

## **DbI Review**

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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.

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Cover: Presentation at the National Conference on Deafblindness, New Delhi, 2009

## **A message from the President**

Dear Friends and Colleagues

As you are in the process of reading this message you are probably preparing for your well-deserved summer holiday or, in some cases, winter holiday.

Within Deafblind International many changes will be taking place in the upcoming months. These changes reflect our commitment to the new strategic plan and are being developed with the support of our membership at all levels. Your Management Committee and Council will be meeting during the European Conference in Senegallia, Italy, and reporting further to the General Assembly. Concerning this conference, I sincerely hope that many of you will be able to attend this unique occasion for sharing, learning and networking. More information about the content of the network mornings has been posted on the conference website and Dbl website. Do visit the website!

One of the outcomes of the strategic plan is to identify the roles needed by ManCom and Council to ensure future projects and functions. We are in the process of discussing the profiles of the people and/or agencies which could have a leading role in furthering the goals of our association.

I would like to take this opportunity to mention just a few of my activities this year. Firstly, an extremely interesting conference discussed Rubella Syndrome and the consequences during the lifeline of those affected by this virus. It was good to see so many passionate people sharing ideas, worries, solutions and knowledge. (report on page 39).

In Italy, in April, the European Society for Mental Health and Deafness organised a special interest group meeting. In fact, participants showed an interest in the possibility of forming a European network in this area. This is a very welcome development.

A delightful part of our job is the celebration of success on all levels. Earlier this year we were present at the 30 year anniversary of Blindeninstitut in Würzburg/Germany. Many invited guests were there to acknowledge those involved in this achievement. Following this event the Dbl communication network organised a two day seminar for the host country. This was an unforgettable experience for all of the many participants.

May I take also this moment to remind you think about nominating someone special for an award. We like to show our appreciation to those who have shown so much passion, dedication and commitment over the years. You will find the information about the awards nomination procedure on our website.

I have just been told of the passing of one of Deafblind International's founders. Joan Shields from England, gave much of her life working with deafblind children, their families and professionals in the field. Our thoughts are with her family at this time.

...and again thanks to all of you for making what sometimes seems to be impossible... possible.

William

## **Editorial**

Dear friends

Another packed magazine – with, I hope, something for everyone.

In spite of the gloomy economic times affecting us all worldwide we continue to press forward to ensure that the rights of deafblind people, and the services they require to live full lives, are provided and respected. The evidence is here in the commitment and optimism of our contributors!

We have David Brown's final article in his series about "the senses". What a wonderful response we have had to them – and many requests to translate and reproduce! These articles will appear, with many others, in a new section for members on the website which will have the archived articles from previous editions of the magazine. Sharon and Mike from Australia have explained with great clarity and insight the role of sighted-guide. It informs from all points of view!

Two powerful stories about exceptional young woman appear: Shazia demonstrates her developing literacy in an insightful piece from Dipti Karnad in India and we hear from Leonie, a talented and reflective young woman, who stars in a short documentary film that can be viewed on the web. You will feel inspired.

There is continuing progress toward the right to effective education from both India and Africa and we have exciting news from parents in Spain. Our partner ICEVI also reports admirable progress in its campaign for education for all.

I mentioned in the last magazine that a group of information professionals from Dbl has given time and energy to the recommendations from the new strategy about information. I am really grateful to them and there is a brief report included here.

Thank you again for being in touch and sharing your ideas!

Eileen

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## **The sensory integration perspective and what it offers us in the field of deafblindness**

**David Brown from California DeafBlind Services concludes his article**

Adapting the therapy approach to allow for deafblindness

Whenever I recommend a Sensory Integration evaluation for a child I tend to call it “a Sensory Integration-type approach”, and I also suggest that ideally it should be instigated by a trained occupational therapist if this is possible, although it can take a long time to locate and involve a suitably trained therapist. I stress the need for flexibility and creativity and teamwork otherwise the Sensory Integration Therapy approach may not be productive, especially if the occupational therapist feels unable to assess a child with no language, whose inner drive might be low, whose awareness of external stimuli might be very under-developed, whose movement abilities might be very limited, or whose processing time might be extremely long. Sticking closely to the classic approach will not work at all for most children with deafblindness. Significant adaptations will need to be made to the assessment procedures and also to the way that the therapy program is introduced to the child, but it is perfectly possible to adhere to the principles laid down by Jean Ayres even when working with a child with the most severe multi sensory impairments. If the child is not actively seeking and rejecting sensory inputs by themselves then the assessment will need to involve administering certain stimuli to the child to see what happens.

When requesting a sensory integration evaluation it is very helpful to the therapist to have a list the precise behaviours that have lead to a suspicion of sensory integrative difficulties so that they will be helped to know in advance what at least some of the key issues might be. With children with deafblindness

some of the most commonly encountered indicators of sensory integrative dysfunction are, for example, behaviours like:

- seeking very strong sensory inputs like self-biting or scratching, skin picking, spinning, rocking, bouncing, shoulder shrugging, leg swinging, hyperventilating, hand flapping, self-slapping, light-gazing.
- sensory defensiveness (such as always withdrawing from touching soft textures, or turning the eyes away from light).
- abnormally low or high pain thresholds (such as rejecting certain sensory inputs as if they are painful, but apparent non-awareness of certain other sensory inputs which for others might be painful, and never crying or seeming to hurt whatever happens to them).
- apparent variability or inconsistency in sensory perception abilities (like rejecting all textures in the mouth apart from pureed food, but mouthing of all kinds of non-food items e.g. stones, wood, cloth, soil, or the absence of chewing and biting on solid foods, but excessive chewing and biting on non-food items, often with persistent teeth grinding).
- unusual postures (like needing regular periods horizontal or upside down, twisting the limbs tightly around each other, or always needing to have the head supported).
- distractibility.
- persistently disturbed sleep patterns.
- problems with regulating arousal levels (often too drowsy or too over-excited, and maybe alternating extreme over-activity with extreme burn-out).
- in the early years, extreme postural insecurity when placed in a sitting or standing position by an adult, or when moved unpredictably, but pleasurable responses to strong rhythmic movement experiences (e.g. rocking, bouncing, swinging) if the body and head are well supported.
- inconsistent or inappropriate use of pressure when touching or grasping with the hands, often described as the child being very 'rough' or 'clumsy' or 'aggressive', and generally poorly graded movements.

Of course any one of these behaviours could be the result of other causes than sensory integration dysfunction, so it is important to remember to observe over time and to share and discuss observations with others to develop an agreement on the best way to proceed. But the existence of several of the types of behaviour on this list would strongly suggest sensory integration difficulties.

I always suggest that if an occupational therapist is approached they should feel free to speak to me and other people involved with the child so that we might be able to help them with the "flexibility and creativity" referred to above, since they have not been trained to use this approach with children with deafblindness. It is reasonable to expect a therapist to take up this suggestion since an interview with family members and others who know the child well forms an important part of the 'sensory history' part of classic sensory integration assessment.

In the meantime, while we are waiting for therapy input, I am very likely to help the family and members of the child's professional team think about the child in multi sensory terms derived from Ayres' ideas, then look for activities and inputs that seem to help with the concerning behaviours, along with all the appropriate cautions about the need to go carefully and the need to OBSERVE to see what is happening as a result of what is being done. The ideas that I recommend are very often activities used in 'classic' Sensory Integration Therapy (eg. deep pressure massage, rhythmic joint compression, a range of large movement activities, the use of weighted clothing). Doing these things carefully with a child while you observe meticulously to see what happens to them as a result, both during the session and afterwards, is valuable research for the highly complex and varied population of children with whom we are working these days.

### Sensory Integration Dysfunction

Sensory integration dysfunction appears to be very common in the population of children with deafblindness, and significant difficulties caused by impaired and poorly modulated sensory systems are very common. Many behaviours, some of them apparently contradictory, like those I have already mentioned, could indicate the need for sensory integration assessment and treatment by a trained occupational therapist.

Some typical ideas suggested by a therapist following a sensory integration assessment include brushing protocols, rhythmic joint compression, deep tissue massage, vibro-tactile input, sucking and blowing activities, textured and/or heavy bed clothing, Lycra clothing for extra pressure input, a range of large movement activities like swinging spinning or rocking, and the use of weighted clothing. A variety of outcomes might be anticipated from implementing these techniques, including improving the child's ability to notice and attend to sensory information in the environment, improving muscle tone, improving awareness and tolerance of touch, improving attention span and decreasing distractibility, reducing the need for self-injurious behaviour, improving sleep patterns, and generally increasing the child's ability to remain both alert and calm in stressful situations.

This kind of sensory integration perspective might be needed, regularly or periodically, throughout the individual's life and should never be automatically regarded as a one-time 'fix'. Experience strongly suggests that every person with deafblindness would benefit from having a regular sensory integration assessment and program under the supervision of a suitably qualified occupational therapist.

Many children with deafblindness need extended time to process information, and often develop techniques that they use to establish a firm physical, emotional, perceptual, and cognitive "base" each time before they respond. Successful teaching frequently depends on allowing for this need and spending some time alerting the child to the fact that you are there, who you are, what you

are going to be doing together, how and where it will be done, and so on. The child may need considerable time, and assistance, in establishing a secure and stable physical base as a first priority in every communicative interaction.

### Anecdotes

The following anecdotes of children with CHARGE syndrome are examples of behaviours that were considered to be “challenging” by family or school that were solved or avoided, or moved to the non-challenging category, by taking a multi sensory view, based upon our knowledge of all the sensory difficulties associated with CHARGE. In many of these examples there was a clear need for sensory integration assessment and programming along with the other strategies mentioned:

- A young child who was said to be self stimulating “all the time” was actually practicing and developing his mobility and orientation skills, and using vision and touch to explore objects, very creatively. While doing this he needed to get onto his back on the floor to reorganize his sensory system with brief episodes of limb shaking and hyper-ventilating every 10 to 20 minutes.
- A child in kindergarten was often self-abusive when he got distracted and over-aroused by incidental touch and air movement caused by people repeatedly walking behind his chair. Once his chair was placed with its back securely against a wall he was less self-abusive and more amenable to social interaction.
- People were concerned when a young boy began to insist on the unusual idea of wearing band-aids wound tightly around the tips of all his fingers and thumbs every day. He was expressing his need for more and stronger pressure and tactile inputs as a part of his sensory diet.
- Every morning in a pre-school program a student refused to sit on the floor with the rest of her class to watch the teacher sign a story. Her missing vestibular sense, low muscle tone, and poor tactile and proprioceptive feedback made unsupported floor sitting an insecure and exhausting posture for her, which demanded all the energy and attention that she wanted to put into following the story. When an appropriate chair was provided the student sat and attended with great interest and a growing level of participation.
- Many children who were unable to sit on a regular chair and attend to an activity for very long showed an extended attention span and better visual, fine motor, and cognitive functioning once given chairs with footrests and armrests. One child rarely used the armrests for his arms but instead sat with his legs spread wide and his outer thighs pressed hard against the sides of the seat, the extra tactile and pressure input giving him the requisite equilibrium to function effectively in the upright seated position.
- A girl was described as very disruptive during sessions that required the class to sit still and participate in a signed lesson with the teacher for up to 30 minutes. When the teacher used a strategy of asking the student to move periodically to carry out small chores during these sessions (to fetch a pen, open



a door, bring a book, take a paper to the school office) the disruptive behaviours largely ceased.

- A teenager enjoyed, and was quite good at, soccer in the school gym in winter, but was unwilling or unable to play it outdoors when the summer came. The absence of strong vertical visual markers to aid his equilibrium outdoors (remember the Equilibrium Triad) made it impossible for him to maintain a secure upright position while also running around looking for and kicking a ball. The ability to participate in such complex physical activities outdoors did not develop until significant adaptations were introduced.
- A different teenager was unwilling to go outside during school recess because of problems with glare and photophobia that impacted mobility and orientation, as well as limiting his ability to participate in signed conversations. This difficulty was eventually solved by the provision of tinted glasses and a sun visor.
- During Orientation and Mobility sessions a teenager was refusing to stand still to receive spoken/signed instructions, but the problem was solved when the student was allowed to stabilize himself by leaning against a pole or a tree or a wall, or by placing one hand on the instructor's shoulder during these conversations.

I want to conclude by talking about a few aspects of sensory integration that are especially relevant to many of the children with whom I am currently working.

### Sensory modulation, enhancing, inhibition

When our sensory systems are well modulated we can function effectively with all the many sensory messages coming into our brains from the world around us. But the complex and never-ending task of having to 'select, enhance, inhibit, compare, and associate' sensory information is extremely difficult for children with deafblindness. In particular, it might be very hard for them to know which sensory stimuli need their conscious attention and which do not. As a way of coping with this challenge many of the children I see are 'one-thing-at-a-time' people, able to focus on only one sensory input at a time, or maybe two at the most, and switch their brains off to the rest, so that the multiple complexities of life are simplified right down to basics. For these children true sensory integration might be an unattainable goal and our best help might be to create carefully structured environments for them within which they are supported in this process of simplification. Minimizing distractions and removing competing sensory inputs is an obvious first resort to use with these children, and, although we never say 'never', this simplification may become a life-long need, just as it is to some extent for all of us.

### Sensory diet

This is one of my favorite aspects of Ayres' theory and therapy approach – the idea that we all need varied sensory inputs at different times for different reasons, the way that we also need nutritional inputs of food and drink. The idea helps us to see children's behaviours as fulfilling essential sensory needs rather than just being 'self-stimulating' or 'self-abusive' or 'avoiding'. Jan van Dijk taught us decades ago that the best way to begin to teach a child with persistent rocking behaviour might be to join them in their rocking and even help to facilitate it to enhance and intensify the stimulation (in this case primarily proprioceptive and vestibular) that the behaviour provided for the child. He was emphasizing the need to begin by forming a positive and supportive relationship with the child, but from Ayres' point of view the idea also facilitates better functioning for the child by giving them more of the very sensory inputs that they are so obviously seeking through the rocking. Both van Dijk and Ayres believed that the child should be an active and communicating partner in these interactions, never the purely passive recipient of sensory stimulation, and the adult was to remain alert and attentive to the child, never the mindless hand that rocked the boat or pushed the swing or stroked with the brush or whatever.

