

DbI Review

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DbI 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 DbI.

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Cover: Rubella immunization time in Tanzania

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A message from the President

Dear Friends and colleagues,

Our last Management Committee (Man Com) and Board meeting were held in Belfast during the ADBN conference in November. Some of us also attended the Usher Syndrome pre-conference. As usual ADBN's conference was packed with interesting presentations and workshops. A great week all round. There is more on the conference in this edition so I will leave you to read for yourself.

Dbl was delighted to welcome Lord Low, President of ICEVI to our meeting. We were grateful for Lord Low's contribution to our Board and his presentation at the AGM. The World Federation of Deafblind invited us to their meeting but unfortunately our dates clashed. Nevertheless it's great to be ever developing links with our partners.

We are currently looking at our budgets for next year and in particular sponsorships. We have a very small budget but are all too aware that the demands for people to attend events and conferences are increasing. Fundraising remains a struggle and there are no easy answers here I'm afraid.

It was also good to welcome James Thornberry from Sense International and Tony Best, chair of the scientific committee for the Dbl world conference in Romania in May 2015. The abstracts are coming in and Tony is delighted with how the programme is shaping up. The registrations are also coming through. Those of you who have organised Dbl conferences will remember only too well how important it is to get this right. Congratulations to Denmark for organising the next Dbl European conference in 2017. They have already started their work which is fantastic.

The Man Com is equally interested in the progress of nominations for 2015. Huge thanks must go to Cathy Proll and her team for guiding Dbl through the process. We are really keen that our members take an active interest and vote for their officers and Board membership. I offer many thanks to the Board members who contributed to a review of the strategic plan. Carolyn Monaco and Matthew led this session. It will be the job of the new/refreshed Board in 2015 to check they are happy with the draft strategy or make their changes.

We take our responsibilities for Networks very seriously and Lucy Drescher gave an interim report. The annual reports will be available in January 2015 and we look forward to hearing from all our colleagues and getting the up to date news. It's important that Dbl recognise the contributions that so many of you make. Without your commitment we wouldn't be able to have such an energetic and inspirational organisation. So if you haven't sent your nominations for awards to Bernadette and her team, please do so now. So indeed it's a busy time with lots going on and as ever our Review will bring you up to date with all the activities. Finally Sense is delighted to be following in the footsteps of Royal Dutch Kentalis and sponsoring this edition. Happy reading and all the best from everyone at Dbl.

Kind Regards
Gill Morbey
President

Editorial

Welcome to the 54th edition of Dbl review.

This edition begins with the theme of conferences. Just around the corner is the 16th Dbl World Conference, hosted by Sense International and Sense International Romania during the last week of May 2015. Conference Chair Tony Best has an interesting update that should entice potential participants to register soon to attend this – the first world conference held in Eastern Europe!

In early November, Sense Northern Ireland hosted the Usher Syndrome Conference (the first since 2010) followed by the 10th ADBN Conference. Both were smashing successes. This edition features a sampling of the many practical and provocative plenary and workshop presentations featured during the full five days of these events.

Several articles featured from the Usher preconference included: Emma Boswell's overview, a shortened version of Megan Mann's brilliant presentation about the personal Emotional Journeys experienced by several individuals from the UK; and from Mark Dunning, parent of Bella with Usher Syndrome (who was in attendance with her Dad) and Chair of the USA based Usher Coalition, an emphatic declaration of how important family members are in fostering key genetic research into Usher Syndrome.

This edition also presents just a few of the ADBN Conference presentations, including: a brief overview from the editor; Dbl President Gill Morbey's welcoming address; a philosophical plenary from Henrik Brink about 'working as professionals' in the field of deafblindness; and a detailed description by Angela Wills of a trekking adventure in Western Australia undertaken by a group of adventuresome individuals with Usher Syndrome.

Once again, Dbl Review magazine features another paper in the series of CHARGE Syndrome articles from Dr. Tim Hartshorne and his associates. It should be noted that Dr. Hartshorne is another parent of an individual with a sensory related disability who has taken on a significant professional role in the deafblindness field.

Sense International, a co-sponsor of the upcoming Dbl World Conference, has several international and ground-breaking articles featured in this edition. Two articles in particular report on the long awaited introduction of the rubella vaccine in the sub-continent of India and in Tanzania, East Africa. Other articles include: a report on educational programs for deafblind children in East Africa; a highly successful approach in Peru that resulted in deafblindness being now recognised by law in that country, and Cristiana Solomie's inspiring story (see Country reports) detailing the journey taken by Sense International (Romania) to improve the lives of children with deafblindness in her country.

It's always special to read the Country Report section to hear about the significant progress taking place. Take Brazil for example, with the report from Grupo Brasil that explains how their efforts led to an important public policy change in the large state of São Paulo that ensured that deafblind students have the right to a guide interpreter or an intervenor to support their inclusion in regular schools throughout the state. In Hungary, through the efforts of the Hungarian Deafblind Association (SVOE), the government included deafblindness as a category in their 2011 National Census. Consequently, they were able to determine the number of individuals with deafblindness in the country necessary to provide necessary information for developing their service plans. Similarly, the Republic of Ireland published an article titled 'Deafblindness in Ireland' providing the Anne Sullivan Centre with the opportunity to raise awareness of Deafblindness in Ireland and to campaign for the improvement of services.

The magazine would not be complete without reports from the various Networks. Check out new plans for a conference in the report from the Communication Network. Follow the activities of one of our newest networks, the Youth Network. Don't hesitate to contact Simon to obtain a copy of their recent publication 'A Collection of Inspirational Stories' which was launched at the recent ADBN conference. Their Network production of the Helen Keller story provided the entertainment for the opening night of the conference.

Special honours were bestowed on two past members of Dbl who represented the Perkins School for the Blind. The late Michael Collins, former President, was posthumously enshrined in the Hall of Fame for Leaders and Legends in the Blindness Field. Aubrey Webson, who served briefly on the Dbl Board, was named Antigua and Barbuda's Permanent Representative to the United Nations and Head of the Antigua and Barbuda Office in New York. We thank them both for their contributions to Dbl.

Finally, Dbl Review is pleased to once again have a sponsor – this time Sense (UK) supported the publication and distribution of this edition. Check out their colourful advertisement near the end of the magazine. We hope other organizations may offer some degree of sponsorship for future editions.

On a personal note, this is the 10th edition that I have had the privilege of being editor. Thanks so much to the many contributors and to the Dbl Board for its continued support.

Stan Munroe

Vice Presidents' Messages

Bernadette M. Kappen reports:

We are in the process of preparing for the World Conference in Romania in 2015. This will be an exciting time to renew friendships, make new friends and gather new ideas to make our programs better. The program and venue for the Conference is outstanding and I encourage you to try to be there. In an effort to support individuals to attend the Conference, Dbl will provide a limited number of sponsorships. If you are interested in sponsorship, you can find the application form on the Dbl website (<http://www.deafblindinternational.org/sponsorship.html>).

I want to remind you to consider nominating a colleague for one of the Dbl Awards. People working with individuals who are deafblind are outstanding. They go about their work and never ask for praise but this is the time we should honor individuals and share their achievements with others. The nomination form is on the website (<http://www.deafblindinternational.org/awards.html>) for the Young Professional Leadership Award, the Distinguished Service Award and the Lifetime Achievement Award.

At the Board meeting in Belfast, the strategic plan for the past four years was reviewed. It was so encouraging and motivating to see how many of the activities have been completed. As with any strategic plan – we are never finished. When we meet again in Romania it will be a time to celebrate the accomplishments of Dbl and to wish the new Board and ManCom the best in continuing the work of making the world a better place for individuals who are deafblind.

Bernadette M. Kappen

Carolyn Monaco reports:

With the four-year term of the present Man Com and Board ending at the Dbl International conference in Bucharest, Romania in only four months our more recent efforts have evolved around assessment and review of our accomplishments to date and those tasks still to be completed. Board members responded to a survey as part of our strategic plan evaluation and engaged in further discussions on this topic at our meeting in the fall. Preliminary ideas were discussed and documented so that

the 2015-2019 Board will have an initial frame of reference upon which they can build their new strategic plan.

I had the pleasure of attending the ADBN conference in Belfast in November and it was not only informative but inspirational. The opportunity to network with so many people working within an area of our field that I am a little less familiar with was wonderful. I hope that in the future Dbl through the use of technology will be able to make at least portions of the scientific programs of events like this available to persons around the world who are unable to attend in person.

I am especially looking forward to the conference in Bucharest in May where I will be joined by at least a few of my students graduating in April from the Intervenor Program here in Toronto. The enthusiasm with which they anticipate their attendance reminds me of my first international conference in the early 80's and of which I wrote in my first message on this page four short years ago. Sometimes life is just ironic!

Carolyn

Conference Itinerary Update

16th Dbl World Conference Programme update

The Scientific committee has recently held its 2nd meeting and finalised all the planning for the conference programme¹. We are now busy putting the plan into action, contacting speakers, inviting participants to chair sessions and will soon be arranging the presentations into the daily sessions.

Keynote speakers have just been announced and information about them is now on the conference website. As previously advertised, the conference will include plenary sessions on Education & Learning, Identity & Belonging, and Advocacy & Campaigning.

Plenary discussions

Suzanne Zeedyk² (Dundee University) will introduce the topic of Identity & Belonging, focussing on the vital role emotional connection plays in all human functioning. Her new book on the topic will be published in May, 2015.

Lars Bosselmann, Director of Christian Blind Mission's (CBM)³ Department for International Alliances and Advocacy, will talk about the principles of Advocacy.⁴ His work on the Millennium Development goals and the UN Convention on the Rights of Persons with Disabilities⁵, gives him invaluable experience which will be relevant to national and local campaigning.

All the plenary sessions will include presentations and discussion by respondents who will describe how they have found local solutions, appropriate to their region and culture, to meet the needs described.

Workshops and posters – the heart of the conference

The Scientific Committee has developed a programme that emphasises interactivity, and the workshops and poster sessions will be a central part of the programme. Both of these will include the opportunity to discuss presenter's ideas, to ask questions and to share experiences. We anticipate this being a highly valued element in this conference with over 100 presentations to choose from. Further details of the programme will be available on the conference website, when it is finalised in March.

Opportunity for all

The conference will give an opportunity for small groups with a special interest to meet outside of the main programme times. These groups can create their own agenda, for example, they may explore one problem, or plan future projects or simply exchange information to help with future contacts.

In addition there will be the ever popular DbI Network afternoon. Each network focusses on a specific topic, and has its own priorities. The World Conference is a unique opportunity to meet people from throughout the world who share a specific interest, and these sessions can be used to plan, create, develop and enjoy. This should be a truly personal and interactive experience.

Final deadlines are NOW!

Please note the final deadline for submitting an application for a workshop or poster session is 30 January 2015, and it is vital to register before the end of January 2015, to secure the low registration fee.

For the latest information about the conference visit the DbI conference website:
www.dbi2015romania.com

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¹ A draft of the conference program was published in Edition 53, DbI Review, July 2014.

² <http://www.educationscotland.gov.uk/>

³ www.cbm.org

⁴ www.un.org/millenniumgoals

⁵ www.un.org/disabilities/convention/conventionfull.shtml

Welcoming speech by Gill Morbey, CEO Sense and President Dbl

I'm delighted to be part of the opening of the tenth Acquired Deafblind Network Conference here in Belfast, Northern Ireland, entitled Life, Love and Laughter. Dbl is grateful to the ADBN Network for putting the spotlight on Acquired Deafblindness. I attended the last ADBN conference in Lund Sweden in 2012 and was impressed with the quality of the program and the new thinking that was coming out of that conference and I know from the program here that this one won't be any different. Your plenary speakers on this opening day, Professor Richard Schoch and Henrik Brink, will bring to you thoughtful presentations.

Yesterday I was able to attend several excellent presentations of the Usher Syndrome preconference. While sitting there I was reminded of the late Mary Guest and her huge commitment to Usher Syndrome. I felt Mary on my shoulder a couple of times. I went with Mary in the mid 1980's to Louisiana (USA), an area with a high incident of Usher Syndrome, and was reflecting on that as I was listening to yesterday's presentations. At the preconference we also had a clown. Those of you who weren't there might not know what I'm talking about. But if you don't know, could you ask Megan Mann! And last night wasn't it special to be entertained by this wonderful group of young people from the Youth Network, spearheaded by Simon Allison?

As I welcome you today, I take the opportunity for some reflections. First, I feel that the future of Dbl and our organizations and deafblind services is safe as I look around at the more youthful faces that are in the audience.

Secondly, these periodic conferences and meetings are further justification for why we need to get together! It is important to get together; to renew and refresh our friendships and share knowledge. Ours is a large and dispersed community not able to come together often enough. When we do meet, we pick up where we ended the last time; a sure sign of a tight community. It's important to renew our faith and remind ourselves why we are here.

I want now to speak from the point of view of CEO Sense to say "it's tough out there". I've been in this field for over 35 years and I've never seen so many challenges facing us. Funding for services in the UK is being cut from all sides despite the fact that the need for services is not diminishing. Organisations outside the UK are experiencing similar difficulties. So, it is important to get together and gather strength from each other.

The population of individuals that we're working with is not diminishing. Many of us are working with children and observing the growing population of children with CHARGE and other rare syndromes. Furthermore, there is an ever growing elder population with which we are working. Like those with Usher Syndrome, this growing population of the elderly facing isolation caused by sensory impairments is an issue that we need to become more focussed on.

An issue that I am proud to have with our 'community' is our worldwide perspective. At this conference we are pleased to welcome over 150 delegates, from over 14 countries. Despite this, in Dbl we still have huge gaps in terms of representation from many parts of Asia, Africa and Russia. It's a huge task to get representation

from those populations. I'm delighted that we have a delegate from Ethiopia with us. Take a moment to talk to him or see his workshop to see his fantastic work. I was in India recently, and I was interested in the debates that they were having. More and more they are talking about inclusive education which is interesting for such a huge country where half of the children are not going to school at all. There are absolutely massive challenges there. For example, I went to see a school where there were still many children who were deafblind through rubella. Indian children and those from the African countries as well, are still being damaged needlessly by rubella. We still have massive work to do on prevention of sensory disabilities. Further to the subject of the international perspective, I want to mention that earlier in the week the Dbl Board was privileged to have in attendance, Lord Colin Low, President of the International Council for Education of Visually Impaired (ICEVI). I mention this since Lord Low is influential in the development of the United Nations Post-Millennium goals. It may be surprising to know that when the initial Millennium goals were set, there were goals stated for gender equality, poverty and education, etc but not a single mention of disability. Can you imagine? I know this might seem a long way from your day jobs. The reason this matters is that inevitably when the UN looks at new goals for post 2015, funding is expected to follow. So we need to pay attention to this issue as funding is also necessary for the important research that is required for Usher Syndrome, as an example. Beginning next week I will be in London because I'm going to be part of the 'Bond for International Development Conference' which for the first time will be looking at disability. So we have a real chance to get the word 'disability' in the post—millennium goals and that is really critical for us, because in a year's time, we will see whether this eases our flow of policy and funding. We don't expect to get deafblindness or hearing impairment included in the goals. Since individuals with visual impairment represent a huge population in the developing world, we might see vision included. What we are hoping for at a minimum is the recognition of disability. Even with this recognition we could observe some positive improvements. I know that I stand between you and Professor Richard Schoch so I'm not going to speak for much longer. I'm not surprised by the ADBN's title: Life, Love and Laughter and I fully agree with it. I turn to India the Indian guru and spiritual leader Sai Babba for a quote which aptly reflects the theme of this conference: "Life is a song-sing it; Life is a game-play it; Life is a challenge-meet it; Life is a dream- realise it; Life is a sacrifice-offer it; Life is love; enjoy it". Have a great conference folks!

ADBN Belfast, 2014 was full of 'Life, Love and Laughter'

Congratulations to the ADBN Coordinating Committee and the Local Sense Northern Ireland Planning Committee for the successful 10th Dbl Acquired Deafblindness Network Conference held in Belfast, November 4-7, 2014. This

marked the first time since the 5th ADBN Conference was held in Harrogate, North Yorkshire in 2004 that this event has occurred in the UK.

The conference got off to a special start with a very touching performance of the Helen Keller story performed by some of the members of Dbl Youth Network under the direction of Simon Allison.

The committee worked their magic with their six plenary sessions together satisfying the conference theme: 'Life, Love and Laughter'. The Day One Opening Plenary kicked off with Professor Richard Schoch, from Belfast, suggesting "What the Art of Happiness and Well-being means for all of us". Later in the day, Henrik Brink from Sweden provided some insight into self-examining oneself as a professional and helping built a toolkit for new ways of working.

Paul Hart from Scotland primed everyone on Day Two with an inspirational plenary 'Exploring the meaning of Happiness developed through building Relationships through Trust and Communication'. This thoughtful presentation was followed by two young ladies from the Netherlands, Afroditi Manolaki and Hedda de Roo who 'put themselves out there' explaining their personal life experiences with Usher Syndrome.

Day Three started out with a plenary from Canada, presented by Jane Sayer and Bonnie Heath. They traced how a group of individuals who are deafblind formed their own organization in the Province of Manitoba and successfully obtaining government funding for services. The conference ended with a plenary from Collette Gray and Martin Quinn (Sense Northern Ireland) describing the prevalence, profile and needs of people who are deafblind in Northern Ireland.

To complement the plenaries, a complex array of 30 workshops were held throughout the three days on topics that varied from: Stress in People with Usher Syndrome, Creating Social Networks, Motivating Others, Bushwalking in Australia, Orientation and Mobility, Living and Working With a Rare Condition, Facing Death – Choosing Life, From Life Support to Supporting Others, to name a few.

And who can forget the climax evening event at the Belfast Castle¹, including the double decker bus trip, the excellent meal and the traditional Irish entertainment?

The conference was well attended, with over 170 persons registering from:

Australia, Brazil, Canada, Denmark, Ethiopia, France, Germany, Ireland, Netherlands, Norway, Russia, Sweden, Switzerland and the UK (Northern Ireland, England, Scotland and Wales).

The conference venue, the Holiday Inn Belfast, was an excellent location. The food, including the breakfast and lunch buffets and coffee breaks ensured that many returned home suffering from excess calories.

Congratulations again ADBN Network organizing committee for another excellent event.

Stan Munroe
Dbl Information Officer

To work in a professional way¹

Henrik Brink

This Plenary is designed to be a practical session mixed with some of my ideas and theories that I will hope will provide some useful tools.

I open my presentation with a series of paragraphs² taken from the writings of Danish philosopher Søren Kierkegaard's which illustrate his thoughts on the art of helping.

"If one is truly to succeed in leading a person to a specific place, one must first and foremost take care to find him where he is and begin there. This is the secret in the entire art of helping.

Anyone who cannot do this is himself under a delusion if he thinks he is able to help someone else. In order truly to help someone else, I must understand more than he – but certainly first and foremost understand what he understands.

If I do not do that, then my greater understanding does not help him at all. If I nevertheless want to assert my greater understanding, then it is because I am vain or proud, then basically instead of benefiting him I really want to be admired by him. But all true helping begins with a humbling.

The helper must first humble himself under the person he wants to help and thereby understand that to help is not to dominate but to serve, that to help is a not to be the most dominating but the most patient, that to help is a willingness for the time being to put up with being in the wrong and not understanding what the other understands."

I am often reminded of these words when I am working and things not working according to the plan. What is wrong? Could it be what is mentioned above?

Basically, you and I have a need for confirmation and we get confirmation through others. I have a need to feel needed and useful. Am I good enough? Do I have what it takes? Do I find meaning in my work? Can I be there for another person?

"People want to be loved; failing that admired; failing that feared; failing that hated and despised.

They want to evoke some sort of sentiment. The soul shudders before oblivion and seeks connection at any price."

Hjalmar Söderberg, Doctor Glas³

Why did you choose your profession?

