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THE MAGAZINE
OF DEAFBLIND
INTERNATIONAL

Number 21 • January - June 1998

Review



The Arts *see pages 16-31*

A MESSAGE FROM THE PRESIDENT

Dbl 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 coming 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 or Spanish 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 *Dbl*.

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

Dbl Review is also available in Spanish. If you are interested in receiving the Spanish edition please contact:

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We are living in very interesting times: seeing the fruits of the strategic planning which has taken place in recent years.

In the middle of the 1990's, the need for long-term planning became very obvious. We had to rediscover our aims, which activities our members prefer, how should we organise the association and how we manage and administer it.

So we agreed that we are a world association to promote services, that we want a flexible organisation allowing involvement of the members and also requiring active participation and the sharing of responsibility. An important way of achieving these aims is through the development of networks. As a result, we have changed the name to underline that we do not only deal with education, but all aspects of deafblindness. Now the association's name is **Deafblind International** and accordingly our magazine ***Dbl Review***.

We have a new constitution awaiting ratification in Lisbon. This means that next year we are ready to live up to its principles!

We are happy that with increased corporate membership *Dbl's* budget has grown and we look forward to supporting the conferences and especially

members from developing countries or starting programmes.

When the elections are held for Council next year I hope that all the membership will contribute to the search for good candidates. For the first time, Networks can be represented and I think it is important to have a wide range of people.

I would like to end on a personal note. At the end of June I am going to move to Finland, my home country, which I left 10 years ago first for Denmark and NUD, then Mo Gård.

These have been good and interesting years working at two very special and competent institutions. I have learnt a lot and made many friends along the way. But now it feels good to go back to Finland and speak the beautiful Finnish language every day! What is even better is that I have an opportunity to work with the Foundation for the Deaf, which has also agreed to pay my costs as President of *Dbl*.

I am practically sitting on removal boxes, but still enjoying the beautiful early summer here in Sweden. So, Season's Greetings to all of you whatever season you are enjoying at the moment.

Marjaana Suosalmi

LAST COPY DATE FOR THE NEXT EDITION: 10 October 1998

EDITORIAL

Welcome to the first edition of *Dbi Review*. Our new name has given us the opportunity to redesign the magazine and to reflect the changing nature of the Association as it recognises the challenges facing professionals, families and deafblind people as we move towards the Millennium. So, we hope you like our new look and enjoy the content of this rather special edition. From now on the magazine will be available on disc (on request) and "a taster" will be posted on the Dbi website which is currently under construction.

The themed section celebrates the value of the expressive arts and Klaus Vilhelmsen describes, with such clarity, the profound significance of aesthetic experience for us all. We also have the opportunity to enjoy the work of artists from around the world in a special one-off colour section, and to hear the teachers' perceptive on both the visual arts and dance.

The Dbi Interim Council and Management Committee have been very busy over recent months and we bring you a summary of their deliberations and decision making. We know this will stimulate wider participation.

Happily we are receiving an increasing number of reports from around the world which demonstrate the enormous skill and energy of Dbi members. We would like to thank you all for keeping us in touch with your activities and we look forward to hearing your news for the next edition when we will be focusing on environments.

Eileen and Jacqueline

January - June 1998

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The Interim Council and Management Committee of Dbl met in Lisbon during the weekend of 14-17 May 1998. As well as enjoying the kind hospitality of Casa Pia de Lisboa, hosts of the 1999 Dbl World Conference, the Interim Council discussed management and strategic issues including the preparations for the 1999 conference. Here is a summary of the discussions and key decisions.



Rodney Clark,
Secretary

The main changes to Dbl's Constitution have included a new name, a new membership structure and new decision-making structure made up of the General Assembly, Council and Management Committee. The Interim Council have approved the new constitution and it will be ratified by the General Assembly in Lisbon 1999.

Over the next few months, non-voting members can expect to receive a new information leaflet and a request to reconfirm their subscriptions. Members are advised to complete this form

to ensure membership is both renewed and recognised.

1999 General Assembly

The next General Assembly will take place on the afternoon of **20 July 1999**, the arrival day for the Lisbon Conference. Non-voting members will be invited to attend but only voting members will be issued with voting cards. The agenda will include: elections of the President, Vice-President

and Council; a report for the last four years, the accounts and the new constitution.

A Nominations Committee has been set up to identify and propose nominations for Council members, including President and Vice-President. Those who attended the Interim Council meeting will remain as members of Council until a new Council is elected in 1999.

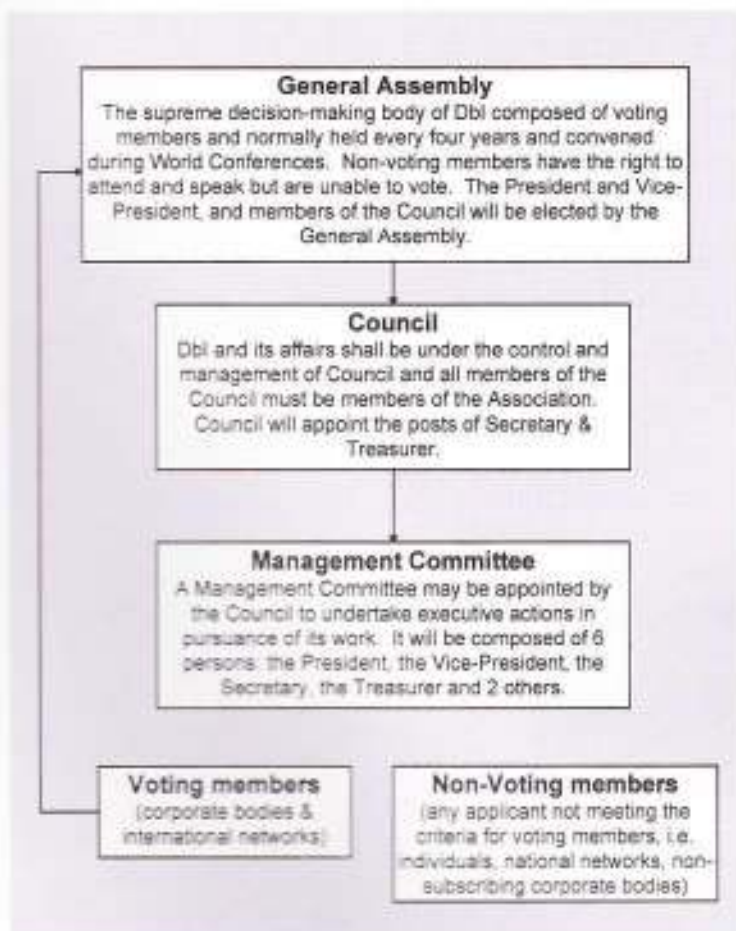
Network Recognition

The Interim Council have decided that networks can be recognised as soon as they are established on the proviso they meet the criteria set by Dbl. However, networks will not be eligible for a seat on Council if younger than two years and a network must be active for the whole four-year term of the Council.

The Interim Council recognised the five existing networks affiliated to Dbl. These are all European networks:

- European Usher Syndrome Study Group
- Working Group on Communication
- Committee on Congenital Deafblindness in Adulthood
- Acquired Deafblindness Network
- EUCO Unit/Sub-Committee on Staff Development

The following information will also need to be provided in



In order for a proposed Network to be recognised by Dbl the following criteria must be in place:

Network Recognition

The Network must:

- be in sympathy with the objectives of Dbl
- involve at least three countries
- have an agreed means for communication between members
- be project based and time limited **or** an ongoing interest group with an action plan
- provide details of a Contact Person
- report to Dbl at least every two years

order that Dbl can consider recognising a proposed Network and should be provided in updating reports. National networks or other groups not meeting the above

- **Proposed Network Name**
- Name and contact details of **Contact Person** (including telephone/fax numbers and email addresses)
- **Aims and Goals** of Network
- **Target membership**
- Is the Network an **ongoing interest group or project based and time limited?** If time limited then what duration is proposed?
- Specify the number of **countries** involved in the Network
- Do you have a **management development group?** If so, state the names of key members and the countries they are from
- When was the Network first formed?
- List activities undertaken so far
- **Materials and documents** produced to date
- **Activity programme and timetable** for the next two-year period
- How are/were your activities **funded?**
- What means do you use to **communicate** with and inform your Network membership?
- Description of the reporting and procedure to Dbl members and Council
- How do people become a member of your Network?

criteria can join Dbl as non-voting members but will not be recognised as networks.

