

## **DbI Review issue Number 46 • January – June 2011**

Deafblind International was formerly known as the International Association for the Education of Deafblind People.

DbI Review appears twice yearly, the two editions are dated January-June and July-December.

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 and drawings are welcome; they will be copied and returned.

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.

DbI Review is also available on disk. If you are interested in receiving your copy on disk, please contact:

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Cover: Japanese drumming at Osaka Big Stage

## A message from the President

Dear friends and colleagues,

Another year is drawing to an end. While many exciting things have taken place during 2010, many changes occurred too. The DbI Board Meeting In Aalborg, Denmark, September 27-28, showed us that we are in command of the situation, mainly because of the commitment of the Management Committee and Board offering their time, passion and interest in our organisation.

The Management Committee and Board meetings were followed by what I heard was a great Network Conference on acquired deafblindness. It was not possible for all of us to stay on for the conference, but I have been assured of the quality of the logistics and content.

Another activity that everyone is talking about was the meeting in Paris of the communication network (the Magic of Dialogue). This network event was very much appreciated by all of those who were able to attend. Its outcome, through subsequent publications and information on the website, should be of great benefit to many others not able to participate

Many new people are becoming interested in our organisation and are willing to devote their time to continue the progress we are making. But of course we must not forget the past and the many people who have contributed to DbI and deafblind services over the years. Earlier this year I had the opportunity to be at a retirement party for one such person. Gini B. has always been available for DbI; it was a pleasure to offer her a small thank you for what she has done. There are many like her, including Eileen B., Tony B., Inger R., Rodney C., Richard H., Jacques S., and so so many more than I can remember at this moment. Many people who have not been maybe so visible as the above, should also be thanked and appreciated just as much. These include the teachers, educators, intervenors and family members and many more who are never in the limelight but contribute daily so much to the quality of life of deafblind children and adults. Furthermore, many unfortunately have left our field; gone, but certainly not forgotten.

To celebrate the past, Skadalen School in Oslo, Norway created a wonderful occasion to remember the developments over the 30 years of their existence. Our congratulations for their well deserved achievements.

While some have gone, others have stepped into new roles which have consequences for DbI. We welcome Gill Morbey in her new leading role at Sense UK and Aubrey Webson as the new director of Perkins International. We wish them all of the very best and look forward to maintaining the close relationships we have enjoyed in the past with them and the organisations they represent, which have contributed so much in the past.

Next year other changes and transitions will take place noticeably because of the elections of the new board and management committee. The nominations committee is actively encouraging nominations to these all important roles to fill. Give your thoughts to Knut Johansen, chair of the committee, so your voice can be heard. It will be an exciting time at the World Conference in Brazil next September, when the elections will be completed. The organisation of the conference is well under way and I hope as usual that many can make it to Sao Paulo.

During the subsequent board meetings, ample time will be given to discussion of the strategic plan and its consequences. Input from our membership will be of utmost importance and will help to form DbI in the future to be the representation that you expect from it.

On a final note and once again thank you all for all you are doing for our field and the organisation.

William

## Editorial

Dear Colleagues

By the time this edition reaches your desk, the holiday season will be over and you will be gearing up for what I hope will be a prosperous and successful 2011.

It will be difficult to describe an overall theme for this edition due to the wide subject matter of the articles. Perhaps this suggests to me that the field is expanding at such an incredible rate that it is simply “bursting at the seams”.

This edition portrays a wide spectrum of activities around the world, including articles on staff development and education in Switzerland, Romania and Hungary; a new initiative in Pennsylvania, USA; a Nordic Welfare development project in the Baltic States, and the establishment of a Latin American Families Federation sponsored by Perkins International.

In Country News, important announcements are made, including new legislation in Finland promoting the equality for deafblind persons, which would be the envy of many countries. The Canadian organization, CDBA, announces an Intervenor Competency framework established to address the need for a standardized knowledge and skill set for Intervenors working with individuals with congenital deafblindness. This could be very useful to other organizations which employ Intervenors, contact persons and interpreter guides. We welcome a report from Japan. Akemi, whom some of us met at ADBN in Aalborg, describes how deafblind theatrical performers contributed positively towards awareness of their disability during commemorative events in Osaka.

Articles of a more technical nature include an extensive article by Dr. Rowland (USA) describing an on-line assessment tool for early communicators who are deafblind, and an exploration from Karen Wickham (Australia) into the world of mental illness within the deafblind community. Gail Deuce and David Brown return to the magazine with an interesting study describing the results of conversations with families and individuals about their CHARGE syndrome condition.

I was fortunate to have attended the 8th ADBN Conference in Aalborg, Denmark in late September 2010. Of the excellent plenary sessions, we are featuring four stories about important relationships, family and otherwise, which affect the lives of deafblind people. Included are Femke’s connection with her social worker; Linn’s relationship as the daughter; Sabine’s reflections as the sister, and Annette’s personal insight as a contact person. These very personal stories are very powerful.

I encourage members and professionals who read this magazine to come to Brazil in late September 2011 to attend the 15th DbI World Conference in Sao Paulo. Check out the conference website for more details on the Call for Papers. Expect to have a wonderful experience in Sao Paulo, both intellectually and socially. Vula’s introductory article ‘Sao Paulo Welcomes the World’ is a good primer.

Congratulations to Sense Scotland for their flagship centre, TouchBase, receiving recognition as a UNESCO Creative City of Music arts and music venue.

I mentioned in my last editorial that Dbl was considering converting the magazine's current print format to being primarily web based. Readers should not despair any further about the loss of the print magazine. The Board recently decided to continue with the current print magazine format and add a web-based version later. Finally thanks for the compliments for the previous edition and the overwhelming contributions for this edition. Keep them coming!

Stan Munroe

## **São Paulo – Brazil**

### **Welcomes the World to the 15th Dbl World Conference on Deafblindness**

São Paulo will host the 15th Dbl World Conference on Deafblindness from 27 September through 01 October, 2011.

#### **About São Paulo**

São Paulo, one of the megacities of the world with 11 million inhabitants, supports the largest hotel complexes in Latin America. It is the second biggest city in numbers of restaurants (boasting 12,500) featuring some fifty-two different types of cuisine.

Opportunities to enjoy entertainment, culture and leisure activities are plentiful in the city that hosts ninety museums, 160 theater houses, 55 movie theaters, 45 green parks, seven theme parks and seven soccer stadiums. Its one car race track hosts the Grand Prix Formula 1, the only one in Latin America. This is just a sample!

The Conference venue

In the heart of the beautiful and green neighborhood of Moema is located the Ibirapuera Convention Center where the conference will be held. Moema is considered the neighborhood with the best quality of life in São Paulo. Its near vicinity to Ibirapuera Park, one of the city's postcard sites, and being adjacent to the Ibirapuera Shopping Mall, makes this venue a very special place.

The Convention Center and hotel offers more than 650 rooms, a fitness center, saunas, a swimming pool, bars and restaurants. This Centre can host events with more than 1000 people. Its broad foyers and open spaces are an invitation to get together between plenary sessions or workshops. In addition to the Conference hotel, many other hotels are located within walking distance.

#### **Food and shopping at hand**

The Ibirapuera Shopping Mall is right next to the Convention Center. One can choose from a wide variety of more than 450 stores distributed among its four stories. Its three excellent food courts will be the source of lunches on conference days. The Mall is conveniently open daily from 10:00 am to 10:00 pm, except Sundays when it opens from 2:00 pm to 8:00 pm. If one prefers to walk outside, Moema is crowded with nice

shops, restaurants and bars that get crowded during happy hour with beautiful people – some who wish to relax after a day's work, or those who might be looking for some romance!

### **Lots to see and do**

In São Paulo it is impossible to stay still with so much that the city offers. The many cultural and historical tourist opportunities include many museums and art galleries; historical buildings and squares; traditional Japanese, Italian or Lebanese quarters with their typical restaurants. A city tour would also take one to Paulista Avenue and through upscale neighborhoods such as Jardins and Higienópolis.

In São Paulo there are many huge and impressive Shopping malls. Or if one would rather find more popular items, a visit to the street 25 de Março would prove a good choice. This is close to the Municipal Market, where having lunch on the second floor with the building's vitral windows is a must see!

### **Nightlife: More hustle and bustle than during the day**

Don't even think of going to bed early while in São Paulo! At night there's more car traffic than during the day. There are street fairs that are open all through the night; many supermarkets and stores are open 24 hours. If you enjoy dancing you should definitely visit one of the Samba Schools that have specialized presentations during Carnival. An alternative would be a Forró dancing restaurant to learn a few steps. In São Paulo one will find any kind of dance and food to your liking; including typical Brazilian, jazz, R&B, country and rock nightclubs.

### **Day trips**

Surrounding the city one has a choice of beach, mountain or countryside, just one to two hours by coach ride. If you prefer the beach, Guarujá is the perfect place where one can enjoy a walk along Enseada Beach with its sea shore kiosks featuring coconut water or some exquisite cocktail. Perhaps choose one of the many restaurants and try a traditional scrumptious fish dish prepared in clay pans.

If you like the mountain atmosphere, Campos do Jordão brings that sense of 'being in Europe'. It will certainly get to you with its charm and elegance.

It is a rather romantic city; often a choice for newlyweds.

The countryside is for more adventurous people, who might be into extreme sports. You can go rappelling or rafting at Brotas; the brave ones can try parachuting in Boituva. Hands down, there are choices for everyone.

### **Spend a few more days in our beautiful and appealing country**

Thinking about stretching the trip a little bit? Brazil is a land of diversity; divided into 5 regions, each one with its own culture, traditions, typical food, different fauna and flora and, of course, beautiful people.

Good coaches are available every 30 minutes to Rio de Janeiro (5 hours), Belo Horizonte (6hours), Curitiba (5 hours), and Campinas (1 hour). São Paulo also features two of the busiest airports in Brazil: Guarulhos International and Congonhas, both offering many options for flights abroad and for all major cities in Brazil.

Everyone has heard of the Rainforest! A trip to the north of the country would take you to the Amazon River. Here one can witness the encounter of the waters of two rivers; they don't get mixed, they flow side by side. If you go to the Center-West, there's the wonderful Pantanal Region. This means wetlands, where people can see alligators, many species of birds and the breathtaking view of the scenery during a boat trip.

Further south the weather is more temperate and where one can experience a more European style of life. This is also where you can see the border between three countries: Brazil, Argentina and Paraguai at the spectacular Iguazu Falls.

The Northeast is the place to be if you simply wish to relax on the beach. Porto de Galinhas, Porto Seguro and many other have all inclusive resorts.

### **The Scientific Program**

The movement towards inclusion has grown stronger in the recent years, especially after Salamanca and more recently the UN Convention on the Rights of the Persons with Disabilities. At this conference we will be delighted if you could come and share your views as well as your best practices along with studies and researches so we all can develop and offer better services and support to improve the quality of life of the deafblind people and their families.

The plenary sessions and workshops we have planned will address the following issues:

- Assistive Technology
- Changing Population
- Communication and Language
- Transition to Adult Life
- Inclusive Education
- Neurological/Cortical Etiology
- Pediatric Rehabilitation
- Syndromes
- Elder Individuals
- United Nations Convention on the Rights of Persons with

Disabilities/Advocacy

Brazilian natural beauties and richness are not only found in the cultural and environmental aspects, but also in its diversity. Come join our Conference and add to the richness of diversity, you may find that you too have the face (and heart) of Latin America.

Vula Maria Ikonomidis on behalf of the XV DbI World Conference Local Planning Committee

**Perkins International Córdoba, Argentina, June 28-30, 2010**

## **Meeting of Latin American families of individuals with visual impairments and additional disabilities and/or deafblindness**

Perkins International brought together leading parents from 15 Latin American countries in late June 2010 for the purpose of creating a Latin American-wide parent organization.

At this meeting there were leaders from various countries who have just started the search for solutions for their children. They had the opportunity to meet members of other parent organizations that have been struggling for the last 20 years for better services for individuals with visual impairments and additional disabilities and/or deafblindness in Latin America.

Special guests from the government of the Province of Cordoba attended the second day of the meeting.

Perkins International strongly believes that collaboration between professionals and families is the best way to develop services and opportunities that bring about quality educational services for the children. This is why Steve Perrault, Graciela Ferioli and other team members, as part of Perkins International, worked so hard to ensure this meeting would be successful.

The meeting was held in the city of Córdoba, Argentina, on June 28- 30, 2010. The attending countries were represented by leading parents selected from each of the following countries: Argentina, Bolivia, Brazil, Colombia, Costa Rica, Chile, Ecuador, Guatemala, Mexico, Panama, Paraguay, Uruguay, Dominican Republic, Venezuela, and Peru. The meeting coordinators were Lic. Alicia Rosaz, Prof. Verónica Cajal and Prof. Áurea Soza; themselves leading mothers as well as Perkins consultants.

At the opening ceremony, a candle representing dreams and wishes, was lit on the Tree of Life by each attendant. All attendants, each determined to strike down barriers, acknowledged with thanks the opportunity provided by Perkins and its Latin American representatives to join the work team as active members.

The presentation, enhanced with a Tree of Life, was really touching. Each attendant narrated how their way was illuminated by the other parents they met. Experiences, hopes, and dreams that paved the way for a new start were also shared by organizations such as FUNDAL (Guatemala), Fundapas (Venezuela), Abraspasem (Brazil), APPS (Argentina), APPEDIVIDA (Uruguay), Fundación Braille (Paraguay), ASOMULTIDIS (Ecuador) and Leaders Parents (Chile).

Encouraging and discouraging experiences were shared and exchanged during the meeting, all of which resulted in the determination to build a Latin American network of families. To attain such a goal, the following issues were discussed: models, leadership, empowerment, vision, mission, organization chart, roles, tutors, and family rights.

A result of the meeting was the creation of Latin American Federation of Families of Individuals with Deafblindness and/or Multiple Disabilities. The main objectives of this new federation were agreed to be as follows: provide information, training, support and empowerment to families and parent organizations; raise awareness and empathy; form parent and professionals partnerships; become involved in public policies; promote social inclusion and new services or programs; organize local and international conferences; provide encouragement and exchange experiences; conduct surveys; create libraries and maintain records.

It was agreed that the new Federation shall be organized as follows: Four facilitators, each representing the countries of their region, shall act in Latin America as the Federation's Joint Coordinators (Brazil, Guatemala, Venezuela, and Argentina). Their role shall be to guide and facilitate processes, give advice, promote actions, ensure effective communication and inform both Perkins International and the Federation about the actions taken by each region and country. Likewise, each country shall appoint a representative for a term of 2 years, until the continuity of the agreements made is assured. Through this time the representatives shall be working on the plan of action that they developed at the LA Parent Meeting with the local parents at their own country with the support and guide of their facilitator.

The group formulated the following 2010 action plan for the new federation:

Rights of Parents of Individuals with Deafblindness and/or with Visual Impairment and Additional Disabilities

Brainstorming by the attending parents resulted developing the following statements of rights and priorities:

- We have the right to access information and be involved in school collaborative teams and services;
- We have the right to receive training;
- We have the right to participate and make decisions in educational teams;
- We have the right to be parents and not professionals of our children;
- We have the right to vacations and be happy.

## **Other Meeting Discussions**

During the sessions, parents shared their experiences, their dreams and difficulties. Positive support from each parent became apparent towards the development of this new Federation and its action plan.

Furthermore, each parent's story acknowledged organizations like Perkins for their respect and recognition and the opportunity to become part of a professional team. It became apparent that the use of technological tools for contact purposes may turn out to be a challenge for some members of the new group. Parents may need to be trained and/or updated on new technology. However it must be taken into account that access to technology, and not technology itself, can be the issue. It is worth highlighting that ethnical diversity must be protected in its own context, so parents will be required to become knowledgeable about each country's legal regulations. Parents have learned from experience that one way of being healthy is to be patient with state bureaucracy. Government officials and parents time are not always the same! So, it might prove beneficial for some parents to use mediators to access government officials.

The meeting featured lunches, tourism and recreational activities thanks to the collaboration of friends and government authorities who made transportation and their friendship available.

The Perkins organizers explained a new joint service project "Transition to Adult Life Program: Independent Living Experiences" which was developed by the Under-Secretariat for Child and Youth Protection (Córdoba), FOAL, Perkins International, and Asociación Sullai. The leaders of new joint service program emphasized the need to build a collaborative administration; the combined effort of which should encourage each social sector to comply with its role, this being the cornerstone of any sustainable development. The need to respect the rights of individuals with disabilities through the provision of quality services, was also strongly reinforced. Likewise, the



importance of getting the family involved in work teams was highlighted as necessary step towards these changes.

At the closing ceremony, Steve Perrault kindly addressed the audience through videoconference. He congratulated the participants on their achievements and their new challenges ahead.

To close, the highly enthusiastic participants exchanged gifts along with good intentions which, we hope, may soon be accomplished.

A special note of thanks was extended to Perkins International for creating the opportunity to bring these Latin American parents together for a most productive meeting.

VIVA .... VIVA..... LATINO AMÉRICA!!!!!!

Report prepared by:  
María Verónica Cajal,  
Córdoba, Argentina

## The Regional Facilitators

Nº	Name	Home Country	Other Countries represented
1	Massiel Denice Requena de Iriarte	Venezuela	Panama, Ecuador, and Colombia
2	Amanda Elena Sinibaldi de Bonillas	Guatemala	Costa Rica, Dominican Republic, & Mexico
3	Susana María Mana de Araoz	Brazil	Chile, Peru
4	Alicia Rozas	Argentina	Uruguay, Paraguay, and Bolivia

## The Country Representatives

Nº	Name	Country
1	Brígida Belkis Reyes Cabrera	Dominican Republic
2	Magda Susana Román	Colombia
3	Rosa Elvira Bernedo Orihuela	Peru
4	Cuevas Gonzaga Luis Eduardo	Ecuador
5	Patricio Jorge Castillo Díaz	Chile
6	Marta Loreto Castillo	Chile
7	Aidee Flores Rodriguez	Bolivia
8	Okky María Ulate Chacón	Costa Rica
9	Desireé Caicedo	Panama
10	Estela Beatriz Gonzales de Sarubbi	Paraguay
11	María Magdalena Galeano	Paraguay
12	Schleske Morales maría del Carmen	Mexico
13	Betina Elizabet Silvera Campelo	Uruguay
14	María Inés Claudino Gallardo	Uruguay

## **Federation's Proposed Action Plan 2010**

Objective	Activity	Date	Person responsible	Assessment
Identify representative for each country.	Call a national meeting.	August 16, 2010	Facilitator	Make a list of all facilitators available by organization and country. Indicate office or role within the organization.
Election of new representatives and facilitators	Voting	August, 2012	Facilitators	List new federation representatives and facilitators
Determine the profile and role of each country's representative.	Meetings via internet once a week.	July 15, 2010	Facilitators	Make a written profile of representatives available to members of the Federation.
Socialize and share knowledge acquired in parents meetings.	Meeting of parents from each country.	November 15, 2010	Facilitators & representatives.	Reports to be written by a representative to the regional facilitator.
Inform the progress of actions taken by each country every 3 months.	Make a report listing strengths, needs and strategies to overcome difficulties.	Beginning September, 2010	Perkins International, Áurea Soza and facilitators.	Prepare reports with data about individuals and families served, services provided and programs, etc.

## **Depending independence:**

### **The complex relationship between a deafblind client and the social worker**

#### **Femke Krijger, Plenary Presentation, 8th ADBN Conference, Aalborg, Denmark**

##### **Introduction**

I am honoured to be able to share some thoughts with you about this issue at this conference. During this presentation I would like to look closer at these dynamics from a personal point of view to learn more about the interaction between the deafblind client and the social worker. But before this I will state a little about relationship dynamics in general.

##### **Relationship dynamics**

When I speak of the dynamics of a relationship I speak of the power or forces that are working in a relationship. There are three basic dynamics involved in all relationships: power, affection and respect.

The dynamic of power basically is about the question 'who is in charge?'. The dynamic of affection involves issues of liking and disliking. Finally, the dynamic of respect comes down to the question 'does my opinion matter?'.