Perhaps through different circumstances, you just ended up where you are. What is the drive behind your work? What is your engine, what are you fueled by? Many

would answer: I'd like to help. I'd like to help people and I think I have something to contribute.

What makes you skilled in your profession?

Think for a moment, what quality or character you possess that makes you especially good in what you are doing? Has it always been there or has it developed throughout time?

Knowledge is something that grows through time.

Learning about deafblindness takes time. There are many different kinds of knowledge, both theoretical and practical, that we need to learn. We all acquire the knowledge in our own different ways. Some of us are visual learners; others may be auditory, kinesthetic or tactile learners. Despite our different learning modes, the categories of learning are the same: unaware ignorance – aware ignorance; aware knowledge – unaware knowledge.

I relate this to my personal journey of learning about Deafblindness: 1) First, I don't know that I don't know much about Deafblindness; 2) As I started working I became very aware of my ignorance; 3) As time went on I realized I understood about viruses and audiograms and different types of Usher Syndrome; then, 4) I became no longer aware of my knowledge.

What makes a person with a profession, professional?

I believe that most of us think of professionals as people having a profession. But why are these two words the same? I believe this is because we are meant to do work in professional way. The question is what makes our way of working professional? Looking the other way around, people in our work who don't do good work are considered as not being professional. The meaning of the word professional is: to work professionally in contrast to those who are laymen/amateurs or doing something as a hobby. It is also defined as a way of working that can be described as conduct between a client and a professional and not as a friend. It is a way of listening and being empathetic while keeping a distance to enable the client to find his or her own solutions.

Let's get the tools out!

The basis of this Plenary is boiled down into one question: How can I become better equipped in to do good professional work? I will present a few essential tools that should help in our daily work. For some of you, this may be well known information; for others it might be new. Personally, the day I say that I know it all is the time for me to move on.

Empathy

Many clients coming to us are usually dependent upon others. First, how can we perceive a dependent 18-year old in various situations where normally we wouldn't be? Have we ever tried being deafblind? How hard was that? For a better way

understanding of that person we should go back to the Kierkegaard quotes mentioned earlier. We need to be empathetic as a professional.

When one thinks about the deafblind person's dependency, we should look at this from personal perspectives. Am I an independent person? How often do I ask for help? If I receive support from another, how does that feel? Or do I avoid asking because of my pride? What would happen if we would allow a client to teach us, to feel dependent on him/her?

Timing

While timing is important, there are questions to consider. If I start a process with an individual, will I be able to finish a session with an agreement with the person? What if I leave the session when the person needs more time together? Session times need not be fixed but experience suggests that one hour is sufficient. At the same time we need not to make ourselves indispensable. As professionals we must strive to be respectful of our time, the time spent with our client and our time schedule with other clients.

Awareness of the personal needs of each individual deafblind person is important. Recognizing when to act is just as important. In our business we are committed to helping when we observe individual's immediate needs. My advice is not to rush the process as their needs will not go away. As professionals we should give ourselves time to think about our best practises; then make an individual plan for the deafblind person through a collegial team effort. This will ensure that their need will be met in good time.

Dare to be silent

One of the hardest things I find during a session with an individual is to be quiet or silent. We should let silence work for us; wait for things to sink in for the person. In my opinion it is an awkward situation when guiding someone; we want to chat and be social since this is what we are used to. I need to allow myself to be quiet while guiding/walking with the client; letting him/her focus on their walking which is comforting for the individual.

Seeking approval

Approval from our clients for our work is important; we all need confirmation. It's a good feeling knowing one has done a good job. But, personally, this does not motivate my work; nor should it be the driving factor for any professional in the field. People who are deafblind or their family members might dislike me as they will other colleagues. For example, I had a mother recently who indicated she wanted to exchange me for one of my colleagues as she didn't trust me anymore. While I didn't like this I consider it a part of the work.

Recently a colleague told me he had a two hour session with a couple. The session was initially planned for one hour; but because they were on the verge of separation, the colleague felt he could not leave them. I questioned why he participated alone

and his answer was that the wife wanted the meeting but the husband refused to meet if someone else was joining. This type of session should not have been held with one colleague; especially when in fact the couple needed marriage counselling instead. While my colleague was motivated to help the couple, he was affected by the potential lack of approval from the couple had he said no. In my opinion this was a mistake by my colleague.

Using the right words!

This is professionalism for me.

For example, how often do you use the word 'we'? "We have decided ..."; "When we last met ..."; "Right, so we're finished..."

'We' is a very complicated word. For me, I rarely use the word 'we' with my clients. There is 'you' and 'I'. Using the word 'we' is confusing for anyone. Honestly, who else is included? 'We' suggests that 'you' and 'I' are in agreement on the same level. Actually, using 'I' make 'us', as professionals more distinct and is more respectful to our clients as well as they become an individual on their own.

Using the proper word in the correct context mentioned above is the same as in any organization. It is not correct for a supervisor to say that: "'we' decided in our last meeting..." We don't ever decide here, but 'we' can have a discussion; it's the supervisor (you) who makes the decisions.

More could be said about this topic of being professional. My aim with this Plenary is to start a process of talking about Professionalism. I am sure you have different perspectives and that is good. Acknowledging that I don't know everything and that I am keen on learning more is elementary. What do I have in my toolbox and what is still missing?

Henrik Brink
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(email: Henrik.Brink@skane.se)

¹ Plenary Presentation, 10th ADBN Conference, Belfast Northern Ireland, November 04-07, 2014

² The Essential Kierkegaard by Søren Kierkegaard (Author), from Chapter A2, Volume 22 translated by Howard V. Hong and Edna H. Hong

³ en.wikipedia.org/wiki/Doctor_Glas

Deafblind bushwalkers in Western Australia¹

Research has suggested that a person who is deafblind is at greater risk of developing conditions affecting their physical and mental health. Studies have

identified a greater mortality risk to people who are deafblind compared with the general population.

For a person who is deafblind there is often limited opportunity for physical activity impacting on their overall health with the potential over time of developing health conditions such as diabetes, hypertension and heart disease.

Likewise depression, anxiety and other mental health conditions can be attributed to the social isolation that many people with deafblindness experience.

Sharyn Mitchell (age 50) has Usher Type II and is an active member of the Usher Syndrome Support Group in Western Australia (USSGWA). Early in 2013 Sharyn set herself a challenge to walk the Bibbulmun Track end-to-end that would take between 7 and 8 weeks to complete.

The Bibbulmun Track² is listed in the top 20 World Best Hikes: Epic Trails in the National Geographic. "South Western Australia's answer to the Appalachian Trail..." Officially opened in 1998 following an extension and upgrade, the Bibbulmun Track was named after an Aboriginal sub-group of the Noongar people in the South West of Australia. Winding through State Forrest the Track covers almost 1000 km (over 600 miles) of isolated, rugged bushland, in the largest state of Australia, starting in Kalamunda (near Perth) and finishing in Albany on the Southern Ocean.

Other members of the USSGWA expressed an interest in joining Sharyn. This was not a Senses Australia initiative and the deafblind walkers took the lead in planning and organising the challenge under Sharyn's leadership calling themselves the Usher Army! Their goal:

- To walk the Bibbulmun Track
 - To raise awareness of Usher Syndrome
 - To raise funds to support the USSGWA
- ... and to Defy Adversity!

The group were soon to be joined by two other deafblind walkers.

Greg (age 36, previously from Western Australia, now living in New South Wales).

...and Rita (age 53 – Usher II) who joined July 2013 having emigrated from the UK to Perth

What preparation was required to make this dream a reality?

Some difficult decisions were made along the way. Due to personal circumstances Sharyn decided that she would not continue with the walking, however, she and her partner would remain involved in the planning and practical support needed on the walks.

The other decision made due to the logistics of coordinating walkers and volunteers around work commitments was to walk the track in sections (there are 9 sections in

total) rather than walking end-to-end in one go. One section has now been completed. The next trek is planned for April 2015.

Fund raising was a must. Sharyn and her partner were involved in fund raising, securing small grants and sponsorship and Senses Australia also supported in applying for grants.

Guidance was sought from local “experts” who provided their knowledge of practical skills needed and advising of numerous risks associated with the bush walking, some seasonal such as snakes, spiders and ticks. Other risks included potential falls and rough terrain, dehydration and availability of water. Walking during summer months was avoided due to extreme weather conditions and potential of bush fires.

Sighted guide volunteers were recruited including a number of staff from Senses Australia. Training started in May 2013 with practice walks initially every 2 to 3 weeks eventually becoming weekly training walks averaging around 8 km gradually increasing in length up to 25 km to build up fitness levels.

Sighted guide volunteers were recruited including a number of staff from Senses Australia. Training started in May 2013 with practice walks initially every 2 to 3 weeks eventually becoming weekly training walks averaging around 8 km gradually increasing in length up to 25 km to build up fitness levels... ..and stepping it up to the bush walks practising the real thing with back packs weighted as this would be a requirement when camping.

Sighted guiding required lots of concentration, as seen with Don and Kirsten-Lee supporting George to negotiate a deep drop using tactile signs agreed beforehand to deal with tricky terrain.

Health benefits of Bushwalking

As time went on some positive changes in the Usher walkers were observed including increased confidence, and evidence of health benefits. There was also a social aspect to the walking, meeting at the pub afterwards!

Beyond Blue, a national depression initiative in Australia promotes the benefits of bush walking to improve mental health, stating that contact with nature and green spaces is a key to aid physical and psychological well-being (Beyond Blue to Green: The benefits of contact with nature for mental health and well-being, 2010 |

.beyondblue.org.au)

Questionnaires and Interviews

After completing the first section of the Bibbulmun Track recently, all six deafblind walkers were approached to complete a questionnaire and to be interviewed on their personal experience of bush walking.

Six out of six questionnaires were completed and five interviews took place (one of the walkers was about to move to the Eastern States).

Summary of responses to the questionnaire:

Although Sharyn was no longer walking with the group she reported that she was walking most days along the beach in her local area.

Having individual personal goals and the overall goal of walking the track gave the deafblind walkers a sense of achievement that motivated them to increase their exercise routines.

Question	Answer
Have you been involved in other forms of exercise?	All six respondents started other forms of exercise to build up stamina eg. <ul style="list-style-type: none">• Swimming• Gym• Additional walking
Was the bushwalking related to a goal you wanted to achieve?	<ul style="list-style-type: none">• Overall goal – to walk Bibbulmun Track• To lose/maintain weight• To have a healthy lifestyle

Question	Answer
Have you been bush walking regularly?	Five deafblind walkers answered yes.
When did you start regular bushwalking?	15 – 18 months ago
How often have you been bushwalking?	Started fortnightly building up to weekly walks in preparation for “big walk”

Physical Health:

All six deafblind walkers reported an improvement in their physical health and all reported weight loss.

At time of interview Rita was recovering from major cancer surgery. Medical staff indicated that Rita’s recovery was aided by her fitness levels associated with walking.

Mental Health

All six deafblind walkers said they had experienced depression. Sharyn was open in her experience of depression saying that “In the past, and absolutely in the present and I would say in the future, it’s one of those constant effects because in particular with Usher Syndrome it’s a constant degeneration. You are always worsening.”

Five of the walkers acknowledged the benefits of bush walking in reducing mental health and a positive attitude. Likewise Sharyn felt her involvement in the project at an organisational level was also beneficial by having something to focus on. The goal of completing the Bibbilumun Track is ongoing.

Emotional Health

All deafblind walkers reported learning new skills such as leadership skills, teamwork, organisational skills in addition to the practical skills required such as packing a back pack, bush etiquette, erecting a tent and survival in the bush.

Social Participation

All deafblind walkers said their social network had extended through the walks, meeting other walkers on the way, connecting with the community through fund raising and building friendships with volunteers.

Walkers were asked one final question. Were there any additional challenges you faced?

Rita of course had serious health problems that had challenged her recently.

David’s moved to Victoria just after the first walk may present challenges for him to join treks in the future.

Question	Answer
Have you experienced an improvement in your health since being involved in bushwalking?	<ul style="list-style-type: none">• Having good fitness levels aided recovery from major surgery for cancer• Reduced blood pressure• Reduced breathlessness• Improved stamina• Increased energy levels• Physical strength aided recovery following knee replacement surgery• Healthier eating• Reduced risk of diabetes• Recognition from GP of benefits of walking• Improvement in asthma symptoms• Reduced stress• Improved concentration

All reported having falls at different times George said “When you walk along the bush and you fall, the challenge is to get back up and you do that time and time again”.

On one of the practice walks Eddie fell 2m from a bridge while walking ahead of the group to take photos, with little peripheral vision he missed the bridge fracturing his scapula. He returned to walking soon after. Limited access for emergency services meant it took 50 minutes for an ambulance to arrive.

To summarise:

Through their involvement in the walks all deafblind walkers experienced:

- Weight loss
- Improved confidence and self-esteem
- Health benefits
- Motivation to continue
- Working as a team
- Support and encouragement from family and friends
- Reduced isolation

and they said walking helps:

- To take your mind off things
- Socialising and interacting with other people
- To feel part of a team
- To sleep better
- To reduce stress
- Increase independence in orientation and mobility
- Influenced decision to have a guide dog
- To keep active
- A sense of belonging
- Reducing isolation and loneliness
- Having fun!

As David said “The social element was a huge part of building a strong bond to facilitate safety, enjoyment and laughter”

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Usher Syndrome PreConference

An unforgettable two days, November 03 and 04, 2014, the Usher Network Pre-conference successfully achieved all the committee set out to do. Held in Belfast Northern Ireland, with ten excellent presenters, the Usher Network brought together over fifty people from around the world¹ to meet, learn and listen to some of the most cutting edge thinking in the field of Usher. One prominent member of our committee, Dr. Nadja Hogner from Humboldt-Universität zu Berlin was able to attend and give an insightful presentation on the role of humour and the Usher community. Attendees ranged from Usher professionals, medical consultants and specialists, family members, language professionals and more importantly several Usher people who served as great role models for the overall event. The seminars were held in the backdrop of a relaxing and welcoming venue and participants were treated to topics as far ranging as Mental Health, Stress, lifestyle factors of Usher people, as well as in-depth medical information.

Medical expertise from the likes of the prominent Professor Andrew Webster and the latest in stem cell research from Professor Maria Bitner-Glindzicz provided much food for thought and after dinner discussions. Of course no Usher Conference would be complete without an appearance from Megan Mann's alter ego and Megan did not disappoint! She provided a humorous start to her presentation by providing those who wanted to, a tactile tour of her clown's outfit, followed by an extremely engaging presentation representing the theme of 'Love, Life and Laughter' perfectly. The network were extremely grateful that Mark Dunning from USA, and his daughter, Bella could spend some time with us in Belfast giving an informative talk on how things are progressing stateside and with respect to the Usher Syndrome Coalition². At the end of the two days, the audience participated in group discussions about the future of the Usher Network, giving the committee members lots of ideas to work and develop on. Watch this space in the near future. Also, Watch for activity on our site on the Dbl website: <http://ushersyndrome.deafblindinternational.org> On behalf of the committee I would like to say a huge thanks to everyone for being an enthusiastic and engaging audience, as well as special thanks to our presenters and the other members of the network. This has been my first taste of being on the committee and I have to say it has been an overwhelming experience, and on a personal level I found it to be a rewarding and empowering conference.

For more information, contact Emma Boswell, Chair Usher Network
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¹ Countries represented included: Australia, Brazil, Canada, Denmark, Ethiopia, Germany, Ireland, Netherlands, Norway, Sweden, Russia, UK and USA

² usher-syndrome.org

Usher, an Emotional Journey¹

Quentin Crisp², the English writer once described life in the following way,

“You fall out of your mother’s womb, you crawl across open country under fire, and drop into your grave.”

What a jolly chap he must have been. However, his comments must be considered in the light of his experiences in life. He was a controversial character who was subject to bullying and prejudice as well as fame and fortune. Did his experiences colour his view of life? From birth we start a journey, an emotional journey through life and we will all, to some degree, face adversity. How we cope with adversity will depend on many factors: our personality, our relationship with others, our upbringing, our support networks, our emotional and intellectual development. Those factors determine the difference between having a positive or negative response to those difficult situations. The theme of the Usher conference focused on life, the emotion of love and the physical reaction of laughter. Does having limited sight and hearing mean that love is more elusive and that there is very little opportunity to laugh? Should that person’s journey be seen through the eyes of Quentin Crisp, as an arduous journey constantly under fire?

I spent some time with four people with Usher – Ann, James, Angela and Jeremy who described their different journeys through life experiencing love, life and laughter³.

Love and relationships

I heard from them first about their different experiences with parental love and relationships. In English we have one word for love, in sign language there is one sign for love but going back in history to the ancient Greeks, it is worth noting that in their language they had at least five different words for love⁴, depending on the type of love that was being shown. There was Agape love, which was love based on principle, an unconditional, selfless love extended to both friends and strangers. Storge love referred to the love shown between family members. Philial love was love felt between friends, when that special connection is made between two people resulting in a friendship that lasts a lifetime. Eros was the romantic love in a partnership which would hopefully, in time, turn into Pragma love. This was a mature love born out of tolerance and compromise leading to a deep understanding and respect for each other.

Finding a partner, someone to share your life with is a tricky business for most people. Developing that close bond takes time and patience. It’s not easy is it? The psychologist Erich Fromm⁵ said,

“We spend too much energy on falling in love and need to learn more about how to stand in love.”

Once you have found a partner, at some point you might want to consider having a family. Parenting is the most demanding, confusing, challenging job that anyone

could undertake. We seem to think that parenting difficulties are a modern phenomenon but John Willmot⁶, a satirist and friend of King Charles II once said, "Before I got married I had six theories about bringing up children, now I have six children and no theories."

Laughter

It is often said that laughter is the best medicine. There have been conferences on laughter, research on humour and articles on how it can have a positive impact on mental health. There's no doubt about it, having a good belly laugh can be good for the soul. However, psychologists would say that humour can also be used as a defence mechanism against negative feelings. An example of this is making a joke about something that has happened to you, when the real feelings might be deep shame or embarrassment. It may not be appropriate to use humour if the problem really needs to be dealt with and handled, rather than minimized or ignored. Some people might use humour to make the unbearable bearable. It can be a useful coping strategy, as several of my contacts indicated, to see the funny side of Usher and not to take one self too seriously.

Life

The Quentin Crisp quote highlighted the fact that life has its challenges. There are times when it's difficult to laugh, when love is tested, when we are hurt and disappointed, and when we experience loss. There are times when life throws a curved ball, when life seems to be upside down, back to front and inside out.

Life with Usher Syndrome presents unique challenges. Parents who have that first-hand knowledge of their children must be listened to. Information given at the time of diagnosis must be clear. Ann, James, Angela and Jeremy have talked about those challenges, how at times humour has helped, and how they have experienced different kinds of love.

Forget Quentin Crisp and his painful trek through life I much prefer the quote from William Purkey who urged us all to:

"Dance like there's nobody watching,
Love like you'll never be hurt,
Sing like there's nobody listening,
And live like it's heaven on earth."

Megan Mann

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¹ Paper presented at the Usher Syndrome PreConference, Belfast Northern Ireland, November 03-04, 2014

² en.wikipedia.org/wiki/Quentin_Crisp

³ For the complete transcripts of their journeys, see the text of full paper "Usher, An Emotional Journey" on the Usher Syndrome Network subsite of the DbI website (<http://usher.deafblindinternational.org>)

⁴ <http://en.wikipedia.org/wiki/Love>

⁵ http://1.brainyquote.com/quotes/authors/e/erich_fromm.html

⁶ en.wikipedia.org/wiki/John_Wilmot,_2nd_Earl_of_Rochester

The Importance of an Usher Syndrome Community¹

Usher syndrome is the most common cause of deafblindness. It is an emotionally devastating and socially isolating disease. The vision loss is progressive so families deal with an ongoing sense of grief. As vision declines in adults with Usher Syndrome, fewer of them are able to work in competitive jobs, causing a reported an 82% unemployment rate among those individuals. Such an example leads to a loss of identity and self-esteem leading to increased feelings of worthlessness and higher rates of depression and suicide.

