

Widening Horizons

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: “Exploring”... a student from
Les Hauts Bregille, Besançon.

A message from the president

It seems just like yesterday that many of us were in Presov, Slovakia at the European Conference. This extremely successful event brought many people together from many countries including a strong representation from Central and Eastern Europe. A large number of people put in many hours of work, both in the preparation and during the conference itself, to make it work so well. I would like to add my personal gratitude to local and scientific planning committee members, speakers and stream leaders and the invaluable work of our “orange angels”, who as volunteers, delighted and supported us so well. I must also express gratitude to Richard Hawkes, who joined the local planning committee to support them to achieve their dream. The conference proceedings will soon be completed and distributed.

Prior and during the conference the Management Committee and the Council met to discuss the issues currently affecting the development of our organisation and our future goals. As a result the Management Committee will be undertaking some strategic planning to take account of these discussions. It will look at mechanisms to involve members as fully as possible in the process. Once we have met in January, at the Asian Conference in Dhaka, it will be possible to let you know more about the process.

It has been an extremely busy period since Slovakia but also an exciting one. Meeting professionals, parents and deafblind people from different countries and in particular Greece and Cyprus was a highlight this Autumn. They showed great interest in joining us. I look forward to welcoming them into our organisation as they are preparing their applications as small Corporates and as individual members.

Another opportunity, which will stay in my mind, was the opportunity to attend the well-organised Rubella course at the Nordic Staff Training Centre. Apart from the content and programme, which I found stimulating, I enjoyed meeting colleagues and was delighted to learn that a network may be on the cards. They will be among a number of groups applying for recognition and I know our network co-ordinator is in touch with them for the formal procedure to be fulfilled.

There is really so many things happening or being planned that it is only possible to mention a few of them. The Review reflects our many activities. Deafblind International is growing and we are all aiming to make our activities more encompassing and inclusive. This can only happen thanks to the contribution of people and organisations that support us with their continued membership and by giving time to help us develop. My sincere thanks.

The Council meeting will take place in Kuala Lumpur later in the year at the ICEVI conference. I hope to meet many of you there.

William

Editorial

I think this issue is our largest yet – confirming the hard work and enthusiasm of deafblind members, families and professionals alike to share their ideas on a range of topics. We have a number of well researched articles including material that will extend our knowledge and thinking in both acquired and congenital deafblindness in practical and theoretical ways. A clear and comprehensive article about Usher syndrome, covering the history of the condition, as well as the developments in genetic research up to the present day provides an excellent update. Barbara Miles also inspires us with her thoughts and practice in both observing and using touch when working with children.

We have two reports of different types of service development from Canada – both rich in information and demonstrating that meeting individual needs and involving people in their services is at the heart of their thinking.

We also have some fantastic arts events reported – with the theatre featuring strongly – and another in our series of articles about the importance of aesthetic experience for everyone, including those who are deafblind.

In preparing this issue I have the chance to talk to people I have never spoken to – by email of course – and bring their special stories to a wider audience. Alfia Valiullina, (mother of Elvira) from “Omat” in Ufa in the republic of Bashkiria reports how they moving forward - with help and support from the Usher-Forum (Moscow).

Dbl members are very good a working together!

Seasons Greetings! And keep those articles and stories coming in!

Eileen

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Listening and Talking Hands...

Barbara Miles is a consultant working in the United States and across the world. She is one of the founder members of The DbI Tactile Communication Network

A number of years ago a thought occurred to me which changed – and continues to change – the way I interact with children and adults who are deafblind. The thought went like this:

I, as a seeing, hearing person, use my hands mostly as tools. I use my fingers and thumbs to grasp things, manipulate things and hold things. (I am holding a pen right now and using it to write. The pen, the tool, could be seen as an extension of my hand.)

Many, if not most, children and adults who are deafblind need to use their hands as tools, too, but (and here was the important part of my thought) they need also to use their hands as eyes and ears – as ways of getting information and as a kind of voice – as a primary way of expressing themselves. Many also use their hands as ways to stimulate themselves – they may flap their hands or tap their heads, for example, seeking perhaps to give themselves some of the stimulation they miss through their eyes and ears. (I do similar things in less obvious forms, sometimes tapping my fingers or twisting my hair or playing with a pen.)

Realizing that a person who is deafblind uses their hands for so many reasons, and realizing how important their hands are for them, I now interact differently. One thing I almost always do now when I first meet a child who is deafblind (and also when I begin any interaction) is to notice their hands very carefully. I look to see how they are using their hands at various moments. When are they using their hands like eyes? Like ears? Like tools? Like voice? For self-stimulation? It is not always easy to differentiate these functions of hands as the distinctions may be subtle, but I have found that the more I practice making these distinctions, the better I can relate to a child through the hands.

I may, for example, notice a child reach her flat hand out with sweeping motions, scanning a table in front of her. I see that she is “looking” with her hands, using them as substitutes for her eyes. Moments later I may see her pick up a cup she has found and bring it to her lips – her hands are then acting as tools. Maybe I see her set the cup down and use one finger to trace a texture on the edge of the cup – again she is looking, this time in a very careful way. Perhaps she places her hand flat on the table in front of her to feel the vibrations of heavy footsteps walking by – her hand has become an ear for a moment, feeling the sound. She may then reach toward where she supposes the footsteps to be coming from, in a gesture that seems to say, “Come here!” or “Who is that?” – her hands at that moment became like a voice. If she is left alone for some time, she may begin tapping her head with her fingertips – this might be a way of giving herself stimulation.

Sometimes I cannot differentiate the functions with my eyes alone. Just watching a child touch an object or another person may not let me know whether she is

really “looking” with her hands or whether she is just casually glancing, using her hands for self-stimulation rather than for getting information. If I offer my own hands, however, then I can feel for myself the quality of her touch. My own hands can listen and tell me whether hers are genuinely receptive, or absent-minded, or eagerly expressive. Sometimes when I interact with a child’s hands I close my own eyes for a few moments so that I can better concentrate on my own sense of touch and so I can enter her tactile world for at least a short time. This practice in interacting with the child’s hands, while keeping in mind these various functions of hands, improves my skill in relating.

There are several gestures that I use a great deal during the conversations that my hands have with the hands of a child who is deafblind. One thing I often do is what I have just described – I simply offer my hands to theirs in a receptive way, usually palms-up, under their hands. I have found that children can tell when my own hands are listening to theirs. If my hands are open, flexible, relaxed and alive, the child nearly always responds by either exploring or gesturing or initiating a game. This gesture is equivalent to saying, “I’m here with you, and I’m listening carefully. What do you have to say?” Who doesn’t like to be listened to? When a child initiates a movement game with her hands, I can respond with my own movements, in resonance with hers. We can make a conversation with our hands that can develop over time. We can take turns, we can invent new movements – we can come to know each other’s hands. Often with very young children, or with children who are not yet curious about the world of objects, this is a fine beginning point. It can lead to building a trusting relationship and to a child’s gradual growing interest in the world of objects outside her own body. Another very powerful gesture is what I might call “mutual tactile attention,” which is the tactile equivalent of the pointing gesture so often used with a child who can see. “Look!” says father, “A dog!” And he points to what they are both looking at. This is a crucial step in language development and must be replicated in the tactile mode for a child who is blind or who doesn’t use her vision for getting information.

Mutual tactile attention begins with noticing what a child is paying attention to with her fingertips or hand, and then touching along with her in a way that lets her know that I “see” it too. A relevant story comes from a pre-school classroom where a four-year-old child, who was blind (and could speak), came to school one day and said to her teacher, “Look! I got a new ribbon for my hair!” Her teacher said, “It’s lovely!” The little girl said, “Wait! You didn’t see it yet!” Whereupon the teacher, realizing her mistake, touched the ribbon. Then the teacher said, “Yes. It’s lovely.” Only then did the girl smile. The girl, of course, hadn’t felt the teacher’s hand touch the bow so she thought the teacher hadn’t seen it. [Story from Peg Palmer, BESB, Connecticut, USA.] Satisfactory conversations between sighted people and young blind or deafblind children must initially include mutual tactile attention. I must touch many things along with a child in order for her to know that I have “seen” them.

There must be many experiences of mutual tactile attention in order for language to have a mutual reference. That touch, however, is very delicate and requires much practice on the part of teachers and conversation partners. I must touch

without controlling, and I must be sure that the child knows with her own fingers or body that I “see” the object, too, and that I see the details of the object in the way that the child does. Often this means moving my fingers just alongside a child’s fingers as they scan. Or it can mean putting my fingers just under her last two fingers (not the first ones – they are the ones that get the most information and I don’t want to interfere with their perception) as she moves her whole hand. I have been practicing this skill for twenty years, and I still need to learn its subtleties with each new child I meet. One key I’ve found is to actually become interested in the particular textures and shapes that interest the child. If I only do this as a technique, and not with genuine interest, children can usually tell, and either push me away or lose interest themselves.

Once a child is accustomed to sharing mutual tactile attention with me, and once she is comfortable with my hands as an interesting and responsive part of her tactile world, then I can “name” things we touch together. We can use gestures, signs, speech, pictures, and objects – whatever symbolic modes are most comfortable and accessible for her. Language can become grounded in looking together at the world, just as it is for the sighted child when a father sees his toddler looking at a dog and points, saying, “Dog! Look at the dog!”

I can also invite the child’s hands outward into the world and encourage her sense of exploration. With my hand under the child’s hand, which rests comfortably on mine if I have been patient in making friends with her hands, I can move my hand toward something I want her to touch (“see” with her hand). I can touch and explore the object or person myself, and the child can discover it for herself. If she is uncomfortable, she can pull away, as long as I leave her hand free. My experience over twenty years is that a child, whose hands are respected with careful non-controlling touch, becomes gradually more trusting and curious about the world around her, more expressive with her hands, and stronger as an individual. Our hands, after all, are agents of the self. They are ways of expressing ourselves in the world and for blind and deafblind children they are also crucial ways of knowing the world. Touching together, we can learn together and together we can become respectful of the world’s myriad textures and shapes. Together we can learn to feel more and more the aliveness of everything around us.

But what if a child cannot use her hands?

For a child who has little or no use of her hands, these same principles apply. The difference is that rather than looking to her hands for clues on how she learns about the world, I need to look at her whole body. Perhaps it is with her feet that she learns about things or people. Or perhaps it is with her arms? Or with her face? In each of these instances, I must find a way to make mutual tactile attention by making careful contact with her in a way that will let her know that I “see” what she sees, however she sees it. The individual way of doing this will vary from child to child, as each child knows the world in her unique ways. For each child, the conversation partners need to be continually attentive to these unique ways of learning and continually seek ways to explore the world together with the child.

Reference:

Barbara Miles, "Talking the Language of the Hands to the Hands," DBLink publications, available at www.DBLINK.org

Deafblindness in Quebec city: an evolving issue

Specialised services for deafblind people in Quebec city (in the Province of Quebec, Canada) have been emerging since the 1980s. This article presents a description of this clientele whose characteristics and needs greatly vary. It addresses the impacts of deafblindness on life habits and the psychosocial consequences of this double sensory impairment. The recently revised services offered by the Institut de Réadaptation en Déficience Physique de Québec (IRD PQ) are also presented.

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ver the course of the years and experiences, deaf-blindness has shed its hyphen to become deafblindness. At first glance, this matter seems to be for purely linguistic sake. However, this modification demonstrates the evolution of the reality of deafblindness. Deafblindness has finally been acknowledged as more than the sum of its parts – hearing and eyesight loss. It is a distinct reality, recognized as such since the beginning of the 1990s. The Ministère de la Santé et des Services Sociaux (MSSS – Health and Social Services Minister) became aware of the problems experienced by deafblind people during the hearing impairment meeting held in 1986. Consultative committees began their work in June 1991 and the MSSS granted a development budget to the Institut des Sourds de Charlesbourg (Charlesbourg Institute for the Deaf). This Institute is now merged with the other physical impairment rehabilitation centres of the Quebec City region and is known as known as the Institut de Réadaptation en Déficience Physique de Québec (IRD PQ). It has the remit to set up services for the deafblind population of the Eastern Quebec region (supra-regional mandate). The Deafblind Program is an ultraspecialised rehabilitation program of national caliber that is intended for a clientele of all ages. The prevalence of this double sensory impairment is small (between 3 and 6 individuals out of 100 000), yet it is a problem that is specific and complex.

Defining deafblindness in Quebec city

When people with impairment to the ocular system also have auricular system impairment, they have a condition that is known throughout the world as deafblindness This double sensory impairment (DSI) results in specific disabilities that do not occur among people presenting impairment to only one of these systems. The Deafblindness Program exists to respond to the unique

needs of these users, with the assistance of specialised clinicians, aids, strategies and means that take into account the interaction between the consequences of both impairments on autonomy and social integration. The Deafblind International organization describes deafblindness as a condition combining hearing and eyesight impairments of varying degrees. Two sensory impairments multiply and intensify the effects on one another, thus creating a severe disability that is different and unique. People with deafblindness are unable to use a sensory modality to fully compensate the disabilities resulting from the other modality. Consequently, their service needs are different from those that were developed for people with exclusively visual or auditory disabilities. After having considered the different definitions and taking into consideration the Disability Creation Process conceptual model (DCP, 1998), the definition adopted by the Deafblind program of IRDPQ is the following: "Deafblindness refers to the presence of impairment to both hearing and vision. This combination leads to significant deficits, given that neither of these two senses provide reliable access to information and communication. These problems hinder an individual's learning capabilities throughout his or her development, as well as his or her current ability to accomplish life activities or fulfill social roles".

Admission criteria for the Deafblindness Program (fall 2003)

A person of any age who:

- responds to the general admission criteria of the IRDPQ;
- resides within the Eastern Quebec territory;
- presents both a visual and auditory disability whose origins are situated in the auricular, ocular or nervous system (note that other impairments may be associated with deafblindness);
- has a rehabilitation potential.

Depending on the data contained in the audiological and ophthalmologic reports, admission or orientation towards another resource is made known to the user. In the case where one of the following two conditions is present, the persons are automatically admitted to the program.

This would include:

- a diagnosis of Usher's syndrome, congenital rubella, Refsum or CHARGE (or other syndromes/conditions associated with deafblindness);
- results of visual and auditory assessments conducted by an ophthalmologist and an otorhinolaryngologist, as well as responses to visual and auditory stimuli of the environment that are inconsistent. Impairment to the auricular, visual or neurological system must be medically diagnosed in all cases.

Referral procedure

- The user forwards his or her request him/herself or via a healthcare institution to the IRDPQ liaison office (registration form to be filled out);
- The referring agency or user must also forward to the liaison office :
 - An oculo-visual assessment (less than one year old);
 - An audiogram (less than one year old).

The variability of individual characteristics associated with the impairments and disabilities

To date, there are more than 150 causes of deafblindness that have been identified. Table 1 indicates the most often mentioned causes of deafblindness according to the “Centre de Ressources Expérimental pour enfants et adultes Sourds-Aveugles et sourds-Malvoyants” (CRESAM).