Conference Proceedings

Key proceedings arising from Cordoba 1995 World Conference will be placed onto the new Dbl website and the Madrid 1997 European Conference proceedings will be published in due course; we will inform you of their availability.

12th World Conference Lisbon 1999

The first announcement for Dbl's 12th World Conference in Lisbon 1999 has been circulated to all members. The theme of the conference will be Developing Through Relationships – Celebrating Achievement see page 7 for details.

Dbl Leaflet

A general leaflet on Dbl will be produced later this year. It will briefly outline the objectives and activities of Dbl and will provide people with the information they need in order to join Dbl, to set up a network or to make local contacts.

Dbl and the Internet

From August 1998 Dbl will be on the world wide web and can be found at

<http://www.sense.org.uk/sense/html/dbi.htm>

The focus of the website will be information on the objectives and activities of Dbl including how Dbl works, details on networks, contact details, conference news, information exchange and selected *Dbl Review* articles.

The next General Assembly will take place in Lisbon on the afternoon of 20 July 1999

Dbi Conferences

The Interim Council have agreed to a revised *Application Procedure* for hosting Dbi World and/or Regional Conferences. The revised application is a *Statement of Interest to Host a Dbi Conference* and should enable applicants to inform Dbi of their resources and ideas from which a conference will evolve. At this stage of application detailed information will not be essential.

Dbi World Conference 2003

As an urgent issue, the Interim Council are seeking suggestions for the 2003 World Conference. If you are interested in or considering hosting a Dbi conference and would like further information and an application form then please contact Tamar Underhill, Assistant Secretary Dbi, telephone +44 171 272 7774 or fax +44 171 272 6012 or email dbi@sense.org.uk.

As a reminder of past and planned Dbi conferences here is a comprehensive list of all the World and European Conferences which have taken place.

World Conferences

1962	Shrewsbury, UK
1965	Kalundborg, Denmark
1968	St Michielsgestel, Netherlands
1971	Boston, USA
1974	Shrewsbury, UK
1976	Sydney, Australia
1980	Hanover, Germany
1984	New York, USA
1987	Poitiers, France
1991	Örebro, Sweden
1994	Cordoba, Argentina
1999	Lisboa, Portugal

European Conferences

1986	Brugge, Belgium
1989	Warwick, UK
1993	Potsdam, Germany
1997	Madrid, Spain
2001	Noordwyk, Netherlands

Revised Application Procedure

- 1 The Management Committee will accept applications to host either World or Regional Conferences on a rolling basis. That is to say, any agency may apply at any time to host the World or European Conference or a conference for another Dbi Region.
- 2 All applications will follow a prescribed format and address questions and criteria as defined in the application form. This form is taken as a Statement of Interest from the potential conference holder.
- 3 Within each Management Committee meeting, discussion will be held on all such applications, and applications which qualify as being strong enough to merit a positive decision will be put on an active list to be considered for all future conferences. The accepted application will remain on this list until either a) the applicant withdraws it or, b) the applicant hosts a conference.
- 4 In applying, the applicant must specify whether they wish to be put on the active list for world conferences, regional conferences or both.
- 5 If an applicant's application is accepted, such acceptance in no way obligates Dbi for any financial obligations for the conference. Financial assistance from Dbi must be requested to the Management Committee separate from this application.
- 6 In each meeting of the full Council, the Management Committee will review all applications received and put forth its recommendations on acceptance or denial of each. The Council will then either ratify these recommendations or return them to the Management Committee with recommendations for further consideration.
- 7 Once a particular country has been selected to host a conference, the host country must then submit a full application and a detailed budget to the Management Committee.
- 8 At times, the Management Committee may recommend to the Council that it vote, as part of its strategic planning, on more than one future conference at the same time, if it appears advantageous to the applicants and the organisation to do so.

Statement of Interest to host a Dbi Conference

- 1 Why do you want to host the conference?
- 2 Who are the host agencies? Is this a partnership between agencies? *Please specify*
- 3 What benefits will there be to you and your country in hosting this conference?
- 4 What unique features or special attributes does your country offer which would be an important reason for Dbi to choose your site?
- 5 How will the conference be financed? Are there local contributors (e.g. agencies, governments, corporations, etc.) to subsidise some of the cost? How much local financial assistance is possible?
- 6 What kind of facilities are available in your city for
 - a Residential arrangements
 - b Meeting space
- 7 What social arrangements and activities are possible on your site?
- 8 Do you have less expensive hotel accommodation options for participants from developing countries?
- 9 Do you have sources for providing financial assistance to participants from developing countries?

The Development of Communication in Persons with Congenital Deafblindness 10-14 April 1999

Emergence of the first representations, symbol formation and first use of language.

Presentation of the Pre-Course (10 April 1999)

To allow those who missed the first part of this course which took place in June 1996 and for those who would like to review it, to feel comfortable with the second part.

Presentation of Course (11-14 April 1999)

To allow professionals and families to build adapted means of observation and intervention with congenital deafblind persons in language and communication.

For more information, please contact:

CNEFEI, Bureau des relations extérieures, 58-60 avenue des Landes, 92150 Suresnes, France; telephone +1 41 44 31 22; fax +1 41 44 34 23; email: cnefei_brex@education.gouv.fr

OR

Formanpsa – CESSA, Larnay, 86580 Biard, France; telephone: +5 49 62 67 67; fax: +5 49 62 67 68; email: souriau@interpc.fr

XII Dbl World Conference 20 to 25 July 1999

Developing Through Relationships – Celebrating Achievement

In July 1999, Lisbon will be the World capital on education and rehabilitation of deafblind people when Casa Pia de Lisboa hosts the 12th Dbl World Conference.

For more information about the conference please contact Antonio Rebelo, Casa Pia de Lisboa, Colégio A.A.C. Ferreira, 1700 Lisbon, Portugal. Telephone: +351 1 362 71 35; Fax: +351 1 363 34 48; Email: cpl.educa@mail.telepac.pt

Elderly Deafblindness

Third European Seminar of the 'Acquired Deafblindness Network',

2-7 October 1998 Osimo, Italy

The seminar is to be hosted by Lega del Filo d'Oro (the Italian National Association of DeafBlind) and will take place in Osimo near Ancona in the eastern part of Italy. The seminar will focus on the awareness of the needs of older deafblind/dual sensory impaired people, including the development of policy and practice.

Speakers have been invited from UK, Sweden, Italy, Denmark, USA, Finland, Norway, the Netherlands and Spain, and the working languages of the seminar are English and Italian.

For more information about program content contact: Anneke Balder, Stichting Doof-Blinden, Professor Bronkhorstlaan 10, 3723 MB BILTHOVEN, The Netherlands, fax: +31 30 229 18 84. For more information about payment, accommodation and other practical issues contact William Green, Lega del Filo d'Oro, fax +39 71 71 71 02

2001 Dbl European Conference

The 5th European Conference will be held in the Netherlands from 24 until 29 July 2001. There is a possibility for workshops, courses and seminars to "piggy back" the conference from Saturday 21 until Tuesday 24 July. If you are interested in taking up this opportunity please contact:

Anneke Balder
Stichting Doof-Blinden
Professor Brouleharstlaan 10,
3723 MB Bilthoven
The Netherlands
Telephone: +31 30 2250604,
fax: +31 30 2291884.

CUEmmunication: Beginning communication with people who are deafblind

Sharon Barrey Grassick Co-ordinator of Deaf-Blind Services
at Western Australia Deaf-Blind Association (Inc)

Where to Begin

Clear and concise information can be particularly useful for supporters of deafblind people who may be starting work on communication for the first time. Although the following practical guidelines have been written primarily for use with people who are congenitally, or pre-lingually, deafblind, steps 1-4 in particular contain information that can be useful when communicating with individuals who are adventitiously deafblind.

Approach

The initial contact you make with a person who is congenitally deafblind is critically important – it may even open the gateway to communication and language development.

