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Review



Integrating Services in Gujarat

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The horse can help deafblind children to develop a greater awareness of body image and posture, as well as spatial orientation through the stimulation of the tactile and kinaesthetic system.

interpret what each individual is trying to say or do and to know how they react in certain situations.

Most of the assistants, helpers and teachers in our group have previously worked with the children, so the atmosphere is relaxed and friendly as the children are familiar with the staff involved. This enables the staff to meet training and educational goals more successfully.

Due to the success of the programme to date, therapeutic riding is now on the school curriculum at the author's school.

The benefits of riding

Before a child is selected for the riding programme we evaluate their abilities and try to estimate the overall benefits to each individual child.

All the riders are medically assessed prior to starting the programme. They attend the programme once a week for two hours as a group,



although their time with or on a horse in individualised and lasts between 20-30 minutes.

The riding centre staff try to combine leisure and therapy and for this group of children therapy is the primary focus. Riding skills are adapted for specific therapeutic benefits. The horse supplies the motive for achieving the goals in the rider's therapeutic programme, as a result there is a natural bonding between the children and the horses.



The Programme Goals are as follows:

- to enable riders to gain self-confidence and self-esteem, by mastering the control of a large animal with appropriate instructions and supervision;
- to develop the rider's perceptual and motor skills;
- to enable the riders to improve their ability to use sensory information to understand and effectively interact with people and objects during play, school and self-care activities;
- to improve the ability of riders to work with others in pairs and groups by sharing responsibility for care and control of the horse;
- to enable riders to experience opportunities which will enhance social and emotional adjustment and growth;
- to enable riders to receive the many benefits of exercise and therapy of a challenging outdoor sport;
- to help riders to overcome a wide range of fears, for example, the fear of moving their body while on a moving surface;
- to build riders' self confidence through the recognition of their ability to learn new and complex skills;
- to enable riders to improve **balance, posture and mobility.**

Structure of the Lesson

All children are required to wear appropriate headgear to satisfy the high safety

standards required by the programme. Despite such strict safety procedures the staff still work towards making the lessons as enjoyable as possible.

The lessons are structured as follows:

- mounting
- warm up
- exercises
- riding skills
- relaxation
- dismounting

Once the rider or the riders are mounted, the class can begin. During the warm up the rider has the opportunity to focus on the horse and riding activity, putting aside other worries and concerns. Riders also have a chance to warm up and relax their muscles.

The movement and the body of the horse provides the deafblind rider with strongly graded sensory information in the form of tactile, proprioceptive and vestibular experiences.

The warmth of the horse, heavy touch pressure and weight-shift help to normalise tactile, hyper or hypo-sensitivity and, in addition, encourages vestibular stimulation through changes in speed, direction and body position. The positive, psychological effects of human-animal bonding is the final benefit for each child.

During the lesson, the movement of the rider and the horse become coupled together so that they interact and influence one another. Some of our deafblind riders have limited freedom of movement enabling them only to sit straight at a slow walk. After several sessions, some of these riders are able to adapt to the movement of the horse at a fast walk or



when riding in a circle. This is a real achievement.

The rhythmical 3-dimensional movement of the horse helps to relax the muscles, mobilise the trunk and pelvis, reduce involuntary movements and encourage symmetrical body movement.

Balance is improved because as the horse moves riders must unconsciously adjust their position.

Learning through riding is natural ...

Learning is enhanced through riding. Riding is an activity that stimulates all of our primary sensory systems; tactile, vestibular, kinaesthetic visual, auditory and even olfactory. The smell, feel, and motion of the horse can be comforting and certainly is a major part of the riding experience for deafblind riders.

In addition, the rider is motivated into understanding and communicating effectively with the horse. As the rider learns to trust and rely on the horse a non-threatening relationship develops between them. This relationship, combined with the sensory stimulation and relaxation of muscles, appears to help communication in the rider with multiple handicaps.

The horse can help deafblind children to develop a greater awareness of body image and posture, as well as spatial orientation through the stimulation of the tactile and kinaesthetic system. This programme seeks to encourage many areas of sensory-motor integration and to develop fine and gross motor skills. In all activities, *whether mounted or observed*, the horse and rider can react and co-operate together – proving that learning can be fun!

Working in Escuela Para Niños con Sordoceguera ALEX

Amanda Elena Sinibaldi de Bonilla, the mother of Alex, a deafblind child, describes the first year of a school for deafblind children in Guatemala.

Starting a school for deafblind children has not been easy! Being the first to start any project represents hard work, not only preparing professionals for this specialised and complex task, but also creating a "school for parents" too, in order to give the children the best support for their development.

Working with the children in a direct manner has been the most rewarding task. It has been a time for learning for all of us: the children, the parents and staff in the school. There have been moments of joy when a child has achieved a small achievement which represents a huge leap forward. On the other hand, sometimes we have felt somewhat sad because a child has not responded in the way we would like. But all this has been part of our work, and nothing has diminished our enthusiasm to keep going. Just having contact with children gives us enough motivation.

Working to create the "school for parents" has also had its difficulties. The teachers have worked hard to develop programmes for the parents to implement at home with their children. Our task begins by getting to know each home environment and family situation in order that we can develop each child's individual homework programme. But it has not all been serious work and hard

planning. There have been moments to share feelings and this kind of motivation has played an important role in the school's development. We have made efforts to create and maintain a mutual support group with the parents. There has been a family day when the entire school enjoyed games, recreational activities, food, and, most importantly, we had the opportunity to get to know each other better.

A year has gone by since the school was first opened, in March of 1998. For those involved in deafblindness in Guatemala it has been a very significant year. There has been hard work, not only from the school's staff members, but also, and very importantly, from the Foundation's members, the community, the volunteers and other non-profit making organisations. A whole social network has been created in order to provide the necessary means for the school to function. We have also received international help, including support from several Latin American centres. The Hilton/Perkins Program has also helped with staff training, teaching aids and references, school materials and parent support. We take this opportunity to thank them all for their confidence in our work and the support we have received. This support has guided us for the past year in our efforts to provide the best possible standard of education for the children in school.





RUSSIA

In March 1999, Tatiana Basilova and Irena Salomatina from the Institute of Special Education in Moscow, organised a three day conference to mark the 110th anniversary of the birth of Ivan Sokolansky. The work of Sokolansky has had a profound effect on teaching methods for deafblind children in Russia.

The conference attracted teachers, volunteers, deafblind people, psychologists, paediatricians and some members of the Moscow Deaf Association; the only two foreign speakers were Professor Nobuo Hiroseon from Japan and Mary Guest from the UK.

The conference was held in three venues – the Institute for Special Education in Pogodinskaya Street; School No. 65, a school for the deaf in Moscow; and the school for deafblind children in Sergiev Posad (formerly Zagorsk) which is north of Moscow. Dividing the conference between three venues enabled the bringing together of a range of professionals from different backgrounds who are

interested in deafblindness.

One of the highlights of the conference was a concert given by the pupils at the School for Deafblind Children in Sergiev Posad. The pupils, dressed in national costume, danced and played with great gusto. Some of the pupils live five days journey from Sergiev Posad and spend much of their young lives away from home.

Following the conference, Mary Guest had in-depth discussions with Tatiana Basilova, Irena Salomatina and Anna Komanova from School No. 65, on areas of international collaboration. Three possible areas of development were identified:

- ▶ Usher Forum is now a registered charity. The Forum continues to meet regularly and is supported by a group of dedicated young volunteers who help with guiding and communication. The aim now is to strengthen the Forum including extending its membership; using existing volunteers to train new volunteers and to develop the skill of its membership including self advocacy.

- ▶ A class for multi-sensory-impaired children within a kindergarten for deaf children will be opening in late Spring 1999. Training is needed for two teachers of the deaf as they establish the class. The class will start to work with two deafblind children with a view to working with two more. There are also future plans to train more teachers of the deaf and parents.
- ▶ There are long-term plans for a seminar on vision health care in the deaf population for teachers of the deaf, student teachers including deaf teachers of the deaf, paediatricians and social care teachers. A possible venue is School No. 65 for the deaf which has 320 pupils and 150 teachers of the deaf.

Sergiev Posad

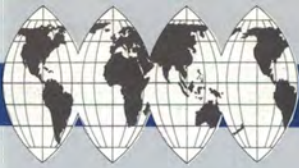
Three staff from the Hilton/Perkins Deafblind Program – Martha Majors, Mary Zatta and Kim O'Donnell – travelled to the Deafblind Children's Home in Sergiev Posad where approximately 130 deafblind children attend school.