Depending on the cause, there are multiple combinations of impairments to the ocular and auricular systems. Moreover, these conditions are often associated with other impairments of varying degrees. Disabilities resulting from impairments specific to deafblindness (decrease in auditory acuity and discrimination, decrease in visual acuity, etc.) and age at which these impairments occurred are additional personal factors that play a fundamental role in the portraits of individuals with deafblindness. It has been possible to identify several distinct profiles responding to the Deafblindness Program’s admissibility criteria. These profiles resemble each other in terms of their diagnoses and disabilities, but each individual profile calls for compensatory and professional services specific to the life conditions and the multiple and variable handicap situations experienced, according to the individual’s environmental context.

The profiles can be classified into one of the following 4 categories:

- People with congenital deafblindness (or present before the age of two years). Congenital rubella and Refsum syndromes are examples from a list of around 150 hereditary metabolic diseases.
- People with a congenital hearing disability to which is added an eyesight disability that has appeared after two years of age. Usher syndrome, for which 11 genetically different types have been identified (Lorenz, Preising, 2002), is the main cause.
- People with a congenital eyesight disability to which is added a hearing disability that appeared after two years of age (i.e. diabetic retinopathy associated with occupational deafness).
- People with acquired hearing and eyesight disabilities. The most common combination of causes is presbycusis and macular degeneration.

Description of the Deafblindness Program’s clientele

Figures 1, 2 and 3 describe the clientele’s sociodemographic data as of June 2004. It is comprised of 323 users, among which 64 % (n=207) are women.

The consequences of deafblindness: life habits and psychosocial aspects

Our eyes and ears represent our windows on the world. With these two preferred learning paths, sensory information is continuously transmitted to our brain to help us construct our representation of reality. Each minute of our life, we receive a phenomenal quantity of information that is precious to our functioning.

Deafblind people must learn to live with a significant privation of this information. Therefore, the simplest activities of daily life become a challenge for them and require several adaptations. If the environment is familiar to them and they can exert a certain control over the environment, they can live within it with ease.

However, in unfamiliar places or when faced with unexpected changes and events, they may feel their environment to be an unpredictable and threatening place.

For example, they may be caught off guard by a person who suddenly addresses them and whose presence was, until then, unknown to them; even more so if they cannot recognize his or her face or voice. For several people, withdrawal may become a refuge from such numerous difficulties. When the person presents severe sensory losses (profound blindness and deafness) and when others in the environment cannot present the world in a comprehensible manner through communication strategies, orientation and mobility techniques, and environmental adaptations, the challenge is insurmountable. Deafblindness may lead to severe isolation and the development of cognitive, emotional and behavioural problems. In order to prevent these consequences, early intervention among this clientele and their living environment is essential.

Deafblindness is a complex reality due to the combination of multiple factors. Here, we present an overall description of three main program user groups who receive specific programming because of their special characteristics and needs.

1) Users with congenital deafblindness

This category is mainly comprised of children with multiple impairments that require the collaboration of interdisciplinary teams. Intervention by a third party is necessary to enable the child to perceive stimuli at a distance, which is normally possible through hearing and vision. This intervention favours understanding of oneself and his or her world through a stable routine. It promotes the learning of human relations and language, prerequisite conditions to a minimum of independence and control. Early identification of children with deafblindness is essential to effectively and efficiently respond to their unique needs with regards to learning, and to ensure actualisation of their developmental potential. Intervention among this clientele must be creative, developmental and transdisciplinary. Specialised assessment is conducted by different professionals who work together to identify the best means of communicating and to elaborate a stimulation program favoring the child's overall development. The focus is placed on the users' strengths and involves family and program clinicians in the process of creating an intervention plan.

2) Users with Usher syndrome

Among adolescents and adults, the most frequent diagnosis associated with deafblindness is Usher syndrome (ref. : dossier Surdicécité). Although the literature has identified 11 different types, we will present the three most common. Among deaf signing persons (Usher's syndrome type I), blindness represents a serious threat to their autonomy as communication and adjustment to the world of hearing people has rested, since childhood, on their visual abilities. For hard of hearing people (Usher syndrome type II), they can count on, at least in part, their hearing abilities to compensate their loss of vision. However, even if their hearing level remains stable, gradual vision losses will have an impact on communication and the accomplishment of life habits. Type III is

distinguished from types I and II by a later appearance of deafness (postlinguistic) and pigmentary retinitis.

In terms of adjustment, it is particularly demanding for the persons with Usher syndrome because at each life stage, the person will have to adapt to the presence of gradually evolving sensory limitations. After having lived since childhood, with deafness and its resulting disabilities, they are faced with new challenges to overcome as their visual abilities decrease (moving away from home to independence, school to working world, becoming parent...). At each pre-diagnostic stage, a person with this syndrome will gradually become aware of difficulties without being able to clearly identify the cause. Several know that something is not right and will begin to isolate themselves before the diagnosis: "I was always a clumsy and awkward person. I noticed that I was clumsy more and more often. I hesitated to go out in the evening and I had several cycling accidents. At the beginning, I thought it was just stress, but I finally had a vision test..." The following elements are indicators justifying referral for a vision test:

- the person does not always seem to perceive you or ignores you when you are close to him or her;
- he or she is indisposed by backlight and complains of glare;
- has a tendency to trip over objects, has difficulty moving around in dark places, and has an uncertain gait.

It is recognised that the earlier intervention begins, better the general adaptation of the user and his or her family. As such, beyond transitional periods, information, increasing awareness, psychological support and interventions targeting adjustment are necessary. This helps to decrease ignorance, resistance to changes by certain users or their social network, denial, or parental overprotection as soon as the diagnosis is made. Furthermore, as adolescence or early adulthood is a critical adaptation period and that this diagnosis may represent the loss of all hopes of accomplishment, the offer psychological support is recommended to favour adjustment and to be vigilant in order to detect people presenting suicidal risk.

As such, given the evolving nature of the pathology, rehabilitation interventions focus on regular and rigorous monitoring by clinicians of the interdisciplinary team. It aims to support the user in becoming aware of changes in their abilities and limitations, and of the impact of these changes on their functioning. This step is crucial in order to orient towards the search for what best suits him or her and to succeed in gradually adjusting to his or her situation.

3) Users with an acquired double sensory impairment

Due to the high prevalence of vision and hearing losses with age, this is the group with the greatest number of users. Because these losses progressively increase, the problem is not often recognized by the person. Changes in behaviour that are indicators of sensory losses may be falsely attributed to cognitive decline or emotional problems. This is even more so the case among elderly people as it is assumed that their abilities are declining. The following are indicators justifying referral for a hearing or eyesight test:

- a person who seems confused;

- a person who does not recognize familiar people;
- a person who has difficulty finding or locating small objects;
- a person who does not appropriately respond to questions;
- A person who seems disoriented.

The most frequent deafblindness diagnosis is a combination of macular degeneration and presbycusis. These people often have several other health problems related to aging. The complexity of dealing with the reality of two acquired impairments at an age where adjustment capabilities have decreased represents a particular challenge. It is important to carefully target priority intervention targets and to collaborate closely with their support network. This might be their family, CLSC clinicians, day centre, home care workers, physicians, worker of an integrated services network for elderly people. Moreover, intervention beginning early on in the appearance of disabilities related to one or the other impairments facilitates adjustment to deafblindness. These interventions enable the person to maintain his or her personal and socio-residential autonomy, as well as significant social links with his or her natural support network.

The IRDPQ's services in relation to its partners

The team is comprised of a chief of service, a clinical coordinator and 10 specialists from different disciplines (vision and hearing impairment specialists integrated into the same team) working as needed in inter and trans-disciplinary way. In order to respond to the complexity of deafblindness, the actions of these clinicians must be integrated with a preoccupation for congruity and completeness. The basic principle of the intervention is also applied to relationships with the users' close relations, the clinicians from other rehabilitation programs and network partners. Our intervention philosophy is essentially based on respect for the characteristics and needs of specific clientele. Despite their severe limitations, the team believes in the potential of each user and his or her capacity to develop at his or her own rhythm. Finally, due to specific problems related to accessing information and communication, the user is often deprived of his or her power to make decisions. Through our actions, we aim to promote free and informed choice and to facilitate self-determination in the accomplishment of rehabilitation activities and in one's daily life.

Deafblindness, even more so than with other disabilities, brings into play the individuals' relationships with family and close relations, as well as their capacity to remain in contact with their environment and to act upon or with the reality surrounding them. We recognise the support role played by family and close relations in the adjustment process and their specific needs with regard to deafblindness. They are essential partners to attaining the intervention objectives. Significant people and intervenor partners are invited to participate in the development of the intervention plan.

Research and development

Because we belong to a health establishment that is recognised that, as a university institute and dedicated to a clientele needing an ultraspecialised approach, we are involved in the process of developing knowledge and know-how. Our services are constantly evolving and propose novel approaches or intervention tools to better respond to the specific needs of people with deafblindness. For example:

- assessment of auditory localisation capabilities (ref: dossier surdicécité);
- development of enlarged hearing prostheses to facilitate teaching users with a vision impairment how to manipulate them;
- development of tool to increase awareness among close relations of people with sensory impairments;
- experimentation of a group therapy focussing life transition among clients with Usher's syndrome type II;
- training and support for intervenors (program managed by the IRDPQ);
- social integration support group for people with acquired deafblindness.

Role of expert council

Clinicians from the Deafblindness Program offer support to various integration environments (CHSLD or intellectual impairment rehabilitation centre clinicians, day centers, workplace, schools, family, friends), They work through interventions within these living environments, as well as tailored information or training, enabling them to adapt their services to the specific needs of people with deafblindness and to decrease the handicapping situations faced by these people.

SUCCESS MADE POSSIBLE THROUGH PARTNERSHIP DEVELOPMENT

We hope that this article has convinced you that deafblindness services cannot be accomplished without the close connections between clinicians of all disciplines and the different collaborators within the user's living environment. For example, ties with the specialised cochlear implant program have been developed to facilitate the rehabilitation process of deafblind people with these implants. Furthermore, collaboration with genetic assessment service of a hospital was created to better inform our shared users and to efficiently orient consultation requests.

We invite all potential partners (regional rehabilitation centres, hospitals, CLSCs, integrated service networks for elderly people with loss of autonomy, etc.) to contact us in order to better identify the complementary services that we could offer. If we consider the user's viewpoint, services would be satisfying if they involve a combined effort, are facilitating (notably through identification of an intervention plan coordinator), complete and appropriately targeted according to each individual's priorities. While this expertise mandate is entrusted to us, it cannot be developed within a vacuum. On the contrary, it can only be accomplished through continuous exchanges focusing on the sharing of knowledge and fruitful experiments conducted in collaboration with outside contributors.

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Whoever you are...whatever you are... the STAGE IS YOURS!!!

This is an account of the Danish theatre project "Breaking the Silent Dark" which was developed for presentation in Slovakia this summer.

Grit Bethelsen sets the scene:

Be aware of the danger – who will get nervous? We are all aware of the risk of inviting ridicule, but we are attracted by the adrenalin buzz, the heat of the spotlight, the sense and "smell" of a large audience and, last but not least, the hilarity and exhaustion of success. Once the curtain rises, we feel at home on the stage, even in Slovakia it is a very new and different experience.

Who Are We?

We are the people behind the performance "Breaking the Silent Dark", which is the result of co-operation between The Deafblind Centre, Årborg and Limfjordsskolen, Løgstør. This co-operation started in 2003 with theoretical discussions concerning aesthetics, and one of the results was that we agreed to do some practical work!

The present theatre group was founded in spring 2004, and comprises 4 born deaf-blind persons, 4 staff members from The Deafblind Centre, functioning as supporters and interpreters, and my colleague and me from Limfjordsskolen. We have skills in instruction and light and sound, and have been offering art and theatre courses since 1989, primarily to disabled adults. We took the challenge even though we didn't have any specific knowledge or experience with deafblind persons. We did not know sign language, but we were willing to communicate, to inspire and be inspired by the deafblind performers and be jointly creative and innovative.

The 4 performers took the challenge too, exceeded limits and accepted that working in the theatre demands concentration, discipline, timing and responsibility. They experienced being a part of a theatre group, where everyone is needed and indispensable. They dared to discover new horizons.

The first performance, “Humans in backlighting”, which toured in Denmark and the Netherlands, opened our eyes and gave us “inside information”, that enhanced the possibility of formulating individual parts in the second performance.

The aim of the theatre group is to ensure that deafblind people become more visible and get the opportunity to contribute to society by generating experimental and symbolic theatre, where individual expression and natural movement form the basic elements. Each part of the play is the result of improvisation and mutual inspiration, during which, the process of production crystallises as “sublimates” of the individual’s resources and abilities.

Although innovation and inspiration are indispensable, all performers must know their part by heart when the play is presented to the public.

Diary of a Theatre Production

The project started at the end of May, and we only had 8 full working days, including a final rehearsal. Normally we have at least 7 weeks to produce a play! We were lucky to know the actors in advance.

Day 1

The sound of 2 wheelchairs reaches us from the long corridor, which leads to the theatre room. The 4 performers are coming. They are energetic and eager to get started, in spite of a one hour tiring bus ride. For the sake of confidence and recognition, we have chosen to use the same backstage as in the previous play which turned out to be a good choice. Heavy eyed, like early risers, the 4 performers immediately start to take shoes and socks off. The “Barefoot Company” has sensed the theatre. But the stage looks strange – a known backstage – an unknown stage, full of corrugated paper, silk scarves and bells! There is a call for the folding rule and we start with common drama exercises and explanation through the interpreters.

Day 2 ..then improvisations – what is going to happen?

This performance is intended for an international deafblind conference at Presov in Slovakia. Before this conference a presentation is planned in a village near Kosice, where a deafblind centre will open next year, but the village inhabitants have neither seen nor met a deafblind person! Having a lot of hard work ahead of us, we are under extreme time pressure, so, in order to preserve the group’s confidence, it might be necessary to re-use, with slight changes, a number of scenes from our last performance. Despite that, we continue experimenting and improvising. Once again we are reminded that theatre demands discipline, which also indicates that toilet visits must be at the arrival and during the breaks. The rules are accepted and it shows very quickly that the “deafblind world” is not necessarily slow. The activity level is very high and everybody is in the right place at the right time. The aim this time is to create more scenes, where the deafblind actors are more independent of support – the ideal is no supporters at all.

On the 3rd day a draft manuscript is prepared. The sequences are structured and a preliminary description of the individual scenes is prepared. During the process, notes are revised according to new input/inspiration from the performers. The group is alert and aware of the challenge – even subtle hints are quickly caught. All possible types of communication are used – parallel acting, rolling on the floor, verbal sign instruction e.g. the folding rule is still a wonder, what is he measuring? The two performers start to communicate and inspire each other. What can be measured?

