shared their views and knowledge on the situation of refugees and migrants with disabilities in Europe. In particular, it was underlined that the needs of refugees and migrants with disabilities should be taken into consideration by all the authorities and agencies acting on this issue.

Furthermore, it was approved a resolution concerning the UK referendum on EU membership (Brexit). While recognising the democratic right of British people to vote freely on this matter, EDF and its members believe that a common European human rights agenda is better achieved together, within a strong EU.

Accessible technology for independent living

With the motto "Accessible Technology for independent living," an event took place at the headquarters of the European Parliament in Brussels, March, 2016. It was chaired by Evelyne Gebhardt (Member of European Parliament)⁸, organized by the European Disability Forum and Google.org. The latter organization invests \$20 million in grants and scholarships stimulating technological innovation of European nonprofit creators working for people with disabilities. The most significant were:

- Umesh Pandya who spoke about Wayfindr⁹, an application that facilitates both the blind and those with limited vision to travel independently by subway through the entire London transport network, using the technology of smartphones and Bluetooth LE¹⁰ (Bluetooth low energy).
- Neil Heslop (the Royal National Institute for Blind People – RNIB¹¹ and Kristina Tsvetanova worked together to develop a touchscreen tablet with Braille called BLITAB¹². This new technology for those who are blind and visually impaired is 90% cheaper than the current one in existence.

Santiago for deafblindness (the "camino de santiago" for deafblind people), September 2016

This year we present a new initiative called "To Santiago for Deafblindness (2s4db)". The Camino de Santiago¹³ is a pilgrimage practiced for hundreds of years to reach the city of Santiago de Compostela in the Galicia¹⁴ region of Spain, where the relics of St. James lie. The pilgrims make their way for the most diverse reasons: because they are devoted; keen on learning more, or just because of the feeling of adventure. We will walk the Camino de Santiago with people with deafblindness, their relatives, friends and professionals who work in deafblindness settings all over the world this coming September 2016. Our objective is to complete the last 100 km of the route by bike, tandem or walking.

The first edition will take place from 5th to 11th September 2016; with our intention to repeat this yearly.

Some organizations are planning to join us celebrating similar activities in their own countries on 11th September, when we arrive in Santiago. This way, we all work to

make more visible our challenge. If you want to walk the Camino with us or to prepare a representative activity, do not hesitate to contact us. You can also visit <http://2s4db.org/> for more information.

The red & white cane campaign

During the challenge “To Santiago for Deafblindness” we will use the white and red cane, which represents people with deafblindness. It has red bands on the white material, in order to differentiate it from the classic cane for blind people. For many years we have considered the red and white cane as a symbol of deafblindness and an aid to orientation and mobility. This symbol was launched in Spain by FESOCE¹⁵ in December 2015 and its goal is to favour the autonomy, visibility and safety of deafblind people. We would like to encourage all the European deafblindness organizations to support and promote this campaign, so deafblind people can have their own cane.

European Monitoring Centre for Deafblindness (EMCDB) or European Observatory of Deafblindness

EDbN is working to build a European Monitoring Centre for Deafblindness. The mission will be providing the EU Member States, specialized organizations, agencies, professionals and the media with a factual overview of European deafblindness problems and a solid evidence base to support the policies and best practices. It would be highly desirable to provide:

- A)** An annual report on the state of the deafblindness in the European Union;
- B)** An online statistical bulletin providing a yearly overview of the latest European situation and trends regarding deafblindness. and
- C)** A comprehensive ICF (International Classification of Functioning, Disability and Health of WHO)¹⁶ core set for deafblindness.

European Deafblind Indicators

As a part of the Monitoring Centre, we are preparing a second phase of this project. Coming soon, we will send a data collection form to all expert groups. The aim is to make a comparison with the data collected in 2014. The project was awarded with the STAR PROJECT granted by the European Commission¹⁷. This means that the subjects and the information included in our project has been assessed very positively providing good impact for European people with deafblindness. As a Star Project all our results were transferred from the European Shared Treasure (EST)¹⁸ to the European Dissemination Platform (EVE)¹⁹ and will be promoted as Good Practices.

European Platform of Deafness, Hard of Hearing and Deafblindness epdhdb.eu

We have created a European Platform of Deafness, Hard of Hearing and Deafblindness that comprise all the entities related to the deafness across Europe. A meeting is held every 3 months in Brussels. As EDbN, two other members of the platform (European Union of the Deaf²⁰ and European Federation of Hard of Hearing People²¹) obtained a seat on the board of EDF. Consequently, the platform has a

strong position on such topics as accessibility, statistical reporting, employment and UNCRPD. The monitoring centre can play an important role with high quality policy papers to represent our position.

EDbN launched the pro-ject

We Can be Connected to the Euro-pean Union. It was a proposal to achieve accessibility equipment to low-income individuals who are deafblind emulating the USA project "I Can Connect". This project was submitted to the European Commission but it did not reach the success we expected. We are working on a triennial project with the European Parliament and Commission.