It was an opportunity for teachers to exchange methodologies and strategies for working with younger multi-disabled deafblind children. The teaching staff, under the guidance of Chief Director Galina Epifanova, use a child centred and language based approach to activities.

Several classes also have an emphasis on functional skills.

Perkins and the Deafblind Children's Home, will continue sharing program ideas through future staff visits.





CANADA Registry of Individuals who are Deafblind in Canada

The development of a database on individuals who are deafblind in Canada has been a long-time in the making, having been first identified in 1984 by the Federal Task Force Report on Services for the Deafblind in Canada. The Registry project is now being implemented by the CDBRA in co-operation with Rotary Cheshire Homes, Canadian National Society of Deaf-Blind Persons, Canadian National Institute for the Blind and the W. Ross Macdonald School.

A great deal of preliminary work was necessary before the real focus of the project could occur. This included establishing a comprehensive mailing list, preparing correspondence explaining the nature of the

project in both French and English, preparing guidelines about confidentiality of the database, developing questionnaires in both languages, and preparing a computer format for data management purposes.

Two variations of the same questionnaire were developed, to reflect the two different populations of individuals who are deafblind, those whose deafblindness is congenital and those having acquired deafblindness. The "congenital" questionnaire is intended to be completed by family members, advocates or professionals, while the "acquired" questionnaire is designed to be completed by the deafblind person. Both questionnaires were produced in French and English and the 'acquired' questionnaire is available in several formats.

The major work of the project requires locating individuals who are deafblind throughout the country and

disseminating the questionnaires. The success of this tracking is dependent upon the co-operation and participation of many organizations and facilities. To date, the co-operation and participation has been very satisfying. This has been due to a detailed planning process designed to encourage as many organisations and individuals to participate and to the production of "user friendly" materials.

Completion of a questionnaire by an individual is totally voluntary. Participants personal information will be held in the strictest confidence. The first stage of the project will be largely completed by Fall of 1999 and a second stage will follow.

They will gather additional information about levels of present service provision and note the type of services people would like to receive.

Stan Munroe

Information Technology Project

The New Brunswick Chapter of the Canadian Deafblind and Rubella Association recently received approval from the Health Info-structure Support Program (HISP) of Health Canada for an Information Technology project that would focus on improving electronic communications options for individuals who are deafblind.

The project has three objectives

- ▶ to provide the means by which those with vision and hearing impairments can effectively communicate via the Internet

- ▶ to provide the means by which Interveners and parents can communicate via the Internet; and
- ▶ to offer awareness and prevention programs of deafblindness through the use of information technology.

The project involves developing the CDBRA New Brunswick Chapter Web Site by making it both attractive and efficient while ensuring the design is compatible with users who have vision and hearing impairments.

Extensive design, development, implementation and evaluation will be a significant part of the web site development process. Researching and locating suitable software packages, will be undertaken. The pilot

project will involve providing a computer to an individual who is deafblind and has sufficient skills to learn the technology and to the CDBRA Chapter office for monitoring and evaluation purposes.

The project is expected to be of about forty weeks duration and will be managed by the International Nursing Institute of Canada. The project constitutes the first phase of ensuring improved communication opportunities for individuals who are deafblind, and hence, improving their quality of life. It is anticipated that the project results will lead to more individuals who are deafblind receiving the appropriate technology to enhance their communication possibilities.

Stan Munroe



ROMANIA **Small Steps – Big Achievements!**

In November 1997 Richard Hawkes, Director of Sense International, visited Romania and met representatives from national and local government, NGOs, universities, special schools and kindergartens. Many of these people expressed an interest in deafblindness but recognised their complete lack of knowledge of this field.

As a result of recommendations made from this visit Sense International arranged for a group of five UK professionals to visit Romania in March 1998 to attend a National Seminar on Deafblindness. In addition arrangements were made for a day lecture to staff and students in the Department for Special Education at the University of Cluj, specialist staff training at three schools for deaf children, a regional seminar in Iasi and visits and meetings to other centres and individuals.

Since March 1998 the response from people in Romania has been overwhelming. The greatest achievement has been the creation of a new Association of Parents of Deafblind Children (APCSR) formed as



a result of the initiatives of parents from the Eminescu kindergarten for deaf children in Bucharest. For the first time ever, some representatives of this Association will attend the big RENINCO Conference in Timisoara 27-28 May. RENINCO is the National Network of Information and Co-operation for the Integration of Children with Special Needs.

The other big step has been the recruitment of myself as Sense International Romanian Development Manager. Since joining I have already undertaken a detailed induction programme and I am now fully involved in my new work. In March I



attended the European Deafblind Network Seminar in Poitiers, France, on communication. It was a good opportunity for me to meet specialists, parents and deafblind people working together.

I am working very closely with the Department for Special Education within Romania's Ministry of Education to set up some small units for children with sensory impairments within special schools. Very good contact has also been established with the National Deaf Association with whom we hope to organise a joint programme on identifying deafblind adults. A joint seminar on Usher syndrome has been recommended and we hope we will achieve this in the near future.



Cristiana Salomie, Development Manager for Sense International, Romania discusses the recent developments in Romania.



LATIN-AMERICA

Ten Years of Progress

Ximena Serpa reflects on the development of deafblind education and services in Latin America over the last 10 years.

There have been many changes in Latin America over the past ten years. In 1989 there were only programmes for deafblind children in Argentina and Brazil and there were no services, programmes or interpreters for adults at all.

In the majority of Latin-American countries families had to search for practical support, often finding closed doors to education or rehabilitation services for their deafblind relative.

Step by step, with lots of support from like-minded associations, both in Latin America and abroad, access to teacher training programmes and courses for professionals were provided.

This made it possible to get projects started in many countries. Bolivia, Brazil, Argentina, Venezuela, Peru, Chile and Uruguay all developed programmes.

Now, in 1999, there are networks and wonderful programmes supporting deafblind children and their families, not only in the original countries, but in Ecuador, Colombia, Costa Rica, Guatemala, and the Dominican Republic as well.

For deafblind adults the POSCAL project has made possible the creation of organisations for deafblind people in Latin America. The project started as the idea of Yolanda de Rodriguez, a Colombian deafblind woman,

who presented it to the 5th Helen Keller World Conference in Italy.

POSCAL started with five Andean Region countries but during the 6th Helen Keller Conference in Colombia, with the support of ULAC and ONCE, it now covers a total of 15 countries. There are already 7 associations with more than 1200 deafblind people.

There are now qualified interpreters for deafblind people working in Colombia and POSCAL has a project providing short "interpreter courses" for relatives and friends of deafblind people in the countries which already have associations. At a meeting during the last week of February, 1999, the associations belonging to POSCAL founded the "Deafblind Latin-American Council".

HUNGARY

The Hilton/Perkins Program continues to provide technical assistance for two schools in Budapest who are working with deafblind children. There are classrooms at the Elementary School for the Blind and the Laszlo Batthyany Roman-Catholic Home for Blind Children.

Carol Crook, a teacher in the Perkins Deafblind Programme, has consulted with Andras Abel and Dorottya Kiralyhidi about communication, assessment and programme planning, and behaviour considerations. The ways in which these two classrooms can collaborate and work together in order to offer more to the children was also discussed.

ESTONIA

Dennis Lolli of the Hilton/Perkins Program met with individuals from the Estonian Federation of the Blind and the Porkuni School, a school for the deaf which is now beginning to work with deafblind children. It is hoped this collaboration will provide a centralised location for the development of deafblind education in Estonia.

Olga Ilgina, a teacher for the visually impaired, has been instrumental in Estonia's early work with deafblind children. Her interest in deafblindness came as a direct result of her participation in the 1994 IAEDB conference in Bydgoszcz, Poland.



PAPUA NEW GUINEA

In December 1998, Karl Shore, Regional Services manager for Sense North, went to Papua New Guinea to carry out an assessment of services and needs and a workshop on deafblindness and communication, at the Mount Sion Centre for the Blind in Goroka.

Papua New Guinea is an Island nation located just north of Australia in the North West Pacific Ocean. I visited the Mount Sion Centre for the

Blind in Goroka, one of the major towns in the Eastern highlands province of Papua New Guinea. I was met in Goroka by Don Waibe who is responsible for Mount Sion's deafblind work.