In a production, where hopefully the performers' capacity for expression is being respectfully expanded, the cumulative life experience of the individual performer determines pace and timing. Is it possible to be "incorrect" in personal expression or movement in connection with drama production?

Finally ...the light and sound

These two techniques enhance the look and expression of the performer and the atmosphere. However, light or sound should never overshadow or kill the sentiments expressed.

Our final rehearsal ...caused blushing cheeks and butterflies in the stomach, and all this nervousness flew along with us to Slovakia! All of a sudden it was Sunday, the day of our performance, and the Priest in the village at Kosice announced our performance during the noon Mass. The theatre hall, an old post office, was crowded in the afternoon heat.

Our first public presentation

From now on is it up to the audience to "measure" – to judge the artistic experience and quality. The result... this audience was moved and touched to tears and all expectations were surpassed.

What are we measuring?

If one of the results of doing this work is frontier-exceeding acceptance and respect for a very fragile group of people in our society, this could be an extraordinary good reason for creating theatre, if not the only one.

The audience measured the performance, but how many meters was the process? The folding rule will tell!

Changing horizons for people with Usher in the 21st century

Clinical and genetic research in Usher syndrome

The eleventh Usher Study Group was held this year in Prešov in Slovakia for two days after the 6th DbI European Conference on Deafblindness.

This article is a summary of the presentations by keynote speaker Dr.

Ronald Pennings from the department of Otorhinolaryngology, Radboud University Medical Centre in Nijmegen, the Netherlands.

Historical perspective of the development of research in Usher syndrome
In the second part of the 19th century, the first reports on hereditary causes of deafness and blindness were published. One of the first pioneers in research into deafness was Sir William Wilde, an Irish otologist. In 1853, about a decade before the introduction of Mendel's laws, William Wilde was the first to describe autosomal dominant inheritance of hearing impairment in Irish families. In 1857, Donders, the famous Dutch ophthalmologist, described the bone spicule formation we now know as retinitis pigmentosa. Alfred Graefe was the first ophthalmologist who noticed the combination of deafness and retinitis pigmentosa in 3 related persons and suspected a hereditary cause. His uncle, the famous ophthalmologist Albrecht von Graefe, described these three cases in his scientific journal in 1858. During the 19th century, the first large studies of populations with hearing impairment were conducted and it was noted that in many cases the hearing impairment was accompanied by other disorders such as ophthalmological diseases, mental retardation, epilepsy and polydactyly. Liebreich, another German ophthalmologist, performed systematic examinations on a large group of 341 deaf inhabitants of Berlin. The proportion of retinitis pigmentosa in this group of deaf persons was high, and remarkably, even higher in consanguineous Jewish families.

At that time, Gregor Johann Mendel, a monk and biologist from Brno who performed studies on pea pod plants, published his "Versuche über Pflanzen-Hybriden", which later became the basis for the establishment of modern genetics. In this work he proposed the principles of heredity and introduced the concept of dominantly and recessively inherited genes to explain how characteristic features can be repressed in one generation, but appear in the next. Although his work already had been published in 1866, it was relatively unappreciated until the beginning of the 20th century.

Arthur Hartmann, a German otologist, was one of the first to describe an indirect (recessive) inheritance pattern of hearing impairment in his book on deaf-mutes published in 1880. A chapter on deafness and blindness again accurately stressed the combination of profound deafness and retinitis pigmentosa and its relation to consanguineous marriages. He also emphasised the difficulties in educating individuals with visual as well as hearing impairment and promoted the oral method for the education of hearing impaired individuals, which at that time was not generally accepted. In 1919, De Wilde was one of the first Dutch doctors who reported on individuals with a combination of hearing impairment and visual impairment in the Netherlands. He concluded that 38 of 167 (22%) Dutch people with retinitis pigmentosa also suffered from hearing impairment; 13 of them had been born in consanguineous marriages.

The syndromal combination of hearing impairment and retinitis pigmentosa was finally named after the Scottish ophthalmologist Charles Howard Usher (1865-

1942). He was born 7 years (!) after the first description of deafness and retinitis pigmentosa in a person and two of his siblings by Albrecht von Graefe. Charles Usher was the fourth son in a prominent Edinburgh family. After studying at Cambridge University he got his medical degree at the St Thomas Hospital in London. He was very dedicated to his work and spent much time on performing extensive family studies, especially in the Highlands of Scotland. Influenced by his mentor Edward Nettleship, an eminent ophthalmologist of that time, he decided to study a population of visually impaired people. The results of these elaborate studies were described in his book entitled "On the inheritance of retinitis pigmentosa, with notes of cases", which was published in 1914. In this book he only briefly mentioned that 19 of 69 people with retinitis pigmentosa to some degree had hearing impairment. After his presentation in 1935 of the Bowman Lecture "On a few hereditary eye affections", in which several families with eye disorders were presented to a large group of scientists, his name became an eponym for the syndromal combination of retinitis pigmentosa and hearing impairment. This is very remarkable, because in his Bowman lecture he did not mention the association of hearing impairment and retinitis pigmentosa. Regarding history, it should have been more appropriate to name the syndrome after Alfred Graefe or after Liebreich.

In the past century, the studies of Usher syndrome were conducted from two clinical perspectives. The studies by Usher, Bell, Nettleship, Von Wibaut and Kjerrumgaard were performed from an ophthalmological perspective, i.e. data on groups of retinitis pigmentosa persons were collected and it was evaluated for how many of them also were hearing impaired. The studies performed from an otological perspective merely focused on the examination of large groups of deaf persons attending schools for the deaf, who in addition had retinitis pigmentosa. In three Scandinavian countries, Norway, Sweden and Denmark, examinations of large groups of deaf individuals were performed on a national scale and two observational studies, by Hallgren in 1959 and Nuutila in 1970, comprised nationwide evaluations of Usher syndrome persons in Sweden and Finland, respectively.

Hallgren was the first to report on the prevalence of Usher syndrome; it was estimated to be about 3 per 100,000 inhabitants. This estimate was based on his study of the Swedish deaf population and on the international literature available at that time. At present, the prevalence of Usher syndrome is estimated to range from 3.5 – 6.2 per 100,000. It accounts for about 3-6 % of the congenital types of deafness, about 18% of the pigmentary retinopathies and over 50% of all persons with deafblindness.

Already in 1922 Julia Bell, one of the first prominent female geneticists, was the first to report on a difference in the degree of hearing impairment in Usher syndrome. She emphasised that there were two groups of persons, one in which hearing impairment was profound and a second one in which the persons suffered from a moderate to severe type of hearing impairment. Hallgren, in 1959, suggested that these two clinical types of Usher syndrome might be caused by two different genes. In his studies, Hallgren also described psychiatric problems in people with Usher syndrome and for some time this was regarded as

a separate type of Usher syndrome, which was referred to as Hallgren syndrome. To date, psychiatric illness is no longer defined as a key feature in any of the known types of Usher syndrome.

Whereas Julia Bell already emphasised the clinical heterogeneity of Usher syndrome in 1922, several other studies also reported on the variability in clinical features. In 1977, this finally led to the original classification described by Davenport and Omenn (Table 1, adjusted to recent findings). Although mental retardation and psychosis at that time were suspected to be part of the syndrome, Davenport and Omenn decided to exclude these features from the classification, because they regarded them to be secondary to the inherent double sensory deprivation.

Usher syndrome, types and subtypes

Usher syndrome is characterised by hearing impairment, retinitis pigmentosa and in some cases vestibular impairment. On the basis of clinical characteristics, it can be divided into three clinical types (Table 1). Usher syndrome type I is characterised by profound congenital deafness, retinitis pigmentosa and an absent vestibular function. Usher syndrome type II is characterised by high-frequency sensorineural hearing impairment, retinitis pigmentosa and an intact vestibular function on testing. Usher syndrome type III is mainly seen in the Scandinavian countries and is rather rare outside these areas. It is known for its progression of hearing impairment which is variable in onset age and degree. In addition, a variable vestibular function and retinitis pigmentosa is seen.

Usher syndrome is an inherited disease that shows autosomal recessive inheritance (Figure 1). This means that the parents of the person with Usher will be carriers of a gene mutation, although they will not experience the disease itself. All DNA is stored in 46 chromosomes (23 pairs) located in the nucleus of all cells. On these chromosomes, 30,000 genes are located. Every gene contains a code to develop a protein that has a specific function in the body. In Usher syndrome, the genes encode proteins that have a specific function in the retina and in the inner ear. When two mutations in the same gene are identified in one person (one from father and one from mother), the genetic code to process a normal protein is disturbed and this leads to dysfunction of the protein that results in hearing impairment and retinitis pigmentosa.

In the past two decades genetic research in Usher syndrome has revealed that Usher syndrome is a heterogeneous disease. At first, it was believed that each type of Usher syndrome was caused by mutations in one specific gene. However, research in the last decade has shown that these three clinical types can be divided into several genetic subtypes (Table 2). Currently, 5 of the 7 genes known to be involved in Usher syndrome type I have been identified. Also, 2 out of 3 genes in Usher syndrome type II and the responsible gene involved in Usher syndrome type III is also known.

Clinical diagnosis in Usher syndrome

To establish a diagnosis of Usher syndrome in a suspected individual, several examinations are necessary to come to a clinical as well as a genetic diagnosis. A multi-disciplinary approach is essential because several professions deal with the various symptoms of Usher syndrome. The otorhinolaryngologist examines hearing and vestibular function. The ophthalmologist examines the visual function and the clinical geneticist gives the individual with Usher syndrome and his family genetic counselling and may arrange genetic analysis when requested. Most persons with Usher syndrome will be born with sensorineural hearing impairment. Later in life the diagnosis of retinitis pigmentosa will be added. Table 3 shows the different types of examinations that can be performed by the different professions in persons recently diagnosed with Usher syndrome. This table does not show a complete overview of all available examinations, however, the most important examinations for establishing the diagnosis are shown. Recently, the Usher syndrome micro-array became available for fast and cost-effective mutation analysis. This is a very important development because through this chip, all currently known mutations in all different Usher syndrome genes can be tested. This way, a genetic diagnosis has become much more accessible for people with Usher syndrome.

Recent developments in genetic and clinical studies

In the past 20 years, knowledge about the genetic causes of Usher syndrome has increased. At that time it was believed that the clinical types of Usher syndrome were all caused by mutations in 1 gene each. Currently, however, already 11 loci and 8 genes have been identified to play a role in the development of Usher syndrome (Table 2).

Recent genetic studies mainly focus on the identification of new genes, on the function of the related proteins and interactions between the proteins. Genetic studies have shown that all currently known Usher syndrome type I proteins interact in the cohesion of the stereocilia on the hair cells of the inner ear. The knowledge of the function of the Usher syndrome proteins is developing rapidly. With increasing knowledge the possibility of a therapeutic approach will be coming nearer, however, currently there still is no cure or therapy available for Usher syndrome. Future therapeutic approaches focus on gene therapy, stem cell therapy and the development of drugs that interact with the underlying pathogenetic mechanism. In addition, retinal implants are being developed in order to achieve similar results for vision as is seen with cochlear implantation in profoundly deaf persons.

Recent clinical studies have analysed the visual and audiometric function of specific genetic subtypes of Usher syndrome. The Nijmegen Usher syndrome studies started at the beginning of the 90's of the previous century under direction of Cor Cremers. Persons with USH1b, USH1d and USH2a mainly have been examined because of high prevalence. Mutation analysis results were established through close collaboration with our own otogenetic laboratory (Hannie Kremer) and the Centre for the Study and Treatment of Usher syndrome (Bill Kimberling, Boys Town National Research Hospital, Omaha, USA). In collaboration with Finnish researchers (Eeva Marja Sankila, Leenamajja

Kleemola), the audiometric and visual characteristics of USH3 persons have been re-examined and these results were compared to those obtained for USH1b and USH2a. The general aim of these studies is to develop some kind of general prognosis of the deterioration of vision and hearing for a specific genetic subtype. This prognosis can be useful for counselling.

1. Hearing impairment studies

Persons with Usher syndrome type I in general are born profoundly deaf and have a disturbed speech language development. These people benefit a lot from cochlear implantation, especially at young age. Hearing impairment in Usher syndrome type II in general is characterised as high-frequency sensorineural hearing impairment that can be treated well with hearing aids. In USH2a, slight progression of hearing impairment can be seen. This is quite comparable to the deterioration of hearing related to presbycusis in normal hearing individuals. However, the progression noticed in the low frequencies is significantly more severe than seen in presbycusis. USH3 is mainly known for its progression of hearing impairment. There is a lot of variation in onset age and degree of impairment, however, in general the hearing impairment is much more progressive and is more severe than is seen in USH2a and may resemble USH2a at young age and USH1b at higher age.

2. Visual impairment studies

In general it is thought that Usher syndrome type I has a more severe visual impairment than Usher syndrome type II. In order to evaluate and compare the visual function between USH1b, USH2a and USH3, a functional vision score was established based on visual acuity and visual field size (according to the American Medical Association Guides for Visual Impairment). Analysis showed that both the visual acuity and visual field size deteriorate in all three genetic subtypes; i.e. Usher syndrome is a progressive retinal disease. No statistical differences could be identified between USH1b and USH2a or USH3, however, there was a statistical significant difference between the functional vision score in USH3 and USH2a. USH3 persons experience an earlier onset of a similar degree of deterioration of visual function when compared to USH2a, i.e. USH3 persons have a similar deterioration of vision that starts at an earlier age when compared to USH2a persons. In these studies also a big difference in visual function was seen within the genetic subtypes itself, unrelated to the type of mutation involved. This variability can even be observed within siblings with the same mutation and environment in which they grow up and so far no explanation can be given for this phenomenon. It therefore remains difficult to give an individually based prognosis of the deterioration of vision. Therefore, only in general terms the deterioration of vision can be described during counselling issues.

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References used for this manuscript are available upon request.

Besançon and the work of Les Hauts de Bregille

Annick Crestin-Billet writes in our series of articles about the development of services for deafblind children in France

In the East of France, Besançon, in Franche-Comté, is a medium-sized town of 140,000 inhabitants. On a hill, near the town centre, “Les Hauts de Bregille” is home from home for 26 multi-disabled children. The ground-floor structure is welcoming and, inside, warm colours play with the light. With wide halls, single bedrooms, 4 boarding units, lively classrooms, educational workshops, re-education rooms... everything has been designed perfectly for children with difficulties. This big house opened in 2000 and belongs to the “Centre Régional d’Education et d’Enseignement Spécialisé pour Déficients Visuels” (The Regional Education and Special Education Centre for Visually Impaired Children) and is managed by the association “Les Salins de Bregille”.

The premises are new, but this service was created in 1978, and some of us were already here on the morning of the first school day, to welcome 8 multi-disabled blind or visually impaired children. It was our first meeting with these very dependent children, but we were inspired, seeking Utopia, and highly motivated to begin this long “story”.