But while the disease may convey a sense of worthlessness, people with Usher syndrome could not be more valuable to society. People with Usher syndrome are critical to finding treatments for Usher syndrome. Clinical trials on treatments for Usher syndrome would be suspended, abandoned, or simply not begun without the involvement of people with Usher syndrome. People with Usher syndrome are, quite literally, the cure!

Usher Families are Key

Families with Usher syndrome are THE experts on the disease. We experience Usher, day and night, month after month, in every possible life scenario and condition. We are the holders of the genetic cause of the disease. We raise the awareness and the money that provides the funding for research. Without the participation of Usher families, researchers would know nothing about the disease. Yet we are in constant danger of losing that connection between researchers and families because the scientific process is onerous. Researchers spend much of their time in the lab, studying proteins, observing mice, writing and reviewing papers. It is trial and error. It takes a long time to get from the lab to something worth testing in the clinic. So it is easy for researchers to become estranged from the very families they are working to help.

The nature of Usher syndrome doesn't encourage engagement from families either. Families are devastated by the diagnosis. Transportation is more difficult for individuals; it is hard to navigate crowds. Social interaction in dark or loud places is next to impossible. Families with Usher are prone to withdrawal from the rest of society.

The Usher Syndrome Coalition² seeks to build an Usher syndrome community that brings together the passion and expertise of families and prominent researchers from around the world in an urgent movement to find a cure. We serve as a vital

resource for people affected by Usher syndrome, their families and researchers. Our mission is to raise awareness and accelerate research for this most common cause of deafblindness. An Usher syndrome community is our most powerful tool.

International Symposium at Harvard Medical School

In July 2014 we saw the power of the Usher community at the International Symposium on Usher Syndrome held at Harvard Medical School. The Symposium, July 10 and 11, brought together the leading researchers in the world and Usher syndrome families from around the globe for a two day scientific conference and a one day family conference, July 12. It was a huge success. Families called it “life-changing”. Researchers said “the presence of families was excellent and achieved just the right balance and perspective.”

One of the main outputs from the symposium was a roadmap to help guide investment in Usher syndrome research. As part of the roadmap discussion the Usher Coalition asked the researchers in attendance what was the greatest barrier to treatment development. Their answer was unanimous and it was not what you might expect. They didn't say that they lacked funding or that there were insurmountable scientific hurdles. No, when asked the greatest barrier to treatment development, the leading Usher syndrome researchers in the world said “We are not in touch with enough families with Usher syndrome.” The reasoning is simple.

So where does the Usher Syndrome Coalition come into this?

The science is advancing. We are reaching the point where potential treatments can move from the lab to clinical trials. But clinical trials cannot be conducted without enough candidates. Candidates mean people with Usher syndrome and a huge pool of people is needed to find enough candidates for even a single trial. Just because you have Usher doesn't mean you are a candidate for a particular clinical trial. You have to have the right genetic cause, be of the right age, have the right amount of vision, and have the ability and the desire to participate. It takes hundreds of potential candidates to find just a few that are appropriate.

So one of the main goals of the Usher Syndrome Coalition is to identify everyone in the world with Usher syndrome. We maintain an international voluntary, Health Insurance Portability and Accountability Act (HIPAA)³ compliant, online registry⁴ that contains more than 700 families from 40 countries. The registry is available in several languages. Joining the registry doesn't mean a person is volunteering for clinical trials; it ensures that we can inform them about any trials. Researchers have no direct access to names in the registry. Information about trials is shared by the Coalition on behalf of the researchers. It is then up to the families to contact researchers if they are interested in a particular trial.

Keep in mind that everything about the disease, from the way the diagnosis is delivered to the psychosocial impact, drives families in to seclusion. So the Usher Syndrome Coalition also provides information and support to individuals and families affected by Usher syndrome. We run an annual Family Conference, the next of

which will be held in New Orleans on July 11, 2015. We have organized an International Family Network that connects families from over 20 different countries. We run monthly conference calls featuring talks from the world's leading experts live captioned and open to anyone that wants to attend. The notes from the call are read by almost 1500 people world-wide. We have a 5-star Facebook⁵ page with more than 1,000 likes, a Twitter⁶ account with hundreds of followers, and a blog⁷ called 'the most thoughtful exploration of Usher syndrome on the internet.'

The Usher Syndrome Coalition is there for families because families are critical to finding treatments. The Usher Syndrome Coalition is there for researchers because researchers need a means to connect with families. But most importantly the Usher Syndrome Coalition aims to provide a better quality of life for people with Usher syndrome by building a community that encourages ownership of the scientific process and provides them with the hope they deserve.

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¹ Article based on presentation at Dbi Usher Network Pre-Conference, Belfast, November 03-04, 2014

² usher-syndrome.org

³ en.wikipedia.org/.../Health_Insurance_Portability_and_Accountability_Act

⁴ usher-registry.org

⁵ <https://1.facebook.com/UsherSyndromeCoalition>

⁶ <https://twitter.com/ushercoalition>

⁷ usher-syndrome.org/index.cfm/event/blog

Self-Regulation of emotion in CHARGE Syndrome

Benjamin Kennert¹, Maria Ramirez², Timothy S. Hartshorne³, Gail Deuce⁴, Jude Nicholas⁵

"I am starting to be stressed by this article. I wanted it completed some time ago. As my emotions get on edge, I become a bit grumpy, and find that I am less pleasant with the people around me, particularly my co-authors. As I notice my feelings become more aroused, I remind myself that this is a group process, we are all busy, we are making progress, and it will be good. Telling myself these things helps me to relax a bit and calm myself down. I have lowered my level of emotional arousal and am better able to focus on the task at hand. I have self-regulated my emotions".
(Tim Hartshorne)

The self-regulation of emotions is a process that involves the analysis, control, alteration, or prevention of emotional expression and experiences that are adaptive for a situation. Emotion self-regulation may occur at different times relative to the

emotional response. Emotions may be regulated either by manipulating antecedents to emotional response tendencies or by manipulating responses to those tendencies (Gross, 1998).

When focusing on manipulating the antecedents to emotional response, self-regulatory strategies may include situation selection, situation modification, attention deployment, or cognitive change (Gross & Thompson, 2007). Situation selection refers to approaching or avoiding certain people, situations, or environments on the basis of their likely emotional impact. This strategy requires an understanding of emotional responses that can be expected from interaction or lack of interaction with these people, situations, and environments. For example, talking with a certain person always leads to heightened, negative emotion, and so you avoid that person. During situation modification, an individual modifies the environment to alter its emotional impact. If you cannot avoid talking to that person, you might bring a friend along with you to help you stay calm. Attention deployment is turning one's attention away from something in order to influence emotions. You are in a situation where there is this person you do not want to talk with, and so you make sure that you are constantly engaged in talk with others. Cognitive change refers to the way with which we mentally appraise a situation to alter its emotional significance. This may be done by changing how we think about the situation or about our capacity to manage the demand it poses. Cognitive change requires strong cognitive self-regulation skills. For example, one can mentally prepare for having a conversation with someone and tell oneself that it will be "no big deal."

When focusing on the emotional response itself, self-regulation strategies include those that intensify, diminish, prolong, or curtail ongoing emotional experience, expression, or physiological responding (Gross, 1998). For example, after a challenging conversation with a person, saying to oneself "That is an idiotic position to take, or thing to say, but I do not have to be bothered by it," could reduce emotional arousal.

It is important to note that emotion regulation is used not only to reduce a negative level of arousal, but also to intensify or prolong. In order to increase one's motivation for doing well on an exam, a person might actively seek to increase emotions of anxiety.

When discussing the self-regulation of emotions, it is important to provide an understanding of what we mean by the term 'emotion'. Emotions occur when an individual evaluates internal or external emotional cues, and this evaluation triggers a coordinated set of behavioral, experiential, and physiological emotional response tendencies (Gross, 1998). These tendencies may be modulated, and this modulation gives final shape to outward emotional responses. During emotion self-regulation, a person may increase, decrease, or maintain positive and negative emotions (Koole, 2009).

An interesting study conducted by Barrett, Gross, Christensen & Benvenuto (2001) showed that individuals with more highly differentiated and more intense negative emotional experience reported greater emotion regulation, while positive emotional differentiation and intensity were unrelated to emotion regulation. Sometimes our emotions can be kind of a mess and difficult to sort out, but for those individuals who

are able to be clear about what they are feeling, particularly in the case of negative feelings, self-regulation appears to be easier. This suggests that the regulation of emotions might be considered separately for positive and negative emotions. This may be because negative emotions tend to have more immediate consequences if they are not dealt with.

Developmental studies have shown self-regulation to play a crucial role in children's social competence (Cicchetti, 1994; Eisenberg, Guthrie, Fabes, Shepard, Losoya, Murphy, Jones, Poulin & Reiser, M. (2000). In other words, impairments in emotion self-regulation affects children's capacity to regulate their emotions, and emotion dysregulation in turn leads to social difficulties. Difficulties with emotion regulation may result in psychosocial problems, such as high levels of negative affect and escalation of anger, aggressive-disruptive behaviors, antisocial behaviors, addictions, suicidal ideations, and mood disorders such as depression (Wyman, Cross, Brown, Yu, Q., Yu, X. & Eberly (2010). Emotion self-regulation recruits less cortical activation in the ventral-prefrontal cortex with age, suggesting that individuals are better able to regulate emotions with age and development (Lamm & Lewis, 2010). Activation of the ventral medial prefrontal cortex is associated with successful suppression of emotional responses to a negative emotional signal (Hänsel & Känel, 2008).

Emotion self-regulation skills closely relate to the other dimensions of self-regulation: physiological, behavioral, and cognitive. According to Saarikallio (2010), the regulation of emotion is accompanied by the regulation of physiological and behavioral processes related to the specific emotion. Thinking about the situation one is in and what one wants out of the situation, influences the emotional arousal. Thus, improved cognitive self-regulation will result in a greater ability to assess emotional situations, monitor emotional situations, and respond using cognitive or meta-cognitive strategies. In return, a stronger ability to self-regulate emotions will result in a stronger ability to mentally assess a situation, and respond with appropriate behavior.

Self-Regulation in CHARGE Syndrome

It is often difficult for children with severe disabilities, including CHARGE, to develop self-regulation skills, and challenging emotional outbursts are common. Conditions that may contribute to difficulty with emotion self-regulating include multiple sensory impairments, difficulty and delay in language development, executive dysfunction, communication difficulties, and poor health and pain. Communication and sensory information are important for learning how to regulate through experiences and feedback, and it is likely that impairments in these areas contribute to poor self-regulation among individuals with CHARGE. Hearing impairment may cause difficulty processing new information, answering questions, and following directions, while vision impairment may cause difficulty in processing facial expressions, imitating socially acceptable behavior, and focusing on other visual stimuli. Learning how to interpret and express emotions is highly dependent on how the experience is

shaped through modeling, which is reduced by communication and sensory problems.

A study by Hartshorne, Nicholas, Grialou & Russ (2007) explored executive dysfunction among children with CHARGE Syndrome using the Behavior Rating Inventory of Executive Function (Gioia, Isquith, Guy & Kenworthy, 2000). The study confirmed the presence of executive dysfunction in over half of children with CHARGE. These children displayed difficulty with items measuring shifting from one activity or focus to another, tracking their own behavior and its effect on others, and controlling their impulses and terminating behaviors as required (Hartshorne et al., 2007). The authors report that about one third of individuals had difficulty on the emotional control scale of the instrument, and half had clinical scores on the behavioral regulation index. Thus it appears that individuals with CHARGE may have some difficulty with self-regulating their emotions. Due to the many challenges faced by these individuals, it may be difficult for someone with CHARGE to understand when they are feeling an emotion, what it is that they are feeling, and how to regulate or control it. As DeGangi (2000) points out, early deficiencies in self-regulation may lead to challenging behavior, and deficits in attention and inhibition.

Intervention

An important step in teaching children to self-regulate their emotions is first teaching those children what it means when they are feeling an emotion. Teaching a feeling vocabulary to a child may be useful here. This could be done using scaffolding techniques, or breaking the process of recognizing and responding to emotions down into smaller, discrete tasks. Modeling of emotions and how to respond in specific situations, as well as using role-play activities, is a useful method when teaching feeling words and how to recognize each feeling. When modeling emotions, mirroring feelings using exaggerated facial and body movements may help children understand how to recognize emotions in other people. The use of differential reinforcement can be very effective in teaching appropriate emotional responses by rewarding positive, appropriate emotions in a situation and reducing negative, inappropriate emotions. It is important to take advantage of opportunities to teach a child feelings when they are noticeably feeling an emotion. When you know that a child is feeling happy, angry, or frustrated, for example, this could be a good time to help them understand that emotion by modeling, and by showing them appropriate responses to that emotion. Concrete aids may help children understand or express emotions as well. Examples of concrete aids may be using a color or face chart to describe feelings, or using a 'traffic light' to describe the strength of the feeling. For children with more significant difficulties, repetition may be important when teaching about feelings.

While teaching the child a feeling vocabulary is useful, strategies for reducing the strong, negative emotions are necessary. When self-regulating emotions, an individual may either alter or avoid triggers that produce an emotional feeling, or alter the emotional feeling after it occurs. By helping children to recognize situations in which they are likely to have a strong feeling, you may begin to teach them how to

engage or avoid those situations, or limit their emotional effect. When dealing with a feeling after it occurs, practicing how to respond to feelings with the child or walking them through how to deal with the feeling will likely be helpful. It is also important to teach the child calming techniques when they are feeling a negative emotion. Calming techniques may include breathing techniques, exercise or mindfulness techniques such as meditation, Tai Chi, or yoga, or having attachment or stress reduction objects available. Having a 'safe place' available for the child to go to during an emotional response may help that child calm down. For children with significant difficulties, maintaining a consistent environment and routine may also be important to reducing inappropriate emotional responses. However, it is also important to teach the child how to respond in different situations and with different people, and to help the child form secure stable relationships with as many people as possible. This will help the child's self-regulation skills to generalize to new environments, situations, and people.

Case example

Before starting at a new residential school, Sarah, age 14 and diagnosed with CHARGE syndrome, had been excluded from school for two years as a consequence of her difficult behavior. Some of Sarah's issues were:

- Regular emotional outbursts
- Unable to tolerate being with her peers and being very easily annoyed or upset
- Inappropriate attempts to initiate interactions
- Saying hurtful and inappropriate things to others
- Being very angry with herself, with a negative self-image and self-esteem
- Lack of awareness of her own emotions – Sarah had an analytical understanding but was not able to link this information to what she herself was feeling
- Unable to negotiate or tolerate when things did not go her way
- Difficulty coping with the unexpected
- Difficulty controlling her own behavior and impulsivity (saying "I just want someone to make me stop.")

A full team of practitioners were involved in developing a program to support Sarah, which was regularly monitored and strategies developed or adapted in response. Some strategies developed to support Sarah in this area were:

- Providing Sarah with her own space, with a gradual reintroduction to being in the room with her peers.
- Ensuring a consistent routine, with any changes kept to a minimum and every effort undertaken to prepare Sarah for changes.
- A highly individualized curriculum, using Sarah's strengths and interests to build her confidence and self-esteem.
- Modeling and discussing how Sarah might respond in different social situations. For example, in preparation for attending a local youth club, staff

discussed with Sarah what was likely to happen; how to respond if someone said hello; how to initiate a conversation; how to move away if the situation became too much. A picture-board sequence was used to provide a concrete visual cue.

- Sarah struggled during role play, and so plastic characters were used. Social scenes were enacted, exploring different ways a person might respond in each situation. This was also used to re-enact situations that Sarah had found difficult, exploring what might have been a more positive way of managing the situation.
- Weekly yoga was introduced to help Sarah develop and regulate her physiological state more effectively. ‘Deep belly breathing’ became a useful strategy for Sarah to use independently to help her calm.
- Pet therapy provided Sarah with the opportunity to enjoy caring for and nurturing Darcy the dog.
- Discussing Sarah’s own emotional state. Initially she found this extremely difficult, and staff who knew her well, labeled her emotional states for her (e.g. “I think you are feeling a bit frustrated,” etc.). A break though came when Sarah was in conversation about a forthcoming trip and suddenly said: “I’m feeling something”. Unable to label what she felt, the supporting adult explained she was probably feeling a bit excited and also anxious.

Now 18, it has taken time but Sarah has made huge progress. She is a much happier young lady who is fully included in her class and making real friendships. She is much more socially aware and able to socially engage, sharing a joke and coping with gentle teasing. Sarah is more in touch with her own emotional state and is better able to regulate her emotions and behavior. Very importantly, Sarah is now able to talk about how she is feeling which has proved to be vital as she has undergone a period of ill-health requiring hospitalization and surgery. Overall she has grown in confidence and is looking forward to moving on to college in the near future.

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St. Francis Foundation (Stiftung St. Franziskus) hosts International Congress 'Deafblind Education Meets Medicine'

The size of the population of people with deafblindness should not determine the amount of effort expended on improving quality of life outcomes.

More than 180 national and international professionals, including speakers from five countries, gathered at the St. Francis Foundation (Stiftung St. Franziskus)¹ in

Heiligenbronn, Germany. Over September 19 and 20, 2014, these representatives from the field of deafblind education examined multiple perspectives, including medical considerations, through lectures and workshops.

In opening the conference, Foundation Director Hubert Bernard quoted Helen Keller: "Blindness separates us from things, deafness from people". In her honor, participants released balloons bearing inspirational sayings into a bright blue sky. The gathering was enriched by an appearance by the Heiligenbronn School's band, 'No Guggies', who thrilled the audience with their performance of the song "Only For You" from the Wise Guys².

The foundation has been developing and expanding its offerings for people with deafblindness and dual sensory impairment in an effort to become a center of excellence in the field. The final meeting of the European Union project 'PropäK' was expanded to include the international congress "Deafblind Education Meets Medicine", which was co-sponsored by the Epilepsy Center in Kehl-Kork, Germany⁴. Consequently, additional professionals and representatives of government ministries and agencies were also in attendance.

The Minister of Social Affairs from Baden-Württemberg, Katrin Altpeter, sponsored the Congress. Verena Bentele, the new federal Disabilities Commissioner also greeted the participants. Assistant Director of the Ministry of Social Affairs, Petra Clauss recognized in her welcoming address to the Congress: "We are paying close attention to the interdisciplinary exchange that is being cultivated here." Related to the current government coalition agreement in Berlin and discussions about recognizing the category TBL (the German abbreviation for Deafblind) on disability identification cards, she assured the audience that people with deafblindness and dual sensory-impairment, as a specific population, have gained political recognition.

Special education should exclude no one

Dr. Erwin Löhle, professor at the HNO Clinic in Freiburg, Germany⁴, reported that the issue of deafblindness has been introduced into the political sphere through the efforts of the National Working Group on Deafblindness. Assistant Director Sönke Asmussen from the Baden-Württemberg Ministry of Cultural Affairs defended the approach of special education with the slogan "From Child to Program". The size of the population of people with deafblindness should not determine the amount of effort expended on education and improving quality of life outcomes. The success of education for children with multiple disabilities and deafblindness cannot be compromised: "Special education should exclude no one."

Atypical reactions to pain

Dr. Peter Martin, Clinical Director of the Séquin Clinic at the Epilepsy Center in Kehl-Kork, Germany, who has also worked for many years with residents of Heiligenbronn, presented a medical perspective. He discussed the diagnosis of pain in people with severe, multiple disabilities: "Manifestations of pain must be taken

seriously; Pain is a warning sign.” He urged greater sensitivity in working with this population, especially because their reactions to pain are not always typical.