The Mount Sion Centre for the Blind consists of a hostel for fifteen blind or partially sighted children, most of whom are integrated into the local community school. They also have a screening programme in the local schools and villages, which identifies people with difficulties with either vision or hearing. They have an optical workshop and pre-school classes for teaching deaf children to use sign language.

Karl writes ...

My main reason for visiting Mount Sion was to look at the services currently being provided for three deafblind children in Goroka and neighbouring Asaro.

We visited Jonah Michael, a deafblind boy, in his village in Asaro province, twenty kilometres or so along a dirt track in the hills. Prior to Don's involvement Jonah has spent all of his time in a hut while his family worked on the land. It was extremely pleasing to see that he was now outside with his family, who have built standing frames for him, which have greatly increased his mobility. We spent a few hours with the family and learned (via Don's translation) of the great value they placed on the work done by Don and the Mount Sion Centre. I also met Ellis Jo and her family who live in Goroka, Ellis is a deafblind girl who attends the centre half a day per week, I watched Don work with her and take her through her planned activities with great skill and sensitivity.



I spent part of the week delivering training on deafblindness to the teachers for the deaf and the teachers for the blind, based at Mount Sion. They were all very skilled in their field and received the training with great enthusiasm and knowledge.

So what are the difficulties in working with deafblind children in Papua New Guinea? Well, the two most significant ones are those of transport and finance. Don's access to transport is extremely limited, which means that just getting to visit children and their family is sometimes not possible for weeks on end. Finance for the Centre is also limited and unpredictable, which means that it is very difficult to plan and make resources available for the deafblind work which is carried out. Despite these problems it was clear that the work done has had great benefits for both the deafblind children and their families; a tribute to the Mount Sion Centre and the work of its skilled and dedicated staff, and particularly Don. After a fascinating and enjoyable week I said goodbye to a spectacularly beautiful country and the workers and deafblind people at the Mount Sion Centre for the Blind.



In the sixth in our occasional series on causes of deafblindness, this edition examines

Rubella and Congenital Rubella Syndrome

Rubella

Rubella is a childhood disease. It is caused by a virus which may be transmitted from person to person in the air as droplets through coughing and sneezing or close contact. A person with rubella is infectious for about two weeks, or occasionally a little longer, starting from five to seven days before the rash appears. However, an affected person may not know that they have rubella and feel perfectly well and may not even develop a rash. If someone has been in contact with an infectious person it takes two to three weeks before they develop the infection too. A person infected with rubella may feel generally unwell for a couple of days, perhaps have swollen glands, a slight temperature, or a sore throat, and may get a rash which starts around the face and can spread

down the body and the limbs. Some people, particularly women, may experience pain or discomfort in their joints. Other people may be infectious but show no signs or symptoms of having rubella at all.

Pregnancy and Rubella

Infection with Rubella is particularly dangerous for pregnant women as it affects the growing foetus. Although a woman who contracts rubella in pregnancy does not always pass it on to her baby, the earlier in her pregnancy she has the infection, the more likely transmission is, and as a result identifiable damage. Contact up to the 18th week of pregnancy is particularly serious. The virus is passed in the maternal blood stream to the placenta and from there to the foetus. If transmission does occur, then it will happen just before or around the time that the woman gets the rubella rash.

Occasionally, rubella infection in pregnancy can result in miscarriage or stillbirth.

Babies born with congenital rubella have the virus circulating in their bodies for much longer than adults or children with the acquired infection. This means that a congenitally affected baby can remain infectious for six months to a year, or occasionally even longer.

Possible outcomes of rubella infection in pregnancy

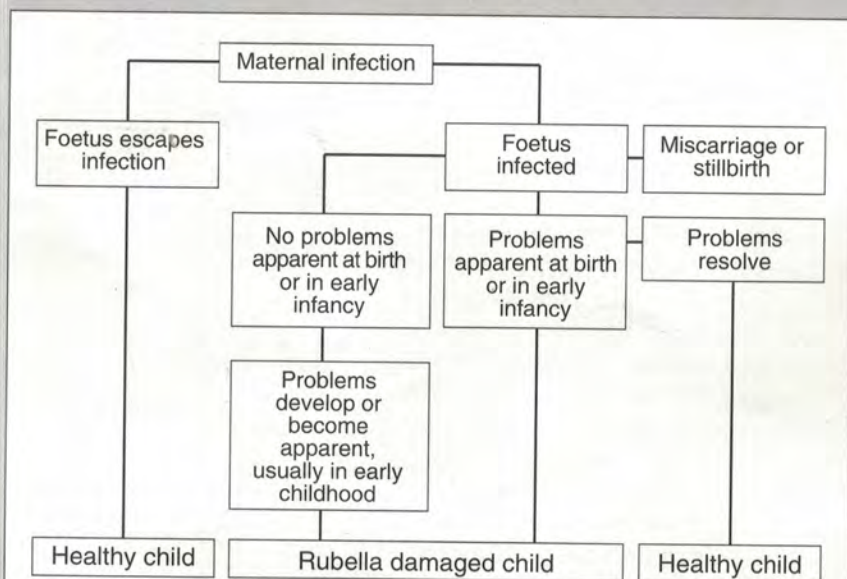
Damage is not inevitable following maternal rubella infection, or even foetal infection, but it is more likely the earlier the infection occurs. After the first four months of pregnancy it is rare. Damage or disability not related to rubella is always possible, even if it is unlikely.

Effects of Rubella

Rubella may damage the eye, resulting in cataract (opaqueness of the lens). This is one of the typical signs of congenital rubella. One eye may escape harm or both may be affected. Sometimes microphthalmos (abnormally small eye or eyes) is present as well, though it is uncommon. Pigmentary retinopathy (speckled colouring of the retina) is very common in children with congenital rubella, but does not affect the sight.

Hearing loss which may be conductive or sensorineural, is one of the commonest results of congenital rubella and may often appear as the only defect. The Organ of Corti is the part of the inner ear which links the ear and the brain, and is often the part that is damaged by rubella. Hearing loss may be mild or severe, present in one or both ears and can also deteriorate over time.

Heart abnormalities are



Damage is not inevitable following maternal rubella infection, or even foetal infection, but is more likely the earlier the infection occurs. After the first four months of pregnancy it is rare. Damage or disability not related to rubella is always possible, even if it is unlikely.

Manifestations of Congenital Rubella in Canada

sometimes seen in babies with congenital rubella and may include failure of the duct between the pulmonary artery and aorta to close (patent ductus arteriosus); opening(s) in the dividing wall between left and right ventricles (ventricular septal defect), or other heart defects.

Many babies with congenital rubella do not grow properly in the womb. Why this happens is not altogether understood. It may be because the infected placenta is not able to function to full capacity and thus affects nutritional supply to the foetus. It could be that the rubella virus may be directly responsible for slowing down the foetal rate of growth.

The rubella virus may also cause neurological problems which may be mild to severe, although this does not always occur. Learning disabilities, mental retardation and seizure disorders can occur but may not do so.

It is important to be aware that congenital rubella can affect people in different ways. Evidence suggests that people with congenital rubella may develop some problems later in life, including hearing and vision deterioration and endocrinological dysfunction. People with congenital rubella should have access to regular health check-ups, including vision and hearing assessments throughout their life.

According to WHO there is an estimated 300,000 babies affected by rubella every year¹. Congenital rubella is preventable with the rubella vaccine, available as a single vaccine or the combined measles, mumps and rubella (MMR) vaccine. Mass vaccination programmes are in action in many countries around the world.

Fiona Hall Jones

¹ Children's Vaccine Initiative. *CVI Forum*. 1998 No.15

Stan Munroe provides a summary of his recently published Canadian survey. His full report is now available in print and on the web.