Consider the following: a person with hearing and vision is given many incidental cues about another person approaching even from quite a distance. One may be able to tell whether it is a child or an adult; whether male or female. As the person comes closer, one may recognise the voice, facial expressions and body language. One will certainly know whether the person is familiar or a complete stranger, and it may be possible to establish the mood that person is in.

The person who is deafblind will not have the advantage of this distance information that hearing and sighted people take for granted.

The person who is deafblind must therefore be approached appropriately. This means offering useful, meaningful information in the most non-threatening way possible.

How can this be achieved?

Until reliable assessments of hearing and vision can be made, we must never assume that a person who is deafblind knows we are approaching, or knows who we are once contact is made. CUEmmunication, or Touch-Cue Communication, can be used to provide meaningful information through a combination of approach, tangible object cues, touch cues, and touch signs/gestures.

Consistent use of the following techniques will provide an opportunity for establishing a predictable

routine upon which further communication and language development can be built. This simple, but structured, technique can be used with very young children, as well as adults.

Practical Steps to CUEmmunication

Before making any contact with the person who is deafblind, it is important to consult with parents and service providers to gain information with regard to types of communication that have been used, sign names and preferred activities.

Remember, the following steps will need to be adapted to suit the individual needs and preferences of the deafblind person.

STEP 1

Before making any physical contact approach from the front, if at all possible, and move to the side as you come closer. This gives the person the opportunity to use whatever residual vision, central or peripheral, he may have.

STEP 2

Talk naturally as you approach, saying the person's name, and saying who you are, e.g. "Hi Joe. It's Sharon here". This gives the person the opportunity to use whatever residual hearing he may have. Move to about 20cm of his ear and continue to "chat" naturally. Speak clearly and use good voice inflection and intonation.

Never shout. Shouting only distorts sound and may cause discomfort.

At this close proximity important information can be gained from intonation, pitch and/or breath stream. Any scent of perfume or after-shave may give the person a valuable cue as to who you are.

However, do not wear strong perfume or after-shave. This can be very offensive to some people, as can the smell of cigarette smoke on hands or breath.

STEP 3

Now you can introduce yourself. Gently place the back of your hand against the back of his hand. Leave

your hand there until he initiates further contact, such as moving his fingers or feeling your hands for rings or a bracelet.

Be patient. Wait for the person to make the next move.

If there is a piece of jewellery that is always worn, or a distinguishing characteristic such as a beard, guide his hand to it each time. If this is done consistently, he will eventually seek the "cue" himself. Never grab or force things into the palms of the hands, as these are the 'eyes' of a person who is deafblind.

STEP 4

Say "Hello". If he offers a palm you may make a circular movement onto his palm to say "hello" or on to the back of his hand.

Remember, forcing hands or objects into a deafblind person's hand without warning or introduction can result in untold damage.

STEP 5

Initially use only one letter or sign as a sign name for the person. A possible sign name would be to fingerspell the first letter of his name, e.g., "hello J" and direct his hand to point to himself, and say "You are J(oe)." Then guide his hand to point to you and to touch your personal distinguishing cue as you say your name, "I'm Sharon". Then guide his hand back to point to himself and to fingerspell 'J' into his hand. Repeat the procedure.

Always give the person enough time to initiate a response. Sometimes we are too eager to 'help' and we shape or prompt the person's hands into a response before they have had enough time to process their next move.

STEP 6

You can now proceed with an activity. Take Joe's lead. Respond to any communication attempts. If he indicates a preference for a particular activity, respond accordingly. At this stage he may wait for you to initiate an activity.

STEP 7

Give him meaningful information about the forthcoming activity. Never assume that he understands what you expect him to do, or what you plan to do with him. Consistent use of a meaningful object, or cue, presented before an activity can help in the development of an association with and an anticipation of that activity.

The object, or cue, should be meaningful to him, consistently used and relate to the activity.

- Remember to choose appropriate objects for characteristics that will appeal to the individual person.
- The object can be presented before the activity and if this is done consistently he will build up

associations and will begin to anticipate the related activities presented with the object.

- The object goes with him and stays with him during the activity. When finished, he can then place the object in a particular container. The container could be the object to indicate the concept of 'finished'.
- Natural gestures and iconic signs can be paired with the objects, e.g. moving the arms to indicate swimming; hand to mouth to indicate eat; hand on head to indicate hat for going outside, etc.
- Always use you voice and tell him what is happening. Give every opportunity for language input.
- If the person is in a chair, never move the chair in or out without first indicating what you intend to do, e.g., tap the back of the chair or the handles (if it is a wheelchair). Always let the person know who is there.

STEP 8

Make a conscious effort to say "hello" and "goodbye". The person who is deafblind will not see you coming or going, nor will he hear you saying "hello" or "goodbye", so you must approach him to give him this information.

Respect the deafblind person's need for consistent CUEmmunication.

STEP 9

If you must leave the person for a short period indicate this by telling him and accompany it by a touch cue, perhaps a gently squeeze on the shoulder.

Always let him know who you are when you come back to him, even if you have only been away for a minute.

STEP 10

CUEmmunication is really nothing more than good common sense. Used consistently it will give the deafblind person a reason to trust you and motivation to actively communicate.

What is important in effective communication is not so much the variety of communication methods and number or signs you know, but how you use that knowledge. Respect for the communication method that is used and understood by the deafblind person is an essential first step

ASSUME NOTHING!

For further information on CUEmmunication including references and recommended reading please contact Sharon Barrey Grassick, Co-ordinator of Deaf-Blind Services, WA Deaf-Blind Association (Inc), 151 Guildford Road, P.O. Box 14, Maylands 6051. Telephone +9 272 1122 (voice) + 9 272 370 3524 (text), fax + 9 272 6600, email grassick@iinet.net.au.

Body signing: a functional strategy for introducing language to students who are deafblind

Sandy A Joint is Educational Advisor on Deafblindness for the state of Queensland in Australia

The concept of Body Signing began in 1979 with a ten year old boy who was born profoundly deaf and with less than 6/60 sight. He had lost most of his sight through Glaucoma and had little more than shape perception in one eye. It was therefore decided that tactile fingerspelling be introduced to him. In the interim to maintain his existing communication, an expressive vocabulary of 18 manual signs were presented onto his body. The result was the development of a communication system and methodology that combined fingerspelling, body signs, speech, models and Braille to maximise language development.

The student flourished and later became the first deafblind student to be integrated into a high school, upon completion he entered university. In 1990 he was awarded the "Young Australian of the Year Award". The student, Brendan Borellini, is now studying Sociology at the University of Queensland, and is expected to gain a Bachelor of Arts in 1998. For quick and incidental communication he continues to use Body Signs and has helped to demonstrate the technique of body signing in this article.

What is body signing?

Body signing is both a tactile communication system and a methodology designed to assist language development of deafblind and dual sensory impaired students who have no, or extremely limited expressive language.

This communication system involves the communicator pointing, drawing or making varied hand shapes and movements directly onto the face, arms, body and legs of the student. In many ways body signing is an elaborate system of touch clues. The difference is that body signs are consistent and can be presented in sentence form.

The rationale behind the body signing system of communication was the need to find the most effective method to communicate a sign to a student with the least possibility of mis-interpretation. The system ensures that the presentation of the sign allows at least one hand free to maintain contact with the environment, an object or experience being communicated. As the student does not have to cease

an activity and have both hands manipulated to communicate, there is greater understanding of the concept being communicated, and importantly tolerance of the communication process.

Body signing methodology is based on natural development. As a result, the first stages of the methodology concentrate on the development of receptive language. Receptive language with an infant is not automatic, it is learnt and takes time. Infants require over a year of intense receptive language input to express a few simple words that can be understood by those closest to them. With Body Signing the emphasis is on language immersion to "make the child ready", rather than forcing signing shapes before an understanding of what signed shapes mean or why they are needed.