## **The dynamic of power**

Two main issues come to my mind when thinking about the dynamic of power between the client and the social worker: equality and focus of assistance.

### **Different equality**

Power is about control; about the question 'who is in charge?'. Considering the relationship between the deafblind client and the social worker we should observe that there exists an intrinsic inequality. The client is in need and this makes him depending on someone to help him. This other person holds the power of deciding to help or not, as well as the power of the quality of his assistance.

I will give you examples of both. At an earlier time, I expressed my wish at the rehabilitation centre to learn Braille. The reaction at the rehabilitation centre was very disappointing. They did not support my wish because of their policy that as long as you could see anything, learning Braille would be too difficult. I was determined to keep looking for someone who would agree with my point of view. This one person had the power to deny my wish with arguments that did not counter my own. This person was holding the power and decided not to help.

Besides the power of deciding, the social worker holds power on the quality of his support. This power shows clearly such as advice on such aids as cane. Since I walk a lot, and mostly rather fast, I prefer a cane that is as light as possible. The first time ever I had to choose a cane, the social worker gave me the choice among some general canes. After trying them, I was wondering if there was not a lighter version. A deafblind friend gave me some information about her cane and I went with this information to the rehabilitation centre. They told me that there were lighter canes, but they were much more expensive and the insurance company would not pay for it automatically. I should write a letter to the insurance company with a special request of permission. I did and received the permission.

### **Different focus**

A second aspect connected to the dynamic of power is the focus of assistance. Usher, the cause of my deafblindness, has a tremendous impact on all aspects of my life.

Deafblindness is only one factor creating my identity. This means that when I enter the rehabilitation centre to meet a social worker I am not walking deafblindness, I am Femke, a person who happens to be deafblind.

However, in the relationship with the social worker the focus of assistance is on deafblindness. This is the very reason I come to the social worker. It is important for me to realize that the thresholds that occur because of my deafblindness are keeping me from living my life as I want. The focus of assistance, therefore, should be: living my life as I want as much as possible. The focus should be on helping me pass thresholds to live my life as Femke.

In my experience, there is often little time to dwell on the subject of how I will implement the suggestions in my daily life. Let me explain. Some years ago I went to a rehabilitation centre to get advice on lighting. That day I sat in a dark room at a

white table with differently coloured place-mats. Behind the table I discovered a bookshelf with some pottery and an armchair standing next to the bookshelf. The first thought crossing my mind was how ugly this all was. However, I did understand that I was not there to comment on the furnishings, but to learn something about the light that would be best for me. The social worker changed the lightening in the room and I was supposed to tell what I preferred? He asked me if I saw this or that, and I was wondering if I should tell him if I saw it at all or if I could easily see it. The reason I was wondering, was because I know that the better I can see something, the less energy is required. Besides, if I could see only a very small part of something, my mind did often a great job in guessing what it might be.

After about one hour I could leave the room. The outcome of this examination was written advice on the amount of lux I needed at home. The advice did not help me achieving any thresholds at all. It told me I could use a lot of light, which I knew beforehand. However, it did raise new thresholds: I had to find out what this number of lux actually meant standing in a lamp-store. And I had to weigh between the need of much light and the wish of a cozy home, something my husband too had a say in. Then there was the threshold of money. Adapting the house considering lightening would be expensive. Maybe I could receive an allowance from the community centre; but I had to check. If the advice would had taken into account my personal lighting needs, wishes and thresholds, the advice probably would have been much more effective.

## **The dynamic of affection**

We come to the second issue involved in relationships, the issue of affection.

### **Different persons**

You might say that in professional relationships the issue of liking or disliking should not play a role. I don't think this is true. Relationships are about having a connection; and being interconnected means sharing something of who you are.

This does not contradict the fact that there should be a professional attitude towards one another in this relationship. On the contrary, the professional attitude regulates the exchange of non-verbal information of how we feel about the other person. The professional attitude requires awareness of the fact that we always signal feelings we have towards the other person, such as warmth, acceptance, coldness, indifference, etc. Awareness of this makes room to attune to the other person and to what he is willing to share.

Secondly, it is good to realize that visual and auditory information is lacking because of deafblindness. However sensitive information is increasing to compensate this deficiency. A deafblind person may not see your body language literally, but he will often sense whatever you signal. The information received by the sense of touch is as powerful or maybe even more powerful as information received by the sense of sight and hearing.

Finally, communication with someone with deafblindness demands the understanding of vicinity. If you want to tell me where to sit best, you may take my hand and lead me. If you want to catch my attention, you may put your hand on my shoulder. If you want me to see and hear you the best I can, we should sit not too far away from each other. This physical vicinity easily leads to a closer bond between the client and the

social worker. If you lead me by taking my hand, I feel the temperature, the energy and the tension of your hand.

What I would like to state is that the relationship between the deafblind client and the social worker carries a very complex interaction that takes affection into consideration.

## **The dynamic of respect**

The third dynamic I would like to discuss with you is the dynamic of respect.

## **Different realities**

What I find very important is the mutual understanding between the client and the social worker when two different realities come together when they meet. The impact of deafblindness colours my reality in the way that I connect to people, the way I move, the way I orientate myself, my energy expenditure and my sensitivity. I live in a very different world compared to sighted and hearing people.

The difficulty is that my world coloured by deafblindness is not my native ground. I was born in the world of sighted and hearing people. Because of the progressive influence of deafblindness I now need to explore this exotic, unknown world. The social worker should realize that, he should not only help me to find ways to stay in touch with the sighted and hearing world, but also help me to find ways to live in this new reality. Only when I have found a new home base can I get into contact with the sighted and hearing world, without getting lost.

I realize that this request is not an easy request. I ask you to open up your own reality to make room and to attune to my reality and to explore it together with me.

## **Different knowledge**

Although as a deafblind person I need help in coping with deafblindness, I do have a lot of knowledge on the subject already. Not every deafblind person is aware of the fact that he already holds important knowledge on the subject of his need, because adaptive behavior arises spontaneously. For example, opening my handpalms in order to receive whatever information the person in front wants me to receive. I am using body language, with my hands, to express that I am willing to receive and therefore making a connection.

Both the client and the social worker may benefit from paying attention to the clients knowledge in two ways: First, attuning to the existing knowledge improves the chance that rehabilitation support fits the need of the client and, secondly that the support given by the social worker may complement the coping strategies of the client, rather than replace them.

## **Different interest**

The underlying interest of my need is the wish to improve the quality of my life. The underlying interest of the social workers willingness to help is his wish to fulfill his duties as employee. I am not saying that there is no personal involvement for most of the social workers, for I know that many of the social workers are very much involved into their work. Notwithstanding this involvement, we should be open to the fact that

their help is primarily based on their profession. However, it is good to realize the difference between my existential interest as a deafblind client and the professional interest of the social worker. As a client I can be very demanding. This is not always easy and may sometimes even cause feelings of insecurity with the social worker. But I am fighting for the quality of my life and I ask him to join me.

## **Conclusion**

I discussed the dynamic of power, affection and respect considering the relationship between the deafblind client and the social worker. Studying these three dynamics I discussed important differences between what the client and social worker brings to the discussion. Differences are not necessarily conflicts. On the contrary, I believe that these differences can be made fruitful to improve rehabilitation outcomes. Keys to make them fruitful are: awareness and attuning. We are depending on each other, to be independent. I cannot be independent without the help of the social worker, who can offer me valuable, necessary knowledge and skills. The social worker cannot work independently, but is depending on my trust and knowledge by experience to reach the best outcome possible.

## **Super Sister**

### **Sabine Kersten**

#### **Plenary Presentation, 8th ADBN Conference, Aalborg, Denmark**

Everywhere I'm turning  
Nothing seems complete  
I stand up and I'm searching  
For the better part of me

I hang my head from sorrow  
State of humanity  
I wear it on my shoulders  
Gotta find strength in me

'Cause I am a superwoman  
Yes I am,  
Still when I'm a mess, I still put on a vest  
With an S on my chest  
Oh yes, I'm a superwoman  
Superwoman (by Alicia Keys)

For me this song represents the family members of deafblind children and adults. No matter how long it takes, no matter how hard it is, we will always continue our fight for a good quality of life for our deafblind family members.

### **The facts:**

I have only one brother, Raymond. He has Usher syndrome, type 1 with vision of 3 or 4 %. Our parents are still alive, getting older, having (small) health problems. I have my own family, with a husband and two children.

Our parents have worked very hard to ensure Raymond's quality of life; making sure he received the care he needed, trying to make sure he could reach his full potential, using all of his talents.

I simply grew up, very independent; always stuck in second place. Don't get me wrong, I don't blame my parents for anything. They were there when I needed them, and most important, they did the best they could.

I am sure many of you have brothers and sisters. Have you ever realized that the sibling relationship is the longest lasting family relation we normally endure during our lifespan? Under the best of conditions, this can mean the potential for intimate sharing with a beloved companion throughout one's life. However, when a brother or sister has special needs, it also means enduring responsibilities for the siblings.

My parents are no longer able to give Raymond the care he needs; there is no one to take over except me. Raymond does get some professional help, but this is not enough to guarantee his quality of life. Knowing that Raymond (and our parents) count on me, brings a lot of pressure. I have to figure out what my role in Raymond's life will be, having to divide my time between my family life, work and Raymond. I do this all this while trying not to lose myself.

Finding this balance has been a difficult process which still continues. Every day things happen and I have to think how to react. Should I do something? Or is there someone else who can? Having two children of my own also forces me to think how to handle when Raymond needs help. This does not mean I don't like doing all this for Raymond. On the contrary, I really enjoy our time together even though it is not always easy.

I never asked to be part of the deafblind world, and no one asked me if I wanted to be part of it. But I am part of the deafblind world and deafblindness is a part of me. I never imagined myself advocating for Raymond's rights, talking to our local authorities to make sure Raymond gets all the care and equipment he needs to lead his life, even going to court if necessary, which is exactly what I am doing at the moment. Someone dear to me once asked me "How would a perfect deafblind world look like?" I could not answer that, but it made me think. I am still not able to answer it, but I am going to give it a try, from my point of view.

I want Raymond to live a meaningful life, and he is the one to define meaningful. I want him to be able to explore his talents and to pursue his dreams.

In a perfect deafblind world Raymond will continue to live independently. He cannot do so on his own; he needs help with that. The care he needs will be provided by professionals, who respect him and treat him with dignity.

The authorities will work with us, not against us. They will do their best to guarantee Raymond the best possible quality of life. This will mean they will pay the necessary costs, without having to go through the same difficult and lengthy process of proving his disability and the consequences of this again, and again, and again.

He will be surrounded by family members and friends. If he makes new friends, they will not abuse his trust and his ignorance of the bigger world he cannot see, hear or feel.

We still have a long way to go to create this perfect world. I cannot do it on my own, and more important I do not want to do it on my own. I need the right people along with me, and I am trying to these people: Professional's who are able to support me, help me and who will, this way, let me be Raymond's sister.

Usher Syndrome is not just losing hearing and sight. There are many more issues one has to deal with. Genetic issues have been very important to me, and still are. During both of my pregnancies, the fear for Usher syndrome was at the back of my mind the whole time. This, in spite of what several different doctors said about my chances of having a child with Usher syndrome.

Communication is a very big issue for us, as a family, at this moment.

But there is a deeper consequence, which in my opinion is one of the most difficult things about Usher Syndrome: the fact that it is progressive.

This means that dealing with Usher syndrome means dealing with an ongoing process of mourning. This process is never ending; the condition will change, get worse, sometimes even on a daily basis. People understand that this must be very difficult for Raymond to deal with. They may even understand that this is very difficult for our parents. But not so many people really understand that I am going through the same difficult process.

Over the last ten years, Raymond's sight has significantly deteriorated.

Communication became an issue; five years ago he was still able to lip read but now he needs tactile sign language. This is a complete new language we all, including Raymond, had to learn over the last years. And we are not there yet. He is no longer able to fly his airplanes, his passion for as long as I remember. He still tries to build them though, but that is becoming more and more difficult. He used to make drawings for my son, but when my daughter was born two years later, he was not able to make her a drawing anymore.

So it is not just Raymond who needs to constantly change his view on life. My brother changes, his point of view on life changes as his condition deteriorates. His attitude towards me changes. Just like all of you have a picture in your head about your relation with your brothers and sister, I have a picture in my head of how our brother – sister relationship should be. But this picture must also change constantly due to his condition. Let me tell you, it is difficult to lose bits and pieces of my brother along the way.

Several people I know have recently left the deafblind field for various reasons, which has upset me and left me disappointed. Later I realized I was jealous; I wondered why. After some sleepless nights I found the answer: they can get out of the deafblind field, leaving it behind and finding a job in a different area. Many of you, sitting here today, are able to leave the deafblind field if you want to. But I, as some you, am never able to leave the deafblind field. For me, being Raymond's sister, this is not just a job, this is life.

So, even when I am a mess, I still put on a vest with an S on my chest. But I am not a super woman!

## **Super Daughter**



## **Linn Bjerkli, Plenary Presentation, 8th ADBN Conference, Aalborg, Denmark**

Hi, my name is Linn Marie Bjerkli and I live in Norway. I want to present my subjective experience from my childhood with a mother who is deaf blind.

I grew up with a mother who was deafblind, a father who was deaf and two younger siblings. Now I have my own family, and live with my husband and two children, who are 4 and 6 years old, both of them are hearing. I studied to become a sign language interpreter, and have been working as an interpreter for 10 years. Now I have started to study again.

My mother has Retinitis Pigmentosa and diagnosed with Usher Syndrome Type 1. When she was a young girl, she lost the sight of one eye through an accident. In the last year a cataract has occurred in her other eye.

### **Trying to seeing the world through mother's eyes**

I was 28 years old when a woman came to visit us to provide us with information about our mother's eye disease. She brought equipment along to allow us to see the world through our mother's eyes, and get an understanding about her sight. When we tried the glasses, we stumbled and fell; we couldn't see each other or what we were looking at. It was an experience that made us understand how bad my mother's sight was, after so many years. We have always known that our mother didn't see well; but we never realised how bad it was. While she appeared to do everything without any problems, we believe now that it required a lot of energy to hide it from us. Suddenly we now understood our mother much better. This conversation and support should have been offered to us much earlier.

During my childhood I didn't notice as much my mother's sight loss as her lack of hearing. This was mainly due to the early stage of Usher phase making it not as obvious for others to notice. Maybe she hadn't accepted the illness herself yet; I think she struggled with this for quite a long time. This made it more difficult for us to understand her situation and needs.

### **Challenges for family and friends**

It was often challenging for our family to do things together and create common experiences which would bring the family more together. Maybe it was difficult because of the cultural difference between deaf and hearing. I also think it was because of my mother's limited sight and poor balance. We always had to adapt to her needs, which sometimes was frustrating for a child. We felt that the consideration for our mother always came before our wishes.

The communication with other hearing people was challenging for my mother causing her to miss out on a lot of information. She often needed to have things repeated several times to make sure that she had understood everything correctly. I remembered that my siblings and I thought this was tiresome; but it had to be frustrating for my mother as well. This insecurity and the feeling of not having control must have been very difficult for her.

It was hard to us to follow up with homework, school and friends. What did us as children talk about around the dinner table, on the telephone or when we had friends over? It was also difficult for her to keep contact with other parents; it was not easy pick up the telephone and call, or go over for a talk. Other parents did not know how to be around deaf people - how should they express themselves or make themselves

understood. Consequently in many cases they preferred to draw themselves back. I was often impatient and did not always give my mother the time and repetition that she often needed in order to understand what was being said. At the same time I developed a lot of bad conscience, because I always felt that I could have done more for her knowing her needs.

### **Taking on the responsibility as an interpreter**

I was not very old when I started to interpret for my parents. While I didn't always understand what the adults were talking about, I visualized it in a way. When I got older I interpreted more and I believe I functioned better as an interpreter. At that time there was a very limited interpreter service available, thus my parents had little choice. I interpreted me and my sibling's parents meetings at school, at the bank, for doctors appointments and for other situations.

When I think back, it is interesting that none of the staff at the various institutions like kindergarten, school, health service etc. reacted that I was interpreting for my parents. As I remember, they thought it was charming. I obtained much information about my parent's life, which a child should not know and worry about. I didn't think so much about it then; it was my childhood. I remembered people often asked me: "how is it really to have deaf parents?" I thought it was a silly question, and didn't know what to answer. I didn't know about anything else; I never had hearing parents. For me it was normal. But I remember I was fed up with helping them all the time as I often preferred to go out and play with my friends.

It was like a role change. When I was interpreting I got a lot of information. Even if I translated it to my parents, I had a feeling that I had to take responsibility. Did I understand everything? Did they understand what they had to do further? All the applications they had to fill out, the letters they had to read and write? Often I took the tasks because it was much easier and faster to do it myself since I had all the information needed, and I did not need to include them. Now I see that I took away some of my parents independence and some control over their situation. I took the control and the responsibility without knowing it, and without wanting to do it. In this way I made them even more dependent on my help. At the same time I was tired of helping them with all these things all of the time. I felt that I was an adult quite early, even though I was not ready.

### **Interpreting for mother: was it fair?**

I remember I thought it was very unfair that, despite me being the oldest of the three siblings, it was only me that was expected to interpret. This feeling of injustice increased when my brother and sister got much more attention, support and care than I did. Possibly it was because the others saw me in a different role. While I appeared strong and independent, likely they didn't see the little girl hidden behind the interpreters role with all that responsibility. The truth was that I was insecure and needed help with different things. However there were no room for that as I had to learn to arrange everything myself. While it all went well during the early years, a reaction to all this responsibility came later when I became an adult. Unfortunately this has affected my relationship to my mother and father.

## **Mother's coping difficulties**

I can see that it is difficult for my mother to live with this disease and the uncertainty related to the development of it. I understand that she constantly has a permanent sadness about it. Different situations in everyday life, constantly remind her that her sight has deteriorated. It is difficult for us who are close to our mother. How can we console a person who is deaf and gradually losing her sight? I think that my mother would have been in a much better situation if she had been offered professional help to discuss her condition and the challenges she is facing. When she is not talking about the condition and trying to hide it, I believe that she is isolating herself, making the situation worse. I do not think that the support around my mother has been satisfactory which had led to most of the load pushed on to the family. There has been limited information available about the rights and supports available. One has to be strong, independent and knowledgeable to know what to ask for and to promote our needs to the official agencies and others.

## **A difficult decision time**

Some years ago I became burned out partly because of my past role and the responsibility I felt for my parents. I felt I had to take a decision with the role I had in the family. It has been very difficult and wounding, but at the same time necessary. I could no longer continue to be the person I had been for my parents. I now had my own family and felt that I had more than enough with the responsibility I had for them. I missed just being a daughter and their child.

When I gave up the role I used to have in the family, I felt a kind of emptiness. We no longer had so much to talk about and, I realized that much of our relationship was grounded on duties and practical tasks. Through the years I maybe pushed myself too much, when it came to duties and responsibility. So today I struggle with impatience towards my parents, but at the same time I often with a bad conscience. I feel bad about our relationship and I wish the family had received more help and support earlier. Then it would have been a pleasure to assist them when they needed it.

## **Family counselling would have been an answer**

I also think my family would have a lot of advantages from family consulting, who could have given us the opportunity to understand each other much better, and together we would have found better solutions. If my parents had been given the opportunity to have somebody outside the family to rely on when they needed it, then less responsibilities and tasks would have been imposed on us children. I believe that a professional would have been more inclusive, which would have made my parents more independent and may have increased their self-esteem.

Both my mother and father are two very kind persons, with a lot of love and care. I am sure that they always wanted the best for me. But sometimes I felt they didn't see me and the challenges I had in the family. I don't blame them because they didn't have much choice. But I wish I could have been just a child in my childhood without all that responsibility. Even though I was not forced into the role, I think it is natural for a child to do what you can, in order to help and take care of the people you love.

# **Super Contact Person**

## **Anette Rosenquist, Plenary Presentation, 8th ADBN Conference, Aalborg, Denmark**

I am, what you would call in Denmark, a contact person. I have been working as a full time contact person for about 14 years. For the last 7 years I have worked mostly with one client, although I also still work with other deafblind people.