- One hundred individuals participated in a study to document the incidence of early and late emerging manifestations believed related to the congenital rubella syndrome in Canada. This project was conducted by the Canadian Deafblind and Rubella Association in 1997-1998.
- Participants in the study ranged in age from five to sixty-two years. Three-quarters of the respondents reported contracting congenital rubella during the major epidemic period of the 1960's and 1970's. Eight reported contracting rubella since the 1980's while twenty contracted rubella prior to 1960.
- Individuals reported the following incidence rate of *early* manifestations of congenital rubella:
 - visual loss (86%);
 - hearing loss (93.9%);
 - heart defect (65.7%);
 - microcephaly (33.3%);
 - combined visual loss and hearing loss (80.2%);
 - combined visual loss, hearing loss, and heart defect (58.9%);
 - combined visual loss, hearing loss, heart defect and microcephaly (23.9%).Congenital cataracts, reported by 79.6% of individuals, were responsible for most early visual loss. Glaucoma was reported by 32.3% of individuals.
- The following *later* manifestations of congenital rubella were reported:
 - change in visual acuity from all causes (27%)
 - change in hearing ability (24.1%)
 - treatment for mental health (26.5%)
 - reporting at least one of aggression, self injury, tantrums, and property destruction (23.2%)
 - seizures (30%)
 - incidence of one of scoliosis, kyphosis, lordosis (26%)
 - deterioration in energy level, stamina and endurance (21%)
 - clinically diagnosed with thyroid dysfunction (10%)
 - clinically diagnosed with diabetes (12.1%)
 - clinically diagnosed with osteoporosis (7.1%)

The report entitled *A Summary of Late Emerging Manifestations of Congenital Rubella in Canada, 1999* is published and now available (the document is available in both French and English for \$15.00CAD).

For copies, please advise the Canadian Deafblind and Rubella Association
350 Brant Avenue
Brantford
Ontario, N3T 3J9.

phone 519-754-0729
fax 519-754-5400
email

The document will also be available on the CDBRA's website: at www.cdbra.ca.

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. If you are interested in receiving the Spanish edition please contact:

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A MESSAGE FROM THE CHAIR

With the imminent World Conference in mind I think of its theme, especially the last part of it – **celebrating achievements**.

Deafblind people in many parts of the world lack services, not only in developing countries, but also in industrial areas where the economic depression in the 90's has brought about a decrease in service provision. However, just because we are actively campaigning for more and better services, we do not intend to forget the achievements we have made in recent years.

Firstly, we must remember that new programmes have started in many countries. The 'established' programmes have recognised their responsibility to help the new programmes in many ways: through financial and professional



support and, by offering encouragement. The new programmes are welcome as partners in on-going discussion and development.

Secondly, we know more about deafblind people and their development than we did before. Our attitudes have changed: we recognise deafblind people as having the same needs as others. But we are also aware that deafblind people do things in different ways. We have learned much about the nature of deafblindness and especially the tactile sense, which is so little used by us hearing and sighted people. All this has increased our

EDITORIAL

I often think that the process of making this magazine is a little like making a meal. Sometimes, it's possible to choose all the ingredients in advance and confidently predict the outcome. Sometimes more experimentation is involved because the temptation to include the many good things in the cupboard is irresistible!

In this issue we bring you a taste of three continents. We start in India with news of an exciting project in Gujerat; we move to Latin America to start a short series of articles that give a lead on how cheap and plentiful materials

can be adapted to make individualised equipment and then we travel to Greece to explore the beauty and benefits of the horse in the therapeutic setting.

The news of DbI Networks give a flavour of the way that progress can be made when individuals get together with a common interest. The momentum generated by like minded people when they are able to share ideas both strengthens their professional resolve and serves to sustain them personally. Networking is a crucial activity for us all and there are opportunities to be involved for all those who

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Farewell Jean-François

Jacques Souriau, Immediate Past Chairman of Dbl and colleague and friend of Jean-François Guerineau pays tribute to his life and many accomplishments ...

Jean-François has left us. Many of the members of our Association knew him very well. He was a very active member of Dbl and of the French Association for the Deafblind (ANPSA : *Association Nationale pour les Sourds-Aveugles*).

In September 1985, Jean-François started to work in the Foyer pour Sourds et Sourds-Aveugles La Varenne, near Poitiers, first as an Educator and, as of January 1987, as Deputy Director. In January 1994, he took the responsibility for the sheltered workshop "La Chaume" near Poitiers. All these institutions are run by APSA (*Association de Patronage des établissements pour Sourds, Aveugles et Sourds-aveugles du centre-ouest de la France*).

Before working for APSA, in the deafblind field, Jean-François worked in other contexts : professional rehabilitation of handicapped people and supporting people with social problems.

While working, Jean-François successfully studied for, and was awarded, the Diploma of Director of Social Services and Master of Social Science.

All the people Jean-François was in contact with in the sheltered workshop, families, staff and deafblind workers appreciated his warm personal qualities and his knowledge and dedication to deafblind people.

In addition to his daily work



in the sheltered workshop, Jean-François was extremely concerned and active in many areas concerning people with acquired deafblindness.

During the last few years, he had the responsibility of organising, jointly with a group of deafblind people, the yearly deafblind gathering. As a result he was well known by many deafblind people all over the country and he was a very good friend of many of them.

Jean-François also took part in many international activities, within Dbl, and more precisely, as a member

of the European Acquired Deafblindness Network. In 1996, he was the key organiser of the European Seminar on acquired deafblindness which took place in Poitiers.

For many months, Jean-François fought courageously against his cancer and went on working without a break in spite of his physical weakness. In the end, he had to give up and quietly passed away on the 22nd of January 1999.

Jean-François is the father of two children and also has a grand daughter. His wife also works in the school for the deafblind in Larnay and in the National Resource Centre.

Farewell ... Jean-François. We feel that you are still with us, probably smiling gently at all the poor words we found to express our gratitude for working with you.

Jacques



DbI European Conference 2001

European organisations serving deafblind people and Networks are invited to conduct activities such as a Network day, workshops, training and courses at the 2001 DbI European Conference.

There will also be opportunities to organise "piggy back" activities or meetings on 21-23 July 2001 at the conference venue – Leeuwenhorst, Noordwijkerhout, The Netherlands.

For further information on organising pre-conference activities please contact Anneke Balder before 1 November 1999 at the following address: Anneke Balder c/o Unit Deafblindness SDG, PO Box 222, 3500 AE Utrecht, The Netherlands; telephone: +31 30 276 9970; fax: +31 271 2892 or email: sgd@wxs.nl

'Deafblindness: Keeping in Touch Beyond 2000'

National Deafblind Conference Australia

7-10 April 2000

Call for Papers: all interested parties are invited to offer papers/workshops for the 2000 National Deafblind Conference. It is envisioned that there will be three streams of concurrent sessions:

- 1 Delegates who are deafblind
- 2 Families carers and advocates
- 3 Professionals/service providers

Please send an abstract of 10 to 15 lines describing the paper or workshop you would like to offer for the conference, including your contact details and your interest in deafblindness. Please indicate which of the above sessions your paper/workshop would be targeted at.

For further information please contact: WA Deafblind Association, PO Box 14 Maylands, West Australia 6051, Australia. Telephone: +61 8 9272 1122 (voice); +61 8 9370 3524 Fax: +61 8 9271 3129 E-mail: wadba@nw.com.au

Retinitis Pigmentosa & Diabetes

Professor G.B Arden of City University in London is anxious to contact people who have both RP and Diabetes. If you had both conditions before you were 30, Professor Arden would like to send you a brief questionnaire which will be strictly confidential. The aim is to discover more about one of the most severe complications of diabetes, diabetic retinopathy.

Professor Arden can be contacted at: Applied Vision Research Centre, City University, 311 Goswell Road, London EC1V 7DD, UK; fax: +44 171 477 8355; email: g.arden@city.ac.uk

Co-creating Communication

Nord-Press are please to announce the publication of Anne Varran Nafstad and Inger Rodbroe book '*Co-creating Communication – perspectives on diagnostic education for individuals who are congenitally deafblind and individuals whose impairments may have similar effects.*'

Co-creating Communication costs 134,000 DKK and to order a copy please contact: Forlaget Nord-Press, Nr. Ringgade 2, DK-9330 Dronninglund, Denmark; telephone: +45 98 84 10 20; fax: +45 98 84 24 88 or email: basistryk@email.dk

Deafblindness in Old Age

The proceedings from the two latest events organised by the Acquired Deafblindness Network are now available. Both documents will soon be on the DbI web site.

Paper copies of the documents can be ordered by contacting Malcolm Matthews at Sense

fax # +44 171 272 6012

e-mail: mmatthews@sense.org.uk

Paper copies delivered by post will cost: £6.00 (sterling) for the conference proceedings and £4.00 (sterling) for the report from the expert meeting, plus postage.