The Body Signing Method has been divided into stages. Stage one of Body Signing is appropriate for students with none or extremely limited language. Words introduced are based upon:

- words used by parents to babies
- words needed to undertake care tasks/ development of daily living skills
- words that make most use of the senses that have not been affected e.g. names of objects touched by deafblind students in familiar environments
- commonly eaten foods
- ease of sign production

How to produce Body Signs

The secret to Body Signing is being able to look at any manual sign and then decide how it could best be presented or adapted to form an effective tactile sign, be it a Body Sign, or one handed co-active, or hand over hand sign.

Signs made manually on or near to the body are usually the easiest to adapt. The adaptation usually involves the communicator using one hand pointing, drawing or making hand shapes directly onto the person who is deafblind in the same position as the manual sign.

What are the advantages of body signing?

There are many advantages of body signing. Firstly because body signing is a method of presenting signs it can be adapted to any signing code e.g., Makaton, Signed English, Auslan, Amslan. As Body Signs are based on a manual method the student's vocabulary can be easily expanded, this allows the student the opportunity to be able to communicate with the deaf community. In addition:

- body signs can be presented beside the student so there is less invasion of space
- young deafblind babies and people who are deafblind without language often do not like the manipulation that occurs with full co-active signing
- body signs help prepare the student to tolerate and understand the need for co-active instruction
- there is less fatigue for both the student and the communicator
- the technique allows communicators more opportunities to repeat simple sentences and emphasise specific words – the cornerstone of the methodology
- communication using body signs is instantaneous, signing related words or sentences while the student is experiencing an emotion, object, or experience
- there is no requirement to wait for a student to stop an activity before signing to them
- the functional use of residual hearing and vision is enhanced as body signs help to fill in the gaps of

what can not be understood through sight and sound.

Concepts are therefore much easier to associate to signs. If a student is eating food, the name of the food should be presented repeatedly. The student can then learn to express actual choices and not manipulated "guessed choices".

Signs should be made on the student's body to express feelings. For instance if a child is smiling a smile sign should be drawn onto their face to reinforce the concept of smile. If the student is crying, a cry sign can be used to express crying. This helps the bonding process and improves responsiveness between the student and the communicator.

Perhaps the greatest advantage of Body Signing and its strategies is that it provides a better and more precise warning system. This allows the student to know exactly what is about to happen to them, or anticipate what they are about to eat or drink. The confusion of day to day activities and the fear of the unknown is greatly reduced.

Body Signing in Action

Body Signing as a communication system has recently been introduced to students in some Queensland schools and some residential post-school settings. Through interactive workshops a very positive start has been made to underline the use of body signing with children and young people.

For more information on Body Signing please contact: Sandy A Joint, Educational Advisor Deafblindness (Statewide), Low Incidence Unit, Narbethong State Special School, 25 Salisbury Street, Buranda, Queensland, Australia 4102. Tel: +61 7 3391 7711; Fax: +61 7 3393 0994, or Deafblind Association of Queensland, Fax +61 7 38 31 4507

- 1 Shower** – place fingertips of cupped hand gently on the top of the student's head twice ▼



- 2 Wake up** – place your index finger and thumb together next to the eye of the student, move this formation apart ▲

Examples of Body Signs demonstrated by Brenden and Sandy



- 3 Smile** – move the tip of your index finger from the lip crease of the student to their lower cheek in a small arc ▲

Congenital Rubella Study

Late last autumn, the Canadian Deafblind and Rubella Association (CDBRA) launched its study of the late emerging medical and behavioural manifestations related to congenital rubella. This study is being undertaken through funding from the Canadian Federal Government. The rubella study is being co-ordinated by Stan Munroe, Vice President of the CDBRA, and himself a parent of a young man with congenital rubella. Stan was assisted in the development of this study by a steering committee of persons experienced in the education of individuals with deafblindness caused by congenital rubella and who were also working with adults who are congenitally deafblind.

The steering committee first developed a detailed questionnaire aimed at capturing the educational, health and developmental profile of individuals with congenital rubella, from birth to their current age. The questionnaire was also designed to obtain information on such aspects as the nature of the rubella infection, the period of pregnancy during which the mother contracted rubella, particulars about the individual's birth, and specific information about the health of the birth mothers.

The study was designed to locate as many individuals as possible in Canada who were victims of congenital rubella. This included individuals who were deaf, blind and deafblind whose disability could be traced to congenital rubella. This study focus required a complicated endeavour to locate from the target sensory disability groups and from all age groups a sample size large enough to make statistically significant observations and conclusions.

The project leader established a large network of contacts or facilitators throughout Canada, from the province of Newfoundland to the province of British Columbia. These facilitators

The study was designed to locate as many individuals as possible in Canada who were victims of congenital rubella.

were recruited to assist with locating individuals with congenital rubella, to gain consent from these individuals or family members to participate in the study, to assist with the distribution of questionnaires and to assist individuals and family members, if requested, to complete the questionnaires.

Contacts were established by the project leader with an array of individuals, family members, organizations and facilities. These included key representatives from the various Chapters of the CDBRA; key personnel from the independent living facilities and adult programs; deafblind services consultants with various Provincial offices of the Canadian National Institute for the Blind; education and health personnel with various Provincial Schools for the Blind and Schools for the Deaf; consultants from several Hearing Impaired Associations and psychologists and health personnel from a number of regional psychiatric centres.

Once the questionnaires were distributed, the intent was to have individuals complete the surveys themselves, if that was possible, or with assistance from a facilitator. Where this was not feasible, family

members were urged to complete the surveys by themselves. In a few circumstances, where neither of these two situations was possible, facilitators completed the surveys, following consent received from family members, relying on the medical history files located in facilities where the individuals resided.

By 1 April 1998, some 155 questionnaires were distributed by the project leader to consenting individuals and family members and to the wide network of facilitators established throughout Canada. The facilitators in turn distributed questionnaires to individuals and family members to whom they had made contact and gained consent. This number of questionnaires is expected to increase to 200 or more as more individuals are located who meet the qualifying criteria. As of May 15, some 60 completed questionnaires were received. A preliminary report on the study is planned for presentation at the 6th Annual Canadian Conference on Deafblindness, Mississauga, Ontario, August 12-15, 1998. A more complete and comprehensive analysis of the study is expected to be completed by the end of August, 1998.

Latvia project

The National Swedish Agency for Special Needs Education (SIH) has taken on the job of passing on information on deafblindness in Latvia and Lithuania. Hannele Sundberg, Project Co-ordinator, writes about the Latvia project and the Seminar on Deafblindness held in Riga, Latvia in February.

In Latvian the word "deafblind" does not exist. "We don't have any deafblind people" was the surprising response over the phone from the Latvian capital, Riga. "As there aren't any, there's no need to train our staff."

I worked on the Latvia project with my colleague at SIH's Uppsala office, Eva Ekstedt, a consultant for visually impaired children. When, on our first visit to the capital, we clarified the Nordic definition in more detail, explaining that a deafblind person need not be entirely deaf and blind but may be blind and have a severe hearing impairment or, for example, be severely visually and hearing impaired, there was much more interest. We agreed that instead of using the word "deafblind", we would use the term "combined visual and hearing impairment".

In the first phase of the project, defining deafblindness was a complicated problem. Deafblind people have been seen as psychologically disturbed and placed in mental homes or cared for by close relatives. They never appeared in any statistics and seldom found their way to organisations for the blind or the deaf "You have no future," was the comment

made by one doctor to a 35 year-old deafblind man!

According to the above definition, in purely statistical terms there should be 400—500 adult deafblind people in Latvia. After three visits to the country and a four day seminar, we have heard about ten in the Riga area. So where are the other 390—490?

Although the Latvians were initially doubtful about our work, interest in the project increased with every phone call we made and each fax we sent. When the seminar started in February there was little space for all the teachers, doctors and social workers who were keen to attend. At its most crowded, we had 55 people squeezed into our small conference room, a former artist's studio in the attic of a renovated nineteenth century house in the charming old part of the town.

Because we succeeded in raising the profile of the deafblind issue, bringing it to attention at ministry level, the right people listened to our message at an early stage. This raised the status of the project and increased interest in the seminar. Leading representatives of organisations for the blind and the deaf also took part in all discussions and for the first time teachers and medical specialists discussed

the most common form of deafblindness – Usher syndrome.