### **Contact persons no longer volunteers**

Historically, being a contact person was undertaken as voluntary work, which meant that the quality of the environmental description and interpretation varied wildly. We saw some difficult situations, for example, sometimes at parties held at deaf associations. Deafblind people were given little information or completely forgotten about, as the contact workers were partying. So in the early 1980's the role was professionalized, and deafblind people had the opportunity to decide for themselves how they wanted to live their lives. The problem was, and sometimes still is, that many people decide to hire their friends. This can cause problems, as sometimes you can be too close to the situation, and this can cause difficulties in remaining objective. Even though our job carries a huge responsibility, we don't have formal training. We are sent on a two day course once a year, and receive monthly supervision from a consultant on deafblindness.

This means that in our job, we have to rely on individuals' willingness to cooperate, and, most of all, develop confidence and trust between the deafblind person and the contact person. It also means that our skills vary, as we all have different 'stuff in our rucksacks'! Some, for example, may have a pedagogical education while others have no related education at all.

### **The need to basic education**

A basic education geared for contact persons is desperately wanted and needed. But we cannot avoid "learning by doing" as all deafblind people have individual needs. For example, people will have different preferences of how they want to be guided. Normally in Denmark it is the interpreter who interprets when a deafblind person participates in a course, gives a lecture, visits the doctor etc. As contact persons, we facilitate the daily communication. We are also the ones who usually give the environmental information, or to put it another way, describe the surroundings. Luckily, this is an area which employs many deaf people. Employing deaf people in this role has benefits for all, as no hearing person can sign like a deaf person. Many deafblind people say they feel safer with a deaf person, as communication is equal and easier for them to receive. Deaf people also make the best relay interpreters. Some deafblind people prefer to use a deaf contact person as their interpreter rather than an hearing interpreter, but this is mostly older deafblind people.

## **A description of the role of the contact person**

I will now briefly describe what I do when meeting a deafblind person, so you get a picture of the roles and boundaries.

When I meet a deafblind person, I do what I call a “scan”. I assess their communication level, whether they use sign language, pretactile or tactile communication, what level of vision they have, etc.

But what I consider being the most important part in my job is to see the person and not the impairment. I ask myself, what is their background, their life story, their sense of humour? Then I try to figure out how I can support them in the best way possible.

It is not my job to do something they already can do for themselves. It is my job to try to make them more independent and self reliant. Of course it is nice to be told that I am appreciated, but if I have made a person dependant of me, then I have failed.

So I am not the person who provides a lot of 'care' type services, like picking up canes, pouring coffee or fetching food whilst the deafblind person sits twiddling their thumbs.

I have found it is important to let the deafblind person be as independent as possible. It may not be an easy task and perhaps we don't succeed every time, but I try to let the deafblind person be the kingpin in his or her own life.

Of course there are some deafblind people to whom I have to give that kind of help, for example elderly people, who haven't yet developed the techniques of how to avoid pouring too much water in a glass, finding the keyhole, to distinguish between different values of money and so on.

As I said before, I try to find out their sense of humour, because I think a good laugh is a good cure. Being able to laugh together is worth a lot. And being able to laugh at oneself is, as I see it, a good way to survive.

We are often the person who first sees and talks to a deafblind person when they are frustrated. This could be for a variety of reasons, for example if they have had an application refused for some adaptive equipment, or been rejected for a course. We are also the ones who work closely with deafblind people through times of depression or sorrow if their condition worsens. This requires a lot from us, and it is sometimes very difficult to find a way to support people in these situations.

## **Good humour is the answer**

Some deafblind people accept who they are, but are of course sometimes angry or irritated by their limitations. I think humour is a good way to show a person that you accept who they are by joking with them and saying things like “Yes, I do know you have some disabilities, but you are still a human being”. For example, if I were to throw my car keys over to the deafblind person and say: “I have been driving the whole day now it is your turn”.

One example of using humour that sticks in my mind was when I was guiding a man and his stick went between a women's legs in the street, and I said something like: “You really know how to pick up a woman!”. Another example is when a deafblind person complained to me that she caught the wrong bus and it took her quite a while before she got home. At first I listened and showed empathy, making sure nothing serious has happened. But in the end I said something like: “Well, playing tourist in your own town is not a bad idea”.

I am aware though that I can't do that with everybody. We have to know each other very well, but being able to laugh at those small situations makes it easier to talk about the more serious issues in their lives.

I don't feel sorry for deafblind people, because if I did, I don't think I will be able to help them with respect. It would be as if I was looking down on them, and not seeing them as human beings.

I don't ever use the clichés such as "I know how you are feeling" . That would be disrespectful. No matter how many hours I walk about blindfolded and with earplugs, I know deep down inside that I, unlike deafblind people, can take them off any time, and that is something I have to bear in mind every day.

## **Positive results from the process**

As I mentioned before, I have been working with one particular client for the last 7 years. When I started, she gave me some rather new challenges. She had been using very few tactile signs, as they were previously called, but now she wanted to develop more. I gladly accepted the challenge, as I have experienced the feelings of inadequacy when a deafblind person has been sitting and looking at the interpreter, but wasn't able to have access to environmental information. We know that the coffee is here, we know someone has left the room, we know the woman sat next to me is bored, but the deafblind person doesn't. The feeling that I was unable to tell this to the deafblind person was really annoying. So what an opportunity this gave me! Together, we took small one step at a time; I guess creativity was the keyword. Together, we were thinking "What are the signs?" Together we tried to make the signs on her back (Haptic Communication). Some signs work, some signs don't. It wasn't for me that the sign has to work; it has to work for the client.

Later we had the opportunity to attend a lecture by the late Trine Næss from Norway. During that lecture we both realized that we actually had come quite far with this communication. Trine's lecture was a great inspiration for us to take this even further. Often I have to work with an interpreter. Between the client, the interpreter and myself, we decide who does what. We clarify our expectations and roles, and work together to support each other. If I know a sign name for some one, I give it to the interpreter and if they see something I missed, they support me. It is the deafblind person who is our focus.

## **How to maintain the professional distance**

When working so close to someone, especially someone like my client, it can be difficult not to become best friends. We experience so many things together. We develop our own language; we have our own conversations. However if we were to become best friends, it would somewhat "muddy" our roles, and make our professional boundaries unclear. I wouldn't be able to provide the kind of help that will support her for her independence. I think it would be difficult, for example, to meet socially, dine together, drink wine together, and then behave professionally the next day.

So to remain professional, it is important that we don't see each other in a social context, and we keep a professional distance between us. Of course, as we often work together, my client can sense if there is something wrong. So I tell her that if I am behaving differently today, it has nothing to do with her. She respects this, of course, and doesn't ask any more questions.

Sometimes, when I think about the future, I know that if I stop being a contact person, I would still like to be a part of my client's life, only as a friend. She has such an

interesting life and we have many things to talk about, I have to say that I would miss her terribly if she just disappeared from my life.

My job is very challenging, and it is a job which never stops developing. As well as the language, the demands and expectations from deafblind people are changing. They are no longer living as a passive and dependant passenger. They want to play the lead part in their own lives, and participate equally in society, and it is that which keep us on our toes.

## **The 13th European Deafblind Week**

### **European Rehabilitation and Cultural Week of the Deafblind 2011 in Tuusula, Finland**

Monday 1st to Sunday 7th August, 2011

Hosted by the Finnish Deafblind Association

Dear Friends

The European Rehabilitation and Cultural Week of the Deafblind in 2011 will be held in Tuusula, Finland from Monday 1st to Sunday 7th August, 2011. The venue takes place in Onnela Inn and nearby Gustavelund Hotel and Conference Centre.

Tuusula is a small town with a rich cultural heritage. Both Onnela Inn and Gustavelund are situated next to beautiful Tuusula Lake, only half an hour from Helsinki and just 15 minutes from the airport.

The participation fee is 450 euros per person, including accommodation, full board and activities. Your registration is valid when the participation fee is fully paid.

Final date for payment is 31st March 2011.

For further information about the program, registration and methods of payment, please follow the Internet pages of the Finnish Deafblind Association at [www.kuurosokeat.fi/en](http://www.kuurosokeat.fi/en).

Finnish Deafblind Association was founded in 1971.

Year 2011 will be our 40th anniversary. We are proud to welcome you to the European Rehabilitation and Cultural Week of the Deafblind 2011 as part of our 40th anniversary celebration.

For more information, please contact

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# **Developing an Intervenor Competency Framework in Canada**

Since the first educational program began at the W. Ross Macdonald School in the early 1970's followed by the formation of Canadian Deafblind Association (formerly the Canadian Deafblind and Rubella Association), consumers, parents and professionals in Canada have been advocating the practise of intervention as a means of meeting many of the "access to information" needs of Canadians who are deafblind. In most parts of Canada, it goes without saying that services for individuals who are deafblind and the implementation of the philosophy of intervention are very closely linked.

## **What is Intervention and who are Intervenors?**

Intervention is described as "the process that allows an individual who is deafblind to receive non-distorted information such that he or she can interact with his or her environment".

An intervenor is "a person who provides intervention to an individual who is deafblind. An intervenor mediates between the person who is deafblind and his or her environment to enable him or her to communicate effectively with and receive non-distorted information from the world around them". An intervenor acts as the eyes and ears of the person with deafblindness.

## **Why was a Competency Framework needed?**

The function of the intervenor in Canada has evolved over many years which has resulted in the lack of a standardized knowledge and skill set among intervenors across the country. Intervenors have come into the field from many different backgrounds and with varied levels of training. Many intervenors were previously trained as educational assistants, personal support workers, child and youth workers, sign language interpreters or other professionals. They have acquired an understanding of the philosophy of intervention and the additional skills needed to work with individuals who are deafblind either through practical experience or through attending courses or workshops. A minority of intervenors receive more intensive training in the two year college diploma Intervenor Program offered at George Brown College in Toronto, Ontario or the Certificate in Congenital Deafblindness offered through Douglas College in New Westminster, British Columbia.

The lack of consistency and the resulting uneven scope or quality of intervention detracts from the effectiveness, profile and status of the profession. There is limited understanding of the role of an intervenor and the impact that skilled intervention can make to the quality of life of an individual who is deafblind. Consequently, CDBA believed strongly, that if the consistency and comprehensiveness of intervention skills and knowledge could be increased then the effectiveness of intervention across the country would vastly improve. A further result would hopefully be that individual practitioners and the profession as a whole could benefit, leading to a higher appreciation of the value of intervenors.

These concerns about the absence of standardization led CDBA to launch a project in 2005 to establish a framework of intervenor competencies. CDBA believed that this



project would lead to the establishment of more consistent standardized training programs for intervenors throughout Canada. The long term aim of this endeavour may lead to the development of a professional designation for intervenors in Canada.

## **Process for developing the Framework**

A Competency Committee was appointed by CDBA in 2005. It was charged with the task of producing a Competency Framework that would guide the establishment of consistent and effective training for intervenors throughout Canada. The Committee represented stakeholders and service providers from across Canada, and included practicing intervenors, educators, employers and family members.

A first draft of the competency framework was distributed to service providers and various stakeholders throughout Canada requesting comments and suggestions for improvement.

Following the initial feedback from the first draft, it was determined that the competency framework would focus on intervenors working primarily with the population of persons with congenital deafblindness. This was consistent with CDBA's initial approach to intervention as originally developed at the W. Ross Macdonald School. The group recognized that while most of the competencies for intervenors serving both populations would be similar, the skill set for intervenors for individuals with congenital deafblindness are different.

## **What does the Competency Framework entail?**

The CDBA Competency Framework describes standards for intervenors, which can be used to support consistent, high quality deafblind intervention practices. It reflects the characteristics of Canadian-developed expertise, philosophy and values, as well as knowledge and skills developed across the international field of deafblind intervention.

The Competency Framework can be used by:

- Trainers of intervenors , to guide professional development programs and activities;
- Employers of intervenors, to assess the organization's program delivery strengths and indicate areas for further development, and
- Intervenors, to evaluate their own knowledge and skills and identify areas where they may want to develop further proficiency.

The Competency Framework is organized into ten standards, or categories, with a total of 133 competencies. The competencies are divided between: Core Competencies -general knowledge and skills required for effective intervention for individuals with deafblindness and Individual Specific Competencies - knowledge and skills that pertain to working with a specific individual, primarily one who is congenitally deafblind and/or an emergent communicator.

The Competency Framework also provides a foundation for other tools to be developed by CDBA such as inventory of training resources, a portfolio format for intervenors to track their skills and other training materials.

The final framework draws on input from stakeholders and service providers in Canada and work done by non-Canadian organizations, including SKI-HI institute, the National Technical Assistance Institute and the Texas DeafBlind Project.

## **Implementation**

Following the approval of the Competency Framework by CDBA National in 2009, the Competency Committee of CDBA is now embarking on developing an implementation process. This will involve hands-on experience sessions with representatives from the various CDBA chapters to explore ways to utilize the Competency Framework. These sessions will also serve as a pilot for the development of materials and guidelines for the on-going use of the Framework. The initial sessions began in October, 2010.

To view the Intervenor Competency Framework and the Principles of the Canadian Concept of Intervention, refer to the CDBA website ([www.cdbanational.com](http://www.cdbanational.com)).

1: Members of the CDBA National Competency Committee were Carolyn Monaco, Lorraine Williams, Cheryl Ramey, Barbara Horvath, Joyce Olson, Cathy Pascuttini and Betty Jean Reid.

## **Minding the Difference:**

**talking to individuals about their condition of CHARGE syndrome**

### **Gail Deuce and David Brown (2010)**

There are so many challenges for any family that has a child with CHARGE Syndrome. With the passing of time we have been hearing about a problem that an increasing number of parents are facing as their children grow and mature – when, and how, and why should you talk to your child with CHARGE about the syndrome? We are usually asked about this at a time when the parents are already feeling that they have got this complicated task wrong, often after their child has become upset at some sudden revelation of their own difference or of some limitation in their abilities.

Recent examples of this include a 12 year old girl who became upset at the sudden awareness that her two sisters did not wear hearing aids like she did; a teenager who showed great anger and then a long period of depression after being told that he would never be able to drive a car; and a 5 year old who refused to wear both glasses and hearing aids as soon as he entered school because he saw that none of his peers were wearing them.

For families whose child with CHARGE has little or no language this is clearly an even more imponderable situation.

## **Investigation**

In response to requests from parents we decided that this issue needed some investigation, and we based this on structured interviews to find out what families felt about this issue, what they had done and what had worked.

The interviews were undertaken either by telephone, email or face-to-face contact, using a series of structured questions. The questions asked focussed on discovering

the importance of sharing information about CHARGE, what information to share, and how to share it.

The nine families all had a family member with a medical diagnosis of CHARGE (ages ranging from 14-32 years). Because of limited time and resources we included only parents whose children had a good level of language in our group of interviewees, nine families in total from three different countries (the United Kingdom, New Zealand, and the United States).

## Findings

Eight of the nine families asked had chosen to speak to their child about having CHARGE. The remaining family had chosen not to although they had spoken about some of the anomalies without reference to the overall condition. Their reason for this was that their child identifies himself with the deaf community and it was felt that to talk to him directly about CHARGE would adversely affect his self-identity.

The eight families who had talked to their child about having CHARGE felt it was important to do so for a number of reasons. All of these families reported that the affected child had noticed that s/he was different and was asking “Why?”; it was accepted that the child is likely to face many challenges and difficulties and it was felt that it is sometimes helpful to have a reason why. All the families commented that it is important for the individual to know about CHARGE to help him/her understand and accept what s/he can do, to recognise what his or her limitations are, and also to understand why s/he might find it hard to do those things that their siblings and friends often seem able to do much more easily.

All the families reported that sharing information is an ongoing process that is often a response to the child asking questions or bringing up an issue that needs to be talked through. Information had been offered when it was felt to be appropriate and this was dependent on their child’s maturity and capacity to understand. The need for lots of repetition was raised, with time for the child to absorb it and internalise it. Information tended to be shared through informal conversation that included other immediate family members and often occurred around the dining table during a meal. It was felt to be important to include siblings and other close family members so that the child felt their condition was accepted. One family reported that the older brother and sister had accepted the diagnosis but would not allow it to be used as an excuse! Only one family had involved anyone from outside their immediate family to share information, that being a counsellor at school who was involved because of friendship difficulties. The families who had shared all felt that it is important to be honest and open.

For example, “Will my hearing get better?”- “No”; “Will my hearing get worse?” – “Possibly, like your mum and dad aging, but it could be worse”. Families felt they shared all relevant information, but that sometimes they were not very explicit, usually when it was concerning information that perhaps was more difficult to share. It was interesting to note that the issue of infertility or not being able to drive a car were issues that were frequently identified, although not by every family. The need to maintain a sense of humour was also highlighted, as well as being sensible and realistic, but at the same time not overcompensating and assuming that CHARGE can be ‘blamed’ for everything.

Very little advice or support had been made available to families in relation to sharing with their child about CHARGE and all the families reported that they had to commit to discovering much of the information themselves. Families highlighted the need for access to appropriate professionals that they would maintain links with over time.

They also commented that they would like regular access to professionals who had an in-depth knowledge of CHARGE, and that all professionals involved with their child should have at least some understanding of CHARGE. One family suggested it might be helpful to set up a group for teenagers with CHARGE where they could meet socially and have an opportunity to talk. It was recognised that there would be a need for the involvement of a skilled person to mediate, provide information etc. as needed.

## **Discussion**

The majority of families questioned felt it is important to share with their child about CHARGE as it helped with the development of self-identity and explained why their child is as they are. As one family said: 'The more informed he is, the less taboo there is around who he is'.

It needs to be recognised that what is right for one child may not be right for another; the family that had chosen not to share had done so because their child identifies himself as a part of the deaf community and it was felt that his self-identity could be adversely affected.

So much of this issue also seems to be tied up with how the family themselves is feeling about CHARGE and all that it entails (for example, their own feelings about infertility, and the possibility of not being able to have grandchildren). It seems that this needs to be discussed and explored by the adults before issues can be discussed and explained to the child. Two of the individuals with CHARGE involved in the study had told their mothers and fathers that it was they as parents that had the 'hang ups' about CHARGE which did not affect the individuals themselves - they were more focussed on what they needed!

A theme was identified that emerged throughout the answers given to the questions asked. It is not an emphasis on the clinical condition that is so important, but rather to focus on what the implications are for everyday living, and how these challenges can be tackled. The individuals with CHARGE were not really interested in hearing about CHARGE as a medical condition, but they did want to talk about and explore the adaptations that helped them.

For parents to be able to share information about CHARGE effectively and fully with their child clearly depends on the parents themselves being well-informed.

Parents need to be provided with clear information on CHARGE on an ongoing basis, and kept up-to-date about new information as it emerges. This might be offered in a number of ways through:

- involved medical professionals
- other involved professionals
- family support groups
- conferences
- information leaflets
- the internet
- research papers and other published articles

There is a need for professionals to increase their knowledge and understanding of CHARGE, and in particular the practical implications of this condition, to ensure they are in a position to help equip parents to share with their child when they feel it is appropriate. This whole process relies on parents having the knowledge themselves to be able to share it with their child.

This sharing of information is part of the whole process of developing self-advocacy and self-determination in the individual with CHARGE. Although this study was

restricted to discussing the subject matter with families of an individual who had a good level of language, this is appropriate for the whole population of individuals with CHARGE in relation to self-advocacy and self-determination, enabling the person to take control as far as they are able to do so. For example:

- Your eyes hurt in bright sunlight: wear a peaked hat and/or sunglasses
- Supporting and encouraging to wear cochlear implant processor
- Learning not to pull out the gastrostomy tube

We recognise some people will continue to need a high level of support, but they can still make real choices and exert some control if we enable them to do so.