European Network on Staff Development

Networks

ACQUIRED DEAFBLINDNESS NETWORK

c/o Anneke Balder
Stichting Doof-Blinden
c/o SDG
Christian Krammloan 2
3571 AX Utrecht
THE NETHERLANDS
Tel: +31 - 30 -
276 9970/0459
Fax: +31 - 30 -
271 2892

COMMUNICATION NETWORK

c/o Jacques Souriau
L'Habit d'Or
Marigny - Brizay
86380 Vendevre 4
FRANCE
Tel: +33 - 5 -
49 52 09 24
Email: souriau@interpc.fr

CONGENITAL DEAFBLINDNESS IN ADULTS NETWORK

c/o Bob Snow
Sense North
122 Westgate
Wakefield WF1 1XP
UK
Tel: +44 - 192 -
420 1778
Fax: +44 - 192 -
436 6307
Email:
bobsensen@aol.com

EUCO UNIT/STAFF DEVELOPMENT NETWORK

c/o Lieke de Leuw
IvD International
Instituut voor Doven
Theerestraat 42
5271 GD Sint-
Michielsgestel
THE NETHERLANDS
Tel: +31 - 73 -
5588111
Fax: +31 - 73 -
5517897
Email:
ivd.international@rdt.ivd.nl

EUROPEAN USHER SYNDROME STUDY GROUP (EUSSG)

c/o Mary Guest
Sense
11 - 13 Clifton Terrace
Finsbury Park
London N4 3SR
UK
Tel: +44 - 171 -
272 7774
Fax: +44 - 171 -
272 6012
Email:
MGuest@sense.org.uk

You will recall that this group has been referred to as the EUCO unit – European co-ordinating unit on staff development – and has most recently benefited from the support of Sint-Michielsgestel, who provide administrative backup.

There has been some minor changes to the membership. Walter Tibosch, who was Chair, has resigned from the group because his new duties take him away from involvement in direct services for deafblind children. His position on the network has been taken over by Ger van Rijn also from Sint-Michielsgestel, and the role of Chair has been taken by Virginia von Malachowski, Sense.

The group met in Warsaw in January this year at the invitation of The Polish Society for the Blind. It was the first time the group had met since the Spring Seminar which had been held in Holland the previous year. A key task was to decide how the objectives agreed at the end of that event would be taken forward. The details will be presented at the Lisbon Conference but the main outcomes are:

- ▶ to collate details of conferences, events and other opportunities for staff development which are organised in Europe
- ▶ to circulate details of individuals who are willing to offer advice and

guidance to professionals in developing services

- ▶ to organise an event which enables key services to share knowledge on their differing approaches to staff development

Readers are invited to submit information on all staff development activities for 1999 and the first quarter of 2000 to Leike de Leuw at Sint-Michielsgestel.

You are also invited to register interest in participating in a three day event which will precede the 2001 European Conference. This will explore the key approaches adopted in working with deafblind people and the consequential staff development which supports these approaches.

Acquired Deafblindness

Ole Mortensen, from the Information Centre for Acquired Deafblindness in Denmark, and a member of the Co-ordinating Group of the Acquired Deafblindness Network reports on the Network's developments.

The Acquired Deafblindness Network has existed now for 10 years. During this time we have arranged three seminars, in 1994, 1996 and 1998, and an expert meeting in 1998. We have also published proceedings and other material from these events and organised network focus days at World and European Conferences. At the same time acquired

deafblindness has been developing as a professional field, and through these events, we have come in contact with an increasing number of professionals who are interested in having a more active role in international collaboration with the Acquired Deafblindness Network.

At our meeting in Holland in February, the Co-ordinating Group of the Acquired Deafblindness Network decided to reorganise its structure. The Network will now provide the context for project based activities in different subgroups, focusing on specific areas. At the

moment the sub groups include:

- ▶ Raising awareness on acquired deafblindness in Europe, led by Malcolm Matthews, UK
- ▶ Investigating definitions of deafblindness and the demographics that these definitions may lead to. Else-Marie Svingen, Norway
- ▶ Old age deafblindness, led by Liz Duncan, UK. An expert meeting will be held 17th-21st November in Bradford, England
- ▶ Network focus day at the World Conference in July 1999, led by Anneke Balder, The Netherlands,

European Usher Syndrome Network

Following Mary Guest's report, in the December 1998 edition of *DBI Review*, Peter Palmer, Co-ordinator of the European Usher Syndrome Network, outlines the work of the network's working group.

The first meeting of the European Usher Syndrome Working Group was held in Copenhagen, Denmark, in January 1998 and was followed by a second meeting in Nurnberg in September 1998.

In Copenhagen, we looked at the different ways a network could help people with Ushers, including creating awareness in Europe, collecting and distributing information, training and education, diagnostics and assessment, research, communication, fund-raising, conferences, electronic communication, support and back-up for the national Usher groups and 'help lines'.

The second meeting in Nurnberg

looked at the organisation and structure of the proposed network. We discussed aims and objectives, regulations, election of the Board, establishment of a secretariat, recruitment of members, including organisations.

Our third meeting was held in Manchester, England, on 6 March 1999, where we discussed the constitution, structure, formation of management committee and future relations of EUSN.

It was decided to proceed with the formation of a European Usher Syndrome Network (EUSN) but to approach it with caution. At this stage we will not have a Constitution, as this may restrict our activities. We do have broad aims and objectives that give us a clear direction, yet allow us to adjust to the requirements of the Network as it grows and develops. We are looking into the possibility of

presenting the proposed EUSN at a European Conference sometime in the latter half of the year 2000.

We are grateful to the European Deafblind Network for its help and support so far and we hope this will continue. Our thanks also to Sense and the European Usher Syndrome Study Group for their help.

We realise there is a lot of hard work ahead and there will be more 'midnight oil' to burn with a few 'mountains to climb' but we are certain we have the **Expertise, Determination, Effort and Enthusiasm** needed to complete this project and make a success of it for the sake of people with Usher Syndrome throughout Europe.

For further information on the European Usher Syndrome Network, please contact Peter Palmer by email: Peter.Palmer@btinternet.com, or fax +44 1255 852616.

Network

- and Ole Mortensen, Denmark
- ▶ Conferences and other international events on acquired deafblindness. As yet nobody is responsible for this subgroup. The following events have been suggested: an international seminar on acquired deafblindness in 2000; a one day seminar on acquired deafblindness in connection with the European Conference on Deafblindness in The Netherlands in July 2001; and an international conference on acquired deafblindness in 2002.
- ▶ Maintaining the contact list database with names and addresses of the participants in the Network and sending out materials to the Network

(Malcolm Matthews, UK, is in charge of this at the moment, but wants to hand over this responsibility to someone else).

Inviting more people to join

The Co-ordinating Group sent out a letter in April to the participants in the Network inviting more people to be actively involved, either in one of the two vacant positions mentioned above or as a working member in one of the subgroups. There is room and a need for people to be involved in all the subgroups, so we would like to have many more colleagues join the network.

The work in the subgroups is expected to take place mainly by telephone, e-mails and faxes, and therefore it will not be necessary to travel to be involved in the work. The Co-ordinating Group is also investigating the possibilities for using the Internet's chat functions

as platforms for the international collaboration in the subgroups.

If you are interested in taking an active part in the Network in any capacity or if you want to have your name on the contact list and receive information about the work in the groups, then please contact Chairperson **Anneke Balder** at the following address: Anneke Balder, SDG, Unit Deafblindness, PO Box 222, 3500 AE Utrecht, The Netherlands. tel. +31 30 276 99 70 fax: +31 30 271 28 92 e-mail: sdg@wxs.nl

At the Dbl World Conference in Lisbon, Portugal this Summer the Acquired Deafblindness Network is conducting a network session on the 23rd July where different speakers will share information on new developments in the field of acquired deafblindness. The Network will also try to find a way to mark its 10th anniversary during the Conference.



**Sense
International**
and



**The European
Deafblind Network
(Edbn)**

First Announcement 3rd European Family Conference

Kosice, Slovakia, 9 – 11 September 1999

Jointly organised by Sense International and the
Evanjelicka Deafblind School in Slovakia

**“PARENTS AS RESOURCES – How parents can help
other parents and professionals.”**

We are pleased to announce that the 3rd European Parents Conference will take place in September 1999 in Kosice, Slovakia organised by Sense International and the Evanjelicka Deafblind School. The theme of this conference will be Parents as Resources – How parents can help other parents and professionals. The Conference will emphasise the wealth of knowledge that parents have and the ways in which this can be of benefit to other parents and professionals. In particular the conference will aim to be a forum for parents from Central and Eastern European countries to meet with other parents not only from their region but other countries in Europe. The Conference will take place over two days and consist of a mixture of plenaries and workshops.