### Level of Arousal

This concept has been mentioned a lot throughout my presentations, and it offers invaluable ways of thinking about children learning and attending and recognizing and remembering. There are different but similar descriptions of the spectrum of arousal, and one that I often use comes from the 'Carolina Record of Infant Behaviour', which is helpful when thinking about people of all ages, not just infants, and it shows the spectrum running from the most alert and excited state (Uncontrollable agitation) to the least (Deep sleep):

- Uncontrollable agitation
- Mild agitation
- Fussy awake
- Active awake
- Quiet awake
- Drowsy
- Active sleep
- Quiet sleep
- Deep sleep

Knowing how to identify where a child is on this spectrum at any given moment, knowing where they need to be on the spectrum in order to achieve a specific goal, and knowing how we can help them to move themselves, or how we can move them, up or down the spectrum, is one of the most relevant insights that we can cultivate in our work with children with deafblindness. This is an area of assessment and teaching where familiarity with Jean Ayres' work has special resonance. No one level on the spectrum is inherently 'better' than any other,

each can serve a useful purpose, but being at some levels will facilitate better functioning than being at others for different people with different needs and different goals. For example, I am inclined to do better with my work when I am at the 'Fussy awake' or even the 'Mild agitation' levels of arousal, but I have a colleague who needs to be at the 'Quiet awake' level for optimal work output. I knew a child with deafblindness who was very visual in her behaviour and functionally completely deaf when she was at the 'Active awake' or 'Fussy awake' levels of arousal and had plenty of energy. Only when she got really tired and reached the "Drowsy" level of arousal did she abandon using her vision for moving around and, flat out on the floor, attend to stimuli coming in through her hearing sense, and do it remarkably well considering the nature of her hearing loss. She reminds us of the dangers of making generalized assumptions about children, and that 'knowing the child' is the best guiding principle in our attempts to educate children with deafblindness.

## **“Out of isolation and into society”**

**Ursula Heinemann and Barbara Latzelsberger report a wonderful development in Vienna, Austria**

Since 2007 a new competence centre has been proclaiming its existence and enthusiastically shouting about this hardly known form of disability in Austria – deafblindness – to enable fast and efficient help for people concerned.

“Out of isolation and into society” – that is the aim the advisory centre wants to achieve for all deafblind and significantly visually and hearing impaired people living in Austria. The multiple aims of the centre are to provide;

- competent consultancy for deafblind people, their relatives, as well as for professionals
- the establishment of an Austrian wide network
- the education and development of adequately trained professionals

The project has been founded by the “The Austrian Relief Organization for People Who Are Deafblind and People with Significant Vision and Hearing Impairments”.

Celebrating the opening of the new Centre

Some facts

About 400 to 1400 deafblind people are living in Austria. This estimation is based on international evaluations. But the estimated figure of unknown deafblind people is very high. All these facts make Austrian-wide networking and cooperation between the institutions and professionals working in this area, very important. Without this high level of co-operation it will be harder to improve the individual lives, needs and the overall situation of deafblind people.

Why do we need a centre of competence for deafblindness?

The centre has its roots in an initiative of the ÖHTB (The Austrian Relief Organization for People Who Are Deafblind and People with Significant Vision and Hearing Impairments) and was founded with the idea of improving the quality of life of people living with this disability and offering a competence centre for them and their relatives. A central focus is the professionalism of the mentoring experts and our work is financed by the ministry of social affairs.

What do we want to achieve in Austria?

Our eventual aim is to establish a competence centre or an advisory centre in each one of the nine Austrian provinces, and therefore offer an full national support and deafblind people of every age and their relatives to be part of a national and international network.

At the moment we are focusing on the following key aspects:

- Information/ advisory service/networking
- Cooperation across Austria and the establishment of a network
- Supporting the foundation and the establishment of advisory centres in all provinces through specialized knowledge and practical guidance
- Workshops and training to build up qualified professionals in Austria
- Creating a point of reference for Austria
- Public relations, awareness training and campaigning

Furthermore we are working on an Austrian wide evaluation of the concerned population and planning a symposium and other single events for this year relating to the topic "visually and hearing impairment and communication".

We want to combine theoretical elements with practical work through a close collaboration with Universities and colleges of higher education. The co-operation with professional medical specialists is also developing.

What do we offer?

In our competence centre we offer the following services:

- Counseling interviews with deafblind people, their relatives and professionals
- Guidance in building up communication and possible methods
- Intermediation of, and companionship in, qualification projects
- Advisory and support related to legal issues
- Intermediation of volunteers, interns and freelancers
- Intermediation of assistance services, interpreters and communication partners
- Creation of suitable leisure time facilities for deafblind people
- Advisory function in political boards, committees for disabled people or institutions

We will be making our business to raise awareness across Austria and with our recent press conference we have already been able to reach a broader public than before.

Deafblindness is a still widely unknown and invisible disability. We will be seeking to establish legal recognition in Austria. For about 1400 people in Austria living with this disability, this will ultimately be the key to and integration into society. Please get in touch with us!

E-mail: [sinnesbehindert@zentrale.oehtb.at](mailto:sinnesbehindert@zentrale.oehtb.at)

Homepage: [www.sinnesbehindert.at](http://www.sinnesbehindert.at)

(at the moment only in German)

## **Sighted-guide techniques for individuals who are deafblind**

**Sharon Barrey Grassick, Deafblind Education Specialist WA Adjunct Lecturer, RIDBC Renwick Centre, NSW**

**Mike Steer, Senior Lecturer, Vision Impairment, RIDBC, Renwick Centre, NSW**

Everyone starts life as a child, and children who later grow to adults, whether or not they have a disability learn about their environment as a consequence of being able to move through it. It is, then, the interaction between a child or adult and their environment that produces information about people and objects, sizes, shapes, and distances (Gense & Gense, 2004). Those authors, writing primarily about the needs in the early years, have pointed out that for typically developing children the senses of sight and hearing provide the greatest motivation for exploration. This assertion is true, of course, for individuals of any age. Children who can hear and see (and who will later become adults), will use their vision and hearing to gather information about their surroundings while growing in understanding of their own bodies and their own movement capabilities (p.1). The sight of toys or people and the sounds of voices or objects encourage them to move and discover. As they do so, they gather, recognize, and interpret an amazing array of sensory information.

On the other hand, a child who is deafblind or an adult who becomes deafblind, must learn to understand his or her environment with minimal or distorted visual and auditory information (Olsen, n.d.). Limited sight and/or hearing may inhibit natural curiosity and the motivation to move about. As a group, learners who are deafblind are quite diverse and may include those with physical, cognitive, or health problems in addition to combined hearing and vision losses (Gense &

Gense, 2004). Some may feel insecure or frightened when moving about in an environment they can neither see nor hear clearly. Others might, for example, run on the athletics team or use motorised wheelchairs. Some communicate with speech or sign language, while others may not have had enough experiences in the environment to understand even basic concepts about that environment or about objects found in it. It is essential that both children and adults who are deafblind receive learning opportunities and instruction that facilitate purposeful movement.

Orientation and Mobility (O&M) instruction provides children who are deafblind and adults as well, with a set of foundational skills to use residual visual, auditory and other sensory information to understand their environment Gense & Gense, 2004). For both the child and adult who is deafblind, movement is an opportunity to gather sensory information, to communicate, and to make choices. O&M instruction provides opportunities and skills that can broaden the recipient's awareness of the environment, resulting in increased motivation, independence and safety. Orientation and mobility training is provided to teach children and adults how to learn to walk through familiar and unfamiliar environments safely. Learning takes place in a variety of real-world situations, including hall ways, furnished rooms, and cross walks. Training is time consuming, sometimes risky, and limited to the number of environments available to the student or client, and the O&M Training Specialist (Inman & Loge (1998).

Very few pre-school, school or adult rehabilitation programs, as Sauerberger (2008) points out, specifically serve children or adults who have both a vision and a hearing impairment, even though this combination produces unique situations requiring unique strategies and solutions. Instead, people who are deafblind must seek services from programs that serve either (a) deaf people or (b) blind people and which usually have staff who are prepared only to serve one or the other. The frustrations and fears that this situation causes both professionals and deafblind people are legion. The purpose of this article, therefore, is to provide easy to understand guidelines in the hope that they are useful to staff in residential settings and specialised employment programs, as well as to family members, on ways of ensuring that their clients or family member with a dual disability better cope with the challenges presented in safely negotiating their environments

### Safely guiding a person who is deafblind

Guiding a person safely from one place to another is called 'sighted-guide'. Safely is the key word. Providing sighted-guide for a person who is deafblind uses the same basic techniques as sighted-guide for a person who is blind or vision impaired. However, there are distinct and important considerations, particularly in regard to communication, as a person who is deafblind may not be able to hear or hear clearly enough to follow verbal directions. Many people who are deafblind have unique and personalised communication systems; some may

use nonverbal methods such as touch cues, object-symbols or gestures. Some people may use formal tactile communication methods such as Deafblind Fingerspelling or Tactile Signing (reading Auslan through touch). When using close-vision signing or a tactile method, guiding must halt during communication. To guide effectively and safely, it is vital that the person providing sighted-guide be familiar with the person's preferred individual communication method and any other individual needs, e.g. Some people may have balance issues that must be taken into consideration.

### Sighted-guide for people who are deafblind

The following guidelines may need to be adapted to suit individual preferences and situations. Note: do not assume that a person knows these techniques; they might need to be taught:

#### Communication

- Remember, guiding must halt for any close-vision or tactile communication.
- Communicate any environmental changes or hazards.
- In an emergency, act quickly and explain afterwards.

-

Person will respond to your sudden body movement of either stopping or moving swiftly in another direction.

-

You may wish to decide upon an emergency signal, such as an 'x' made quickly on hand or arm; however, in reality, an emergency requires immediate action.

- Establish how much additional environmental information is required by the person.
- Communicate any interruptions.
  - E.g. a person stopping to say 'hello'
- Body movement can give a lot of information, including the following:

-

An upward movement of your arm to indicate 'up'; downward movement to indicate 'down'

- Stop/wait – a firm flat hand on person's upper shoulder

#### Approach

- Approach slowly from the front, at eye level if possible.
  - Wave your hand – a moving hand and arm may be noticed even by someone with very low vision.
  - This gives the person the opportunity to use whatever functional vision there may be.
- Say person's name, eg. "Joe, hi."
  - This gives the person the opportunity to use whatever functional hearing there may be.

-

Identify yourself, eg. "Sharon here."

- Place your hand on back of person's hand to enable person to locate where you are.
- Introduce yourself using the person's preferred method of communication.

Offer

- Offer sighted-guide by placing the back of your hand against the back of the person's hand.
- Some people who are deafblind, depending upon individual eye conditions such as 'night blindness', may not require sighted-guide during the daytime; however, at night or in changing light conditions, they may welcome the offer of sighted-guide.

Grip

- If the person wants guiding s/he will run a hand up your forearm and grip your arm just above the elbow, with their thumb on the outside of your arm and fingers on inside of your arm, forming a 'C' grip.
- The grip needs to be firm, but not too tight, so the person can easily feel and follow your movements.
- The person may have better hearing or vision on one side than the other and therefore may show a preference as to which arm to grip.
  - Establish which side is preferred.

Stance

- The person being guided relaxes his/her arm at a 90 degree angle, close to the side of their body
- As the sighted-guide keep your arm relaxed, by your side; this stance naturally places the person a safe half-pace behind you.

Pace

- Establish the person's preferred walking pace, particularly as many people who are deafblind may have difficulties with balance.

Narrow places

- Before going through doorways, aisles and other narrow spaces, move your guiding arm in a definite movement to the centre of your back and the person will straighten his/her arm and fall in directly behind you.
  - Some people may feel more secure by placing their other hand on your shoulder
- When through the space, return your arm to original position at your side; person will respond by returning to position half a pace behind.



### Opening doors

- Communicate that a door is ahead, using person's preferred method of communication.
- Person should be on hinge side of the door.
- If not, change arms by placing your guiding arm behind your back then offering your other arm behind your back; person then changes to other side.
- Open the door and communicate, using hand-under-hand, for person to hold door until you have both gone through, then person shuts the door behind.

### Curbs

- Communicate that a curb, step or slope is ahead, and if up or down.
- Approach 'square on', with toes almost touching curb/step.
- Pause briefly before stepping up or down.

### Stairs

- Communicate that stairs are ahead, and if up or down; you may communicate how many steps or if there are 'many'.
- Approach step/curb square-on.
- Pause briefly before stepping up or down.
- Using hand-under-hand, guide person's hand to rail, with your hand making contact with the rail first, then moving your hand away to enable person's hand to make contact with rail.
- Remain one step ahead and proceed together naturally.
- Pause again at top or bottom before proceeding.

### Getting into a chair or seat

- Make contact with back of chair with your hand first then move your hand away as person makes contact.
- Person may move their hand down your arm to locate chair, or you may offer your hand under his/her hand to direct, again with your hand making contact with the chair first.
- If there is no chair back or it is a bench, alert person to wall behind to avoid banging head; this can be done by offering other hand under theirs to locate wall.

### Getting into a Car

- Same as above; you make contact with door handle first, then person can open door.
- When door is open, offer your hand under the person's free hand to guide to roof of car, then to back of car seat.

### Time

- Allow extra time as stopping to communicate environmental information by tactile methods will take longer.
- Rushing or running to catch a bus or train is too dangerous, particularly if there are difficulties with balance.

#### Hand-under-hand

- When guiding to a chair or to reach an object such as a cup, offer your hand under the person's hand; make contact with the item first, then move your hand away as the person makes contact with it.
- This hand-under-hand method offers greater independence to the person.

#### General guidelines

- Safety is the key issue, so
  - Pay attention!
- Do not assume a person knows these techniques; they may need to be taught.
- If in doubt about individual needs or preferences, ask the person; or if person has limited or no formal language, check with a carer.
- Offer your hands under – do not manipulate or take control of person's hands.
- A hint: Keep your hands free – use a small back pack or bum-bag instead of shoulder bags which can slip or create a barrier.
- Note: Some people who are deafblind may not have learned the techniques described in these guidelines; some people may prefer linking arms or placing their hand on your shoulder.
  - Respect individual preferences.

#### Conclusion

For all of these modifications the key, as Marx, (2004) has pointed out, is repetition. Remember, Rome was not built in a day. Those you seek to assist will need these modifications routinely in order to gain understanding of their purpose and meaning. May these initial modifications assist you in teaching your clients or family member to develop to the fullness of their O&M potential.

#### References

Association for the Blind of Western Australia (2008). How to Guide a Blind Person Safely. Perth, WA: Authors  
 Barrey Grassick, S. (1997). Deafblindness: A Training Package for Support Providers. Project funded by Disability Services Commission and Lotteries Commission of WA.