A significant result of the seminar was that the participants, doctors, teachers and social workers alike, recognised that deafblind people should be seen as a separate group of disabled people and that initiative must be taken as soon as possible to trace the hundreds of deafblind Latvians who are living in isolation, most of them over 50 years old.

Once this is done, work can proceed in training interpreters, helpers, and specialists – to build on the excellent work that has started with this successful seminar.

Deafblind people have been seen as psychologically disturbed and placed in mental homes or cared for by close relatives.



A deafblind pensioner who in the days preceding the seminar gained a place in the rehabilitation centre for the blind in Riga. He is now learning to weave various types of basket.

Beroz N Vacha

Beroz Vacha, Director of the Helen Keller Institute for the Deaf and Deafblind, has been honoured twice in recent months for her outstanding contribution to the development of services to children and adults with sensory impairments in India. She has received the **National Award for Individual for Best Work Done in the Cause of the Disabled** and been awarded the **1997 Diwaliben Mohanlal Mehta Award for Excellence in Application**

of Science & Technology in Hearing Impairment. Both highly prestigious awards, Beroz graciously accepted them from the President of India and the Dalai Lama respectively. The Institute staff are naturally particularly proud of their director and the Dbl salutes her outstanding achievements.

Beroz has travelled widely over the years and is very well known around the world for her wisdom, kindness and, above all, her determination. Recently, she has been working hard to

establish the Helen Keller Institute and residential centre on the same site in a new building in New Bombay. For the past three to four years fundraising and planning have been going hand-in-hand, and a start will be made soon.

Beroz is a brilliant networker and a key figure within the international deafblind community.

One long standing friend and colleague Ann Barnet, former Chief Executive of the National Deaf-Blind League (now Deafblind UK), provides

us with this insight:

'The quotation which Beroz lives by is so apt

"A hundred times a day, I remind myself, that my inner and outer life depends on the labours of other people living and dead, and I must exert in the same measure that which I have received and am receiving and pass it on to posterity"

No one can be more deserving than Beroz. Beroz never assumes personal acclaim but considers herself a representative of the school and her colleagues, whose patient work and caring dedication overcome seemingly insurmountable challenges and problems. Beroz's late husband Nari was supportive of her work especially in raising money for the school and gave her strength and encouragement to succeed in all her endeavours.

Beroz gives, and is, an inspiration to us all. A quiet leader who achieves so much and shares with others her knowledge, experience and her home – it could be a visitor, student or one of the children from the school with no where to go. One of my fondest memories is of the little deafblind baby Ashok. Where others could not see his potential Beroz's belief that every child should be loved and educated gave him, and other deafblind children, a place in society.

I know of no other person who works so tirelessly, gives so much so selflessly for the benefit of others.'

Ximena Serpa

"I really appreciate that almost after ten years of work for deafblind persons in Colombia, I finally got a recognition in my own country".



The award commemorates a famous woman who, at the tender age of 15, fought for independence to protect Colombian soldiers from the Spanish. As a result she was shot when she was just 21 years old.

Given by the Rotary club of her native city a medal is awarded to a woman working for the good of the community. It is accompanied by a parchment scroll.

On receiving this award, Ximena explained the work she does with children and adults who are deafblind. She explained the hard work in setting up her private program, the success with the adults in Latinamerica and the new work in Bolivia, Uruguay and Brazil working for Sense International to increase services for deafblind persons. She acknowledged the support of the Swedish Government.

The celebrations for the award involved a musical event with children playing and afterwards a service at the main church. In all the houses the Colombian flag was on show in the windows

and in the town itself each person had a little Colombian flag in his-her hand.

Then the whole procession went, with the same band, to the monument dedicated to the heroine for a minute's silence. They then continued with the children to visit the museum to her honour and afterwards lunch with the "Mayor".

Ximena was deeply affected by the attention she received from the townspeople, who wanted her photograph and to express their gratitude for the services she operates in Colombia and Latinamerica for deafblind people. She was particularly proud as her husband and daughter were present. As Ximena told them: "I really appreciate that almost after ten years of work for deafblind persons in Colombia, I finally got a recognition in my own country".

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

Goldenhar Syndrome



Goldenhar Syndrome was named in 1952, when Dr Goldenhar wrote about a number of facial problems that tend to occur together. Goldenhar is quite variable with some common abnormalities.

Definition

A variety of terms have been used to describe this extremely variable disorder. According to medical literature, when malformations primarily involve the jaw, mouth, and ears and, in most cases, affect one side of the body (unilateral), the disorder is often referred to as **Hemifacial Microsomia**. If abnormalities of the vertebrae and the eyes are also present, the disorder is often called **Goldenhar Syndrome**. Within medical literature, the term **Oculo-Auriculo-Vertebral (OAV) Spectrum** is often used synonymously with Goldenhar Syndrome and Hemifacial Microsomia. However, due to the complexity and varying severity and expression of OAV Spectrum, some researchers suggest that Hemifacial Microsomia and Goldenhar Syndrome actually represent different aspects or levels of severity of OAV Spectrum. Goldenhar Syndrome is also considered a variant of **Cranofacial Microsomia** which is the second most common facial birth defect after cleft lip and palate.

Occurrence & Inheritance Patterns

Goldenhar is prevalent in males (70%) and affected individuals may have asymmetrical small

ears and mouth with hypoplasia of the jaw, mouth and eyes (with epibular dermoids). In addition abnormalities often involve the skeletal, cardiac, central nervous and renal systems. Hearing loss varies from near normal to severe; vision defect, including diplopia of various degrees. Moderate learning disabilities may occur in about 10% of cases.

There is very little evidence to explain why Goldenhar Syndrome occurs. In most cases it appears to occur randomly, with no apparent cause; nothing similar has ever happened in the family before, and there is little chance of it happening again. However, in some cases, positive family histories have been present that have suggested autosomal dominant or recessive inheritance. In addition, some researchers suggest that the disorder may be caused by the interaction of many genes, possibly in combination with environmental factors – multifactorial inheritance.

There are cases of identical twins in which only one has the syndrome, even though they received the same genetic blueprint; whilst other researchers describe examples of siblings having Goldenhar Syndrome. There are a few families with an affected person having a 50% chance of passing on the syndrome. Family history may include cleft lip or palate, unusually shaped ears, asymmetry of face, small chin, skeletal problems, eye abnormalities, internal problems or speech and dental problems.

What is known is that a baby's face forms during the 8th-12th week of pregnancy, by several different types of tissue growing together, meeting at the same time

and place to form facial features. The tissues that will become the face and jaw start out separate from the upper part of the face. In Goldenhar Syndrome, something goes wrong with this meeting. Sometimes the tissue does not seal leaving the mouth and upper jaw longer on one side; sometimes there is extra skin where tissue has sealed near the ear, or skin covers the ear opening; and sometimes the chin and jaw lines do not properly develop.

Prognosis

Children with Goldenhar Syndrome usually look forward to a long life and normal intelligence.

Useful Contacts

Mrs Nicola Woodgate
Goldenhar Syndrome Family
Support Group
9 Hartley Court Gardens
Cranbrook
Kent TN17 3QY

National Organization for Rare
Disorders Inc.
P.O Box 8923
New Fairfield
CT 06812-8923, USA

<http://www.goldenhar.com/goldenhar.html>

Culture and Creative Being

Klaus Vilhelmsen is head of the school department at Institutionen for Døvblinde, Denmark. IDB is the Danish provision for congenitally deafblind adults.

“To attain the freedom to live happily with others you need to see yourself as part of the culture and the culture as part of yourself”

A couple of years ago we developed an exciting project about water. As part of the project we visited the beach and collected a lot of different things. We collected seaweed, stones, sand, snail shells, wooden boxes, plastic bottles, fishing-nets, etc. On our return, we made a sculpture out of the materials. The sculpture became richly coloured and had different structures and scents. On the top we placed a plastic can with a lot of perforations. We connected a water hose to the can so that water could run down the whole sculpture. It certainly was a sculpture creating a lot of sensory impressions.

During the parents weekend shortly after we had finished the sculpture, we made a similar visit to the beach. The parents, the students and staff made a new sculpture. When it was finished I stood beside a father and we talked about it. He pointed at the sculpture and said: “Well Klaus, is this really art?”