DATES: **Arrival:** 9 September
Conference: 10 & 11 September
Departure: 12 September

VENUE: House of the Deaf in Kosice, Slovakia

ACCOMMODATION:

Twin and single rooms have been booked in local hotels to accommodate up to 50 delegates. These will be allocated on a first come first serve basis.

COSTS: Sense International is pleased to announce that we will cover the costs of accommodation and meals during the conference and therefore no registration fees will be sought.

TRAVEL GRANTS:

Participants are encouraged to find sponsorship for their travel costs from local organisations. However, a limited number of travel grants will be available. Please apply in writing to the following address.

For further information please contact: Emanuela Brahamsha, Sense International, 11-13 Clifton Terrace, Finsbury Park, London, N4 3SR UK.

Tel: +44 – 171 – 272 7774 Fax: +44 – 171 – 272 6012

Email: ebrahim@sense.org.uk

Young Deafblind People and the United Nations Standard Rules

29 October – 4 November 1999

Almäsa, Västerhaninge, Sweden

We are continuing with the planning work for the seminar on the United Nations Standard Rules for young deafblind people from all over Europe.

**Please, notice that the dates for the seminar
have changed!**

The seminar will now take place on **October 29th to November 4th 1999**. It will be hosted by the **Association of the Swedish Deafblind (FSDB)** and **Deafblind Youth (DBU)** in collaboration with **Mobility International** and with support from **Sense International** and **Lega del Filo d'Oro**.

The programme will include:

- information about the United Nations Standard Rules and how to use them, experiences of discrimination and social exclusion,
- discussions about opportunities for young deafblind people and future European
- co-operation.

We will also have plenty of time for fun and relaxation!

We would like to invite one deafblind delegate – with interpreter(s) – between the ages of 15 and 30 years from each country. If there is no appropriate participant of this age group in your country, it may be possible to send a deafblind person who is a few years older.

There will be a participation fee of 2.500 SEK for each participant, plus a contribution of about 25% of travel expenses, which we expect the national organisation of the participant to pay. (Swiss nationals must apply for grants to their local Youth for Europe-office.)

We hope there will be no fee or contribution for travel expenses for the interpreters, but the national organisations will have to pay any interpreter wages.

Please do not confirm your tickets until you have got further information from us.

The official seminar language will be English.

Deadline for registration is August 8th 1999.

More information about the travels and the programme will be sent out after the end of the period of registration. If you have questions, please do not hesitate to get in touch with us.

Questions and registrations can be addressed to:

Linda Eriksson FSDB/DBU S-122 88 Enskede Sweden
Tel: +46 8 39 90 00 Fax: +46 8 659 50 42 to FSDB/DBU
or +46 19 36 39 34

E-mail: linda.eriksson@tp44.frukt.org

Helen Keller World Conference, October 2001

Deafblind NZ Incorporated is delighted to announce that it will be hosting the seventh Helen Keller World Conference in Auckland in October 2001. It will be the first Helen Keller World Conference to be held in New Zealand.

The theme of the conference will be: *'What it means to be Deafblind, Identity, Rights, Unity.'* It will be a great opportunity for deafblind people in this part of the world to attend and put their views forward and speak about their needs.

The conference will

run at the same time as the first General Assembly of the World Federation of the Deafblind, a newly organised group formed at the sixth Helen Keller World Conference held in September 1997.

Updates on the Conference will be given as soon as they are known.

For further information please contact:

Jan Scahill, Conference Convenor, International Conference Committee, PO Box 14-076, Tauranga, New Zealand.

Deafblindness: Keeping in Touch Beyond 2000

National Deafblind Conference

7-10 April 2000

Fremantle, West Australia

Friday 7 April 1999 Pre-conference Training Day, specifically targeted at professionals and service providers.

Saturday 8 and Monday 10 April Conference days with plenary sessions and workshops

Sunday 9 April Social Day

We are very fortunate to have Graham Hicks from Sense in the UK as Keynote Speaker. The conference languages will be English and AUSLAN (Australian Sign Language). Interpreters other than AUSLAN and tactile two-hand manual will not be provided – international delegates will be expected to provide their own interpreters.

For further information please contact: WA Deafblind Association, PO Box 14 Maylands, West Australia 6051, Australia.

Telephone: +61 8 9272 1122 (voice); +61 8 9370

3524 Fax: +61 8 9271 3129

E-mail: wadba@nw.com.au

International Conference in Denmark

'The Learning Child – the facilitation of learning in children with learning difficulties'

30 September to 2 October 1999

HC Andersen Hotel, Odense, Denmark

Keynote speakers will be Dr Johan van der Poel from South Africa and Dr Lilli Nielsen from Denmark. The conference should be of interest to all professionals and parents involved in the interdisciplinary assessment, and the planning and implementation of development programmes for children and young adults.

Deadline for registration: 15 August 1999

For further information please contact: Mr Preben Frederiksen, The Ministry of Social Affairs, 22 Holmens Kanal, 1060 Copenhagen K, Denmark.

Fax: +33 93 25 18

E-mail: dppfr@sm.dk



The Management Committee recently met on 14 -15 April in Paris, France. Many issues were discussed including details of the Lisbon Conference, the European Conference in 2001 in the Netherlands, as well as the possible location of the next World Conference in 2003.

The issues around developing the networks were discussed and it was with great pleasure that the Management Committee approved the European Deafblind Network (EDbN). This will be ratified by Council and General Assembly. It is very much hoped that the emphasis on developing networks will continue.

Seven people from countries with developing deafblind services were chosen to attend the Dbl World Conference in

Lisbon. The seven will be the first recipients of the small Dbl sponsorship fund that was announced in the last issue of *Dbl Review*. The participants come from a range of countries including South Africa, Slovakia, Russia, Estonia and Brazil.

The Nominations Committee reported on their progress to date. This committee was established by the Interim Council to manage the election process for membership of the first Council under the new Constitution, and the election of the President and Vice-President. It was charged with ensuring that the composition of the Council reflects the diverse interest areas and needs of Dbl's constituency. It has contacted all existing voting members – Corporate Members and

Networks for their nominations and will be reporting to the General Assembly at the Lisbon conference in July.

The next meeting of the General Assembly will take place on Tuesday 20 July 1999 at 16:30 in the Auditorium of the Centro Escolar Turistico e Hoteleiro, Estoril, Portugal.

The General Assembly is the supreme decision-making body of Dbl. All interested persons are welcome to attend. Any person may speak but only voting members may vote. Voting members are the representatives of corporate members who have paid their 1999 subscription fees by 30 June 1999, and the representatives of recognised Dbl networks. A list of voting members will be available at the meeting.

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 1999 subscription fees by 30 June 1999, and the representatives of recognised Dbl networks. A list of voting members will be available at the meeting.

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

Large Corporates are guaranteed members of the Council of Dbl. Small Corporates can be nominated to sit on the Council.

AGENDA

- 1 Welcome by the President of Dbl, Marjaana Suosalmi**
- 2 Apologies for Absence**
- 3 The new Dbl Constitution, a brief summary: Wolfgang Angermann**
- 4 The Report of the Interim Council for the period 1995 – 1999 since the last meeting of the General Assembly in Cordoba, Argentina, including major Dbl activities: Marjaana Suosalmi and Rodney Clark**
- 5 Financial Report for the period 1995 – 1999 since the last meeting: Rodney Clark**
- 6 Dbl Publications and Information: Malcolm Matthews**
- 7 Dbl Networks and Network Development: William Green**
- 8 Election of the Dbl Council, 1999 – 2003: William Green, Chairman, Nominations Committee**
- 9 Election of the Dbl President and Vice-President: William Green, Chairman, Nominations Committee**
- 10 Resolutions**
- 11 Presentation on the development of deafblind services world-wide during the period 1995 – 1999: Richard Hawkes.**

Individual Membership

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

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

Please debit my Visa American Express Mastercard

□□□□ □□□□ □□□□ □□□□ Expiry Date

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

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 _____

(Please include full STD code)

Tel _____

Fax _____

Email _____

DbI Review (*please tick one box in each category*)

I would prefer to receive *DbI Review* in English Spanish

I would prefer to receive *DbI Review* on disk

Please return to Tamar Underhill, Deafblind International, c/o 11-13 Clifton Terrace, Finsbury Park, London N4 3SR, UK.