Ricard López, Representing EDbN (rlopez@edbn.org)

¹ The Russian Deaf-Blind Support Foundation is a small corporate member of Dbl (www.so-edinenie.org/en)

² www.edf-feph.org

³ www.un.org/disabilities/convention/conventionfull.shtml

⁴ ec.europa.eu/social/main.jsp?catId=1137

⁵ ec.europa.eu/priorities/.../towards-european-pillar-social-rights_en

⁶ ec.europa.eu/social/main.jsp?catId=1202&langId=en

⁷ www.unhcr.org/

⁸ www.europarl.europa.eu

⁹ <https://www.wayfindr.net>

¹⁰ <https://www.bluetooth.com/what-is-bluetooth.../bluetooth.../low-energy>

¹¹ www.rnib.org.uk

¹² blitab.com

¹³ santiago-compostela.net

¹⁴ [https://en.wikipedia.org/wiki/Galicia_\(Spain\)](https://en.wikipedia.org/wiki/Galicia_(Spain))

¹⁵ Fecoce (www.fecoce.org) is a small corporate member of Dbl.

¹⁶ www.who.int/classifications/icf/en

¹⁷ <https://ec.europa.eu/research/star/home.html>

¹⁸ <https://www.erasmusplus.org.uk/european-shared-treasure>

¹⁹ <http://erasmus-plus.ro/eve-dissemination-exploitation-results>

²⁰ www.eud.eu

²¹ www.efhoh.org

Usher Network

Emma Boswell Reports:

The Usher Network is progressing nicely. One of our committee members and Network co-chair Nadja Högner, has developed, in cooperation with the other members, a new webpage about Usher syndrome around the world including UK, Europe, Russia, Australia and USA. This includes information about medical and psychosocial aspects of Usher syndrome, worldwide support systems and various links about Usher syndrome. You can get to know the committee members, too.

Please visit our website link: <http://usher.deafblindinternational.org/>

In the near future we will also be installing a communication platform on the website for members to get in contact with each other.

Another member of our committee, Karen Wickham, is organising an event in Australia. The 10th National Deafblind conference will be preceded by an Usher preconference and the National Deafblind camp will follow on from the conference.

Dates are November 15th– 20th, 2016 in Perth Western Australia. These events are being planned in association with Senses Australia. Please contact Karen for more information Karen.wickham@senses.org.au or go directly to the conference website <http://deafblind2016.com.au/registration>

Lastly, we are very pleased to announce that we are holding an Usher Network Pre-conference in Denmark on Sunday 3rd and Monday 4th September 2017. More details will be following soon. If you want more information or to add your names to the mailing list, please contact emma.boswell@sense.org.uk

Emma Boswell
(emma.boswell@sense.org.uk), Co-Chair of Usher Network

Outdoor Network

Joe Gibson reports:

May has been a busy month! Two network members, myself and Miguel Olio (Brazil) presented at the VI International Forum on deafblindness and multiple sensory disabilities in Sao Paulo, Brazil. My presentation was on the benefits of outdoor activities and Miguel's discussed some exciting projects happening in Brazil. This resulted in a number of new people joining the network via both the mailing list and the Facebook page.

Earlier in May the Nordic Centre for Welfare and Social Issues (Nordens Velfærdscenter)¹ also ran a course on "Meaningful Activities", which was attended by a number of network members. The course focused on what activities can be done, what are the benefits of the activities (with a focus on health and communication) and how to help the participants make sense of what is happening. Membership in the Outdoor Network continues to grow. The Outdoor Network Facebook page now has 81 members and can be found by searching on Facebook for Outdoor Network, Deafblind International ([https://www.facebook.com/grpi\[s/771554296237459\]](https://www.facebook.com/grpi[s/771554296237459])). The mailing list now has 106 members from 22 different countries. You can join the mailing list by contacting Joe Gibson at the address below.

Preparations are well underway for this year's outdoor week this year to be held in England hosted by Sense at the Calvert Trust in Exmoor, September 12–16. All the places are now taken and a report from this event will follow in due course. Please note a change in contact details for the Outdoor Network.

For more information, contact Joe Gibson at his new email: deafblindoutdoors@gmail.com

¹ The Nordic Centre for Welfare and Social Issues (<http://nordicwelfare.org>) is a small corporate member of Dbl.

Research Network

Walter Wittich reports:

As the Dbl Research Network is moving into its second year of existence, we continue to grow and expand. As of May 2016, we now have 96 members on our e-mail contact list.

Saskia Damen and Flemming Ask Larsen continue the maintenance of the Deafblind International Research Network – Facebook Group¹, currently at 143 members and growing. Christine Lehane continues to maintain our Deafblind International Research Network LinkedIn Group², currently with 10 different conversation streams.

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 Dbl Research Network, in case you have an idea you would like to share.

In the context of research distribution and dissemination, Flemming Ask Larsen has good news: He received an invitation to the launch of the first international journal in the world on deafblindness. “Journal of Deafblind Studies on Communication”³ was launched November 19th 2015 from University of Groningen⁴. As part of the Journal’s editorial board, he would like to invite you to read their first issue, and urge you to use the journal for publications in the future. It will only get as good as its contributors.

One of the more recent research training opportunities includes the creation of a Master’s Program at the University of Montreal⁵ (available in both English and French) that has specific possibilities in the context of deafblindness: I am excited to introduce you today to a new option in graduate studies in the field of sensory impairment – a new Master’s program in Vision Science at the University of Montreal, Canada.

The School of Optometry⁶ has strong research and teaching links to the School of Audiology and Speech and Language Pathology, with some professors teaching in both departments. The curriculum contains a multi-disciplinary seminar that deals with comorbidities, including deafblindness. In addition, there are collaborative links for research in deafblindness across all age groups, as well as affiliations with the three sensory rehabilitation centres in Montreal that operate the two deafblindness rehabilitation programs. The School of Optometry also offers doctoral studies (PhD-level) within the Vision Rehabilitation option that can easily accommodate projects in deafblindness. Please have a look at their website and please contact them directly if you would like any specific additional information. You can also request an accessible version of the flyer directly.