## **Second Announcement**

# **XV Deafblind International World Conference**

## **Bourbon Convention Ibirapuera**

### **São Paulo City, Brazil**

### **27th September – 1st October, 2011**

Conference Theme: Inclusion for a Lifetime of Opportunities

The Local Planning and Scientific Committees of the XV DbI World Conference in Brazil are seeking conference participants for international input to define solutions and recommendations for the development of lifelong services for individuals who are deafblind. Conference hosts are anxious to share Brazil and Latin America stories and experiences to help promote regional policy and program development.

### **Conference Participants**

Conference organizers welcome deafblind persons, their family members and caregivers; education and rehabilitation professionals; representatives from academia, government and disability rights organizations, NGO/INGOS and medical and health professionals.

### **Call for Papers**

The coordinating committee is inviting the submission of abstracts for workshops and poster sessions for the XV World Deafblind International Conference. Submissions should relate to the theme of the conference and focus on one of the following sub-themes: Assistive Technology, Changing Population, Communication and Language, Transition to Adult Life, Inclusive Education, Neurological/Cortical Etiology, Pediatric Rehabilitation, Syndromes, Elder Individuals and the United Nations Convention on the Rights of Persons with Disabilities.

### **Questions:**

Any inquiries relating to abstract submission or requests for additional information, should be submitted to the Local Planning Committee via [secretary@dbi2011.com.br](mailto:secretary@dbi2011.com.br) or through the conference website at [www.dbi2011.com.br](http://www.dbi2011.com.br)

SEE YOU IN São PAULO!!!!!!Venue:

## **Country news**

### **Australia**

#### **National DeafBlind Conference 2010 & Deafness Sector Summit 2010**

Reports for both these events are available on the Australian Deaf-Blind Council's (ADBC) website at <http://www.deafblind.org.au/reports.asp>

#### **Productivity Commission-Inquiry into Disability Care & Support**

ADBC's Committee Working Group wrote a submission for this Inquiry that was submitted at the beginning of June. It is available at <http://www.deafblind.org.au/reports.asp>. ADBC President Sven Topp appeared at a Productivity Commission Hearing on 21 July 2010 in Sydney.

#### **Senate Inquiry on Hearing Health**

ADBC is pleased to announce that one of the recommendations it strongly supported, i.e. the funding of speech processor replacements in cochlear implant for adults, is a recommendation that the Inquiry has proposed to the Federal Government. It is hoped that the government will take up the challenge and adopt the recommendation as policy.

#### **Let's Connect**

Training sessions for people with deafblindness, and professionals working with people with deafblindness were held in May and June in Melbourne. They were well attended and received positive feedback. These training sessions were held again in Sydney in July and in Brisbane in September and October.

#### **Deafblindness Training in Western Australia**

Senses Foundation in Western Australia hosted a training event in May with Paul Hart and Megan Mann from Sense in the UK. The two modules delivered were Dual Sensory Impairment 1 and Communication 1 from the accredited Deafblind Studies course in the UK. Forty-five participants from across Australia and New Zealand took part and the feedback was positive. Senses are currently exploring opportunities for future training events. For further information contact [elvira.edwards@senses.asn.au](mailto:elvira.edwards@senses.asn.au)

## **Australian Communications Consumer Action Network (ACCAN) – Grant**

Able Australia has been successful in receiving a grant from ACCAN to research the telecommunications options currently available to deafblind Australians. The project titled “Research and practical telecommunication solutions for deafblind Australians” will employ a research officer to survey deafblind people about the different types of telecommunication devices they use i.e. TTY, MSN, fax etc. The new research project will also develop a website to display the different types of telecommunication devices that are currently available to deafblind people. The new project will begin in August and will take place over a 6 month period. For more information please contact Emely McCord at [emely.mccord@ableaustralia.org.au](mailto:emely.mccord@ableaustralia.org.au)

## **Day on the Bay**

Able Australia’s day on the bay is planned to go ahead in either November or December this year. With a wide variety of boating and other activities on offer on that day, it is the perfect opportunity for deafblind people to come along and try something new. The date is pending. For more information please contact Emely McCord at [emely.mccord@ableaustralia.org.au](mailto:emely.mccord@ableaustralia.org.au)

## **Australian Federal Budget**

The 2010-11 Commonwealth budget contains a number of measures aimed at Australians with disabilities, including those who are deafblind. These measures totalled more than A\$20 billion, and include:

- \$12.9 billion on the national Disability Support Pension
- \$5.1 billion on payments to carers (majority to carers of people with disability)
- \$310 million on Australian Disability Enterprises
- \$14 million on young carers
- \$1.2 billion on improved Disability Employment Services
- \$1.04 billion in payments to States and Territories through the National

Disability Agreement

Government in its press releases acknowledged that there is still much more to be done in disability, but that more support is on the way. The National Disability Strategy, to be released before the end of the year, is aimed at removing more of the barriers that are still faced by people with disability.

## **Government Review of Funding for Schools.**

In April this year, the former Minister for Education, now Prime Minister Julia Gillard, announced that a review of school funding arrangements will commence in 2010 and conclude in 2011. This is the first time since 1973 that funding arrangements for all schools will be reviewed. The review intends to draw on the best available evidence from Australia and around the world. Its aim is to be fair and transparent and not advantage one system over another. All Australians with an interest in school funding, and particularly to funding for students with disabilities, will be given the opportunity to contribute and build the strongest possible platform for long-term investment and improvements in educational outcomes beyond 2012.

The review will examine all funding to all schools. Government intends that its process will be transparent, open and consultative.

### **Improved Accessibility in Cinemas**

Australians who are blind or vision impaired and people with deafness or hearing impairment will be able to enjoy improved access to cinemas thanks to a landmark agreement to provide captioning and audio description services in Australia. The Australian Human Rights Commission announced on 17 July that agreement had been reached between representatives from the disability sector and major cinema chains. By 2014, Hoyts, Village Cinemas, Event Cinemas and Reading International have agreed to provide captioning and audio description at every session in each of the 132 cinema complexes they operate throughout Australia and in multiple screens in the larger complexes – where currently only 12 screens provide captioning at three sessions per week, nationwide.

Connecting Up Australia (operators of the DonorTec program) are joining forces with the Community's 'Communities in Control' conference to host a blockbuster non-profit event week in Melbourne. 'Communities in Control' will be held on 30 to 31 May 2011 and be immediately followed at the same venue by 'Connecting Up 2011' on June 1 and 2. For more information please see <http://www.ourcommunity.com.au/>

### **Tax Help for People with Blindness or Vision Impairment**

Vision Australia has joined with the Australian Taxation Office in a key initiative to provide trained volunteers to help people with blindness or vision impairment complete straightforward tax affairs. Services are available through Vision Australia offices in NSW, Victoria and Queensland. The Tax Office also provides free audio CD, e-text, Braille and large print versions of the TaxPack every year. E-tax online is also now available for people who prefer to lodge their tax online. More information available at: <http://www.ato.gov.au/individuals/pathway.asp?pc=001/002/014>

### **Testing the Safety of Hybrid Vehicles**

Guide Dogs Queensland is helping the RAC Queensland to test the safety issues of hybrid vehicles for people with sensory disabilities. It is a matter of critical concern that people with blindness or vision impairment may be placed at risk when crossing roads due to the fact that hybrid vehicles are quieter than vehicles with petrol or diesel engines. For more information please see:

[http://www.guidedogsqld.com.au/page/About\\_Us/News\\_and\\_Events/Guide\\_Dogs\\_Queensland\\_News\\_and\\_Events/Guide\\_Dogs\\_Queensland\\_welcomes\\_study\\_on\\_safety\\_of\\_hybrid\\_cars\\_-\\_20\\_May\\_2010/](http://www.guidedogsqld.com.au/page/About_Us/News_and_Events/Guide_Dogs_Queensland_News_and_Events/Guide_Dogs_Queensland_welcomes_study_on_safety_of_hybrid_cars_-_20_May_2010/)

### **The Australian Childhood Vision Impairment Register**

The Australian Childhood Vision Impairment Register is sponsored by the Royal Institute for Deaf and Blind Children, in partnership with children, families, teachers, health professionals and low vision service providers. The Register is capturing uniquely Australian data on children living with vision impairment, including children



with deafblindness, These data will be used for improved service provision and research.

Families are warmly invited to register their children. The age range is from 0 to 18 years, with any eye condition that causes vision impairment. Each family joining the register is asked about their child's level of vision, their health, their family history, their ethnicity, and their current level of support. Data are also collected from eye professionals about the child's pathology, ocular diagnosis and current visual status. Information is also collected on any associated conditions and disabilities.

The Register's is to be a resource that contains accurate details of the causes of vision impairment, associated disabilities, the number of affected children and levels of service access. Analysis of preliminary data has already provided some insight into vision impairment despite the relatively small sample size to date (N=225). For example, the average wait time from 'suspicion' of vision impairment to diagnosis was 3.5 months, 67% of children registered also have additional disabilities, 19% were premature births, and 62% of families reported accessing support, with an average wait time of 8.5 months from referral to receipt of non-government support services.

As joining the Register is voluntary, support is necessary from the service sector to ensure that families are offered an opportunity to participate. The advantage in joining is that information will be used to support improved planning of services and will benefit researchers working on improved strategies to treat and prevent vision impairment. For further details on the Register and to obtain promotional literature, please contact the Renwick Centre at RIDBC on (02) 9872 0303 or <http://www.ridbc.org.au/renwick/research/ozviskids/>

Media Access Australia reviews Apple's new i-phone MAA has reviewed the accessibility features of the iOS 4 model for use by people with blindness or vision impairment. You can find their informative and interesting article at [http://www.mediaaccess.org.au/index.php?option=com\\_content&view=article&id=962:ios-4-has-arrived-with-new-accessibility-features](http://www.mediaaccess.org.au/index.php?option=com_content&view=article&id=962:ios-4-has-arrived-with-new-accessibility-features)

## **Let's Connect Project**

Melbourne-based Able Australia were successful in gaining a grant for a three year project to offer Deafblind Awareness training for service providers, as well as Assertiveness Training for people with deafblindness in each Australian capital city. The project commenced in February 2010 and workshops have so far been held in Melbourne, Sydney and Brisbane with positive participant feedback. All workshops have been well attended, highlighting the need for this type of training. For further information about the project please contact Meredith Prain at [meredith.prain@ableaustralia.org.au](mailto:meredith.prain@ableaustralia.org.au)

## **Conferences**

2011 Biennial Conference of the South Pacific Educators in Vision Impairment (SPEVI) is to be held from 16 to 21 January 2011 in Sydney.

The theme is "Unlocking Student's Potential: What's working for you?" The program will be important for educators, vision professionals including the allied professions, ophthalmologists, orthoptists, opticians, pediatricians, GP's, teacher aides, agencies,

parents and community groups. The program will feature an impressive array of high quality guest speakers from our South Pacific Region. Please see the Conference Flyer at <http://www.e-bility.com/spevi/conf2011.php> for more information.

International Mobility Conference 2012, 'Mobility through the Ages, Up, Over and Down Under' will be held in Palmerston North, New Zealand on 13 to 17 February 2012.

The call for abstracts opens in February 2011 and closes 30 April 2011. To register your interest, please see the conference website at <http://www.imc14.com/page.php?1>

## **Western Australia Update from Senses Foundation**

### **Communication Guides Pilot Project**

Currently there are a number of countries providing this specialised support to people who have a dual sensory loss however no program has yet been established in Australia. There has been limited research in the benefits of this specialised support, with only one small study that has been located evaluating the impact on the individual's functional skills.

Senses Foundation has commenced a study, where 14 adult participants who have a dual sensory loss, are being provided with six months of weekly specialised "Communication Guide" support provided by Communication Guides. The study design is a series of single case studies, using mixed methods including pre-post analysis of quality of life, health and occupational performance standardised measures and grounded theory analysis of interviews. The Communication Guides underwent competency based training and provide services to participants using person-centred approaches.

## **Rural and Remote Support**

Senses Foundation is committed to providing support to people throughout Western Australia who have deafblindness. Due to the sheer size and diversity of the state, the logistics and costs of undertaking such a commitment is challenging. Since June 2009, Senses Foundation has travelled throughout the state and provided specialist communication education, training and resources to individuals with deafblindness, their families, carers and service providers. Senses Foundation has also provided education and training to health care workers and educationalists working with indigenous communities.

The objectives of the rural and remote initiative are:

- To increase knowledge and skills of service providers working with people who are deafblind throughout Western Australia;
- To provide resources and training to assist individuals who are deafblind and their families and carers that maximises their life outcomes;
- To train and educate key health care workers in the Indigenous communities in the causes of deafblindness and vision impairment with additional disabilities; and
- To develop key links with local stakeholders in the regional centres, including key personnel within the local Indigenous communities.

## **Scotland**

Challenging stigmas, celebrating disability

### **Sense Scotland receives UNESCO recognition**

On the 11 June 2010 around three hundred disabled and non disabled participants traveled to Glasgow to take part in 'Good Vibrations', a day of musical workshops, recognising TouchBase, Sense Scotland's flagship centre as a UNESCO Creative City of Music arts and music venue. The event was jointly launched by The Scottish Minister for culture and external affairs Fiona Hyslop MSP and UNESCO Scotland chair Joanne Orr.

UNESCO's recent EFA (Education for All) Global Monitoring report estimates around 150 million children in the world with disabilities continue to be excluded from society due to the stigmas attached to disability. Recognition by The UK National Commission for UNESCO through work with UNESCO Scotland supports our vision in a society where children and adults with disabilities can enjoy full creative expression as artists, as well as share unique contributions to the artistic and cultural development of our nations.

Sense Scotland is considered to be one of the leading disability arts organisations that utilises the arts with people who have communication support needs because of deafblindness, sensory impairment, learning and physical disabilities. We hope this recognition will allow the work of Sense Scotland, through its local, national and international partnerships, will continue to support UNESCO's work in promoting the sharing of ideas across boundaries.

With Scotland being the only country in the world that has two UNESCO Creative cities, Sense Scotland will be developing longer term partnerships with UNESCO Scotland and already plans are underway to contribute to a cross cities UNESCO Creative Cities programme. This is an ideal opportunity to raise the profile of not only artists and musicians supported by Sense Scotland but also The Helen Keller International Award, which is open to deafblind artists, disabled and non disabled artists across art forms. Last year 180 artists submitted artworks from 11 different countries from across the world.

Through profile programmes such as Good Vibrations and The Helen Keller International Award, artists with complex disabilities have opportunities to use creative approaches as a tool for communication. As well as providing the wider community an insight to the unique ways that deafblind and disabled people experience the world, participation in the arts helps to challenge the stigmas attached to disability, contributing to the social, learning and cultural development of our nations.

The Helen Keller programme encourages artists to submit artworks that challenge perceptions to deafblindness and sensory impairments.

More information on The 9th Helen Keller International Award and Sense Scotland Arts is available at [www.sensescotland.org.uk](http://www.sensescotland.org.uk).

The closing date for 2010 awards was December 03, 2010. During the week beginning January 10, 2011 a selection panel will select the long-list of artworks. Long-listed entrants will be asked to submit final work between 16th–18th February 2011.

## **Moving beyond the common touchpoint**

In September 2010, Paul Hart was awarded a PhD from the University of Dundee for his thesis entitled: *Moving Beyond the Common Touchpoint – discovering language with congenitally deafblind people*. The thesis of Paul's doctorate is about partnerships involving congenitally deafblind people journeying towards language. The focus of the study is about the first steps of that journey – how partnerships make initial moves away from the here-and-now. In order to understand how this happens in the tactile medium, Paul draws on a model developed by Vasu Reddy showing how infants expand their awareness of the objects of another's attention. Paul uses this model to analyse how both partners (deafblind and non-deafblind) are able to share attention: to self, what self does, what self perceives and finally what self remembers. Demonstrating that both partners can operate at each of these four stages in the tactile medium then allowed Paul to focus particularly on the final stage – what self remembers. This final stage then asks: what happens within partnerships if either partner brings movements, gestures or signs that refer to people, objects, places or events not present? Do both partners come to comprehend and produce such referential movements, gestures and signs in forms perceivable by both? Such questions are considered against the backdrop of the dialogical framework, since in any exploration of human interaction, it makes no sense simply to consider it from one perspective. At all times throughout this thesis, the focus is on partnership. Paul's thesis raises a number of practical recommendations about approaches and attitudes that need to be adopted by non-deafblind partners if language is going to be an outcome for their partnerships with congenitally deafblind people. The work concludes with a number of theoretical questions about how we define language in the first place.

The complete PhD thesis is available to download from the library of Dundee University: <http://discovery.dundee.ac.uk/handle/10588/1299>

## **Hungary**

### **Workshop on deafblindness organised by the Association of Deafblind People in Hungary**

Between March 26-27, 2010, the Association of Deafblind People in Hungary hosted a workshop on services for the deafblind. Among the topics discussed were: development possibilities for deafblind children, specialities in interpreting, the use of alternative communication methods, adaptations in the field of basic rehabilitation services, types of psychological assistance available to help deafblind clients cope with their disability, recreational activities etc.

Representatives from Bulgaria, Slovenia, Slovakia and Romania (Sense International) presented the situation of existing services for deafblind people in their respective countries.

## Romania

### Using Callier-Azusa Scales (G&H) in assessing deafblind children in Romania

In May 2010, Sense International (Romania) translated and published the book called “Instruments to Assess Multisensory Impaired/Deafblind Children – Callier-Azusa Scales G and H” developed by Professor Robert D. Stillman, Callier Centre for Communication Disorders, Texas University (Dallas). The translation and adaptation was made by Mihaela Moldovan, PhD (Psychology), national trainer in deafblindness and a member of the Early Intervention Support Centre from Oradea, Romania. Dr. Moldovan said: “I have translated these scales hoping they will prove useful to us all, those working with severe or profound multisensory impairments. Like any scale, Callier-Azusa scales present advantages and disadvantages, strengths and weaknesses. In spite of all this, many specialists consider them to be the most appropriate instruments at our disposal to assess poorly functional deafblind or multisensory impaired children.

I have collected the information in the introductory part of each scale from articles published by Professor Robert D. Stillman and his collaborators over the years. I believed it is useful to include this information, for a more in-depth understanding of these scales.

I want to thank Sense International (Romania), Sense International UK and the Special Education Department of Babes-Bolyai, University Cluj Napoca for their constant effort to train us as specialists, all of us working with deafblind/ multisensory impaired people in Romania.”

For many years Sense International (Romania) has been preoccupied with locating, for its specialist teachers, a comprehensive assessment tool, specifically designed for deafblind and/or people having severe and multiple disabilities. Assessment is one of the most important steps in planning multi-disabled children’s individual development programme. We have determined that key components of these assessments should include obtaining information about these children doing routine activities in their everyday environment in order to decide how to address their educational needs. CALLIER – AZUSA Scales (G&H) are considered among the best instruments for assessing the children’s skills. Other tools we are aware of include those described in the Oregon Project, Help, Insite, Carolina Curriculum, Communication Matrix, etc. We wrote to Professor Robert Stillman from Callier Centre for Communication Disorders, the holder of the copyright for both scales. To our great surprise, Professor Stillman had the kindness to give us his permission to translate the scales and distribute the books in Romania, free of charge without restriction. We also respect the author’s request to credit the authors and the University of Texas at Dallas and the Callier Centre for Communication Disorders in the document.

The Use of Callier-Azusa Scales G and H in the Evaluation of Deafblind/ Multisensory Impaired Children was the theme of the special education teachers’ network meeting, organised in Timisoara October 15-17, 2010.

Forty-five persons, all of them involved in providing medical and educational services to deafblind and MSI children, attended the event in Timisoara. Specialist teachers, audiologists, ophthalmologists, therapists, psychologists, directors of special schools

and a few parents heard the presentation of the assessment documents. During the network meeting, there were opportunities to test the assessment tools.

Dr. Mihaela Moldovan started the seminar by making the theoretical presentation of the Scales (G&H), explaining the strong and weak points of the tools. She explained that CA scales (G) are specifically designed for use with children who are deafblind and/or have other severe and multiple disabilities. They are intended for use by classroom personnel in planning intervention programmes and measuring progress. CA scales (H) are designed to assess the communicative abilities of children who are deafblind. They provide for a highly detailed evaluation of communicative skills in representational and symbolic development, receptive communication, expressive communication and reciprocity.