Corporate Membership

We would like to join DbI 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 (*please delete as appropriate*).

Cheque or international postal order

Bank Transfer

Name of Bank: RABOBANK

Address of Bank: Sint-Michielsgestel,
The Netherlands

Account Name: Instituut voor Doven:
INZAKE DBI

Account Number: 11.29.09.825

Member Details

Organisation _____

Representative _____

Address _____

(Please include full STD code)

Tel _____

Fax _____

Email _____

Please return this form to Adri van Grinsven, Finance Officer, DbI c/o Instituut voor Doven, Theerestraat 42, 5271 GD Sint-Michielsgestel, The Netherlands.

Fax: +31 73 55 12 157

knowledge and, as a result, the quality of services has improved.

Thirdly, we have realised that the development of deafblind people is dependant on competent partners. We have learned to look at ourselves and ask many questions:

- Do I give the deafblind person the best opportunities for development?
- Do I listen to the person?
- Do I react?
- Do I confirm, that I have understood him?
- Do I respect his own way of doing things instead of trying to sell my own?

And we have learned to accept that often the answer is no. And that, in itself, is an achievement! As a result of this realisation a huge

amount of professional development work has been started world-wide.

Fourthly, we have also learned what fun it is to do things together with deafblind people. Not only to assist them, but to join in the activities ourselves. As an colleague of mine says: "This work is fun – think how privileged we are!"

For some of us there is the excitement of meeting in Estoril, Portugal, this summer – catching up with old friends, making new ones, and in doing so celebrating some great achievements in the field. For the many, who will not be present, we promise to be in touch in other ways in the coming years and look forward to meeting in the future.

Marjaana Suosalmi

wish it. The development of electronic communication has made a huge difference and, even though many of our professional friends and colleagues are in remote regions of the world, we are hopeful that, even given the financial and technical constraints, more of us will be in touch with each other, more directly, in this way. We have established our website over the past 12 months under the wing of Sense, and some of you have visited it, but now we have taken the decision to move to our own independent slot at www.deafblindinternational.org

It is the right time to establish our own independent identity in this way and start to encourage more participation in the development of its contents. Articles and ideas from *Dbi Review* will continue to be posted, as will up-to-date news of Conference and Network activity. However the site, like the magazine, is only as good and up to date as the information its editor receives and so we do need your help and support to make it work!

Our thanks to all our contributors ...

Good wishes
Eileen and Jacqueline

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Integrated Services for Deafblind People in the State of Gujarat

Vimal Thawani, Project Coordinator at the Blind People's Association describes some major developments in services to deafblind people in the Indian State of Gujarat

The Blind People's Association (formerly known as the Blind Men's Association) is one of the largest organisations in Asia working for the comprehensive rehabilitation of people with visual impairment and other categories of disability.

The BPA adopts a dynamic approach to rehabilitation, anticipating the changing role of special schools for the blind. The BPA has always been synonymous with developing new programmes and has taken the lead in innovating and adopting new approaches. Bearing in mind the changing pattern of disabilities and noting that almost no services were available for people with deafblindness in the country, and particularly in Gujarat, the BPA realised that there was a genuine need for new services to be developed to meet the needs of deafblind people.

With the professional, as well as financial, support from the Sense International India, the BPA has been able to start comprehensive services for the first time for people in Gujarat who are deafblind.

The BPA adopts a dynamic approach to rehabilitation, anticipating the changing role of special schools for the blind.

The programme has been started with a commitment to a multi-pronged approach to rehabilitation. Rather than adopting any single approach, the BPA has initiated an adapted response based on the following steps:

- Training of existing Community Based Rehabilitation workers in identification and skill training
- Conducting a survey by building on to existing programmes
- Screening of the target group through multi-disciplinary approaches
- Developing skill training in institutional and CBR settings
- Training for parents living in areas outside the scope of BPA services
- Orientation and sensitisation in deafblindness of single sensory impairment special educators
- Coverage through the CBR strategy
- Integration of children with deafblindness in the single category schools

- Developing appropriate print and audio visual material for parents and workers with deafblind people

Our experience at BPA establishes that all these options and strategies are appropriate, effective, viable and result-oriented. For achieving these objectives, the identification of people who are deafblind was the first and the most important step for starting the service.

Orientation of Community Based Rehabilitation Workers

The BPA has a large network of community based rehabilitation programmes in urban areas of Ahmedabad and in most of the districts of Gujarat. The CBR workers work with people with visual impairment and provide rehabilitation services at their door steps.

The BPA decided to make use of this established resource and arranged a one week intensive training course consisting of deafblind awareness as well as hands on working with children with multiple disabilities and deafblindness.



Vimal Thawani and Nandini Rawal advise in the community

Survey of people who are deafblind

On completion of this training, the CBR workers conducted a door-to-door survey using a pre-planned schedule and as a result were able to refer children with multiple disabilities to the BPA for further screening and assessment. The requisite information was compiled in a special format prepared by the BPA team.

The BPA team also made other workers aware so that they would refer on the children with multiple disabilities that they encounter in their work. The result of this training was that there was an immediate spurt of referrals arising from this new awareness. Within a

couple of weeks the BPA team was flooded with enquiries about children suspected of being deafblind.

Good use was made of the Urban Medical Camps. The BPA has a very large urban network of health workers, who constantly screen persons with disabilities and provide rehabilitative services locally. These workers were also made aware and immediately started identifying people with multiple disabilities in the weekly medical camps being conducted in the slums.

Screening Camps

The BPA has a core team which consists of special educators, Project Co-

ordinator and Project Director. This team has planned a schedule for conducting mobile screening camps in different areas.

These camps were organised in August, September and November '98 in three different districts of Gujarat at Idar, Surendranagar and Viramgam respectively.

Around 138 children with more than one disability already identified by field workers or itinerant teachers came to these camps with their parents. The team examined each child, carried out an initial functional assessment and identified 9 children in the age group of 3-21 years with dual sensory impairment with learning difficulties and

The parents of such children were invited, in batches, for intensive parental training.

communication problems. So far, the BPA through its urban and rural CBR programmes has identified 26 people with deafblindness in a short span of six months.

Deafblind children in institutional settings

The children with deafblindness identified in the urban areas were assessed by medical specialists who in conjunction with the special educators drew up individualised rehabilitation plans. Five children were offered places in the deafblind day care centre and have shown remarkable progress. The other children who could not be admitted are being given education and training in their own homes through an outreach programme.

Children living in areas not served by BPA

Not surprisingly the BPA has come across a large number of children with deafblindness who have been referred from the areas where the BPA does not have a programme. As a result, the parents and these children were invited to the BPA for assessment, counselling and training. Their progress is being monitored regularly by the centre.

Parental Training and Support

The BPA team realised that all the children could not enjoy services through special educators or trained CBR workers. The parents of such children were invited, in batches, for intensive parental training. These parents are now providing "hands on" services to the children with the weekly intervention of the trained CBR worker. The centre team monitors the

The centre team monitors the progress of each child and gives input on a regular basis.



progress of each child and gives input on a regular basis.

Training opportunities for single sensory impairment special educators

If the coverage of children with deafblindness is to be adequately increased, the schools for the deaf and for those with learning disability, which have a significant number of children who could be classified as deafblind, need to be involved. The BPA is thus planning to organise orientation for teachers from these schools.

Future Plans

Identification is an ongoing process of the BPA's comprehensive project. The BPA is planning to offer awareness training to paediatricians through a one

day workshop. This is designed to help them to understand functional assessment and other services for deafblind children, so that in future, they may identify and refer them for rehabilitative services.

In addition the Government of Gujarat is planning to survey the disabled population in Gujarat. The BPA is trying to ensure that deafblindness is incorporated as a separate category in that survey. This will establish the actual demographic pattern of people with deafblindness in Gujarat. This evidence will help in planning and developing both existing and new services across the region to ensure that need is met wherever possible.



fundamental tools: **creativity** and **imagination**.

Before building any cardboard adapted equipment you will need certain tools and materials, and the cardboard will need preparation.