So please feel free to check out the networking opportunities on our web page and contact us with your interests and ideas.

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

University of Montreal School of Optometry Contacts:

Olga Overbury, Ph.D. (Graduate School Director)
P.O. Box 6128, Station Centre-ville
Montreal, Quebec H3C 3J7
Tel: (514) 343-2384; olga.overbury@umontreal.ca

Sabine Démosthènes (Graduate Program Assistant)
3744 Jean-Brillant St., Room 260–9
Montreal, Quebec H3T 1P1
Tel: (514) 343-6325; sabine.demosthenes@umontreal.ca

¹ <https://www.facebook.com/groups/158743377516989/>

² [www//linkedin.com/groups/8339092/](http://www.linkedin.com/groups/8339092/)

³ <http://jdbsc.rug.nl>

⁴ See Dbl Review January 2016 – Communication Network report

⁵ www.umontreal.ca

⁶ www.opto.umontreal.ca

Youth Network

Simon Allison reports:

These are exciting times for the Youth Network. We are delighted in our acceptance to be represented on the Dbl Board. Young deafblind people have huge potential to inspire their peers in the future, thus representation on the Board is an important opportunity to do this.

The network is busy preparing plans for our 'European Adventure' in September 2016. Members will have the opportunity to meet together at Disneyland Paris¹ for a week of activities and developing friendships. There will also be the opportunity for each young person to inform others about services in respective countries and suggest solutions to certain challenges faced. The event will conclude with a drama based consultation event seeking the views of the young people to take the network forward. A few spaces are still available through contacting the network coordinator The Network's USA representative Emily Taylor-Snell from the Florida and Virgin Islands Deaf-Blind Collaborative² reports on their present goals to develop the network throughout the American states. These include:

- Sharing information with transition related initiatives including presentations at conferences, state-wide transition workgroups and at State Schools for Deaf and Blind

- Showcasing DbIYN at the annual Summer Transition Institute for Deafblind Youth sponsored by Southeast Deafblind Projects³
- Sharing the e-copy of the network publication A Glimpse of Our Lives with youth at Transition Institute and encourage them to share their stories for the second edition
- Sharing and promoting the next DbI World Conference (2019 in Gold Coast, Australia) with the view to youth delegates from USA attending

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

¹ www.disneylandparis.com

² <https://nationaldb.org/members/stateproject/FL>

³ www.tsbvi.edu

Conferences

Deafblind International Youth Network

DISNEYLAND RESORT PARIS 2016 SHORT BREAK

**September 26th–28th September 2016
Total Cost: £300**

STAYING AT THE HOTEL DISNEY CHEYENNE

3 nights hotel stay + 2 days Entry to Disney Parks + Network mini conference included in the cost (travel to Disney not included)

Enquiries to simon.allison@sense.org.uk

Senses Australia is proud to host the 2016 10th Australian Deafblind Conference on behalf of the Australian Deafblind Council

The theme of the conference is “Celebrating Experiences Across the Lifespan”

The program will cater for a range of interests, from early childhood, congenital deafblindness, to elderly people with acquired combined vision and hearing impairment. Advocacy, research and best practice will feature in the program.

Key note speakers are Dr Walter Wittich, Assistant Professor at the School of Optometry at the University of Montreal, Quebec and Molly Watt, a young deafblind campaigner from England, who was born with Usher syndrome.

The conference is in Fremantle, Western Australia on 16th and 17th November 2016. An Usher preconference workshop, held in collaboration between Senses Australia and the Dbl Usher Network will be on 15th November.

Further information can be found at: www.deafblind2016.com.au

Usher Pre-Conference Calls for Expressions of Interest

The Usher pre-conference presented by Senses Australia and Deafblind International (DbI) Usher Syndrome Network will be held on Tuesday 15th November, 2016, prior to the 10th National Deafblind Conference, Perth, Western Australia.

The Deafblind International Usher Network is the reformed and renamed Usher Study Group. The Usher Study Group was originally formed as a professional and medical group in 1985 and has continued to meet bi-annually since its inception. The last Usher Network preconference was held in Belfast, 2014, preceding the Acquired Deafblind Conference.

The Usher preconference will give the Australian deafblind community, its supporters and professionals working in the field the opportunity to: come together to share knowledge and experiences and learn more about new developments, results from research projects, exciting projects, best practices and lived experiences from people living with Usher syndrome and their families.

We are planning an exciting programme concentrating on the 10th National Deafblind Conference Theme “Experiences across the life span” with a special focus on relationships, family dynamics, mental health and well-being.

If you are interested in presenting at the Pre-Conference, please contact Karen Wickham – Karen.wickham@senses.org.au

The format will be relatively informal with extensive group exchange and discussions.