The presentation was followed by numerous practical examples, with case studies where our colleagues, the national trainers, provided examples showing models of best practice in applying the CA scales.

Topics like "Formative Usage of the Scales in Planning Mike's educational intervention", "Aspects of the Assessment of the Receptive Communication using CA(H)," Assessing Mary's Daily Living Skills using CA(G)" are only a few examples which have been highly appreciated.

Interactive activities with groups have been developed by the participants, which included mainly teachers and medical doctors. They have dealt with the cases from their point of view; sharing and bringing in extremely useful information from their own fields of activities.

A visit to Timisoara Early Intervention Support Centre was the last item on the meeting agenda. The visitors met the colleagues from the centre who presented case studies of the children in the intervention programme. The group discussed the assessment results and concluded that the multidisciplinary team at the centre had obtained representative samples of the children's social, communication and learning skills, so useful in designing the children's rehabilitation programme.

Questionnaires distributed at the end of the teachers' network meeting have reassured us that the seminar has been extremely useful and that the teachers will make a good use of these assessment scales. The main purpose of a good educational assessment tool is to develop an educational programme that fits the child's strengths, needs and interests, followed by an opportunity to evaluate the effectiveness of the child's intervention programme.

Cristiana Salomie  
Sense International (Romania)

## **Canada**

### **CDBA Celebrates 35 years**

During its Annual General Meeting weekend October 16-17, 2010, the Canadian Deafblind Association celebrated its 35th Anniversary in Brantford, Ontario, the city

where the organization was founded in 1975. Three of the original founders of the organization, Gerry Brogan, Patricia Curtis and Stan Munroe were on hand. During the evening banquet, various awards were presented. Long serving and outgoing Board member Marilyn Robinson from Winnipeg Manitoba was awarded the Cherry Bulmer award. The award is awarded to an individual who has made an outstanding volunteer contribution to the CDBA at the National and Chapter levels and shares the same passion and commitment as Cherry Bulmer. Cherry was a long term member of the national organization and was editor of Intervention Magazine for many years. Stan Munroe was awarded a plaque as the outgoing Executive Director of CDBA.

Gifts were presented to those who volunteered as members of the Intervenor Competency Committee which produced the Intervenor Competency Framework and participated in the Competency Field Training Program.

### **Returns as President**

Carolyn Monaco was re-elected as President of the National Association for her fourth one year term. Except for an absence from the Board of four years, Carolyn has been associated with the national organization since the late 1970's. Carolyn is a Professor in the Intervenor Program at George Brown College, Toronto, Ontario and is currently a member of the Board of Deafblind International.

## **Canadian Staff Exchange:**

### **DeafBlind Ontario Services and Sense UK**

In March 2007, Ges Roulston, Peter Cheer, Jon Stone and Shaun Gibbons (SENSE UK) were invited to Canada to view the residential and Intervenor services run by the DeafBlind Ontario Services. This proved to be a very interesting visit and gave us a very good impression of how small, independent services could be established using schemes similar to the supported living set up in England.

Last year Shaun invited Karen Keyes, Kelly Paterson and Roxanna Spruyt-Rocks from DeafBlind Ontario Services to England to visit Sense services in the southwest. With the success of the visit, the Canadian team was keen to set up an exchange scheme for care workers to visit and work in services run by Sense.

After much discussion a procedure was drawn up for selection of staff to go on the exchange. Marissa Axon was the successful staff member from Canada and Judy Stone the chosen Sense member of staff.

Here is the story of the exchange from the point of view of Marissa and Judy

#### **Marissa Axon's story:**

The Sense/DeafBlind Ontario Services staff exchange was open to any employee of DeafBlind Ontario Services who has been with the organization for at least one year. The first phase of the competition was answering some questions about why they felt they should be chosen. Five staff were short listed, and asked to write an essay about what being an Intervener meant to me. To my surprise, I received a call saying I was

in the final list of two! I started working on my presentation. Having been an Intervener for almost eight years with DeafBlind Ontario Services, the only way to describe what we do as Interveners is to show people. With my hands-on tactile presentation I went in, nervous but surprisingly confident. After all I was talking about something I am truly passionate about... intervention! A few days later I received the call. I was going to England.

I was fortunate to be able to stay with Shaun and his family while in England. It was a real home away from home. I was very eager to get started. I couldn't wait to see the programs that Sense provided for its' residents. Shaun had arranged for me to attend their new Intervener training at Providence Court, which was very similar to internal training in our TOUCH program.

I had the opportunity to explore and observe the programs at Providence Court. We all would benefit from a place like Providence Court, not only as a program and learning environment but also as a social environment for the residents to go and spend time with their friends.

The ideas that came out of Seafield Road, a residential home in Seaton, for making the residents life easier were significant. I was particularly impressed with the floor markings, tactile railings, tactile room markings, and a "staff working today" board.

Another interesting idea was in a bedroom. A large strip of Velcro was placed on the wall. Residents could remove the Velcro objects. This encouraged tactile exploration and the items could be changed frequently.

Later in the week, I returned to Seaton house to observe a vision assessment. This was really surprising to see what ideas and techniques can be used to help determine someone's field of vision. The communication board used with the ladies at Norbins house in Glastonbury was also very unique, as was the "scent of the day" at Andlaw House in Exeter and Applemead House in Whimble, Devon. This is a communication system where messages are conveyed through a different scent each day of the week. I was also able to attend an art class in the community with the Applemead residents. It was wonderful to see so many great ideas and practices that I could take back to Canada with me. I was most intrigued at the staffing and accessibility that Sense has to services. Everyone I met was incredible and so willing to share information. In this field, the more we can share with each other the more successful all of us will be, meaning we can provide a much better service to the residents we support, and that's what it all comes down to.

I am truly grateful for the experience of a lifetime. It helped me to renew my excitement and passion for Intervenor Services, and develop a renewed appreciation for communication. Thank you to all, on both sides of the world, for making this exchange a reality. Most of all, I would like to thank all of the residents that allowed me into their homes and shared their lives with me. I will remember you all and be forever grateful.

### **Judy Stone takes up the story**

Having worked for Sense since 2002, I was very keen to apply for an exchange with another organisation that supports deafblind people. I felt very excited, following a successful application process, to be heading off to Deafblind Ontario Services in Canada to spend some time with staff and the deafblind individuals they support.



I was eager to meet people who have the same philosophy as Sense, but who may have found different, though equally valid and effective, approaches to enabling deafblind people. I felt strongly that sharing information and the many successful methods of support that each organisation has developed would improve and enhance our work practice and would ultimately benefit all the deafblind people we came into contact with.

During my stay in the province of Ontario, Canada I was fortunate to visit nine residential homes, meet numerous deafblind people and talk to and exchange information and ideas with many of the dedicated staff working for Deafblind Ontario Services. Whilst visiting the homes, in Bradford, Peterborough and York and Simcoe regions, I was interested to discover how the houses fitted within the community. I was impressed with the size and layout of the houses, the facilities within each home and how their daily activities were structured.

What I discovered was that the houses differed from the Sense homes, being mostly bungalow style houses with huge basements; all with beautiful wooden floors throughout – a must in the snowy weather. The houses all appeared to be situated in quiet residential areas, with few local facilities within walking distance, meaning that Intervenor make the most of their vehicle to take the deafblind people to activities in the surrounding area. DeafBlind Ontario Services aims to have elevators in each house to enable the basement space to be utilized in a beneficial way depending on the needs and interests of the individuals living in that house. Snoezelen rooms are being created in at least one house in every region.

Deafblind Ontario Services have developed a formal partnership with Bob Rumball Home for the Deaf where, between the two organizations, they have created a fantastic Snoezelen facility where deafblind people from the homes in the Simcoe County Region are able to make use of the multi-sensory environment. The Sense house I work already has a great Snoezelen facility, but I felt that you can't have too much information about sensory equipment. The tactile seascape mural has given me some great ideas that I think one deafblind man would enjoy back in the UK!

Of great interest to me was learning that some of the deafblind individuals living in DeafBlind Ontario Services houses have "jobs" within their local community, such as putting the recycling out at the local Fire station, packing boxes at the pizza store or wiping down tables at a nearby café. These activities take place with one-one support of the Intervenor, enabling the deafblind people to participate in their community, to improve their communication and interaction skills and to build valued relationships with people outside of the organisation.

Probably the most interesting and possibly one of the most valuable aspects of my visit was learning about the "Calendar" communication systems that are used throughout DeafBlind Ontario Services. Calendar systems are used in conjunction with Adaptive Interactive Tactile Sign Language (AITSL). This system is a collection of concrete objects or pictures that symbolize an activity or routine which has proven to help develop and enhance the receptive and expressive communication of many of the deafblind people supported by DeafBlind Ontario Services. These calendar systems include: "Now" and "Finished" boxes or baskets; "Morning", "Afternoon" and "Evening" pigeon holes, and larger Calendar systems which have information about several activities each day for a whole week. Staff reported that this system gives the individuals tactile information about activities being offered, which enables the prediction of future events thus helping to build memories about their routines and activities. The people who are deafblind can use this system to make decisions and choices as to what activity they wish to take part in.

Having seen first-hand the many varieties of this Calendar system, all implemented to meet the needs and abilities of each deafblind individual; having the opportunity to talk to various staff about its benefits and in particular experiencing the practical application of such a potentially empowering method of enhancing communication, has left me really inspired! I feel very excited about the possibility that this system will prove to be a useful addition to the communication methods already in use back at home. I am now planning to deliver an initial feedback session to Sense staff. I will explain my experiences with the calendar systems used by the DeafBlind Ontario Services staff, with the aspiration that the information is then passed to as many Sense staff as possible.

Towards the end of the exchange I was fortunate enough to attend the Spirit of Intervenors Symposium 'Carrying the Torch of Knowledge', hosted by the Deafblind Coalition of Ontario. This is an association of individuals and organizations advocating for access to appropriate Intervenor services for all citizens who are deafblind living in Ontario. This, the largest gathering of Intervenors in the world, was held over 3 days (February 24-27, 2010).and was attended by 355 Intervenors from 13 different organisations who all support deafblind people. There were presentations about each organisations work, workshops which informed and explored many key issues, uplifting presentations from many inspirational speakers and of course great opportunities to network with others to share ideas and work practices.

I feel almost overwhelmed by the warm and friendly reception I received from the many dedicated and motivated Intervenors I met. I was enormously privileged to have met the deafblind individuals and especially to have been able to join them on the wonderful, though snowy, sleigh ride.

I have made some firm friends who I will be keeping in contact with. I feel sure both Sense and Deafblind Ontario Services will continue to value our strengthening relationship so that we can continue to share innovative ideas, best working practices and professional development.

The next phase of the Canadian exchange is continuing this year.

Shaun Gibbons

Assistant Director, Community Services

SENSE

Susan Manahan

Manager, Community Engagement

DeafBlind Ontario Services

## **Joyce Thompson presented with the Junefest Award of Excellence**

This past year, Rotary Cheshire Homes Inc. and the Canadian Helen Keller Centre Inc. established an annual award to recognize outstanding achievements of Canadian individuals, consumer groups or service providers who make significant and lasting contributions to the Canadian deafblind community in the areas of Awareness, Expansion and Involvement.

The JuneFest Award of Excellence was presented to Joyce "JT" Thompson for the pivotal role she played in founding Rotary Cheshire Homes, The Canadian Helen Keller Centre, Deaf-Blind Awareness Month in Ontario and JuneFest. Throughout her

27-year career, Joyce brought awareness to the disability of deafblindness, expansion to the services available and ensured consumer involvement at all times. Joyce received her award at the 8th Annual JuneFest on June 16, 2010 at Mel Lastman Square in Toronto, Ontario, Canada. The ceremony was attended by consumers, service providers, dignitaries, family and friends. Beginning in 2011, the award will become The JT Award – a reference to Joyce’s “sign name” – in honour of her many accomplishments. The JT Award will be presented annually to one deserving Canadian recipient who exemplifies the standard she set in all of her activities.

## **Denmark**

### **Nordic Centre Project**

#### **Deafblindness in the Baltic States and Kaliningrad**

D

uring 2009, the Nordic Centre for Welfare and Social Issues (formerly NUD) had one of Denmark’s most experienced experts on children and young people with deafblindness run a project in Estonia, Latvia, Lithuania and Kaliningrad. Bente Ramsing Özgür visited the countries several times, sharing the Nordic knowledge on communication and language development as well as identifying deafblindness. This has opened eyes, ears and minds of a number of professionals from countries which, while geographically very close to the Nordic countries, are marked by history from an era of Soviet domination. This has created completely different views of people with disabilities than we have grown accustomed to in the West.

The report describes the results of the project in each of the countries. It also contains recommendations for further work, which, with advantage, could be done while a lot of people still have a fresh memory of hearing something new – or just something – on deafblindness.

The report, which is in English, may be downloaded at:

[www.nordicwelfare.org/balticstates2009](http://www.nordicwelfare.org/balticstates2009)

We can also provide a printed version at no cost. Order your copy at:

[nvcdk@nordicwelfare.org](mailto:nvcdk@nordicwelfare.org)

Lasse Winther Wehner  
Nordic Centre for Welfare and Social Issues  
Information Officer

## Switzerland

### Three perspectives – one conclusion

#### Staff development in Switzerland

In the course of a 3-day conference at Tanne1, Swiss Centre for Deafblind People ([www.tanne.ch](http://www.tanne.ch)), in August 2010, Tanne staff and visitors from Switzerland, Germany and Austria had the chance to learn from, and discuss relevant issues with, three experts: Prof. Dr. phil. Dr. rer. nat. Gerhard Roth (Head of the Brain Research Institute at the University of Bremen), Prof. Dr. Jan van Dijk (Netherlands) and Inger Rødbrøe (Denmark), the latter two needing little introduction to the readers of this journal.

#### Neurobiological insights (Gerhard Roth)

Neuroscientific knowledge provides important insights for our work with deafblind people. The rich input Professor Roth gave us included the following points. The brain's key task is to constantly assess whether or not a particular action is life-sustaining, not only in the biological but also in the social sense. The sensory systems play an important role within this continual process: only if I can perceive a sound to be extremely loud or a person to be meaning well (their eyes will give me the most important cues) is my brain able to assess the experience and adjust my future behaviour accordingly.

Of equal significance are the sensory systems in connection with sensorimotor feedback which works, to put it simply, like this:

- (a) The brain gives an order – Raise index finger! – and anticipates its consequences.
- (b) The order is carried out, its execution perceived by the sensory systems and the perception reported back to the brain.
- (c) The brain compares the anticipated feedback with the actual feedback and concludes: 'Order is correctly carried out!'

This sensorimotor feedback is the result of the highly complex coordination between the sensory and the motor systems. If one of these systems fails to function properly, the overall system becomes unreliable. Sensorimotor feedback also affects a person's ability to recognize the boundary between his or her own body and the rest of the world.

The human brain has an amazing capacity to compensate, at least partially, for the failure or limited function of one of its domains by strengthening and extending its capacities in another domain. Thus in blind people, those brain domains which normally serve the visual system, begin to work for the tactile and the auditory systems. The brain's compensatory potential, if it is to be fully exploited, not only depends on regular training over many years but equally so on human bonding between a deafblind person and those who accompany him or her during learning processes.

Another important insight from neurobiology concerns the fact that, thanks to the tactile sense (which is one of our primary senses), even completely deafblind people can perceive three-dimensional space. Concluding his talk, Professor Roth suggested

this probably means that despite their multiple sensory problems, deafblind people share with those who see and hear a fundamental understanding of what the world is like around them.

### **Assessing a deafblind person's abilities (Jan van Dijk)**

For several decades now, Jan van Dijk has been amongst the most influential experts on deafblindness. In his talk, Dr. van Dijk presented the Child-guided Assessment that he has developed together with colleagues. It has been published and is available at [www.drjanvandijk.org/](http://www.drjanvandijk.org/).

This assessment is based on the thorough observation of a deafblind person's behaviour. It aims at recognizing his or her strengths and potentials, with the intent to focus on these rather than their weaknesses. Ultimately, this leads to a better quality of life instead of constant frustration at failing to do things.

The assessment comprises several domains, among them memory, anticipation, problem solving, social interaction and communication.

In a short film sequence, for example, we see little Iris playing a puzzle with her mother. Observing the scene closely, we recognize Iris' ability to solve problems and her ability to follow a routine. First, she turns to her mother for help; after having finished the puzzle, Iris puts it away in its proper place in the room. In another sequence, she goes to fetch the key to her toy house; after having checked one last time that it is the right one, she opens its door. Observing her, we recognize that Iris is capable of anticipation, an ability which is of tremendous significance for human development. Iris opens the toy house's door, puts a small block inside and waves the block 'good-bye'. This indicates her ability for symbolic representation (i.e., the block represents a person).

It is not by accident that 'playing' serves such a central role in this analysis, because play, Jan van Dijk emphasized, offers almost infinite opportunities for learning and practising elementary skills.

### **The deafblind person as an active participant in interaction and communication (Inger Rødbroe)**

The final speaker was Inger Rødbroe who spoke to us about her most important insights concerning communication with deafblind people. Inger Rødbroe has been working with deafblind people and their communication partners over the last thirty years. She has become well known through her contributions to the Deafblind International Communication Network and especially the publication of her and Anna Nafstad's book, *Co-Creating Communication* (1999).

According to Inger, the key to communicative development is understanding communication as created by both partners, with the deafblind person taking an active role in this process. Co-creating communication draws on interactional and dialogical theories, because dialogically oriented social interaction and communication is crucial for every human being's psychological well being. Thus, it is essential to reflect about psychological aspects of life such as self and personhood. Trust and agency – that is one's ability to act upon the world and the awareness of this ability – are fundamental to communication and develop in contact with other people. Inger Rødbroe presented a number of different concepts which are relevant to our everyday educational activities, among them social availability. It is important for deafblind people to experience that their partners enjoy being with them, and that they can influence what

is happening or not. Their partners should be available as often as possible without requiring anything in particular of the deafblind person. At the same time, they should be attentive to the deafblind persons' communicative expressions. Deafblind people's self-confidence can be strengthened when they experience their partner's interest in, and willingness to engage with, their personality and when they communicate with their partners about shared experiences.

This in turn increases their pleasure with interacting and communicating, thus enhancing their development chances.

### **Gathering the strands of thought...**

Starting with neurobiological insights into the deafblind person's situation and potentials, moving to assessing their strengths and abilities, and finally to discussing our own behaviour as communication partners, all three speakers together emphasized one point: It is essential for us to be aware that emotional involvement and emotionally charged experiences provide one of the pillars to quality of life and the ability to learn. Social interaction within valuable relationships strengthens the brain's compensatory potential, enables deafblind people to show their strengths and offers an opportunity to co-create communication

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Tanne,, Centre for Deafblind People, Switzerland (www.tanne.ch)

Tanne is the centre for deafblind or dual-sensory impaired persons in the German-speaking part of Switzerland (www.tanne.ch)

Tanne Newsletter: <http://www.tanne.ch/tanne-newsletter/oktober-2010>

### **Further reading:**

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- Nelson, C., Van Dijk, J., Oster, T., & McDonell, A. (2009). Child-guided Strategies: The Van Dijk approach to assessment. American Printing House for the Blind
- Rødbroe, I. & Janssen, M. (2006). Communication and congenital Deafblindness. I: Congenital deafblindness and the core principles of Intervention. VCDBF/Viataal

## USA

### **Deaf-blind young adults carry advocacy message to Washington, DC**

Six deaf-blind young adults traveled to Washington, DC, last year to develop leadership and advocacy skills and to put a face on the issues affecting persons who are deaf-blind. They were participants in a one-week course to build and apply their skills in meetings with Senators, members of Congress, and the President of the United States. Following this experience, the participants evaluated and discussed their perceptions of the benefits of the program to help shape its future direction. George, an 18-year-old from Florida who graduated from high school with honors, is blind and uses hearing aids for moderate hearing loss. Crystal, a 24-year-old college graduate from Texas, was born with vision and hearing loss. She uses a combination of speech and sign language and works with a guide dog. These two young people and four others studied how best to present their messages and how to handle any situations that might arise. For instance, how should they respond if a Senator were to address the interpreter rather than the advocate?