At that particular moment I did not know what to answer. I had to think it over. This is a question I will come back to later in this article.

Culture

At the Institution for Deafblind people, we all work inside a cultural framework. During the last few years we have been discussing the value of seeing teaching and learning in the light of deafblind culture. If a group has no perceived cultural belonging, its members are in danger of losing their identity. This leads to a marginalisation in society with the possible risk of losing fundamental human rights.

We agreed deafblind culture consists of three elements:

- ◆ the common culture in society,
- ◆ specific deafblind elements,
- ◆ the individual institution.

With this in mind the deafblind people, their families and staff will all be part of the cultural experience in our institution.

One thing that deafblind people can teach us in particular, is to learn to pay more attention to all our senses. But this is not easy. A Danish philosopher says about this: “As human beings

we have two – and only two – ways in which we can structure our approach to the world. One is by cognitive understanding and the other is through sense perception.

In our culture, however, we have that problem that our sense perception is drowned by our cognitive understanding. We always experience our senses on the conditions of our cognitive understanding.

At the Institution for the Deafblind we don't see the concept of culture as a fashionable idea, but as a social framework through which the deafblind person can understand himself through perceiving, having experiences and through self-expression both for his own benefit and for the continued development of the culture.

Aesthetics and the development of identity

We look at culture as a framework embracing the three concepts – creativity, identity and quality of life. Where creativity is the basis for development of identity, and where the possibility of using and developing ones creativity as basis for exploring one's identity is possible, a better and more fulfilling quality of life is experienced.

We understand creativity to mean "the ability to create oneself again". In this way new understanding and new possibilities for action are created. Creativity is also the dimension, which evokes the connection between fantasy and product.

The ability to be creative can be looked upon as one of the essential components identity.

You cannot be given an identity, it is developed through a personal process. So by giving peace, space, and access to deafblind people they can initiate and motivate this personal process. In order to do this, deafblind people must be given the possibility for self-management, independence, and participation in making decisions. It's important to see the "actions" of a deafblind person as an expression of identity.

At IDB we agreed that aesthetic education is an important dimension in the formation of identity in deafblind people. Aesthetics in this regard has to be understood broadly as sense perception together with the expression which the deafblind person gives it. It is important that every single person can express himself in his own terms.

When we use the aesthetic perspective as part of the basis for co-operation with the students, we find at least two important consequences for teaching and learning:

- ◆ working together with deafblind adults, is not just about compensating for functional disabilities. We have to look at the human being behind the handicap and give this person the opportunity to grow and demonstrate self expression;

- ◆ the deafblind person must have the opportunity to have sensory experiences, refine these experiences, and develop ways of expressing them. In this way it will be possible for other people to relate to the artistic expressions of the deafblind person. In other words, a communication is established.

Back to the water sculpture. Is this really art, the father asked me. What is most important, the process or the product? The process that involves co-operation in creating the sculpture as well as the individual contributions really is important. The product is important as it contributes to communication and the common culture.

At our centre the adults have a range of ways to develop different aesthetic modes of self expression. If they want to, they can work artistically in the sheltered workshop, but in addition there are opportunities to work on longer term projects including theatre work with professional actors. One such project was the development of a play in which sound effects and music were used and shadow-theatre was also part of the performance.

The deafblind perspective

One consequence of working together with deafblind adults is that we have recognised that our job is not just about compensating for functional disabilities. We have to look at the person behind the handicap and give this person the opportunity to grow and show self expression.

The Danish philosopher Søren Kierkegaard has tackled the same question. He says: "If you understand the secret of forgetting yourself, while talking with another person, you have found the best way to learn what this other person is all about".

When we work on theatre projects, for example, we have the opportunity to get to know one another. This is a good way to be together as it involves a lot of learning such as imitation, co-operation, and involvement in social situations.

It is also important for both deafblind and non-deafblind participants that it is fun, and at the same time an opportunity to share and learn new things about each other!

Music is another medium for sharing and learning creatively. Now we also look at music not just from the educational or therapeutic view, but as a cultural experience. We all listen to music, it is a powerful medium and deafblind people experience music, sound, and vibrations in their own way.

Freedom, Self Expression and Identity

In an old Nordic sense the concept of freedom is the same as having a "whole spirit". We believe that deafblind culture derives from creativity which helps to develop strong personal identity, and as a result a better quality of life.

A sense of identity is linked with the concept of freedom. If you don't have an identity, you don't have the basis for freedom and independence, and as a result to be equal with other people in a cultural context.



'Water Sculpture' -
a collaborative piece

Tina Olsen

Tina lives at IDB. She has a well developed sense of touch in her hands, feet, and lips, by which she explores her surroundings. Tina explores persons and things, and she works a lot with dolls and figures – out of which she creates her sculptures. She makes sculptures out of old clothing, which are filled out with foam, rubber or other materials. The results are always sculptures full of fantasy.

Tina has her own studio and exhibits her work regularly. She knows, that what she creates has a meaning to other people and through her work she communicates with them.



Anja Sick

Anja lives at IDB, she is congenitally deafblind with some sight and hearing. Anja works with different kinds of aesthetical expressions. She makes expressive drawings and paintings, and also works figuratively.

◀ Anja's 'A Ship'

Sasha Gyori

I am 17 years old and I come from Dummerston, VT. I have been a student at Perkins School for the Blind since I was 5 years old. I am legally blind and hearing impaired.

I like bright colours, doing crafts, drawing, painting, working with plants and gardening. My favourite thing to do is draw.

Now that I am 17 I have several work experiences including working at a greenhouse in the community and the Howe Press

GALLERY



▲ 'Jimmy'



▲ 'Hancock Building'



▶ 'San Francisco'

Lewis Scott

Lewis Scott lives in Pollokshields on the south side of Glasgow. He was born in 1963 in Northern Ireland where his family continue to live.

Lewis has always had a keen interest in Art and a recognised talent which in 1995 led to his receiving the Helen Keller Award for the most exciting submission in any art medium on the subject of dual sensory impairment. This particular work was purchased by the Kelvingrove Museum of Art Gallery, Glasgow.



Lewis works between Sense's Durham Street Day Centre and Project Ability in Glasgow. Although his art work takes many forms it is his drawings and paintings that prove most successful and satisfying for Lewis. He has most recently exhibited as part of the Glasgow Art Fair.

For further details about the 1998 Helen Keller Award and entry form please see page 31.

Alison Hendry

Alison came to Sense 11 years ago and since June 1994 has been a resident of the Coatbridge House. She attends Durham Street Education Centre regularly to make use of the Art facilities.

Alison has a dual sensory impairment and although she communicates primarily by sign and the written word her art work has proven to be valuable communication tool for her, both in the narrative sense as well as a means of

expressing her feelings and emotions.

Alison has both exhibited and sold pieces of her work over the years. She has chosen to write a little about herself:

"My name is Alison. I live in Coatbridge with four friends Mark, David, Peter and Tracy. I like painting and working in the Art room at the Day Centre. I like swimming and working with children on Friday morning at the Nursery."





▲ 'Space'

Gabrielle Labossiere

I am 18 years old, I am deaf and visually impaired. I grew up in New York City and came to Perkins School for the Blind when I was 11 years old. I like going to deaf camp, playing baseball and visiting places. My favourite activities are drawing and writing stories.

I like to do many kinds of art. I am skilled at drawing. I use middle or large sized paper, markers, coloured pencils and crayons. I also enjoy working with clay, paint and glitter.

I am interested in space and rockets. I do like to study about the planets. I love to see many shiny stars and comets.



▶ 'Deaf Camp'

Ivanas Jakoneras

When Ivanas Jakoneras, sculptor, of Vilnius, Lithuania who is deafblind got his hands on a big lump of clay for the first time in his life, he didn't ever want to let it go. Hour after hour he sat at the table, squeezing it, feeling it and shaping it. After eight hours he had sculptured a 27 cm high Franciscan monk.

Ivanas is 59. He lost his hearing at the age of 3 due to exposure to loud noise during the Second World War and together with the other members of the family, was expelled from Lithuania by the Nazis. His mother was tortured when she refused to work for the Nazis and died when he was only eight.

