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THE MAGAZINE
OF DEAFBLIND
INTERNATIONAL

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Review



Developing Communication

A MESSAGE FROM THE PRESIDENT

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 the education of deafblind children and young adults. Photographs and drawings are welcome; they will be copied and returned.

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

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

Dbi Review is also available in Spanish or on disk. If you are interested in receiving your copy in either of these formats please contact:

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Just a few weeks ago I had the pleasure of chairing our meeting of the Management Committee of Dbi in London, a meeting in which many important issues regarding the way forward for the organization are being resolved. We had the opportunity to review a lot of the upcoming work and events sponsored under the Dbi banner. In that line, let us please welcome aboard Emma Fisher, who will be working within the Secretary's office at Sense handling a lot of the office and clerical needs of our association.

As you will recall, we had planned a conference for the Africa region of Dbi for 2002. However, due to some unforeseeable circumstances, we have had to postpone that event for the time being. On a more positive note, in March I had the honor of attending the first South African National Conference on services to blind multi-impaired and deafblind children. This event

was organized by Sam Boshielo of the Sibonile School, along with Anlo van Heerden of the Pioneer School, and the committee for the multiply impaired of the South Africa National Council for the Blind. Over 70 people from many schools throughout the country were in attendance.

To see so many gathered to learn about deafblindness was most inspiring. Not long ago there was only one program for the deafblind in South Africa, at the Pioneer School in Worcester. In recent years the Sibonile School's program was begun by Sam Boshielo to serve some of the black population. Now, of course, both these programs are quite integrated. At present, there are four schools serving deafblind children as a special focus within their curriculum. Many others in attendance at the conference have identified deafblind and blind multi-handicapped children and are planning to start serving them in the

EDITORIAL

Life here has been very busy since the last issue and it's been very good to hear from so many friends from all over the world during the Spring. With the theme of the magazine leaning, yet again, toward communication I think we can all agree that getting in touch with people who are far away has, at least for many of us, really improved as a result of new technologies being



adapted and made more widely accessible and affordable to us all. One of

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coming year. Theo Pauw, one of the early founders of Dbl and godfather of deafblind education in South Africa, presented a keynote address, in which he expressed his excitement at seeing this new expansion of interest in deafblindness within his country.

We now look forward to a most comprehensive program that has been planned for the 5th European Conference being held this Summer in the Netherlands. It is very good news that about 68 people from Central and Eastern Europe will be sponsored to attend this event, with lots of support

our lead stories this time is about "The Link" in Victoria, Australia. Here's an example of technology providing new opportunities with great success. In contrast, and accentuating the personal touch, Daniel Alvarez Reyes from Spain describes the development of his own communication system, and reveals how it affects his life. Those who have met Daniel are fascinated by the speed at which he works with his interpreters and this article provides many personal and revealing insights.

from NGOs and the European Union. Our thanks too go to the many Eastern and Central European agencies who have expressed interest in hosting the next European conference in 2005. We will be making a decision on the applications within the next couple of months.

We are all looking forward to the next World Conference, to be held in Mississauga, Ontario, in 2003, hosted by our friends of the Canadian Deafblind and Rubella Association. We will have much more detail about this meeting available at the Holland conference, but in the meantime you can visit their web site at www.dbconferencecanada.com.

I would lastly remind you that we take rolling applications for hosting conferences. You may apply at any time for a future conference. Therefore if you are interested in hosting the world conference to be held in 2007, please contact Emma Fisher at the Secretariat for an application form.

Michael Collins

Without our email here we certainly wouldn't have been in touch with Kathleen Prime, whose timely thoughts I am sure will bring her many new friends. Our old friends Jan and Graham Scahill from New Zealand also use this medium to share news. They are at the centre of conference organisation in the Southern Hemisphere at the moment – as are many others in Europe – so enjoy the meetings and keep in touch!

Eileen

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The 'Dactyls' method of communication

Daniel Alvarez Reyes, President of ASOCIDE in Spain, describes how his personal communication system has developed and how it has made communication easier...

Introduction

When an individual loses their hearing, they begin to rely on other methods of communication. The method adopted will depend on whether the individual has congenital or acquired deafness. Individuals with acquired deafness may be able to continue to express themselves orally, but, in both cases individuals will change their receptive communication: lip-reading, sign-language, bimodal, etc. All these receptive methods are visual, i.e. the deaf person "hears" through their eyes.

However, what happens if an individual is blind or severely visually impaired as well as deaf? This presents far more serious problems in terms of communication. As the individual can no longer use the visual or audio channels of communication, he is left with the sense of touch. The hands act as the channel for receptive communication, using systems adapted for receiving information by touch, and as the means of gaining information about his surroundings.

Effective communication is therefore the key to social

interaction for deafblind people in their social and cultural environment. Both professionals and deafblind people take a keen interest in any development relating to communication, in the search for quicker and more effective methods of communication.

One of the greatest problems with the methods of communication used by deaf people, especially with manual alphabets, is the slow speed in transmitting information. This is because communication is performed manually, letter by letter, using different finger positions or writing letters with the index finger in the palm of the hand. Pressures of time make it difficult for the speaker or interpreter to use these systems to transmit information about what is being said and what is happening in the surrounding area.

Another method, sign language, which does not rely on the alphabet, offers greater potential as it is a faster method. Deafblind people who learn this system can receive information more quickly and effectively with sign language than with the manual alphabet. This is the main advantage of sign language as a basis for developing faster communication for those who use manual alphabets.

Deafblind people who learn this system can receive information more quickly and effectively with sign language than with the manual alphabet.

Daniel's method

Sign language is the first language for individuals affected by congenital deafness. If they later lose their sight, they can adapt from the visual to the tactile version of sign language and continue to use it. However, individuals who lose their hearing in later life do not generally learn sign language. People with acquired deafness usually learn one of the manual alphabets, since these retain the structure of speech. It is also difficult to learn sign language, though an individual may learn a few signs or basic symbols.

I will now explain my method of communication which developed naturally. It has always attracted a lot of attention and interest from professionals and deafblind people, not only in Spain but worldwide. They have asked me on many occasions to write an article on my method. In fact this method is already being imitated by interpreters and deafblind people in parts of Scandinavia and Latin America due to the advantages it offers in communication.

Before I explain the method, I should point out that I have learned and used sign language although my deafness is not congenital. I

learned sign language at the age of 18 when I lost my hearing. This knowledge of sign language was a decisive factor in developing my system. I hope to present it as clearly as possible.

The combined alphabet and sign method

The system I use, which I refer to as "Dactyls", has always attracted attention due to its speed of communication. This became apparent in meetings and international conferences as my interpreter completed the translation before other interpreters. What was the reason?

My system combines the Spanish manual alphabet for deafblind people with signs from Spanish Sign Language (LSE), adapted for use in the palm of the hand, i.e. it uses both letters and signs in the hand. Depending on the information, it either spells out the word letter by letter or, where there is a sign, this is represented in the palm of the hand; the greater the number of signs, the quicker the tactile communication.

I have incorporated the most common words as signs in this system and have also included many technical words relating to my work in the field of deafblindness. Less common words, articles, pronouns, etc. are spelt out with the manual alphabet and the structure of speech is retained through the use of signs and letters.

I have already included a large number of signs and with practice continue to increase this number. I initially included signs made on the face but found this very inconvenient so now limit signs to the hand, wrist,

forearm, arm, shoulder and chest.

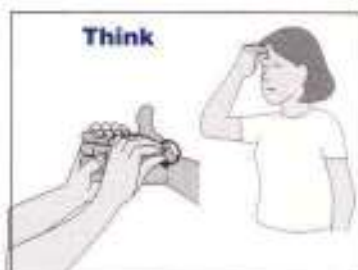
Most signs use just one hand, but two hands may be used when necessary to adapt a sign.

Keys to using signs

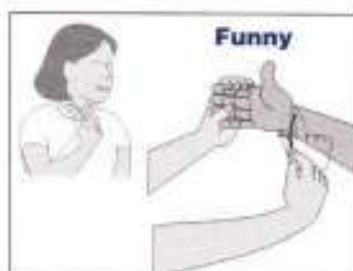
The signs used are based on Spanish Sign Language and represented in the palm of the hand. When a sign is not easily intelligible in the palm, either due to its position or movement, it is adapted to a close variant. One very important rule is that signs must be understood clearly and quickly by touch so it may be necessary to change signs or on occasions to invent a new alternative sign.

Keys to developing the system

One of the keys when adapting this system was to consider the hand, from the tip of the fingers to the wrist, as the face of a person. Therefore if an LSE sign was made on the face, this sign would be represented on the palm of the hand with the same configuration and movement. For instance, if a sign was made on a specific part of the face, the same sign would be made in the corresponding position on the palm: the forehead is the upper palm, the wrist represents the neck, the tip of the thumb the ear, etc. To illustrate this:



In the same way, the wrist can represent the neck, and the forearm the chest to represent signs.



However, many signs are also made in the palm of the hand, wrist or forearm which do not necessarily represent the head, neck or chest.



Clarity is one of the most important factors which adapting signs: a sign must be represented so as to be understood by touch either by its position or by movement, and the head-hand analogy is not a fixed rule.

Advantages and disadvantages of the system

This system does retain the same structure as speech in transmitting information. The use of the manual alphabet alone, i.e. communication letter by letter, is slow and does not permit an individual to follow the speed of speech,

especially when people speak quickly. There is also no time to translate, to "see" what is happening if there are any changes in the surroundings.

The incorporation of signs increases the speed of communication, as a word, for example "professional", can be represented by a single sign in the palm of the hand.

This system can be as fast or faster than sign language, although it is not intended to replace it: deafblind people with congenital deafness who have learned sign language are advised to continue to use this method, as adapted from the visual to the tactile version, i.e. the deafblind person places his hands on the interpreter's hands to read what is being said.

I consider my system to be most useful for people who learned to speak before becoming deafblind, who are therefore able to express themselves orally. Such individuals do not generally know Sign Language and normally learn to use the manual alphabet as a means of receiving information by touch. It is very difficult to teach Sign Language, but it is possible to teach a number of signs or symbols, the more the better, to allow greater speed in communication. Besides, this system does retain the structure of speech as I mentioned earlier.

The disadvantage of my system is the need to teach it

The perception of emotions in others is very important as it enables us to be more expressive.

What is vitally important to me is to be able to gain clear and speedy information about what is being said and what is happening around me and to be able to act accordingly.

to each person or interpreter, which takes time. For this reason, very few people use it (friends, regular interpreters, etc). It would be necessary to draw up a visual dictionary showing how to represent each sign, if the system was to be used more widely. It would not be appropriate to develop the system without such a dictionary as each deafblind person would use their own signs that could not be used to communicate between each other. If an interpreter learned the signs for one deafblind person, they could not be used or understood by another.

One further important advantage is that by combining letters and signs, the method can represent information about the emotions of the interpreter or speaker. It is possible to capture nervousness, by a subtle change in the way of representing the sign, a greater pressure, etc. It is also possible to note that they have lost the thread, lost interest or are either tired or delighted to be speaking. This is very important information, as it allows us to appreciate emotions that cannot be seen and tones which cannot be heard.

It is a pleasure to know when our interpreter is laughing or tells us that our speaker is laughing as we can respond with a smile.

The perception of emotions in others is very important as it enables us to be more expressive. If we do not know what is happening around us, it is not surprising when deafblind people remain lacking in expression.

Conclusions

When I became deafblind, I began to use the method of writing Capital Letters in the palm of the hand, a system that proved very slow. I therefore started to incorporate signs (I knew Sign Language), to increase the speed of communicating information. Later I learned the Spanish manual alphabet, which is much faster than writing in the palm, which enabled me to develop a perfect combination for receiving information as words could be either spelt out or signed as appropriate.