Gense, D.J. & Gense, M. (2004). The importance of orientation and mobility skills for students who are deaf-blind. Deaf-Blind Link. Retrieved 27 October 2008 from: <http://www.dblink.org/lib/o&m.htm>

Inman, D.P. & Loge, K. (1998). Teaching orientation and mobility skills to deaf-blind children using computer generated simulated sound environments.

Disability Information Resources. Retrieved 26 October 2008 from:

[http://www.dinf.ne.jp/doc/english/Us\\_Eu/conf/csun\\_99/session0242.html](http://www.dinf.ne.jp/doc/english/Us_Eu/conf/csun_99/session0242.html)

Marx, M. (2004). Orientation and mobility training for students who are deafblind: Going beyond the Blue Book. See/Hear Newsletter. Retrieved 26 October 2008 from: <http://www.tsbvi.edu/Outreach/seehear/summer04/deafblind.htm>

Olsen, T.R. (n.d.). Orientation to deaf-blind. Retrieved 26 October 2008 from <http://www.geocities.com/dblnj/dbreport.html>

Sauerburger, D. (1993). Independence Without Sight or Sound. New York: American Foundation for the Blind.

Sauerberger, D. (2008). Orientation and mobility for deaf-blind people. Health Care Industry. Retrieved 26 October 2008 from:

[http://findarticles.com/p/articles/mi\\_m0842/is\\_n3\\_v23/ai\\_20618731](http://findarticles.com/p/articles/mi_m0842/is_n3_v23/ai_20618731)

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Bronwen Scott, O & M Instructor

## **Conference**

Able Australia presents the

8th National Deafblind Conference

“Deafblindness in Australia – New Ideas, Directions and Solutions”

28-30 April 2010, Melbourne

Able Australia Services is proud to be hosting the 8th National Deafblind Conference – a major calendar event for people with deafblindness, their families and service providers – on behalf of the Australian Deafblind Council (ADBC) in Melbourne, 2010.

The 2010 Melbourne Conference will present the latest news, research and developments relating to deafblindness and provide networking opportunities among people with deafblindness, their families, industry experts and medical professionals, as well as showcasing the latest in technology, products and services.

The 3-day Conference aims to explore new ideas, directions and solutions on how best to support people with deafblindness and their families in order to have influence on the development of policies that support and strengthen their roles in the community.

According to the social policy research group Access Economics, "there are currently in excess of 288,000 Australians with dual sensory impairment in Australia and many of these individuals have high complex support needs, often requiring high cost care". The number of deafblind Australians is predicted to rise dramatically in the future, with nearly three million people [or 9% of Australia's population] estimated to have dual sensory impairment, or a sensory impairment with another form of disability, by 2050.

The conference will be an opportunity for all participants to discuss priorities and actions for the future in order to address this critical situation.

The 2010 Melbourne Conference is a must for people with deafblindness, their families and carers, Australian governments, policy makers, experts in the disability and aged care fields, health professionals, social health innovators and academics.

People with deafblindness will have access to mobility and communication support including interpreters, note takers, captioning, and access to support staff and volunteers throughout the conference to ensure inclusion and full participation in all activities.

Date: 28-30 April 2010

Location: Jasper Hotel, 489 Elizabeth Street, Melbourne, AUSTRALIA

Attendees: 200-300 delegates are expected from around Australia and overseas, including people who are deafblind, carers, State and Federal Government officials, disability/deafblind industry groups and suppliers, and medical professionals working in the field of disability support services.

For further information please contact: Patricia Karagiorgos

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## **The Spanish Association of Parents of Deafblind People (APASCIDE) shares news with us...**

**Dolores Romero, Chairman, writes...**

Since establishing the Association our aim has been to offer services and opportunities for deafblind people in Spain and to collaborate with families from other countries.

From the beginning one of our biggest projects was to improve the quality of life for our children without losing our vision for their future.

**Building the Day Centre and the First Residential Centre for congenital deafblind young and adults**

Part of our dream for our children was to have a place where they could live more independently and this has now become a reality.

In September of last year the Vadecon Construction Company started to build these two centres in Sevilla.

We expect the Day centre to be up and running this year and the residential centre in 2010. The Day centre will be adapted to meet the needs of the deafblind people, providing a comfortable environment with plenty of space. It will include vocational workshops, an organic farm, gym, physiotherapy and an indoor swimming pool.

**Summer Camp 2008**

I also wanted to share with you some of the activities that took place at the summer camp in Jaen last year.

It was an extraordinary experience with many activities taking place such as canoeing, horse riding, arts and crafts and climbing. Being at one with nature was a wonderful experience.

**Fundraising Events**

Finally, we had the opportunity to organise a fundraising day in Madrid where the Queen of Spain performed the opening ceremony.

We had a very busy and exciting 2008 and we are now looking forward to an even busier and more exciting 2009. We continue to aim to get the best for deafblind people as well as improving the quality of their lives.

If you would like more information about APASCIDE please go to [www.apascide.org](http://www.apascide.org). or blog on [www.apascide.es/blog](http://www.apascide.es/blog)

**Inauguration of Marleen Janssen to the**

**Chair of congenital and early acquired deafblindness**

Congratulations Marleen!

On February 17th a large number of people had travelled to Groningen, in the north of the Netherlands, to witness the inauguration of Marleen Janssen at the University of Groningen. At this university Marleen has assumed, as a professor, the learning assignment to advance the education and research on behalf of people with congenital or early acquired deafblindness.

A long history has preceded the establishment of this professorial chair, in which the Dbl Network group on Communication has played a leading part. As many people know, this Network group started its activities in the early part of the nineteen nineties. For many years study meetings of the members of this workgroup have alternated with the organization of invitational meetings, conferences and publications. At the moment workgroup members are completing booklet 4 in the series 'Communication and congenital deafblindness'.

Since 2004 the workgroup has looked for opportunities for a better way to secure, spread and, at the same time, substantiate scientifically the gathered knowledge. Underlying everything was the explicit premise that this should involve continuous international cooperation.

Viataal, the former Institute for the Deaf in Sint-Michielsgestel, proposed the idea to the University of Groningen. This university proved to be prepared to give its support for education and research in this new area and to encourage cooperation with the Dbl Network group on Communication and Viataal. A first result of this cooperation was the beginning of the Master degree training course on Communication and Congenital Deafblindness in 2007. In 2010 this course will take its fourth cohort of students.

Marleen's inauguration was a very special event – first and foremost, because of the great passion with which Marleen talked about her work and the video clips she showed! The attendance of many deafblind people, parents of deafblind children and colleagues from the Netherlands, as well as from Europe and the USA, gave this meeting a special quality as well.

In her inaugural lecture, Marleen particularly went into the matter of the scientific substantiation of the work that is done by many of us. Among other things she talked about the research programme she has started. At the moment this includes five major areas of research that are primarily taking place in the Netherlands. Marleen is exploring the possibilities of executing parts of this research simultaneously, abroad. An overall wish of the Dbl Network group is to help the various universities that do research in our field to be brought into contact with each other, or even better, to work together to further research. Marleen will be one of the plenary speakers during the European Conference in Senegalia. In this lecture she will undoubtedly return to parts of her inaugural lecture and talk about her research.

The festivities around the inauguration were concluded the next day with the one day conference 'Practice Based Evidence and Evidence Based Practice'. The plenary sessions on this conference were provided by the members of the Dbl-

workgroup: Jacques Souriau, Anne Nafstad, Inger Rodbroe and Marlene Daelman, as well as by colleague professors of Marleen Janssen: Jan van Dijk, Deborah Chen, Cathy Nelson and Rosanne Silberman.

All in all, two engaging days – which will always be remembered! We hope this initiative and the profile it provides will promote the development of our field far outside Europe!

Ton Visser  
DbI Network Group on Communication

## **Developments in deafblindness in Burundi: an update...**

**Jacques Souriau**

In the last issue of DbI review, I described how a programme for the Deafblind children is developing in Burundi, in a school for the deaf in GITEGA, the second town of the country. At the end of last February, I spent again two weeks there with my wife and Gervais Kiyakara (both educators of Deafblind children). We worked very intensively with our Burundian colleagues at organising the programme and developing specific staff competencies.

In spite of a very difficult economic situation (which makes it very difficult to buy enough food for the children), the three deafblind children who belong to this small programme are in good shape and live in a very warm affective environment. These two weeks allowed us to put together our Burundian colleagues' competencies and our knowledge of deafblindness. When we left the school, the context of education and living had changed a lot. In a nutshell, we managed to connect the talents of our colleagues as regards body contact and participation in daily activities and our know-how related to language development.

The children are now engaged in using elements of language and the staff has a better vision of how they can progress. We are looking forward to seeing how all this develops. Our plan is to go back to Burundi next year to follow up the project. Eileen Boothroyd, the editor of the DbI Review offered me to renew an appeal for support.

The readers who are interested in helping this program can contact me (jacques.souriau@wanadoo.fr) or send money to ANPSA, 18 rue ETEX, 75018 PARIS, mentioning that the money should go to helping the program in Burundi.

Thanks to all.

Jacques Souriau

## **The World Federation of the DeafBlind 9th Helen Keller World Conference of Persons with Deafblindness**

WFDB – 3rd General Assembly, October 23 – 27

CRPD, changing the lives of persons with deafblindness

The UN Convention on the Rights of Persons with Disabilities, CRPD, is a human rights instrument. How can we use this instrument to ensure that the rights of persons with deafblindness are respected and enforced?

Plenary sessions and the 16 workshops will cover the following themes:

- What is CRPD and what does it mean for persons with deafblindness?
- How can organisations work towards ratification of CRPD in their country?
- When a country has ratified CRPD, what changes will happen?
- How can deafblind organisations and individuals use CRPD and its provisions as well as different aspects of the Convention

ALSO

The new African Federation of the Deafblind (AFDB) will hold its founding General Assembly

The Latin American Federation of Deafblind (FLASC) will have its Annual meeting

Our Hotel

The venue of the conference is the 5-star fully accessible Speke Resort, Munyonyo on the shore of Lake Victoria. The venue has a large garden with waterfalls and fountains, tropical plants and birds and there is a new marina where boats can be hired. It has all the advantages of being in a gated, secure hotel with comfortable bedroom facilities, swimming pool and internet access.

[www.Spekeresort.com](http://www.Spekeresort.com)

We are expecting to have 400 International participants, representing WFDB 60 member countries worldwide and 100 Ugandan participants.

**JOIN US! REGISTER NOW**

Registration for the conference can be done by filling out the registration form on the WFDB website: [www.WFDB.org](http://www.WFDB.org)

## **Country News**

### **Australia**

Mike Steer

Deafblind International Secretariat has been awarded to Senses Foundation in Western Australia (WA) for the next four years. Senses was formed in 2001



when the Royal WA Institute for the Blind amalgamated with the WA Deafblind Association and is the primary advocate and service provider for people who are deafblind or blind with additional disabilities in WA. For more information about Senses and the Secretariat, go to <http://www.senses.asn.au>

LIVEWIRE is a free online social networking website for young people aged 10 to 18 years with a chronic illness or disability living in Australia. Members can engage in chat events, have their say in forums and check out all the latest in movies, music, games etc. The website is a closed community with chat hosts available from 12 noon to 8.00pm daily. Members are divided into age categories to different sites (10 to 12, 13 to 15, 16 to 18) with age-appropriate content in each. Every application is authorised with written parental consent and proof of ID. Operated by the Starlight Foundation, the website is at <http://www.livewire.org.au>.

#### International Journal of Orientation & Mobility (IJOM)

Edited in Australia, the first issue of this peer-reviewed journal has just been launched. The foreword is by Jordie (Retired Guide Dog) of Graeme Innes AM and the articles, research and practice reports cover a wide range of issues. For more information about the journal go to <http://www.ijorientationandmobility.com> or contact Dr Desiree Gallimore of Guide Dogs NSW/ACT on phone 02 9412 9300 or email [dgallimore@guidedogs.com.au](mailto:dgallimore@guidedogs.com.au)

#### Access to Interpreting Services

As part of the 2007-08 Victorian State Budget, the Government made a commitment of \$2 million over four years to improve access to Auslan interpreting services for Victoria's Deaf and Hard of Hearing communities through information communication technology (ICT), for example, high speed broadband and video communication. The Auslan Video Relay Interpreting (VRI) Service will improve communication for Deaf and Hard of Hearing people in a range of health and community settings, particularly hospitals, community health services, Deaf and Hard of Hearing services and Department of Human Services regional offices. A project to trial an Auslan VRI Service is currently underway with a commencement date of March 2009. The trial will involve establishing VRI infrastructure at six DHS nominated health and community services in regional Victoria. Information sheets and other forms of communication will be made available. The first information sheet is available under "What's New" on the Disability Services website at: <http://www.dhs.vic.gov.au/disability>

#### Access to Premises Standards

The House of Representatives Legal and Constitutional Affairs Committee will review the appropriateness and effectiveness of the Australian Government's draft Access to Premises Standards. The draft standards were developed by the

Australian Building Codes Board and the Australian Human Rights Commission to make public buildings more accessible for people with mobility, vision and hearing impairments and are available at <http://www.ag.gov.au/premisesstandards>. Submissions addressing the Inquiry terms of reference are due by 13 February 2009 and public hearings are likely to be conducted in March 2009. For background information, go to <http://www.aph.gov.au/house/committee/laca/disabilitystandards/index.htm>

#### National Human Rights Consultation

The Australian Government has appointed an independent Committee to undertake an Australia-wide community consultation for protecting and promoting human rights and corresponding responsibilities in Australia. The Committee, chaired by Frank Brennan, will consult broadly with the community, particularly those who live in rural and regional areas. A consultation paper will be released, with submissions to be made by 29 May 2009. The Committee is due to report to the Australian Government by 31 July 2009. For more information, go to <http://www.humanrightsconsultation.gov.au/>

#### **Romania**

Teodora Seiciuc reports:

#### **Education Programme**

As part of the educational programme developed in partnership with the Ministry of Education and Research: Special Education Department, Sense International (Romania) organized the second annual network meeting for the teachers working at deafblind/ MSI units in special schools in Romania. The event took place in Cluj Napoca, at Babes-Bolyai University – the Faculty of Psychology and Education Sciences, Special Education Department. The theme of the meeting was the “Application of the curriculum for deafblind children in the educational process”. In this meeting, Prof. Dr. Vasile Preda awarded the national trainers with Certificates issued by the Ministry of Education and Research, acknowledging their participation in the development of the curriculum. In November, the follow-up programme began and the national trainers started to offer hands-on support in the classroom to teachers working with deafblind/ MSI children. This is the third consecutive school year that this follow-up programme has been implemented.