In 1945 the family were able to return to their home town of Vilnius. Ivanas went to the school for the deaf, became the best student and was considered to be highly gifted. He was offered the chance to study in Moscow but instead worked in a shoe factory for 30 years. Suffering from glaucoma and cataracts, his sight deteriorated. An operation was unsuccessful and today he can only just see his way about in very strong light. He lives with his hearing impaired wife Benedikta, who has been diagnosed with Usher's syndrome, and his 86 year-old step mother who looked after him when he was little.



The Margareta Löfqvist Foundation in Sweden has been working with deafblind people in Lithuania. The support from the foundation primarily centred on six deafblind people and around 40 blind, visually-impaired and deaf-blind orphans in Vilnius. A four day activity course for deafblind people and their relatives was organised. The course offered the chance to try out various types of activity, including the first lesson in how to sculpture figures and useful objects from clay.

For Ivanas, Benedikta and three other deafblind people and their relatives, the course, which was free of charge complete with food and lodging, was a great holiday and a much-needed change of environment. It was also an opportunity to demonstrate to the authorities that it is worthwhile to provide activities for people who can neither see nor hear. Deafblind people must have the opportunity to develop their healthy senses, such as touch.

The foundation also paid for the cost of a trip to a famous sculpture park just outside the capital, where deafblind people can walk around and study the work of the artists using only their hands. The visitors were so affected by what they were able to feel that one of them burst into tears. Now they all want to visit the park again and the foundation is planning a repeat trip. New cultural activities are planned in the summer.

Bo Damm, Freelance Journalist, Sweden



Art in the School Curriculum

Janka Šarišská, Director of the Evangelical School for Deafblind Children in Slovakia, discusses the importance of art as part of the educational programme in her school which originally opened its doors in 1993 and now has eight children in attendance.

From the beginning Art Education has played a very important place in our educational work. Through painting and drawing children are encouraged to develop in a variety of ways. Art education has a special importance for our pupils because it develops their attention, visual perception, recognition of reality and builds their spatial imagination. Pupils can express themselves through drawing, painting or modelling. In addition by developing their creative ability we are providing opportunities for an aesthetic appreciation to develop.

In this article I would like to show how, for two of our

students, art has contributed to the development and formation of their characters and personalities during their five years at our school. Deafblind children get to know and understand the world around them through sensory means. It is on this basis that they learn about themselves and develop a conceptual framework for intellectual development.

Natália and Peter

Natália is 12. She has some residual hearing, convergent strabismus and learning disability. Peter is 14. He is deaf, has a prosthetic left eye



The Wedding
– Peter (1997/98)

and a right eye which is myopic with nystagmus. Both attended the school for deaf but the programme was not suitable for them. When they came to our school 5 years ago they used their vision for orientation in small spaces like the classroom, dining room and toilet. The larger spaces were a problem for them. Their favourite activity was looking at pictures of practical household things in catalogues. These were the things of which they had some experience and could recognise. Our challenge was to increase the number of signs they used and we did this by using pictures and illustrations. Many activities like the drawing of lines, modelling, cutting, gluing, are helpful in developing fine motor skills. The goal of these activities was to prepare the children for the next stage – artistic expression.

▼ Apple picking – Natália (1995)



Drawing & Signing from Experience

A very important activity for their development was painting and drawing their own experiences. Every experience they had we spoke about using sign language. Then I would draw this experience and the children watched me. We did the drawing and painting of experience all through the year until they were encouraged to draw themselves. The first drawings were very hard to recognise. Natália usually used the right colours but the shape of the drawing was not identifiable. Peter drew people, places and other details of experiences but the drawing was only recognisable to him. What was pleasing is that the children were able to explain the content of their drawing. We drew their experiences every week and the results improved. But the results were dependent on the level of development of the child.

So, how did this ability develop?

Today Peter is able to express himself by drawing and painting in more detail than by using sign language alone. When we speak about his experiences, Peter can recollect them, he enjoys them again and he has a need to put them on paper.

Firstly Peter did exercises to improve his eye-hand co-ordination, attention, concentration and will. His drawing then became more skillful and his hand was more sure! The content of his drawings was dependent on the development of his

thinking and imagination, and, as they improved, so did his pictures! Gradually he started to draw people, objects and the world around him. Interestingly the figures he portrays are usually without clothes but when he had the very enjoyable experience of joining the wedding reception for his favourite teacher, he painted the happy couple in clothes! He is fascinated by different machines and he is able to draw them exactly. Drawings of the towns of Presov and Kosice where the airport,

swimming pool and café all feature in his work are particular favourites and rich in imagery. An interesting feature of his pictures is the time sequences. When we do analyses of his pictures he is able to explain them very particularly.

Natália has progressed well in comparison with the beginning of her stay at school. But her results are not so skilled because she is younger and has more severe disabilities than Peter. Her favourite theme is to picture families, special buggies and small children,

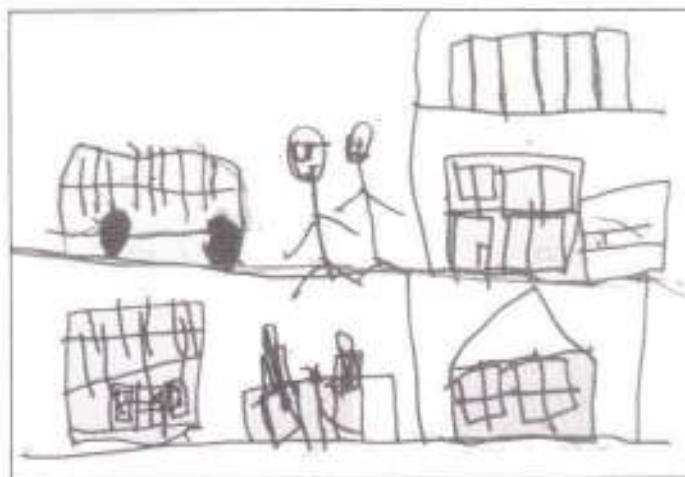
3-Dimensional Work

Natália and Peter have another favourite activity. They like to create different things from big boxes. They have worked together to create furniture, a car, a suitcase, etc., which they later used together in role play.

Natália and Peter have achieved the best results of all the students studying art. The other students are younger and each is on a different developmental level. The experience the school has gained in working with Natália and Peter is now applied to other students who also have residual vision. But we always need to adapt

these experiences to each individual child.

The children create very simple ideas which also are aesthetically effective. The children through representing shapes, features and figures are able to tell what is important for them and what is happening in their internal world. They also signal the development of imagination, memory, thinking and sign language. But it is the moments of children's relaxation while drawing or painting, which bring them pleasure and enjoyment that we regard as the goal of our teaching at the school.



A trip to small town, lunch in restaurant – Peter (1997/98)

Dance is perceived as a visual art form which needs to be visually experienced in order to be understood. It apparently depends upon music and, like all physical activity involving skills, cannot happen without the acquisition of full body awareness of precise movement patterns or language.

How then does one teach dance to people with a disability of both sight and hearing?

Dance predates all physical activities other than walking, running and climbing. Dance has always been used to express feelings, family occasions and events within the community. It has always been a vital part of life, with more than just recreational or "high" cultural meaning. Body-mind integration comes through movement and movement is generally considered essential to a balanced lifestyle; a way to express emotion, release tension and communicate.

Dance is therefore *not* a purely visual form. Increasingly dance education is integrating 'listening' skills into training with less emphasis on the visual and peripheral swing of the limbs, and more emphasis on 'sensing' the source of movement from the centre of the body. The proprioceptive sense informs us of where we are, how we are sitting, standing and our relationship to gravity. We do not need sight or hearing to know our position or to feel subtle changes. It is through the proprioception of movement that I work with sensory-impaired people through a movement form called Contact Improvisation (CI).

Contact Improvisation balances tactile, non-visually based learning process with movement patterning and spatial awareness. Participants lead each other in a dialogue guided through the physical contact they sustain with each other. Through this physical contact they learn to read the intention of their partner, to follow or to initiate a change in direction. This might involve a dipping down to prepare a lift, or a sudden increase in energy to initiate a burst of energetic dancing, rolling, tumbling onto the floor.