This system changed my life and has proved tremendously useful in my work, in attending conferences, seminars and meetings, and in all activities I undertake. What is vitally important to me is to be able to gain clear and speedy information about what is being said and what is happening around me and to be able to act accordingly.

As this system has been very useful for me, I believe it could be very useful for many others.

I would like to thank all those who have contributed to the development of this system, which gives me the most effective communication I could ask for.

Translated by Julie Allday



The Link

Celestine Hare discusses the development of a project that is changing the lives of disabled people in Victoria and across Australia.

Following a submission to the National Office of the Information Economy (NOIE), The Deaf-Blind Association was successful in receiving an AccessAbility grant in September 1998. The grant was to establish, over a two-year period, a Computer and Internet Access training program, with appropriate adaptive technology, for 10-15 people with deafblindness in Victoria, subsequently named "The Link".

This project started from nothing and we are constantly learning new things! Our experience to date has reinforced the need for customised programs to meet the individual needs of participants. This means addressing not only adaptive technology requirements but also screen colours, font size preference, and sequencing of training modules.

The Link is proving to be a unique and wonderful opportunity to reduce the isolation of deafblindness and we are very excited about the extension of this opportunity beyond Victoria.

A typical day at *The Link*:

- Checking and making repairs if necessary to the computers.
- Trouble shooting any problems people may be having.
- Reinstalling programs when necessary.
- Communicating with visitors.

- Helping with signing classes at *The Link*.
- Helping to solve any problems accessing the Internet at *The Link*, or even at their home.
- Listening to ideas and answering any questions.
- Making sure everyone has tea, coffee and milk available for the day – very important.
- Co-ordinating other volunteer support to assist any participants dropping-in.
- Answering the Telephone Typewriter.
- Making sure *The Link* is a safe, clean and fun environment.

Intranet Home Page

Over the past year we have put together an intranet home page that can be read by everyone who visits *The Link*. Every computer in *The Link* network can access this and input from volunteers, trainees and staff is encouraged at all times. Tuition is given in designing the home page, how to add additional information and surfing *The Link*'s Home Page. As people became more confident in using, designing and adding links to this page it was uploaded to the Internet and made our launch onto the World Wide Web possible. (<http://www.netspace.net.au/~dbalink/>)



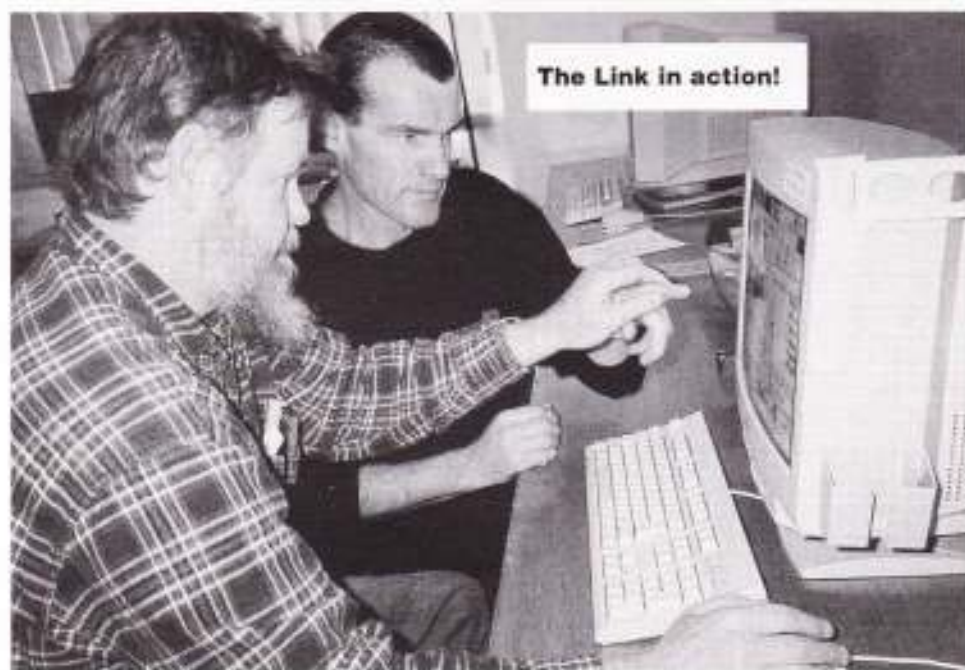
Celestine Hare

The Link is a major voice in information and technology for people who are deafblind throughout Australia and there is no turning back!

Being able to customize user profiles has been an essential element in the success of *The Link*. Each client can be assured at startup that they can read the screen with the following customized settings:

- display settings – background colour and text colour and size,
- mouse pointer – size and colour,
- email account – private account where they have control over how many emails they receive and who from.

Our experience to date has reinforced the need for customised programs to meet the individual needs of participants.



The Link in action!

- internet favourites folder,
- desktop icons,
- startup programs.

Identifiable outcomes and benefits

Access to private email accounts

Email gives people with deafblindness instant access to a wide range of information and people, with relative immediacy. Prior to email, they had to rely on having their written material in large print, Braille or read to them by another person.

Participants can now talk to email friends around the world, can organize social outings and arrange service with agencies with ease and reliability.

Internet Relay Chat

Chatting on the computer was mainly conducted at *The Link* with known people. Monthly technical meetings were conducted without an interpreter as participants could each sit at a computer and participate by typing and

reading. Whenever there were more than two participants wanting a conversation or when visitors arrived, they could converse via the computer.

Generally participants were reluctant to join an online chat room as the speed of the chat was too much to read and they felt a little intimidated by the topics. At one stage they tried to set up a chat room but the program did not support customized screen display settings and they were not able to participate.

Internet

All the obvious advantages of the Internet are equally true for people with deafblindness. Looking up football and cricket scores, checking the weather, reading the newspaper are regular highlights and even more essential as deafblind people don't hear the scores on the radio, TV or read them in the paper. They are also able to follow their special interests: American baseball, cooking recipes, knitting patterns or gardening hints.

Some have been looking

at banking and shopping online but are still yet to take up this activity!

Word Processing

General independence in word processing has produced regular newsletters, mailing labels, articles, meeting reports and agendas, invitations and letters.

Scanning

Scanning has allowed the incorporation of photos in the above documents and has proved very popular in email correspondence.

Text scanning with optical character recognition has enabled complete independence for participants in reading all manner of correspondence. This material is read on the computer via Braille or printed in Braille for permanent copy.

The Next Step

The Link is an essential service for people with deafblindness, and we plan to continue to enhance the Train-the-Trainer program based on the knowledge and skills established over the last two years. The provision of training to interstate representatives will be a key in making this program national.

The deafblind community has embraced the opportunity to develop their computer skills. The impact of technology in reducing individual isolation cannot be underestimated. With the program being so successful, we are now seeking further support from government, the corporate and the philanthropic communities, to ensure this vital resource is not lost to the community.

Check the link out yourself at:

<http://www.netSPACE.net.au/~dbalink>

The Link, 3rd Floor, Ross House, 247 Flinders Lane, Melbourne 3000 Australia

Text: (03) 9639-7900

Fax: (03) 9650 3689

Voice: (03) 9654-7133

Aspects of acquired deafblindness

Anneke Balder, Chair of the Acquired Deafblindness Network and co-ordinator of the Unit for Deafblindness of the Netherlands Foundation for Rehabilitation (formerly Stichting Doof-Blinden) writes about acquired deafblindness and the people it affects.



Deafblind people are people who are deaf or hard of hearing and blind or visually impaired. When we talk about acquired deafblindness we talk about a group of deafblind people who have acquired their deafblindness later in life. There are three groups of acquired deafblind people:

- 1 people born with normal sight and hearing.
- 2 congenitally deaf or hard of hearing people with acquired problems with their vision.
- 3 congenitally blind or visually impaired people with acquired problems with their hearing.

It is clear that a person who is born with normal sight and hearing and who acquires deafblindness because of an illness, accident or another reason, belongs to the acquired deafblind group. But congenitally deaf or hard of hearing people who get serious problems with their vision (like people with Usher Syndrome) and congenitally blind or visually impaired people who get serious problems with hearing belong to the group of acquired deafblind people too. That means that the group of people with acquired deafblindness is a group of people with very different

backgrounds and a complex set of problems. Some of the difficulties that individuals have encountered can be seen in the stories below.

Esther

Esther was born with a severe progressive visual impairment. Shortly after her fourth birthday, she became totally blind. She went to a primary school for children with a visual impairment and attended a normal school for her secondary education. She started to train to be a social worker. In the first year of this course, she had severe problems with hearing, the cause of which is unknown. A hearing aid was made available, and with the help of different guides, volunteers and friends Esther can finish her education.

Henk

Henk is congenitally deaf. As a small boy he went to a school and group home for deaf children. So Henk grew up in the deaf world and sign language was his first language. From when he was very young, Henk had problems with night blindness. When he was about fifteen years old, he started having problems with sight during the day. When he was nearly 30 years old, his vision became so bad that he could not see sign language any more. He became severely socially isolated, because he could not communicate any more with his family and friends in sign language. He had to learn another form of communication. For Henk, tactual sign language is some kind of solution.

Awareness raising is vital for the progression of this work





Nicole

As a result of meningitis, Nicole became deafblind when she was eighteen years old. Isolated from the people around her, who could not communicate with her, she suffered from severe depression. Then someone showed her letters in relief. She recognised the letters and made words with them. Then the communication with the people around her developed quickly. She learnt tactual finger spelling. Later, she discovered the Lorm system. The advantage of Lorm is that her friends learn to use it in about an hour. Braille gives her access to the computer; she can study, work with the computer and use e-mail and the Internet to keep her social contacts.

Riet

'I am 86 year old. I cannot hear any more and my vision is very bad. Some years ago, when I was only deaf, I could understand the people by lip-reading. That is impossible now. I have given my television to my granddaughter. Reading is impossible and the ringing of the house bell I cannot hear. But the most terrible thing is that people do not come to visit me any more, because they cannot talk with me. Often I think it is evening and it is only 3.00 am. I do not want to live any more ...'

Number of people affected?

Careful estimates, based on different research say that in every million people at least 250 are deafblind; 10% belong to the group of congenitally deafblind people, 90% to the group of acquired

Looking at the needs of acquired deafblind and elderly deafblind people, you see a strong need for services and projects with an emphasis on rehabilitation and support

deafblind people. That means that the group of acquired deafblind people is much bigger than the group of congenitally deafblind people. The sad fact is that (even in Europe) we know less about the kind of services acquired deafblind people need, than about the kind of services congenitally deafblind people need.

When you look at the age range within the whole group of deafblind people we see that 75% are older than 65 years and 25% older than 90 years old. Analysing the composition of this group of old and very old deafblind people we had to conclude that most of these people have acquired their deafblindness as a result of their age: they are born with normal sight and hearing, they have had a normal social and working career and acquire the dual sensory impairment later in life.

A special need for services

Although there is no common agreement yet about the blueprint for services for acquired and elderly deafblind people, some things can be said about this.

It is good to remember that acquired deafblind people have acquired the deafblindness later in life. That means that they have had a normal development from childhood to adulthood.

Looking at the needs of congenitally deafblind people, you see a strong need for services and projects with an emphasis on development: development of communication, development of all day living activities and the development of mobility.

Looking at the needs of acquired deafblind and elderly deafblind people, you see a strong need for services and projects with an emphasis on rehabilitation and support, both focused on maintaining independence.

With regard to rehabilitation, the activities that are important are



learning new communication skills, training for mobility, psychosocial help and all daily living activities.

With regard to support services we must think about services like interpreting services, guide/help services and volunteers.