## **General Assembly of the Association of Deafblind People in Romania**

The General Assembly of the Association of Deafblind People in Romania took place on November 7, 2008. The main topics on the agenda were the annual activity report, the operational plan for 2009 and the election of the Board of Directors.

Before elections, a moment of silence was held in memory of Mr. Ladislau Tacsu, a former member of the Board of Directors.

Of the seven members elected, five are deafblind people – three are from Timisoara, two are from Cluj, one from Arad and one from Bucharest.

The new president of the Association of Deafblind People in Romania is Mrs. Elena Gherghel from Cluj.

## **Germany**

**Hanne Pittroff**

### **Celebrating an important anniversary in Würzburg**

Founded in 1853 by Count of Bentheim-Tecklenburg the institute for the education of blind people was started in Würzburg, an medieval city in the north of Bavaria. In 1972 there was an important change in the population to be educated: blind children with additional handicaps came into the focus of education. Of course, there were also children with additional hearing problems amongst them and to improve their educational service in 1978/79 a department for deafblind children was founded.

Right now we are looking back to 30 years of education for deafblind students. Our specialist services include early intervention, preschool and school-services, prevocational training and sheltered workshops as well as facilities for lifelong living of deafblind people. The Blindeninstitutsstiftung has become the umbrella of six different institutes scattered all over Bavaria and Thuringia. Because we have quite a reasonable number of deafblind individuals in Würzburg there are a broad range of experiences and competencies to be found here.

We felt that at this special landmark in our development we should look back what we have been doing, celebrate our achievements but also reflect on the challenges to come.

So, our 30 years of educational services for deafblind people were marked with an international reception here in Würzburg. We invited very distinguished colleagues from all over Europe for this and in particular the European Working

group on Communication to support an educational seminar for people working with deafblind people.

It is not very common in Germany, or in other countries, to have the chance to discuss opportunities and requirements for deafblind people because the numbers are small and often not a high priority for policy makers. Therefore it is our hope to build a broad platform and to create better information with and for deafblind people. For this reason we really appreciated having the members of the European working group at our side, to be a partner in developing and creating new ideas and to contribute in the conference.

We would like to thank them all for their friendship, their friendliness and the confidence they showed in us. They always have been a very important partner for us in building up the system for deafblind children, young people and adults to give them more participating in the society.

## **India**

**“...from Isolation to Inclusion – for people with deafblindness”**

### **A report of the all-India conference**

As a step forward in the same direction the first ever National Conference on Deafblindness was held in New Delhi in January 2009, which was Sponsored by the European Commission and supported by Hilton/Perkins International Program (USA) and the Rehabilitation Council of India. Sense International (India) joined hands with the National Institute for Empowerment of Persons with Multiple Disabilities (NIEPMD), Ministry of Social Justice and Empowerment, Govt. of India. Mrs. Anne Marchal, Head of Development Cooperation, Delegation of the European Commission to India, Bhutan and Nepal, inaugurated the conference and was joined by Dr. Shantikarn, Regional Director-DPR, WHO–SEARO and Maj. Gen. (Retd) Ian Cardozo, Chairperson, Rehabilitation Council of India. The Keynote address was given by Mr. Rodney Clarke (OBE) and the conference focused on the theme “from Isolation to Inclusion - for people with deafblindness”.

The highlights of the conference were book releases, distinguished service awards, and constructive discussions.

About 265 participants, including development practitioners, policy makers, researchers, family members, educators, experts from related fields and deafblind persons themselves discussed the challenges of inclusion and shared experiences to bring deafblind persons in the mainstream. The participants

stressed the importance of designing strategies for developing best practice and systematic follow-up for the inclusion of deafblindness in the disability policy and legislation of the country. Some of the key issues that emerged during the three day conference included:

- the need for a proper system of certification of deafblindness/MSI;
- better access to information communication technology, Rural development programs and
- increased collaboration between NGOs to avoid duplication.

Overall, the conference served the purpose of cumulative introspection on the progress made till date and also helped define the path ahead. Over the past few years a solid foundation has been laid for the inclusion of deafblind persons in e society as equal partners and we are hopeful that there will be a life of dignity and opportunity for deafblind children.

Akhil Paul

## **Brazil**

### **A Deafblind Gaucho from Brazil...**

**...joins the exchange program for professionals in the USA!**

Alex Garcia, who is President of AGAPASM Gaucha Association of the Parents and Friends of Deafblind and People With Multiple Disabilities writes...

From March, 15th to April 05th, 2009 the International Leadership, Employment and Disability (I-LEAD) professional exchange program took place in Eugene, Oregon, in the USA. This is a professional exchange program directed towards the employment of people with disabilities. The program was based on visits to centres and organizations related to work and employment and included experience of education, transportation, legislation, accessibility and public policies.

The program lasted 20 days and during this time there was a lot of observation, reflection and exchange of experience. We had the opportunity to exchange ideas and information with people who represented many supporting organizations and universities and all those people spoke about successful stories concerning employment, education and inclusion of people with disabilities.

People who are fight actively for inclusion in their countries representing Brazil, Costa Rica, El Salvador, Guatemala and Mexico took part.

A very special Mayor

Participating of the program I must highlight the important presence in the program, the Mayor of Eugene, Mrs. Kitty Pierce, who was an educator in elementary school. Because of her awareness of people's needs, she became one of the most celebrated mayors in history because she has created an accessible city – Eugene. What a fantastic record – from an educator to the mayor of the most accessible city in the world.

What relevant aspect did I see about the American way of life?

The most significant thing I saw was their democratic way of living. I really could “feel” an active democracy. It's impressive to note their constant process of elimination of inequalities through education and respect of people to include disabled people in things which belong to all society. They have achieved this level by thinking in an intelligent way. Accessibility has brought equality between people and, as a consequence of it, respect. Accessible Eugene exports its characteristics. In Eugene, people with disabilities are not afraid of showing themselves in public. They aren't afraid to talk about the difficulties they face.

In relation to the advances in Eugene, what could be applied in Latin societies like Brazil?

With will power, intelligence and investment, it is possible to build our cities on a model like Eugene. Accessibility is for all people. Investing in accessibility would help to halt the progress of crimes committed by young people (which has been increasing) and would provide better facilities for young people at school, because accessibility would bring new opportunities. All this investment would return to society twice over. An accessible structure would cause a chain reaction in Latin society and in Brazil – and all for the best.

Alex Garcia

[www.agapasm.com.br](http://www.agapasm.com.br)

## **Ireland**

### **Deafblind Ireland**

The trustee body of DB Ireland held their first quarterly meeting of 2009 in Longford in January. Prior to this 2 members had a formal meeting with the CEO of The National Council for Special Education, the government body set up to oversee education to children with special needs in ROI. The meeting was to raise awareness of the unique needs of children with deafblindness and current gaps in education provision for this group in Ireland.

The trustee meeting discussed plans for events in Ireland for deafblind awareness week in June, possible attendance at the ICEVI conference in Dublin in July and another training event for professionals in November, following the very successful event held in Dublin in November 2008, where 80 professionals working with deafblind children came to hear experts from the UK share their experiences and skills in working with deafblind children.

Ges Roulstone, Chair, DB Ireland

## **Canada**

### **Stan Munroe writes**

#### **CDBRA is now CDBA!**

We've revised our name and our logo, but our principles and strong commitment to individuals who are deafblind, their families and personnel working in the field continues to be at the heart of what we believe and what we do.

After almost 35 years of operation as the Canadian Deafblind and Rubella Association (CDBRA), the organization has rebranded itself as the Canadian Deafblind Association (CDBA). The National Board of Directors believes that it is necessary to update the image of the organization to better reflect the broader community of individuals who are deafblind in Canada. While we have removed "Rubella" from our name, we will always have high regard for those who were the root of our inception as an organization in 1975. Indeed it was because of those individuals largely with congenital rubella syndrome that we, in Canada, developed the concept and principles of intervention, intervenor services and the network of Independent Living Residences. But today, new cases of congenital rubella syndrome are rarely seen as a cause of deafblindness in Canada, as in most western countries, thanks to the effectiveness of the immunization program. This has led to the decision to rebrand ourselves in order to demonstrate greater inclusion.

Along with our new name we have modified the logo to reflect that the organization is Canadian, while maintaining its original core values; that those individuals who are deafblind, intervention and communication are at the forefront of everything we do.

## **Working at both ends of the spectrum**

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

On behalf of all of us at ICEVI let me extend warm greetings to our colleagues at Deafblind International. It is a privilege for ICEVI to be able to regularly share information about our work through your magazine "Dbl Review" and I know our members enjoy learning about Dbl's work through your regular contributions to our magazine "The Educator".

By now most of you are probably aware of a global initiative that was launched by ICEVI in 2006 in partnership with the World Blind Union. The "Global Campaign on Education for All Children with Visual Impairment" (EFA-VI) is working to reach the more than 4 million children with a disabling visual impairment who currently have no access to education. The primary focus of this campaign is on reaching children at the pre-school and primary level by working with governments and non-government organizations to assure that children with visual impairments (including those with additional disabilities) are included within national "Education For All" plans that currently receive significant support from UNESCO, UNICEF and The World Bank.

Unfortunately, these national EFA plans often overlook the needs of children with serious sensory impairments. The EFA-VI campaign is there to change that situation, and to date the results are quite gratifying. The EFA-VI program is now underway in nine countries with a number of others currently completing final preparations to launch their national action plan to assure that children with visual impairment have equal access to education. Only last week ICEVI's Secretary General was in Vietnam where he reported that progress to date is most gratifying. Over the past two years more than 3,800 regular classroom teachers have received training and more than 13,000 visually impaired children, who previously had no access to education, are now enrolled in school.

While our attention remains on reaching children at the pre-school and primary level, we recognize the importance of addressing needs at all levels of the education system. With generous support from The Nippon Foundation the EFA-VI Global Campaign is currently working on an interesting project in the East Asia region that involves visually impaired students enrolled in higher education. This effort grew out of a small research project ICEVI conducted several years ago in our East and West Asia regions to determine what barriers were being faced by visually impaired students enrolled in university education.

Over the past three years this project has grown from its starting point in two major cities on the island of Java, in Indonesia to additional locations in Indonesia and expansion to the Philippines and Vietnam. Initially the project provided technology to students enrolled in higher education to help them



address one of the major barriers identified by the earlier research; lack of access to information.

As the project has expanded we have identified three additional areas of concern shared by university students in all three countries: 1. the need for more portable technology that can be carried to university classrooms, 2. the need to create a more welcoming environment within the university and 3. improved access to specialized and technical materials in Braille.

ICEVI and The Nippon Foundation are learning important lessons from this work in Indonesia, the Philippines and Vietnam. Within the next few months our project partners will meet to discuss the next phase of this effort. It is our hope that over time this project will not only be able to expand the much needed assistance to the visually impaired students who are its primary beneficiaries but will lead to positive changes in public policy. Only when governments recognize and accept their responsibility for providing equal access to education at all levels of the system can we declare that “education for all” is truly a right and a reality.

## **Artist from Helen Keller’s home State collaborates with sensory impaired people!**

### **Congratulations Rich Curtis!**

“The Helen Keller International Award is a unique opportunity for artists from across the world to reflect on deafblindness and disability, through a range of artforms.” Gillian Morbey, Chief Executive of Sense Scotland.

The winners of the Helen Keller International Award main and under-16 prizes have been revealed at a ceremony in the Glasgow Royal Concert Hall. Run by Sense Scotland, the exhibition featured art that challenges perceptions of deafblindness and was exhibited at the Concert Hall and Sense Scotland’s TouchBase venue in Glasgow.

The £1500 main prize went to Rich Curtis, from Alabama, USA (he is from the same Shoals area where Dr Helen Keller was born). His work titled ‘Sight Unseen’, comprises 20 textured paintings on paper, and was collaboration with sensory impaired people. The £100 cheque for the under 16 prize went to ‘Medusa’ a large sculptural piece made from recycled material and found objects, by Shawlands Academy in collaboration with Hazelwood School (a school for children and young people with sensory impairment); both schools are based in Glasgow. Sense Scotland Patron, the Duchess of Sutherland, made presentations.

Judges Pauline McLean, Monica Callaghan, Amanda Catto and Keith Salmon (an artist who has a visual impairment), had no knowledge of the artists’ identities

until they had completed the judging. The Helen Keller International Award was funded and supported by the Scottish Arts Council, ITV and Glasgow's Concert Halls. Although Rich was unable to attend the awards he took time to answer some questions about his work.

Question & Answer with winning artist:

What interested you about the Helen Keller International Award?

I found a call for artists to submit work and felt the work I had been doing with the Sight Unseen project fit well with the mission and concept of the exhibition. The added coincidence of living near Keller's home, Ivy Green, also piqued my interest. Once I researched a little about Sense Scotland, and found what an incredible organisation they are, I was compelled to enter the competition.

What inspired you to start the 'Sight Unseen' project?

I was sitting in a coffee shop and this man walked in carrying his mobility cane. He called out to everyone in the shop that he needed a ride to an appointment. Someone he was familiar with volunteered before I was able to speak up. That one simple instance got me thinking about working with blind people. My original idea was to ask individuals who are blind to lead me through their day, navigating their world. After some modifications, I developed this exercise of collecting sound-response drawings.

How did you choose the people to collaborate with on the project?

I contacted the Alabama Institute for the Deaf and Blind, to find willing participants. It was a year-long process of contacting the regional centers and schools, talking with instructors, gaining their trust, finding clients who were willing to participate,

How did you choose the pieces of music for people to respond to?

I have a large and esoteric collection of strange music that ranges from experimental free-improvised jazz to Tuvan throat singing to solo drumming. I chose music that I felt the participants would not have heard before, and therefore have no prior relationship with. I wanted the responses to be immediate, not meditated, and corporeal.

What do you feel you learned through this particular collaborative process?

The contact and collaboration with the participants was enriching. I am partial to the drawings made by the participants who have been totally blind since birth. The lack of inhibition was inspiring to watch, and the freely intuitive, gestural marks are so beautiful on the page.

How do you feel about being chosen as the winner of the Helen Keller International Award?

I am truly delighted. I was happy to participate in the first place. But, to win the competition among such wonderful fellow artists makes me very pleased. I am honored.