Was it by mere chance that Murielle and her parents arrived first? These parents were exhausted by caring for their little 4 year-old girl. At night, as well as during the day, in spite of being deaf and having only a small amount of vision left, she was standing up on a wardrobe, balancing! Only the rays of the sun seemed to mean something to her, and she was endlessly waving her long and nimble fingers in front of her eyes, forming arabesques. Murielle had already had several operations, including heart and cataract. Now, she was rejecting her hearing-aids and seemed to be lost in a world of sensations – so fragile, but so determined – having no language, but so expressive. Progressively, she appropriated the space near the windows and explored the furniture in order to climb on it. How could we win her over, create links, be allowed to sit closer everyday? How could we make friends?

We looked for help from the deaf world, but the real answers came from Poitiers – Jacques Souriau knew deafblind children so well. Today, “Les Hauts de Bregille” still has a particular affection for children with dual sensory impairment

and our we have 6 children who share daily life and space with other children who have more or less disabling cerebro-motor impairment.

After Murielle, other deafblind children came: Maxime, Patrick, Michael, Elie, Frederic, Alexia, Yohan, Meryem, Manuel, Elodie, Yann. Today, in the “Tangerine Service”, we still have 6 deafblind children who live in the boarding school during the week.

But the team has come a long way together. After the necessary training sessions with Jacques Souriau – our theoretician – we did some research on body dialogue and dance therapy with Dr Benoît Lesage, and, more generally, we worked on sensory stimulation using the Frolich method. Today, our experience has enabled us to use these educational techniques, but with some adjustment. We had to give up on Utopia on the way, but we are still looking for a “tuning”.

So, when I observe how these children live, and while I am thinking before writing these few lines, I feel proud and grateful about this multidisciplinary educational team. I don’t feel any “wearing out”, but I feel an obvious vitality, which is re-activated whenever the smallest skill emerges. Of course, there are periods of doubt and discouragement, there are periods that seem so long, then, suddenly, something just clicks into place... Why? That’s the secret of shared life – spring after the coldness of winter! These youngsters with dual sensory impairment do not use many of the “communication codes” – objects, symbol-objects, miniatures, pictograms, raised lines, Sign Language – but in emergency situations, they all know how to tell us – and show us – that they understand their meaning and usefulness.

Apart from a long process of teaching in “awakening” classes, the teacher’s permanent and creative research results in a “book”. In this book everyone records the story of their life: their life as a baby, a much loved baby, then the child, then to the present teenager, now facing puberty before he becomes a man, like his father.

The importance of daily life experiences that allow for exceptional things to happen is recognised. These children benefit from the dynamics of the Institute, and sometimes they are amazing in unexpected situations. Manuel is roller-skating like Sonia; Meryem likes sledging and roars with laughter in the snow; Catherine goes to another unit during week-ends, but this is no problem because her electric fan is put in a strategic place enabling her to find her bedroom! Sometimes they meet children in electric chairs: they have ignored each other for a long time, then progressively they touched and discovered a child without speech, like them, but who seemed immobile. And Manuel wanted to understand what was Mathieu’s problem, with pencils, paper and pictograms. These deafblind children go out a lot; they take part in every party at the Institute. They like to dress up and dress up their teachers, they invite people in and have days out with the educational team.

Increasingly, and in spite of serious personality disorders with sometimes violent expressive outbursts, they are less and less frightened inside and outside the establishment. They do not hesitate to go out together in the neighbourhood, all six of them. Every Wednesday, in the evening, they are in a structured and

organized service, where they can settle and rest, with their landmarks and rituals. They have the situation under control and they have a smile, an expression of serenity for this known and recognized hand that is offered to them. Manuel, who is sometimes so faraway, will not be a contradiction: in the evening, before dinner, he takes down the 6 young peoples' coats from the coat rack and carefully spreads them on the floor... yes, they are all here... they are back: he can eat in peace.

They are deaf, blind, partially sighted, or hard of hearing, but they exist, no, they live, with a feeling of belonging to the human race, because of this group. They have access to a form of freedom, with the ability to go and "see" what the outside world is like.

As a conclusion, for these young deafblind people, this is a real life project, a life with other people, with positive support.

Light is heard in Zig Zag

"Light is heard in Zig Zag" – a production by Nalaga'at Theatre Company, Israel

Adina Tal, Theatre Director and Actress explains

When Eran Gur, a former business man, and I met and established "Nalaga'at", 3 years ago, we did not believe, even in our wildest dreams, that this article would be written less than 3 weeks after coming back from our third international tour within a little more than a year!

Neither of us had any background with deafblind people and I had never even worked with disabled people but when, by pure coincidence, I began to work with a group of deafblind people I very soon decided that this will not be "just another Drama Class.

At first, making theatre, which is the art of communication between the actors and the audience, with a group of people, for whom communication is their biggest problem, seemed almost impossible. However, we found ways to work together as a group and created a play based on their reality, and their dreams – dreams of being a famous singer, driving a car and just being able to go into a supermarket and see the sell-by date. Many vignettes, some of them sad, some of them with a lot of humour – this is the stuff that "Light is heard in Zig Zag" is made up of.

"Leave me alone, I do not want to see deaf-blind people on stage, I have my own problems"

Yes, this was a very typical reaction when we first started to run the show. But soon it changed. The show was very well received. We got great press and television coverage, played full houses all over Israel – more than 40

performances – with 12 deafblind actors giving the hearing and seeing audience the gift of art.

Next stop:

DBI conference in Mississauga,
Canada 2003

I could not believe my eyes, to meet so many people from so many different countries, all of them working with deafblind people. I was very nervous when I gave a presentation of our work. I made the participants tap on each others' knees so they could get an idea of how we work in our rehearsals, and showed a short video about the group working and performing.

After the presentation Steven Rothstein, President of Perkins School for the Blind approached us and said "you really should bring this show to North America". We thought that this was a great idea.

June 2004

After a month of arduous preparation, the Nalaga'at's North American tour finally became reality. The tour group included 32 people; 12 actors, 12 interpreters, 4 assistants (including light and sound technicians and yoga instructors), 2 cameramen and Eran and myself.

We produced 8 performances in English of "Light is heard in Zig Zag" in Toronto, Montreal, Boston and New York. The shows were all sold out. The high-point of the tour was the performance at the Symphony Space, on off-Broadway, Manhattan (800 seats), with a fifteen minutes standing ovation at the end of the show. After every show the audience met with the actors and a lot of them asked for autographs and souvenirs.

Press was good!

"Today we are celebrating the 100th anniversary of Helen Keller's graduation from University. I am proud to participate in an evening that will be celebrated 100 years hence: a performance of Nalaga'at in the United States"
Steven Rothstein, President of Perkins School for the Blind, Boston.

"Helen Keller had tremendous imagination and foresight, but I don't think even she could have imagined that in 50 years time a deafblind theatre company from Israel would perform in New York with such a great success"

Joe McNulty, Director of the Helen Keller National Center, New York.

The shows received generous coverage in the press, on radio and television. After the first show in Toronto we sat in a local bar and all of a sudden we heard familiar sounds from the huge television. It was a scene from the show in the late night news! The owner of the bar was very proud to have the people from the television in his bar and invited all of us for a nightcap!

In addition to the shows, I gave joint theatre workshops for deafblind Americans with our actors as my assistants. This was an incredible experience and I hope that this was just the beginning.

Back home again

When we came back home to Israel we started to rehearse a new production. As our actors live all over Israel we can only afford one rehearsal a week, so we decided to have a 4-day theatre workshop, to give other artists a chance to work with the group. We worked with musicians and Circus people and they are still working with us on our new production.

Who said that the Swiss are cold and reserved?

I myself was born and grew up in Switzerland, I have lived in Israel for over 30 years now, but still, it seemed natural that Switzerland would be our next stop. It all began with a few meetings with old friends and soon became like a giant snowball and at the end of March 2005 Nalaga'at left for its second international tour, in Switzerland.

March 30 – April 14,
2005 – Tour in Switzerland

The Swiss Premiere was scheduled to take place in the most prestigious theatre in Switzerland – Zurich's Schauspielhaus (750 seats). Again we received a lot of excellent press coverage from the news and visual media. The show was sold out more than a month beforehand and we did 10 performances in 14 days in Zurich, Basel, Bern and Geneva, with one of them at the UN headquarters, and again we had rave reviews:

We performed in German, French and English. We stayed in Flumserberg, a small village in the mountains. In the little free time we had, we enjoyed the late snow and the visit of Swiss deafblind people for a joint workshop. We went snowshoe walking, made cheese and, of course, ate Fondue.

When we left Switzerland we all felt as though we were leaving a lot of new friends, and the official "Swiss friends of Nalaga'at" was founded.

And then New York again!

We actually did not plan another tour, as we wanted to stay at home and work on our new production and on the Centre we are planning to open next year, but we just could not say "no" to an invitation to perform at the Lincoln Center in New York. We would be headlining at the Jewish music and heritage festival and performing on one of the most prestigious stages in the world!

Even now as I write I still find it hard to believe. Shoshana, one of our actors said: "even in a movie things like that do not happen".

Back home

We had a great year, but we also know that this is a Cinderella story. There is so much that should and must be done, so many more deafblind people here in Israel still living in complete silence and darkness. We are working hard to open the Nalaga'at Centre next summer in Jaffo, Tel Aviv, with our new production and a restaurant in the dark. This will be the beginning!

We plan to start a new group of Jewish and Arab deafblind people and hope that many more deafblind people will work at the Centre, focusing on their abilities and not on their disabilities. We believe that Nalaga'at is a message of hope for all deafblind people in the world. We cannot do it alone and we are looking for partners who would like to join us on this journey and who believe, as we do, that there is no limit to human spirit.

The non-profit organisation Nalaga'at (Do-touch), established in Israel in December 2002, has raised the curtain for 12 deafblind people, allowing them to enjoy the most basic of rights: to give. Nalaga'at is staging "Light is heard in Zig Zag", a theatre production performed by deafblind actors who share their dreams and realities with the audience.

Stage Production and Direction: Adina Tal Group Manager: Eran Gur
www.Nalagaat.org.il

Deafblind Programming for a New Era

Susan Manahan shares the ideas and "process for change" management that the Independent Living Residences in Ontario have devised to better meet the needs of deafblind people

For the past 16 years, Independent Living Residences for the Deafblind in Ontario (ILRDBO) has been providing community-based housing, trained Intervenors, independent living skills, work experience and social programs to individuals whose primary disability is congenital or early adventitious deafblindness. Trained Intervenors support the individuals to achieve their personal goals and facilitate relationships and skills which promote effective participation in the community. ILRDBO currently runs eight three-person homes and one individual apartment program in York Region, Simcoe County and London, Ontario (Canada) supporting 25 adults with deafblindness.

Close to a year ago, ILRDBO began re-evaluating the process and function of the service they provided. Research was conducted to ensure that the service was still meeting the needs of the individuals in the adult stage of their lives and that they were adapting to the changes that may occur during this aging process. It was concluded that the educational model on which the service was based was no longer ideal to meet these needs during this stage of their lives. A new Program Module was therefore developed.

Concurrent with the previous educational model, the new approach determines the best suited goal for each resident through choice. Yet the fundamental reason to revise this model is to be certain that the current abilities, preferences

and involvement in goal making are individualized for the resident. ILRDBO has always taken pride in its individually tailored service and now it has taken that approach a few steps further to ensure that the service it offers involves the facets needed to ensure the best service possible for the individuals it supports. During the last ten months, beginning at committee level, ILRDBO has been extensively engaged in re-evaluating, researching, piloting and launching approaches for this Program Module. This module would continue to build on the current individualized framework of its program and would include other facets such as ways to secure funding, to develop an individualized approach to goal setting and to utilize a measurement criterion to ensure that the goal setting approach meets the needs of the individuals' program. It was concluded by the committee that the framework of the Program Module would entail Service Tracking, Resident Program Portfolio and Outcome Measurements.

Service Tracking

This process is completed by staff who track the delivered service directly and indirectly with the resident or organization. This provides statistical information when applying for funding and presents identifiable areas of the service ILRDBO provides. Each area of the process continuously revolves; Service Tracking is required to obtain funding, funding is needed to provide an individualized service for the residents and the service delivered provides information for Service Tracking. This process was successfully piloted in each region and in mid-September ILRDBO launched Service Tracking organization wide.

The Resident Program Portfolio

This entails a Person Centered Approach to goal setting and it supports the Mission, Vision and Values of ILRDBO – to support choice and individualized programming. This portion of the module also ensures that the current abilities, desires and preferences of the individuals are being met and that the goals developed with the residents are measurable and attainable. The portfolio involves a variety of elements to facilitate the Person Centered Approach, through the use of assessment tools, which depict the needs and abilities of the individual. Another element is utilizing a goal planning tool kit, offering choices in the process, frequency and focus of activities. A Multi Disciplinary Program Team (MDPT) is also another essential part of the goal setting process. The MDPT does not just involve the individual and staff, but brings insight and knowledge from other sources, such as family, friends and other regular community contacts, to assist with the review and goal process. Incorporating all these tools to create individualized programming, which is based upon the needs, desires and choices of the resident, is the essential result of an individualized Resident Program Plan.

Since March of this year, a pilot group of three residents and Key Intervenors (responsible for development and facilitation of the program) has been completing and evaluating this portion of the Program Module. Through the review process, and shared input from the pilot group, changes have already been made to build on the framework of this portion of the module. The second

pilot group, consisting of five residents and five Key Intervenors, is preparing to pilot the process of the Multi Disciplinary Program Team meeting. The rest of the organization will launch this facet of the module in the New Year.

Outcome Measurements

This quantifiable tool provides information on the effectiveness of program planning. The benefit of utilizing such a tool is to assist with planning more productively for budget and funding submissions, based on the requirements of the Resident Program Plan. The quantifiable detail provides government, funders, and the program and board level with information to make decisions to keep or reform programs. This ensures that the criteria are being met and achieved through the program service and through individual Resident Program Plans. This portion of the Program Module will also be launched in the New Year. Creating a Program Module consisting of these three facets will assist in securing funding to fulfill the support needed to provide an individualized service. ILRDBO is dedicated towards the fulfillment of the individuals' needs, goals and program, through continuous review of this service. The framework of the Program Module will continue to evolve and strengthen, allowing the individuals to grow, experience and embark on the fulfillment of their independence and quality of life.

For further information on the Program Module, feel free to contact ILRDBO (905)770-4948 or email us at admin@ilrdbbo.ca.

ILRDBO gratefully acknowledges the support of the Ontario Trillium Foundation for funding this venture.

100 years of support for deafblind people in Potsdam, Germany

Katherine Biesecke describes the very start of the celebrations for this very special birthday at the Oberlinhaus!