Other presentations

The director of the foundation’s deafblind program, Roland Flaig, did a presentation about the Heiligenbronn center of excellence, which serves people throughout the German state of Baden-Württemberg, and the networking project PropäK. Deafblind educator and Coordinator of Deafblind Services at the foundation, Dr. Andrea Wanka, emphasized the importance of relationship-building, shared experiences and openness to emotional exchange in communication in general, but especially with people with multiple disabilities, as seen in CHARGE Syndrome.

Deafblind pastor Peter Hepp from Rottweil, Germany, along with a group of congress participants, led an impactful prayer to St. Patrick using gestures and touch. Ulrike Broy, Director of Deafblind Consulting Services, spoke in her presentation “I see myself speaking” about video analysis as a tool for reflection, and communicative musicality as a method of getting to know a deafblind partner. Professors Markus Lang and Klaus Sarimski and their colleague Elisa Keesen from the Heidelberg School of Education presented the results of a survey about educational services for children and adolescents with dual sensory impairment (vision and hearing). More than 80% of the cases of deafblindness with severe intellectual impairment had never been diagnosed. The size of this target group is most likely underestimated. The presenters called for greater focus on the issue of deafblind education.

Dr. Johannes Fellingner, Director of the Institute for Neurology of Senses and Language in Linz, Austria, presented evidence that people with dual sensory impairment are often not correctly diagnosed as such. In their social connections, their hand becomes an important tool for relationship building and communication, but one which requires additional time for processing.

The program included eleven workshops that were repeated throughout the congress. Many critical questions about communication and identity were addressed and expanded upon, such as the use of cochlear implants and audiology. In his closing remarks, Foundation Director Michael Wollek declared the congress a success and predicted that the friendly atmosphere of the event would carry over into many other areas of practice.

Ewald Graf, Public Relations, Stiftung St. Franziskus
Translated by Jim Witmer

¹ <http://www.stiftung-st-franziskus.de>

² <https://www.youtube.com/watch?v=0yVprFDmezA>

³ www.epilepsiezentrum.de

⁴ www.hno-arzt-freiburg.de

Conclusion of the First European Union Project on Deafblindness – ‘PropäK’

Exchange and innovation increased

What began in Heiligenbronn has ended here, as well – at least for the time being. The EU-sponsored project to develop a network for professionals in the field of deafblindness in German-speaking countries, named “PropäK” (an abbreviation of the German words for ‘professionalizing educational concepts’), concluded at a final session in Heiligenbronn, Germany, where it had initially begun¹. Although a follow-up project, “PropäK II”, has already been applied for, the discussion here was about “PropäK I”, that is now completed.

The organizations participating in this Leonardo Program-funded networking project included the St. Francis Foundation (stiftung st. franziskus), which coordinated the project, as well as the Deafblind Center in Hannover, Germany, the Foundation for the Blind in Würzburg, Germany, the Dutch foundation Kentalis, the Swiss Tanne Centre of Competence for the Deafblind and the Austrian Relief Organization for People Who Are Deafblind and People with Significant Vision and Hearing Impairments. Over the course of the project, Oberlinhaus in Potsdam, Germany, and the University of Groningen in the Netherlands also joined as partners.

Special competencies required

Roland Flaig, the director of disability services at the St. Francis Foundation in Heiligenbronn outlined the formation and course of the EU-sponsored networking project. Working with people with deafblindness and dual sensory impairment requires specific knowledge and competencies. However, due to the distances between them, the exchange between international specialists had previously been very difficult.

Meaningful momentum

The project partners set as their goal the improvement of initial and ongoing staff training. The original idea, which began in the still-new deafblind center in Heiligenbronn, received wide-spread support. “The effort was worth it”, said Roland Flaig in the closing session, “the work has been enriching and created meaningful momentum.” The exchange of knowledge and experiences has increased: “As I see it, our work with children, adolescents and adults with deafblindness and dual sensory impairment has become more transparent, the exchange more international, the relationships closer and the practice more firmly rooted in theory.”

Meetings in four countries

The core team, under the direction of Heiligenbronn deafblind services coordinator, Dr. Andrea Wanka, reviewed the course of the project since its beginning in September 2012. Innovative approaches and concepts have been discussed and further developed. A 'search-offer' database was established to enable the exchange of ideas. The ground was laid for a common training program. Transitions from school to work were also discussed. Meetings were held in Heiligenbronn and Hannover (Germany), Vienna (Austria), Langnau (Switzerland) and Kentalis (Netherlands).

Shoulder to shoulder

The Dutch partners presented a retrospective on the project with a slideshow accompanied by the song "Schouder aan Schouder" (Shoulder to Shoulder), which captured the emotional closeness that has developed among the participants of the project. During the closing session, the directors and leaders of the assembled organizations expressed their thanks to the Heiligenbronn foundation for the project's formation and organization. Thanks to this relatively new deafblind center, "new passion has been reawakened for all of us." Gifts for the organizers further underscored their gratitude.

Foundation Director Hubert Bernhard also added his thanks to the Heiligenbronn team. The foundation "is proud and grateful for your dedication" and for the inspirational atmosphere of the project.

Ewald Graf, Public Relations, Stiftung St. Franziskus
Translated by Jim Witmer

¹ See article reporting on the 2012 session in DbI Review, Edition 50, January 2013

Touch, explore, create:

Students prove artistic vision means so much more than sight. By ANNA MILLER

Fourteen-year-old Mike dips a long asparagus spear into a cup of red paint. He transforms the vegetable into a paintbrush, carefully making bold crimson lines on a pristine white piece of paper. He then takes a turn with broccoli, stopping to ponder the texture in his hands before bouncing it contentedly to create splashes of vibrant purple.

“Art is a really great way for him to express himself, relax, unwind and just go for it,” said Sara Martello, an instructor in Perkins Deafblind¹ creative arts program, who orchestrated the painting-with-vegetables-and-fruit project.

Mike isn’t the only one enjoying the art-making process. All of his classmates are exploring the materials as well, discovering textures that they may not have encountered before.

“Art class is about the whole experience, rather than the finished product,” Martello said. “It’s all about touching different mediums and experiencing something new.” At a nearby table, Alexis, 7, grins with delight as a teaching assistant guides her hand to roll a blue-hued ear of corn across a page. She giggles as she feels the kernels and oozing paint beneath her fingers.

Making art tangible

Perkins art teachers are frequently asked by the public, “How do you teach students who can’t see to make art?”

The answer, they say, is simple: make the art process a tactile, multi-sensory experience. Use materials that a child who is blind, deafblind or visually impaired can explore through touch or smell. That can mean working with clay, making textural collages and quilts, and even finger painting with pudding.

“Art instills in the students a sense of self-esteem, and they enjoy being able to work with their hands to create something,” said Lower School art teacher Rocky Tomascoff. “In here, we’re working on many of the same goals, skills and objectives that they are in other classes; it’s just with different materials.”

Nowhere is the diversity of materials more plentiful than in Tomascoff’s classroom. The cabinets are chock-full of neatly stacked containers holding art supplies of all colors, shapes, sizes and consistencies. One shelf is devoted to a range of fine-grained colored sands; another contains a variety of split peas, macaroni, seashells and smooth sea glass. One cupboard is filled with birdseed, pinecones, fragrant dried flowers and aromatic herbs. There’s even marshmallows, for when art projects – or a student’s imagination — calls for that spongy, puffy texture.

On one particular morning, Lower School students Amalia and Ethan, both 11, work on artistic journal entries about their week. Noting recent ferocious thunderstorms and unpredictable weather, Amalia decides to cut a piece of smooth, shiny mylar to create a lightning bolt.

“I’m going to make the lightning big and long!” she said enthusiastically, leaning in close to examine her work. She cuts out shapes for the sun and glues on lightly teased, billowing cotton balls for the clouds.

At a nearby table, Ethan recreates on paper a new route that he recently learned to navigate across campus. He chooses red felt to represent a school building and thick silver tape to construct the sidewalk. Tomascoff initially guides Ethan’s hand as he uses the scissors, and then she stretches the cloth out for him to divide down the middle. Following her instructions, Ethan trims a few inches of fabric.

“Good!” said Tomascoff encouragingly. “And cut!”

Ethan, completely focused on the task at hand, snips away until a large square is cut out. He feels around for the sticky glue, and laughs with Tomascoff as he presses the felt flat onto the page.

Although Ethan and Amalia are working on art projects, they are practicing important skills along the way. They make their own choices, communicate ideas and gain independence while using tools. Both think about spatial concepts and solve problems that arise.

Students in the Lower School, Secondary and Deafblind programs all benefit differently from art classes. Teachers have found that nonverbal students are especially motivated to use symbols and gestures to communicate while making art. Other students experience the soothing, therapeutic nature of creating artwork, they said. It helps anxious students to relax, breathe and just focus on the task at hand. For many, art class also happens to be a lot of fun.

For students to have a successful and positive experience, teachers adapt art projects to fit each child's abilities. If a student is unable to maneuver a paintbrush against a sheet of paper, an instructor may encourage him or her to flick paint and fluffy shaving cream on a canvas instead. Students with low muscle tone also can develop stronger hands and fingers during the creative process.

"It's great when you are working with clay, because you have to squeeze it, roll it and pinch it," said Tomascoff. "You strengthen those muscles. And there's the added bonus, because at the end of the day they have an art project that they can feel proud of."

Award-winning artists

Students often take their projects home to share with their families and friends. But in addition, the Lower School and Deafblind Program each host an annual art show where everyone is invited to celebrate the young artists' creations.

Exhibit-goers are dazzled by hand-drawn superhero comic books, endearing sculptures and textural paintings in every shade. Each piece of artwork expresses the maker's personality, and highlights students' imaginations and abilities.

"People are very impressed that our students are able to produce such wonderful artwork," said Martello. Most importantly, she added, students feel a great sense of accomplishment. "You can see in all of their faces that sense of pride. 'Look what I can do!'"

Student talent is also gaining recognition off campus. Perkins students recently received top honors at "A Different Vision" art exhibit, a juried tactile show held at the Plymouth Center for the Arts in Plymouth, Mass. Judges from Boston's Museum of Fine Arts selected Perkins' student work from more than 90 submissions by sighted and non-sighted artists throughout the state.

Among them was Matthew, 16, a student in the Deafblind Program. He wowed the judges with "Feel the Rainbow," a meticulously constructed mosaic that earned him first place in the mixed-media category. Matthew had diligently worked on the project for two weeks, often carefully arranging the composition with a huge smile across his face.

“It was wonderful for Matthew to have that moment with his artwork hanging on the wall with the big blue ribbon,” said Martello, beaming with pride as she recalled the exhibition’s award ceremony. “Everyone was cheering for him, and he was over the moon.”

Instructors celebrate students’ every accomplishment, whether he or she wins an award or reaches out to touch a floret of broccoli for the first time. It’s all personal growth.

“Art is a great way for students to express themselves and show what they are capable of doing,” said Martello. “It offers them a chance to shine.”

- [perkins.org/perspectives/features/touch-explore-create.html](https://www.perkins.org/perspectives/features/touch-explore-create.html)

¹ Perkins School for the Blind is a large corporate member of DbI.

News and Resources from the Latin America and Caribbean Regional Office

of Perkins International

We are pleased to share some of the developments of resources that can help to spread the theme of deafblindness and multiple disabilities through the Spanish speaking population.

This year we have developed specific publications on topics of interest to families, professionals and officer governments working with children and young people. We could reach this goal with the constant support of the regional governments and private organizations such as Fundación Once para América Latina (FOAL) and Christoffel Blindenmission (CBM) .

We are proud to share our recent Documents:

1 Transition to Adult Life of Youth with Multiple Disabilities and Deafblindness¹. This resource highlights the main aspects of the transition process and shares some best practices in Latin America.

2 Guide for Inclusion of Children and Young People with Deafblindness and Multiple Disabilities in Argentina². This guide focuses on the best practices which need to be considered to guarantee successful inclusion.

3 Manual Physical Education³: This manual describes proper methods, materials and equipment to be used with our population involved in Physical Education. It has a chapter which focuses on health prevention. The manual is useful for teachers and families.

4 Manual Technology⁴. This guide provides strategies for teachers and parents to use technology in the daily life for a child.

Also from our website in Spanish, we have added a new section called 5 “Virtual Classroom”⁵, a place to share online courses, webinars and educational videos on specific topics. You can look up for new resources and e-learning at: <http://l.perkinsla.org/aulavirtual.php>

All these resources are aligned to meet the goals for education in the twenty-first century through engaging and working collaboratively with professionals, family, educational authorities and the governments throughout the region.

For more information contact Perkins International Latin America at: hperkins@fibertel.com.ar

¹ l.perkinsla.org. Perkins Latin America is a small corporate member of DbI

² l.foal.es

³ l.cbm.org. CBM is a large corporate member of DbI

⁴ See article in DbI Review Edition 53, July 2014

⁵ See article in DbI Review Edition 53, July 2014

Michael Collins of Perkins named to Hall of Fame

for Leaders and Legends of the Blindness Field

The late Michael T. Collins was inducted into the Hall of Fame for Leaders and Legends of the Blindness Field in Louisville, Kentucky, on October 17, 2014. Collins, who passed away in 2008, led education programs for children who are deafblind at Perkins School for the Blind¹ for 30 years, including the supervision of Perkins’ renowned Deafblind Program. Most notably, he launched Hilton/Perkins International to expand deafblind education. Under his leadership, the program grew from serving a few hundred students to reaching tens of thousands of children, families and educators in 67 countries. He traveled the world championing education and government policies to improve opportunities for children who are deafblind and blind with additional disabilities.

“Mike Collins represented what is best about humankind,” says Dave Power, CEO & President of Perkins. “He saw a need and went about the difficult and quiet work of solving it for three decades. By making a positive difference in the lives of children who are deafblind in the developing world, he enriched the lives of all of us. This is a fitting honor and remembrance.”

In addition to his work with Perkins, Collins also led Deafblind International, served on the board of the International Council for Education of People with Visual

Impairment and founded the National Coalition on Deafblindness. He received the distinguished Perkins' Annie Sullivan Award, Deafblind International's Lifetime Achievement Award and their Distinguished Service Award. Collins studied theology at St. John's Seminary in Boston and earned a master's degree in Special Education from Boston College.

Collins will be most vividly remembered for the way he touched the lives of individual children. "His love for children with multiple disabilities and his deep understanding of their needs was evident when he visited programs and dangled children on his knee." Nandini Rawal, project director of the Blind People's Association in Gujarat, India.

The Hall of Fame² is dedicated to preserving the tradition of excellence manifested by specific individuals through the history of outstanding services provided to people who are blind or visually impaired in North America. It is housed at the American Printing House for the Blind (APH) in Louisville, Kentucky, but belongs to all. Read more about Mike Collins in Perkins Perspectives³ magazine.

Perkins reaches nearly a million people each year in 67 countries providing education, services and products to help people who are blind or deafblind build more productive and meaningful lives. Founded in 1829 as the first U.S. school for the blind, Perkins advances its mission through its various divisions: School for the Blind, International, Library, eLearning, and Products. Learn more at [I .Perkins.org](http://www.perkins.org).

¹ www.perkins.org. Perkins School for the Blind is a large corporate member of DbI.

² www.aph.org/hall/about.html

³ www.perkins.org/perspectives

Dr. Walton Alfonso "Aubrey" Webson¹, MD

Named Antigua and Barbuda's Permanent Representative to the United Nations and Head of the Antigua and Barbuda Office in New York

Press Release: New York, NY, 28th September, 2014...

...Prime Minister of Antigua and Barbuda the Hon. Gaston Browne has announced that Dr. Walton Alfonso "Aubrey" Webson has been appointed as the country's Permanent Representative to the United Nations as Ambassador Extraordinary and Plenipotentiary.

In a letter to Secretary General of the United Nations, Prime Minister Browne said the Dr. Webson is an outstanding citizen of Antigua and Barbuda who has made significant contributions to the social development of people with disabilities around the world.

"As a visually impaired individual, Dr. Webson has worked extensively in Latin America, the Caribbean and Africa, helping to shape educational services for children with disabilities. He has also supported governments and social workers in

policy development. I am confident that he is very suitable for the responsibilities entrusted to him,” outlined Prime Minister Browne.

Prime Minister Browne also introduced Dr. Webson to Antiguan and Barbudans living in New York during a town hall meeting on Friday in the Bronx. He told the over three hundred nationals in attendance that Dr. Webson will be the Head of the Antigua and Barbuda Office in New York with the various department heads reporting to him under a new arrangement which sees the Tourist Office, the Consulate and the Mission to the UN being merged as a single unit.

During the town hall meeting, Prime Minister Browne also announced that an offer has been made to Dr. Dave Ray to be the Diaspora Liaison Officer creating a link between the Diaspora and the government. He said the move is designed to strengthen the relations with Antiguan and Barbudans in the Diaspora and to have them play an active role in the development of their homeland. He said the aim is to have Dr. Dave Ray, as Diaspora Liaison Officer, capture the issues of Antiguan and Barbudans in the Diaspora and he will then liaise with the Antigua Office in New York headed by Dr. Webson.

Dr. Webson’s appointment as Permanent Representative to the United Nations takes effect from 1st November, 2014.

¹ Dr. Webson was a member of the DbI Board representing Perkins School for the Blind, a large corporate member of DbI.

India to roll out vaccine against Rubella

In a long-awaited development, India’s Prime Minister has announced that a vaccine against rubella has been added to India’s Universal Immunisation Programme.

As readers of DbI Review will not need to be reminded, if a pregnant woman catches rubella then the effects can be devastating. A child born with Congenital Rubella Syndrome (CRS)¹ may have hearing and vision impairments, heart problems, learning disabilities and other health problems.

To prevent women who are pregnant from catching rubella from someone else the rubella virus needs to be eradicated from the population as a whole – and the only way to do this is by vaccination. It is estimated that nearly 2,000 babies are born with congenital defects each year in India. Therefore this announcement of an immunisation campaign is a huge boost in the battle to eradicate rubella.

The numbers of young women in India who are susceptible to rubella infection and of children born with congenital rubella are hard to evaluate. However Indian medical experts have stated in the British Medical Journal² that ‘Rubella is endemic in India’.

The rubella vaccine is one of four new vaccines to be added to India’s immunisation programme³ – the others being Japanese Encephalitis, rotavirus, and polio (injectable). With these new vaccines, India’s Universal Immunization Program⁴ will

now provide free vaccines against 13 life threatening diseases, to 27 million children annually.

Prime Minister Narendra Modi said: “India is committed to tackling child mortality and providing health for all. Strengthening routine immunisation is an essential investment in India’s children and will ensure a healthy future of the country.

“Many of these vaccines are already available through private practitioners to those who can afford them. The government will now ensure that the benefits of vaccination reach all sections of the society, regardless of social and economic status.”

Akhil Paul, Director of Sense International India⁵, said: “We are delighted that the Indian Government taken this step. Rubella can be a devastating condition and we hope that, like in many other parts of the world, the threat of rubella will recede once the immunisation programme is fully established.”

The World Health Organisation estimates that there are more than 100,000 children born with birth defects as a result of CRS every year in developing countries.

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¹ 1 .who.int/mediacentre/factsheets/fs367/en

² 1 .bmj.com/content/349/bmj.g4844/rr/761918

³ http://1 .gavi.org/Library/News/Statements/2014/India-to-introduce-four-new-vaccines/

⁴ 1 .gavi.org/about/governance

⁵ 1 .senseintindia.org. Sense International India is a small corporate member of DbI.

⁶ 1 .who.int

Rubella vaccination spreads

There has been encouraging progress in the introduction of the rubella vaccine – with important initiatives in Tanzania and India this autumn.

The World Health Organisation estimates that more than 100,000 children are born in developing countries each year with birth defects as a result of Congenital Rubella Syndrome. Currently just over 130 countries out of 193 deliver the rubella vaccine.

Mass VACCINATION in Tanzania

In October, 21 million children were vaccinated against rubella and measles in Tanzania. The campaign was one of the largest public health campaigns ever delivered in Tanzania and East Africa. Tanzania has a population of 45 million and is the sixth most populated country in Africa.