“We would like to thank all our entrants. Twelve countries contributed 130 entries, many of them from colleague organisations,” explained Gillian Morbey.” Without their continued interest and support we couldn’t continue with this unique competition.

For more information go to: [www.sensescotland.org.uk/helenkeller](http://www.sensescotland.org.uk/helenkeller)

## **Music means so much to Russ Palmer...**

### **...“Warm Summer Days” has just been released**

This CD has taken Russ on a long and challenging journey especially if one considers he is Deafblind. He was born severely deaf and was registered blind in 1991. He took early retirement at the age of 30 and decided to qualify as an international Music Therapist at Sibelius Academy in Helsinki, Finland 1999. In 2004 he had a Cochlear Implant (CI) operation which enabled him to continue his love for music both as a composer and performer. He put together a musical biographical album titled Reflections in 2003 with his producer Jon Rosslund, fearing he would not be able to sing, perform or compose his music.

Russ explains....

Reflections was my first demo album which I refer to as “Before Cochlear Implant” (BCI) and now this album Warm Summer Days should really be titled “After CI” (ACI) and was surprised at the enormous difference in the presentations of my songs. Where I was struggling during the BCI time to hear if I was singing in tune, getting the right pronunciation etc, now I was able to focus more on interpreting the lyrics and presentation of the all of my vocal tracks. This may not appear to a hearing person to be such an issue but you have to remember I have never heard normal sound only what I have taught myself to hear through my high powered hearing aids, and since having the CI in 2004. Russ was quoted as being the world’s first “Deafblind Music Therapist” in 1997 at a Deafblind International conference from a Music Therapist colleague. All the music is composed by Russ over a time period from 1974 to 2003 with lyrics by Russ and his father Peter Palmer and Iris Brocke (A Hunter’s Cry & Warm Summer Days). Seven of the vocals are performed and sung by Russ with two vocals by Peter Palmer (If You Go & Dreaming). There are also two piano solos

performed by Russ (Mystic Lady & Going Home) and an instrumental track Tequila Magic performed by a Norwegian musician Terje Johannesen. The production, arranging, mixing and mastering was done by a Norwegian composer Jon Rosslund who works also as a Special Teacher at SIGNO (resource centre for the Deaf children and adults with learning disabilities) in Andebu, Norway. The recordings for the CD started at Frinton-on-Sea in the U.K. and at Jon's home studio in Norway from the period January – September 2003 with selective recordings from 2006 until October 2008 when the album was finally completed.

For further information contact:

Email: [rpalmer2@tiscali.co.uk](mailto:rpalmer2@tiscali.co.uk)

Website: [www.russpalmer.com](http://www.russpalmer.com)

Or order through the Ear Foundation website:

[www.earfoundation.org.uk/shop/items/107](http://www.earfoundation.org.uk/shop/items/107)

## **CHARGE syndrome – how can we provide better support?**

**Gail Deuce from Sense reports the results of a pilot project in the UK involving families and children**

As the UK's leading organisation working in the field of deafblindness, Sense is committed to supporting children and young people with CHARGE Syndrome and their families.

A significant number of children supported by Sense have CHARGE Syndrome, as do an increasing proportion of new referrals each month, these often being children who are newly diagnosed.

Finding out more

One of the team's working with children, the Family, Education and Advisory Service (FEAS), in the South East felt it would be advantageous to find out more about the children themselves and the services their families receive. To do this a questionnaire was developed to gather information to:

- build upon existing knowledge of CHARGE Syndrome
- help recognise areas of need
- After analysis, the team would then be able to use this to improve the support Sense is able to provide to the children/young people, their families, and to the professionals working with them

## The pilot questionnaire

A pilot questionnaire was devised and eight families approached, all of whom kindly agreed to complete it. With one exception, this was undertaken with the direct support of a consultant teacher from the FEAS team.

The questionnaire covered:

- General information: date of birth, address, siblings, etc.
- Diagnosis: using Blake et al (1998) Revised Diagnostic Criteria, considering where, when and by whom the diagnosis was made
- Medication
- Developmental patterns
- Educational provision (including the Statement of Special Educational Needs)

## Synopsis of findings

### The participating children

The initial pilot questionnaire involved eight families of children/ young people with CHARGE with an age range of 1.6 – 17.2 years. A small sample, but enough to encourage us continue to full project because some interesting points arose.

### Diagnosis

- 5 children were identified in days or weeks with diagnoses being made by geneticists and paediatricians, and in one case, an endocrinologist.
- Of the 3 remaining children, the youngest child in the survey was diagnosed at 8 months; the two remaining later diagnoses were made at 9 years and 2 years and were in older children in the sample.

This earlier diagnosis is encouraging since it suggests a development in the knowledge and recognition of CHARGE Syndrome though there is some concern since several families reported a different diagnosis before CHARGE was identified.

### Hospitalisation

Souriau et al (2000) recognised that children with CHARGE Syndrome often experience lengthy periods of hospitalisation following birth and during infancy. 6 of the 8 children from the pilot questionnaire shared this experience with the period in hospital following birth ranging from 2 days to 5 months, and the average stay being 55 days.

### Development

The variance in the development of these children shows just how individual each child is. However, some significant observations were reported:

- 6 of the children were able to walk holding on 6 months to 1 year before they were able to stand unsupported

– 1 child achieved independent walking before being able to stand still unsupported.

This is not surprising if we consider the fact that sensory integration dysfunction difficulties are now thought to be inherent in CHARGE (Brown, 2003).

#### Pre-school support

The four pre-school children were all receiving different packages of support. However all the children:

– had input from a teacher for the visually impaired and a teacher for the deaf, together with a specialist teacher for deafblindness/multi-Sensory Impairment (via Sense).

– had therapists involved.

#### School support

The four children and young people in the older group required increased provision to meet their individual needs and support once they reached school age;

– all four children/young people of this age were in some form of specialist provision (SLD school, VI, HI or SEN resourced provision as part of a mainstream school).

– all were supported full-time, although only one, by a named intervenor.

– the support provided by the teachers for the visually impaired or teachers of the deaf was variable, as was the input by therapists.

– one child was not supported by a Deafblind/MSI teacher

– none received support from a specialist in sensory integration dysfunction.

These findings appeared to confirm the need for flexibility and a range of provision being made available.

#### Statements of Educational Needs

Six of the eight children in the pilot had finalised or agreed Statements of Special Educational Needs. Of the two children without a Statement, the family of one had initiated the process and the remaining child was too young and already receiving appropriate early input and support.

Concern was raised as:

- only 3 of the completed Statements had received advice from a Deafblind/MSI specialist.

- in all the Statements CHARGE Syndrome was identified but only half then had the implications of CHARGE set out to assist with allocating resources and to support school staff with the additional information they required to meet needs.

Deafblind/MSI teacher support was included in all the Statements although the frequency of input varied. This was added at a later stage for two of the children, on one occasion after a diagnosis of CHARGE had been made. However it should be stressed that all of these parents were supported by Sense. One great concern emerging from the questionnaire was that whilst parents were happy with the support given in the early years/ pre-school provision, half of the parents then became unhappy with the provision once the children were at statutory school age. This requires further exploration.

Follow up with the participating families

It was extremely helpful to be able to follow-up the pilot questionnaire by meeting many of the parents as a group and being able to discuss issues further and highlighting action required.

Further work

A revised questionnaire is now being prepared so that the information gained in the small pilot can be built on. Some revision has been made after reflecting on the administration of the questionnaire, parental comments and new information emerging from the field:

- Hefner and Davenport (2004) criteria have replaced the earlier Blake et al(1998) criteria, identifying those features now felt to be the major characteristics of CHARGE. It is also felt these are more precise, more easily understood and more manageable
- questions concerning gene testing and identification of the ChD7 gene will be included
- questions concerning growth hormone treatment and the involvement of an endocrinologist will be included

It is likely that further revisions will continue to be needed over time as further research in this field continues to broaden our understanding of CHARGE.

Parents rate early education more highly

It would appear from the response of parents taking part in the survey that appropriate early input is felt to be effective in supporting the child with CHARGE and his/her family.

However, 2 of the 4 families of children of statutory school age were not satisfied with the child's educational placement. Concerns were raised by all parents that there is inadequate recognition of the child's changing needs over time. In addition, a range of specialist provision is not always available within a child's locality and that a mainstream placement is not always effective, even when the child/ young person is more able.

Further work on how to support the school years

There is a need to identify the reasons why the child with CHARGE may encounter difficulties as s/he progresses through the school years because these factors then need to be addressed. Information needs to be provided and pro-active work undertaken to try and overcome potential barriers to learning in the future.

During the parental discussions requests were made for:

- A folder of 'Useful Information' for professionals in the UK, including fact sheets and some medical information
- A list of professionals the diagnosing consultant will need to consider referring the child to, for example, other medical professionals, therapists, specialist teachers, Social Services
- Guidelines for information to be included in the Statement of Special Educational Needs

Awareness of the sensory integration issues affecting the day to day life and learning of the child with CHARGE also need addressing. It is possible that once the child has learnt to walk and develops compensatory strategies the challenges the child is constantly overcoming are less obvious to the teacher but just as real to the child. Research has shown that this can then present in 'challenging' behaviours in the classroom (Brown, 2000; Hartshorne et al, 2000)

Parents felt there is an ongoing need for more therapists trained in sensory integration dysfunction.

In conclusion

This pilot study has proved a useful starting point in gaining more information about children and young people with CHARGE Syndrome and has assisted in the process of identifying more clearly areas for further work.

Gail Deuce

References

Brown D. (Published Online 2000)

CHARGE syndrome "behaviours": Challenges or adaptations?

American Journal of Medical Genetics Part A

Brown D. (2003)

Some behavioural implications of sensory difficulties found in children with CHARGE Syndrome

CHARGE and Usher Syndrome in Europe (CAUSE) Conference, Hinckley, England



Hartshorne T., Hefner M., Davenport S (Published Online 2000)  
Behaviour in CHARGE syndrome: Introduction to the special topic.  
American Journal of Medical Genetics Part A

Souriau J., Gimenes M., Blouin C., Benbrik I., Benbrik E, Churakowskyi A.,  
Churakowskyi B. (Published Online 2000)  
CHARGE syndrome: Developmental and behavioural data  
American Journal of Medical Genetics Part A

## **Network News**

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## **Usher Study Group**

### **Marylin Kilsby reports:**

The next Usher Study Group will take place as a pre-conference seminar to the ADBN conference in Aalborg, Denmark, in September 2010. The Usher Study Group will run from midday on Monday 27 September until 4.30 p.m. approximately on Tuesday 28 September 2010. The ADBN conference dates are Wednesday 29 September until Sunday 3 October 2010.

The USG is for people with Usher, their families, friends and interested professionals. Topics often covered are research, employment, technology, Usher life stories and the latest information about Usher. We also have a meal together and plenty of opportunity to socialise and learn from each other. However, moving the USG to just before the ADBN conference does not mean that the Usher Study Group will be missing from the Dbl European conference in Senigallia this year. We will be taking part in the Network morning during this conference.

More details about the Usher Study Group in Denmark will be available later this year, as well as a call for papers. We look forward to welcoming you!

Marylin Kilsby  
National Usher Coordinator

Sense

## **ADbN**

### **Acquired Deafblindness Network**

#### **Ges Roulstone**

The Co-ordinating group of ADBN met in London in February 2009 and discussed feedback from the successful seminar which took place in Bergen in October 2008. Over 200 people attended the event (hereafter to be called a conference) and thoughts turned to the next event in Aalborg in 2010 (29 September – 3 October – Mark the date in your diary now!) A conference theme was agreed and initial decisions take on potential keynote speakers. ADbN will be having a network morning at the Dbl European conference in September 2009 and look forward to meeting up again with network members then.

Ges Roulstone  
Chair  
ADBN

## **The Siblings Network**

The Dbl European conference is coming up and when you read this we will be busy finalising the programme for the Siblings Network morning.

During this morning there will be presentations about several issues concerning brothers and sisters of children with special needs. We will also talk about the Siblings Network, our goals and plans for the future.

A group of siblings coming from Osimo (Italy) will be one of our presenters. They will also present a workshop called "Is my brother an only child", scheduled in the regular programme of the conference. Here they will present some personal experiences and what role their siblings group has in their life.

When I founded this network six years ago professionals hardly took notice of brothers and sisters in their work. Their focus was on the children and adults affected by deafblindness and their parents. Slowly things start to change and professionals start to acknowledge the role of brothers and sisters within families. Now, six years later I am proud to say that one of the plenary lectures will be about brothers and sisters.

I hope to welcome many of you during our network morning and am looking forward to meeting you in Italy!

Sabine Kersten  
siblingsnetwork@gmx.net

## **Congenital rubella syndrome – health and wellbeing**

**Sarah Butler and Joff McGill report:**

This joint Sense and Sense Scotland event, which took place between 6th-7th March in the UK, brought together fifty practitioners, as well as scientists, families and people with CRS to share our latest knowledge about congenital rubella syndrome and its ongoing impact on individual's health.

Sense has produced a full report of the information gathered; visit [www.sense.org.uk/rubellaconference](http://www.sense.org.uk/rubellaconference)

An overview

In much of Europe and the Americas rubella is now almost absent because of comprehensive immunisation programmes, though elsewhere rubella is still a significant problem. Even where new cases of CRS are rare, adults continue to live with CRS: so we need to understand the on going health concerns of individuals with CRS and how to support them.

Though scientific research into the effects of CRS on adults is still limited, we do know that people with CRS are more likely to suffer thyroid conditions and diabetes than other people. We also suspect that CRS may cause other conditions to develop earlier or more often.

There are a number of studies of CRS, often carried out by deafblind organisations. There are difficulties in comparing these studies because of differences in sample groups (type and size), different people responding to the study, and different timescales (when the study happened, the age of those studied and the year in which they caught rubella). None the less, they give us useful indicators as to the health indicators we need to look for in our work. More importantly they point to a clear role for support staff and professionals, that of health detective. Staff have a crucial role to play observing and recording what they see, reflecting on this and finding out what health issues people may have. It doesn't stop there though – we need to identify what we can do to help and find ways to be taken seriously when working with health professionals.

Supporting healthy living is vital – we all need to make friends, keep active, eat and drink well, discuss our feelings, have a break, do things we are good at and have a sense of purpose. As professionals and support staff we need to find ways to support well-being.