In 1887 the first deafblind girl, Hertha Schulz, moved into the Oberlinhaus in Potsdam. At first she lived with children with other disabilities but then more deafblind children followed. So, in 1906, a home was founded, where only deafblind children were taught – the first ever home for deafblind children in Germany. It was a small house for about 6-8 children, who lived together with some Sisters and were taught by a teacher of deaf children. Some years later the house became too small and so a bigger house was built – the house where we still live and work – it was last renovated in 2001. Today we have a home for 20 deafblind children, another home for 26 elderly deafblind people and a school

where currently 37 deafblind pupils are taught. The school and the home for the children are in the old house from 1912 and we call it “Hertha-Schulz-Haus”. Next year we celebrate the 100th anniversary of the first home for deafblind children. We have already started the celebrations and had the first party on the 31 August 2005, when all deafblind people living with us celebrated together with all the staff! The youngest boy is 6 years old and the oldest woman, Mrs. Osterburg, is already 91 years old.

We started the party with a big dance for more than 80 people in the courtyard of the “Hertha-Schulz-Haus”. Then we had fun while testing lots of things by touching and smelling. We all experienced this with hands, feet, noses and tongues. We had a barbecue and a session where we painted and formed some works of art.

A high point of the day was an activity called “happy hands” where we made casts of our own hands! At first your hand was creamed, then you had to put your hand into iced water. Afterwards it was put into hot wax and again into cold water. The feeling was very intense and because the wax was coloured and perfumed, everybody got a hand of his own – in red or blue or black with a special scent!

Cherry Harvest –

an excursion from the home for deafblind people in Potsdam

Ralf Herrmann and Katherine Biesecke describe a special time of year

I
t is a very nice day in June! Wherever you look – bright green. The air is glimmering and there is enough hope left that we might have a picture-book summer. Fourteen deafblind men and women who live in our home for deafblind people went out to relieve the cherry trees of their wonderful fruit! Our destination is a fruit estate in the Havelland where big fruit orchards are open for self-harvesting. When we arrived some of our deafblind people started right away with the harvesting, while others, at first, enjoyed the sun!

Mrs. Linda Weiß, a woman about 80-years-old, with Usher Syndrome, reached out with masterly skill for the cherries and put them carefully into the harvest-basket on her shoulder. You could clearly see the pleasure in her face. Later she told us in sign language about the cherry harvest in her childhood in the countryside in pre-war Poland.

Mrs. Cindy Preuss, a 29-year-old congenitally deafblind woman did not seem interested in harvesting – she mostly enjoyed the car trip. At the orchard she sat down on her seat-ball, which she always takes with her, and enjoyed the sun! She also liked the cherries she shared with those who harvested.

So everybody had fun on the trip and also lots of personal experiences. We took a lot of cherries home with us – to make cake and jam in the days that followed!

Let the two minds work together!

Ove Vedel Andersen and Henriette Hermann Olesen, The Danish Centre for the Education of People with Congenital Deafblindness.

In this article Ove, a teacher of special education, and Henriette, a consultant for children with congenital deafblindness, ask “Is there a connection between aesthetics and communication?”

In August 2005 they presented their ideas to the European Conference on Deafblindness in Slovakia. For some years they have been working on writing a book about the aesthetics concerning interaction and communication with people with congenital deafblindness. They like to share and discuss this work, and the theory behind it, with professionals in Europe, and, as this is an ongoing process, the meeting with colleagues in Slovakia, and other places, are very important for them.

Through studying theories of aesthetics we feel that these theories, to some extent, match the theories that can be used to establish and create communication with people with congenital deafblindness. “Seeing and catching” the meaningfulness of the expressions developed or “invented” by the deafblind person themselves – vocally or bodily – has been the essence of our work so far, in order to make these expressions active in communication. With a little help from aesthetics we think we can improve our ability to “see and catch” and thereby legitimize these expressions, because aesthetics helps us to see the beauty of them.

In cooperation with various types of artists (a dancer, actor, sculptor, singer) we have seen examples of magnification, clarification, differentiation and beautification of the types of expression used by deafblind people. These are expressions that we may not have noticed before, or we may even have thought they were unconventional. Maybe we even assumed them to be stereotypical or socially unacceptable behaviour. This made us more curious about aesthetics and how this could be important to our work concerning interaction and communication.

Looking back on our work, we could hear ourselves describing our ambitions of being “roomy” or spacious, being able to embrace the human being as a whole,

but we could not define exactly what it takes to make this spaciousness present in our work on a daily basis – we had a feeling that we had experienced some limitations in relation to this spaciousness! Sometimes we also found ourselves feeling that everything in the interaction with the congenitally deafblind person worked fine, but we were not quite conscious of what had actually made this happen.

We had a good theoretical background for the daily work. Words like interaction and communication were, and are, keywords and we used them when we discussed our work. We understood the importance of an individual's possibility to interact and communicate with other people, but often we had to question why we sometimes achieved success and sometimes we did not.

This feeling of success has been described by a number of theorists. Daniel Stern calls it “the present moment” as an expression describing mutual participation. Per Lorentzen uses the term “the aesthetic meeting”. Birgith Kirkebæk describes it as “a qualitative leap in the intersubjective exchange”. A participant in the workshop in Slovakia had his own personal way of describing it, namely as “the flow”.

In the workshop we presented a video clip that showed a successful interaction between a congenitally deafblind woman and her caretaker. The caretaker follows the expressive communication from the deafblind woman and suggests other expressions. They take turns and enjoy themselves. The interesting part was the caretaker's description of it – she excused herself to the person who was videotaping the sequence and said: “This has become more of play and joy, I'm afraid...” – she divided play and joy from real work, because she was expecting a “proper” linguistic dialogue and she didn't see this as an important part of working with interaction and communication. This is good example of how we sometimes use our head and logic and think that if we are having fun, it isn't serious work. For a number of years we have worked with various artists and they have contributed to showing us the beauty and the importance of play, joy and special personal expressive acts – however strange they might seem. Klaus mentioned the dancer Riccardo Morrison, who has worked as a contact-improvisation-dancer for many years, and showed us a beautiful dance with a woman. He carried her on his back, danced around and followed the movements of her arms. They ended up in a sculptural setting where he was standing on one leg and she was lying on his back, both stretching their arms into the air. It was a beautiful and very serious work.

We could see how he, and the other artists, worked very seriously with play and enjoyment, working both extrovertly (from the deafblind persons' expressive acts, through a theatre play or a sculpture) and introvertly (from the deafblind persons' expressions, producing aesthetic process and the feeling of being equal partners). It was this we found interesting in our daily work, as we saw how the artists magnified, and legitimized, the expressions from deafblind people and enjoyed working with them – they seemed to “sense” more than “logical thinking” in their work.

A German philosopher, Baumgarten, once said that aesthetics is: "The science of the sensation and the beauty in itself, as the experience of a total unit of contents, order and expressions."

But what are we saying now? Is our goal to work as the artist does, by sensing our way into the interaction and communication? No, it isn't! We are certain that that is not enough. Is our goal to be better logical thinkers? No, it isn't! We are certain, that that, too, it is not enough. Baumgarten helps us out here – he also said that we have two ways of thinking: the aesthetic mind, and the logical mind. The aesthetic mind makes us think and see the beauty, it makes us sense, it makes us experience and acknowledge.

The logical mind makes us see the logic, makes us rational, conceptual and intellectual – looking for truth.

So if the human being is blessed with two minds, maybe we should let these two minds work together in our work with the congenitally deafblind persons. How about acknowledging the rational in our work? How about seeing the beauty in the logic? How about experiencing and intellectualising? How about seeing the beauty and the truth? How about seeing the logical and the aesthetics?

So what we are saying now is that we think it is of great importance to know logically how theories describe the development of creating communicative acts, and what the disability deafblindness means for this development. In our presentation we used the model of Anne Nafstad and Inger Rodbroe: "To create communication with deafblind persons". We think it is important to know what various types of expressive acts mean. We need to understand whether they signify regulation of social interaction, proximity and distance, exploration, or emotions. Or is it being used as vocabulary?

At the same time we think it is very important that we aesthetically sense the deafblind person as an equal partner in the interaction and communication. If we can be a genuine partner in communication we think we will experience more success with our interactions.

So... if expressions end up being natural elements in the spontaneous daily communicative interaction of both partners – the professional and the deafblind person – the "circle is completed". We can understand, and see, in the interaction, the "total unit of contents, order and expression".

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Invitation

The 9th European Deafblind Holiday (European Deafblind Socio-cultural Exchange)

Dolni Becva, Wallachia (East Moravia), Czech Republic. 12 - 19 August 2006

Dear friends,

We are pleased to invite you to join the 9th European Deafblind Holiday that we are arranging in the Czech Republic next summer from 12th to 19th August 2006. The holiday is for deafblind adults from European countries and will offer a range of social, cultural, sporting and recreational activities.

The programme will include walking, swimming and other moderate sporting activities. This will be combined with music and dance, cultural visits, excursions, and shopping. Time to sit with friends, relax and simply enjoy being together is an essential component of the holiday.

The participants will have the chance to get acquainted with other people through the sharing of experiences and the exchange of information, while discovering new communication skills. The holiday will therefore enable deafblind persons to broaden their horizons through socio-cultural exchange and partnership.

Practical information:

Dates: Arrival: Saturday 12th August 2006; Departure: Saturday 19th August 2006.

Venue: Recreational facility Orbita, which is a leisure centre and school.

Accommodation will be in double rooms, although two triple rooms are also available. All rooms are equipped with WC and shower and the centre has good Czech cooking and beer!! The centre has a bar and a play area which allows for recreational activities.

Location: The centre Orbita is situated in a quiet area surrounded by a forest. It is close to the town of Roznov pod Radhostem. This town is an important tourist and holiday centre in the east of the Czech Republic. It is in Wallachia, in the Moravian-Silesian Beskydy Mountains, East Moravia. The region of Wallachia is remarkable for its specific folk culture and natural beauty.

Transport: The nearest airport is Airport Ostrava (Mosnov), which is about 40 km from the centre Orbita. The nearest main railway station is Valasske Mezirici, 15 km from the centre Orbita. Transport will be provided from and to the Airport Ostrava as well as the railway station Valasske Mezirici.

Participation fee: We will be deciding on the fees after finalizing the programme. The fee will include full board and lodging, activities and transport scheduled within the holiday programme.

Official language: We will be using English in order that everyone will be able to communicate during the holiday. Therefore it is important that the deafblind participants or their interpreters/guides speak English.

Travel insurance: The participants themselves must make sure that they have appropriate insurance for the journey and for their stay in the Czech Republic.

More information: The first announcement will be made in November 2005, as soon as we are sure of the programme and participation fee. We will distribute the first announcement by e-mail to the addresses of deafblind people (and their organizations) who are already on our list.

Organizer: Jan Jakes and the other members of the VIA Deafblind Association

If you know of any deafblind people who might be interested in this holiday, please forward this preliminary invitation to them or send us their address.

For more information or to announce your interest or to register using the preliminary form please contact by email as soon as possible.

Email: jajakes@volny.cz

VIA Deafblind Association

K Vodojemu 29, 150 00 Praha 5, Czech Republic. Tel: +420 251 556 381

Best regards!

We hope to meet you in Wallachia, Czech Republic, next summer.

Contact

Understanding the characteristics of specific interaction to build reciprocal interaction with congenital deafblind persons

A cd-rom for interaction partners of deafblind persons, e.g. parents, siblings, caregivers, teachers and consultants, or other professionals working with deafblind persons.

By Bernadette van den Tillaart and Marleen Janssen

Deafblind persons who have to live with dual sensory impairments from birth, live exclusively in a world of proximity and touch. With a foundation of high quality interaction they can develop feelings of security and competence. When the deafblind person and interaction partner attune their body language in such a way that they can share experiences and emotions, "real contact", in the form of shared affective involvement, can come into existence.

About the authors

Bernadette Van Den Tillaart and Marleen Janssen worked at the deafblind department of Viataal (the former Institute for the Deaf) at Sint Michielsgestel, The Netherlands for many years. Now Bernadette works in the USA and Marleen works at the University of Groningen.

Both the authors are highly experienced and knowledgeable on this subject. Bernadette has developed the guidance model and staff training materials on interaction. She has also developed a number of products to support learning and understanding about the significant needs of deafblind children and young people. Marleen, now at the University of Groningen, evaluated the effectiveness of the interaction guidance, based on a controlled scientific research, and described the results in her dissertation.

The Interaction Model

In 'The Interaction Model' concepts like interaction patterns, regulation characteristics and the course of an interaction episode, are described. The model can be used for other multiply-handicapped persons for whom this seems appropriate.

Implementation of this knowledge consists of two complementary strategies: participation in the training course 'Social interaction with Deafblind Persons', and implementation of 'The Guidance Model' in the practical situation. The interaction coaches are trained and certified in the deafblind specific 'Training on Video Interaction and Communication Guidance'. The Guidance Model guarantees the initiative of the deafblind person as the key factor. Video-interaction analysis is an indispensable technique.

CD-ROM CONTACT

To share and exchange with others, this knowledge and strategies are recorded on the CD-ROM CONTACT. The introduction is written by both authors. The sections for interaction partners and for interaction coaches are written and video-illustrated by Bernadette.

Implementation of The Guidance Protocol and elements of the Interaction Model are empirically evaluated. The participating deafblind persons derived more pleasure in contact with their interaction partners, and showed less stress and challenging problems after a guidance process. They established a more reciprocal contact with their interaction partner(s) and developed themselves in different other areas.

If you are interested in this cd-rom (29.50), please contact Viataal for an order form on:

centrumvoorexperise@viataal.nl

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Tactile Communication Network

Bernadette van den Tillaart

The members of the Tactile Communication Network met at the Dbl European Conference in Prešov. They presented their work within the 'communication stream'. Unfortunately, one of founding members, Barbara Bettenmann, will not be able to be actively involved anymore because of increasing obligations at Heim Tanne, her work place. We will miss her in-depth practical experience and like to thank her for her wonderful contributions! As a new member, we have welcomed Paul Hart, and we all look forward working together! We are planning to meet each other in the Spring, hosted by Sense Scotland in Glasgow! The date of the meeting is January 13th and we are looking forward to it!

The Siblings Network

The Dbl conference in Slovakia was a successful one for the siblings network. Five members of our network joined the conference, and some of the presentations within the family stream were about siblings. The word siblings was mentioned many times during the conference, so I think we can say there is more awareness. But of course there is still lots of work to do!

We also had our own "Just for siblings workshop", during which we exchanged experiences and discussed some of our thoughts and concerns. Time was too short and all siblings taking part felt it would be very nice if we could continue this conversation.

We came home with new experiences and lots of ideas, and we hope we will be able to carry out some of them.

One event has already been scheduled: Listen to me 3 will be held in Salou (near Barcelona) in Spain, from 1 – 7 October 2006. During this family event we will organise several workshops and activities for siblings.

When you would like to receive more information on Listen to me 3, or if you would like to know more about the network, please contact me at: siblingsnetwork@gmx.net

Sabine Kersten

Communication Network

Jacques Souriau

The big event, this summer, for the Communication Network, was the European Dbl Conference in Presov, Slovakia. The scientific committee provided our group with the opportunity to run a 12 hour stream on communication. It was a success, not only because of the number of the participants, but first and foremost because of the quality of the presenters and of the audience.