Please register your interest in attending the Pre-Conference by contacting Karen Wickham (karen.wickham@senses.org.au)

Or register your interest via <http://deafblind2016.com.au>

10th Anniversary of the Masters in Communication and Deafblindness

November 15–17 2016

Groningen

The Dbl Communication Network and the Department of Special Needs Education and Youth Care University of Groningen, welcome participants for the conference:

Communication in the context of congenital deafblindness

10 years of studies

How knowledge and practice develops

15.11.2016

Keynote: Theory and Practice

By Anne Nafstad and Marlene Daelman
(Members Dbl Communication Network)

Response by Prof. Wied Ruijssenaars
(University of Groningen)

Case studies in a dialogical perspective

By Prof. Ivana Markova
(Stirling University – Scotland)

Response by Anne Nafstad

16.11.2016

Language development: Valuable observations

By Prof. dr. Stephen von Tetzchner
(University of Oslo – Norway)

Response by Marleen Janssen

17.11.2016

Embodiment, agency and intersubjectivity

By Prof. dr. Shaun Gallagher
(University of Memphis – USA)

Response by Jacques Souriau
(Member Dbl Communication Network)

Plenary feedback presentation

By Prof. dr. Per Linell

(University of Gothenburg – Sweden)

Topics

- Dialogicality
- Embodiment
- Language and deafblindness
- Analyzing complex communication processes
- Development of knowledge and practice

Workshops

- Sharing knowledge
- Analyzing videos
- Connecting theoretical concepts
- Discussing interactively
- Gaining new insights

Registration is open now.

For more information, check out the conference website: <http://10yearscdbmaster.nl>

9th Dbl European Conference, Aalborg Denmark September 5–8, 2017

Deafblind International, together with Centre for Deafblindness and Hearing Loss (CDH), CFD and ADBN welcomes participants for the 9th Dbl European Conference.

The title of the conference is ***Touch of Closeness – maintaining social connectedness***. The central theme of the conference is social connectedness. Social connectedness is about how people come together and interact. At the final plenary of the 8th European conference on Deafblindness in Lille 2013, the main conclusion was that the two “sides of deafblindness” need to interact and learn more of each other. There is a need to look at the commonalities across deafblindness and to relate the knowledge of acquired deafblindness and congenital deafblindness to each other in such a way that one completes the other. The European conference on Deafblindness in Aalborg (Denmark) 2017 will reflect this duality and exciting interaction. We are pleased to host this conference and we look forward to a conference of high quality and of relevance to parents, people living with deafblindness and professionals of both acquired and congenital deafblindness. The scientific program will include plenary sessions, workshops, posters, a research symposium, network meetings and a possibility of visiting the Center for Deafblindness and Hearing Loss¹ in Aalborg.

The speakers of the plenary sessions will address the main title and the subthemes (Social connectedness, Touch and Closeness) of the conference. The invited speakers are professionals working within and outside the field of deafblindness, and people with deafblindness. On the last day of the program, we will focus on the

future and we promise that it will have an inspiring and optimistic view. The scientific program will be available on our website in August 2016.

We hope that our program will be inspiring so that we receive many submissions for workshops and poster presentations related to the sub themes. The Call for Abstracts for workshops will be open on October 1, 2016 and available on our website.

The scientific program has given a special focus to research by arranging a research symposium during the conference. The symposium will consist of several brief presentations related to research topics of importance to both congenital and acquired deafblindness. The main purpose of the research symposium is to bring together researchers at the conference to discuss current research that has important implications for persons with deafblindness and create opportunities for discussion between researchers and practitioners. There will be a program committee responsible for the organization and selection of topics for the research symposium. However, we encourage researchers or research groups to send us information regarding their research work to make sure we don't miss important and relevant research that is happening in Europe in the field of deafblindness. This information can be sent to the Scientific Committee: jytte.olsen@rn.dk

During the conference, there will be dedicated time for all the ongoing Dbl networks to have the opportunity to share their work with members and others interested in their topics. It is also possible to meet up in new groups of interests and maybe start a new collaboration with people from different countries.

The Conference Venue is the Aalborg Congress & Culture Centre², one of Scandinavia's largest congress and culture centers.

Registration opens in October 1, 2016

For more information, check out the conference website:

<http://dbi2017denmark.com/> and Facebook: [dbi2017denmark](https://www.facebook.com/dbi2017denmark)

¹ The Centre for Deafblindness and Hearing Loss is a small corporate member of Dbl (www.dbc.rn.dk)

² <http://uk.akkc.dk/about-akkc>

European Conference coordinator requests notification of interest in Pre-Conference sessions

Dbl networks, working groups or any special deafblindness related interest groups wishing to organize a Pre-Conference on Monday, September 4, 2017 contact: Helle Buelund Selling, Dbl European Conference Coordinator, Center for Døvblindhed og Høretab, Email: helle.buelund@rn.dk

Dbi World Conference 2015 – what did participants think?

Introduction

This survey provides unique information about participants' responses to a Dbl conference and, based on this information, the article presents some suggestions and offers guidance for future Dbl events.

This conference evaluation was achieved through a survey sent to all participants of the Dbl World Conference in Bucharest, 2015, around 4 weeks after the event. One hundred and eighty-five (185) people responded out of 390 people who were at the conference. This a response rate of almost 50%, providing a significant number of responses from which to make valid conclusions. In addition, a short survey was completed by 80 participants at the conference. This focused on the future of Dbl but included some feedback on the conference.

The questionnaire was constructed by Patricia Lee, from Perkins School USA, who is experienced in program evaluation and questionnaire design. The analysis was made by Tony Best, who was also chair of the Scientific Committee. The short survey was compiled and analysed by Dennis Lolli, member of the Scientific Committee, and his initial results were presented in the conference final plenary. The raw data from the Survey, the rated questions and individual comments, is available to Dbl so that it can be examined by interested parties – perhaps particularly those engaged in planning future conferences.

Participants

Around 40% of respondents said this was the first Dbl conference they had attended, with 60% having attend previous conferences. This is an encouraging number of new participants, and particularly so as Dbl Secretariat signed up 35 new members at the conference.