The seminar chose to focus on the following:

- Endocrine problems: thyroid conditions and diabetes
- Vision
- Hearing
- Circulatory issues
- The Brain and behaviour

#### Endocrinal problems

The way that hormones work in our bodies is extremely complex and not yet fully understood. We do know, however, that people with CRS are more likely to develop certain hormone-related problems, in particular thyroid problems and diabetes.

The thyroid may become over stimulated, which causes the body's systems to run at high speed. Or, if the thyroid is underactive the body's systems slow down. Both conditions can be treated with medication.

Diabetes is extremely common, and is caused by a lack of insulin. This means that the body cannot absorb glucose, and so cannot derive energy from food. Though a small proportion of diabetics need to inject insulin, most can control the problem by managing their diet, exercise and lifestyle.

#### Vision

A defining feature of CRS is the eye problems that people are born with. Many babies are born with cataracts – which nowadays are operated on, and replacement lenses inserted. Some may be born with small eyes and most have some vision problems.

As people with CRS grow older it seems that they are more prone to other eye conditions than the general population. The most common conditions are cataracts, glaucoma and retinal detachment. In addition, because more people with CRS develop diabetes, they are also more likely to develop diabetic retinopathy.

It is therefore crucial that everyone with CRS has regular eye checks. For some people these eye checks can be difficult but they are worthwhile for everyone. The key to successful eye checks is to build good relations with the eye clinic and to prepare well.

It is also important to be aware of the signs of deteriorating vision such as a person becoming clumsier, or finding it hard to judge the height of steps and curbs. Staff need to watch out for these symptoms and to seek help urgently as they can indicate a serious problem that needs immediate treatment.

#### Hearing

Ear problems are the most common effect of CRS and are present from birth. Because both the inner and middle ear may be damaged this may cause problems not only with hearing but also with balance and movement. As people get older they may also experience age-related hearing loss and loss caused by damage to the ears by loud or persistent noise.

The most common ear problems experienced by people with CRS are tinnitus, recruitment (where certain frequencies are very loud), loss of balance, auditory processing disorder, and problems with integrating the senses.

It is often hard to tell the effects of damage to the ear as clinical tests are at best a rough guide. We therefore also carry out extensive functional tests to see how someone hears, and how different situations affect this.

### Heart conditions

The most common heart problems in people with CRS are patent ductus arteriosus (PDA) and pulmonary artery stenosis. In PDA the child has a hole in the heart that has to be closed by surgery or some type of plug: very rarely an adult needs treatment for PDA if it was not dealt with in childhood. Pulmonary artery stenosis describes a narrowing of an artery which causes reduced blood flow to the lungs and puts a strain on the heart. The artery can be widened by inflating a balloon via a catheter.

When a deafblind person receives treatment in hospital they will need support: preparation (such as familiarising them with the room where they will be staying) will make this much easier.

### CRS, the brain and behaviour

Rubella affects the developing brain, which may in turn affect a person's relationship with the world and their behaviour. The rubella virus can disrupt the development of the neural paths in the sensory, motor and cognitive and integrative systems. Early damage may not have observable effects straight away – we may only see the effects when the affected part of the brain is called into action as the person develops.

While we can use standard checklists to assess a person with CRS's behaviour, looking for possible neural impairment, we must always bear in mind the powerful effect of deafblindness itself. So while a person's changing behaviour may be due to impairments in the brain, it may also be due to the way that deafblindness affects their ability to communicate and understanding of the world.

We all behave in challenging ways from time to time – we all lose our tempers, for example, and would hate to be labelled by this behaviour. It's only an expression of the way we feel, of communicating our feelings or needs. People with CRS are no different – the only difference is that we label some of their behaviour as challenging because it carries risk and because we can find it hard to cope with.

There are many possible causes of challenging behaviour – a particular incident will be caused by many factors. Though it can be a long and complex task to unravel why someone uses challenging behaviours, it is worth the effort as by doing this we can build effective support.

Supporting communication and providing meaningful experiences that form the basis of conversations and shared memories is vital in this.

## Summary

The incidence of CRS is low enough that many non-specialist health professionals know little about it. This can be enormously frustrating for people with CRS and their families. So we have a duty to learn more, to support better and to listen properly.

As delegates from all over the world reflected on the seminar, three themes emerged:

- the importance of understanding the initial and ongoing medical effects of CRS and their implications on individual's health
- the importance of communication between professionals and the person with CRS
- the importance of collaboration between professionals.

All too often our work in this area focuses on congenitally deafblind people, but if we are truly to understand the on-going health issues that people with CRS face we need to listen to and learn from individuals with CRS who have fewer disabilities, but as many health worries.

More than anything we have to remember the role we play in supporting the health and well-being of those we work with. Being a reflective health detective is as good a start point as any.

There are two groups online where you can share and learn more about CRS. Both are moderated by Nancy O'Donnell at the Helen Keller Centre in New York. One group is for people affected by CRS (many were at school together in Boston, USA): it's busy, and has two key professional contributors, Nancy O'Donnell and Pam Ryan from Perkins school. The other group is for worldwide professionals working with deafblind people. To find out more about joining, email Nancy O'Donnell at [HKNCNOD@aol.com](mailto:HKNCNOD@aol.com)

## Conference

Dear Dbl members, dear friends,

From 21 – 22 of September 2009, the pre-conference on Communication and Congenital Deafblindness, will take place in Senigallia, Italy. The pre-conference will be held as a start of the 7th Deafblind International European Conference.

A theoretical framework for co-creating communication with persons with congenital deafblindness has been developed by Deafblind International's Communication Network during the last 15 years. In a Dutch Nordic project, 4



booklets have been created describing this theoretical framework and how it can be implemented in practise with congenitally deafblind children and adults.

The material consists of 4 booklets including video illustrations of the concepts and intervention strategies described in the booklets.

The booklets are co-written by members of the Communication Network and specialists from the Netherlands and the 5 Nordic countries.

In this pre-conference the main content of the booklets will be presented by some of the writers. Video examples from the 4 DVD's will be analysed to illustrate what the theoretical concepts can look like in the case of congenital deafblindness.

On behalf of the committee I would like to invite you to attend the pre-conference. More information about the registration, accommodation, conference fee and the programme will be published on [www.dbiconference2009.it /pre-conference](http://www.dbiconference2009.it/pre-conference) within a few weeks.

If you have any requests, please contact me personally at [a.vddonk@viataal.nl](mailto:a.vddonk@viataal.nl) or on my mobile phone +31 (0)6 11055550.

Hope to meet you in Senigallia, Italy!

With kind regards,

On behalf of the organizing committee,

Anja van der Donk

Projectmanager Events

Centre for Expertise

Viataal, the Netherlands

## Conference

Congenital deafblindness and communication

The magic of dialogue

DbI Communication Network Course

June 22 - 25, 2010

Paris - INS HEA 58/60 Avenue des Landes • 92150, Suresnes

The course will focus on the dialogical dimension of human minds as it is reflected and used in daily communication and education of people who are congenitally deafblind. It will address more specifically the domains of

- Culture
- Language
- Narrativity
- Trust

- Identity

As in previous courses, participants will be able to attend

- Plenary lectures of scientists not related to the field of deafblindness
- Plenary lectures of the Communication network members presenting the deafblind perspective.
- Video analysis workshops following up the plenaries.
- Free papers of the participants.

First announcement INS HEA

Nordisk Velfærdscenter

32 • Dbl Review • July - December 2009

## **Shazia has dreams; do you know what they are?**

**Dipti Karnad from the Clarke School in Chennai discusses developing language and literacy skills in children with deafblindness and introduces us to a rather special student...**

Children who are born with deafblindness do not have casual access to language and, as a result, whatever language and communicative environment surrounds the child must be brought to him or her. Our aim is to give such children an opportunity to learn language and develop literacy skills without which she or he will be withdrawn from people and the environment or live a life of frustration and deprivation from social interaction.

What is literacy?

- In ordinary terms, literacy generally refers to the ability to read and write.

A Broader Definition of Literacy

- Literacy is communication especially when the concepts and issues are applied to students with deafblindness. In this respect, then, literacy is the most basic foundation for all learning, for receiving and imparting information, and for initiating interactions with others.
- What is more important for students with deafblindness is that literacy opens the doors to personal relationships, shared interests, leisure activities, learning strategies, partial to full independence at home and in the community, and vocational possibilities" (Langley, 2000, p. 1)

Literacy for students Who Are Deafblind

A broader definition of literacy is needed due to the fact that:

- Not all students will be traditional readers and writers, but they will have literacy!

- Communication is often the primary need of students with deafblindness.
- A variety of communication modes are used by students with deafblindness.

### Facets of Literacy

The three facets of literacy are

- Emergent Literacy
- Academic Literacy
- Functional Literacy

### Emergent Literacy

Emergent literacy is the process of developing literacy that begins at birth and ends when children begin to engage in conventional or functional reading and writing (Sulzby & Teale, 1991)

### Academic Literacy

The basic reading and writing skills taught in a conventional literacy medium during elementary and middle school years” is known as academic literacy. (Koenig & Holbrook, p. 265, 2000)

### Functional Literacy

“The application of literacy skills and the use of a variety of literacy tools to accomplish daily tasks in the home, school, community and work setting” – This is functional literacy. (Koenig, 1992).

In the case of a child who is deafblind emergent literacy would mean “reading” and “creating” tactile representations of real life experiences that are permanent for the child to access .This child may not have symbolic language skills to participate in literacy activities These experiences would provide her or him with literacy experiences.

### Meet Shazia

This paper follows the development of language and literacy of Shazia Fathima, a pretty young girl with deafblindness. She has low vision and has a profound hearing loss. Her intervention started at age three plus as the first two and half years of her life were spent in and out of hospital due to eye and heart surgeries. She joined the Sadhana Unit in late 1999. Initially she did not like to wear her glasses and hearing aids. She loved to spin, run around and gaze at lights. She was intelligent but what she lacked was a means to communicate. Her eyes, facial expressions and body language made it evident that she needed a way to express herself. Hence, communication was made a priority and work was started on object based communication, sign language, finger spelling, exposure to reading materials, picture books and the like.

Everyone bombarded her with language which was age appropriate. However, in doing so we kept in mind that we followed a logical order in presenting the different modes of communication. Soon, her “so called behaviours” reduced and she began to accept her glasses and hearing aids.

How we introduced language and literacy to Shazia

As a young child she enjoyed outdoor activities. Her favourite outdoor activity was to go to Nageshwara Rao Park with her class. The activity would mean carrying her snack bag, wearing her cap and taking a ride in the bus. Once at the park, she would go to her favourite slide, eat snack under the tree and drink APPY from the tetra pack. Of course, before getting back to school she would gather seeds from under the huge jamun tree.

Back in school, her teacher would prepare a story or memory box and recreate the outing to the park tactilely using items from the trip e.g., the bus ticket, the straw for the drink that she had, the empty snack packet and of course the jamun seeds. She would then discuss the event while encouraging Shazia to manipulate each object in the “story or memory” box. Each item would be labelled in large print. In the evening after school, teacher would hand over the story box to Shazia’s mother so that she could use the materials to refresh her memory.

Building on real experiences that children enjoy as a beginning point for literacy experiences by referring to tactile items associated with these experiences. Soon these tactile items were organized in a “story or memory” book so that the child could refer to events and “reread” these stories.

For Shazia, objects were replaced by photographs, then line drawings before she moved on to children’s storybooks.

By exposing the child to braille and large print in a similar manner that young sighted children are exposed to print, e.g., on labels, the child learns to assign meaning to Braille dots and letters although at first she may not be able to read the abstract symbol system.

When it was time to go shopping. Shazia needed to make a shopping list to buying ingredients to make jam sandwiches in class. Teacher and she would discuss what materials were needed. Teacher would show her a slice of bread and the bread wrapper, a small empty jam bottle and an empty butter packet. Together they would make a shopping list which was very tactile and visual. Teacher would staple the empty bread wrapper on to a card and write “BREAD” in large print on it. On another card she would tie the empty jam bottle and write “JAM” and on a third card, she would write “BUTTER” after stapling the empty butter packet on it. Shazia would go to her calendar box, find the shopping symbol and get ready to go shopping. At the shop, she would match the objects that her teacher had prepared as a shopping list and make the correct purchase, of course with teacher’s assistance.

After a lot of practice and a substantial growth in vocabulary, Shazia is now able to make her own shopping list and buy materials in the supermarket. Her mother also encourages her to help her make the shopping list for the household groceries.

“My first lesson in literacy was when I recognized the letter ‘F’ on a hoarding. This made my teacher very happy. Soon I learnt that everything had a name and I even made up my own name sign, an ‘f’, as in Fathima, fluttering like a butterfly in the air. I learnt the sign names of others in the unit and also made up name signs for new children and now trainees, too. My sign vocabulary began to grow. I became less naughty. Everyone wondered if it was the same ‘me’,” reminisces Shazia.

Shazia began to “read” a schedule that consisted of objects arranged in the order of the events they represented. But we realized that Shazia was quick in picking up new concepts so we moved from the calendar boxes to portable picture schedule with photographs and words written below them. She moved very quickly to line drawings and then by the end of 2000, she showed a clear preference for the written word. Likewise, she was able to point to a picture from a menu of pictures in order to express a desire or make a comment.

As we all know, for a child with deafblindness the concept of time passing is very difficult and that the days of the week and months of the year cannot be learnt by rote. For Shazia, we used the schedule or calendar system as the basis. We used one favourite activity per day to teach the days of the week e.g.

- Monday – Shopping
- Tuesday – Cooking
- Wednesday – Outdoor Play
- Thursday – Art and craft
- Friday – Trip
- Saturday – No school
- Sunday – No school.

We showed the signs for each day and encouraged her to use cards to complete the sentences

Today is \_\_\_\_\_.

The sentence was also signed alongside. A teacher made calendar was used so that she could put the dates. In this way Shazia learnt the meaning of “yesterday” and “tomorrow” along with the verb changes that came automatically.

Teaching the months of the year was more of a challenge since a new month comes only after thirty or thirty one days and sometimes after twenty eight days. But we used birthdays and important holidays for teaching this. And hey Presto! Shazia suddenly became hungry to know the birthdays of each child and staff of the Unit not to forget her family members. She is now conversant with everyone’s

birthdays and is ready to wish them in advance. All this was possible through conversations galore.