It was amazing how, in spite of the variety of the presenters and the difficulty of the main topic (semiotics), we managed to address thoroughly and deeply, many aspects related to meaning-making in the field of deafblindness and in its many sub-fields: congenital and acquired deafblindness (including elderly people), tactile and low vision communication, etc. We were also impressed by the quality of the presentations made by family members, which were as excellent as the professional ones from a technical and scientific point of view.

The main topics addressed were the following:

- a history of this field of research,
- an introduction to semiotics related to deafblindness, and
- a series of presentations illustrating aspects of the meaning-making process:
 - How do we understand each other?
 - Analysis of communication between a young adult with congenital deafblindness and a competent partner;
 - The development of social concepts by the tactile mode
 - Communication with children or adults with multiple sensory disabilities
 - A holistic approach to communication with an acquired profoundly deafblind person.

Future events

It is important to mention a conference which will take place in Oslo, 25th – 29th April 2006, on “Sharing Culture with Persons with Congenital Deafblindness”. For further information concerning the programme and the administration please contact NUD.

Acquired Deafblindness Network (AdbN)

The co-ordinating group of ADBN met in Aarhus in Denmark on the weekend of 14-16 October for one of their twice yearly business meetings. At this meeting the group were able to confirm the dates and venue of the 6th International conference on Acquired Deafblindness. This will take place between 1 – 5 November, 2006 in Groningen, Netherlands. The Dutch organisation, Visio, will be hosting the event. Please make a note in your diaries now!

Now that the dates have been fixed the second announcement will be issued, inviting abstracts for papers. These should reflect the title of the conference; “The art of communication – creating solutions on the individual, societal and organisational level in the world of Acquired Deafblindness”.

In line with the key words of “art” and “creating”, the co-ordinating committee has decided to invite deafblind artists to submit examples of their work for inclusion in an exhibition to accompany the conference. Details of this will be contained in the second announcement.

The group will meet again in April 2006 to complete work on the conference programme for Groningen.

Ges Roulstone
Chairperson
ADBN

Usher Study Group

Prešov, Slovakia 7-9 August 2005

Mary Guest

To be honest, it was quite a challenge to hold an Usher Study Group in Slovakia this year. Awareness of Usher syndrome seemed to be very low – Janka Sarisska said she only knew of one adult! We did not know anyone working with children or adults with Usher and we did not know anything about Presov or possible venues for us to meet. However, we felt that we should try to put a programme together which would attract people who wanted to learn more. We were fortunate that Dr. Ronald Pennings from the Department of Otorhinolaryngology at the University of Nijmegen agreed to give the keynote paper on the theme of ‘Changing Horizons for People with Usher in the 21st Century’. His centre in the Netherlands is at the forefront of clinical and genetic research into Usher syndrome. They see many families and have pioneered a molecular mutation chip that has helped speed up the process of looking for changes in the genes that cause various forms of Usher.

Maria Mikova, who works at the school for the deaf in Presov, kindly offered her school as a venue and provided much local information that we needed. She facilitated the first time attendance of 7 Slovakian teachers of the deaf. She was our ‘mother’ – organizing refreshments and making us feel welcome.

Our first speakers, Colin Bennett (UK), Carol Brill (Ireland) and Peter Hepp (Germany) took us right into living with Usher. Everyone described times of loss but they also talked about new directions that have led to rich and interesting experiences. The keynote speaker took us through the background that led to the

condition of Usher being recognized as a genetic cause of deafblindness in adults. Ronald's wonderful presentation is published here on page 17.

It was good to welcome Dr Hanna Siedlecka, an audiologist from Poland, who has been tracking people with Usher in Warsaw for some years. We hope that, as a result of making contact with Hanna, the teachers in Slovakia and also the three teachers from Kiev (Ukraine) who asked to attend, will get together in the future and have their own workshop on Usher. Let's watch this space!

Bente Ramsing from Denmark presented a joint paper with Bente Heilesen (who helped with early planning) comparing and contrasting support for two families with children diagnosed with Usher who have cochlear implants. This study has just started and we look forward to hearing the results and their conclusions when we meet again, perhaps in Australia in 2007.

How families go through the process of informed consent as they are recruited into research programs was the theme of Liz Cook's talk. She is the Family Coordinator for the National Collaborative Usher Study being carried out by the Institute for Child Health and the Institute for Ophthalmology, in collaboration with Sense, in the UK. She has a special concern for sign language users – particularly those who use tactile or 'hands on' signing. The NCUS is recruiting 200 families for research over 3 years and is entering the third year.

We hope very much that the new people who came from Eastern Europe will feel inspired to develop outreach to people with Usher in their countries. We also hope that we will soon hear about workshops and seminars, as well as social activities with people with Usher and their families, springing up in Slovakia, Ukraine and Poland.

I would like to thank Viliam, our wonderful interpreter, the technicians, Maria Mikova and the staff at the school for the deaf and also Anna Misinova who gave us so much friendly support. Also grateful thanks to Bente Ramsing who helped out so ably during the 3 days and to her colleague Bente Heilesen who could not attend but whose enthusiasm was the catalyst which helped to bring about an Usher Study Group in Slovakia.

Usher Network News

Carole Brill

Hello everyone!

At the recent DBI conference in Slovakia, the Usher stream was well attended. In total there were 6 fantastic presentations followed by 2 workshops. The final workshop involved discussing the future of the European Usher Syndrome Network and at the end of the workshop, it was unanimously agreed that this Network should be re-formed into the Usher Network. This will mainly take the form of a communications network for those with Usher, families and friends, professionals, including sign language interpreters. There will be no committee

formed as it is purely an information sharing network. There will be opportunities for the network to meet, at the DBI conferences, for example.

For the immediate future, anyone who wishes to share information related to Usher is welcome to send an email to ushernetwork@eircom.net and then the email will be circulated to everyone on the list. But for this to happen, your help is required. So how can you help? There are 2 ways. The first way is you tell everyone about this Usher Network and its email address. Tell them to send an email and then their name shall be included on the circulation list. The second way you can help is to send information about what is happening for Usher in your country.

It is intended to research the possibility of setting up a webpage on the Dbl site and perhaps a membership chatroom. But these will take time. However, please forward any suggestions as they will be welcome.

Interpreter Network

My name is Mirjam Leusink. Just a little over 2 years ago I graduated as a Dutch Sign language interpreter. Ever since my first contact with deafblind people (which was during my period of study) I have been interested in interpreting for deafblind people.

Last August I attended the Interpreter stream at the 6th Dbl conference in Presov Slovakia. During this stream we discussed reinstating the Interpreting Development Network (I.D.N.), but they needed someone to re-initiate it, a chairperson for the Network. Irma Bosman, who is also from the Netherlands and who was one of my teachers, asked if I wanted to take on this challenge. After a little thinking I decided to do so! So here I am introducing myself to you in Dbl Review as the chairperson of the I.D.N.

I really want to emphasize that I cannot do this alone. I'm quite new to all of this. So I hope to get a lot of input from all of you, interpreters, deafblind people, and family members. Together we can make this work. Together we can develop interpreting for deafblind people! So I look forward to hearing from you if you would like to be in at the start and also if you have any information that might be of interest for this network.

Please don't hesitate to contact me at: mirjam.leusink@planet.nl

Gill Morbey from Sense Scotland makes a proposal for an Arts Network

"A number of us have found that various forms of artwork can be extremely successful when working with deafblind people. Many countries are involved in the arts and we feel it is time to pull this wonderful expertise together in a Dbl network around the arts."

I believe that Dbl should establish an arts network and in support of this I have made a number of assumptions. I have noted these below:

1. The deafblind person.

- We know that communication can present difficulties for the deafblind person and the significant others around that person.
- We know that these communication challenges can result in challenging and other stereotyped behaviours from the deafblind person and in turn this can lead to stress and anxiety with parents, carers and teachers.
- Communication is best developed from the 'natural inclination' of the individual. By this I mean that we should work with what is most comfortable and easy for the person concerned. We know, certainly with congenital deafblind people, that this will not always follow formal sign language and, in many instances, it will develop on a personal level – often between mum and child.
- We believe in giving as many communication opportunities to deafblind people as possible. We have developed this through variations and combinations of natural gesture, tactile signifiers, speech, and sign language through to symbolic language.
- Through our own experiences we know that learning is best when people are happy, engaged and relaxed. Having fun through play for example is a long established tool for learning.
- Deafblind people often lack a sense of identity and self esteem.

2. The International perspective

- Through Dbl and other international organisations we are committed to working across country boundaries and yet we also know how difficult this can be for sighted hearing professional people. We have different languages and cultures.
- We believe we should be more proactive, for example by forging partnerships for joint working and funding applications.
- A number of countries are engaged in artwork in various forms. This is part informed by key people and partly an intuitive response to engaging with deafblind people. We do it because we have success and we feel it is right.

3. Why the arts?

We believe that all of the above can be addressed to varying levels through the arts.

- The arts range from visual, tactile, music and drama and thus offer communication opportunities in various and multi-level ways. We use music in a teaching sense to encourage auditory stimulation through to experiencing an emotional response. As sighted hearing people we experience emotion through music, it doesn't have to have words and can transcend language and culture. We have no reason to believe that a deafblind person with residual hearing can't also experience this response. We reduce tactile sensitivity through messy and other forms of play and it is a natural progression to use this in the arts through sculpture with paper mache, clay etc.

- Our communication with deafblind children tends to be instructive: 'sit down' 'time for dinner, toilet etc'. We don't place sufficient emphasis on emotions and wellbeing, yet we know these are essential to learning. We don't learn when we are angry or frustrated. The arts can help to redress the balance. It is not the sculpture or the painting that is critical but rather the process of expression, fun and the multi-layered communication opportunities. We can 'talk' about colour, sound, touch, the project, and the emotional response. Both the deafblind person and the worker are sharing the same experiences.
- We know that identity, wellbeing and self esteem are improved through the arts. Recent drama productions from various countries demonstrated how deafblind people respond to being in control and 'centre stage'.
- An arts network would give us the framework for increased partnership-working, drawing the expertise together from individual countries.
- An arts network would cross cultural and language boundaries and give us a framework for joint funding applications, for example through European funding. It would already be in place and we wouldn't have the continuing difficulties in seeking co-organisers and partner countries.

4. How will the emerging network operate?

We will follow the principles and values of Dbl.

- We will work together, sharing practice, and be open to new experiences and learning.
- Some countries have already worked together on different projects. We will build on this and sign up a core group to further develop the working arrangements.
- We will start by e-mail exchange that will encourage the sharing of good practice. As it is the arts we will encourage sharing video and photographic experiences.
- We will share these experiences on the web site giving practical and easily understood activities and ideas.
- We will publish articles in the Dbl newsletter.
- We will seek to evaluate and monitor our work through evaluation forms, interviews, video footage and reports to Dbl.
- We will continue to proactively seek joint funding opportunities, particularly through European funding.

To register interest contact gorbey@sensescotland.org.uk

Employment Network

Greetings from Finland! My name is Seija Troyano. To my great delight I have had the opportunity to work twice with Dbl Scientific Committees, first in Holland and last summer in Slovakia, working on the Conferences from start to finish. I have Usher – diagnosed at first simply as Usher Syndrome, then Usher type 2, then type 3. In December I celebrated my 10th year with a cochlear implant and it

has been a very positive experience. My history includes 10 years in England and then back to my roots where I live now – in the East of Finland, Varkaus. I am a qualified school assistant, but at the moment I work as a town councillor, in my hometown, with other decision making bodies.

Why is employment so important?

The right to work, and to be educated, has always been a matter of course for me. Unfortunately deafblind and other disabled people often have to fight for these things and still lose out when they look for a job. Far too often the problem is society's attitudes and an unhelpful environment. It is easy to become frustrated! Today more and more deafblind people study and become qualified. So why don't they have the right to expect the same as anybody else – to find a job? There are so many modern ways to support people if only society would give them a chance. Working in a "different" way certainly does not mean that you are incapable of work at all!

However, we will not get a lasting change in our rights before we are ready to fight for that change ourselves – we have to put this subject on the table and invite our professionals to work with us. We also hope that Employment will be one of those regular topics at future conferences, just as rehabilitation, communication, schooling and education are already!

Last August in Slovakia I ran the Employment stream and the outcome was to create a Dbl Employment Network where more people can work together. In this way, by involving a lot more people, we hope to make sure that there is always someone supporting and developing action for change. It also means that people need not work alone but share ideas and methods.

Finally I take this opportunity to greet everyone with whom I have worked during the past years! Thank you, take care & stay well! But also get in touch and help get our Network moving forward.

seija.troyano@dnainternet.net

Norway and Bulgaria

International Deafblind Sports and Culture Organisation – IDBSC

Dimitar Parapanov and Geir Jensen announce this new initiative.

During the 8th European holiday week in Varna, Bulgaria, a contact group (interim committee) was formed to establish this new international initiative. The contact group consists of the following members:

- Dimitar Parapanov, Bulgaria - (coordinator)
- Geir Jensen, Norway
- Jan Jakes, Czech Republic
- Peter Van Houtte, Belgium

- Nadejda Golovan, Russia

The purpose of this contact group is to work for international sporting and cultural activities for deafblind people as a continuation of the national activity in Bulgaria. Among other things, the contact group will discuss how to organize international sporting and cultural activities, work out a draft constitution and develop a programme and budget for the organization.

The contact group will also consider whether the International Deafblind Sports and Cultural Organisation is to be established as an independent organisation or as an organisation within EDBU.

We hope EDBU and WFDB are supportive of the work started already and are willing to give the work their full support. Please get in touch if you are interested.

UK

Deafblind information worldwide

Sense's new Information and Library service is a major new source of knowledge about deafblindness. The new service gives deafblind people, their families and professionals around the world the chance to stay in touch with all the latest information and research.

A specialist library on deafblindness.

Sense's library has a growing collection of over 2,000 items which cover a wide range of topics related to deafblindness – everything from autobiographies of deafblind people, to how to provide services for people with multi-sensory impairments. The collection contains books, reports, journal articles and CD, and material can be made available in other formats on request.

To see the contents of the library, or to search on a particular theme or topic, you can visit the new online catalogue on Sense's website: www.sense.org.uk/library. Visitors will also be able to read the latest Current Awareness Bulletins which lists all the latest publications about deafblindness.

The Library does not lend books internationally. However it does offer a free enquiry and photocopying service for people contacting us from outside the UK.

Deafblind Information Line

We are also offering a new information line that is run by two members of staff who deal with a wide range of enquiries from deafblind people, their families and professionals.

To find out more about Sense's library and information service please email stephen.mccarthy@sense.org.uk

Deafblindness is now recognised in Colombia!