Participants came from all over the world although, as is expected given the location, the majority came from Europe. Previous conferences have had a similar attendance pattern, with the majority of participants from the host country and close surrounding areas. It is possible, from registration information, to give a *rough* indication of the attendance by geographical region;

| | | | | | |
|---------------|-----------------------------|--------------------------------------|------------------------|--------------------------|----------------------|
| Africa: 2% | Asia & Australia: 10% | East European & Russia: 20% | West Europe: 55% | North America: 10% | South America: 3% |
|---------------|-----------------------------|--------------------------------------|------------------------|--------------------------|----------------------|

Overall impressions

The overwhelming majority of comments about the conference were in praise of the high quality organisation. Around 96% of respondents agreed the conference was well organised, and 94% said they would recommend attending a similar conference. This enthusiasm was confirmed in the many positive comments, e.g. 'a relaxed but organised atmosphere', 'an openness and willingness to share', 'good organisation and the large amount of interesting topics', 'the sharing of knowledge was incredible- I loved every minute of it', 'it was a great conference and I was able

to meet new friends and network easily'. Overall, more than 50 of the 128 comments expressed strong satisfaction with the conference.

Accessibility

One critical feature of the organisation was the loop system, available in every room. 98% of comments about accessibility were about the excellence of the loop system, both in terms of its presence and its quality. Clearly, for a large number of participants (maybe as many as 180), this was critical in allowing access to the content. One respondent said that they thought a similar system should be an essential part of all future Dbl events.

The presence of the International Sign Language interpreters was also highly valued. They were present in all the plenary sessions, but also volunteered on request to interpret the workshops. Their presence was considered essential by some of the respondents – although it is not possible to calculate how many sign language users responded with comments.

How many participants needed the loop system and sign language interpreters? The survey asked for information about communication needs, but no figure is available for the number of people with a disability, as this was not a direct question in the registration process. However, this question and the open ended responses, showed that 84 (47%) of the respondents commented on the use of the loop system or sign language interpreters. If all these participants have a significant hearing impairment, this would give a total of around half the participants having a hearing impairment- a figure far greater than at previous conferences. If accurate, this may indicate a trend in attendance that could have major implications for the organisation and delivery of future conferences.

Workshops – best or worst?

When asked about the best feature of the conference, around 70% of the responses identified the workshops, praising the wide variety of topics, good choice in each session, good geographical spread of presenters, opportunity to network and for follow-up discussion. Around 87% of respondents found the workshops useful, and over 89% said the presenters were well prepared. Respondents to the short survey also identified the workshops as a valuable part of the conference.

However, when asked how the conference could be improved, nearly 80% of responses asked for a longer time for each workshops- at least 45 minutes, and several asked for 60 minutes. Some respondents praised the attempt to encourage interaction within the workshops, and the emphasis on shorter presentations than is usual for Dbl. (The Scientific Committee had aimed for the TED talk criteria of 'short, powerful talks of 18 minutes or less, with the slogan 'ideas worth spreading').

Despite this, of all the comments in the whole survey, the majority commented on the difficulty created by the short time for each workshop, for example of speakers not having time to complete their presentation, of discussions having to finish after just a few minutes, of presenters speaking too quickly in order to fit into the short time available.

Respondents said they recognised that reverting to longer sessions would mean including fewer workshops. 100 workshops were accepted for the conference, and around 20 submissions were not able to be included. If there had been sessions of 45 minutes, then only 70 workshops would have been possible. It is not possible to know the impact on conference attendance and satisfaction if many fewer submissions were presented.

Whatever the length of the sessions, several respondents asked that future conferences provide very clear guidance on the need to speak slowly, and to check that the content can be delivered within the allocated time, as this has been a problem in previous conferences.

Networks

Networks are a core part of Dbl activities and give an opportunity for members to meet with colleagues who have similar interests. At the conference 9 Dbl networks held sessions of half a day each.

Fewer participants attended the network meetings than the workshops – 12% of the respondents said they did not attend a Network. Of those who did attend, the majority found it useful and relevant.

Positive comments included ‘successful as an active working session’, ‘there was lots of discussion and exchange of ideas’, ‘the meeting has already resulted in follow-up information’. Other comments pointed out that some meetings had a very small number of people attending, there had not been adequate information before the session about what was to happen and what to expect. A number of respondents said that they had not been able to attend all the meetings they wanted to, as all the networks were held at the same time, and suggested repeating the meetings during the conference. One comment suggested holding the Network meetings at the beginning of the conference, so only those interested need attend, and participants would be able to meet colleagues with similar interests at the beginning of the conference (helpful for participants attending for the first time). There was enthusiasm for the principle of meetings with like-minded colleagues, but the responses seem to indicate that, at present, the Networks and conference-based meetings, do not fully meet expectations.

How could the conference be improved?

A number of more specific comments were received, identifying aspects of the conference that had contributed to the high quality or could have improved the conference. These comments may provide some guidance to the organisers of future events, as they seem to be aspects that are highly valued by participants. Here, the focus is on those ideas expressed by more than 5 respondents, although the full response data includes all the comments.

The single location for plenary, workshops, posters and meals was very well received. It allowed for discussions and informal meetings as well as making the movement between sessions efficient.

The posters were very well received. The format was popular as it provided opportunities to discuss content with the authors, and the range of topics was

praised. However, several respondents felt the posters should have had a more prominent part in this conference. It was suggested there could have been more posters, while having fewer workshops. To ensure they are visited, it was suggested that part of one day should be available when only poster sessions were presented- at this conference they were available during the whole day but, in practice, could be visited only when no plenary or workshops were running.