The program participants reviewed and advocated for four legislative topics regarding deaf-blindness: the need for Support Service Providers, support for state technical assistance projects, inclusion in the 21st Century Telecommunications and Video Description Act, and increased support for the Helen Keller National Center. The participants also turned their focus inward, evaluating their training and experiences to identify the most important aspects. They considered access to information on policy issues, knowledgeable mentors who understand deaf-blindness, and opportunities to practice advocacy skills while engaging with elected officials to be the most effective parts of the program. Their input will help improve the program in the future.

As a result of their experiences, the six program participants also expressed awareness of their ability to bring about change in a national context for other people who are deaf-blind. All have plans to become involved in mentoring other young adults who are deaf-blind to encourage participation in policy efforts.

Although deaf-blindness creates barriers to communication, these young men and women benefited from a positive experience. Several participants have continued advocacy efforts on state and local levels, while some have pursued international experiences. They have maintained contact with one another and others involved in the course. Some participants also plan to share their experiences at national conferences.

The full text of this article “Deaf-Blind Young Adults in Action: Legislative Advocacy and Leadership,” can be found in the special Fall 2010 issue of *AER Journal: Research and Practice in Visual Impairment and Blindness*, available at <http://www2.allenpress.com/pdf/aerj-03-04-124-131.pdf>.

News Release from the Association for the Education and Rehabilitation of Blind and Visually Impaired (AER). To learn more about the association, please visit: [www.aerbvi.org](http://www.aerbvi.org)

## **Finland**

### **Finland now has new legislation concerning interpreting services**

**by Stina Ojala, Head of Communication Unit, Finnish Deafblind Association**

New legislation concerning interpreting services in Finland has transferred the responsibility of providing the services from municipalities and boroughs to the Social Insurance Institution of Finland. This legislation is reversionary, and covers interpreting services, if no other law preceding covers them.

This responsibility of providing the interpreting services covers the salaries and all the accompanying charges and travel expenses of the interpreter(s) going abroad. The interpreting services are free of charge for the individual using these services. There is a minimum of 360 hours of interpreting services a year for a deafblind individual. It is a fairly easy procedure to receive additional hours when needed. Interpreting hours for study related purposes are separate from this amount.

The deafblind individual has a subjective right for these interpreting services. The interpreting services are provided according to an individual profile application. This profile document application includes a description of the individual's methods of communication and interpreting needs.

There are special definitions for interpreting services for deafblind individuals. The interpreting services for those who are deafblind are divided into three categories: interpreting, guiding and environmental description. Interpreting can be done between different languages, e.g. between spoken Finnish and Finnish Sign Language, and within a single language, e.g. interpreting from spoken Finnish to written Finnish. Guiding is needed when the situation involves moving from one place to another. Environmental description is the practice of providing non-lingual information to the deafblind individual, including: what can be seen, who is present, what sounds there are, and in general, what is happening within an interpreting situation.

Personal assistance for deafblind people in Finland now governed by new legislation  
By Stina Ojala

There has been a change in legislation concerning services for severely disabled persons in Finland. This change brings personal assistance as one of the subjective rights for a disabled person. Personal assistance covers assistance for daily living in a home environment according to their needs, and for free time activities to a minimum of 10 hours per month. From January 01, 2011, personal assistance hours will be for a minimum of 30 hours per month. This new legislation promotes equality for disabled persons in Finland.

### **Deafblind Expertise Team in Finland**

by Ritva Rouvinen, Regional Director, Finnish Deafblind Association



A Deafblind Expertise Team has been established in Finland to achieve better knowledge and understanding of deafblindness, especially in the field of medicine. The expertise team tries to improve the recognition and place of deafblind people in Finnish society, and especially among health care providers.

The expert team is an interdisciplinary group of consultants working closely with the Finnish Deafblind Association. The expert team consists of an ophthalmologist, an audiologist and a doctor of genetic medicine, complemented by experts in communication, special education and deafblindness. In order to influence the society there is also a representative from the public administration.

## Japan

### **Celebrating Deafblindness in Osaka**

The Deafblind Service Center “SMILE” was established in 1999 in Osaka Japan for people with deafblindness. Organizers at SMILE have developed various services so that people with deafblindness can lead active lives and can be accepted as equal member of society.

We celebrated our 10th anniversary at Kadoma City Hall in Osaka, Japan, 13 November, 2010. We held four commemorative events during this year to raise public awareness about this disability in our region. Our message is that people with deafblindness are all around us, they have potential and the ability to live on their own. During each event we featured performances by people with deafblindness, to highlight their abilities.

In the event “5th Big Stage of People with Deafblindness in OSAKA 2010” we four-walled (self-created) a movie featuring people with deafblindness who provided musical performances using Japanese drums as well as traditional Japanese dancing. This ‘four-wall’ movie, demonstrated to the audience the challenges and needs facing these individuals.

While practicing for these performances, the most difficult part was attempting to have the individuals understand the sounds and the movements. Music and dance evoke various emotions, which were then associated with figurative expressions. This demanded of them much patience and creativity until they learned what was a ‘sharp’ sound, how to make a ‘free’ sound, what is ‘loose’ movement and how to make ‘easy’ movements. It was a great challenge to explain to these individuals what we, as hearing and seeing individuals, can actually hear and see! To do this we had to make a lot of body contacts using the tactile senses.

With a great deal of effort, these people with deafblindness were successful in gaining positive experiences through playing drums and dancing. What they had obtained through these experiences was not only new skills but also new confidence. Big Stage was indeed a wonderful opportunity for self expression and self realization for these individuals.

We are happy and proud that the audience enjoyed our Big Stage and that the deafblind individuals were able to achieve their goals.

Truly it is a disadvantage to live in a world without sight and sound. At the same time, this theatrical experience was a wonderful opportunity for these deafblind people to 'step into the other side!'

In closing, we extend our appreciation to William Green, President of DbI, who contributed a message for our commemorative publication.

Akemi Fujii

SMILE

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## **27th Annual Pacific Rim**

### **International Conference on Disabilities**

#### **“Humanity: Advancing Inclusion, Equality and Diversity”**

April 18 & 19, 2011

Hawaii Convention Center

1801 Kalakaua Avenue

Honolulu, HI 96815

You are invited to participate in the 27th Annual Pacific Rim International Conference on Disabilities on April 18 & 19, 2011 at the Hawaii Convention Center in Honolulu. Join over 1,000 participants in this year's international theme “Humanity: Advancing Inclusion, Equality and Diversity”, featuring 15 topics & 30 keynote speakers.

This event is hosted by the Center on Disability Studies (CDS), a University of Hawaii Board of Regents recognized center of programs focused on the development and conduct of interdisciplinary education/training, research/demonstration and evaluation, through university and community services.

Center on Disability Studies, University of Hawaii at Manoa

Charmaine Crockett

1776 University Avenue, UA 4-6 Honolulu, Hawaii 96822

(808) 956-7539

[www.pacrim.hawaii.edu](http://www.pacrim.hawaii.edu)

## **LISTEN TO ME 5**

## **Conference for deafblind people and their families**

**July 27 – August 1, 2010**

The fifth international conference for the deafblind and their families, LISTEN TO ME 5, was held in Olomouc, the Czech Republic, from 27 July to 1 August 2010. The conference was organized by Záblesk Association, the association of deafblind children's parents and friends, along with strong support from international organizations (Perkins International, DbI, Sense International, EdbN, Lega delfilodóro) and sponsors from the Czech Republic (O2, Nadace Leontinka and many others).

The conference was attended by 125 participants, 21 families from 14 countries. Other conference attendees included experts, representatives of other organizations for the deafblind in the Czech Republic (VIA, Club of Red and White Stick Friends), SEN (Special Education Needs) teachers, psychologists, assistants and those from the general public attending other activities organized by the hotel, such as Children's Day and Summer Beauty Queen 2010 competition.

Thanks to the help of Olomouc SEN teachers (Olomouc has only school class for deafblind students in the Czech Republic) and assistants (secondary school and university students), deafblind children and young adults, as well as their brothers and sisters, could enjoy an interesting and varied programme which included touching zoo, canistherapy (thereapy using dogs), music therapy, various walks and trips, arts activities, bowling competition and an organ concert in St. Michael's Church.

Therefore, the parents could attend the plenary sessions and workshops which were held in the conference rooms of the Flora Hotel, where the participants were also staying. The workshops and lectures were thematically oriented and included topics such as the life of a family and its deafblind child, services for the deafblind in the Czech Republic and other participating countries as well as the sharing of experiences from organizations and parents.

Together with the representatives of the village of Olsany u Prostejova, Záblesk Association presented its pilot project of sheltered housing for young deafblind people in the Czech Republic. At present, this is the only facility for deafblind young people in our country.

The participants could also see interesting places and monuments of the City of Olomouc and its surroundings: Litovel, Lostice, Roznov pod Radostem and Kromeríz. Activities presenting Czech customs and traditions were also an integral part of the programme.

The families, as well as other participants, were leaving for home full of impressions and experiences; with new knowledge and experience in the field of deafblindness, education and upbringing of deafblind children, along with developing new friendships with other families and people not only from Europe, but from the whole world.

Ivana RECKOVA, President ZÁBLESK – The Association of Parents and Friends of Deafblind Children

# dovblind

## DEAFBLIND: DAILY LIFE

PROFESSIONALISM VISIBILITY DOCUMENTATION

**April 23-26, 2012**  
**Oslo, Norway**

A conference for deafblind persons, staff, consultants, physicians and researchers who work within the fields of either acquired or congenital deafblindness.

First announcement!

The conference will focus on the competition in the Nordic Welfare Systems. To better compete, we need to ensure the professional quality, document it and publicize it!

The conference language will be Scandinavian. All plenary speeches and many workshops will be interpreted into Finnish and Icelandic.

Stay tuned for more info coming up at [www.nordicwelfare.org](http://www.nordicwelfare.org)

Nordic Centre for Welfare and Social Issues



 **norden**  
Nordic Centre for  
Welfare and Social Issues

# **An invitation to use a Free Online Assessment Tool for Early Communicators who are Deafblind**

**Charity Rowland, Ph.D.**

**Oregon Health & Science University, Portland, Oregon, USA**

**rowlandc@ohsu.edu**

Children learn to use a variety of pre-speech behaviors to interact with family members and other people before they learn to speak. When it does appear, speech is only the culmination of an evolving communicative competence that begins at (if not before) birth (Bates, Benigni, Camaioni & Volterra, 1979; McCathren, Warren & Yoder, 1996). In other words, speech does not miraculously appear between the ages of 12-24 months; it is the result of an orderly progression from the earliest of parent-infant interactions to the use of formal language systems. This means that if speech does not appear spontaneously, we can look for other means of expression to replace speech or to fill the gap until the child is ready to use speech.

To begin this process, we need to determine which communication mode or system will capitalize on the child's current strengths, providing an immediate means of communication, as well as providing a foundation for future growth. An accurate assessment of a child's communication skills is the cornerstone of educational planning and intervention (Chen, Rowland, Stillman & Mar, in press). A thorough evaluation of the child's current functional means of expression will be far more illuminating than mere knowledge of his or her disabilities, diagnosis or etiology. A good assessment paints a clear picture of what the child can do, not a litany of what he or she can't do. The online Communication Matrix (Rowland, 2009) was developed to make this task easier for parents and professionals. It is widely used in the U.S. to evaluate the expressive communication skills of deafblind children. This article introduces this free assessment service and invites parents and professionals to use it to assess deafblind children and adults and who are operating at the earliest stages of communication. (See fig 1)

## **Description of the Communication Matrix**

The Communication Matrix is designed to pinpoint exactly how someone is communicating, with or without speech, and to provide a framework for determining logical communication goals. The Matrix was first published in 1990 and was revised in 1996 and 2004. The original version (Rowland, 2004a) was designed primarily for speech-language pathologists and educators to document the expressive communication skills of children who have severe or multiple disabilities, including sensory, motor and cognitive impairments. Its format is concise, and it is designed for rapid administration by persons familiar with the instrument. A second version of the Matrix was developed especially for parents in English (Rowland, 2004b) and in Spanish (Rowland, 2006). This version is longer, but more "user friendly." An online version, based on the parent format, has been developed as a free web-based service and is currently available in English and Spanish (Rowland, 2009). The online version

was developed for several reasons: to make the Matrix easier to use; to make it widely and freely available to potential users; to encourage collaboration between professionals and parents; and to create a database of information that would advance scientific knowledge about communication development in specific populations with complex communication needs.

## **Design of the Communication Matrix**

The Matrix is structured around seven levels of communication that occur in the typically developing child between the ages of 0-24 months. The levels range from Pre-Intentional Behavior (the very earliest behavior that is not under the child's voluntary control) to Language (combining 2-3 words, or any type of symbol, into phrases). Level V (Concrete Symbols) does not constitute a distinct stage in infants without disabilities, but may be a critical stage for some individuals who are deafblind. In contrast to abstract symbols, such as spoken words or manual signs, concrete symbols physically resemble the referents that they stand for. They look like, feel like, move like, or sound like what they represent. Concrete symbols include pictures, objects (such as a shoelace to represent "shoe"), "iconic" gestures (such as patting a chair to say "sit down") and certain vocalizations (such as making a buzzing sound to mean "bee"). For some children, concrete symbols may be the only type of symbol that will ever make sense to them. For others, concrete symbols may serve as a bridge to the use of abstract symbols such as spoken words and manual signs.

The Matrix is further organized into four early reasons to communicate: to refuse things that we don't want; to obtain things that we do want; to engage in social interaction, and to provide or seek information. The Matrix is completed by answering questions about the messages expressed at each of the seven levels of communication. As an example, question C3 (Requests Attention) asks, "Does your child intentionally try to attract your attention?" These questions are answered by indicating which (if any) communicative behaviors are used to express each message. Many different behaviors may be used to communicate at any level. In the Matrix, behaviors are classified into nine categories: body movements, early sounds, facial expressions, visual behavior, simple gestures, conventional gestures/vocalizations, concrete symbols, abstract symbols and language. Specific representative behaviors are provided in each category for each of the 24 questions. For instance, under Question C2 (Requests More of an Action), the body movements category includes these specific behavior options: whole body movements (example: lunge), arm/hand movements (example: bat arms) and leg movements (example: kick). To train users, three demonstration videos that explain how to use the Matrix and how to interpret results are included on the website. A 26-page handbook may be downloaded from the web site at no cost.

## **Results Generated by the Communication Matrix**

Once the evaluator has answered the 24 questions by indicating which behaviors the individual uses to express each message, results are generated online. The one-page profile reveals at a glance how the individual is functioning. The cells on the profile represent all possible combinations of messages with the seven levels of communication, are color coded to show skills as mastered, surpassed, emerging or not used. An individual with severe motor constraints, who has very limited means of

expression, may have a similar profile to someone with an extensive repertoire of behaviors. Since the emphasis is on the number of messages that are expressed, the profile does not penalize the individual who is unable to produce many behaviors. A comprehensive communication skills list is also generated that catalogs each message, the categories of behavior used to communicate each message, the specific behaviors used, as well as the level of mastery.

In-depth “mastery” views of each level are available online that quantify the depth of an individual’s behavioral repertoire graphically and quantitatively. The mastery view is useful for reviewing results online with a team. For individuals on whom two or more administrations have been completed, animated views of progress are available. To encourage sharing between professionals and family members, a link of the assessment results may be emailed to others. The research database associated with the assessment service collects all the information entered about an individual’s communication skills and demographics, while strict security measures ensure that the data cannot be linked to users.

We have just developed a new customized report capacity to generate detailed individualized reports that include educational goals and suggestions for intervention. Users may specify which components to include in the report and may choose from sample goals and recommendations on the web site or generate their own free-text entries. This feature is in a beta-test mode and is free (although we hope that eventually this capacity may generate funds to support the web site). We are very interested in user’s impressions of this new feature and will incorporate feedback from users into the final version. At this juncture, we do not have support to provide the reports feature in non-English languages.

### **Widespread use by the Deafblind Community**

The online Communication Matrix is becoming widely used. At this writing, over 12,500 Matrix profiles have been completed on over 10,000 individuals, many of whom have been assessed multiple times. Currently, almost 300 new sets of data are entered per week. Demographic information collected through the online version shows that 11% of users are family members, 43% are speech-language pathologists, 41% are teachers, other educators or therapists, and 6% are “other.” The relatively large number of family members using the service suggests that it is encouraging parents to participate in the assessment process, as hoped. Although people of all ages are represented in the database, most of the individuals assessed are young children, including 32% between the ages of 0 and 5 years, 35% between 6 and 10 years, 17% between 11 and 15 years and the remaining 16% above 15 years of age. Users come from 104 different countries, with 72% of users from the U.S.

One of the hopes in developing the online version was that data could be collected on the communication skills of children with low-incidence disabilities on whom little data can be aggregated in any one geographical location. This expectation is being realized. Individuals assessed using the online Matrix represent many different etiologies, diagnoses and health conditions, but fully 11% have a primary diagnosis of deafblindness. As we know, deafblindness is a label that is associated with many different etiologies. As of this writing, the database includes data on 749 individuals aged 0-21 years with a primary diagnosis of deafblindness associated with 32 specific etiologies. This is approximately 8% of the 9,827 children ages 0-21 identified in the U.S. in the 2008 deafblind child count conducted by the National Consortium on Deafblindness. The information contained in the database will provide new insight

into the development of communication skills in individuals who are deafblind. We plan to publish a series of scientific articles based on these data.

The Matrix has been suggested as an appropriate assessment tool for a variety of populations, including children who are deafblind (Holte et al., 2006), young communicators using “augmentative and alternative” communication systems (Buzolich, 2009), children with severe disabilities or sensory impairments (Proctor & Oswalt, 2008), and users of alternative communication modes (Beukelman & Mirenda, 2005). The appropriateness of the Matrix for assessing deafblind individuals may be attributed to the fact that it accommodates all possible communicative behaviors and that it breaks down communication development into smaller steps than other assessment instruments.

### **Future directions**

Grants from the U.S. Department of Education have supported sweeping improvements to the online Matrix. The website is now available in English and Spanish and will soon be translated into the following languages: Chinese, Vietnamese, Korean, and Russian. The new language versions will encourage more non-English-speaking parents and professionals to use the service. Users who speak other languages occasionally volunteer to provide translations into additional languages. It is our desire to make new translations available, but this is a complex and expensive process. Individuals and organizations interested in facilitating new translations should contact the author. Although grant funds are temporarily available to support the web site, this funding will draw to an end in about a year. Maintaining and updating the burgeoning web site is not without cost. We are exploring mechanisms to support the service in the future, with the goal of continuing to offer the basic assessment capacity as a free service. Any suggestions in this regard are appreciated. In the meantime, please use the service and feel free to offer your suggestions for improvement. It is only with the input of users that we are able to continue to improve this collaborative web site.

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## **Depression in the Deafblind community:**

### **Working from a Social Work Perspective**

Mental health problems can affect anyone regardless of age, race, gender or social background. Even though the assessment and treatment of depression is a well researched area, there is a limited amount of literature that has considered depression in deafblind people. Deafblind individuals encounter practical, emotional and social problems that are unique and beyond those experienced by individuals with single sensory impairment. These challenges and difficulties in turn increase the risk of people who are deafblind developing depression and experiencing mental health issues.

### **Maintaining good mental health can pose considerable challenges**

Maintaining good mental health can pose considerable challenges for a person living with deafblindness. Dual sensory loss, whether progressive or sudden, whether in part or total, will categorically have an impact on an individual's psychological profile (Boldue et al., 2006). The incidents of depression and mental health issues in individuals that are deafblind will vary with the influence of multiple factors including: age, mode of communication, part of deaf culture or not, nature of sensory loss, education level, employment, financial situation, social network, personality etc

(Williams & Abeles, 2004). The impact will be modulated by the magnitude of the loss, the personal resources of the individual, the support received from the individuals' social network, as well as the community or professional services they may be receiving. This paper has highlighted issues mainly related to adults with acquired deafblindness.