Ximena Serpa reports

The Deaf Federation of Colombia (FENASCOL) and the Colombian Deafblind Association (SURCOE) are pleased to announce that Law 982 was passed on 2 August 2005, "whereby regulations are established aimed at determining equal opportunities for deaf and deafblind persons, and other provisions are stipulated". As a result of this law, deafblind people have managed to get deafblindness recognised as a unique disability, one with its own character and needs, and this represents major progress in the struggle to achieve equal opportunities. This law has been passed as a result of the hard work that was put in by the following organisations: the National Institute for the Deaf (INSOR), the CINDA Foundation, Sense International (Latin America), and the organisations which group together and represent deaf and deafblind people in Colombia, namely the Deaf Federation of Colombia (FENASCOL) and the Colombian Deafblind Association (SURCOE).

This group of organisations worked hard together to draw up, edit and present the bill, with the sole objective of ensuring that the interests and needs of the different groups of deaf and deafblind people, all of which are heterogeneous in nature, were covered by the law.

The deaf and deafblind communities now have the task of ensuring that state groups and authorities comply with the law. This should be made easier as a result of the experience they have gained in the progressive compliance with Law 324 of 1996 and regulatory decrees on this, and also because government groups have become aware of the issues involved due to the demands made by the different deaf associations over the last twenty years or more.

Initiatives promoted by organisations, such as the Provincial and Municipal Education Departments, the Public Prosecution Service, the Supreme Council of the Judicature, the Bogotá Health Department, SENA, the Pedagogic University, the National University, the Ministry of Social Protection, COLDEPORTES, the Bogotá Recreation and Sports Institute (IDRD) and the Bogotá Social Welfare Administration Department (DABS), have gradually been guaranteeing the right of deaf and deafblind people to enter their programmes and courses under equal conditions using interpreting and guide-interpreter services. This will help improve the living conditions of those people who use sign language or alternative communication methods, and who, in the past, could do no more than aspire to a deficient level of primary education and to jobs involving things like handicrafts. The new Law 982 of 2005 is a fundamental tool for both deaf people, and particularly deafblind people, who have managed to get deafblindness recognised as a unique disability - something which very few countries in the world have achieved.

A big Gracias

Graciela Ferioli, Beatriz Zoppi and Ma. Luz Neri de Troconis. (3 "terremotos" of Latin America)

We want to express our acknowledgment to Hilton Perkins Program, Perkins School for the Blind and FOAL for believing in us and giving us the important opportunity to get a Master's Degree at the University of Birmingham.

We would especially like to thank Mr. Norman Brown, Programme Co-ordinator, Distance Education MSI Programme at the School of Education, University of Birmingham. He has been a “visionary” Professor offering support, advice, trust, motivation, guidance and friendship.

Russia

Alfia Valiullina describes the success of “Omat” in supporting deafblind children and adults.

Making a difference – changing attitudes and spreading the word in Ufa, Bashkiria

I

In the national republic of Bashkiria we had a serious lack of awareness about deafblindness. Our organisation “Omat”, which means “Hope” in English, was born in 2003. We continue to work hard in our Republic to make the government understand the problems of deafblind people and provide them with support. We identified 139 deafblind people. The doctors were not ready to help these people and we began to work to support the people ourselves. After the first meeting of the parents of the deafblind children with the doctors, we concluded that these children need joint action from different specialists. So we invited specialists to discuss the problems of Usher syndrome in our Republic. Soon after the event we started making plans for a medical conference and, thanks to partnership from Sense International and Usher-Forum (Moscow), we had the opportunity to hold this conference in April 2005. It was the first medical conference in the history of Russia. Specialists came to discuss the medical, psychological and organisational questions relating to the challenges of Usher syndrome. We are very proud of this event!

What is the result of this conference?

Our specialists

- made plans for working with this category of people;
- began to learn about and carry out genetic research to find out about deafblind people;
- began to work with pupils with dual sensory impairment; and
- developed a special programme for the early screening of deafblindness.

How do we help our specialists?

We encouraged our specialists to work in partnership and gave them more information about Usher syndrome. We put together special questionnaires for the Institute of Biochemistry and Genetics, which has the opportunity to carry out research about deafblindness. Everything is free of charge for us. Our first success!

Another success

Another conference on Usher Syndrome will be held by the specialists from the Centre for Hearing Impairment. This happened as a result of our opportunity to raise awareness at our own conference!

Our leader

Nothing was possible without a good leader; the Director of our organisation, Nina Urlova. She has Usher syndrome and began to work with deafblind people, on her own initiative, in 1999. When I saw her for the first time I was surprised at her cheerfulness, and it was hard not to notice her leadership qualities - she is very active and purposeful. Nina has now visited the UK and has learnt a great deal about fighting for the rights of deafblind people.

Thanks to Sense International I was invited to the 6th Dbl European Conference on Deafblindness in Slovakia. I have no words to describe my feelings. It was my first visit to another country and I met specialists, parents and siblings of deafblind people there. I am full of admiration for the work that they are all doing. The atmosphere was so warm that it made me feel welcome. I have gained many new ideas as a result of the conference and I have also got more useful materials for our work in Ufa. I want to thank everybody who supported me there. I am very happy to meet new friends!

I also presented a paper called "Being pushy. It is the way of getting all support we need". I would advise other parents to keep pushing forwards despite the obstacles!

Australia

Recent Developments Downunder

Mike Steer reports

Migrant women at increased risk of rubella infection

Celestine Hare, CEO of Victoria's Deafblind Association reports that women born outside Australia are at a substantially increased risk of rubella infection during pregnancy. This claim is in accordance with data from the Mercy Hospital for Women, published in The American Journal of Public Health earlier this year. In a study of over 65,000 women over a 25 year period, women who were born in developing countries always had a significantly higher risk of infection than women who were born in Australia. In the year 2000, those born in Asia, Sub-Saharan Africa and South America, had five times the risk compared to their Australian-born counterparts. For women born in China this increase in risk was ten fold.

These data correlate with those from the Australian Perinatal Statistics Unit which has been collecting data on congenital rubella infection since 1993. Since that time, 14 out of 35 children born with congenital rubella infection were born to mothers from countries with no rubella vaccination programs – principally Asia and Africa. Similar experiences have been reported from other countries.

The Deafness Foundation of Victoria has therefore urged the Australian Federal Departments of Health and Immigration to do more to promote rubella vaccination in migrants from these countries. Clearly, existing programs are not reaching these women and they are being disadvantaged.

“We believe that almost all women will accept vaccination once the benefits have been explained to them. It is not that these women refuse vaccination, they just do not appreciate the significance of rubella infection in pregnancy and how it can be prevented” said Dr Adrian Thomas, chairman of the State of Victoria’s Rubella Committee.

Inquiries: Dr Adrian Thomas 001 61 3 9419 7918; or to Ms Monica Haverkamp, Rubella Education Officer 001 61 3 9887 8683.

Interesting statistics

The Australian Bureau of Statistics Survey of Disability, Ageing and Carers, indicates that one in five people in Australia (3,958,300 or 20%) reported a disability. The labour force participation rate was 53% and the unemployment rate 8.6%, compared to 81% and 5% for people without a disability. People aged 60 years and over accounted for 3.35 million or 17% of the population. Just over half had a reported disability and 19% had a profound or severe core-activity limitation. There were no discrete data in Deafblindness.

To access the Summary of Findings, go to

<http://www.abs.gov.au/AUSSTATS/abs/40.nsf/mf/4430.0?OpenDocument>

Guidelines on Information Access

The Australian (Universities) Vice-Chancellors’ Committee (AVCC) has released Guidelines on Information Access for Students with a Print Disability. The working party that developed the Guidelines was formed following the 2002 Human Rights and Equal Opportunity Commission (HREOC) sponsored forum in Sydney. The Guidelines can be downloaded as a Word document (172k) from the AVCC web site at

http://www.avcc.edu.au/news/public_statements/publications/GuidelineOnInfoAccessForStudentsWithDisabilities.doc

Good Reading

Round Table on Information Access for People with Print Disabilities:

Proceedings from the 2004 Conference are available at http://www.e-bility.com/roundtable/conf_proceedings04.php.

‘Thanks mate, I’ll try that’ has been published by RBS.RVIB.VAF Ltd (trading as Royal Victorian Institute for the Blind). The book, based on interviews with men who like working with their hands, both at work and in their free time, gives handy hints for practical work. It can be downloaded from

<http://www.rvib.org.au/publications/pubs/Thanks20mate20I27I20try20that.pdf>.

World Conference

Good news is sometimes hard to get, so here it is again. Some Dbl Review readers may already know that Senses Foundation has won the bid to host the next Deafblind International World Conference in Western Australia in 2007! So start saving your pennies. We are hoping for a large delegation of ADBC members and neighbours from the Oceania region and hope that many of you will consider offering papers or posters for presentation. The Conference will be held from 25-30 September 2007 at Burswood Resort in Perth, Western Australia

Register your interest NOW! 25-30 September 2007 - Perth
On the website: www.dbiconference2007.asn.au
or email: conference@senses.asn.au

Spain

Recent publication

Pilar Gomez Viñas writes about a book that she has been working on, “La Sordoceguera”. It’s a really comprehensive and highly recommended publication in Spanish, is written and published by ONCE in Spain. (ISBN 84-484-0142-5) or contact email address: asesorci@once.es

CHARGE SYNDROME : dual sensory impairment, cognitive development and anxiety

Charlotte Reau, Corinne Blouin, Christine Tap are all psychologists working in France and Christine is also the Headteacher of CESSA, a school for deafblind children. This new research is divided onto three articles which will discuss methodology, cognitive development and the first clinical observations about anxiety. The first article introduces the work and focusses on the research methodology employed.

To begin...a little about our research team: The CESSA is a special school for deafblind children near Poitiers. The children are in residence during the school week and go back home at the weekend. The 29 children currently in the school are very different regarding:

- their visual handicap
- their hearing loss
- their cognitive level
- Their motor competencies.

Over the years, a change has taken place in this population of children with more and more presenting with genetic conditions. Among those, CHARGE syndrome takes an important place: 9 children are currently in the school.

We would like to thank the parents and children, CESSA professionals and psychology students for their contribution to this study.

In September 2004 a conference on CHARGE syndrome took place in POITIERS, during which a number of questions emerged:

- Is there a cause and effect link between visual impairment and intellectual development? We have heard of one piece of research emanating from Paris that indicates this.
- Do vestibular problems have an influence on learning difficulties?
- Why do the children have so many difficulties in taking the initiative?
- Why do the children seem to be more learning disabled than they really are?
- Why do they have so much difficulty in communicating
- What is the origin of the difficulty they have in communication?

All these questions led us to the following research project.

The Research

Its aim

To discover the links between sensory impairments, cognitive development and anxiety.

Its objective

To gain an insight into the children in order to improve their education.

Timescale

The time scale is 3 to 4 years. Children with CHARGE will be compared with the other deafblind children who do not have CHARGE.

Our participants

Our research involves 9 children, 5 boys and 4 girls, all presenting a double visual and auditory impairment. They are between 8 and 20 years old.

The methodology

We started the research in November 2004 and the first 8 months were used to adapt tests and to administrate them with the children. At the same time we built educational grids.

For our research, we designed the following procedure

1) Family interviews

Here is a broad outline of the various topics addressed

- general data on the family: date of birth, profession, and siblings...
- questions about
- Birth : pregnancy, the childbirth...

- diagnosis: time, information about the diagnosis.
- early childhood (hospital admissions, different type of care and interventions...)
- relational and communicative aspects (the sibling and the child, communication with the child, the 1st smile, 1st glance...)
- kinaesthetic aspects (positions of the child, kinaesthetic sensations); food and feeding...
- cognitive aspects (play, attention, orientation in space capacity to take initiative, interests of the child...)
- emotional aspects (type of character, presence and type of anxiety, expressivity of emotions by the child, sleep.)
- behaviour and the development (1st months of life.....,sensory motor developmental aspects...)

It is a framework to collect information about the child, and about the links between the parent/child/disability. We expect that better knowledge of the first link will help us understand the current relationship of the child with the environment and the origins of the manifestation of anxiety. We know that emotional security is the basis for learning involvement and that the emotional balance of the child is related to the quality of the child-parent relationship. In the research a constant link will thus be established, for each child, between the results of the tests and the data collected during the discussion with the family.

2) The educational field

CESSA professionals developed a grid designed to collect observations indicating attitudes to

- body security
- showing a search for kinaesthetic information about the positioning of the body in space
- attitudes with respect to the social situation
- taking the initiative

3) The psychomotor field

- Complete assessment

4) The medical field and analysis of the functional use of the senses

- Vision
- Vestibular functions
- Taste and sense of smell
- Tactile and kinaesthetic senses

We are in the process of developing a medical protocol with medical specialists of the Poitiers Hospital. This involves an ENT surgeon, ophthalmologist, and geneticist.

We think it is strange that touch, smell, taste and the vestibular senses are little studied although we believe that with other deficiencies, they can increase the child's difficulties in grasping information from the environment.

5) The psychological field

- Clinical talks with the child aiming at seeking his manifestations of anxiety
- Scale of early social communication: ECSP

Three functions of socio-communicative development are evaluated by the ECSP: social interaction, joint attention and regulation of the behaviour.

An adaptation was carried out for the children having linguistic capacities.

- Neuropsychological scale NEPSY: aims at evaluating various cognitive competencies. NEPSY is a test assessing the development of the neuropsychological functions in 5 fields:

- Attention and executive functions
- Language
- Sensorimotor functions
- Visual and spatial processing
- Memory and learning

- EDEIR: scale of cognition development. It is a test to evaluate intellectual competence for the child from birth to 12 years of age adapted for the autistic child or presenting auditory impairment

Test of factor G: Cubes of Khos (in progress)

In the methodology, when we started, we wanted to have more information from different sources, in order to compare the results. The tests used are adapted to children of 3 to 12 years' old. In our study, most children are older, but their communicative capacities are below normal. We still keep doing these tests because we do not want to get a mental age or intellectual level. We want to understand each child's problem solving strategy problem solving strategy.

In this figure we describe 4 axes around the sensory impairment: attachment, anxiety, access to the world, cognition and learning.

We want to see how these 4 axes interact with each other.

Initial results

This figure does not aim to present complete and final results, but rather the broad outline of our reflections so far. Some assessments are still in progress, and the analysis of the cross comparison has not been carried out yet. In our next article, we will describe the first results about cognitive development.

Chevreuse, the Medical and Educational Institute

Jean-Marc Cluet introduces us to the early work with deafblind infants and their families at this special centre in Paris, France

In 1972, L'Entr'aide Universitaire* undertook, within an associative framework, to promote and develop welfare activities in various fields where urgent needs were emerging. Alerted by some families that could not find any adapted services for their children with the double handicap of blindness and deafness, L'Entr'aide Universitaire studied various possibilities of facing this issue.

One of the main causes of this dual impairment was rubella in pregnancy. There were also after-effects of meningitis, and some congenital deaf people had retinitis pigmentosa.

An evaluation of the needs in France was made by, among others, a parents group CLAPEHA**, and we counted near 200 deafblind children, two thirds of them under the age of 20.