Several respondents felt the conference was too expensive and this seriously reduced the number of people able to attend from some parts of the world. They suggested that Dbl find ways to sponsor or support participants, so that there is a more complete presence of members from throughout the world. This was also a major concern in the short survey, with respondents asking that Dbl provide more support for developing countries, so that more people can attend events from those parts of the world.

In terms of content, there were requests that more research be presented in sessions, rather than program descriptions. However, other comments expressed satisfaction with the content as a good mix of practical ideas and theoretical underpinning.

A few respondents asked that a list of participants, with personal details, is made available at the start of the conference. At this conference, a list was made available during the conference – as the registration form did not include a section asking permission to release contact information.

Conclusion

This Dbl conference seemed to be well received in terms of organisation and content, but there are clearly a number of learning points, and suggestions of alternatives, that could be considered by the organisers of future Dbl activities. This report is just one element in the legacy of this conference. Other elements include a number of papers being published in Dbl Review, abstracts of all presentations issued at the conference, selected papers on the Dbl website, a short DVD featuring main conference events, and a pack of critical event summaries prepared for Dbl ManCom.

The author and conference organisers would like to thank the many conference participants who took the time to respond to the survey and provided so many excellent and useful suggestions. These will undoubtedly have a real influence on the way in which Dbl is able to plan and carry out activities, and provide a rich source of ideas for a better future.

For more information, contact Tony Best (tonybest987@gmail.com)

International conference INS HEA Sensory issues and Disability

Paris 17–19 March 2016

Cité des Sciences¹

Touch to learn, touch to communicate

In partnership with Universcience

The sense of touch is of the utmost importance for people who are deafblind as well as those who live close to them. A lot of expertise and knowledge has developed in this field of disabilities where the lack of vision and hearing has to be compensated for in all the possible ways. But people who are not familiar with deafblindness are not aware of the prominent role that the sense of touch plays in their lives because, in ordinary life, our image of what perception is, is mainly referring to vision (first and foremost) and hearing. That is the reason why the INSHEA² (Institut d'Enseignement Supérieur et de Recherche Handicaps et Besoins Spécifiques Particuliers), a University department dedicated to training people involved in the education of people with disabilities, organized an International Conference on Touch, in Paris, 17–19 March 2016. This event, titled “Touch to Learn, Touch to Communicate” was the most recent of a series of conferences about sensory issues and disability; (“Olfaction, Memory and Learning” in 2009, and “Listening, Acting, Music and Brain Plasticity” in 2011). In the audience, many people were involved in activities of research or education in the field of visual impairment, but not all of them, far from it, which proves that the sense of touch can trigger a universal interest.

The program started with a brilliant presentation by Vincent Hayward (University Pierre et Marie Curie)³ of the state of the arts concerning touch. He provided the audience with many pieces of information that demonstrate that touch is a fascinating aspect of life: Humans are made of 2 kg of skin; the mouth is the most sensitive part of the body and the tips of the finger have 1000 receptors; perceiving with the skin of the hands involves many physical elements (elasticity, sweat, friction) and a conscious and unconscious movement of exploration, which means that it is almost impossible to think of tactile perception without including the kinesthetic components. Therefore, all over the conference, the term ‘haptic perception’⁴ was often preferred to touch.

The program addressed the problem of touch from various perspectives:

- Identifying current scientific knowledge about touch.
- Showing how the use of touch, interacting with other senses and with language, may foster the learning processes, autonomy and access to culture, particularly for people with disabilities or special needs, but also for non-disabled people.
- Allowing participants to meet and exchange views so as to share good practices and skills in this field.

Among the presentations related to the role of touch in normal development, research carried out by Edouard Gentaz (University of Geneva⁵) stands out: it shows that for preschool students, using haptic exploration of raised letters helps them connect their visual representations and their phonological representations, thereby eventually helping them learn to read and write.

Of course, in the country where it was invented, the questions of perceiving and learning braille had to be addressed. Torø Graven (University of Oxford⁶ and Oslo⁷) lectured on *Discrimination strategies for braille* and Mira Tzvetkova-Arsova (University of Sofia, Bulgaria⁸) made a presentation on *Assessment of tactile discrimination skills of blind students of primary school age admitted in special schools for visually impaired* Concerning Deafblindness, two presentations addressed the question of communication: Franck Berteau (CRESAM-France⁹) demonstrated the role of touch in communication with congenitally deafblind people and Riitta Lahtinen (Communication Researcher Consultant – Finland) and Russ Palmer (International Music Therapist – UK) made a big impression on the audience when they presented all the resources they developed to enhance the quality of communication with people who are deafblind through using haptics, touch messages and sharing environmental.

It is also worth mentioning a topic rarely (if ever) addressed in this kind of context: Orgasm without genital sensitivity: compensation for sensitivity impairment following a spinal injury. It was presented by Anne-Cécile Mouget (Caen University¹⁰) who is carrying out a sociological research among people who have heavy neuromotor impairments and from whom she receives a strong support.