Developing awareness

People who work in the field of elderly deafblindness all

know how important raising awareness is for everyone. Awareness raising is vital for the progression of this work. One of the main problems is that elderly deafblindness often is not recognised as a dual-sensory impairment presenting special problems. As a result elderly people are living in enormous isolation, because people around them do not know how to communicate and which technical aids are available.

Making the world aware of deafblindness, as one of the problems of old age, is an activity that must be undertaken in the years to come. Although it is a big job, we must start planning this activity, because it is a sad reflection that everywhere in the world old people with a dual-sensory impairment are living more isolated lives than necessary.



Holidays for deafblind people across Europe

Jan Jakes paints an amazing picture of the holiday programme so far – this year the holidaymakers are all off to Switzerland and could be skiing in Austria soon!



Jan Jakes

The idea of organising international holiday meetings for deafblind people was born in the summer of 1996 during a discussion with the late Jean-François Guerineau, the then director of C.A.T. de la Chaume, who was visiting Prague.

I was thinking about the idea of inviting deafblind people from various European countries to spend their holiday in the Czech Republic. I wanted to create, even for those deafblind people who do not have professional contacts among the deafblind community, a

chance to meet deafblind people from other countries. My idea was a "recreation and relaxation" stay with a programme that would make it possible for the participants to meet each other, establish personal contacts, share their experiences and get to know the host country. I discussed this plan with Jean-François Guerineau and asked him for help in carrying it out. He agreed and suggested that such stays should be organised in a different country every year. We decided that the first stay would be in the Czech Republic in 1997 and then in

France in 1998. We agreed that the programmes would include sport, cultural, educational and social activities.

The aim was to provide deafblind people in Europe with the following practical opportunities:

- to meet each other, establish and develop interpersonal communication;
- to share their experiences and to enjoy new common experiences;
- to go through an interesting holiday programme together;



Making new friends!

INTERNATIONAL HOLIDAYS



Drumming!

- to get acquainted with various countries and how deafblind people live in them;
- to develop and deepen their own initiative and activities; and
- to represent their own organisation and country by organising one of the international holiday stays themselves.

There have been three international holiday stays so far. The first one was organised in the Czech Republic in the summer of 1997. It was attended by 17 deafblind people from seven European countries. Its programme consisted of two parts. First there was a week's stay in the mountains: hiking, horse riding, sauna, hot-springs, swimming, an evening social event with live

music, an evening by the campfire, discussions and talks. The week in the mountains was followed by a two-day stay in Prague, the capital of the Czech Republic. Its programme included sightseeing in Prague with free time for shopping, walking, and a farewell evening party.

The second holiday stay for the deafblind people from Europe was in La Rochelle, France, in September 1998. The stay was organised by Jean-François Guerineau and Florence Chevallier. Eighteen deafblind people from six European countries participated. The programme offered trips to interesting sights on the Atlantic coast (hawser workshop, oyster park, historical towns with ramparts and battlements), sightseeing in La Rochelle, a visit to a marine museum

with fishermen boats and an oceanographic ship excursion, a boat trip to the island of Aix, a picnic, group and individual talks, and evening social events.

During the first holiday stay Peter Vanhoutte, a deafblind participant, volunteered to organise a similar holiday stay in Belgium. That is why the



INTERNATIONAL HOLIDAYS

third European deafblind holiday, EURO 2000, took place in Belgium. This meeting was attended by 16 deafblind people from nine European countries. The organisers, Peter Vanhoutte and Koen Amerlynck, prepared a rich and colourful programme. It was a combination of sporting, educational and cultural activities, multicultural communication, acquaintance games, and talking.

The participants visited farms, a museum and a Flemish Brewery. They also visited the world famous high-tech centres on speech and audio-visual technology 'Flanders Language Valley' and 'Lemout & Hauspie'.

During the last evening of the Belgian stay, the participants agreed to organise the following holiday stay in Switzerland. The stay is being prepared by ARSA

(Association Romande Sourds-Aveugles), FRSA (Fondation Romande en faveur des personnes Sourdes-Aveugles) and UCBA (Union Centrale Suisse pour le Bien des Aveugles). The stay will take place on August 19-28, this year.

It is hoped that a European deafblind holiday will be held every year, each time in a different country. Several organisations replied to our request with concrete suggestions. In 2002, the holiday stay will be held in Croatia, and in Poland in 2003.

So far we have met during the summer holidays. Now, Austria has come with an interesting suggestion. There they would like to organise a winter sport skiing activity next year! This would mean a chance for those deafblind people who like skiing, or would like to try it, to participate!

It is certain that deafblind people like to visit other countries and to get acquainted with other deafblind people. The European holiday meeting is a very interesting and quite exciting experience for many of them. Such events can contribute to the establishment and development of closer friendly relations among the people of Europe. On the basis of these social, cultural, sporting, and/or other recreational activities it is possible to do the following in a practical way:

- to promote social contacts, intercommunication, and sociability;
- to raise morale and competence; and
- to enhance their self-consciousness, self-reliance, and self-confidence.



At the funfair

INTERNATIONAL HOLIDAYS



For the future

It would be excellent if other national organisations of deafblind people would be willing to organise holidays in the future. The holiday could reflect what is interesting about the host country – and of course, the main task and goal; to help the deafblind individuals.

To make organising the stays easier, an informal 'ad hoc' co-ordinating unit was formed. The present co-ordinators are Peter Vanhoutte and I, Jan Jakes, both of us deafblind people, and we are happy to co-ordinate the holiday calendar and offer advice.



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Deafblind education: a case study in Mampong- Akwapim in Ghana



Ms. Grace Yawo Gadagbui is a Senior Lecturer in the Department of Special Education. Her area of specialisation is Communication Disorders and Sciences (Speech Therapy major) and Audiology (Paediatric Habilitation) and she is a teacher of the hearing impaired. She is now the Dean of the Division of Specialised Professional Studies in Education of the University College of Education of Winneba.

Grace describes a survey she has undertaken this year that gives a picture of the way in which special education is developing in Ghana and highlights aspects of their teacher training programme.

Introduction

Deafblind children, or children with dual sensory impairment, are those who have a combination of sight and hearing impairments, but are not necessarily totally blind or profoundly deaf. Some of these children have residual hearing and vision.

Some of the additional disabilities the deafblind children have are physical, intellectual and social. However, major problems which characterise these children are communication difficulties, underdeveloped motor skills, mobility, social behaviour and cognitive limitations. Deafblind children may have intellectual levels ranging from giftedness (as in the case of Helen Keller who at the age of sixteen lost both sight and hearing) to severe mental retardation. Educational placement in the US, for example, is at residential schools for the blind and deaf, early childhood developmental centres, vocational training centres and regular public schools. (Heward & Orlansky, 1988). In developed countries, such as the U.S, some are able to be integrated or placed in special schools and gain admission to secondary schools with supportive assistance provided by special teachers. Some communities also offer employment in their shops (Kirk et al., 1993). Due to dual impairment, these children obtain most information through secondary

senses, such as, taste, touch, smell, and kinaesthetic means, and also by residual hearing or sight and through indirect information supplied by others. Since communication is a major problem, a strong emphasis is made on some form of sign language, gestures, speech, tactual and speech reading (if appropriate), and for others the use of finger spelling to supplement sign language. In addition to vocational training, daily living skills such as bathing, washing, dressing, cooking, communication, and moving around one's own environment are some of the important skills deafblind people learn.

Deafblind education in Ghana

In Ghana, deafblind education started on 10th January, 1978 at Mampong-Akwapim in the Eastern Region. (Gadagbui: 1998). It began with Ms. Marion Obeng, a teacher of the deaf who was interested in a boy who was both deaf and blind. She sought help and both of them had the opportunity to go to the Perkins School for the Blind in Watertown in the United States (Avoke, 1997). After two years they both came back and with financial support from the CBM, a classroom block with water, hearing aids and a Volkswagen pick-up were acquired. In addition, the CBM sponsored a teacher to attend a course in the Netherlands.

Now, the Government of Ghana trains the teachers at the centre, pays their salaries, and provides board and lodging for the children. To supplement the Government's aid, CBM is still giving financial support, equipment, and materials for teaching and learning. This is also complemented by the Ghana branch of World Vision International.

Admission is by assessment conducted at any of the assessment centres in the country. The centre has been active in promoting its activities with workshops for parents and as a place to make visitors aware of how teachers shape the lives of these children and help them to be independent.

Nevertheless, the deafblind department is the least developed of the special education schools in Ghana. It is not autonomous, but under the administration of the Demonstration School for the Deaf at Mampong-Akwapim. To create awareness of the activities of the deafblind programme in the department, a survey was carried out from 1st of February to 16th February 2001 on the school.

Objectives

The aims were three fold:

- i) to identify the strengths of the children's functioning capabilities,
- ii) to project and promote deafblind awareness to the public,
- iii) to determine the need to focus attention in training teachers for deafblind education in the country.

Methodology

Population

Teachers of the deafblind and deafblind children participated in the study.

Sample

Seventeen participants were involved. Seven teachers made up of five females, including the Headmistress, and two males, and ten deafblind pupils (one female, nine males) aged between 10-25 years participated.

Research Design

Qualitative research tools, such as questionnaires, interviews and observations were used.

Procedure

Interview questions and a questionnaire were used to gather information from the seven teachers on enrolment, academic and professional qualifications, and the institutions attended for deafblind education. In addition, identification of causal factors in the deafblind children at the department were addressed. How courses were taught, principles adapted and communication modes applied, were all areas of interest. Equipment and materials used to facilitate teaching and learning, problems and suggestions to enhance public awareness and teacher competencies were also part of the questions participants answered.

Findings

i) Enrolment

Investigation on enrolment and teachers' professional levels revealed that there are presently seven teachers with a diploma in the education of the visually impaired. Five (71.4%) had their diploma awarded by the University College of Education of Winneba. The remaining two (28.6%) had their Special Education at the then Specialist Training College of the Blind at Mampong-Akwapim and at the Perkins School for the Blind, Watertown, United States, respectively. The range of teaching experience of the teachers is between 10-32 years. However, years of service in the Deafblind Department are between 2-10 years. Each teacher emphasised the time and patience put in to teaching and learning, and the difficulty in measuring knowledge. But they all agreed on the satisfaction obtained if a skill is attained is worth the task. There is no denying teachers' empathy, devotion and commitment to their work. This is to say that, without these attributes, deafblind children at the centre cannot be educated.

Information on the children revealed that out of the ten pupils, three pupils (30%) have low vision and two have spectacles on. Seven (70%) are totally blind and deaf. The only female has a limited vocabulary in Akan, which can be understood though is not very distinctly articulated.

ii) Causal Factors of Deafblindness

The commonest causal factors for deafblindness in Ghana are measles and cerebral spinal meningitis (CSM). However, other causes generally acknowledged are maternal rubella, genetic disorders, Fetal Alcohol Syndrome, Rh blood incompatibility, anoxia, accidents, and brain toxic substances (crack, heroin). (Kirk et al. 1993).

Besides measles and CSM as causal factors of deafblindness in Ghana, lack of facilities for early treatment, herbal treatment of infected ear and eye, coupled with ignorance and superstition, compound the problem. (Ocloo, 1996).

iii) Mannerisms

Each child has his/her particular characteristics, as literature documents. For example, some poke the eyes, hit the bridge of the nose, self injure, swing the head, throw tantrums, flick the fingers, rock the body, make noise, grind their teeth, or laugh excessively. Others knock their head and jump, walk about and clap. Other disabilities which some of the children have are mental retardation and epilepsy. (Heward & Orlansky, 1988). In addition, some become sleepless (insomnia) and sometimes present challenging behaviour. As a result, occasionally, they receive health services from

Patang mental hospital. Other services given are medical care from the 37 Military hospital, and visual checks with Eye Savers International, Ghana.

iv) Courses Taught

The courses taught, which are practically oriented, are vocational skills, life skills, orientation and mobility, sensory training, physical education and hygiene, gardening, cookery and Braille. The main objective of these courses is to help each child acquire the ability to help themselves and learn to be independent.