The campaign targeted all children aged between 9 months and 15 years old. More than 12,000 schools and 6,600 health facilities were involved in just over a one-week period, making it a huge logistical challenge. Thousands of health care professionals, volunteers and NGOs were involved in helping to spread the word and getting the vaccine out. Reaching rural communities and ensuring that parents understand the dangers of rubella is key to uptake.

For the parents of children like Chausika, this is welcome news. Chausika is one of seven children and was born with congenital rubella syndrome. She has no sight or hearing and needs round the clock care from her mother. As a result, her mother is no longer able to work and this has affected the family's income and plunged them in to poverty.

The vaccine is being delivered as part of the WHO's implementation of the Global Measles and Rubella Strategic Plan 2012 – 2020¹.

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¹ www.who.int/.../Measles_Rubella_StrategicPlan_2012_2020.pdf

Educating deafblind children within their communities in East Africa

Stevie Kent, Senior Programmes Manager at Sense International

For the first time ever, deafblind children in East Africa are accessing education from their local mainstream school. This is no small milestone given that until now governments and teachers alike insisted that children with complex disabilities like deafblindness cannot be educated through the mainstream system.

A few lucky children were enrolled in special schools but the vast majority simply missed out on an education. To solve this problem Sense International (East Africa)¹ had to think outside of generally accepted practices and engage parents, teachers, and government officials to innovate together – and find a solution to put an end to the right to an education for deafblind children being systematically violated.

The result of this combined effort was the development of Community Based Education (CBE) for deafblind children, with a pilot programme now being implemented in Kenya, Tanzania and Uganda – funded by the Big Lottery Foundation in the UK².

Existing special schools have been transformed into resource centres with multi-disciplinary teams of educational and health professionals assessing deafblind children and, with the input of parents, developing Individual Education Plans for each child.

Additional special needs teachers have been posted to each resource centre in order to go out into communities and train local mainstream teachers and parents how to provide holistic education and therapy for deafblind children at home. A home-based curriculum has been specially developed in each country, paving the way for similar approaches for other excluded groups of children.

What is so unique about this approach is that unlike most Community Based Rehabilitation approaches, where NGOs are used to deliver home services, this approach utilises existing state infrastructure and human resources to provide non-formal education but following a standardised curriculum and set of quality standards. No longer will home-based services have to come to an end when project funding runs out.

This pilot programme will reach 900 deafblind children and their families (5,400 people), and is building the capacity of nine resource centres, 99 special needs teachers and 900 mainstream teachers to deliver CBE. The mainstream teachers' role is key as they support parents by helping them to make lessons for the children out of everyday activities, based on the curriculum and Individual Education Plans. The results of this pilot programme are impressive but Home Based Education is only the first stage. Once the deafblind child has developed sufficient communication skills, the mainstream teacher will gradually start to include them in school activities and lessons.

We are working with governments to provide classroom teaching assistants to facilitate this next stage in the process. Ultimately our aim is for every deafblind child in all regions of East Africa to access an appropriate and quality education from within their own communities – so that children no longer miss out on the education and therapy they need to achieve their full potential in life.

For more information about Sense International, contact Sense International at info@senseinternational.org

Rehema

CBE has already changed ten-year-old Rehema's life. She has been enrolled at Mukuru Kwa Njenga Primary school in Kenya under the care of teacher Samuel Isaboke. He visits to her home at least three times a week to support her parents in educating her.

In line with the holistic approach of CBE, Rehema has been provided with physiotherapy sessions three times in a week to complement the therapy being provided by her parents and teachers. Her mother comments: "Sense International has helped my daughter a great deal. My daughter's life has been transformed by this project. Rehema's communication skills have improved and she is making very good progress in her mobility skills too."

¹ [.senseinternational.org.uk](http://senseinternational.org.uk). Sense International is a small corporate member of DbI. Sense International (East Africa) has programs in Kenya, Tanzania and Uganda.

² [1 .biglotteryfund.com](http://biglotteryfund.com)

“Everyone is in the sphere of power”

How Sense International (Peru)’s¹ strategic approach to advocacy meant that deafblindness is now recognised in law.

This article describes the strategic goals and activities developed by Sense International (Perú), which led to the creation of Law N° 29524. This recognised deafblindness as a distinct and unique disability for the first time – and set out provisions for the care of deafblind people. This success has led to the development of a series of private-public partnerships to deliver programmes and services as defined by the deafblind people.

Summary

“Everyone in the sphere of power” was the core principle that Sense International pursued in order to achieve its goal of getting recognition and the full implementation of the rights for deafblind people in Peru. Everything had to emanate from the needs and demands of deafblind people and their families and be directed by a core group of key stakeholders who worked together to form the necessary critical mass. Sense International (Peru) built on this platform to develop its advocacy strategy with:

1. A clear definition of what we wanted to achieve,
2. The identification of allies, opponents and adversaries,
3. Clearly distinguishing and defining the proposal from among the different alternatives
4. Agree on the approach and activities,
5. Agreeing on a strategic communication plan (including key messages, definition of brand, use of images etc.)
6. Agreement on the indicators we would use to monitor the process.

Objectives

Because the existing law on disability (Law N° 27050 “General Law of Disabled Person”) did not recognise deafblindness in any form, there was extremely limited statistical data on the needs and numbers of people who were deafblind². The first requirement of our Advocacy Campaign therefore, was to achieve recognition of deafblindness as a unique and specific disability – and to identify the specific requirements of deafblind individuals, as opposed to those with other sensory disabilities.

Our partners & our approach

The second step was to influence and involve key actors who could identify with the cause and were opinion leaders and especially those with senior decision making power. Following the development of a layered stakeholder analysis and agreed approach, in 2008 we utilized our close contacts and allies within the Peruvian Parliament to obtain a series of meetings with Mrs. Auriestela Obando, Chair of the “Fifth Committee on Social Affairs and Human Development of the Andean Parliament”.

At this point, Peru had recently ratified the United Nations Convention on the Rights of People with Disabilities (UNCRPD)³ and was one of the first countries to do so. The climate for advocacy for the rights of people with disabilities was therefore very positive. In the meeting we discussed how important it is that deafblindness is recognized – and the consequences for individuals of its absence in national legislation. An important part of this lobbying was also to share experiences from the Parliaments of the European Union, Spain and Columbia which all recognize deafblindness in their legislation. Following this lobbying exercise we received a formal request to prepare the draft law for recognition of deafblindness as a single disability. This draft was then discussed and adopted by the Andean Parliament and, subsequently, published with the Decision N° 1217 in the Gazette of the Andean Parliament by June, 2008.

This was a significant strategic achievement.

The decision by the Andean Parliament called upon its members (the Andean Community of Nations; Bolivia, Colombia, Ecuador, Perú and Venezuela) to individually adopt legislative, executive and administrative measures that would lead to the national recognition of deafblindness as a single disability – and to call on them to implement specialized services to meet the needs of this group of people in social policy areas such as education, health, employment promotion and human development.

As said, this precedent was a crucial prerequisite to start working at national level and to involve more personalities – such as the Congressman of the Republic and President of the Special Commission on Disability of Congress, Mr. Michael Urtecho Medina, who is also a disabled person.

Our proposal

Based on the concept of “legal capability” which should guarantee respect for the dignity, freedom and autonomy of persons with disabilities, covered in article 3 of the UNCRPD⁴, Sense International (Perú) convened several workshops and meetings of young people and adults with deafblindness that allowed us to collect and consolidate proposals that came from their demands, needs and life expectations. On 24th June 2008, the first draft of the Peruvian Bill on the recognition of deafblindness as a unique disability was presented by a group of 20 young people with deafblindness in the Peruvian Congress of the Republic – being finally approved and published in the official journal “El Peruano” on May 2nd, 2010, as the Law N° 29524.

Following actions

This Law was a watershed moment in the achievement of our objective “of obtaining recognition as well as the full implementation of the rights of deafblind people in Peru”. Not only did the national legislation recognize deafblindness as a unique disability and regulate for the provisions for the care of deafblind people in Peru, it also recognized the official communication systems (sign language, Braille and Dactilology), and also recognized the obligation to provide guide interpreters for deafblind people.

With the new law and, subsequently, its regulations approved by Supreme Decree N° 006-2011-MIMDES, Sense International (Perú) continues to engage and work constructively with public sector groups to help them to fulfil their legal obligations. For instance, with the Peruvian Ministry of Education, a nationwide survey was conducted into alternative communication systems. This led to the recognition and validation of seven alternative communication systems for deafblind people. Furthermore with the Ministry, SI Peru has developed and delivered a series of tailored education training programs specifically addressing the skills development of special needs education teachers, the development of deafblind materials and curriculum adaptations.

Recently, evidence of our advocacy success came when the Ministry of Education appointed Mrs. Genoveva Mejía Farro as the first Latin American specialist in the field of deafblindness in the General Direction of Special Education. At the same time we are now developing a series of similar strategic activities with other national Ministries including: the Ministry of Health, the Ministry of Labour, and the Ministry of Women and Vulnerable Populations. For us this confirms: the sustainability of our approach towards deafblindness, the quality of our relationship with key ministries, and the success of our initial strategic approach.

Lessons

The unique way to achieve a positioning of deafblindness in our country has been through the process identified earlier in points 1 to 6 above. Once the goal had been determined, critical to our success has been the situation analysis and understanding the advocacy environment as well as the identification of opportunities to influence decision makers and to change legislation. Through the search for spaces where the voice of deafblind people can be heard, to ensuring that SI Peru had the skills and capacity to deliver support once the legislation had been passed we recognise that building and working closely in partnerships with key stakeholders was critical to enhance our capacity and to put the plan into action. It is true that the work has really just begun and the challenges ahead are many and varied. However, we know that the quality of the organization, planning, mobilization and proposal will have a direct impact on deafblind people’s lives and their families, so that they can achieve their goals.

Kiomi Parraga, Project Assistant, Sense International (Peru)
For more information contact Ricardo Zevallos (rzevallos@senseintperu.org)

¹ .senseintperu.org. Sense International (www.senseinternational.org.uk) is a small corporate member of Dbl.

² The First National Survey of Disability, in the country, was developed by the National Institute of Statistics and Informatics (INEI) in 2012, where it is determined that there are 1 575 402 people with disabilities in Peru, which means 5.2 % of the total population. <file:///C:/Users/User/Downloads/resultados.pdf>

³ <http://www.un.org/disabilities/convention/conventionfull.shtml>

⁴ Article 3 principles of the present Convention shall be: to) respect for inherent dignity, individual autonomy, including the freedom to make their own decisions, and the independence of the people. This Convention was issued by the United Nations and ratified by the Peru on January, 2008.

Another Public Policy Victory by AHIMSA

in the State of São Paulo, Brazil

Perseverance, secret of all triumphs¹

(Victor Hugo)

In Brazil it is mandatory that all children be enrolled in school. However only the schools in a very few cities, mainly the large metropolis', offer specialized services. We recognized over a decade ago that inclusion was the answer to provide specialized services for all students throughout Brazil. Unfortunately our teachers did not have the necessary qualifications or received any training to teach students with multiple sensory disabilities.

With this in mind, a group of professionals from AHIMSA (Educational Association for Multiple Disabilities) and part of Grupo Brasil² visited Canada in 2004 to learn more about their intervention services program and the professionals called Intervenors. From this experience in Canada, the AHIMSA group came to understand that this type of professional could provide the necessary support to ensure full inclusion of students with deafblindness and multiple sensory disabilities in regular schools in Brazil.

We are pleased to say that hosting the 15th Dbl World Conference in Brazil in 2011 has led to very fruitful results for inclusion programs for our multiple sensory disabled students. Since receiving the support from local governmental agencies for

hosting that event, providing service for deafblindness and multiple sensory disabilities is now more visible in our local educational programs.

In 2012 the State Secretary of Education of São Paulo³ promoted a Regional Forum⁴ where Shirley Maia and Claudia Sofia from AHIMSA participated in 11 seminars that reached a total of over 4000 professionals involved in education, including teachers, school managers and municipal secretaries of education. These information sharing sessions assisted the educational authorities to properly identify the students (with sensory disabilities) that were already in schools but not receiving proper education for their disability due to the lack of knowledge about their condition and appropriate educational needs.

As a result of these efforts, the State Secretary of Education of São Paulo published in their official journal two years later on November 12, 2014, a resolution⁵ that deafblind students and students with multiple sensory disabilities have the right to a guide-interpreter or an intervenor to support their inclusion in regular schools throughout the state of São Paulo. This is a major victory! Once publicly acknowledged in our state and throughout Brazil, we will be able to reach out to more states in Brazil ultimately to have a nationwide agreement for this necessary support of intervenors in the education of people with deafblindness and multiple sensory disabilities. Persevere and you shall triumph! All you need to do is Believe and act accordingly

Shirley Maia and Vula Ikonomidis

For more information, contact: vula2004@hotmail.com

¹ <http://izquotes.com/quote/89081>

² www.grupobrasil.org.br. Grupo Brasil is a small corporate member of DbI.

³ www.educacao.sp.gov.br

⁴ See DbI Review Edition 51, July 2013

⁵ Resolution SE 61, 11-11-2014: Provides for Special Education in the school units of the state school system:

Article 10 – in order to provide the necessary support to students of Special Education, enrolled in classes of elementary or high school education, in any form of education, the school may have the following professionals:

I – interlocutor teacher of Brazilian Sign Language (LIBRAS), admission as regulated by Resolution SE 38/2009 to act in the condition of interlocutor in LIBRAS, of the school curriculum, between the regular class teacher and the deaf student / hearing impaired;

II – teacher translator and interpreter of Brazilian Sign Language (LIBRAS), bearer of one of the qualifications requested for teacher interlocutor of LIBRAS, in the Resolution SE 38/2009 and qualification in one of the disabilities requested, to act as translator or interpreter of the school curriculum, between the regular classroom teacher and the deafblind student;

III – teacher intervenor, bearer of a full degree with qualification in one of the disabilities requested, with the objective to intermediate the school curriculum,

between the regular classroom teacher and the student who may present multiple sensory disabilities in addition to deafblindness or physical disability.

IV – caregiver, according to the Terms of Conduct Adjustment signed between the Public Ministry / Government / SP (São Paulo) and the Secretaries of Education and Health to act as provider of services in the following situations: a) when required and authorized by the family;

b) for students with disabilities whose limitations entail permanent or temporary difficulty in school routine, and who cannot perform, independently and with autonomy, among others, activities related to feeding, oral and personal hygiene, use of bathroom, locomotion, and the administration of medicines with prescription and expressly authorized by the responsible, except in the event that this activity is private to nurses, under the specific legislation.

IIIº International Seminar on Deafblindness and Multiple Sensory Disabilities

As part of celebrating 15 years as an organization, Grupo Brasil¹ held its third seminar on Deafblindness and Multiple Sensory Disabilities, October 27-30, 2014. This was undertaken in partnership with the University São Paulo – USP² and with support from São Paulo Research Foundation, FAPESP³. The theme of the seminar was: ‘School inclusion and Assistive Technology for people with deafblindness and multiple sensory disabilities’. One hundred and fifty professionals from throughout the state of São Paulo and the states of Espírito Santo, Rio de Janeiro and Pará participated in the event.

The program featured keynote presentations and round tables. The two key note speakers were: Dr. Maria Bove (University of Vermont⁴ – USA) lecturing about the ‘Bridges for Inclusion Project’⁵ and Gloria Gil (Perkins International⁶ – USA), speaking about Assistive Technology for People with Deafblindness and Multiple Sensory Disabilities. The three round tables were titled: 1) Public Policies for Educational Services for Students with Deafblindness and Multiple Sensory Disabilities. Participating in this round table were representatives from the Municipal and State Secretaries of Education, the Municipal Secretary on the Rights of the People with Disabilities and Reduced Mobility and the National Secretary on the Promotion of the Rights of the People with Disabilities; 2) The Importance of Families as Communication Partners. Leading these discussions were Dr. Susana Araújo (Rondônia), representing the Brazilian Association of Parents and Friends (Abrapasem) and Dr. Isabel Amaral (Portugal); 3) Building Possibilities for Collaborative Work between Universities and Institutions. Participants leading these discussions were: Dr. Isabel Amaral (Portugal), Dr. Maria Piedade Costa

(Universidade Federal de São Carlos- UFSCAR⁷), Dr. Maria Bove (USA), Gloria Gil (USA) and Dr. Karina Pagnez (USP).

In addition to the keynotes and round tables, the seminar included such workshops as: Communication with Congenital Deafblindness; Communication with Acquired Deafblindness; Working with Families and Accessible Resources and Low Cost Technology.

The seminar concluded with presentations from Grupo Brasil's numerous partners highlighting the success stories of the Grupo Brasil network. These included:

- Two presentations from São Bernardo do Campo – one about specialized educational services offered during home visits for students unable attend school due to health conditions; the other a collaborative team presentation outlining how the entire school (specialized teacher, education coordinator and school director) worked closely with the family to offer full inclusion to students with disabilities.
- Presentation by the School for the Blind in the city Angra dos Reis (Rio de Janeiro State) about Social, Educational, and Family Inclusion in that city.
- Presentation about the Acquired Deafblindness Program offered in the Institute Benjamim Constant⁸, Rio de Janeiro.
- Report about Ahimsa's (Educational Association for Multiple Disabilities)⁹ experience with its Family Partnership Program.
- Presentation from the Daniella Forchetti Dance Group¹⁰ about Social and Cultural Inclusion.
- Presentation of Denise Villas Boas' Doctoral Research titled: "The quality of interactions with children with deafblindness and multiple sensory disabilities"
- Presentation about the training Courses (online) in the areas of deafblindness and multiple sensory disabilities organized by Dr. Susana Araújo at the University CEULJI/ULBRA11 (Rondônia).
- A presentation by a professional from the Helen Keller Bilingual School for the Deaf¹², São Paulo about History Studies undertaken by a student with deafblindness with the support of an educational guide-interpreter¹³.

In conclusion, the experience from this seminar motivated new discussions and proposals for new projects and partnerships to foster the inclusion of people with deafblindness and multiple sensory disabilities in Brazil. The hope was that this experience would enhance further involvement by the Universities to carry out more research and studies to support the actions carried out by Grupo Brasil. As an outcome of this seminar, we are planning future events in partnership with more universities in 2015.

Planned events for 2015

- The III^o Virtual Latin American Forum is being organized with the Federal University of Alagoas¹⁴ (Maceió, Alagoas State), April 28 to May 3, 2015 in honor of the late Michael Collins¹⁵. Note: anyone interested in sharing information with us at the forum please contact vula2004@hotmail.com.

- The IV^o International Seminar will be held July 28-31, 2015 in partnership with the Federal University of Santa Maria, Rio Grande do Sul¹⁶. The theme will be focused around Guide-Interpreters, Intervenors and Assistive Technology.
- The VI^o International Forum, will be organized in partnership with University of São Paulo – USP, November (dates to be determined), 2015. The theme will be: 'Holding Hands in Health, Education and Rights of the People with Deafblindness and Multiple Sensory Disabilities'. The IX^o National Meeting on Deafblindness and Multiple Sensory Disabilities will be held along with this Forum.

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¹ www.grupobrasil.org.br. Grupo Brasil is a small corporate member of DbI.

² www.usp.br

³ www.fapesp.br/en

⁴ www.uvm.edu

⁵ <http://www.eapn.pt/bridgesforinclusion>

⁶ www.perkins.org/international

⁷ <http://.ufscar>

⁸ www.ibr.gov.br

⁹ Ahimsa is a component of Grupo Brasil

¹⁰ daniellaforchetti.blogspot.com

¹¹ www.ulbrajp.edu.br

¹² <http://surdohk.blogspot.ca>

¹³ Teachers for the deaf who have taken the guide-interpreter course for acquired deafblindness.