These are only a few of the many topics that were addressed during this conference. It is possible to get an overview of the program using the following link:
http://www.sensorialite.inshea.fr/sites/default/files/Livret_GB_0.pdf

Jacques SOURIAU (Jacques.souriau@gmail.com)

¹ www.cite-sciences.fr

² www.inshea.fr/

³ <http://www.upmc.fr/en/>

⁴ https://en.wikipedia.org/wiki/Haptic_perception

⁵ www.unige.ch/international/en

⁶ www.ox.ac.uk

⁷ www.uio.no/english/

⁸ <https://www.uni-sofia.bg/index.php/eng/>

⁹ www.cresam.fr/

¹⁰ www.unicaen.fr/

DbI History

Deafblind International celebrates 40 years of service to deafblindness

Deafblind International (Dbi) is celebrating forty years of achievements towards improving the lives of individuals with this unique disability. It officially began in 1976 as an organization of professionals committed to creating a worldwide awareness of and provision of service for persons with deafblindness, however the story of this organization goes back many years earlier.

First a look back at our roots

The roots of Dbi go back to the 1950s, when just a few organizations around the world were beginning to collaborate in discussions concerning educating children who were deafblind. Among this group were representatives from organizations and schools such as Condover Hall¹ in the UK, the School for the Blind in Hannover, Germany, the Institute for Defectology in Moscow², St. Michielsgestel³ in the Netherlands, Perkins School for the Blind⁴ in the USA and several schools from the Nordic countries. This group corresponded by mail, sharing their observations and results, successes and frustrations of their work with children who were deafblind and, on rare occasions, managing to visit each other.

It was in 1962 that this group first met through a formal conference, "Teaching Deaf-Blind Children", hosted by Condover Hall School near Shrewsbury in the UK. Forty-one people attended this first conference representing the UK, USA, USSR, Italy, Norway, Denmark, Iceland, Switzerland, Sweden, Finland and Turkey. This group of attendees can be considered as the 'Founding Members' of an unofficial organization, although it would take some years before it would become an official organization.

Subsequent worldwide meetings involving this were held in Denmark in 1965 (hosted by the State Institute for the Deaf in Kalundborg); in the Netherlands in 1968 (hosted by St. Michielsgestel Institute for the Deaf); in the USA in 1971 (hosted by Perkins School for the Blind, Watertown, Massachusetts); in the UK in 1974 (hosted again by Condover Hall School for the Blind), and in 1976 in Sydney Australia (hosted by the North Rocks Central School for Blind Children).

During this period, nearly all the membership in attendance were connected with the education of children with deafblindness. This was also the time when educators were seeing children with congenital rubella syndrome from the rubella epidemic of the 1960's and 1970's. These early conferences/seminars were organised under the aegis of the International Council for the Education of the Visually Handicapped (later changed to ICEVI⁵) which had created a special interest section or subcommittee for professionals interested in deafblind education.

It was during the 6th formal conference of this group held in Australia in 1976 that the International Association for the Education of the Deafblind (IAEDB) was officially born. The aims of the early organization were clearly defined as two-fold: to promote the education of the deafblind throughout the world and to promote world deafblind conferences. Keith Watkins from Australia was elected as the first President.

Early organizational developments

The organizational structure of the newly formed IAEDB included a Chair, Vice Chair, Secretary-Treasurer and an International Newsletter Editor. These positions were supported by an Executive Committee comprising individual country representatives and Regional Officers established to assist with the dissemination of information about deafblind education in the Regions of Oceania, Central-South America, Scandinavia, Asia, Africa, Europe and North America. Records from the founding IAEDB meeting list the initial senior appointments as follows: Keith Watkins as Chair (Australia); John McInnes as Vice Chair (Canada); T. Grunsell as Treasurer (Australia) and W.Zinger as Newsletter Editor (Australia).

The IAEDB Newsletter was published beginning in 1977. It was renamed in 1988 as Deaf-Blind Education – The Journal of the International Association of the Education of the Deaf-Blind. The magazine had grown originally from a one-page mimeographed sheet to an acclaimed international journal renamed Dbl Review in 1998.

A Secretariat was appointed during the mid-1980's to help manage the growing affairs of the organization. Rodney Clark from Sense UK became the first Secretary of the organization.

An organization review was called for

By the late 1980's, twenty-five years had now passed since the 'Founding Members' in the field first met. Two more world conferences were held (Hannover Germany in 1980 and New York in 1984) since the organization was first formed in 1976. The deafblind field was rapidly changing and there was wide consensus that the organization IAEDB needed to change with it.

While deafblindness education continued to be important, service delivery to the full spectrum of people with deafblindness rose up on the priority list of the growing list of IAEDB members. In addition, parents and family members were wishing a greater voice in the organization as were people with deafblindness. Research initiatives were taking place in various universities and specialists were looking for means to collaborate with each other to explore theories of communication, and discuss and present the latest research.

What was becoming urgent then was that IAEDB needed to become a more truly worldwide organization and better able to represent these broader interests while still including its initial reason for being – education.

It was agreed that a new constitution to build upon the previous one would better serve the organization to function better in the future.

A committee was appointed during the 9th World Conference held in Poitiers, France (1987) to draft a new constitution. The process involved discussions and reviews during subsequent conferences in Orebro, Sweden (1991) and Cordoba, Argentina (1995).

Significant changes in the makeup and focus of the organization resulted from this organizational review. It was decided the organization's focus should expand from solely education and conference hosting to promoting service delivery for the full spectrum of people with deafblindness, from infancy through adulthood.

Consequently, it was decided that membership would be extended to a greater

variety of people interested in deafblind services, including, but not limited to, administrators, clinical specialists, family members, rehabilitation and adult services workers, and deafblind people themselves. This decision has resulted in the rapid expansion of membership and a great growth in the scope of topics covered within meetings and conferences.

Ultimately the organizers agreed that the organization be renamed Deafblind International (DbI); a name that would more accurately represent the array of issues and services represented by its growing international membership.