In vocational skills, pupils are taught to make mufflers, doormats, table mats and fluffy balls as decorations. Some of the children who are more able can make these items on their own provided the cutting of the materials is done for them. In life skills, pupils learn to wash, iron, polish shoes, and make beds. The orientation and mobility course involves teaching related to the environment, using the residence or centre and moving from one point to another. In addition, the pupils are involved in sensory training whereby the children learn to differentiate between money and materials, and different types of textures and shapes. For instance, the centre has concrete items, such as gari, beans and wooden shapes to enable

children to learn to touch and feel the objects. In cookery, they are taught how to cook local dishes, such as bean stew, boiling yams, fried plantains. Before the lesson starts, familiarisation of the foodstuff is carried out in the form of feeling the items in order to have a mental picture of each one of them.

The cutting of such raw foodstuffs is usually monitored by the teachers. All children are made to participate. Some can fan the fire, others are guided to cut the yam into pieces, and others stay around to finish cooking it.

v) Principles in teaching deafblind pupils in Ghana

Teaching for the less able pupils is a one-to-one approach. However, some teachers have a maximum of three pupils who are able to succeed in a group. Since hearing and sight are the main problems, many activities are action packed using body movement, feelings and touching the bodies of the teacher and the learning materials. Much sign language for the deaf is used. Other methods are gestures, miming and multi-sensory approaches, such as tactual (touch), kinaesthetic (feeling) and vibration. Patience and devotion on the part of the teachers is of the utmost importance since five (50%) of the pupils at the centre have some amount of



mental retardation, and they can learn at their own pace. This implies that there are children with high functioning levels and these do not need as much support as others who may need it all the time. As a result of memory loss or lack of retention, the same tasks are repeated. Repetition is a cornerstone of memory retention of a particular task. Task analysis is another essential method teachers use. Task analysis involves breaking a major task into chunks or bits for the learner to learn through repeated activity. Each step is carefully monitored and is grasped before the next step is tackled.

vi) Communication Modes

Sign Language, Braille, gestures, writing, braille and miming are the main modes of communication used. Nevertheless, two of the older children who have low vision can write and Braille. The younger ones are now learning to Braille. Four of them, who have stayed for 10 years in the school for the deaf and have now been transferred to the deafblind department due to eye problems, are perfect in sign language for the deaf children.

vii) Equipment and materials

Since the pupils have to use sign language to communicate as well as braille, the CBM has provided the centre with Braille machines, Braille sheets and jigsaw puzzles to mention but a few. There is equipment for games such as ludo, drafts, football and panorama. Other facilities include a playground, two big classrooms, two toilets and a library which the children share with the deaf children.

viii) Uniqueness of the pupil

The unique talents of these children are shown in art, craftsmanship, and drumming. Finished products of woven mufflers, door mats and table mats are some of the exhibits in the stores for sale and for exhibition purposes. One of the pupils is talented in drumming and belongs to the cultural troupe of the Demonstration School for the Deaf. Another pupil is an excellent artist who drew Princess Anne and former President Jerry John Rawlings of Ghana during the Princess's visit in the year 2000. He also draws instructional aids for teachers in the Demonstration School and the Department of the Deaf-Blind. Many of the children can sweep the school compound, wash uniforms, and plant and water the vegetable garden.

ix) Parental Role

The parents' greatest problem is communication and management of their children. The solution is to organise workshops for all parents once a year to educate each parent on what his/her child is capable of doing so that there is a "carry over" to

the home. The workshop runs from a Wednesday to Saturday after which parents take their child home. The parental collaborative role is one of the major educational aspects of deafblind education.

x) Problems

The teachers at the University College of Education of Winneba are not solely trained to teach deafblind children. The Government's financial support covers only a portion of the children's education and does not extend to areas of equipment, instructional materials and school uniforms. The educational programme for the deafblind children is not purely based on the principles of deafblind education. Instead, it is patterned on deaf education, hence the use of sign language for the deaf. Sign language for the deafblind is neglected. Rather, sign language for the deaf is taught to the deafblind children. The reason given was that, since the children are living with the deaf children, they should only learn the language that enables them to communicate.

It is also observed that skills learnt in the school are lost as children go home since there is no follow up programme. Besides, parents are more sensitive to the children's problems and tend to work for the children instead of helping them to become independent. There are no craft instructors who can expose children to different skills. In addition, many of the children have low intellectual functioning levels so cannot pursue higher academic work and gain employment. There are no workshops and no exclusive transport for the deafblind children. The lack of transportation precludes outreach programmes which can educate the public on achievements, causes and prevention of deafblindness. The school dropout rate is insignificant, however, if it occurs, the reason is either that parents refuse to report with the child or the child feels he is too old and tired with school.

Discussion

Teachers are unable to teach competently since they have not had deafblind training, though their background is blind education. There is the assumption that if they had at least "on the job" training from experts, they would do better. The autonomy of the department may also make teachers more creative in implementing the curriculum and sign language of deafblind children. However, the present position precludes that.

Suggestions

In view of the above problems, the writer suggests that the Department for the Deafblind should be autonomous so that the programme can be tailored solely for deafblind education. Sign language for the deafblind should be introduced to match with those



used in the deafblind institutions in the US. Teachers need to have deafblind education as a programme on its own in the University College of Education of Winneba. As an alternative, the Government of Ghana could liaise with the Perkins School for the Blind, for experts to train teachers on the job.

Students from the University College should have off-campus Teaching Practice at the Deafblind department and also have their School Attachment Programme as well.

Home visits as part of the deafblind education, are an important component of allowing teachers to link home and school together, and to sustain continuity of learning and memory retention of skills learnt. It is worthwhile promoting home visits as well as outreach programmes to educate the communities in which the children live. There is the need for the deafblind department to have autonomy, if possible, so that the curriculum for the deafblind can be carried out with appropriate sign language, finger spelling and speech for those who can use it. An intensive campaign for an advocacy group is needed to fight for employment for those who are talented. For those others, it is the writers' wish that both internal and external non-governmental organisations extend assistance to them in the form of modern instructional teaching aids and the training of teachers.

Acknowledgement

The writer wants to extend her greatest appreciation to the Head of the Deaf-Blind Department and the teaching staff at Mampong-Akwapim for the information given through questionnaire, interview and observations made during her visit to the department. Without them this project would not have been possible.

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Social orientation and its significance in the development of personality

Tatjana Alexandrovna Bassilova of the Institute of Special Education, Moscow, Russia reflects on her long experience as a psychologist and researcher working with deafblind children in a country undergoing change.

Having worked for many years as a psychologist-researcher and diagnostician and as the co-developer of methods and programmes for teaching deafblind children, I have had the opportunity to follow and analyse the results of this teaching process. Twenty years has passed, and those deafblind people who were more than 30 years old when we first got acquainted have become old people now and some of them have passed away. Those that used to be teenagers are now adults! Now I am following a third generation of deafblind people. I have witnessed and recorded many changes since the start.

Discussions with deafblind adults, teachers and parents provide rich information that indicates both failures and successes in the education of deafblind children. The most valuable is the experience of well-educated deafblind adults who can tell us about themselves and who can analyse their own problems. They faced serious problems in their youth and adult lives and we are aware that our professional competence in foreseeing these problems is now in question. The group of deafblind children is changing; their conditions are

more complicated. And those things that were thought to be solved for deafblind and partially sighted deaf children without manifested learning difficulties, now require very different approaches.

This paper is based on the experience of teaching the original population of deafblind children who did not have learning disabilities or mental retardation. It is focused on the development of personality in our deafblind pupils. The children's most serious problems are hidden to emerge in the future. These problems include a lack of opportunity for self-realisation and this is of concern to their parents, teachers, and society in general.

In the early stages, the personal development of a deafblind child is linked with general development. A deafblind child cannot develop as a personality before he masters the object world, before he learns how to orient in time and the environment independently, and before he masters the skills of daily routine. Mastering a means of communication, and after this, reading and writing are also very important. Cognitive development, at this stage, seems to be very important, as it influences the general development of a personality greatly. This is why language



Tatjana Alexandrovna Bassilova

and intellectual development was considered to be practically the only aim of the teaching process. This was true when the system of teaching the deafblind in Russia was being developed. It is well known that it was a dramatic history. Three times this system was created and recreated in our country and, after 20 years of work, halted for long periods of time. The first two were schools for the deafblind in Saint Petersburg and Kharkov. The third attempt was made in 1963 when a school for deafblind children was opened in Zagorsk (now Sergiev Posad). For about 30 years it was a little, and even elite, school for 50 deafblind children. Since 1991 it has grown to take 120 children and young adults in an educational and rehabilitation centre.

The most valuable is the experience of well-educated deafblind adults who can tell us about themselves and who can analyse their own problems

For a long time parents focus on finding a cure for the child, and do not adapt to the new situation.

In the early 80s the content and foundation methods of teaching deafblind children were determined and personal development was made a priority. By this time we could assess the level of readiness for adult life in our first graduates, but we observed their very immature personalities and they were not ready to understand the rights and obligations of an adult member of society.

The problem of the development of a personality becomes very much more important during adolescence when the child is changing in to an adult and becoming a mature person. Our observations show that most deafblind people find difficulty in developing confidence, understanding moral values and codes and identifying as a family member or member of another group; in fact, taking their full part as a citizen. We found out that deafblind people's ideas about their past and future and about the past and future of their families were not well developed.

It is possible to explain these difficulties and for the purposes of this article I have divided them into three main sections:

Deafblindness

The reasons for these difficulties are caused by the impairment itself. Inevitably, a child is isolated in the surrounding world. This isolation inevitably leads to poorly developed and distorted emotional and social ties. This is manifested sometimes in the lifelong egocentrism when the deafblind person becomes the centre of his own isolated world. Because of the deafblindness the person has

great difficulty identifying with others and understanding the differences between people i.e. style of dressing, behaviour and age. This also makes it problematic to understand and develop as an individual.

As a result of the impairments a deafblind child becomes highly dependent for day to day care on other people. The skills of looking after oneself, cooking meals, shopping, taking transport, doing the washing and cleaning will be acquired much later in comparison with his/her sighted and hearing peers. This situation leads to high dependency. The combination of egocentrism and dependency creates the basis for the development of egoism and this can result in the deafblind person rejecting the interests of other people, insisting his interests and needs are the only ones for family and friends as well.

Family of a deafblind individual

This group of reasons are related to the impairments of the child and are connected to the attitude of the "surrounding" people towards him. As a rule, the close adults, when they realise that a child has lost or is losing sight and hearing, show serious anxiety and concern.

For a long time parents focus on finding a cure for the child, and do not adapt to the new situation. The demands made on the child reduce dramatically. A situation of "hyper-wardship" is created. The child becomes the centre of the family existence. The interests of the other family members (parents, siblings) become secondary and less

significant. As a result we observe the overrated self-appraisal of a child. This avoids the difficulties and does not solve them.

School

We can attribute some of the problems with the practice of teaching the deafblind child. In practice a deafblind child remains an object of the teaching process during the whole period of education. He is being taught and educated but is not fully participating in learning and social behaviour. In the special conditions of a boarding school the child lives with children of the same age and disability. This is why he cannot recognise himself as different because of his impairment, and does not learn how to compensate or to understand the influence of this impairment on his future life, which will involve people who see and hear in a different way.