A study undertaken by Mary Tass, a psychologist in Melbourne-based Able Australia Services in 2009, examining depression and anxiety in people who are deafblind concluded the following:

“The results of depression and anxiety in people in the deafblind sample are a reflection of the challenges and difficulties faced by people with dual sensory loss. Many deafblind people have had a life (or large segments of life) of isolation, loneliness, boredom, frustration, communication difficulties and breakdowns, unemployment, and the frustration of relying on support workers for simple tasks and chores. They also have had to make continual adjustments that are necessary as sight or hearing (or both) deteriorate over time. The loss and grief is ongoing, not only because of the deafblindness itself, but the changes and deterioration of the senses that often take place. As changes occur, deafblind people experience fear and worry about the future. They worry about accommodation, support, safety and more years of loneliness and isolation. Distractions in the deafblind person's life are limited and often difficult to sustain. The high percentage of depression and anxiety in the current sample is understandable, given the issues and challenges that arise” (Proceedings, 8th National Deafblind Conference, 2010).

### **Identifying and assessing mental health problems is essential**

Identifying and assessing mental health problems is essential to ensuring access to appropriate treatment and services for people who are deafblind. Without effective language interactions, deafblind individuals may have limited ability to express themselves with others and may also struggle to label their own experiences, thoughts and feelings. Given that communication is critical for all aspects of the therapeutic process, the paramount issue that arises in working with deafblind clients in a social work context is the communication barrier (Briffa, 1999). This is immediately evident when trying to make an accurate assessment and diagnosis of client's situations. It has been identified that psychological assessments used with deafblind people are generally inappropriate; the majority of such tools have been developed as a result of research with white, middle-class, hearing participants (Connolly et al 2006). Mental health professionals who are unfamiliar with the psychosocial development and unique experiences of deafblind individuals can also contribute to invalid assessments and treatments. An example being misdiagnosis by overlooking depressed affect or misinterpreting the active and expressive nature of sign language and reaching conclusions that the deafblind person is disinhibited or manic (Misiaszek et al.; 2004, Fusick, 2008). There is little doubt that the assessment and treatment of depressive symptoms in the deafblind population is a complex process. A practitioners' awareness of the multifaceted problems associated with deafblindness is indispensable for effective evaluation and treatment. All professionals working in this sector are called upon to foster awareness; this includes educating themselves, their clients, their clients' families, mental health and allied health professionals, employers and the wider community about deafblindness and Deaf culture and advocating for services to accommodate the needs of deafblind clients.

## **Not communicating in the same language leads to misunderstandings**

Clearly when people do not communicate in the same language there is a high potential for misunderstandings to occur. Communication breakdowns can perpetuate long established patterns of misunderstanding, isolation and oppression in a client's life (Misiaszek et al., 2004). Working through an interpreter raises several issues. Specifically in the social work context, the inclusion of an interpreter in an interview introduces two more relationships to the interview: interpreter-client and interpreter-social worker. This can have the effect of altering the usual dyadic therapeutic relationship. When an interpreter provides a "voice-over" for a deafblind person, the interpreter aims to reflect the affect of the deafblind person. However, this can be a challenging and somewhat subjective process (Connolly et al., 2006).

There is a minimum standard of competencies involved for social workers and other professionals when working with the deafblind population. These include: the ability to express and receive information in the client's preferred communicative mode taking into consideration the client's level of expressive abilities, the clients preferred modes of receptive communication and their ability to receive communication through these modes. This is coupled with the ability to understand the art and skills of interpreting for clients and to work effectively with an interpreter. All behaviour, healthy or psychopathic, must be recognized and assessed in a context of deafblindness. Practitioners have an obligation to critically examine current research and modes of assessment and treatment along with being mindful of prior misdiagnosis, assumptions and labelling of deafblind clients (Meyers & Thyler, 1997). Social work within the deafblind community also requires the ability to work effectively with multidisciplinary team members including parents and family, and to understand the psychosocial implications of their respective contributions. Along with the capacity to inspire trust and confidence by projecting warmth, caring, and patience and the ability to put all these together into sound recommendations, guided by where the client was, where he/she is, where he/she should be and how to get him/her there. In this context the only 'instrument' designed for this purpose is the practitioner. No instrument or technique can replace interpretive competence and wisdom.

## **A wide variety of psychoanalytic approaches have been successful**

A wide variety of psychoanalytic approaches have been successfully utilized with deafblind clients suffering from depressive illnesses. Dependant on client capacity, but regardless of theoretical orientation, competent social workers need to depathologize deafblindness and concentrate on their clients' strengths and assets (Fusick, 2008; Leigh, 1999). Strengths-based counselling consistently focuses on ability, not disability. A client-centered therapeutic approach is beneficial in that it focuses on the client's interests, strengths, talents, and abilities rather than the client's perceived disadvantages and limitations of their disability.

Understanding a deafblind client in context is a complex and specialized clinical challenge. To be of help, a social worker and other professionals must join each deafblind person in a full and multifaceted exploration of all pertinent dimensions of life. This process takes time and commitment but the exploration is essential for developing a positive relationship, assessing needs accurately and for the delivery of high quality service. Assessment of a deafblind person requires that the practitioner be experienced in appropriate communication modes, in intervening, making behavioural observations, gathering case and family history material. Furthermore, the successful

assessment requires understanding as to how the clients deafblindness impacts on his or her life.

The vulnerability of deafblind individuals to depression and mental health issues has been clearly identified. Major concerns have been highlighted relating to communication difficulties, lack of awareness by health professionals of the issues related to deafblindness, the inappropriateness of some services for deafblind consumers and the inequality of access to information and services. Social workers and other professionals working with clients that are deafblind need to continue to be aware (and raise awareness) of what being deafblindness implies, and the obstacles that deafblind people must overcome in order to effectively utilize knowledge and experience to counsel, advise, and advocate for this unique community.

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## **Alice Betteridge, Australia's Helen Keller**

### **Robyn Cattle Moore, PhD and Michael Steer, PhD**

The Royal Institute for Deaf and Blind Children (RIDBC), situated in suburban Sydney, Australia, is widely regarded as the nation's premier private sector special

educator. The organization provides a broad range of educational and family support services to young children and adolescents who have significant hearing and/or vision loss, including children who have additional disabilities. Founded in colonial New South Wales in 1860, RIDBC is one of Australia's oldest charitable organizations and has an enviable record in educating children with dual-sensory impairments. In October this year (2010) the Royal Institute for Deaf and Blind Children celebrates its sesquicentennial anniversary – “150 years of changing lives through education”.

Alice Betteridge was the first deafblind child to attend the Institute. A spirited little girl from country New South Wales, Alice is often described as “Australia's Helen Keller”. She was born at Sawyer's Gully in the Hunter Valley region of the state in 1901 – the same year that Australia became a nation – and like Helen Keller, lost both her sight and hearing as the result of suspected meningitis at age 2.

When Alice commenced her schooling in 1908, the Institute occupied a prominent building in the centre of town, next door to Sydney University. The mistress in charge of the “Blind School” was a young Arts graduate, Miss Roberta Sinclair Reid, whose role and career are in several ways analogous to those of Anne Sullivan, the dedicated companion and teacher of Helen Keller.

Roberta, or “Berta”, as she was affectionately known, welcomed little Alice into her classroom of 13 blind children and with infinite patience and resolve began to teach her a tactile sign language through ‘finger spelling’. Readers familiar with the Helen Keller story will recall that her communication breakthrough occurred when finger spelling was associated with water flowing over her hands. For Alice, it was a shoe. Being a country girl, Alice had been used to exploring her world barefoot, but each day at school, unseen hands would present her with shoes and a pattern was tapped onto her hand. One day, as Berta gave Alice a shoe and dutifully tapped the word “shoe” onto her hand, Alice tentatively repeated the pattern on Berta's hand. The all-important connection between naming-pattern and object had been realized! Not any longer a frustrated learner, Alice's curiosity and innate intelligence blossomed. She became an avid reader of braille and developed a wide range of interests. In 1920, Alice graduated from Dux of School and was determined that she would stay on at the Institute to help the younger students. Those who knew Alice at this time recall a person who was rarely idle and highly independent. She was extremely well informed on current affairs, learned to type and won prizes for her work in open competition (Thompson, 1990).

Alice remained at the school as a teacher for nearly a decade before returning to her family's farm in the small country township of Denman, NSW. Unlike Helen Keller, whose life and achievements became the subject of films and a West End play, Alice Betteridge settled into a relatively modest lifestyle. In 1939 she moved from her home town to Melbourne, in the southern state of Victoria, to marry Will Chapman, her pen-friend of several years who had become blind as a young adult.

Some years later, when the legendary Helen Keller visited Australia to help raise funds for an American foundation, she met with Alice and Berta at the Institute's school for blind children in Wahroonga. Sadly, just three weeks after the women's historic meeting in 1948, Alice's husband died suddenly of a heart attack.

Bereft of her partner, Alice returned to family in Sydney, but within a few years her adventurous spirit and curiosity led her to travel overseas and tour New Zealand. Her biographer (Thompson, 1990) recalls that without exception, all who knew Alice found her to be “a happy well-adjusted person and a joy to be with” (p.134). When Alice herself died from cancer in 1966, aged 65, she was residing in the appropriately named Helen Keller House, situated in the Sydney suburb of Woollahra.

Roberta Reid's contribution to the life-story of Alice Betteridge was acknowledged in 1951 when she received the highly prestigious Medal of the British Empire for her contribution to the education of children with sensory impairments. Her dedication as a teacher is commemorated by RIDBC in the annual award of the Roberta Reid Prize, and in the name of one of its early childhood programs, The Roberta Reid Preschool.

## **The Legacy**

Alice's legacy continues to inspire through the work of the RIDBC Alice Betteridge School. A centre of education for children aged 3-18 years of age who have a sensory disability and other special learning needs, the Alice Betteridge School (ABS) was named in honour of the outstanding student from Sawyer's Gully – the first deafblind child to be educated in Australia. The school, located on the Royal Institute for Deaf and Blind Children main campus at North Rocks, is recognized both nationally and internationally for the high quality of its curriculum and staff. Each of the 80 or so students at ABS receives a highly individualized educational program through which their family, teachers and therapy staff work together in partnership. The excellence in special education that is the everyday commitment of the RIDBC Alice Betteridge School is a fitting tribute to the memory of a truly remarkable Australian.

More details about Alice Betteridge, including the photo can be at [www.ridbc.org.au](http://www.ridbc.org.au)

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## **Services for Children and Youth with Deafblindness in Pennsylvania, USA**

### **Jackie Brennan, Overbrook School for the Blind**

#### **Philadelphia, Pennsylvania**

The Pennsylvania Deafblind Initiative is a federally and state funded program to provide technical assistance and training throughout the Commonwealth of Pennsylvania (PA) to meet the unique needs of children and youth who are deafblind. Deafblind Projects, which are in every state in the United States, are linked together through the National Consortium on Deaf-Blindness (NCDB). All of these projects are funded through the United States Department of Education and the Office of Special Education Programs (OSEP). The projects provide technical assistance to

children and youth birth to 21 years of age who are deafblind, their families, educators, and service providers.

The Pennsylvania Deafblind Initiative has three educational consultants assigned to three regions of the state—eastern, central, and western Pennsylvania, along with two family liaisons who are parents of children with deafblindness.

The PA Deafblind Initiative has identified goals to address the needs of children and youth who are deafblind. These goals focus on providing training to professionals and family members on research based instructional strategies; collaboration between agencies at the local, state, and national levels; developing competencies for para-educators, educators, and interveners, and developing a family leadership network. Much attention has been placed on goals related to supporting families and reports from families that they are extremely happy with the results. The Deafblind Initiative Staff continue to offer a distance education program called Project SPARKLE (Supporting Parent Access to Resources, Knowledge, Linkages and Education) which was developed by the SKI-HI Institute at the University of Utah. This program is a self study program for parents to learn about deafblindness. In addition to the learning modules, project staff provides monthly conference calls to encourage discussion and to provide supplementary information on each unit.

### **Parents participate in Leadership Network**

As an extension of this program, parents who have completed this training are invited to participate in a Leadership Network to receive additional training in the areas of advocacy, leadership, and parent-to-parent support. The parents also created a steering committee to form the first state affiliate of the National Family Association for the Deafblind (NFADB) called the Pennsylvania Partnership for the Deafblind (PPDB) [www.papdb.org](http://www.papdb.org). This was achieved through a collaboration with the Deafblind Initiative, NCDB, and the Overbrook School for the Blind.

Families are now actively involved in planning for the annual Family Learning Conference weekend that brings together entire families from across the Commonwealth. Parents attend trainings, siblings attend workshops, and all of the children participate in recreation and leisure activities. This is a great opportunity for families of children who have deafblindness to get together for fun and learning. Through the support of DB-Link and NCDB, a listserv was created for PA family members and individuals who are deafblind to talk about issues and concerns, to share information, and to support each other. This listserv is an active group and members frequently share information with each other. Common discussions relate to medical needs and recommendations for doctors, sharing ideas for recreational activities, sharing information on trainings and conferences, and sharing information about their children.

Project staff provides training related to educational needs of the children. This is done through a variety of ways. Training is sponsored by the Deafblind Initiative and the Pennsylvania Department of Education. Training presenters have included many of the leading professionals in the field of deafblindness.

### **Pennsylvania has officially identified the need for interveners**

Recently, Pennsylvania has officially identified the need for interveners in supporting children with deafblindness. The Deafblind Initiative and the PA Bureau of Special Education (BSE) are now addressing this need. Linda Alsop, deafblind educational

consultants and family liaisons have initiated workshops across the state to train teams of professionals working with children with deafblindness. Plans for the future include offering an intervener credential training program.

In addition to this, two advisory committees work with the PA Director of the BSE to provide information and support to meet the needs of students with sensory impairments. Both of these committees - the Educational resources for Children with Hearing Loss (ERCHL) and Pennsylvania's Approach to the National Agenda for the Education of Children and Youths with Visual Impairments, Deafblindness, and Visual and Multiple Disabilities (PANA) - have worked to create agendas to identify and address the needs of children and youth with sensory loss and the needs of those with deafblindness. These committees represent educators from the continuum of placement options, including Overbrook School for the Blind, parents, consumers, and other service providers. The agendas, as adopted by the PA-BSE, take different approaches and together address the broad range and needs of children with deafblindness.

PANA addresses the 10 goals of our national agenda and how they can be achieved in Pennsylvania. These goals range from early identification, intervention, and family involvement to appropriate testing and implementation of the expanded core curriculum (those skills that a student must learn in addition to the general education curriculum due to their visual needs). ERCHL also focuses on early identification, intervention and appropriate assessment. Other areas emphasize language and communication and offering the full continuum of placement options. Language and communication is addressed throughout the document and includes identifying the need for an intervener for a child who is deafblind. ERCHL's agenda is the first document published by the PA Department of Education and the Bureau of Special Education that specifically includes the role of an intervener for a child who is deafblind.

A very exciting time for children and youth with deafblindness in Pennsylvania  
This is a very exciting time for children and youth with deafblindness in the Commonwealth of Pennsylvania. Through the leadership of John Tommasini, Director of the Bureau of Special Education, there is a focus on insuring that our students with deafblindness receive the appropriate supports and services so that they can be successful.

The ERCHL and PANA agendas were published by the Bureau of Special Education and are distributed through its three regional resources centers called the Pennsylvania Training and Technical Assistance Network (PaTTAN).

Copies of the agendas can be obtained through the following sites:

Pennsylvania Agenda for Students Who Are Deaf, Hard of Hearing, or Deafblind  
[www.pattan.net/files/DHOH/ERCHL-Agenda.pdf](http://www.pattan.net/files/DHOH/ERCHL-Agenda.pdf) and

Pennsylvania's Approach to the national Agenda for the Education of Children and Youths with Visual Impairments, Deafblindness, and Visual and Multiple Disabilities  
[www.pattan.net/files/Deafblind/PANA-Agenda.pdf](http://www.pattan.net/files/Deafblind/PANA-Agenda.pdf)



## Network News

Acquired Deafblindness Network

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## **Communications Network**

Since 1996, the DbI Communication Network has regularly organised International courses on the topic of Congenital Deafblindness and Communication. The Communication Network has no specific rule stating that there should be a course every other year; the strategy is rather to cooperate with agencies that are willing to have this kind of course. Therefore, after three events in Paris (1996, 1999, 2001), several courses took place in Dronninglund (Denmark), Gothenborg (Sweden), Oslo (Norway) and Leeds (U.K.).

The 2010 Paris course came back to the place where the courses started in 1996. INS HEA is the new name of CNEFEI that the first participants know well. The reason for this choice is that many Nordic people expressed their desire to have it again in Paris. The Communication Network approached INS HEA and a collaboration was set up between INS HEA, NVC (the staff training centre for the Nordic countries) and VIATAAL (the main organisation for the Deafblind in The Netherlands) in order to make this event happen.

The concept of dialogicality was the leading concept of the course. It reflects the present focus of the Communication Network research. Dialogicality is an essential aspect of the human mind, i.e. its capacity to communicate, think and develop in a dialogical manner. This dialogicality is made visible in the dialogues that partners in conversations co-construct, but also when people think on their own, producing internal dialogues where they talk with themselves, assuming the role of several partners. The dialogicality of the human mind has been promoted by a number of

philosophers and researchers like Bakhtine, Vigotski, Buber and more recently Rommetveit, Luckmann, Markova and Linnel.

The dialogical potential of people whose communicative skills are very vulnerable (and it is the case for congenital deafblindness) is very easily ignored by scientific approaches as well as educational and communicative practices. The purpose of the course was to understand better how dialogicality can be understood in the case of Congenital Deafblindness and to help deafblind partners (professionals and families) to take into account this core aspect of the human mind when they communicate with congenitally deafblind people.

The topic of the course seems to have attracted a lot of attention among professionals and family members in Europe since 150 participants came together in Paris to attend the course. Most of them came from Europe, but it is worth noticing that Canada, Australia, Brazil and Japan were also represented. A special mention must be made of the Swedish participants that made the big effort to miss their Midsummer Night which, in their country, is as important as Christmas.

“The magic of dialogue” explored various domains of life that are relevant for understanding how this dialogicality of mind works; in human beings in general: this aspect was addressed by various university researchers who are not specialists of deafblindness; in the case of congenital deafblindness: the members of the DbI Communications Network took care of that through answers to the main lecturers and video analysis sessions.

Each day addressed a specific topic:

June 22: Dialogicality in Culture

- Lecture by Prof Colwyn Trevarthen (Emeritus University of Edinburgh – Scotland) followed by answers from Paul Hart and Inger Rodbroe.

June 23: Dialogicality and Language

- Video-taped lecture by Prof Per Linell (University of Linköping - Sweden), followed by answers from Marleen Janssen and Marlene Daelman.

June 24: Dialogicality and Narrativity

- Lecture by Prof Jacques Bres (University of Montpellier – France), followed by answers from Jacques Souriau and Flemming Ask Larsen.

June 25: Dialogicality and Trust

- Lecture by Prof Ivana Markova (University of Stirling - Scotland), followed by answers from Anne Nafstad and Ton Visser.

Through plenary sessions and video analysis workshops, the course provided a context for an ongoing dialogue among scientists, specialists of congenital deafblindness and participants.

This Paris course would not have been possible without the hard work of many people, including: Anne Quesada and Nathalie Lewi-Dumont from the INS-HEA, Magnus Gudnaso, Lasse Wehner and Charlotte Larsen from NVC and Ton Visser from VIATAAL. Also we must acknowledge the members of the DbI Communication Network: Anne Nafstad, Inger Rodbroe, Flemming Ask Larsen, Ton Visser, Marleen Janssen, Marlene Daelman, Paul Hart and Jacques Souriau.