Steps were also taken to make DbI a truly worldwide organization through encouraging development of services and participation of members from the developing world, especially in Asia, Africa, the Caribbean, Latin America and Eastern Europe.

Becoming Deafblind International

After a number of years of task forces and Strategic Plans, DbI was officially born at a meeting prior to the opening of the 12th World Conference in Lisbon, Portugal in 1999.

A new governance structure was established, when the former IAEDB Executive Committee was dissolved and replaced by a Council (now called the Board) and a Management Committee. This structure continues to be supported by a number of networks in which people of common interests meet and interact more frequently between conferences. Today, DbI has evolved from an organization initially focussed on education and organizing conferences into a mature, broad based professional organization representing programs and services for thousands of people with deafblindness around the globe.

A thoroughly new membership structure was developed based on two different types of memberships: Corporate Memberships and Individual Memberships. Within the corporate member designation, three levels were established: Large, Small and Mini corporates. Each membership designation has a fee structure which has resulted in greatly increased income to manage the organization. This increased revenue has provided financial support to DbI to better manage its various international activities, including the Secretariat, the Information Program, World and Regional Conferences, Network activities and Strategic Planning.

In the words of Former President of DbI, Mike Collins, the growth and expansion of our organization in the coming decades is limited only by the limits of our imagination.

Prepared by Editor Stan Munroe from archival material and an article written by Michael Collins

Editor's note: More complete details listing the various DbI World and Regional Conferences, Network Conferences, names of past DbI Secretaries, Information Officers, the DbI Constitution and most back copies of the past magazines (IAEDB Newsletter, Deaf-Blind Education and DbI Review) can be located on the DbI webpage: www.deafblindinternational.org.

¹ www.condoverhall.com
² http://www.tandfonline.com/
³ www.kentallia.nl
⁴ www.perkins.org
⁵ Icevi.org

Secretariat News

Meetings

In February 2016 the Management Committee (ManCom) met in Copenhagen to progress the work set out by the Board and specifically to meet with the Scientific Committee and Local Planning Committee for the Dbl European Conference 2017. Key activities included:

- Welcoming new officers Henriette Herman Olesen (Networks Coordinator) and Dennis Lolli (Diversity Officer) and setting tasks in these new roles
- Increasing the diversity of the membership and the Board
- Supporting Dbl Networks
- Increasing use of social media to promote Dbl and share information
- Reviewing the roles on ManCom
- Reviewing the Constitution
- Developing working arrangements for the Nominations Committee
- Developing the 2015–2019 Strategic Plan
- Presentation from conference organisers from Aalborg, Denmark regarding the Dbl European Conference 2017.

On 21st & 22nd August 2016, the Dbl Board will come together for its annual Board meeting and General Meeting. The meetings will be held in Orlando, Florida, USA to coincide with the WBU-ICEVI Joint Assemblies.

Membership

Dbl recognises that the success it achieves worldwide greatly depends upon the support of its individual and corporate members to promote awareness and services. Becoming a member of Dbl is very easy to do. Memberships may be purchased online through our website (www.deafblindinternational.org) or by contacting the Secretariat.

Individual membership

- Individual members are the backbone of Dbl and your support is essential in connecting professionals from across the globe
- Ability to publish articles in the Dbl Review
- Opportunity to be part of a network based on your special interest
- Opportunity to be the Chair of a Dbl Network

- Ability to start a Dbl Network
- Receive regular communication about deafblind activities, including invitations to attend conferences and events
- Support from Dbl Secretariat

Corporate membership of Dbl brings the following benefits: The opportunity to contribute to the decision-making process within Dbl

- You are a voting member of Dbl and can exercise your vote at the General Meeting
- You can be elected to the Dbl Board and take part in shaping the organisation
- You can be a member of task specific committees to work on key strategic actions
- You could be co-opted as a ManCom member and be a part of the team to execute decisions.
- You can link your organisation with the Dbl Website

HOW TO KEEP CONNECTED

You can keep in touch with colleagues a number of different ways:

Via the Networks on the website:

<http://www.deafblindinternational.org/networks.html>

Facebook: <https://www.facebook.com/dbiint/>

Twitter: @DeafblindInt

Old fashioned email: secretariat@deafblindinternational.org

Become a member by contacting us.

Matthew Wittorff & Bronte Pyett

Dbl Secretariat

Proudly hosted by Senses Australia

Dbl Board Membership 2015–2019

Management Committee

The Management Committee for the 2015–2019 period includes the two elected offices: President and two Vice-Presidents, Immediate Past President, Treasurer, Information Officer, Secretary, Development Officer, Strategic Planning Officer, Network Coordinator and Diversity Officer.

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Henriette Hermann Olesen
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Dennis Lolli
Diversity Officer
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Board Observers

DbI's partner organizations, ICEVI and WFDB have observer status on the DbI Board:

International Council for Education of People with Visual Impairment

Lord Colin Low

Contact: colin.low@rnib.org.uk

Website: www.icevi.org

World Federation of the Deafblind

Geir Jensen

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DbI Review – Sponsorship Guidelines

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 via 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 organisations 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 sponsorship 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 on.

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 *DbI Review* 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 advert
- 3 articles (related to individuals who are deafblind)
- 25 x extra copies of *DbI Review*

Level 2 Sponsorship = 4000 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 advert
- 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*

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 3 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.

Date endorsed by DbI Management Committee: _____

Review of guideline: 12 months after date of endorsement

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