As the process of development matches the level of learning, a deafblind child cannot take part in this process emotionally or consciously. The personal experiences of a deafblind pupil, which he gained before school in interactions with family, hearing and sighted peers, children of all ages and the elderly are all forgotten in this environment.

A New Programme

When defining these three influences, we – the immediate participants and developers of the educational system for the deafblind – understood we must change the basis of education. We must turn a deafblind child from the object into the

subject of his education. We must turn him into a subject who can realise the difficulties and the limits of the obstacles, which are created by the deafblindness. This we found to be a complicated process and those considering it needed time to reflect. On the one hand, the assistance of the close family has the potential to open up the deafblind child and assist in the development of the personality, but on the other hand, this relationship can restrict and even distort such development.

Socio-Domestic Orientation

Experimental work on the content of teaching deafblind children became our attempt to break out from the dilemma of this contradiction in the educational process. We wanted to bring education closer to the real life interests of a child. We adopted a new teaching course – Socio-Domestic Orientation (SDO).

The main goal of the work on SDO was to include deafblind students in the social and domestic environment and to equip them with different socio-cultural skills. The acquisition by the deafblind pupils of the knowledge and skills, which will help them to successfully participate in everyday life and leisure, will help them to fulfil this goal.

While working on the content of the SDO programme we saw the main teaching aims as follows:

- to give our pupils ideas on the life pattern of a person,
- to assist in understanding the age differences of development,
- to bring a child with serious impairments of

vision and hearing closer to understanding his disability.

The main topics of the programme became "Family", "School", "Work/Job" and "Leisure". The content of the topics studied was changed from one grade to another. So, the main content of the topic "Family" in the early years is making the knowledge about home more accurate and developing a notion of family structure.

After a while the content of the topic is broadened to discuss the closest relatives and the family relationship between them and the child. Then the child gets details of family history, his nationality and more information about his family. In adolescence, the young person may get his first official document – a passport, and learn about the traditions and procedure of marriage and divorce. Finally, the students learn how to take care of a baby and to take parental responsibility for the education of the children.

It is essential to show the necessity of special preparation for this parental role as the possibility of having a disabled child while being a disabled parent presents any family with challenges. The young people are also taught about the procedure of genetic assessment. The family-models discussed include those of the schoolteachers and classmates. For the older pupils some study is made of society and wider relationships. The school and relations between administration and staff, their rights and obligations, procedures of engagements and dismissals in the work place are all part of this preparation for the adult world.

The SDO programme is very varied and includes all the every day activities that people cope with as a matter of routine. It focuses on social interests and emergency situations and, very importantly, handling money!

This work is being undertaken with the experimental group of deafblind children and at Sergiev Posad Rehabilitation Centre for deafblind children. By the third grade children have already mastered the main skills of self-care, have accumulated elementary knowledge about life in their family and at school and are at the point when such a course can be implemented. A very important part in the SDO programme is the organisation of special excursions to follow the life of adults in different socio-domestic situations in order to master, in practice, the skills which are necessary for their future independent life. According to the methods used in the SDO programme a lot of attention is paid to the content through role playing dramatisation.

How can we hold out to retain high standards of service and save ourselves as real educators?

The language abilities of the students, which they have achieved by this time, do not give them full command of communication and feelings in spoken or even sign languages. The most appropriate way for this to be encouraged has been through drawing and content-role playing. These are the activities that make it possible for partially sighted deaf children to restore the events of their private lives and get acquainted with the

It is essential to show the necessity of special preparation for this role as the possibility of having a disabled child while being a disabled parent presents any family with challenges

Philippine program for blind children with additional disabilities

Yolanda S. Quijano, the Chief Education Program Specialist in the Special Education Division of the Department of Education in the Philippines describes the developing programme in her country.

Filipino blind children with additional disabilities started receiving educational services in 1996 when the Resources for the Blind, Christoffel Blindenmission, the Philippine Normal University and the Department of Education, Culture and Sports (DECS) offered summer courses for teachers of children with visual impairment. One of the topics of the course focused on the education of multi-handicapped children, which was offered as a response to the clamour of special education teachers who were

challenged to accept these children in their classrooms without any formal training.

The program has been strengthened by Hilton Perkins International through Mr. Kirk Horton, the Regional Representative who has conducted a series of activities. One of these is the provision of short-term training to identified teachers who actually work with these children. The training provided the participants with knowledge and information on the characteristics, nature and causes of handicapping conditions, and the various

educational programs and interventions appropriate for these children. It also provided them with specific techniques for working with children who are deafblind, as well as those visually impaired children who could hear but cannot speak, or who have motor problems or cerebral palsy. Another activity was regular school visits (three times in 1999) which provided an avenue for discussions about the child's program with local administrators, the special education teachers, and in some cases, the parents. The visits also reinforced the

Social orientation continued from p.23

experience of other people. But this is not done just simply by drawing or playing a game based on the specially developed plan. We have to create emotionally coloured communication between children and their teacher. This communication is based on signs and words, on art activities and role-playing.

We started this work more than ten years ago. Gradually this approach was included in the curriculum of a school for deafblind children. Finally two years ago our programme was published.

What are the benefits?

Our students are better informed about life outside their school and their outlook and understanding of other people gets broader. They start to think earlier about themselves and their future.

A real interest in learning is being awakened because the children start to understand the necessity of the learned knowledge. But the problems of the development of personality remain, as these are eternal problems and it is impossible to solve them, once and for all.

We understand now that we need a special

programme more concentrated on the process of coming to terms with disability. We feel a need for constant efforts in the moral development of our pupils. This is demanding work and requires better contacts with families of the students.

Our context

But we live in a non-stable society with a widening economic crisis. How can we hold out to retain high standards of service and save ourselves as real educators? And how can we, while safeguarding ourselves, still teach our children how to find themselves?

belief that there are indeed a large number of blind children with additional disabilities in the country, and the Special Education Centres established in regular schools can accept these children in the existing services for the visually impaired. This posed a challenge to the special education teachers who have full time classroom duties in the resource room or in the integrated program. But it was decided that we could respond to this challenge through the creative use of staff and volunteers, specific time schedules and other classroom arrangements. The teachers found these visits very helpful since they were able to discuss the specific needs of individual pupils as well as the educational programs appropriate to each. Among the specific concerns discussed were the need for a more functional curriculum, the utilisation of parents or baby sitters as teacher-aides, teaching techniques for deafblind children, and the purposeful scheduling of classroom activities. During these visits, local educators for the blind, Ms. Mila Wayno of the Resources for the Blind, Inc. and Mr. Romeo Mina of the special education division, DECS, assisted Mr. Horton.

On September 20-22, 2000, the Third National Congress on Visual Impairment was held with the theme, "Reaching Out to Visually Impaired Children with Additional Disabilities". This was sponsored by Resources for the Blind, Hilton Perkins International, Perkins School for the Blind, the Overbrook School for the Blind/Nippon Foundation, the

International Council for the Education of the Visually Impaired and the Department of Education, Culture and Sports (DECS). Two hundred and ninety-eight teachers, administrators, supervisors and other DECS officials participated in the Congress which discussed the issues, concerns and trends in the provision of school services to these children. The main speakers were Kirk Horton and Marianne Riggio, together with local special education teachers who shared their experiences in the assessment process of these children. These speeches were followed by discussions on the educational programs prepared and the implementation of interventions or specific activities that worked well with them. The Congress was capped off with the presentation of the Outstanding Teachers for the Visually Impaired awards to teachers from different regions of the country.

For the school year 2000-2001, a total of 41 visually impaired children with additional disabilities were enrolled in regular and special schools throughout the country. Six of these children are deafblind, while others are blind with autism, speech problems, intellectual disability, cerebral palsy, or motor problems. There are about 21 specialist teachers working with these children. A commitment to serve these children coupled with the desire to learn and try out new things in the field of visual impairment are the two major characteristics shown by the teachers. These assets certainly give the program a hope for expansion.

Final Call for Registration for



'What it Means to be Deafblind: Identity, Rights, Unity'

The Seventh Helen Keller World Conference

&

World Federation of the Deafblind

First General Assembly 7-12th October 2001

Waipuna Hotel and Conference Centre, Auckland, New Zealand

The programme committee has finalised the details of this event that will incorporate both the Helen Keller Conference and the General Assembly of the World Federation of the Deafblind. The workshops and speeches will be presented over 5 days and will include a conference dinner and time for social activities.

The committee hopes that this conference will lead to the development of better services and greater opportunities for deafblind people internationally – both educationally and economically. It is particularly hoped that it will increase Government awareness in New Zealand of the need for more services for deafblind people.

For more information and a registration form please contact:

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PO Box 7150
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Whangarei
New Zealand
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Networks

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CONGENITAL DEAFBLINDNESS IN ADULTS NETWORK

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Acquired Deafblindness Network



Gez Roulstone

International Directory of practitioners in acquired deafblindness

110 questionnaires were sent out in November 2000 to known practitioners in the field of acquired deafblindness. Just over 30 have so far been returned. The questionnaire responses will be entered on a website posting details of practitioners on a European and worldwide basis. If you are a practitioner who has not yet received a copy, or if you know of someone who should receive one please contact by email enquiries@senseeast.org.uk.

On the same note please can we remind everyone who has received a questionnaire to return it in the envelope provided.

Swiss 2002 Seminar

At its meeting in the Netherlands in February the co-ordinating group of the European ADB network finalised the date of the next European seminar on Acquired Deafblindness as October 2002 in

Switzerland. The exact dates and venue are yet to be decided.

The seminar will focus on developments in the field and issues connected with the recognition of acquired deafblindness as a separate disability.

The seminar will also highlight the range of services currently offered throughout Europe to this client group and hear from deafblind people themselves as to the services which providers should be offering.

Research on needs and numbers of elderly people with acquired deafblindness in Europe

Members of the co-ordinating group have been pressing ahead with more up-to-date research on the needs and numbers of elderly acquired db people in Europe.

There have been a number of small side pieces of research in different countries on needs and numbers of the elderly deafblind. These have used different methodologies which have in turn produced different results.

Now practitioners in Norway and Finland are co-ordinating research to move work ahead in this important field of study. It is hoped that work in English translation will be completed by the summer in time for the European conference in Netherlands in July. It is hoped that one outcome from this work will be a single assessment tool for further consistent research throughout Europe.

European Usher Study Group

Since the European Usher Study Group last met in Madrid in 1997 new genetic discoveries in the field of the Usher syndromes alone have accelerated rapidly! In the wider field of genetic study the Human Genome has been mapped; Dolly the sheep has been born from a cloned embryo; more recently it has been reported that 30 babies in the USA have DNA from three parents rather than two.

Advances in genetic science challenge society. What are the implications for us living today and for future generations? For families who know that they carry a genetic condition these rapid advances may appear

bewildering, even alarming. At the same time some genetic advances seem to offer tangible hope for improvement in quality of life.

What about families who carry one of the many genes for Usher syndrome? The theme for the next European Usher Study Group which is entitled 'Ethical aspects of new genetic discoveries; implications for families and for society', provides an opportunity for some of these ethical concerns to be aired, as well as bringing us up to date with the most recent scientific developments. The EUSG will be held on 23-24 July at the Golden Tulip Conference Hotel, Leeuvenhorst,

Noordwijkerhout, the Netherlands. It is hoped that some of the outcomes of this meeting will be reported on in the July-December edition of *Dbl Review*.



Mary Guest

EUSN – European Usher Syndrome Network

Dear friends,

We have to announce the postponement of the European Usher Syndrome Network Conference, 21-23 July 2001

In the last edition of the *Deafblind International Review*, we informed you about the Conference which the European Usher syndrome Network intended to organise from 21-23 July 2001. This EUSN conference was to be a pre-conference activity to the main *Deafblind International* conference. Unfortunately due to unforeseen circumstances the EUSN conference has had to be cancelled.