¹⁴ www.ufal.edu.br

¹⁵ The late Michael Collins, a former President of DbI, was inducted into the Hall of Fame for Leaders and Legends of the Blindness Field. See article in this edition of DbI Review.

¹⁶ www.ufsm.br

Accessibility standards

Founded in 1989, DeafBlind Ontario Services¹ is one of the largest not-for-profit organizations in Ontario providing Intervenor, residential and other specialized services to individuals who are deafblind in communities throughout the province of Ontario, Canada. In the fall of 2014, DeafBlind Ontario Services launched their

Accessibility Standards Guide after a thorough accessibility assessment of its own residential locations.

The purpose of the guide is to share standards and provide helpful tips that focus on establishing inclusive environments for individuals with varying sensory loss. Inclusion of accessible standards and design emphasizes efficient environments, space maneuverability, the importance of illumination, and the use of colour, texture and specialized materials to name a few.

Why develop and incorporate these standards?

The objective of using these standards is to increase functionality, safety, independence and overall accessibility for those with varying abilities.

The Guide is divided into three sections:

The Accessible Design Guidelines and Quick Design Tips sections of the guide were researched and written by an external resource; Lesley MacDonald of Pretium Anderson (Pretium Anderson Building Engineers, Universal Design Consulting Services²). Lesley's background knowledge and experience includes 25 years of experience at Canadian National Institute for the Blind(CNIB)³, development of CNIB's 'Clearing Our Path Universal Design Guidelines for the Built Environment' and a Master's in Orientation and Mobility.

The Accessible Design Guidelines section is a very detailed oriented section that highlights standards for the Bathroom, Bedroom, Exterior Spaces, Kitchen, Laundry Room, and Living and Dining Room. Each section provides measurement specifications for accessibility, safety considerations and material recommendations. The DIY section (Do-It-Yourself) Accessibility and Orientation Enhancements section is intended to share additional projects and products that can increase the accessibility and functionality of the of the environment/activity.

Accessible Design Resource

The Accessibility Standards Guide is an essential resource if you are a builder, member of an accessibility committee or government agency, or work in a recreation centre, retirement/nursing home or other facility or if you support someone with sensory loss.

Get your FREE copy at www.deafblindontario.com.

¹ www.deafblindontario.org; and say Deafblind Ontario Services is a large corporate member of DbI

² www.c3group.com/Pretium-Anderson

³ www.cnib.ca

German Federal Commissioner Verena Bentele learns about services for persons with deafblindness

Verena Bentele¹, Federal Commissioner for Disability Issues, visited the St. Francis Foundation² (Stiftung St. Franziskus) in Heiligenbronn Germany to learn about the Foundation's services for people with deafblindness. Years ago, Ms. Bentele was herself a student at the school for the blind and visually impaired in Heiligenbronn. The Foundation's director, Hubert Bernhard, called it "an honor that you have come here to learn about our work". In addition to meeting with leaders of the Foundation's center of excellence for people with deafblindness, the former student, who attended the residential and school programs from 1988 to 1994, also reunited with a former teacher and residential care provider, Sister Margitta Pitz. Verena Bentele said that she was very pleased about meeting with 'old friends' again and she noted that the school had "contributed greatly" to her personal growth.

Hubert Bernhard reviewed the history and development of the convent and the foundation for the visitor from Berlin and her mother, Monika Bentele, who had accompanied her. Principal Dietmar Stephan described the expansion over the past 20 years of the former school for the blind into a support center for children with blindness, visual impairments, deafblindness and multiple disabilities. Most notably, consulting services for early intervention and school collaboration have become ever more important in a large catchment area. In addition to the 20 students with deafblindness who are included in classes at the school in Heiligenbronn, 74 children and youths with combined hearing and visual impairment are supported by Heiligenbronn's consultants across the state of Baden-Wuerttemberg.

Dr. Andrea Wanka³ presented about the center of excellence for persons with deafblindness and its numerous projects. Ulrike Broy, director of consultation services, and Beate Schork, director of the department for students with deafblindness, reported on communication development and the social learning of children with dual sensory impairment. They shared some of their everyday experiences and answered many of the federal commissioner's questions. Verena Bentele emphasized how important it is for her participation in political discussions, to gather specific insights into the daily lives of people with disabilities.

Roland Flaig, director of services for persons with disabilities, and Nadja Urschel reported on European networking in the field of deafblindness and a project initiated in this context: the translation of the fundamental work 'Communication and Congenital Deafblindness'⁴, originally written in English, which has recently been made accessible for German speakers in the field of deafblindness. The text of the four booklets encompasses 472 pages has been translated into German by an expert in the United States. Ulrike Broy and Nadja Urschel, both staff members of the St. Francis Foundation, took on the task of proofreading and revision during their parental leaves. The booklets have been printed and distributed by publisher Edition Bentheim⁵. Aktion Mensch⁶, the Kniese Foundation in Berlin and the Hermle Foundation in Gosheim subsidized the costs for translation and publishing, as well as for the development of a staff training program based on the booklets.

Roland Flaig presented Commissioner Bentele with an original set of the printed booklets. She also received the booklet abstracts in Braille and an accessible version on DVD, which is also commercially available. Roland Flaig also thanked the two editors for their commitment and presented them each with a portrait painted for them from a photograph by a Dutch artist with deafblindness.

In his closing remarks, Guenter Seger, director of the services for persons with disabilities, spoke about the importance of the code 'deafblindness' on identification cards for people with severe disabilities. This code indicates eligibility for special services, as well as for financial support for persons in this category. Seger asked the federal commissioner to lend her support to this issue. Verena Bentele thanked everyone for all of the information and told the audience how impressed she was by all that she had experienced.

Ewald Graf, Public Relations, Stiftung St.Franziskus
Translated by: Jim Witmer and Ulrike Broy

¹ Verena Bentele is a former German biathlete, cross-country skier, four-time world champion and twelve times Paralympics gold medal winner (http://de.wikipedia.org/wiki/Verena_Bentele)

² <http://www.stiftung-st-franziskus.de>

³ Dr. Andrea Wanka is the Chair of the DbI CHARGE Network and member of the DbI Board

⁴ Booklets prepared by the DbI Communication Network (www.deafblindinternational.org/ccd.html)

⁵ www.edition-bentheim.de

⁶ <https://www.action-human.com>

Hungarian Deafblind Association

Siketvakok Országos Egyesülete

Since 1994, the Hungarian Deafblind Association has been working to increase the quality of life for deafblind people in Hungary by representing their interests through advocacy and other service provisions. We took many steps, large and small, in the last twenty years towards meeting these goals. We are pleased that new services have been founded and new ways of support have appeared. We are confident to say that the opportunities for the deafblind have improved significantly relative to the situation twenty years ago.

The Hungarian Deafblind Association is the only organization in our country that provides rehabilitation, communication support and advocacy for deafblind people.

The Association has three divisions of responsibility:

- An Advocacy and Information Office responsible for Advocacy.
- A Communication Support Service responsible for the Interpreter-guide service and the dissemination of special communication methods developed for deafblind people.
- An Elementary and Vocational Rehabilitation Service Division

At the moment, the association is in contact with approximately 400 people living with deafblindness.

The 2011 Hungarian Census

The Hungarian Deafblind Association, along with other disability groups, started talks in 2009 with the (former) national government about the need to identify more precisely the number of people living with different types of disabilities. These successful talks led the Central Statistical Office which is responsible for the national census to include deafblindness on the list of distinct disabilities identified in the 2011 census.

The 2011 census data was summarized into the following two categories related to deafblindness:

1. People defining themselves as living with deafblindness: 3,262 persons
2. People who did not define themselves as living with deafblindness, but as living with both blindness/visual impairment and with hearing loss/deafness: 12,685 persons

The two diagrams below depict the distribution according to age. Please note that the small numbers in the lower age groups are probably due to the fact that one cannot be diagnosed with deafblindness but might receive early care according to major type of disability.

1. People living with deafblindness, according to gender and age (Central Statistical Office, 2011)

0-14	15-19	20-29	30-39	40-49	50-59	60-64	65-69	70-79	80-	Total
56	24	62	61	115	279	165	123	341	522	1,748
68	37	79	111	130	313	177	138	242	219	1,514
124	61	141	172	245	592	342	261	583	741	3,262

2. Number of people who claimed to live with visual impairment / blindness and hearing loss / but did not classify themselves as deafblind, according to gender and age (Central Statistical Office, 2011)

Age group	0-14	15-19	20-29	30-39	40-49	50-59	60-64	65-69	70-79	80+	Total
Women	25	8	34	91	169	685	473	515	1,781	4,209	7,990
Men	18	22	58	106	211	647	430	403	1,165	1,635	4,695
Total	43	30	92	197	380	1 332	903	918	2,946	5,844	12,685

Report into Deafblindness published in Ireland

Until recently, no large- scale research had ever been conducted into Deafblindness in Ireland. Estimates of the number of people affected by the disability were not available and very little was known about the situation of people living with dual sensory loss in the Irish context. In October 2013, the Anne Sullivan Centre¹, in association with Deafblind Ireland², attempted to change this.

To begin with, statistical information from the 2011 National Census³ was reviewed. Question 16 of the Census was a seven-part question aimed at gathering information on the prevalence of disability in Ireland and proved an invaluable resource. The data collected indicated that there were 51,718 people with 'Blindness or a serious vision impairment' and 92,060 people with 'Deafness or a serious hearing impairment' living in Ireland.

In November 2013, a request was sent from the Anne Sullivan Centre to the Central Statistics Office (CSO), for a special cross-tabulation of these data to ascertain the number of people who had indicated they were both hearing and vision impaired. For the purpose of the analysis, Deafblind was defined by the CSO as, "a combination of Blindness or a serious vision Impairment and Deafness or a serious hearing Impairment". Further correspondence with the CSO provided an additional breakdown of the number of people who were Deafblind in specific age categories in each county.

Summary of Results

The results of the Special cross tabulation indicated that, based on 2011 statistics: 1,749 people are Deafblind in Ireland (CSO, 2013).

1050 of these are over the age of 65 and 699 are under the age of 65.

518 of these lived in Dublin, our capital city.

This figure is equivalent to approximately 57 people in every 100,000

In an effort to discover more, a National Registry of people who are Deafblind was established. Information for the registry was gathered using short surveys mailed to people identified as having a combination of vision and hearing loss, by both the Anne Sullivan Centre and other cooperating organisations nationwide including the National Council for the Blind Ireland (NCBI)⁴, DeafHear⁵ and other intellectual disability services.

In total, 103 surveys were returned for analysis by April 2014. They indicated that:

- At least one third of the Deafblind population in Ireland are over the age of 65, representing the largest diagnostic group within the Deafblind population
- Age Related Deafblindness, Usher Syndrome, CHARGE Syndrome and Congenital Rubella Syndrome are the leading causes of Deafblindness in Ireland.
- Almost 20% of the Deafblind population have a diagnosis of Usher Syndrome. Of these less than one quarter are engaged with a service provider.

- 90% of Deafblind children and young adults have one or more additional disabilities.
- Almost two-thirds of people who are Deafblind live with family. Fewer than 15% live alone and almost 20% live in a residential care facility.
- 55% of people who are Deafblind are not in receipt of any services⁶.

While further consultation with people who are Deafblind and their families is needed to fully assess the situation, the following recommendations have been proposed to advance the rights of people who are Deafblind, based on the findings of this report.

- A campaign for Awareness and Enabling Legislation that includes, but is not limited to, lobbying for Official Recognition of Deafblindness as a separate and unique disability in the Irish context and the adoption of the European Union's Written Declaration 1/2004.
- The establishment of a strong support network of people who are Deafblind, their families and the professionals working with them to advocate for the group at local and national level
- The development of Deafblind Specific Services that meet the individual needs of the diverse population of people who are Deafblind
- Further research into the area of Deafblindness which includes greater consultation with people who are Deafblind and their families to provide the information necessary to plan and develop appropriate services for the growing Deafblind population

The Anne Sullivan Centre is using the publication of the report to raise awareness of Deafblindness in Ireland and to campaign for the improvement of services. We hope that the National Registry will continue to grow in numbers and will provide the foundation for a strong Deafblind community in Ireland.

Finally, we would like to take this opportunity to thank all of the Deafblind International members who contributed to the research – either directly by responding to an email and offering advice or indirectly by being a guiding light for research into Deafblindness. We hope that you find the results both interesting and informative. If anyone would like a copy of the report or have any questions, you can contact the author of the report

Laura English (lenglish@annesullivancentre.ie)

¹ www.annesullivan.ie. The Anne Sullivan Centre is a small corporate member of DbI.

² www.deafblindireland.org. Deafblind Ireland is a small corporate member of DbI.

³ www.cso.ie/census

⁴ https://www.ncbi.ie. NCBI, the national sight loss agency, is a not for profit charitable organisation which provides support and services nationwide to people experiencing sight loss.

⁵ https://www.deafhear.ie. DeafHear has a national network of resource centres providing a range of accessible services to Deaf and Hard of Hearing people and their families and is also actively involved in advocating and lobbying for improved services and new developments

⁶ People who participated in the research were asked if they had access to a) Residential Care, b) Respite Care, c) Day Service, d) Visiting teacher for the Deaf/ HI or Blind VI, e) Personal Assistant, f) Special Education School, g) Other – 55% did not receive any of the above or indicate they received a service from 'other'.

CHARGE Syndrome: an Italian experience

Patrizia Ceccarani, Director of the Rehabilitation Center, Lega del Filo d'Oro, Osimo, Ancona, Italy

The Lega del Filo d'Oro¹ in Osimo is a non-profit organization for people with multi-sensorial impairments. In collaboration with the Pediatric Clinic of the Institute of Maternal-Infantile Sciences in Ancona, Italy we take care of about 60 patients aged between 0 and 35, from all over Italy that are clinically diagnosed with CHARGE syndrome according to the classification described by Blake et.al, 1998². We consider that our caseload is representative of the Italian population of people with CHARGE syndrome.

With this in mind, a study was carried out based on 35 of the identified patients and published (online) in the American Journal of Medical Genetics (2014 Dec;164(12):3042-51. doi: 10.1002/ajmg.a.36758. Epub 2014 Sep 24): Cognitive-Motor Profile, Clinical Characteristics and Diagnosis of CHARGE Syndrome: An Italian Experience.

Lucia Santoroa⁴, Anna Ficcadenti⁴, Federica Zallocco⁴, Giada Del Baldo⁴, Francesca Piraccini⁵, Rosaria Gesuita⁵, Patrizia Ceccarani¹ and Orazio Gabrielli⁴.

Abstract

Since 2005, the Pediatric Clinic of Maternal-Infantile Sciences Institute in Ancona, in collaboration with the Lega del Filo d'Oro in Osimo (Italy), has been taking care of 35 patients with clinical and molecular diagnosis of CHARGE syndrome. Our investigation is the largest Italian cohort study of CHARGE patients. CHARGE syndrome is a multiple malformation syndrome involving ocular coloboma, heart defects, choanal atresia, retardation of growth and/or development, genital anomalies and/or urinary and ear abnormalities which leads to visual–auditory disabilities, cognitive impairment and behavioral abnormalities. Our purpose is to expand the knowledge of this syndrome by reviewing this group of affected patients in order to delineate in detail the natural history of the disease, and in particular to define the cognitive and motor profiles using an Italian questionnaire called “Progress Guide”. Our main results show that Italian CHARGE patients have more delayed development in their physical abilities or skills with respect to normal patients. In particular, the delay is statistically significant in regard to self-care skills (worse at toileting; better with washing) and the communication skill (language). On the other hand, their expressive skills are still preserved. When patients are considered according to their age (≤ 3 years) and (> 3 years), the older ones have more delayed development than the younger ones when compared with healthy individuals of the same age.

For more information contact Patrizia Ceccarani (ceccarani.p@legadelfilodoro.it)

¹ www.legadelfilodoro.it . Lega del Filo d'Oro is a large corporate member of DbI.

² Blake K.D., Davenport S.L., Hall B.D., Hefner M.A., Pagon R.A., Williams M.S., Lin A.E.&Graham J.M. CHARGE association: an update and review for the primary pediatrician. Clin Pediatr (Phila) 1998; 37: 159–73. [PubMed]

Portraits from the Deafblind Program at The Holy Land Institute for Deaf in Jordan

Ten children and two adults are living, staying and learning in the Deafblind program of The Holy Land Institute for Deaf¹. Each one of them is unique and special; it is a pleasure for all the hearing and Deaf staff to be part of their development and see each day even their smallest progress. A speciality of our Deafblind work is that it takes place in an institute for Deaf and Deafblind children. Some of the older Deaf students assist the Deafblind children as part of their vocational training. That enables them to leave behind their own disability and experience the joy of helping someone else in need.

As our Deafblind Unit has been expanded with a part of a new building for the Deafblind, the children have found much fun in the new sports facilities. Here they do exercises and one or the other can show their abilities. It is also a great pleasure that we can play outside on the new roof terrace.

Murhaf

Murhaf five years old is the youngest boy in the Deafblind Unit. He is from a very poor family, who care with much love for him. When Murhaf came to us three years ago, he could neither walk nor communicate in any manner. Meanwhile he understands also a few signs like drinking or eating and has learned to walk. Murhaf loves to put all kind of things he can reach or touch into his mouth.

Hadiel

Twelve year old Hadiel is one of the most active Deafblind children in our facility. With her high spirits and joyful character she keeps her teachers always on the go. She likes to eat sweets and to turn around in a circle. Hadiel understands about 25 signs and in comparison with other Deafblind children she has a very good sleeping cycle. Sometimes when she becomes very nervous, she cries then a lot and rejects any contact, which can be very stressful for the people around her.

Issa

Issa, 13 years old and blind since his birth, has been several years at the school. With his aphasic symptoms and has not started to speak and is hence educated as Deafblind. Issa loves to listen to music, to play for hours and to touch things (preferably those that are soft). He comes from a loving and well-to-do family, who however do not know how to educate their son and to teach him things. He has now learned to walk and to express himself with simple signs. The educators always speak to him and meanwhile he understands a few spoken instructions and can

execute these. The nicest thing is when Issa starts to hum. He manages a few melodies, which makes the people around him always very happy.

Hanady

Hanady is already 53 years old. She came in the beginning of last year for the first time to the school after her mother had passed away. She was already Deaf as a child and on top of that became blind when she was twenty. It is amazing how well she is keeping up at her age and how well she manages the sign language. She is accompanied each day by her Deaf teacher Iman, who trains her with Braille, moving around with the blind stick etc. She is very happy to be here and that she can now live in the boarding school with the Deaf girls.

Rahmeh

Rahmeh was born premature at 6 months and because of this she is Deafblind. She experiences painful problems with her eyes which were replaced by small light blue glass eyes. She has some hearing in one ear which results in her love for music. She loves to jump on the trampoline. She is a very unobtrusively calm girl, who is much loved by the other Deaf students. When she has nothing to do she likes to click with her tongue.

Hazem

Hazem is 14 years old, totally blind but with some residual hearing. He comes from a very loving family who cannot communicate with him.

Repeatedly, Hazem's teacher encourages the parents to learn more sign language because at home the parents only use the simplest signs for "eating" and "drinking". But Hazem understands much more than these signs. As he can hear in one ear a little, he likes to sit down and listen for hours to a CD-Player or a singing toy. As soon as he becomes bored, he makes noises like "wua wua wua" to get the attention of the teachers. It's always very nice to see Hazem when he is happy, then he laughs aloud and shows his happiness by moving his right hand back and forth like he would throw a ball.

Mohammed

Mohammed is seven years old, blind and Deaf. He is still very new in the school and still expresses himself very weakly. Because he has very weak muscles and cannot yet walk, he is always moved around in a small wheel chair.

But the Deaf students and the teachers care lovingly for him and try to teach him many signs. His main activity consists of moving his delicate little fingers back and forth and to play with small cuddle animals.