The Conference Proceedings will eventually be available on the DbI website. In the interim, copies of the papers will be available by contacting Dr. Paul Hart, Sense Scotland (phart@sensescotland.org.uk)

Jacques SOURIAU  
Paris – INS HEA 58-60 avenue des Landes. 92150 SURESNES  
June 22-25, 2010

## **Siblings Network**

### **Sabine Kersten reports**

Autumn, the time of the year to look back on this one and make plans for the new year.

At the end of July I was able to join the wonderful family conference “Listen to me”. It was nice to talk to so many families from all over Europe and to hear their experiences. I think this should be the heart of the work of all people working in the deafblind field: families and their experiences.

I also went to the ADBN Conference in Aalborg, Denmark where I gave a presentation about my own experiences as a sister (which you can read in this magazine). It is not always easy to talk about your own experiences in front of a large audience, but it is a way to show people the impact of living with deafblindness. I also presented a workshop where I talked about different feelings siblings may have and the importance of acknowledgement these feelings.

At this point, the network has two main goals: Raising awareness for siblings and providing information. Information is very important for siblings. It will answer some questions and decrease some worries they may have. I hope we will be able to start developing some age appropriate information this coming year.

I wish you all a wonderful New Year! For more information on the network or what we can do for your organisation, please contact:

Sabine Kersten at  
siblingsnetwork@gmx.net

## **Usher Study Group**

### **Marylin Kilsby reports**

The Usher Study Group was held as a pre-conference seminar to the ADBN conference, on September 27 and 28, 2010. We met at the same venue as the ADBN event, the Hotel Hvide Hus in Aalborg, Denmark.

Thirty-nine people attended from 10 countries – Australia, Denmark, Finland, Germany, Greece, Norway, Sweden, Switzerland, UK and USA. We were a mixture

of Usher people (all three Usher Types were represented), friends, families and professionals, including a group of PhD students from Sweden.

Bill Kimberling from the USA opened the programme with some very interesting information about possible treatments which might, in a few years, stop or slow down the deterioration in sight caused by Retinitis Pigmentosa.

Riitta Lahtinen (Finland) and Russ Palmer (UK) gave an introduction to Social-Haptics. Although this method of describing the environment is becoming popular in Scandinavian and some European countries, it was completely new to delegates from other parts of the world.

During the USG, we had two workshop sessions, each with a choice of three workshops. The first session of three Special Interest Groups took place on the Monday afternoon. Usher Travels was very ably led by Eliza McEwin from Australia and Russ Palmer from the UK, both of whom have Usher. Usher in your Family was led by Mark Dunning from the USA. Mark is the father of an 11 year old with Usher Type 1. Tamsin Wengraf led the third group about the psychological aspects of the three Usher syndromes. Tamsin has Usher and is one of the two Usher Information and Outreach Officers at Sense UK.

We concluded the Monday by enjoying a very nice meal put on for us by the hotel staff. This gave us another opportunity to socialise and to get to know people from various countries.

Claes Möller started off Tuesday with his presentation on different hearing and vision outcomes in Usher siblings. At Sense, we had noticed how siblings with the same Type of Usher very often did not have similar symptoms. It was not unusual to find that one sibling, for example, had much poorer sight than the other or, in the case of Usher Types 2 or 3, would have different hearing losses or a different progression rate of hearing loss. Claes' research into why siblings with Usher Type 2 can experience these variations in sight and / or hearing has proved that these differences do indeed exist but, so far, we are not sure as to why this happens.

One of Claes' PhD students, Moa Wahlqvist, gave an interesting talk on the psychological and physical effects Usher syndrome can have on those with the condition. Moa's session was followed by Mark Dunning from the US, who runs a website on Usher. Mark talked about Usher and the family – an easy to follow presentation which touched a chord with many, I suspect.

We then had a very interesting and insightful presentation from Bettina Kestrup Pedersen, a teacher from Denmark, about transitions and counselling for Usher young people. She was helped by Cecilie, aged 17 and an Usher Type 2 from Denmark, who was there with her mother.

The second set of workshops was more targeted at specific groups than the first set. Live Fuglesang from Norway led the professionals' workshop, Riitta Lahtinen ran a workshop specifically for Usher Friends and Family, while Eliza McEwin led a "Managing Usher Change" (MUC!) workshop for Ushers only.

It was really good to see such a good mix of delegates, including "experienced" Usher people, professionals and students who are learning about Usher through their research and, especially, people who were new to such events, whether they had Usher or were family members. Those in this latter group were particularly pleased to meet others and to have the opportunity to learn about Usher. One family member, who had never been to anything like this before, was previously completely isolated from Usher information and sharing. Hopefully, he will keep up the contacts he has made through the USG and be able to use his increased knowledge and confidence to help his Usher sister.

The next USG will be held as a pre-conference to next the ADBN conference, scheduled in Sweden in 2012. A small planning committee is required to assist to run this event. If anyone is interested in being part of this committee, please email Tamsin Wengraf at [tamsin.wengraf@sense.org.uk](mailto:tamsin.wengraf@sense.org.uk).

I am retiring from Sense this autumn and am sad to leave the Usher Study Group just when developments are gathering more and more momentum. However, I sincerely hope that the USG, which is a recognised network of DbI, will continue to grow and flourish to the benefit of all who have Usher.

Marilyn Kilsby  
Usher Projects Consultant  
Sense UK

## **Employment Network**

### **Seija Troyano reports:**

Thinking of the past 25 years as a member of my Finnish National Association of Deafblind, I can see many changes around me today.

The most significant one is probably that we now have new generation of bright, young members with most of them having high level of education and skills to work with. I am lucky to know most of them personally and I can follow their daily adventures and happenings through facebook.

My young friends are very skilful in so many ways indeed; I can't help admiring them. They have the same disability as I have but it is only the part of their whole personality. When I started as a member of the deafblind association, I was often very tired of the atmosphere around; the main theme people most talked about seemed to be about deafblindness. I think it certainly isn't the subject that brings you close to other people if there is not anything else. These young people have so many ideas today and great capacity to boost each others.

I am very delighted to see and experience this very healthy change among people in this field. We hear much more laughter and joking too!

Employment is a very contemporary subject for all of them. With such a good education and skills, they ought to be able to find a meaningful job. However, it is not that easy at all for them, and this means that much work must go on to solve these problems.

If it is the law with its difficult rules that do not work or open the doors; then we must try to change the law. This is my motto.

I want to say thank you to all of you that I have worked with in the DbI Council. Let's hope we can meet again in Brazil, with the World Conference in September 2011.

Let's stay in touch

Seija Troyano,  
Employment Network  
[seija.troyano@dnainternet.net](mailto:seija.troyano@dnainternet.net)

**Bernadette van den Tillaart sends a first announcement of a pre-Conference to be held prior to the 15th DbI World Conference.**

## **Pre-Conference of the XV Deafblind International World Conference in Brazil**

**September 25 – 26, 2011**

### **Landscape of Touch**

#### **DbI Tactile Communication Network**

This pre-conference is organized upon request of participants at the DbI European Conference in Italy. The overall theme is “Touch as Central to Learning and Access for Persons with Deafblindness”. It will focus on enhancing awareness of touch in seeing-hearing people so that they can become skillful and adequate partners for persons who are deafblind. The members of the Tactile Communication Network will share what they have developed over the last several years.

The pre-conference gathering will include presentations of theoretical frameworks, practical ideas and applications in professional practice. Among the topics are the tactile sense, tactile awareness and experience, tactile comfort and culture, tactile exploration, establishment and continuation of meaningful tactile contact and communication, tactile traces and narrative, tactile access to language and environment, and staff training suggestions. The participants will view the movie ‘Landscape of Touch’, participate in exercises, presentations and discussions and get access to further resources.

You are invited to attend this pre-conference.  
Watch for more information on the DbI Conference website.

## **Financial sponsorship to attend a DbI Event**

### **Bernadette Kappen – Vice President DbI**

The purpose of DbI is to bring together professionals, researchers, families, individuals who are deafblind and administrators to raise awareness of deafblindness.

Central to our work is providing information to staff working in the field of deafblindness. With adequate information it is possible to develop services that enable an individual to have a good quality of life.

One activity that assists in promoting the purpose of DbI is sponsorship at regional and world conferences. Attending an event is often one of the highlights in a person's career. DbI events encourage learning and they also provide an environment where people can come together and freely exchange ideas. It is a place where everyone is focused on the needs of children and adults who are deafblind.

Each year the DbI budget sets aside money for individuals to attend an event. While these funds are limited, we do want to offer some help. Individuals receiving financial sponsorship must be able to demonstrate how their participation in a DbI event and the knowledge acquired at an event will be related to the DbI Strategic Plan.

### **The goals of the Strategic Plan are:**

1. DbI will develop an enhanced organizational capacity to meet the needs of people who are deafblind.
2. DbI will influence the development of services for the benefit of people who are deafblind and their families around the world.
3. DbI will encourage improvements in practice and creation of new knowledge by facilitating improved communication and networking.

Since the funds for sponsorships are limited it will be the applicant's responsibility to indicate how they will get additional support from local resources. DbI will not be able to fully fund individuals to attend events.

If you are a DbI member and need financial support you can find the application for requesting support on the DbI website – [www.deafblindinternational.org](http://www.deafblindinternational.org). An application for support should be sent to the DbI Secretariat

[secretariat@deafblindinternational.org](mailto:secretariat@deafblindinternational.org) a minimum of 5 months prior to the event. Completion of the form does not guarantee financial support but will be reviewed by the Sponsorship Committee in a formal process.

The World Conference is in Sao Paulo, Brazil in September 2011. Applications for financial support to attend this event must be received by April 1, 2011.

## **DbI Leadership nominations for the next four years terminating soon!**

Second notices went out from the Nominations Committee announcing the final call for nominations for President, Vice President(S) and Board members to lead DbI through the period the four year period, 2011-2015.

Nominations close on January 31, 2011 for the offices of the President, the two Vice Presidents and up to 35 seats on the Board, formerly called the Council. Up to 15 seats are available for appointment to large corporate members and up to 20 seats for small corporates.

Once the nomination process is complete, all members who have a right to cast a vote will receive information on the voting process. An electronic system of voting will take place from March through June, 2011. To enable corporate members to participate in this vote, their membership must be paid by February 28, 2011.



The results of the electronic voting of officers and Board members will be ratified at the General Meeting in Sao Paulo Brazil, during the XV DbI World Conference, in September 2011.

Check out the DbI website ([www.deafblindinternational.org](http://www.deafblindinternational.org)) for additional details on the nomination process for the new DbI leadership. The website contains the descriptions and expectations of the various positions as well as the appropriate nomination forms. Any further questions may be put to Knut Johansen ([knut.johansen@signo.no](mailto:knut.johansen@signo.no)) Chair of the Nomination Committee.

## **DbI News and Membership**

### **Strengthening the Partnership between DbI and ICEVI at the National level**

#### **Larry Campbell, President, International Council for Education of People with Visual Impairment**

Regular readers of DbI Review will know that the focus of my remarks in this column during the past few years has been on ICEVI-WBU Global Campaign on Education For All Children with Visual Impairment (EFA-VI) that is dedicated to reaching the estimated 4.4 million visually impaired children in the developing world who currently have no access to education.

#### **Global Campaign now active in 11 countries**

The EFA-VI Global Campaign was launched in mid-2006 with the first countries becoming engaged in 2007. This initiative is now active in 11 countries (Ethiopia, Mozambique, Vietnam, Nepal, Pakistan, Ecuador, Honduras, Nicaragua, Paraguay, Dominican Republic and Fiji) with an additional 6 countries currently finalizing their national EFA-VI plans (Burkina Faso, Cambodia, Papua New Guinea, Guatemala, Bolivia and West Bank, Palestine).

With data now in from the 7 of the first 11 countries that are actively engaged in this initiative, we now know that 30,328 children with visual impairment are today in school who previously were not. While there is a long road ahead, we believe the global campaign demonstrates that by working together we can make significant headway in reaching visually impaired children that have previously been excluded from education.

When I had the pleasure of addressing participants of the DbI International Conference in Perth in 2007, ICEVI invited DbI to work with us to assure that children with deafblindness are included in this global initiative and that their needs and those of their parents and teachers are reflected in the national planning process. Success stories in Latin America to include children with deafblindness in Global Initiative

The Latin America region has provided us with a real success story. The collaboration between ICEVI, WBU (ULAC) and DbI, with three extraordinary international partner members (CBM, ONCE/FOAL and Perkins International) has made it possible to include children with deafblindness in this global initiative.

The challenge before us now is to replicate the progress in Latin America in other regions of the world where, to date, we have been less successful in assuring that children with deafblindness are an integral part of national EFA-VI plans. Until recently, I must admit to being a bit discouraged by the lack of progress in other regions. However, in recent months my mood has changed.

Recent discussions between ICEVI and Perkins International have let me to believe that in the near future collaboration in both The Philippines and Cambodia will lead to EFA-VI initiatives that address the needs of children with deafblindness with the context of the EFA-VI Global Campaign. I urge you, the readers of DbI Review, to regularly visit to EFA-VI section of the ICEVI website [www.icevi.org](http://www.icevi.org) to both follow the progress of the campaign and to become actively engaged on behalf of children with deafblindness as national plans are developed in your country.

Working together we can make a real difference.

## **Benefits to Member Organization**

### **which support DbI Officers and Board Members**

When election time appears and DbI seeks nominations for President, Vice President and members of the Board, Corporate members (large and small) probably question the benefits versus the anticipated costs when nominating an individual for these four year appointments. Perhaps this question of cost is even more critical today considering the current economic climate.

### **What are the costs?**

The elected honorary officers (President and the two Vice Presidents) and the appointed officers are expected to attend two meetings per year, one of which is a Board meeting. Those elected to the Board attend one two-day meeting per year. The costs include travel and accommodation. In addition to these mandatory meetings, the President might be called upon to travel to special international events. These costs might be covered by the inviting party, partly by DbI with the remaining costs subsidized by the individual's employer.

In addition to travel costs, all those elected and nominated to positions, including Board membership, will also be expected to contribute some voluntary time (from their home country) to undertake individual or committee tasks.

### **What are the benefits?**

DbI is an international network and its significance is worldwide collaboration and networking. Offices and members of the Board are at the 'head of the line' in this respect. These positions offer incredible access to information sharing with other

officers also involved in deafblind related services. The positions offer possibilities for international partnerships on various deafblindness projects. In addition, knowing what is happening in others' jurisdictions could be of great benefit to one's 'home' organization.

Furthermore, serving as an officer can provide significant influence to one's home organization. For example, an organization employing the President (or the Vice President) of an international organization could influence what that organization is attempting to accomplish at home. Examples include, but not limited to, seeking improved government services or seeking funds through private corporations, etc. A recent example of a benefit in Italy was that Lega del filo d'oro was successful in having the country declare deafblindness as a unique disability. It goes without saying that having the President of DbI as an employee with the Lega was a distinct advantage in that accomplishment.

On the personal side, one cannot underestimate the personal intangible benefits that can accrue to an individual holding a prestigious international position.

DbI is a volunteer not-for-profit successful networking organization, with a history that goes back over forty years. Together it has accomplished much to improve the awareness of deafblindness and the expansion of services through most countries in the world. DbI is a member driven organization that depends solely on its membership. DbI's continuous mandate to improve the quality of life of individuals who are deafblind around the world is totally dependent on its membership's continued support and generosity.

## **Meetings**

It was a pleasure to meet with ManCom and Council in Aalborg, Denmark recently. A significant amount of work was accomplished at the meetings and we were delighted at the number of Council members in attendance and for the wonderful contribution. Developing the next Strategic Plan for 2012-2015 was the big focus and the discussions that came out of the meetings will lead to an exciting new future for DbI. We look forward to assisting to pull it all together and to have it confirmed by Council in September 2011 for implementation in 2012.

## **ADBN Conference**

Following the ManCom and Council meetings we were pleased to represent and promote DbI at the ADBN Conference in Aalborg, Denmark. We took the opportunity to speak with many of the delegates about DbI and encourage new members.

## **Membership**

DbI is proud to have so many members maintaining their membership status year after year. Our members currently represent 30 countries and we have been pleased to welcome several new members from Russia, Cyprus, Canada, Malta, Germany and the United Kingdom in 2010.

In January 2011 reminders will be sent to members whose membership expires at the end of 2010. We look forward to a positive response and encourage existing members to spread the word about DbI and encourage other colleagues and organizations to

become a member of DbI. All the membership information can be found on the website:  
[www.deafblindinternational.org](http://www.deafblindinternational.org).

## Website and Information function

We have been working closely with the Information Officer, Stan Munroe on the content of the DbI website and we are dedicated to keeping the information relevant, up to date and informative. In particular the What's New section is closely watched and updated to ensure we are providing as much relevant and appropriate information as possible. We also take pride in keeping the contact information of our corporate members, Networks and organization leaders accurate to ensure members can make contact with the right people at any time.

## Nominations Committee

We have supported Knut Johansen, Chair of the Nominations Committee to circulate the Call for Nominations for President, Vice Presidents and Board Members. We encourage members to consider nominating suitable people for these important roles and help shape the future of DbI. Please note only active members of DbI as of 1st March 2011 will be eligible to vote.

THANK YOU

Elvira Edwards & Bronte Pyett  
DbI Secretariat

## Membership

Deafblind International Individual Membership

- I would like to join DbI as an individual member  
 I would like to renew my DbI individual membership

Member details                      Membership No.

Title    Surname                      First name

Organisation

Job Title

Address (Line 1)

Address (Line 2)

Town/City    State/County

Zip/Post Code                      Country

Telephone no. Fax no.

(Please include country and area codes)

E-mail address:

Are you:

a deafblind person     a family member     a professional

Does your organisation work primarily for/with:

blind people     deaf people     deafblind people

disabled people  other (please specify)

Your contact details will be made available to DbI members for DbI purposes but will not be made available for commercial purposes.

DbI Review (please check one box in each category)

I would prefer to receive DbI Review on:  paper  disk\*

(The disk version of DbI Review is supplied in text only format, on floppy disk)

Membership Fee please tick where appropriate

I wish to pay for 4 years' membership at the discounted rate of d100

### Corporate Membership

There are three tiers of Corporate Membership:

Large corporates Annual fees between d 3,000 and d 5,000

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Mini corporates Annual fees between d 100 and d 250

Mini Corporate membership is available to interested organizations from the World Bank list of Heavily Indebted Poor Countries and Low Income Countries

We would like to join DbI as a Large / Small / Mini Corporate Member

Library membership fees d 50 annually

(please delete as appropriate)

We submit an annual fee of d

Corporate members are entitled to receive 25/10/5 copies respectively of DbI Review.

We would like- \_\_\_\_\_ copies

Member Details:

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Address (Line 1)

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Tel: Fax

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### How to pay?

In order to enable us to put your entire membership fee to use, we would kindly ask you to avoid sending us cheques as far as possible. By arranging your fee via bank transfer, we are able to keep banking charges to a minimum, thereby increasing the value of your membership fee. Naturally, for those of you who do not have access to this facility, we will be delighted to accept your fee by credit card, cheque or in cash.

Payment method  Bank Transfer  Credit Card  Cheque

A) Payment by Bank Transfer

If paying by bank transfer, please make payment to the following account:

Name of Bank: RABOBANK

Address of Bank: Sint-Michielsgestel, The Netherlands

Account Name: Instituut voor Doven: INZAKE DBI

Account Number: 11.29.09.825

Swift Address: RABONL2U

IBAN: NL31 RABO 0112 9098 25

Date of Bank Transfer:

Please quote the Swift Address and IBAN number in your instructions for Bank Transfer (If this is impossible and you have to send a cheque or international postal order then please contact us)

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Card type:  VISA  American Express  Mastercard

Card no:

Expiry date                      Name on card:

**C) Payment by cheque**

Please make cheques payable to “Stichting Viataal Zorg inzake DbI” and post to: Ton Groot Zwaaftink – DbI Treasurer, Theerestraat 42, 5271 GD, Sint-Michielsgestel, The Netherlands. If paying by Eurocheque, please make out cheque in euros.

Please fax this whole page to (08) 9473 5499 or return to:

The Secretariat, Deafblind International, PO Box 143, Burswood WA 6100, Australia

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