Instead, we will use the network morning in the main *Dbl* conference to hold a workshop relating to the EUSN. We are convinced that we can offer you a very interesting programme about Usher syndrome from the perspective of both the people with Usher syndrome themselves and also the family members.

Furthermore the EUSN will be holding a European Conference about Usher in 2002 and we will be giving you details of the programme during the network morning. You will also have the opportunity during the network morning to suggest additional topics for this conference. So be there!!!!



See you on Friday 27 July 2001 in Noordwijkerhout.

**Marylin Kilsby
National Co-ordinator,
Usher Resources
Sense**

On behalf of the preparation committee of the EUSN Conference 2002.



Latin America

Venezuela – developments within higher education

A recent collaboration between Birmingham University, ONCE, and the Hilton Perkins Program has initiated exciting developments in Venezuela this year. In April Norman Brown, Distance Education Co-ordinator from the School of Education at Birmingham University, visited Caracas, Venezuela to deliver a Seminar on Multi-Sensory Impairment to three Latin American students. While in the town he visited the CAIS Deafblind Centre and SOCIEVEN Deafblind Association, two services for deafblind children and young adults from Caracas. Norman also delivered two lectures at UCAB – the Catholic University at Andres Bello – and met with a group of parents.

Norman Brown and Stephen Perreault from Hilton Perkins Program of Perkins School for the Blind then met university professors at UCAB in order to discover more about their initiative to launch a distance-learning masters degree program on multi-sensory impairment at the university.

Latin American Parent Leadership Conference

From August 2 – 4, 2001, the Latin American Network of

Parents of Deafblind Children will meet in Miami, USA, and receive training on relevant topics. This meeting will take place in conjunction with "An International Celebration of Empowerment: Sharing Dreams and Visions for Children and Young Adults who are Deafblind." This is the annual conference of the US National Family Association of the Deafblind (NFADB) and the annual parent workshop of the US National Technical Assistance Consortium of the Deafblind (NTAC). It is expected that nearly 100 parents of deafblind children from Latin America, Spain and the USA will attend these activities. More than 30 parents will come from Brazil, Argentina, Colombia, Chile, Uruguay, Peru, Panama, Dominican Republic, Costa Rica, Mexico, Ecuador and Guatemala. Conference activities on offer include:

- ▶ What parents of children who are deafblind want to know;
- ▶ Perspectives on empowerment and self-determination;
- ▶ An overview of personal future planning;
- ▶ The importance of individualised planning;
- ▶ Positive partnerships.

This conference is once again the result of a

collaboration between ONCE and Hilton Perkins Program of Perkins School for the Blind.

Costa Rica

The Deafblind Department at the Centro Nacional de Educacion Especial Fernando Centeno Guell in Costa Rica has recently made changes to the physical environment at the centre to cater for the particular needs of their deafblind, blind and visually impaired children. This is a dream come true for the parents, professionals and administrators at the centre and was made possible through the support of Mrs. Lorena Clare de Rodriguez, first lady of Costa Rica and Mr. Antonio Alvarez Desanti, her deputy.

Brazil

ADEFAB, a deafblind program in Sao Paulo, Brazil, is finally able to make alterations to one of their buildings in order to make it suitable for the needs of their deafblind students. This exciting development is the result of a grant from Mr Peter Schnell, company director of Software Ag Stiftung Am Eichwaldchen 6, in Germany.

Graciela Ferioli

Romania

Sanda Casapu, Headteacher, writes about this new service for families in Bucharest ...

The right to an education

In the school year 1999-2000, a unit for MSI (deafblind) children was set up, as a result of a collaborative partnership agreement between the Ministry of Education and Research and Sense International. The objective of the partnership was to create an institutional

and legal framework for the education and rehabilitation of children with associated sensory impairments. This is because there was no appropriate educational provision in the Romanian mainstream, or special education, system for these children.

The Bucharest



Sanda Casapu



kindergarten for hearing-impaired children found this kind of inclusion to be the best educational option for children with severe additional disabilities.

Our unit is made up of 4 children with associated sensory impairments, and the teaching staff are selected according to the children's diagnoses – they are teachers trained to work with hearing-impaired and visually-impaired children. We have adapted the curriculum for the hearing-impaired and the visually-impaired and opted for

activities that can be delivered through Total Communication. Our fundamental principle is that all activities should focus on the child and the observance of the potential and individuality of each child.

Sense International has generously offered their specialist training expertise for a programme for the teachers of the deafblind unit. The assessment of the deafblind programme has been extremely favourable so far. This fact encourages us to continue, and hopefully

expand the project further in the future.

The "Erminescu" Kindergarten for hearing-impaired children hopes to continue to provide competent services for children with multi-sensory impairments and, with the help of Sense International, to become a resource centre in the near future. The gratitude expressed by the parents of these children is a well-deserved reward for those included in this partnership. We hope that the partnership will continue to grow.

Cornelia Codreanu, Headteacher of the School for the Blind in Cluj-Napoca, writes about the progress being made at the newly established educational provision for deafblind children ...

One of the deafblind units in Romania has been functioning since October 1999 at the School for Visually Impaired Children in Cluj-Napoca. The unit was part of the programme initiated by Sense International in cooperation with the Ministry of Education and Research in Romania. As the unit provides a complex programme of intervention for deafblind children it has benefited from the support of the most senior members of the staff including the head and the deputy head, the local inspectorate and the Babes Bolyai University.

Although the units have been assessed periodically, a more comprehensive analysis has been developed recently and the conclusions put



Cornelia Codreanu, front row

together in a detailed report. This report clearly proved that the children in the unit have developed new skills in many areas and the quality of teaching observed was of a very high standard.

Strong links have been made with the parents of the children in the unit. The parents have often offered valuable information which is an important source of help when drawing up the individual intervention programme for each child. The parents are partners in developing the programmes; the progress of the children is analysed in the presence of

staff and parents in order to establish action plans that might overcome possible obstacles.

The programmes of intervention are periodically analysed for a number of reasons; to assess the children's progress and to see whether the proposed objectives have been achieved; to choose the most efficient method in dealing with the individual child and to increase the variety of teaching materials; to find out the most appropriate way to communicate with the children. Our major objective has been the development and assessment of the real potential of the children.

There are different ways to achieve success in working with disabled children. The Cluj unit's success has been through a fruitful cooperation between the teachers in the unit, the wider school, the teachers and the children's parents, the medical doctors, the psychologist, the speech therapist and the headmistress. Our key for success is working together as a multidisciplinary team for the children's benefit.



Poland

Marzenna Zaorska reports on this exciting opportunity for cross-disciplinary action and understanding.

Research conference on 'Model Solutions to Education and Rehabilitation of the Deafblind'. Olsztyn, 5-6 March 2001

The conference, which took place in Olsztyn (Poland) on 5-6 March, was dedicated to the problems of education of the deafblind. It was organised by Dr Marzenna Zaorska from the Special Pedagogy Institute in the Warmińsko-Mazurski University. The conference was a part of the research project on 'Epidemiology of deafblindness in Poland' initiated by the Scientific Committee (Komitet Badań Naukowych - KBN). The problem has been researched by the Special Pedagogy Institute of the UWM and The Deaf-Blind Society (Towarzystwo Pomocy Głuchoniewidomym - TPG).

The conference was attended by representatives of various disciplines - researchers; specialists from a number of different branches whose work deals with rehabilitation of the deafblind such as psychologists, educators, logopedians, rehabilitators, doctors, specialists in the



correction of hearing; representatives of organisations helping the deafblind - The Deaf-Blind Society (TPG); parents of deafblind children; and deafblind adults themselves.

The conference (the second of its type in our country - the first one, organised by the Adam Mickiewicz University in Poznań in 1995 - was held in order to demonstrate the possibilities for the development of the rehabilitation of the deafblind) was aimed at discussing the best solutions to the organisation of the system of education and rehabilitation of various groups of the deafblind in Poland and the training of specialists to work with these people.

Approximately 50 people attended the conference. There were, to give some examples:

- ▶ high-ranking officials of the Warmińsko-Mazurski University in Olsztyn: Prof. Dr hab. Janusz Piechocki - Vice Rector for student affairs, Prof. Dr hab. Eugeniusz Lapiński - Dean of the Faculty of Pedagogy and Arts, Prof. Dr hab. Stanisław Kawula - Director of the Institute of Pedagogical and Social Sciences, Prof. Dr hab. Czesław Kosakowski - Director of the Special Pedagogy Institute;
- ▶ delegates from The Deaf-Blind Society (TPG): Józef Mendruń - president of the society, Dr Tadeusz

Majewski - vice president, Elsbietta Oleksiak - secretary, Grzegorz Kozłowski - member of the board of directors (członek zarządu), Grazyna Glińska - chairman of the Deaf-Blind Children's Parents Section in the Society;

- ▶ delegates from the Polish Association for the Blind (Polski Związek Niewidomych) in the Warmińsko-Mazurskie province (Tadeusz Milewski - president, Piotr Łoziński - vice president, Danuta Jaśkiewicz - member of the board of directors) and Polish Association for the Deaf (Polski Związek Głuchych) (Zofia Gadzikowska);
- ▶ the Mayor of the Warmińsko-Mazurski province's spokesperson for Disabled Affairs;
- ▶ the inspector for special education from the Education Authorities in Olsztyn;
- ▶ delegates from the National Fund for the Rehabilitation of the Disabled of the Warmińsko-Mazurski Department: Ireneusz Markiewicz - director, Andrzej Jurkian - vice director, Tomasz Czajczyk - member of the board of directors;
- ▶ specialists from the Integrated Kindergarten, the Special School, the Specialised Children's Hospital in Olsztyn;
- ▶ workers of the Early Intervention Centre for Children with Compound Disorders in Warsaw, the Rehabilitation Centre for Hearing Impaired Children in Szczecin, the Counselling Centre for the Blind and Short-Sighted in Poznań, the Centre for the Blind and Short-Sighted in





- ▶ Bydgoszcz and Radom;
- ▶ specialists from the Academy of Medicine in Poznań and Gdańsk; and
- ▶ researchers from the Warsaw University, the Łódzki University, the Podlaska Academy in Siedlce, the Pedagogic Academy in Cracow, the Warmińsko-Mazurski University in Olsztyn.

The speeches at the opening of the conference were made by Prof. Janusz Piechocki, Vice Rector of UWM, Prof. Eugeniusz Łapiński, Dean of the Faculty of Pedagogy and Arts of UWM, and Tadeusz Milewski, President of the Polish Association of the Blind in the Warmińsko-Mazurski Department. During the conference 21 papers were delivered.

The introduction to the problems connected with the issue of deafblindness was presented by Prof. Czesław Kosakowski of the Warmińsko-Mazurski University. Prof. Jan Pańczyk then talked about the possibilities for training specialists to work with deafblind people, and Dr Hanna Zuraw about the peculiar character of social functioning for hearing- and sight-impaired individuals.

Józef Mendruń showed the educational and rehabilitational activity of The Deaf-Blind Society (TPG). Katarzyna Ćwirynkało and Agnieszka Zyta analysed methods and forms of work with the deafblind in the past and the present.

There were two papers portraying the rehabilitation of the deafblind abroad. Methods of carrying out specialised activities directed towards the deafblind in Great Britain were presented by Tamara Cierpiałowska and Małgorzata Hwang from Cracow. Dr Dorota Kornaś of



Cracow then described the methods used by the Centre in Würzburg, Germany.

Two lectures about centres for the blind were also presented. Małgorzata Płóciennik and Danuta Podleśna showed the work of the consultative – diagnostic team in the Counselling Centre for the Blind and Short-sighted in Poznań, followed by Krystyna Klugiewicz who described the Centre for the Blind and Short-Sighted in Bydgoszcz.