Kawthar

Due to a premature birth, 9 year old Kawthar is Deafblind and in addition of a weakness in her muscles. When she came for the first time to the institute, she could neither sit up nor walk. First she learned to sit and then needed a wheel chair for some years. In the meantime she has learned to move about and each step is a success and a joy for everybody. Kawthar is a very quiet child; is seldom nervous and most of the time has a smile on her face. She is one of the smartest children in the Deafblind Unit, who is making good progress. She likes to play the most with a soft toy and her favourite food is a dish of rice. Moreover she comes from a lovely family who cares so much about her and tries to turn the good advices of the teachers into practice.

Brother Andrew de Carpentier

Executive Director

The Holy Land Institute for Deaf and Deafblind, SALT, Jordan

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¹ www.cbm.org/programmes/The-Holy-Land-Institute-for-the-Deaf-292846.php (CBM is a large corporate member of DbI)

From one word – to an inspiring story

Cristiana Salomie describes the ongoing journey that Sense International (Romania) has taken since 1998

Introducing deafblindness (surdocecitate) into the Romanian language was a long and winding road for Sense International (Romania). It all started back in 1998, when a team of experts from Sense came to Romania to assess the situation of children and adults with deafblindness.

They came into contact with me, Cristiana Salomie, who was at that time working for the British Red Cross, which led to a long and fruitful collaboration. Discussions with national authorities led to a surprising and hard-to-believe conclusion: “there are no children with deafblindness in Romania”. It was obvious that talking about deafblindness was not enough; something had to be done to prove to the national and local authorities that these children did exist and that they need specific education services, in an adequate environment.

The first two classes were established in 1999: one in Bucharest, at the Kindergarten for Children with Hearing Impairments and another in Cluj Napoca, at the High School for Children with Visual Impairments. Each class had four children, identified and assessed by Sense specialists. At the same time, six special education teachers were selected to learn everything there was to learn about how to work with these children.

One year later, representatives from the Ministry of National Education were invited to visit the classes. They met the children and they saw the obvious progress they made in only one year. This was enough to convince them that educating children with deafblindness was not only possible, but crucial for their development. A Partnership Agreement was signed, the government committing to support the education of children with deafblindness, using newly created Sense International (Romania)'s technical expertise.

By 2006, there were now 13 classes, where 52 children with deafblindness were receiving proper education services. A team of Romanian national trainers in the field was created to meet the future needs of the education system.

All these efforts – combined with intensive lobby and advocacy work at the national level – made it possible for Sense International (Romania) to ensure that deafblindness was included in the Romanian legislation.

Four important initiatives were to follow.

1) Deafblindness was recognised as a distinct disability in the Law no. 448 enacted in 2006.

2) A special Curriculum for the Education of Children with Deafblindness was included in the national education legislation in 2008.

3) The National Education Law was revised in 2011 to clearly state that children with deafblindness must be educated in classes of maximum 4 children and importantly by special education teachers trained in the field.

4) Early Intervention for Babies with Multisensory Impairments became part of the Romanian legislation in 2013.

Where we are now?

During these 14 years of activity, Sense International (Romania) has ensured rehabilitation, recuperation, early intervention, adequate education and vocational services for 750 children and young people. It has provided counselling and guidance to their families and became involved in facilitating the auditory screening of 70,000 new-born babies and the visual testing of 13,000 babies.

What we do.

EARLY INTERVENTION – We support the rehabilitation and recuperation of newborn babies with sensory impairments in Bucharest, Oradea, Iasi and Timisoara.

EDUCATION – We support the education of pupils with deafblindness in Bucharest, Buzau, Cluj Napoca, Craiova, Falticeni, Galati, Iasi, Oradea, Sibiu, Târgu Frumos and Timisoara.

VOCATIONAL TRAINING – We support young people with deafblindness from Arad, Bucharest, Galati, Iasi and Timisoara to learn a trade in vocational workshops, so that they may lead an independent life after finishing school.

Sense International (Romania)'s strategic approach to working in partnership with the state, rather than creating alternative services which are difficult to sustain, was internationally recognized during the 2009 ERSTE Awards for Social Integration. It was further recognized with the following awards: the Recognition Award, the Practitioners' Award and the Excellency Award for Implication in the Education of Children with Special Needs, received during the Edumanager.ro Gala in 2013.

"The quality of life for people with deafblindness has significantly increased since SI(R) began working in the field. Now, there is someone fighting for laws, for our protection and, most importantly, for the future of children with deafblindness who need an education."

Mr. Vasile Adamescu, a deafblind man who is a special education teacher and writer

"Every moment spent with the staff is a pleasant memory, as with them we found the balance we needed and the strength to keep fighting. We thank them for being there for us!

Mrs. Anuta Banda, mother of Darius, a deafblind boy

"Because my main responsibility within the Ministry of National Education is to coordinate the entire special and special integrated education at national level, I continue to rely on SI(R) to be a key resource in the field of deafblindness for children parents, teachers and authorities."

Mrs. Liliana Mitran, General Inspector for Special and Special Integrated Education in the Ministry of National Education

"SI(R) has become, since 2001 until now, an example of best practices in the world of non-governmental organisations involved in improving the quality of life for people with disabilities. The positive impact in the life of those with deafblindness is the natural result of four converging principles that guide the organization: vision, strategy, resources, promotion."

Mr. Cristian Buica, University Lecturer at the University of Bucharest, a long term collaborator of SI Romania, holding training courses in the field of deafblindness for special education teachers who work with children with deafblindness. (

"I believe SI(R)'s priority over the next years should be the development of vocational services for children and young people with deafblindness, an initiative which they started back in 2012 following the successful grant of 50.000 Euro from Orange Foundation.

Mrs. Amalia Fodor, Director of Orange Foundation Romania, one of Sense International (Romania) most important donors

What is our future? Why not a regional network?

We at Sense International (Romania) believe there are issues specific to Central and Eastern Europe when it comes to deafblindness.

We are absolutely positive that other solutions have been identified in other Central and Eastern European countries. Having been part of the the European Deafblind

Project, through the Lifelong Learning Programme of the European Commission, alongside 33 organisations from 25 countries, we know the existing services in Europe. We therefore make this appeal to organisations and individuals in Albania, Belarus, Bosnia-Herzegovina, Bulgaria, Estonia, Latvia, Lithuania, Poland, Czech Republic, Slovakia, Hungary, Slovenia, Croatia, Kosovo, Macedonia, Montenegro, Serbia, Moldova, Ukraine and Russia to come together and share expertise, knowledge, best practices and concerns through a regional network to promote the rights of people with deafblindness.

Romania will be hosting the 16th Deafblind International World Conference, May 25-30, 2015, the first time that the world conference is taking place in Eastern Europe. Local solutions to common needs, learning and education, identity and belonging, advocacy and recognition – these are the key elements that the 2015 conference will bring to the table.

Organised by Sense International and Sense International (Romania), under the aegis of Deafblind International, the conference will be an excellent opportunity for taking the first steps towards creating a regional network promoting the rights of people with deafblindness.

Looking forward to hearing from you all!

Cristiana Salomie, Director, Sense International (Romania)
(csalomie@senseint.org.ro)

Researching the Voices of Deafblind Children:

an update on research activities at the University of Birmingham¹, UK

I am Liz Hodges. I trained as a teacher of deafblind children and have and have been working with deafblind people for nearly 30 years. My more formal research in deafblindness has focused on acquired deafblindness but my interest in children and congenital deafblindness remains. I work at the University as a teacher trainer in deafblindness for three days a week and as a specialist a teacher of deafblind children for two days a week.

I am Liz Ellis. I am a research fellow at the University of Birmingham and have been so for nearly three years. I first volunteered for a Sense holiday sixteen years ago and have been working in a voluntary and now paid capacity in relation to deafblindness ever since. I have been involved in three research projects about deafblindness since coming to the University. I am a British Sign Language (BSL)² level 2 signer.

We work in the Department of Disability and Inclusion. We have a very strong reputation in the field of special needs, including specialists in hearing impairment and visual impairment and we are committed to deafblindness. Our department has been training specialist teachers of deafblind children for more than 25 years. As researchers, we are social scientists, looking at the ways in which people live their lives, usually through asking them about themselves in relation to the research we are doing. The work we do is focused on helping people to have their voices and opinions heard and validated by research. In three recent projects we have found out how funding changes have affected deafblind people, about how they feel about hospital visits, about the real, lived experience of Usher syndrome, and in all of this, what it is like to be deafblind today.

We focus on meeting people in their own homes and using the communication methods they prefer, be it speech, writing, or sign language. The professional skills in our team and in our department allow us to be flexible and to understand what those needs are, e.g. to produce materials in BSL or in braille.

We are committed to listening to what people say, what they feel and think, about what is happening for them, so that we can reflect these voices in our research. Our work is also founded in social science methodology, so that we look carefully at issues such as sampling, analysis and validity meaning that our reports can be read and respected in academic and government circles. There is an increasing call for evidence based practice, that is, demonstrating the evidence for approaches, or schemes to provide continued commitment to them and this is what our research supports.

We are very proud of the outcomes of our research³. In the last ten years we have completed three projects in relation to people with acquired deafblindness in older age, one of these about people in care homes. These looked at the needs and expectations and the life stories of older people.

More recently we have completed a two year study into the lives of people with Usher Syndrome in the UK. We believe this is among the largest social studies of Usher syndrome and the first to include people with Usher type 3. In telling their own stories, we found that people with Usher met this challenge with a wide range of responses, some being depressed but many developing their ability to adapt and then continue to live their lives to the full and make choices for themselves.

We are currently working on two projects specific to the UK, one looking at the changes in disability related benefits and how this is affecting visually impaired and deafblind people in the UK. The other is looking at how specialist hospital clinics meet the needs of deafblind people with the syndromes Usher, CHARGE, Wolfram⁴, Bardet-Biedl⁵, Stickler⁶ and Alström⁷. We hope that the outcomes of the first project will help organisations to give better advice to people applying for these benefits and to understand what campaigns may be needed to ensure deafblind people get what they are entitled to. For the second project we are hoping to demonstrate models of good practice for hospitals when dealing with deafblindness people, in relation to the environment, communication and sensory awareness.

In addition we support students researching in deafblindness. We have a number of students completing Masters degrees each year, ranging from audits of services to

investigating the world view of practitioners working with deafblind people. Because of the nature of deafblindness, many of these projects, although fairly small scale, represent original research on new topics. We also supervise PhD students working in the field of deafblindness and have a student working with us at the moment on CHARGE syndrome. Students undertaking teacher training in deafblindness benefit from the input of our research and our researchers.

Our work would not be possible without funding and we are deeply grateful to those who have enabled us to take on these projects: Sense, Royal National Institute for the Blind⁸ (RNIB), the Thomas Pocklington Trust⁹, and Bupa (a private healthcare and social care organisation in the UK)¹⁰.

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¹ www.birmingham.ac.uk

² l.britishsignlanguage.com

³ <http://www.birmingham.ac.uk/research/activity/education/victar/research/research-with-people-with-deafblindness.aspx>.

⁴ ghr.nlm.nih.gov/condition/wolfram-syndrome

⁵ ghr.nlm.nih.gov/condition/bardet-biedl-syndrome

⁶ ghr.nlm.nih.gov/condition/stickler-syndrome

⁷ ghr.nlm.nih.gov/condition/alstrom-syndrome

⁸ www.rnib.org.uk/

⁹ www.pocklington-trust.org.uk

¹⁰ www.bupa.co.uk

Network News

Acquired Deafblindness Network

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DbI Youth Network (DbIYN)

Simon Allison reports:

The Youth Network publication 'A Glimpse of Our World' has now been published. This is a collection on eighteen inspirational stories from deafblind young people from around the world. Each story highlights how culture, heritage and service provision influence the lives of deafblind youth. There are some wonderful heart-warming stories featured in the book that provide a unique insight into how young people overcome the many challenges they face. Stories feature from countries including Romania, Malawi, USA, Scotland and Norway. To order a copy please email the youth network coordinator simon.allison@sense.org.uk.

Members of the 'GOT 2 Act' drama group were delighted to participate in the recent ADBN conference in Belfast. 'GOT 2 Act' is a deafblind youth drama group from England who are members of DbIYN. The group have written and produced a play about the early life of Helen Keller. The group have been practicing since June and this was demonstrated in the professionalism of the performance in Belfast. The cast also experienced some of the workshops on the opening day of the conference and made many friends with the delegates.

The Youth Network coordinating group are busy planning an activity for Network members that will take place in 2015. The activity will also include a half day of workshops delivered by young people. Further announcements will be made soon about booking arrangements for the activity.

For more information contact Simon Allison (simon.allison@sense.org.uk).

Watch for activity on our new site on the DbI website:

<http://youthnetwork.deafblindinternational.org>

CHARGE Network

Andrea Wanka reports:

German CHARGE Conference

The 8th international German CHARGE conference took place July 03 – 06, 2014 in Oberwesel, Germany, hosted by the German CHARGE group.

Prior to the main family conference, a professional focused preconference featured such participants as Dr. David Brown (USA), Prof. Dr. Tim Hartshorne (USA), Gail

Deuce (UK), Dr. Kim Blake (Canada) and at the main conference also Prof. Dr. Conny van Ravenswajj (Netherlands).

Before the conference, a youth weekend was organized and a film featuring youth and young adults with CHARGE was produced. This was presented during the conference by the youths and young adults. See www.charge-syndrom.de.

Nordic Network of CHARGE syndrome

Newborns with CHARGE syndrome frequently need intensive care services and many of them undergo surgeries as infants. As soon as the children are in a stable medical condition early intervention services should be initiated by a multidisciplinary team. For those children with deafblindness, coordination of the visual and auditory aids is essential. Due to the rare occurrence of CHARGE syndrome, parents, teachers and other professionals have limited knowledge about it. Therefore, networking and centralisation of services and knowledge is of utmost importance. The Nordic Network of CHARGE syndrome has been operating since 2002. It is organized by the Nordic Centre for Welfare and Social issues (nordicwelfare.org) under the category of deafblindness. Within the Network each of the five Nordic countries (Denmark, Finland, Iceland, Norway and Sweden) is represented by one or two professionals who are active locally in the deafblindness field. The purpose of the Network is to collect, share and spread knowledge on the syndrome within the Nordic countries. The Network focuses on the educational needs, psychological consequences and behavioural aspects of the syndrome. The national representatives meet every year and share knowledge and experience around a certain theme – for instance tactile sense and communication, social aspects of the syndrome and pain. Iceland was the last country to join the Network. As the Icelandic population is small such cooperation is very important. The Nordic Network has already stimulated local networking in Iceland and sharing of information and knowledge among professionals and parents of children with the syndrome. Prepared by Solveig Sigurdardottir (Email address: solveig@greining.is)

Responsibility for CHARGE Syndrome in Norway

In Norway the responsibility for CHARGE syndrome is now located at the Frambu Center For Rare Diseases (www.frambu.no). See detailed article about Frambu in this edition.

For more information, please contact Andrea Wanka:
Andrea-Wanka@dbicharge.org

Watch for the new CHARGE Network subsite on the Dbl website:
<http://chargenetwork.deafblindinternational.org>

Social-Haptic Communication Network

Riitta Lahtinen and Russ Palmer report:

The Social-Haptic Network has been collaborating with different universities in Finland. The Intensive Special Education (ISE) is a new research group at the Department of Teacher Education in the University of Helsinki¹, which started on May 2014. The leader of the research group is Elina Kontu (docent²) from the University of Helsinki. The senior researcher is Riitta Lahtinen (PhD), head of the Communication Unit from the Finnish Deafblind Association³, while Russ Palmer, (SRAT) acts as consultant. The research group consists also of project manager Terhi Ojala (MA) and researcher Irene Rämä (MA), both from the University of Helsinki.

The main research areas related to social-haptic communication during 2014-2015 included:

1. The use of haptics in teaching settings with learners with diverse (special needs) and collection of case studies;
2. Preparing a Scientific Article outlining the use of haptics for describing the environment, objects and multimodal perception , and
3. Outlining the pedagogic approach to social-haptic communication – which is the basis of teaching methodology for teachers using social-haptic communication.

Recent publications included: 'Practice Oriented Safety Procedures in Work Environment with Visually and Hearing Impaired Colleagues' by Lahtinen, R., Palmer, R. & Ojala, S. and a lecture given at the Safe and Secure Cities conference in Turku, Finland published in the Proceedings of the 5th International Conference on Well-Being in the Information Society (WIS2014, p.109-120).

The second stage of the Social-Haptic Communication Studies continued with the Royal Association for the Deaf (RAD)⁴ in the UK in June. There were 30 delegates representing professionals, interpreters, deafblind people and family members. During the day we discussed and shared experiences on how social-haptic communication can be applied in everyday life.

A new group of professionals (including those who are sign language communicators working with deafblind people) started studies in a 6 day credit course called 'Social-Haptics for Different Client Groups Including the Elderly and Autistic People'.

For further information about the Social-Haptic Communication Network, contact: riitta.lahtinen@kolumbus.fi or rpalmer2@tiscali.co.uk; www.russpalmer.com

¹ www.helsinki.fi/university

² en.wikipedia.org/wiki/Docent

³ www.kuurosokeat.fi is a small corporate member of DbI

⁴ www.royaldeaf.org.uk

Communication Network

Ton Visser reports:

It's been some time since we informed about the activities of our network. This doesn't mean nothing has happened; on the contrary! We are happy to inform about our recent activities and plans for the future.

Masters of Communications Course

In our last report we informed the membership that organizing and participating in the high standard Master on Communication (Congenital deafblindness) course at University of Groningen (Netherlands) continues to be one of the main Network priorities. In the last couple of years we dedicated almost all of our energy and time towards further development of this Masters Course. We discuss and develop theoretical frameworks and concepts year by year.

The next Masters Course, the 10th, will start in September 2015. We are very happy that so many people have graduated from this course. With all the research done by the Masters students, we move more towards what we call "Evidence Based Practice" for people with congenital deafblindness, especially through using 'single case experimental designs'.

At this moment we wish to celebrate the successful defense this past October by Marga Martens of her PhD thesis titled "The Intervention Model for Affective Involvement and its Effectiveness"¹. Marga was one of the first students who graduated from the Masters program. Marleen Janssen, Groningen University Masters Program Director, and a member of the Network, expects that 5 additional students will defend their Masters in 2015. Nearly all of them are former Masters program students.

Open access journal

The Open access journal project was much more complicated than we expected. To meet the criteria to realize the standards for such magazine required a lot more work and cooperation with different people than we realized. For the editorial review of the articles we have to follow very strict rules. Nevertheless, the articles for our first edition have been reviewed and are ready to go. Therefore, in cooperation with the University of Groningen, our first edition will be available in the Spring of 2015. In our next report we will give more details about the articles which can be published in this journal. We are now planning for the second edition to be published for Winter/Spring 2016. As we are now more familiar with the proper procedures, we expect to publish future editions much faster.

Proposed Conference – Access to language

A year ago we indicated that we would not be involved again in organizing conferences. At our last Network meeting we decided to review that decision for several reasons. First, we realized that most of the Masters students profited from the work done by our Network. Secondly, we are coming up to a celebration of the 10th anniversary of the Masters Program. Thirdly, and maybe the most important one, is the fact that there has been a lot of theoretical developments in our field since our last conference in 2010. Our initial thoughts are to plan for a conference in March 2017. The title we are considering is: Access to language. In this conference we want to discuss the concepts used over the past years and present new concepts for discussion. The format used in our earlier conferences will be the same: plenary sessions followed by workshops to support the transfer from theory to practice.

Ton Visser (asmvisser1948@gmail.com), on behalf of the Dbl Communication Network

¹ An article pertaining to this PhD research, authored by Marga Martens and Marleen Janssen, appeared in DbI Review Edition 53 (July 2014).

Outdoor Network

Joe Gibson reports:

In September 2014 we had the latest outdoor week, this year in Denmark. Eleven deafblind people and their support staff had a great week in the North of Denmark where, among other things, we built a bridge over a stream on the beach, went fishing on the sea and climbed to the top of a huge sand-dune. All our dinners were self-made and one also self caught, and cooked over an open fire. There was lots of time to meet the new participants and catch up with old friends.