### Use of Conversations

Conversation is what we need to improve the communication or language skills of a child with deafblindness. It can be defined as a dialogue between two partners consisting of multiple turns that are balanced between partners around topics of shared interest. Most of the times we think of using words to fill our turns in a conversation, but we can also use actions, objects, facial expressions, and movements as our response during a conversation. The shrug of our shoulders, waving our arms in response to a question or handing an object to someone are nonverbal strategies that every hearing and sighted person uses. Conversation differs from other types of communicative interactions because the focus is on interaction around a shared topic, rather than communicating concrete needs or wants, instructing or following instructions.

### How conversation has helped Shazia

- We noticed that she had much to tell us and all around her made the best attempt to understand what she wanted to say. We supported in all her efforts to converse and soon we took the help of objects, pictures and short sentences to support her gestures and body language which formed a base for literacy. Towards this end we began to introduce simple news items that began by writing the date, day and month everyday. By doing this she learnt that dates change everyday but the month remains the same for sometime and the year takes longer to change. We also introduced weather in the news along with pictures and encouraged her to take turns to change the date and mark the weather on the teacher made calendar. The mutual respect for each other during conversation led Shazia to repose faith in all the persons in the Unit as well as people at home.
- Conversation helped her to get emotional comfort. Even as a little girl she realized that she had some one who would listen to her. She was able to make her ideas known through her art. She used a lot of drawing to express herself. She began of narrating stories based on her drawings. One of them was her experience at the swimming pool where she pushed her younger sister into the water. Shazia also has a great deal of imagination and expressed it through her drawings- her picture of a person lying on the floor and a lot of stick figures standing around with bent heads. This she interpreted as the funeral of her granduncle who had died. Another example of her imaginative capacity was her picture of the Sun smiling after the rain.
- Earlier it appeared that as a young child Shazia had no topic that interested her. However, we found that the weather was of great interest to her especially when the Sun played peek-a-boo amidst the clouds. Tuning into her interest

helped us to have successful interactions at that moment and also enabled us to catch her attention at future moments when we had something significant to teach or present.

As Shazia acquired more and more language, she began to find topics of conversation from incidents at home, television, newspapers, and magazines. One day about five years back she surprised us by saying her how fair and pretty she would look in October since she had started using “Fair and Lovely Fairness” cream since September 1st. It was clear that she was talking about an advertisement she had seen on television.

Soon she began to read print and as we provided appropriate access to these materials, there was no looking back. Simultaneously she also began to want to write. As her mother reported, “It is not safe to leave paper and pencil in the vicinity of my child as she wants to write all the time.” We provided this access or she would never have any access to them.

- Taking turns is a necessary skill. Pausing often within a conversational interaction to allow him to take a turn will help make a deafblind child’s linguistic environment more natural and draw her into it as an involved partner. Towards this end, we made use of the morning circle time. This activity had features that are good for teaching children to take turns in conversations.

- Simple repetitive structure.

- Playful atmosphere.

- Clearly marked cues for child response.

- Multiple opportunities for child response.

- Reversible roles.

- Peer Interaction

- Peer tutoring

- Opportunity to use different kinds of language forms like questions, statements, comments etc.

This morning circle time soon paved the way for language work and we started writing what each person had said using speech balloons in an attempt to make the conversation a visualized one.

Shazia: Oh! I have a headache!

Arihant: (touching her forehead) Fever?

Dipti: Poor girl! You must go to bed now.

As days went by conversations grew longer and moved from diverse subjects to more common ones and then there was an opportunity to put the conversation in text form so that more of language work could be carried out like filling in the blanks, checking the correct answers, answering questions and finally sequencing.

- Providing material and appropriate access to language is the most crucial aspect of giving a deafblind child access to the environment. Once conversational interactions are developed, language can become a part of those interactions. If access to language is provided in appropriate modes, during conversation, learning will take place naturally and will be pleasurable to both child and teacher or parent. We acted as eyes and ears for Shazia in order to interpret the language and actions in the environment.

Without a conversational foundation, if at all signs and symbols are learned; they will be done in isolation and will have the quality of trained responses lacking the flow of a genuine language and true communication.

Since conversation and interaction were priorities, Shazia had many opportunities to learn, new words, signs, symbols, and functional living skills. Better conversational skills lead to better overall communication skills that are critical to leading a quality life for individuals with deafblindness.

#### Results :

- Shazia is using her ability to read and write to organize and support memory. She has learnt to write her diary. She can use words like “because”, “so”, “but” etc with ease. She writes all the incidents that have taken place at home; of course she takes the help of her mother and sister when she is at a loss for words.
- She can create and maintain relationships and deal with emotions through language and literacy. She is able to write simple notes e.g. the other day, when I was displeased with her and ignored her for the whole day, she slipped a note in my palm which read, “Dipti is angry. I am sorry, tomorrow, I am good girl”. Though the sentence was not grammatically correct, Shazia had the idea that she can make herself understood by writing.
- She can understand and convey instructions through the use of appropriate language. Shazia is able to follow picture recipes and make omelet, sandwich toast, potato salad, carrot halwa and vermicelli kheer. She can follow instruction to do art and craft activities.
- Entertainment through literacy keeps her occupied in her free time. She enjoys reading children’s books with illustrations. Her favourite is reading rebus stories. She is able to operate the CD player and the computer. She enjoys using the “Paint” option on the computer.
- She can solve problems. She enjoys putting together jigsaw puzzles, solving word puzzles and crosswords when clues are given, putting jumbled stories in order, and unscrambling jumbled words. She also likes solving mathematical problems that involve use of language.
- She is able to acquire and transmit knowledge or information. She knows the correct time for her favourite television programs and can set the reminder for them. She is able to select her favourite program on TATA SKY and is very good at doing the activities on the ACTIVE KIDS channel. She loves to listen to and



watch people talk. The teachers in the Unit always tell her what is going on. If any of us is talking over the telephone, she is curious to know who is on the other side and wants the conversation to be interpreted. She loves to share her secrets with her teacher and whispers in her ears. Though for others it may be mumbo jumbo, for me, Shazia's teacher, it is sweet music. She knows the mobile numbers of her teachers and her relatives and is now learning how to send sms on the mobile.

- She can identify things or places. She is able to locate the appropriate shelves and aisles in a Supermarket to make her purchases, where to buy tickets on the suburban railway station and the ladies room in a public place. She is integrated in Std IV of our Hearing Impaired School for Mathematics, Science and Social Science. Science is her favourite subject and she is particularly interested in lessons related to plants, animals and planets. In fact, she loves going to the planetarium where she finds something new every time.

Shazia has dreams; do you know what they are?

"I want to be an air hostess" she said one day.

But that dream was very short-lived.

"What if I become a teacher like you?" she said to the teacher.

Or "Why not an artist?" She wondered.

"Oh, yes, why not?" she thought, as she looked out of the window at the sun going behind the dark clouds one afternoon.

"Hey look... teacher", she cried.

"Look at those grey clouds, it's going to rain soon", she said.

Hardly had she completed her sentence, there was a heavy downpour.

"You can be meteorologist, can't you!" I said.

"The first deafblind meteorologist", I added, taking her small hand into mine.

Her tight clutch gave me the confidence that her dreams would be fulfilled – Air hostess, Teacher, Artist or Meteorologist – "I want you to help my dreams to be fulfilled, Teacher," she said with stars in her eyes.

"Of course, dear," I reassured her as I knew that she had developed language to a very great extent, but there was much more for her to achieve.

# Deafblind Holiday

## The 12th European Deafblind Week

European Rehabilitation and Cultural Week of The Deafblind 2010

in Tübingen, Germany

(formerly known as the European Deafblind Holidays)

Monday 2nd to Sunday 8th August 2010

Hosted by “the Association of the Deafblind in Baden-Württemberg (Germany)”  
and the “diocese of Rottenburg-Stuttgart – pastoral care for deafblind people”

Dear Friends,

We are able to confirm that the 12th European Deafblind Holiday will be arranged in Germany!

Welcome!

This is a warm invitation to all deafblind people who live in Europe, to participate at the 12th European Rehabilitation and Cultural week of the Deafblind. This week will be arranged in Tübingen, near Stuttgart in the south of Germany.

Where?

“Tübingen is an enticing and dynamic Swabian city of culture! It’s 5 miles southwest of Stuttgart Airport / Trade Fair, with about 90,000 inhabitants and 23,000 students. Since its founding in 1477, the university has shaped the character, formed the appearance and brought life to the Universitaetsstadt Tübingen. The university hospitals not only employ many people but also attract patients and visitors from far and near.”

[www.tuepps.de/tuebingen-english.htm](http://www.tuepps.de/tuebingen-english.htm)

Participation

The participation fee amounts to 450 Euros per person. It includes accommodation, full board and activities.

It is possible to apply for financial support to participate at the European Deafblind Holiday. The maximum amount of money individual participations can apply for is 100 Euro.

More information concerning the programme for this week, registration, accommodation and transport will be given in October 2009

Please contact

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## **Ghana commits to supporting deafblind children in inclusive education...**

**Nina Akuorkor tells us more about getting this programme off the ground...**

### **Background**

Over the years the education of persons with disability had been in a segregated residential school. This group of children and young people have places in residential special schools to pursue education and training. In this 21st century the new trend in the education and training of persons with disability is an integrated/ inclusive place alongside their “able” peers.

In view of this new trend an integration programme for two deafblind students is continuing at the School for the Blind, Akropong Akuapem in Ghana, and you have read about this before in a previous issue. The integration programme involves Sylvia Peprah and Asante Boateng who are both totally deaf blind.

### **Sylvia and Asante**

Sylvia was born on the 28th September, 1988 so she is 20 years old. Information from her parents said that she was 8 years when she became seriously sick and was admitted to one of the country’s hospitals for some months. Upon recovery she became deafblind but has some speech. She communicates using speech, sign language as well as Braille. She came to the centre in 2001 at the age of 13 years.

Asante Boateng was born on 11th July 1990. He is a congenitally deafblind boy. He came to the centre in 1995 when he was 5 years.

### **How the programme started**

The integration programme for Sylvia and Asante came about through the initiative of the team from Perkins School for the Blind. Since 2003, they have come to Ghana to train staff at the centre, and three teachers have been sponsored by them to have training at Perkins School for the Blind.

In 2006, when the leader of the team, Martha Majors knowing the academic potential in these students, had a discussion with the headmistress of the entire school, head of the centre for deafblind children/youth, as well as the teachers of the two students, about an integration programme.

Fortunately, the headmaster at time, Mr. Ashiable from the School for the Blind (Akropong) agreed that these two students could be integrated in his school and when the new headmaster, Mr. Annor, arrived he appointed a coordinator in the person of Mr. Tetteh from his school to see to the successful running of the programme.

### **About the young people**

In January 2007 Sylvia started in Primary 6 and she is now in Junior High 2. She takes subjects like Mathematics, English, Social Studies and some Science. In addition to these she attends the library, takes physical education and socializes with her class peers. Sylvia's teacher is Kafui Kom.

Asante Boateng started in Primary 2 and now in Primary 4. He takes subjects like English, Mathematics and Environmental Studies. He joins his classmates in physical education, and going to the library. His teacher is Trudy Segbefia.

The achievements from the programme

- their social interaction is increasing all the time
- their peers, who are blind, are learning sign language so that they can communicate with them effectively
- some teachers at the school are learning signing as well
- most teachers and students are beginning to realize the potential of the deafblind students.
- in respect of Sylvia, she has improved in writing and reading Braille, as well as the efficient use of her residual speech

The challenges of the programme

Travel

The students have to travel to the school every Monday and Wednesday by private transport if the taxi fails to pick them up. This is a problem as paying on the spot for such a service is high.

Speed of learning

Due to their disability, the children are a bit slow in receiving and learning, hence there is a delay in completing the syllabus.

Campus Integration.

There is also a programme of on-campus integration for some of the students who are deafblind but have residual vision. The deafblind children taking this programme are Sharon Afrakumah, Martha, Joe and Michael.

The idea for this on-campus is to enhance students social skills through interaction and increase their functional academic work along side their peers in the deaf programme.

Finally I would like to thank our friends from Perkins for their tremendous support, the Headteacher and teachers for the School for the Blind for their professional commitment.

Contact: [mamaakuorkor@yahoo.com](mailto:mamaakuorkor@yahoo.com)

## **Voelen means “feel” – an evocative film from a young Dutch film maker...**

Stephane Kaas is studying film at the film academy in Amsterdam. He has made a moving and evocative short documentary starring a young deafblind woman. In the film Leonie, a calm and clever young woman describes and discusses her life and her special interest – cows!

We watch Leonie as she takes her life day by day – she is a creative young craftswoman.

It's a wonderful collaboration between the film maker and the subject – have a look!

View it on the internet at this address:

<http://vimeo.com/2132575?pg=embed&sec=>

or on Stephane's website: <http://www.stephanekaas.com/films/voelen.htm>

## **Children at the Deafblind Unit at the Dayadan Orphanage, Kolkata**

**Rodney Clark writes about a recent visit he made to India with Ann Barnett, former CEO of Deafblind UK. He met his old friend and Dbl stalwart Beroz Vacha and made a number of visits, including one to the deafblind unit in one of Mother Theresa's orphanages.**

“This unit was established in 2006 with a grant from Sense International India with funds provided by the Tata Trust. The grant continues until 2011. This project is managed by Dr Ruma Chatterjee, a history lecturer at Kolkata University, in her capacity as a volunteer with the Kolkata Society for the Visually Handicapped, SII's partner.

The orphanage is one of the 20 or so run by the Missionaries of Charity, the order of nuns led until her death in 1997 by Mother Theresa. All the children that live here are street orphans, normally brought by police or locals. Orphans who have an extended family are not accepted. The sisters care well for the children but needed some convincing that those who now attend the unit could possibly benefit from education. Having seen the progress that they have made in a very short time they are more than convinced and are committed to ensuring the children's continued education.

The unit is housed in somewhat cramped accommodation within the orphanage and it is hoped that more space will become available soon. There are 11 children who are taught by 6 trained teachers and one assistant, who is, in fact, the sister of Pradeep Sinha, one of the deafblind workers at the Braille Press at the Helen Keller Institute in Mumbai. At present, resources only allow the school to operate on 3 days a week, but it is hoped to extend this soon, also to include some evenings. Outside these three days, the children receive little in the way of education, and the next step is to involve the sisters and the many overseas volunteers in their programmes, although this will take some delicate negotiation. Another difficulty is that when the children reach a certain age, they must transfer to another institution where it will be almost impossible to continue their programmes.

As can be seen from the picture, the children work with their teacher on a 2 to 1 basis at specially built small tables, with one educator able to work one to one with a child when a full complement of staff is present.”