During the break in the debates the participants of the conference had the opportunity to inspect the hearing correction equipment presented by Oticon Co.

In the afternoon session the following lectures were delivered:

- ▶ Prof. Bogdan Szczepankowski presented the possibilities of early diagnosis of individuals suffering from Usher syndrome;
- ▶ Grzegorz Kozłowski spoke showing the role of technical aids in communication of the deafblind;
- ▶ Mirosława Wichrowska talked about the need to prepare the deafblind children for living in society;
- ▶ Maria Lachowicz – mother of a three-year-old deafblind child – scheduled an address to

people working with deafblind people, describing problems in diagnosing, treating, educating, and rehabilitating deafblind children in the early stages of their lives;

- ▶ Grazyna Szymelfenig – mother of a deafblind girl of 14 – analysed her experiences while bringing up and educating her child;
- ▶ Michał Ostrowski – a student of food technology with Usher syndrome – talked about his path to University;
- ▶ Norbert Barszczewski presented the work of the Centre for the Blind and Short-Sighted in Radom; and, finally,
- ▶ Dr Marzenna Zaorska presented the results obtained from the research project on 'Epidemiology of Deaf-Blindness in Poland' of the Scientific Committee (KBN).





After a few minutes' break the conference participants were shown a play entitled 'Brother and Sister' based on the Grimm brothers production and presented by 'Eurytmia', the Children's Theatre of Motion – a part of Olsztyńska Pantomima. A ceremonial dinner finished the first day of the conference.

On the second day four lectures were given. Dr Tadeusz Majewski from The Deaf-Blind Society (TPG) talked about work rehabilitation of the deafblind. Dr Danuta Paradowska of the Academy of Medicine in

Gdańsk presented the problem of diagnosing hearing among children with a visual impairment. Barbara Nowicka of Olsztyn analysed the latest methods of correcting hearing of the deafblind. Finally, Ewa Dobieżyńska, Madalena Krzysztoń and Marcin Kawczyński from the Academy of Medicine in Poznań described the peculiar character of the rehabilitation of people after cochlear implant.

At the end of the conference there were round table debates, where all the papers were summed up and some conclusions were reached. The participants agreed that there are a lack of good solutions as far as the obtaining of information about deafblind people – especially children – is concerned. There is also a need for efficient solutions in diagnosis and early rehabilitation (from the time of diagnosis of the problem until the start of school education). It would be desirable to organise co-operation between medical services and rehabilitation centres so that information about the diagnosed was always passed on.

Furthermore, knowledge about the peculiar character of the development and possibilities of the deafblind should be developed and spread among various environments.

Special attention was focused on individuals with Usher syndrome. It was stated that they need to obtain special care from psychotherapists and educationalists who would attend to alternative methods of communication, orientation, accomplishing work competence and interests.

Eventually, it was agreed that organising annual conferences dedicated to some specific problems connected to the issue of deafblindness that might include diagnosis of disorders, developing the potential of deafblind people and early stimulation would be highly advisable in Poland. The organisers of the conference hope that it will be the beginning of more systematic actions for deafblind people in our country.

Belgium

Peter Vanhoutte reports

Campaigners in Belgium are hoping to create a new service for deaf and deafblind people, a Writing Interpretation Service. This service would help people who have become deaf or deafblind later in life and who are unable to learn sign language. We feel that it is very important to have qualified interpreters available who can

communicate in a way that the user understands. In Belgium there are currently no recognised writing interpreters; only sign interpreters are paid by the state. Some sign interpreters are willing to write when the user prefers it, but Belgium only has a small number of sign interpreters. We are hoping that in the future writing interpreters will also

be recognised and paid by the government. We would appreciate any advice from other countries who have writing interpretation services with ideas of how to create such a service, the training the interpreters should receive and the way that it works. If you would like to get in touch then please contact Peter Vanhoutte at: pe.vanhoutte@ping.be



East Africa News

Two new groups have recently been launched in Kenya that signify major milestones in the work with deafblind people in the country. These were the launching of The National Association of Parents and the first group meeting of

deafblind adults in the region. The National Association of Parents is an amalgamation of parental representatives from programmes throughout Kenya. The advent of these two groups is extremely important for Kenya and it is hoped that they will lead by

example and encourage increased availability of services for deafblind people throughout the region.

From 'Deafblind News,' a newsletter on Deafblind work in East Africa kindly submitted by Penny May Kamau.

UK

Social Inclusion for deafblind people in Europe

How much do we actually know about how the European Union impacts on the lives of deafblind people? How well documented are the effects of social exclusion in Portugal versus Italy? These are just some of the questions that a new transnational project, coordinated by Sense International with EU funding, will be asking.

Lega del filo d'oro, Casa Pia, the EDbN and Sense International have joined forces for an 18 month project that will result in the publication of three projects:

- looking at social exclusion
- a guide to how deafblind people can work with and influence the EU
- getting deafblindness on the European agenda.

This is vital research which will benefit EU-wide and accession countries, and can

be used as a springboard for future developments on the social inclusion of deafblind people.

If you would like to learn more about the project, please contact Emma Fisher for further details and how you might be able to help at efisher@sense.org.uk

Russia

Usher Forum – Irene Salomatina



Irene (left)

Usher Forum has recently published a small leaflet describing their aims and current projects and inviting people with sight and hearing problems to get in touch with them. On-going services the charity offers to deafblind people and their families include a Communication Club, Leisure Club and regular newsletter. The group also organises seminars and courses for parents and teachers and campaigns on behalf of the rights of people with Usher and other disabilities. For more information please contact; Irene Salomatina
Director
Usher Forum
PO Box 108
103045 Moscow
Russia
Email: lysal@mail.ru

Our programmes and projects:

- **Communication Club** - an audio cassette for communication between deafblind people and their family and friends
- **Leisure** - an evening party and excursion to local and distant places
- **Learning to the Sight** - an audio cassette and booklet for parents, teachers and students in the classroom
- **My Right** - an audio cassette for parents of the children of people with Usher and other disabilities
- **International Aid** - we are full of ideas to help us provide services for people with Usher and other disabilities
- **Newsletter** - our regular newsletter

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In the ninth of our series on causes of deafblindness, this edition examines

Laurence-Moon-Bardet-Biedl Syndrome

(Also known as: Laurence-Moon Syndrome (LMS) or Bardet-Biedl Syndrome (BBS))

Introduction

Until recently, the condition was commonly known as Laurence-Moon-Bardet-Biedl syndrome (LMBBS). It has since, however, been split by its clinical/medical characteristics into Laurence-Moon (LMS) and Bardet-Biedl (BBS) syndromes. Despite this, the original syndrome name is still used in the UK. Both syndromes are characterised by retinitis pigmentosa (more accurately termed rod-cone dystrophy), but distinguished by the presence of other characteristics. There is much overlap between these two syndromes and the terms are often used interchangeably. For the purposes of this article, the term 'Laurence-Moon-Bardet-Biedl syndrome' is used.

Bardet-Biedl syndrome is genetically passed through families by the autosomal recessive pattern of inheritance. This means that for a child to have the syndrome s/he must inherit one mutated gene from each parent. Laurence-Moon-Bardet-Biedl syndrome undoubtedly suffers under-diagnosis and therefore true estimates of the prevalence of the condition within populations are difficult. In certain regions, it is quite common, particularly amongst the Bedouins of Kuwait where LMBBS is present in 1 in 13,500 of the population. This is due to high rates of inter-family marriages (consanguinity). Newfoundland in Canada is another region where LMBBS is prevalent in the order of 1 in 17,500. As well as

consanguinity, this may be due to the 'founder effect' of the original settlers who, incidentally, can be traced back to a handful of families who emigrated from the West Country of England in the 1800s. European studies from the Netherlands and Switzerland estimate prevalence nearer 1 in 160,000, whilst a British study estimated prevalence to be 1 in 125,000.

Diagnosis

Diagnosis of LMBBS is not always straightforward. This is because there is variation in expression of the syndrome, not only between families, but within them as well. For the purpose diagnosis, the features of LMBBS are divided into two categories: Primary features and Secondary features.

Diagnosis of LMBBS requires four primary features to be present or three primary plus two secondary features:

Primary features

Rod-cone dystrophy, Renal anomalies, Polydactyly, Obesity, Learning difficulties, Hypogonadism in males

Secondary Features

Speech disorder, Spasticity, Poor coordination/clumsiness, Polyuria/polydipsia, Left ventricular hypertrophy, Hepatic fibrosis, Hearing loss, Diabetes mellitus, Developmental delay, Brachydactyly, Ataxia.

Signs and symptoms of LMBBS

The following is a brief description of some of the more commonly observed aspects of LMBBS. There are others cited in medical literature, but for brevity are not mentioned here.

The Eyes

Retinitis Pigmentosa is commonly cited in LMBBS. However, the preferred term 'rod-cone dystrophy' is used as it more accurately describes the pathological process. In the early stages of rod-cone dystrophy, there may be no pigmentary changes seen despite significant visual disturbance. A recent study showed rod-cone dystrophy present in 96% of individuals. The average age at which night-blindness was first noted was 9 years, while registration of blindness was 15 years.

Other visual impairments observed in individuals with LMBBS include horizontal nystagmus, optic atrophy, myopia, strabismus, cataracts, glaucoma and macular dystrophy.

The Ears

The presence of conductive hearing loss is observed in 21% of affected children with LMBBS. In most cases, this resolves spontaneously or with treatment by adulthood. Sensorineural hearing loss is observed in 3% of affected individuals.

Hands and feet

The presence of extra digits (polydactyly), either fingers or toes is

present in about 66% of affected individuals. This may range from a small piece of skin to a fully formed digit on all four limbs.

The presence of short, stubby fingers/toes (brachydactyly) is common and observed more frequently in the feet than in the hands. When present in the hands, it can affect an individual's manual dexterity and the ability to use equipment such as computer keyboards.

Webbing (syndactyly) is less frequently observed and is usually partial and confined to the second and third toes.

Obesity

Excess weight-gain tends to commence at approximately 2 years of age and occurs in 75% of affected individuals. It is one of the major problems associated with LMBBS. Obese individuals can experience multiple health problems, which may be the most challenging aspects of this syndrome for affected individuals and their carers to manage. Obesity is very often the reason for frequent medical consultations.

Learning difficulties

Many published medical reports and literature describe mental retardation as being a major feature of LMBBS. However, this is thought to be inaccurate, and affected individuals are now described as having mild to moderate learning difficulties. Some individuals may have problems with short-term memory but have excellent long-term memory. A few have exceptional mathematical skills, usually evidenced by the ability to perform rapid mental arithmetic.

Developmental Delay

Parents report delay in development, particularly with sitting, standing and walking. Delay may be up to one year. Later, parents report clumsiness and poor coordination in 53% of affected children.

Kidney problems

A significant renal component has only been noted in the last 20 years. Kidney abnormalities can be divided loosely into structural and functional. In the former, the foetal kidney has failed to develop properly and is misshaped, but has no bearing on

function. In the latter, there is an inability to concentrate the urine and individuals report excessive thirst and urine production.

A significant number of individuals (30%) develop symptoms or signs of renal disease, such as urinary tract infections while others (5%) will go on to develop end-stage renal failure requiring dialysis or transplantation.

Endocrine Disorders

Non Insulin Dependent Diabetes Mellitus (NIDDM) is seen in 15% of individuals with LMBBS. A previous study, however, has shown an additional 30% to have mild NIDDM when a glucose tolerance test was performed.