First, special consultations for deafblind children were set up at the Centre of Educational Assistance of Rozanoff Street in Paris. Very soon, at L'Entr'aide Universitaire staff came to think about creating a school; it was important to organize early care for these young children who might receive a special education. In 1981, ten people or so went to the Netherlands to join the St Michielsgestel team that had been working with deafblind children for over 20 years, under the leadership of Professor Jan van Dijk, a well-known specialist in deafblindness. This staff came back with lots of information and experience – enough to lay the first stones of the Chevreuse Institute.

The Chevreuse Institute

The Chevreuse Medical and Educational Institute opened in 1982.

To begin with, it served 24 boarders and 6 day-pupils. And for short periods it also saw mothers and their babies, living too far away to come for a consultation.

Early education must begin as early as possible. Too often, mothers are disarmed and it was necessary to teach them how to take care of their infants. Babies must feel they are receiving the attention of their environment, they must feel secure. Clinical information must be refined, in order to make the best of the remaining vision and hearing in an adjusted rehabilitation programme.

This service had 4 independent rooms. Mothers learned repetitive gestures to create contact with babies, and some small physical exercises and some care that steadily and durably will contribute to their child's development. During those first years, a true partnership was created between parents and professionals. They came with their children and took part in activities.

What was it like?

The premises were organized around a central patio and we created 3 autonomous living units, with rooms for the children, one room for their special education teacher, and a living room with a kitchenette.

It was important that the children should feel it was their place, that they should be supported by a limited number of professionals, (always the same), so they should feel secure, and that contacts should be established.

The daily life actions of washing, dressing, tidying up... must be done according to a routine that create bases and enable the child to develop. It is absolutely necessary that all team members totally agree and work in harmony with the child. Everyone did their best to use refined techniques inspired from those used for deaf or blind children, communicating the fruit of his/her observations, and learning from the failures and achievements of each of the children.

Training

The team was organized around the members who had had training in the Netherlands in order to develop skills and knowledge adapted to every child capabilities. The preferred communication was dactylogy involving both the tactile sense and sign language. A set of special equipment, for group or personal use, allowed the maximum use to be made of remaining vision and hearing. With patient active attention, thoughtful repetitiveness, agreement between them, medical and paramedical staff and special education teachers were bringing quality care and, up to a point, educational opportunities to each of these children.

Four teachers were added to the projects but progress was slow, the handicap was severe, and the pathological disorders, mental deficiencies and learning abilities of each of these children would not allow them to become other "Helen Keller".

Difficult times

Around the adolescent period, a kind of split happened between families and institution. It was very hard for families to accept the slow progress of their children and many children did not get past the symbolic stage. The initial vision was very far from reality, and that brought on some disagreement within the teams. This period was in keeping with a sudden awareness of the complexity of the child, a taking into account of learning disability, behaviour and personality disorders. Some children left the Institute, new ones arrived, with various aetiologies: Usher syndrome, CHARGE syndrome, and genetic conditions...

Changes

The leading team, that originated the project, gradually left.

A new dynamic was marked by a new project for the older and the more autonomous of the youngsters. Another unit was opened to answer the question: How can we make the youngsters understand that they are growing up? They left the institute and went to pottery, woodcraft, or cooking workshops... and a lot of outside activities were organized around the teenagers. This was felt as a development with new hope, and the positive exchanges with the families resumed.

*Entr'aide Universitaire: University Mutual Aid

**CLAPEHA : Liaison and Action Committee of Parents of Children and Adults with Associated Handicaps.

The European Holiday – in Bulgaria

Giuseppe Gargano, known as Pino, sends us a postcard from Varna...

My name is Pino, I am both visually and hearing-impaired. I would like to tell you about my time spent in Bulgaria, assisted by my communicator/guide Stefania Scafa.

Saturday 2 July

In the morning we were at the airport in Rome, ready to leave, but the plane was late and we had to wait! We changed planes in Hungary and, because of our initial delay, our second flight was ready without much further delay. We arrived at 3.30 pm but our luggage did not come with us - it had been left in Budapest - so the next day Stefania got up very early to retrieve it.

Sunday 3 July

We went out to visit Varna along with a deafblind woman from Russia and her interpreter. It was raining and we had no umbrella! We went round the shops and then we ate in an underground restaurant. Varna is nice with quite a few shops, but it is not a rich city. Once we returned we had dinner and deafblind people from many European countries had arrived. There was a small group of Bulgarian deafblind people and there were also other Bulgarian people with us on the holiday.

Tuesday 5 July

We went with the group to a place that many years before had been covered by the sea. Over the years the seas have dried up and there were very large standing stones that were described to us as being energy sources. We were encouraged to put our hands onto these stones in order to gain positive energy. That evening there was a party hosted by the President of the Bulgarian Deafblind Association. There was some Bulgarian traditional folk music and it was wonderful.

The next morning we went to the Black Sea where the beach was covered with shells. This beach was 15 minutes walk from the blind school we were staying at. In the afternoon we went to Varna where we were invited to meet the Mayor at the Town Hall.

Wednesday 6 July

We travelled 50 km from the school into the countryside where there was an old Bulgarian farmhouse containing a museum and a restaurant. As we entered we were offered bread that we were told to dip into a bowl of Bulgarian spices, which

is a local custom. I took many photographs of the tools used in the past by Bulgarian farmers and also of the environment they used to work in. A group of local deafblind people came to meet us and apart from singing Bulgarian songs they were also dressed in traditional clothing and they offered us handmade gifts. Some of these were women of 80 years old who gave us handmade woven plant containers. We then went to the sea but the weather had changed and it was cold.

Thursday 7 July

We walked from the school to an equestrian centre and exhibition area where we were able to ride on horses that were led.

We had a free afternoon so I went to the beach where I was able to watch men pulling in their nets from the sea. This is a very hard job that lasted several hours.

Friday 8 July

We visited a park that had trails for disabled people where the names of trees were written in Braille. We had lunch with the group from Belgium and in the afternoon we went for a boat ride on the Black Sea.

Saturday 9 July

We had a free morning and I went to the beach with the French group. In the afternoon there was a chess tournament where the non-Bulgarians played the Bulgarian professionals. The Bulgarians won most games!

That evening there was a dinner and party which lasted all night. We had to say our farewells because everyone was leaving.

Stefania and I stayed a little longer, getting to know the town a little better, shopping for souvenirs and relaxing. Next year the holiday will be in Moravia in the Czech Republic. I hope to meet you there!

**European Conference
Prešov, Slovakia
August 2005**

**Helen Keller World Conference –
Tampere, Finland June 2005**

A letter from Colin Bennett

Suddenly, a group of people moved across the pavement and cut me off from my quarry. I was momentarily disorientated. Where was I? And what was my quarry? Well, I was walking on the streets of Tampere, the second city of Finland (OK: I know the good citizens of Turku claim that they are the second city of Finland but we will let that pass.) My quarry was one of those suitcase trolleys being pulled by a Swedish participant in the conference that we were about to attend. As long as I could keep sight of the trolley I could follow the Swedes in their quest to find their hotel. Everything was alright if I could stay a few metres behind them. I rushed forward and managed to capture the elusive trolley again – until the next time. Eventually we reached their hotel and I was able to get my bearings.

It was early June 2005 and I had just flown into Tampere Airport to attend The 8th Helen Keller World Conference, which is held every four years in different cities across the globe. Interestingly, Helen Keller had visited Finland and there exists a grainy film clip of her visit not long before her death. I was representing Sense, The National Deafblind and Rubella Association: the UK's largest charity in this field. Also taking place at the conference centre was the 2nd General Assembly of the World Federation of the Deafblind (WFDB).

I had last been in Tampere in 1967 and thought I would recognise it but I could not. At the Airport I had met a group of Swedish participants and after “exploring”, eventually I found my hotel which turned out to be a very modern one. I collected my key from the receptionist and I asked her if someone could show me to my room. “No” she said, but I was not surprised or offended. This was Finland after all and people are expected to be self-sufficient. It was very comfortable but I was presented with that terrible Finnish phenomenon: tiny pillows. There is always a spare pillow but trying to sleep on one tiny pillow perched on another or side by side is just as bad as dealing with one. However, Life has brought bigger problems to me than that.

The 4-day conference was based at Tampere Hall and was attended by 417 people from 45 different countries. The slogan of the conference was “Our Right to be Deafblind with Full Participation in Society” and, the participation in, and the organisation of, the conference lived up to that ideal.

The arrangement was the normal one of workshops and plenary sessions. Also normal was the dilemma over which workshop to attend as they clashed. A further complication was the fact that the 2nd General Assembly of the WFDB was being held, largely in parallel. A welcome feature of the conference was the information desk, where very competent Finns were able to answer any questions. There was an unobtrusive contingent of Finnish student sign language interpreters who popped up whenever you needed them, complete with their fetching neckerchiefs. They were very useful for people like me who had no guide or communicator even though I do not sign. They spoke excellent English (the language of the conference) and could sign in Finnish and other sign languages. We all had name badges which we wore day and night (perhaps I exaggerate). I think these badges should be jumbo-sized with large lettering in contrasting colours.

The opening ceremony was preceded by a session in which the arrangements to assist people with sensory loss were explained. For me, with Usher Syndrome 2, this meant induction loops and I am pleased to say that the quality of these was high. Also remarkable was the quality of the simultaneous translation into English and Finnish of other languages including sign languages. There was always a copious supply of sign

language interpreters at the front of the auditorium. An interesting feature of the conference was the continuous description in English and Finnish of everything that was happening on the stage. We got to know the Finnish word for “description” (kuvala) as this word was used whenever the skilful describers gave us very comprehensive information over our headphones.

I will not give a blow-by-blow account of the proceedings of the conference as you can read about this in the published material. I would rather mention the peripheral activities. Near the beginning of the conference we were all invited to a reception at the Tampere Town Hall where the Mayor welcomed us using an excellent PA system. These functions are always difficult for people with serious hearing problems who cannot sign, because of the background noise. I normally retreat to a corner to eat and drink the goodies (never a hardship) and hope that people will come up and talk to me which usually happens. Another big event was the outing to Viikiinsaari, an island in a nearby lake. The island was a typical Finnish holiday place with a dance hall, a sauna and bonfire provisions. I well know that June days in Finland can be really warm and pleasant but I had a job persuading many of the participants that this was the case. The day was so cold and drab and I felt sorry for the African delegates huddled around the bonfire. Still, I think we all had a good time although we were very unlucky with the weather throughout the conference.

Another memorable visit was that to the well-equipped Resource Centre and living quarters on the outskirts of Tampere. This is an exemplar not only for Finland but also for the whole world.

The conference finished on the Tuesday morning but I decided to stay the extra night. It is good practice for Usher people to start a trip as early as possible in the morning to get maximum light, even in the Finnish summer. I wandered around the city and did a dry run at the station for the following morning. Early that next morning I got lost at the station because it is very big and mostly underground. At last I found the platform but I was three minutes late for the train. Amazingly, it was still there so I jumped in just as the doors were closing. When the ticket inspector came along I asked in mock indignation why the train was four minutes late: “What is the world coming to?” He hung his head in mock shame and the ice was broken among all the passengers in the compartment. Finns are like English people – they are rather reserved but they like a joke. So I was able to converse all the way to Helsinki Central Station and was taken right down to the correct line in the new Underground station there. The Metro system had been built since my last visit.

I found my way – I don’t know how – to the headquarters of the Finnish Blind Society where the Deafblind Society has Offices. I met the new chums I had made at the Conference. I spent a couple of days in Helsinki with Heikki and others and then spent a few days with old friends near Lahti.

Colin Bennett
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If you would like to see a lot more photographs of the conference, please contact Colin as he has a Yahoo Photo Gallery.

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Secretariat News

Management Committee

Meetings of the Dbl Management Committee and Council took place in August 2005 prior to the Dbl European Conference in Slovakia. If you want more details on these meetings contact the Secretariat at secretariat@deafblindinternational.org.

The major Dbl events coming up are:

- The 14th Dbl World Conference will be held from 25-30 September 2007 at Burswood Resort in Perth, Western Australia. It is being organised by Senses Foundation. The Scientific Committee had its first meeting in August 2005 and has started to design a programme which we are sure will be interesting and relevant to people from throughout the world.
- The next Dbl European Conference, in 2009, will take place in Italy and will be organised by Lega del Filo d'Oro. This decision was made by the Dbl Council at its meeting during the Slovakia conference. Many congratulations to Italy!!

Membership Update

All Dbl members are encouraged to renew your membership, if you have not done so already. Please quote your specially assigned membership number in all communications.

There are currently more than 650 individual members and 50 corporate members from more than 80 different countries.

If you know of any organisation that may be interested in joining Dbl as a corporate member, please pass on their details to the Secretariat now!

Dbl would like to express its appreciation for the continued support of the large and small corporate members. We strongly encourage individuals to join Dbl in order to contribute to and widen our global community in the field of deafblindness.

If you have any queries regarding the status of your membership, please do not hesitate to contact the Secretariat at secretariat@deafblindinternational.org

Dbl Website

We have redesigned and updated the Dbl website so as to provide regular up-to-date information and make it more user-friendly and easy to access. Please do keep visiting the website and send us your comments and feedback!

We welcome new submissions to the website so if you would like to contribute or advertise an event or recent success, please send details to Eileen Boothroyd, Dbl Information Officer, at Eileen.Boothroyd@sense.org.uk

The Dbl Secretariat

The Dbl Secretariat is always aiming to improve the service that we offer. We look forward to your suggestions, advice and support for providing a timely and effective service.

We hope that you received your copy of the previous issue of Dbl Review (issue 35). If you have not received your copy, please contact the Secretariat. We are also keen to update the information we have about you and your organisation, so kindly make sure you send your membership renewal forms with your latest contact details to the Secretariat.

If you have any queries regarding your current membership or would like to complete the membership form via email, please contact Sumitra Mishra at: secretariat@deafblind

international.org or post your query at: Dbl Secretariat, Post Box No: 9601, Janakpuri, New Delhi – 110058, India.

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 two tiers of Corporate Membership:

Large Corporates:

Annual Fees between 3,000 and 5,000

Small Corporates:

Annual Fees between 300 and 1,500

Corporate Members can be nominated to sit on the Council.

Membership

Deafblind International Individual Membership

n I would like to join Dbl as an individual member

n 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 Spanish

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

Corporate Membership

There are two tiers of Corporate Membership:

Large corporates

Annual fees between 3,000 and 5,000

Small corporates

Annual fees between 300 and 1,500

We would like to join Dbl as a Large/Small

Corporate Member (please delete as appropriate)

We submit an annual fee of

Corporate members are entitled to receive

up to 25 copies of Dbl Review. We would like• - _____ copies in English Spanish

(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 much 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 DbI.

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 91-11-25618430 or return to:

The Secretariat, Deafblind International, Post Box No 9601, Janakpuri, New Delhi – 110058, INDIA.

The World Association Promoting Services for Deafblind People

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