Tools

- awl or prick punch (middle tip)
- paper cutter, serrated knife, manual saw
- small head hammer
- plastic thermoshaping pistol including bars for the pistol (thick and long)

Materials

- cardboard sheet consisting of three layers: plain-corrugated-plain
- glue for cardboard
- T-square – one metre long
- ruler – one metre
- set square – one metre
- skewers cut into different sizes – these are glued and will be used as nails
- basic paint suitable for cardboard or wood
- Acrylic paint in opaque colours

- brushes
- paper tape or sticky tape of six centimetres

Cardboard preparation

Place the cardboard on a flat surface and stick three sheets together. Spread the cement or glue on them – covering the whole surface. The three sheets must measure two centimetres thick in order to be resistant.

Important: do not rest your knees or palms on the cardboard while glueing because the cardboard will remain marked.

Sheets are placed on a flat surface for drying, each separated by newspapers. In order to keep them tightly pressed, a heavy object must be placed on top covering the whole surface for about two or three days.

Construction

The construction of cardboard adaptations depends upon what you are building. It is advisable to start building simple constructions such as

storage boxes and then progress to more complicated adaptations such as chairs and tables.

Here are simple instructions to build a box sized 20cm x 30cm x 10cm.

- First cut the base and then the sides using appropriate tools; the paper cutter, serrated knife or saw.
- The base and sides are glued by contact with the plastic pistol allowing 1cm space over the base.
- Pierce at the four corners and the base using the awl or prick punch.
- If materials are not supposed to resist heavy weights, nail it at the four corners and in the middle of the four sides.
- Place the nails (previously glued skewers) into the holes.
- The whole surface is covered with the paper tape on the inside and outside of the box.

Painting

Once the construction of the cardboard is completed it is painted, firstly with basic paint for wood and then with acrylic paint in opaque colours. Painting is important for resistance and to give a proper finish. If the material is intended for a person with poor vision use contrasting colours for differentiation.

The objective of using adapted equipment is to identify and solve physical problems experienced by the multiply disabled person. In constructing your own adaptations the specific needs of an individual can be catered for and adapted according to changing needs.



It's amazing what can be achieved!

Engineering with Cardboard

In this article Patricia Pastor demonstrates her skills and imagination in the use of this lowcost and plentiful material

The development and subsequent use of high technology adaptive equipment in special education and rehabilitation has been amazing. However, the cost of these innovations is often high and schools and services cannot afford them.

It is therefore important to remember that anybody can build a simple switch and modify a battery-operated toy so that a multiply disabled person can access it and achieve some form of independence.

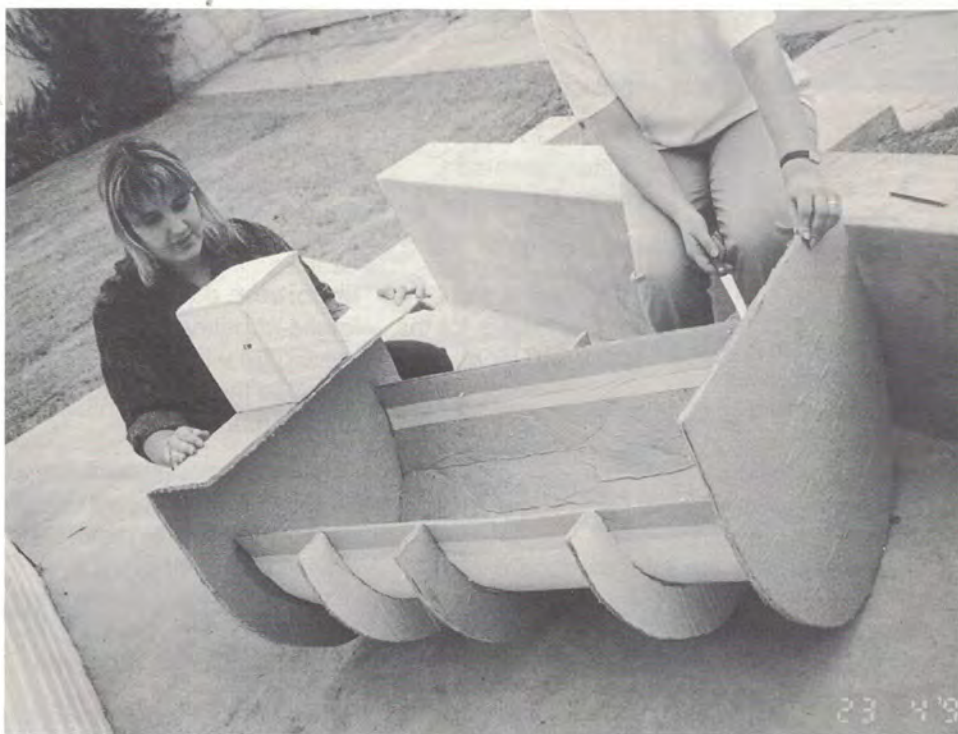
In this article I explain how simple materials like cardboard can be used to create low cost specially adapted equipment.

The Cardboard Technique

As a material, cardboard allows us to create adaptations according to individual needs: chairs for people with brain damage or motor disorders, tables adapted for wheelchairs, foot-holders for body balance and inclined planes to make head-holding easier.

The advantage of using this type of material is that it is low cost, fast to manufacture and easy to handle. Cardboard can be obtained easily: from shops or from electrical appliances boxes used for cookers, refrigerators, TV sets, etc.

Once completed, cardboard equipment is long-lasting, light to carry and designed according to the specific needs of each person. All you need are two



Above and below: Creative ideas in the making



Therapeutic Riding with Deafblind Children in Greece

Georgia Pappa, an occupational therapist who works with the Association of Parents, Tutors and Friends of Deafblind children in Athens outlines an exciting programme which encourages children to enjoy riding and relate to horses.

Therapeutic riding has its roots in ancient history and was probably first used by Hippocrates in Greece between 460-377 B.C.

The horse has been around for centuries and has a noble place in history. It has been used in many different ways; originally for transportation in times of peace and war, as a partner in the workplace and for sports and recreation.

Riding is a pleasant activity for many people. It is a social skill that can be great fun for all involved.

Therapeutic Riding

Therapeutic riding has its roots in ancient history and was probably first used by Hippocrates in Greece between 460-377 B.C.

It is a complete form of therapy which has a positive effect on the physical, mental and psychological well-being of the rider.

Therapeutic riding encompasses many different activities:

- ▶ Riding for sport
- ▶ Psycho-remedial educational riding
- ▶ Hippotherapy – either on horseback or a horse driven carriage can be very appropriate for severely disabled people.

Almost every disabled individual involved in therapeutic riding reports improved general health and well-being, including improvements to the



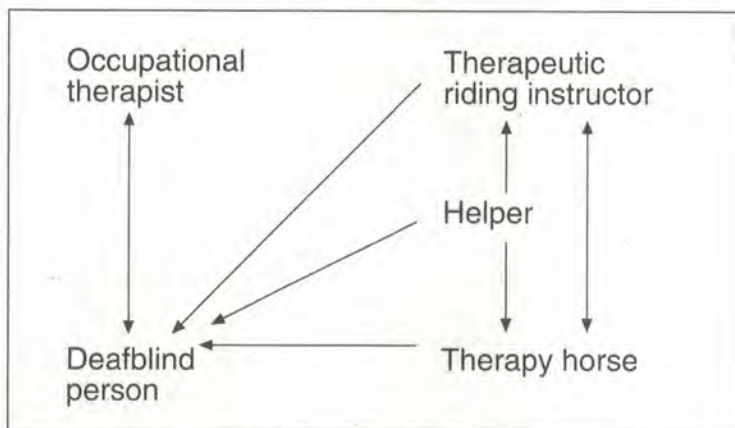
cardiovascular system, stimulation of basic body-function, and a positive influence on muscle function. In addition, there are often improvements in head and trunk control, balance, and body awareness.

The Athens Programme

In our group based in Athens, Greece, we use psycho-remedial educational riding with deafblind children. The group consists of deafblind children with other disabilities

such as autism and mental retardation. They are all at different functional levels: some of them have partial sight while some of them are completely deafblind. Some are residents at state institutions while others are cared for at home. They all come from a variety of social and economic backgrounds.

Before we try to instil confidence into the deafblind riders, which is essential to teach them how to ride, the instructor and helpers first need to establish a level of communication which suits each particular individual. Different methods of communication are used depending on individual levels of understanding. With some children we use speech combined with sign language, with other children we use body signals in the form of a specific motion or gesture. Once communication has been established with the rider, it is then easier to



The treatment team in psycho-remedial educational riding