Hypogonadism (impaired function of the testes or ovaries) is common amongst males, and 10% have undescended testes at birth. Males may produce lower than normal levels of testosterone and are unlikely to be fertile. Hypogonadism in females is much more difficult to assess, but does not appear to be prevalent. Several females with LMBBS have successfully given birth to healthy children.

Treatment/Therapy

There is no cure for LMBBS as the basic biochemical cause is unknown. The prognosis is dependent upon the severity of the condition and the extent to which systems of the body are affected. Management of the syndrome focuses on treating specific organs or systems. For instance, management of obesity may involve a multidisciplinary approach. This might include a combination of careful dietary assessment, diet, behavioural therapy and exercise.

There are no proven treatments to either prevent or alleviate the deterioration of vision associated with rod-cone dystrophy. However, much can be done to prepare for a life with low vision. Access to support that suits an individual's needs and assistive devices such as low vision aids can be valuable.

Research

In 1998 an international Bardet-Biedl Syndrome Consortium was established to aid research into this syndrome. The consortium comprises of Laboratories from three countries:

the United Kingdom (Guys Hospital/ Institute of Child Health, London); Canada (Memorial University, Newfoundland); and the USA (Baylor College of Medicine, Texas). The purpose of the consortium is to pool, data, family resources, technical knowledge and avoid duplication of work. Research is being undertaken to identify one gene, which is believed to be responsible for up to half of all cases of this syndrome in North America and Europe. Identification of this gene could help to understand how and why the problem associated with this syndrome occur. It could also form the basis of a new diagnostic test and prenatal test in families already affected.

Support Groups

Laurence-Moon-Bardet-Biedl Society, 11 Blackthorn Avenue, Southborough, Tunbridge Wells, Kent TN4 9YA, England.
e-mail: julie.sales@lmbbs.org.uk
Website: www.lmbbs.org.uk

Research centres

Division of Molecular and Medical Genetics, Prince Philip Research Laboratories, Guy's Hospital, London, England.
Website: www.isgrd.umds.ac.uk

Centre for Obesity Research, The Luton and Dunstable Hospital, Lewsey Road, Luton LU4 0DZ, Bedfordshire, England.

Department of Ophthalmology, Baylor College of Medicine, Texas Medical Center, Houston, Texas, USA.

Faculty of Medicine, Memorial University of Newfoundland, St John's, Newfoundland, Canada.
Website: www.mun.ca

Other websites

The Low Vision Gateway:
www.lowvision.org/laurence_moon.htm

The Foundation Fighting Blindness:
www.blindness.org/html/vision_disorder/bbardet.html

National Organisation for Rare Disorders (NORD):
www.stepstrn.com

**Fiona Hall-Jones
Sense**

Finding my voice

Kathleen Prime, who is blind herself, has written to us from Long Island, New York – she's inspired!

Last winter, a seemingly trivial incident happened. It was one of those occurrences that seem insignificant on the surface but nonetheless have the power to transform a life.

It was as simple as this: I came down with a bad cold and could not speak for three days. Although this was merely a temporary inconvenience, it was also depressing in its own way because for what seemed like an interminable three days, I felt powerless in a way that I had never experienced before.

For the first time in my life, though I was by no means at a loss for words, I suddenly knew what it was like to lose the power of speech. Yes, it was but a fleeting moment in time, but it taught me a lesson that will remain with me throughout my life.

I firmly believe that there are reasons for everything that happens in life, especially the little things that appear unimportant and only become clear to us later on. Well, in my three days of voicelessness last winter, the seeds of empathy were planted, and little did I know that the deeper meaning of this invaluable lesson would come to light in July of 2000.

From July 7-23, 2000, I



attended a conference sponsored by Mobility International USA. At the MIUSA conference, a new challenge presented itself, one that I had never encountered before. For the first time, I was introduced to

It is wonderful to think that all this can be accomplished through the powerful and expressive sense of touch, a sense that often goes unnoticed in the hearing-sighted world.

the world of the Deaf (which I write with a capital D out of respect for their strong sense of cultural identity). As I began to learn a few words of Sign, a whole new world unfurled before me. Suddenly I wanted to know more and more, to get a glimpse of a world I knew so little about. And as I reflected back to my three long days of silence last winter, I realised that Helen Keller's saying must be true: "Blindness cuts you off from things, but deafness cuts you off from people."

My growing empathy for people who face

communication barriers was further reinforced by a determined young woman I met at the MIUSA exchange program. Her name is Ashveena Tulwa, and she is a Deaf woman from the tiny island of Mauritius, off the coast of Africa. Ashveena's first spoken language is French, but ASL is her easiest means of communication. She and I patiently struggled to understand each other in French, a language we both know, and yet our task was infinitely difficult because of her limited language skills and my own lack of experience with ASL. Ashveena and I did our best, though, and with the help of Leah, a skilful and compassionate interpreter, we were able to converse to a limited extent. When my new Deaf friend was ready to return to Africa at the end of the conference, I couldn't help feeling a deep sadness, first of all because I may never see her again, and secondly, because for all our efforts to communicate and get to know each other, our success had been very limited. I was proud of what we had managed to accomplish, but I also knew that if I did not make an effort to learn Sign, I would miss an opportunity to get to know many more people like Ashveena, people whose minds and hearts would forever elude my

understanding. The seeds of last winter had finally bloomed in mid-summer. Now the direction of my life has changed visibly. Although I still have an interest in putting my French language skills to use, I feel compelled to serve the deafblind community in some way. My goal is to learn more American Sign Language and to employ my Braille and computer skills in the service of those who live without sight and hearing, thus allowing a little light to shine in the darkness and a note of hope to penetrate the silence of their world. It is wonderful to think that for them, all this can be accomplished through the powerful and expressive sense of touch, a sense that often goes unnoticed in the hearing-sighted world.

Although I wish to offer support and practical assistance to people who are deafblind, I believe that the most valuable outcome of this endeavour will be the lessons I learn from this unique and gifted group within the disabled community. Life has taught me to gather strength from the example of those who have already accomplished the task at hand, and also to recognise that the most difficult limitations to overcome are those that we place on ourselves. So now that I have known (if only for a brief moment), the pain of the voiceless, I am prepared to face many new challenges in order to assist them in their struggle to let their voices be heard and recognised by all.



The first book on deafblindness in Hindi!

Meena Nikam, National Co-ordinator of the NAB India Deafblind Programme has recently published the first ever Hindi book on deafblindness. 'Deafblind Children – Early Intervention' covers causes, definitions and characteristics on deafblindness and provides ideas on early intervention techniques. The book is aimed at parents, education professionals and anyone else who would like to work with deafblind children. Sense International India is honoured to be the sponsor of the book and hope that it is

an inspiration for other writers to increase the availability of written resources on deafblindness in Indian languages. If you would like a copy of the book please contact:

Department of Education
National Association for the Blind
Rustom Alpaiwalla Complex
124 – 127 Cotton Depot
Cotton Green
(Near Reay Road Rly.
Station, East)
Mumbai 400 033
INDIA

Bravo! Miss Brown

'Bravo! Miss Brown' is a recently published biography of Mae Brown, the first deafblind person to graduate from the University of Toronto in 1972. The author, Joan Mactavish, was Mae's tutor, guide, interpreter and friend. Mactavish provides an inspiring document of Mae's childhood on a homestead in Canada, her gradual loss of sight and hearing and her persistence in striving to achieve her own goals. Her outstanding achievement in obtaining a university degree was accomplished at a time when people with disabilities were rarely visible within mainstream society and is an interesting historical record of the prevailing attitude towards disabled people at that time. The book gives a

vivid impression of Mae's intelligence, stamina and commitment and is an inspiring account of life as a deafblind woman.

Copies of the book are CDN \$24.95/US \$16.95 and can be ordered by contacting:

Lynne Ford
Hushion House Publishing
Ltd, 36 Northline Road
Toronto, Ontario M4B 3E2
Canada

Tel: (416) 285 6100
Fax: (416) 285 1777

Please quote ISBN number:
0-9688089-0-5.





Management Committee News

The latest Management Committee meeting took place at Sense in London on the 28th and 29th April 2001. Dbl's president, Mike Collins, reported that it had been a very busy time for Dbl, with ongoing preparations for the forthcoming conference in the Netherlands as well as selecting a host country for the European conference in 2005.



Emma Fisher

European Conference – the Netherlands 2001

All preparations are running according to plan and an estimated number of 350 participants is expected. The Dutch Planning Committee has been busy finalising all speakers and workshops, and is looking forward to welcoming everybody involved in July.

Strategic Planning Update

As reported in the last issue of Dbl Review, strategic planning plays an important role in the development of Dbl. Some of the latest plans will be open to discussion at the next Council meeting in the Netherlands.

European Conference 2005

Competition has been fierce for the run to host the 2005 European Conference. A decision has not yet been made but watch this space for further progress reports!

A New Addition to the Secretariat

We are very pleased to announce the appointment of Emma Fisher as the new Dbl Co-ordinator. Emma previously spent three years working for Sense UK fundraising so is not a stranger to the deafblind field. She has a great deal of international experience, both working overseas and co-ordinating transnational activities.

If you would like to find out more about Dbl or even introduce a friend to become a member, then Emma would be happy to

hear from you. You can contact her at efisher@sense.org.uk or at:

Deafblind International
11-13 Clifton Terrace
Finsbury Park
London N4 3SR
UK.

The Dbl Secretariat

The Dbl Secretariat can be contacted at c/o Sense International at:

11-13 Clifton Terrace
Finsbury Park
London, N4 3SR
UK
or by email
dbi@sense.org.uk

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 is free, but an annual donation of US\$30 is requested to cover costs.

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 US\$3,000 and US\$5,000

Small Corporates:

Annual Fees between US\$300 and US\$1,500

Corporate Members can be nominated to sit on the Council.



The Management Committee – April 2001

Non-Voting Membership

I would like to join/re-join Dbl as an individual non-voting member *(please delete as appropriate)*

I wish to make a donation of US\$30 or £20

I wish to make a donation of _____ *(please specify)*

Please debit my Visa American Express
 Mastercard

Expiry Date

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

Please find enclosed my Postal Order

Title (Mr., Mrs., Dr. etc.) _____

Surname _____

First name _____

Organisation _____

Job Title _____

Address _____

Town/City _____

County/State _____

Post/Zip code _____

Country _____

Tel: (please include country & area codes) _____

Fax: (please include country & area codes) _____

Email: _____

Dbi Review *(tick one box in each category)*

I would prefer to receive *Dbi Review* in:

English Spanish

I would prefer to receive *Dbi Review* on:

paper disk

Please return to: Emma Fisher, Dbl,
c/o 11-13 Clifton Terrace,
Finsbury Park, London N4 3SR, UK.

The following person is a member of Dbl:

Name: _____

Address: _____

Signed: _____

Corporate Membership

There are now two tiers of **Corporate Membership**:

Large corporates:

Annual fees between \$US3,000 and US\$5,000

Small corporates:

Annual fees between US\$300 and US\$1,500

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

We submit an annual fee of US\$ _____

Corporate members are entitled to receive up to 25 copies of *Dbi Review*. We would like _____ copies in English/Spanish *(delete as appropriate)*.

Method of payment (must be made in US dollars)

Cheque or international postal order

Bank Transfer

Name of Bank: RABOBANK

Address of Bank: Sint-Michielsgestel, Netherlands

Account Name: Instituut voor Doven: INZAKE DBI

Account Number: 11.29.09.825

Member Details:

Organisation _____

Representative _____

Address _____

Tel: (please include country & area codes) _____

Fax: (please include country & area codes) _____

Email: _____

Please return this form to: Dbl Finance Officer,
c/o Instituut voor Doven, Theerestraat 42,
5271 GD Sint-Michielsgestel, The Netherlands.
(Fax: +31 73 55 12 157)



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