One evening around the fire we discussed the direction of the network. Each year the outdoor weeks have become larger and we talked about the pros and cons of this. We would like to include more people, but if we grow too big, it will be more difficult to administer and might not suite the participants. Perhaps several smaller events will be a better way forward. We also discussed where the week might be next year, and if it is possible to create a winter outdoor week.

There are also some virtual developments. Dbl have recently given the networks some dedicated webspace on their website, watch for the new Outdoor Network Subsite on the Dbl website: <http://outdoornetwork.deafblindinternational.org> We hope to be adding content to this soon!

We also decided to set up a Facebook group. This will be a place where members of the network can share stories of the amazing outdoor experiences happening all through the year, ideas for activities, and to publicise future events. This will be a

private page so people will be free to discuss and share. All current members of the network will receive an invite to the group and if you are not currently a member and wish to join please contact

Joe Gibson (jgibson@sensescotland.org.uk) or
Kari Schjøll Brede (kari.s.brede@eikholt.no)

Siblings Network

Sabine Kersten reports:

I draw your attention to a new book recently produced titled: 'The Sibling Survival Guide: Indispensable Information for Brothers and Sisters of Adults with Disabilities', written and edited by Don Meyer and Emily Holl.

If you're a teenaged or adult brother or sister of someone with a disability, then this book is for you. It offers a sense that you're not alone. It includes tips on how to talk to your parents about plans for your sibling, a crash course in guardianship, medical and legal issues, and government benefits if you're already caring for your sibling. The book focuses on the top issues identified by siblings. It offers practical information and anecdotes about: statistics and research about siblings; younger siblings' feelings; impact on your life decisions; caring for multiple generations; aging and disability; taking care of yourself; getting services and advocacy, and future planning.

This book will be very useful not only for siblings themselves, but also for parents, counselors, and disability service agencies.

As one sister wrote, "We will become caregivers for our sibling when our parents no longer can. Anyone interested in the welfare of people with disabilities ought to be interested in us."

Therefore I do hope you all will read this book, and use it to get to know about us, our concerns, hopes and dreams for the future.

Copies can be purchased online from Amazon.com.

For more information about the Siblings Network, contact Sabine Kersten (siblingsnetwork@gmx.net)

A Glimpse of Our World

A collection of inspirational stories by young deafblind people published by the Deafblind International Youth Network

Young deafblind people live their lives in many different ways. Their choices and decisions are influenced by many things including where they live, their culture and heritage.

Being deafblind in a seeing, hearing world creates challenges. Are these dealt with in different ways in different countries?

The collection of stories provides a unique insight into how deafblind young people from around the world have succeeded in overcoming the many challenges they have faced.

All the money raised from the sale of the publication will contribute to future activities for members of Deafblind International Youth Network.

For copies of this book, contact Simon Allison (Deafblind International Youth Network), Simon.Allison@sense.org.uk

Mapping opportunities for Deafblind people across Europe

Lucy Drescher describes the work of the Grundtvig project which has been collecting data about the position of deafblind people across Europe.

We are now starting to get a clearer picture of the lives of the estimated three million deafblind people across Europe, as the result of a project funded by the European Union.

For the past two years ten organisations from across Europe have been working together to share good practice; develop ways to set standards and produce a questionnaire – the answers to which formed the basis of the final report. The group included Royal Dutch Kentalis¹, Sense UK², Sense Scotland³, Centre for Deafblindness and Hearing Loss (CDH)⁴, Catalan Association for Persons with Deafblindness (APSOCECAT)⁵, Austrian Relief Organisation for People who are Deafblind (OHTB)⁶, France National Resource Centre for Rare Disabilities– Deafblindness (CRESAM)⁷, Hungarian Deafblind Association (SVOE), Slovakian Association of Parents and Friends of Deafblind Children (ZRAPHSD) and Sense International Romania⁸.

The group based their standard setting and the questionnaire on a set of disability indicators (an indicator is a thing that indicates the state or level of something – for example, the number of children who complete secondary education indicates how developed a country is) that were developed by a group of academics called ANED for the European Union.

The indicators cover all different parts of peoples' lives, such as personal and family life, education and employment. They also include things such as whether deafblind children have access to mainstream primary education and/or specialist support and whether deafblind people are entitled to communication support when they go to see the doctor.

These indicators were used to compile a questionnaire which we could use to ask each of the countries in Europe about the situation of deafblind people in their country. We sent out the questionnaire and received 27 replies from 25 countries.

The final report sets out the findings of the questionnaire and makes recommendations for the European Union, national governments, local governments and organisations working with deafblind people.

What did we find out?

A very clear issue that came out of the findings is that there continues to be a lack of recognition of deafblindness as a specific disability – and this has a detrimental effect on the lives of deafblind people in European countries. Here are some of the key findings:

Data

There is not enough information being collected on the numbers of deafblind people, their ages and whether they are male or female. Only three out of 27 states collect official data (i.e. census data) on the number of deafblind people in their population. In addition, organisations working with deafblind people are not collecting enough data on the people they are working with. Without this information it is hard for decision makers to know what funding they need to provide services for deafblind people in their area/country.

Home and family life

There are disparities in opportunities to participate in social and private life which impacts on deafblind peoples' capacity to sustain family relationships. There are also inadequate accommodation options. Only just over a third of states provide deafblind people with the legal right to support for living in a place of their choice.

Choice and control

Restricted access to support in order to vote: While the majority of states have at least one form of support available to enable deafblind people to exercise their right to vote, access to this support is often patchy and only obtained at the request of the deafblind person or their family.

There is little consistency in the mechanisms for organisations representing deafblind people to feed into disability consultation processes.

Access to goods and services

There is a lack of comprehensively accessible services, with both physical and sensory accessibility. There is limited access to public transport in many places. Access to special aids and equipment is patchy and there is a lack of medical services specific to the needs of deafblind people.

Education

There are generally limited educational options for children.

Employment

There was generally a lack of information about employment. Very little information about the employment situations of deafblind people exists in most states – either because there are no requirements to record this information or because very few deafblind people are employed. In addition, support in the workplace is lacking or difficult to access.

Recommendations

In response to these findings, the report makes a number of recommendations at a European and national government level. This includes:

- Establishing a common framework across Europe for the collection of standardised data at a national level – in order to be able to compare differences and developments and the publication of data on deafblindness at a European level by Eurostat and others.
- At a national level the key recommendation is that governments recognise deafblindness as a specific disability and then agree on standardised census questions, to enable governments to collect data on the numbers of people with hearing and sight impairments. There is also a recommendation on the need for a specific budget for communication support, which should be seen as an essential service.

The project funding has now come to an end but the group is continuing to stay in contact and to take the issues raised in the report to decision makers wherever possible. In particular, recommendations are being taken to Members of the European Parliament and officials working in the European Commission.

If you would like a copy of the report or more information about the project go to the project website www.deafblindindicators.eu or email info@deafblindindicators.eu.

Lucy Drescher, Sense International Policy and Support Officer
Email: Lucy.Drescher@sense.org.uk

¹ www.kentalis.nl. Kentalis is a large corporate member of DbI.

² www.sense.org.uk. Sense is a large corporate member of DbI.

³ www.sensescotland.org.uk. Sense Scotland is a large corporate member of DbI.

⁴ www.dbc.m.dk. CDH is a small corporate member of DbI.

⁵ www.apsocecat.org

⁶ www.oehbt.at. OHTB is a small corporate member of DbI.

⁷ www.cresam.org

⁸ www.surdoceitate.ro. Sense International Romania is part of Sense International which is a small corporate member of DbI.

Frambu Resource Center for Rare Disorders

Frambu¹, a private foundation funded by the Norwegian government, provides specialized services for people with rare disorders through a National Resource Centre.

Frambu's vision is to provide leading-edge expertise, knowledge and services in the field of rare disorders for individuals through their entire life cycle from childhood to old age.

The objectives of Frambu are to collate, develop and communicate knowledge about rare disorders and disabilities on behalf of individuals, both with and without a rare disorder, their close/immediate family and the professionals who work with them, so that children, adolescents and adults with impaired abilities can live a life in harmony with their condition, aspirations and needs.

The National Centre organizes its services into the following core areas: specialised tailored courses, summer Camps for children and adolescents, outreach information and counselling services on a local and national level and research and development. These services are supplementary to the regular treatment and care to which every citizen is entitled.

Frambu caters to more than 120 different rare disorders.

Specialized Courses

Courses at Frambu are organized according to specific disorders, groups of disorders or topics that may be relevant to many disorders. While attending a course, people stay at Frambu and come together for lectures, group discussions, consultations and joint activities. Children, including siblings, attend day care and school on site at Frambu, and are supported by play therapists. Courses offered at Frambu are free of charge for the families.

We meet the users in their own environment

Frambu professionals visit users, their families and the professionals who work with them in their own communities. Collaboration with local health services and staff ensures that people with a rare disorder and their families receive treatment, care and services appropriate to their needs within their local community. This service is also provided free of charge.

Popular summer camps

Each summer Frambu arranges four camps for groups of 40 to 50 children and adolescents with rare disabilities, without their accompanying parents. These extremely popular camps last for one to two weeks and enable youngsters to meet others in the same situation as themselves, to share experiences and to build a network of friends and acquaintances. Frambu strives to enable participants to challenge their own boundaries and to discover new possibilities in themselves.

Research and development

Research and development is another of Frambu's activities. The work involves surveying, collating and organizing the knowledge base around rare disorders, gleaning material both from practical experience and from Frambu's day-to-day operations. The aims of our developmental work at Frambu are threefold: to deepen our knowledge both of the specific disorders we work with and of ways of coping with a rare disorder and to contribute to the development of high-level expertise in the field of rare disabilities. To this end, Frambu collaborates with educational institutions and centers of expertise in Norway and abroad.

Information

People with a rare disorder, their immediate family and professionals may contact Frambu by e-mail or telephone for accessible, relevant and professionally reviewed information about the rare disorders for which Frambu caters. Frambu also produces information materials about individual disorders, groups of disorders and topics relevant to many disorders. These resources may be ordered at our website or by direct request to Frambu. The staff of the library at Frambu can also provide guidance on relevant literature and helpful websites. Frambu's information materials are free of charge for people with a diagnosed disorder and their immediate family.

One family's experiences with Frambu

The following is a father's testimony about their experience with Frambu. Their youngest son, who now is 6 years old, was diagnosed with Smith-Magenis Syndrome (SMS)² as a toddler. They have two other sons too.

"Frambu is a very important resource we as a family and our support staff have had good use of. We, as a family, have attended two family courses. One was directed toward families with a rare chromosome disorder in general, the other towards Smith-Magenis syndrome. Our oldest son has also attended a sibling camp, and the grandparents have attended two courses for grandparents.

Our family has also received guidance through participating in a project about SMS and behavior, where our son with SMS has been one of the subjects. The fact that our son has been followed so closely, has given Frambu an insight into him and our family that has been an important resource in the dialog with our support staff, a dialog that often is demanding. Both staff from the kindergarten and the special educational services have attended courses at Frambu. And a special educator, a nurse, and a social worker from Frambu have visited the municipality on different occasions and given counseling and information about SMS and our son's challenges, needs and positive traits.

In general, we perceive Frambu's services to be of a high interdisciplinary standard, and they have a good connection with their user groups, which give them a solid practical foundation. They recognize real challenges and the problems those create

in our daily life. Frambu has also several times given us written statements to attach to applications for resources or other aids we need. Our case workers have also had the opportunity to contact Frambu directly if they have any questions or concerns. The courses we have attended have given us much relevant knowledge and a network of people in similar situations as us. We also believe that through our contact, Frambu has increased their ability to give advice and help to others. We always receive a high level of service and professionalism with sincere commitment from Frambu. One example is when they arranged a meeting for families and friends of families who had a child with SMS. This meeting was intended to be informal allowing attendees to ask questions and obtain information about SMS and the challenges as parents we live with. The parents of children with SMS were not present, making it easier to ask questions they normally wouldn't ask us or ask if we were present. Initiatives like this shows that Frambu understands and acts according to the families situation.

We could, of course, wish that Frambu had more resources and capacity, especially regarding supportive services in the local community and research. The different diagnoses groups are very small and it is hard to create an understanding about the different phenotypical problems in the schools and municipalities in general. More knowledge is needed both for parents to meet our responsibilities and for the professionals who are supposed to support us as a family.”

For more information, contact Wencke E.Grepperud
(Wencke.Grepperud@frambu.no)

¹ <http://www.frambu.no>. Frambu is located in Ostmarka, 17 south of Oslo.

² en.wikipedia.org/wiki/Smith–Magenis_syndrome

Marie's Story:

A new film about a congenitally deafblind girl considered France's Helen Keller

Marie's story¹ is based on real life events that took place in France in the late 19th century. Born deaf and blind, Marie Heurtin, aged 14, is incapable of communicating. Despite the advice of a doctor who believes she is “dumb”, Marie's father, a humble artisan, cannot bring himself to commit her to an asylum. Out of despair, he goes to Larnay Institute² near Poitiers, where nuns take care of young deaf women.

Despite the Mother Superior's scepticism, Sister Marguerite, a young nun, takes this "wild little animal" under her wing and does everything she can to bring her out of her darkness. She will succeed, in spite of some failures and the temptation of discouragement, armed with her joyous faith and love for young Marie.

Historical facts

In the second half of the 19th century, The Larnay Institute, a convent near Poitiers directed by the "Sisters of Wisdom", brought together a group of deaf-blind children to give them an education and teach them to communicate through sign language. Larnay gained worldwide renown after the publication of Louis Arnould's "A Soul in Prison" in which he graphically described the method pursued by Sister Marguerite for the education of Marie Heurtin, deafmute and blind by birth.

Marie Heurtin, often seen as the French Hellen Keller, arrived at Larnay in March 1895 at the age of 10. She was in an even worse state than the American girl: struggling and howling like a wild child, carried by her arms and feet, it was impossible to predict if she could learn anything and how, since she had neither sight, hearing nor power of speech.

Comments by Director Jean-Pierre Améris

This project began with my fascination for the story of Helen Keller. In my research, I came across the lesser known story of Marie Heurtin and I immediately decided to visit the Larnay Institute in Poitiers, where she lived in the 19th century.

The Institute is no longer a religious establishment, yet remains a center for deafblind children. In light of the scientific progress of the last hundred years, I was surprised to find that the institute was still in operation.

It is difficult for me to describe how I felt when I met these children who could only communicate by touch and who were eager to feel my hands and face as soon as I arrived. I felt quite powerless trying to communicate with them.

I also met these children's parents who explained the challenges they faced.

Exactly like Marie Heurtin's father over a century ago, some were told by doctors that their child was mentally challenged and would never be able to communicate.

The parents despair ended when they were introduced to the instructors of the Larnay Institute who taught their children how to make contact with the world.

Jacques Souriau (Jacques.souriau@gmail.com)

¹ Written by Jean-Pierre Améris and Philippe Blasband

² [https://inventaire.poitou-charentes.fr/.../Poitiers ... / ... biard](https://inventaire.poitou-charentes.fr/.../Poitiers.../...biard)

Tactile street name signs¹

One way in which people who are deafblind can find their way around the City of Sydney, Australia, is by the network of tactile street name signs.

The signs were originally developed in 1991 by Sydney City Council with the assistance of the Association of Blind Citizens New South Wales², to help people with vision impairment find their way around the City.

Rubber was selected as the base material at the time in preference to metal or plastic, as metal can become very hot in the middle of summer, and some plastics do not provide sufficient tactility, or they reflect light so that the message becomes blurred.

The City of Sydney Council has decided to up-grade the tactile signs and is currently testing a new material, lightweight aluminium with a photopolymer membrane.

The signs carry the street name and property numbers in raised lettering and in Braille, with white text on a black background. They are always found on the right-hand side of a traffic light pole as the reader faces the curb, adjacent to the audio-tactile pedestrian button and approximately one metre above the pavement.

This location allows easy access to the signs for people who touch-read, and for people with low vision who can read the sign at close range. As Braille is an international form of reading, visitors are able to find their way around the City of Sydney.

The sign in the photograph reads “Margaret St 42 – 60 L”. This indicates that the reader is facing the curb in Margaret Street while standing in front of property number 42, and that property number 60 is to the L (left). At the other end of this city block the sign reads, “Margaret St 60 – 42 R”, to indicate that the reader is standing in front of property number 60 and that property number 42 is to R (right).

Although the signs were originally developed for people with vision impairment, it has been discovered that they also provide independence and dignity for people who have speech and hearing impairments, as they may not be able to ask for directions or hear the answer.

At a time when there is growing interest in Universal Design³ it is hoped that other Cities might adopt a network of tactile street name signs similar to Sydney.

For more information contact: John Evernden, Accessible Public Domain
(www.accessiblepublicdomain.com.au)
Email: jajevernden@gmail.com

¹ Part of presentation made at 9th National Deafblind Conference, Sydney, Australia, June 2014

² www.asnblind-nsw.org.au

³ en.wikipedia.org/wiki/Universal_design. Universal design (often inclusive design) refers to broad-spectrum ideas meant to produce buildings, products and environments that are inherently accessible to older people, people without disabilities, and people with disabilities.

Secretariat News

Meetings

In November 2014, the Dbl Board and Management Committee came together in Belfast, Northern Ireland to participate in the last meeting of the year. A major area of focus was reviewing the progress Dbl has made on the current Strategic Plan. With the wealth of knowledge and experience in the group we were able to gather valuable feedback on areas we can improve on in the future. It was also a wonderful opportunity to acknowledge the achievements so far. The AGM also took place and we were delighted to welcome Lord Colin Low, President of ICEVI to the AGM to report on the activities of ICEVI.

Conferences

ADBN Conference

Immediately following the Dbl meetings, several Board and ManCom members stayed on to attend the 10th Conference of the Dbl Acquired Deafblindness Network (ADBN). The Secretariat manned the Dbl display table to promote Dbl to the delegates.

Dbl World Conference 2015

Registrations are open for the Dbl World Conference 2015. We encourage you to visit the conference website regularly for up to date information <http://www.dbi2015romania.com>. The Dbl Board, Management Committee and Annual General meetings will be held immediately prior to the World Conference where the election of Officers and Board members will be decided.

Awards

The Young Professional Leadership Award is a new Dbl Award and we are excited to be calling for nominations as well as nomination for the Dbl Distinguished Service Award and the Dbl Lifetime Achievement Award.

If you would like to nominate a deserving person, visit www.deafblindinternational.org/awards.html and complete the Awards Nomination Form. All nominations must be received by March 13, 2015.

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.

Thank you to all our members for your support this year. Early in the New Year we will be inviting members to renew their membership to Dbl. You can also visit the Dbl website any time to join online at

<http://deafblindinternational.org/membership.html>

On the back cover of each Dbl Review the current Corporate members are listed. If you know of an organization who should be a member of Dbl we would be happy to send them a letter of invitation. Please pass on any suggestions to:

secretariat@deafblindinternational.org.

We love to hear from you!

Sharing information is at the core of what we do. There is so much great work going on around the world and we can help you reach a wider audience by posting news on the Dbl website. If you have an event or activity coming up, please keep us informed so we can help spread the word. We are happy to facilitate communication amongst Dbl members and our contacts across the world so please keep in touch with us and let us know if we can help.

Matthew Wittorff and Bronte Pyett
Dbl Secretariat
Proudly hosted by Senses Australia

Dbl Board Membership 2011-2015

Management Committee

The Management Committee for the 2011-2015 period includes the two elected offices (President and two Vice-Presidents), Immediate Past President, Treasurer, Information Officer, Secretary and Development Officer:

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(information@deafblindinternational.org)

Board Observers

Dbl's partner organizations, ICEVI and WFDB have observer status on the Dbl 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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