## **Inclusion on the horizon for deafblind children in India**

### **Akhil Paul reports significant policy developments in India...**

Sense International India's role as an advocate for the rights of deafblind people got a boost with the support from this project as we have reached a strategic alignment with the Government of India in their flagship Elementary Education programme- Sarva Shiksha Abhiyaan (SSA), Our consultations have resulted in inclusion of deafblind children in its mandate. State level resource teachers of SSA and Integrated Education Department, faculty members, Area Convenors and Programme Officers of SSA and District Institute of Education and Training (DIET) etc. across the country are trained on deafblindness. This will ensure a cadre of trained teachers at the community and institutional settings for supporting education of deafblind children. The inclusion of deafblindness in State Disability Policy of Chhattisgarh and Bihar state has been facilitated. Meghalaya, Himachal Pradesh and Kerala are now being perused on similar lines. With the support of European commission, Sense International (India) along with four RLCs, have facilitated constructive dialogue between deafblind persons, their families, educators and the local authorities for a greater mutual understanding and solutions.

As a step forward in the same direction the first ever National Conference on Deafblindness was held in New Delhi in January 2009, which was Sponsored by the European Commission and supported by Hilton/Perkins International Program (USA) and the Rehabilitation Council of India. Sense International

(India) joined hands with the National Institute for Empowerment of Persons with Multiple Disabilities (NIEPMD), Ministry of Social Justice and Empowerment, Govt. of India. Mrs. Anne Marchal, Head of Development Cooperation, Delegation of the European Commission to India, Bhutan and Nepal, inaugurated the conference and was joined by Dr. Shantikarn, Regional Director-DPR, WHO–SEARO and Maj. Gen. (Retd) Ian Cardozo, Chairperson, Rehabilitation Council of India. The Keynote address was given by Mr. Rodney Clarke OBE and the conference focused on the theme “from Isolation to Inclusion” for people with deafblindness. The highlights of the conference were book releases, distinguished service awards, and constructive discussions.

About 265 participants, including development practitioners, policy makers, researchers, family members, educators, experts from related fields and deafblind persons themselves discussed the challenges in inclusion and shared experiences to bring deafblind persons in the mainstream. The participants stressed upon designing strategies for developing best practices and systematic follow-up for the inclusion of deafblindness in the disability policy and legislation of the country. Some of the key issues that emerged during the three day conference included: the need for a proper system of certification of Deafblindness/MSI; better access to Information Communication Technology, Rural development programs and increased collaboration between NGO’s to avoid duplication. Overall, the conference served the purpose of cumulative introspection on the progress made till date and also helped define the path ahead. Over the past few years a solid foundation has been laid for the inclusion of deafblind persons in the society as equal partners and we are hopeful that there will be a life of dignity and opportunity for deafblind children.

## **Mental Health Special Interest Group**

**Supported by the European Society for Mental Health and Deafness and the Roberto Wirth Fund**

The Roberto Wirth Fund

The Roberto Wirth Fund is a non-profit association that is dedicated to supporting deaf and deafblind children, and their families.

The association focuses in particular on children from birth to six years and works with programmes that promote an adequate cognitive, affective/emotional, social, linguistic and communicative development that allows children to fully express their personality.

Why we work with deaf and deafblind children

Many deaf and deafblind children in Italy do not receive adequate support during their development. Unfortunately, services, programmes and professionals do not fully respond to their particular needs from birth to diagnosis, and during rehabilitation or habilitation until they attend school. Such deficiencies can affect the process of development and may prevent children from attaining the best quality of life.

Families are often unprepared when they have a deaf or deafblind child, and can be disoriented in choosing the best response to their child's needs.

#### Our activities

- Give support to families.
- Develop programmes.
- Create projects in the field of education, art and sport.
- Provide study scholarships.
- Organise seminars, workshops and conferences on deaf and deafblind themes.
- Carry out research and produce educational materials and information resources.

#### European Society for Mental Health and Deafness

ESMHD is an international Non-Government Organisation for the promotion of the positive mental health of deaf people in Europe.

Mental health includes healthy emotional, psychological and social development, the prevention and treatment of mental illness and other disorders. ESMHD focuses on people, who were born deaf or deafness occurred in early childhood and whose first or preferred language is sign language.

The ESMHD is interested in the mental health of all deaf people, whatever the age of onset or degree of deafness.

#### ESMHD Background

ESMHD was established by a group of concerned people from four European countries in 1986. ESMHD now has representatives from most European Union Countries and some from wider Europe.

Links exist with the European Union of the Deaf, European Regional Council of the World Federation for Mental Health, World Federation of the Deaf Commission on Mental Health, and the European Regional Office of the World Health Organisation.

#### ESMHD Issues

Since the formation of ESMHD new mental health services for deaf people have been established and existing ones expanded and developed.



In spite of progress, the majority of deaf Europeans do not have equal access to mental health services at all levels. In too many countries there is still limited, or no specialist professional expertise in the mental health needs of deaf people. There are significant mental health implications for all that suffer from discrimination and restricted opportunities.

Deaf people have a significant additional challenge, as their language is different from that of their family and most others in their country of origin.

### ESMHD Activities

ESMHD convenes an International Congress every three years and more frequent smaller thematic seminars, workshops and exchanges on current topics. ESMHD promotes networking and the exchanges of personnel and expertise between countries.

### ESMHD Aims

- Mental health practice appropriate to deaf people's needs;
- Access to specialised mental health services for deaf people with mental health problems;
- Specialised habilitation and/or rehabilitation or maintenance of life skills;
- Research into mental health and deafness;
- Opportunities for deaf people to provide the mental health services for other deaf people;
- Networks of interested people in each country;
- Information collection and dissemination;
- Respect for deaf people's language and culture;
- Exchange of ideas.

### ESMHD and Roberto Wirth Fund Special Interest Group

15 – 19 April 2009 Rome

This year's SIG meeting was co-hosted with the Roberto Wirth Fund in Rome. One hundred professionals come from 25 different countries working in the field of deafness and mental health discussed research, developments and services. It provided an opportunity for professionals to meet and share knowledge and experience with each other. This was achieved through special interest groups, where people could present case histories, present research findings and share information about practices and interventions.

Attendees developed new areas that need to be researched in the future to better services for deaf people and their families.

## **Information – taking on the recommendations of the strategic plan**

Providing good opportunities to communicate easily with each other and a top class information function is the key to achieving our strategic aims. So, a small group of information specialist staff from our member organisations met to consider how we can begin to take this forward.

In the meeting we discussed the issues: improving our website, “e” communication for networking and accessibility for non-English language speakers.

An excellent, informed discussion led us to recommend that we develop our website significantly, so it has the potential to provide a “first choice” address for information about deafblindness, as well being able to act as an effective membership hub for our Dbl activities, including the Secretariat and Networks. The group’s suggestions for an improved website will provide the framework for a specification for a new site.

It will be an exciting time for the Information Officer and team to support this initiative and to make sure our systems can support our other activities too!

## **How to make strategic planning fun and win chocolates or whisky!**

**The offer comes from... Gill Morbey**

I am the Dbl co-ordinator for the strategic plan and I know that having read those first few words most of you have moved on to the many more interesting topics in this review. In which case you are unlikely to win the whisky, only by reading this short piece will you find the answers.

So please read on and support those people in Dbl that despite their busy schedules continue to give time to important aspects of our organisation. I think it’s fine not to know all the details of our strategic plan but we should be engaged with the general direction of travel. I know many of you are working on various aspects of the strategy and I know how much you value contributions from the wider membership. It’s really helpful, everyone has something to say.

The new Strategic plan, agreed in Perth in 2007, developed recommendations in 7 areas:

- Members
- Networks
- Information
- Staff Development
- Advocacy

- Organisation
- Finances

The Council then prioritised these areas and the focus of the three strategic planning groups is currently Advocacy led by Ricard Lopez, Networks led by Ges Roulstone and Membership led by Eberhard Fuchs.

This is not to say that there isn't important strategic work going on outside these areas because there is. Ton Visser has been working on our constitution as part of the registration of Dbl and for the audited accounts, work is ongoing on UN recognition and membership is being encouraged by some simple marketing tools like the membership cards and pins Bernadette has organised and the secretariat has done a lot of work in sorting out the data base. Eileen and her group have also been meeting on information and there is a separate report on progress here.

The current 3 strategic groups are all working towards reporting back to the Council in Senigallia in September. The Membership group is keen to find creative ways of engaging with people and to ensure there is a growing sense of 'ownership' of Dbl.

The Network group are considering a number of areas and amongst these is the wish to support creative people while at the same time recognising that if things are done under the Dbl 'banner' we can probably agree that some standards are reasonable.

The Advocacy group asked for assistance in gathering information about the situation of the "Advocacy of people with deafblindness", and sent out a questionnaire to be returned in May.

It will be great to get all this information pulled together in September and no doubt there will be more debate. One thing we are all agreed on is our wish to make the plan a 'living' document so it's fine if our thoughts change. We will build in reviews and room 'to make mistakes' as it's ok not to get everything right first time.

Gill Morbey

If you would like more information or wish to contribute on any aspect of the strategic plan contact.

gmorbey@sensescotland.org.uk

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Now win a box of chocolates or a bottle of whisky:

Questions

How many key areas does the strategic plan identify?

Who is the lead person for the advocacy group?

Who has organised membership cards and pins?

The winner will be announced in September.

## **Secretariat**

The Secretariat in Australia has enjoyed the transition period of taking over responsibility for the Dbl Secretariat and we now feel well at home in this role. We greatly appreciate the support of ManCom, Council and Members and look forward to continuing this positive relationship and making real progress for Dbl.

### **Dbl 7th European Conference 2009**

With the Dbl 7th European Conference 2009 approaching we have enjoyed supporting the conference hosts by sending regular email announcements to members far and wide to encourage participation in what is sure to be a wonderful event.

### **Dbl Membership**

If you renewed your membership this year you will have received the Dbl Welcome Pack. This year we introduced a Membership Certificate for Corporate members and a Membership Card for Individual members to acknowledge your membership status and provide an easy reference of your membership expiry so you can keep track of it in the future. Also in the welcome pack was a promotion CD containing images and information we encourage you to circulate to friends and colleagues to help raise awareness for Dbl and the communities and networks we support.

If you haven't already renewed or would like an update on the status of your membership please contact the Secretariat on [secretariat@deafblindinternational.org](mailto:secretariat@deafblindinternational.org).

### **Dbl Management Committee**

In February this year the Dbl ManCom met in Osimo, Italy. We would like to take this opportunity to sincerely thank Lega del Filo d'Oro for being a most gracious host.

We pass on our sincere gratitude to all the staff at Lega del Filo d'Oro for their wonderful hospitality. The generosity of the organization was recognised and greatly valued.

## Extraordinary General Assembly

We recently wrote to members to inform about the forthcoming Extraordinary General Assembly. The purpose of this Extraordinary General Assembly is to ratify the new Dbl Constitution. The General Assembly will take place in Senigallia, Italy during the week of the 7th European Conference, 22 – 27 September 2009. An exact date, time and venue will be announced in the coming months, however with this announcement we wished to provide members with ample notice to make arrangements for their attendance if they wish to be a part of this event.

## Member News

The Secretariat is always very pleased to learn about the work and events our members are involved with and we encourage you to keep in contact and tell us your news. Where appropriate we are happy to help spread the word for you via the Dbl website. It's wonderful to have up to date news posted on the website for everyone, the general public and members alike, to share in and support. We can grow and strengthen as an organization if we support each others ventures and encourage networking between likeminded individuals and organizations. We hope to meet you all in Senigallia in September and look forward to continued correspondence for the remainder of this year and beyond.

Best wishes,

Elvira Edwards and Bronte Pyett

Dbl Secretariat

Dbl is a vital network for all involved in the field of deafblindness. In order to best serve our members, it is crucial that we raise sufficient funds through fees to finance our basic activities. With this in mind, there is a Corporate as well as an Individual membership form for you to fill in. Please encourage as many people as possible to join.

Non-Voting Members consist of individuals, national networks and non-subscribing Corporates. Non-voting members can contribute to the decision making process of Dbl through either a corporate member or an international network. Non-voting members will receive a copy of Dbl Review and other relevant Dbl information.

Non-voting membership costs £ 30 a year or a discounted £100 for four years.

Voting Members are the representatives of corporate members who have paid their subscription fees, and the representatives of recognised Dbl networks.

There are now three tiers of Corporate Membership:

Large Corporates: Annual Fees between £3,000 and £ 5,000

Small Corporates: Annual Fees between £ 300 and £ 1,500

Mini Corporates: Annual Fees between £ 100 and £ 250  
Corporate Members can be nominated to sit on the Council.

#### Deafblind International Individual Membership

- I would like to join Dbl as an individual member  
 I would like to renew my Dbl 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 Dbl members for Dbl purposes but will not be made available for commercial purposes.

Dbl Review (please check one box in each category)

A. I would prefer to receive Dbl Review in:

- English

B. I would prefer to receive Dbl Review on:  paper  disk\*

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

Membership Fee please tick where appropriate

I wish to pay an annual membership fee of £ 30

I wish to pay for 4 years' membership at the discounted rate of £ 100

Please waive my membership fee as I am unable to pay it at present. Please contact me.

#### Corporate Membership

There are three tiers of Corporate Membership:

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

Small corporates Annual fees between € 300 and € 1,500

Mini corporates Annual fees between € 100 and € 250

We would like to join Dbl as a Large / Small / Mini  
Corporate Member (please delete as appropriate)

We submit an annual fee of €

Corporate members are entitled to receive 25 / 10 / 5 copies of Dbl Review. We  
would like- \_\_\_\_\_ copies in n English

(delete as appropriate)

Member Details:

Organisation

Representative

Address (Line 1)

Address (Line 2)

Town/City State/County

Zip/Post Code Country

Tel:

(please include country & area codes)

Fax:

(please include country & area codes)

Email:

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. However, if it is really not possible for you to pay by  
bank transfer and you do have to pay by cheque or credit card, maybe you could  
do so for four years instead of just the one.

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)

B) Payment by Credit Card

Card type:  VISA  American Express  Mastercard

Card no:

Expiry date                      Name on card:

Please note that credit card payments are made to Sense who then credit Dbl.

C) Payment by cheque

If paying by cheque, please make cheques payable to 'Deafblind International' and send to the address given below. If paying by Eurocheque, please make out cheque in euros.

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

Dbl Secretariat, PO Box 143, Burswood WA 6100, Australia

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