When working with a group of sensory-impaired people with sighted partners, we start the session with stretches in pairs. Sitting back to back, one leads and the other follows. Immediately a dialogue through touch is initiated and each reads what the other is doing through their back. This pattern continues with no solo movement and constant contact. The exercises develop to standing, using each other's body surface to move around as a reference point. Trust is addressed by the very nature of the work, and a stop sign is always agreed

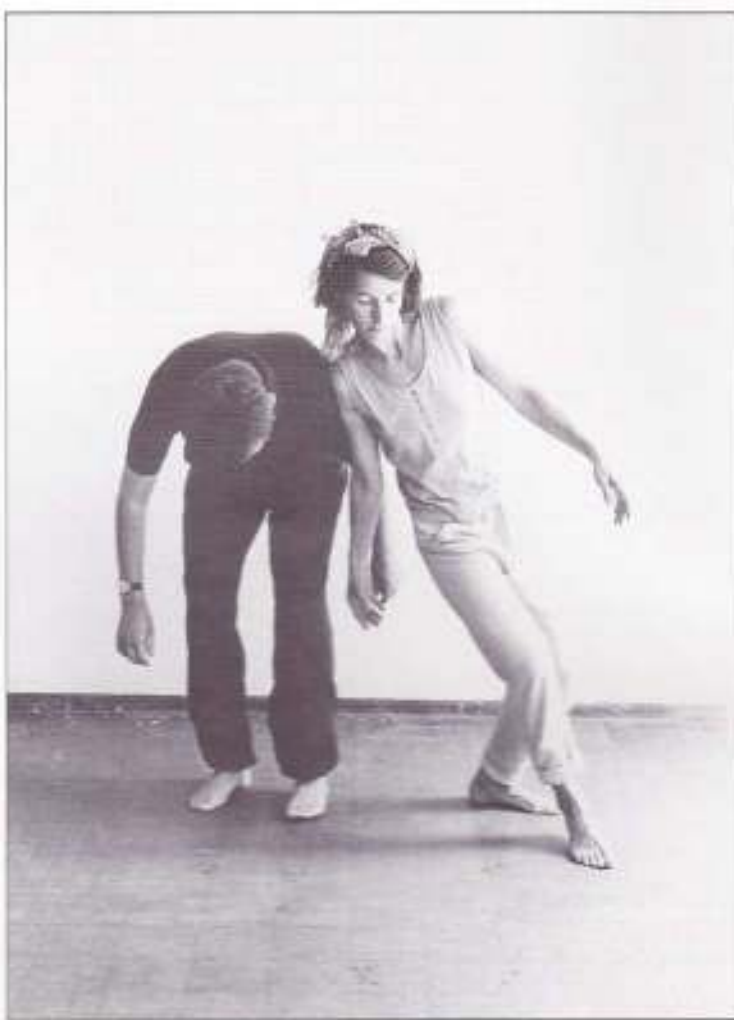
Touchdown

beforehand so at any time either dancer can bring a movement to an end. These exercises enhance each participant's awareness of their and their partners body dimensions. This helps to attain a better understanding of contact and enables the potential to explore new variations.

Having completed the warm-up exercises we move into improvisation. Absence of structure enables participants to integrate all the patterns they have been working on to inter-link and mesh together 'digesting' into their physical memory.

Touchdown Dance is a dance company which specialises in Contact Improvisation. Katy Dymoke describes the workshops the company run for sensory-impaired people.

Each partnership will therefore be a unique moment in time. Partnerships work at their own pace and within their own physical limits. There is no need to keep up with the teacher's ideas, or follow an external



Dance

rhythm which could remove focus and attention and hamper movement.

The purpose of these workshops is to bring each participant as close as possible to the movements that they make. The partnerships reflect the movements and bring them to consciousness, opening them up to more variety and possibilities. Through improvisation one can observe and absorb the kinds of movements the participants tend to feel more comfortable with. More information and embellishments is then

added, such as sensing the shifting of the centre of gravity under our partner when we lift them. I am constantly inspired by the affirmation that dance is innate to the body. An authentic part of our existence, part of the un-ordered and un-thought, that 'DANCE' puts into pure form.

As well as working with groups within schools, day centres and dance studios, training is provided for teachers or staff. The base line is communication through touch, and from this we challenge our perceptions of dance within accessible

processes. Dance is constantly being labeled, if you can't call it something like modern or contemporary, ballet or Kathakali, then it can't be dance! However, expressive movement is not simply therapy or communication. The job is to convince providers and participants, who have assumed that traditional dance "styles" on offer are not appropriate for people with sensory and/or motor impairment, that dance is "for all".

In reality there is plenty of room for a 'movement' session. Touchdown Dance workshop sessions are planned with a developmental theme. Sessions offer a guiding line to enable a rewarding experience and attempts to affirm that dance transcends the body. We condone the 'therapeutic' aspect to dance as any movement is beneficial with therapeutic effects.

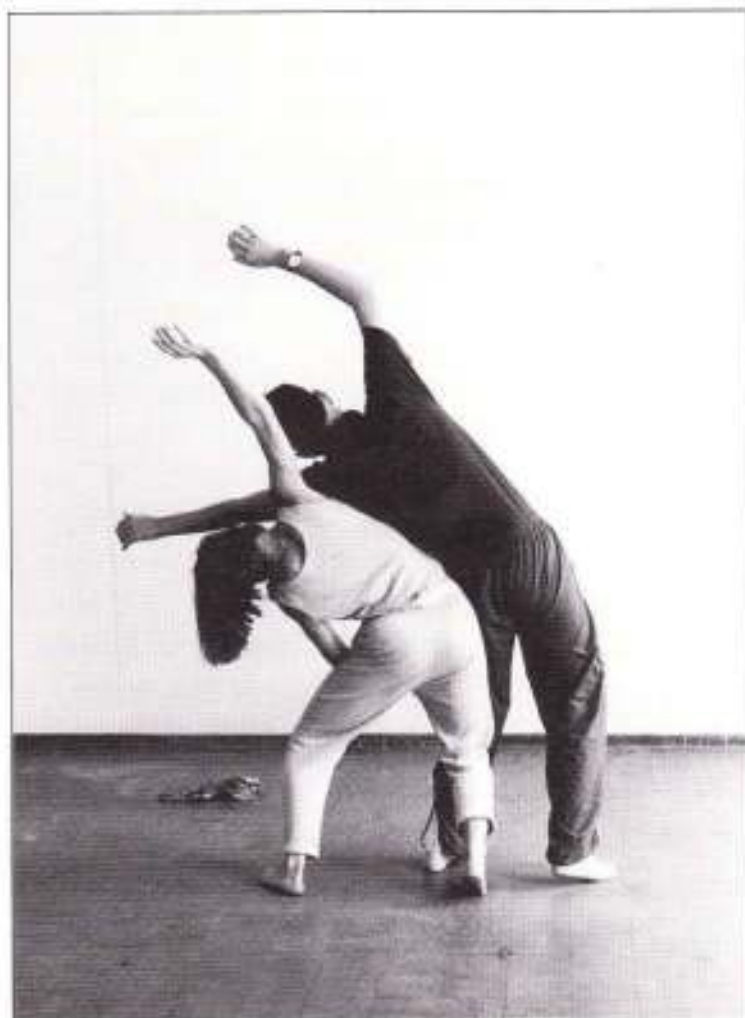
What are the benefits of Dance?

The satisfaction experienced by the participant is the pure physical liberation, the unbound physical expression in a safe environment; the permitted extravagance and indulgence; the expression of feeling shared across the space; the acknowledged legitimacy of this expression, and the feeling of self affirmation, of finding one's personal space.

On discovering oneself in dance, the dancer starts to sense an identity beyond the daily boundaries of experience. All the facilitator can hope for is to nurture this and witness the dancer's discovery. The element of sensing the self is a continuous process, we sense ourselves and who we are through the response of others.

Contact Improvisation transcends form and technique to find a dance style that expresses the meeting of two people, the meeting of two energy sources, and the consequential effervescent movement that carries their bodies through space, with or against gravity, and with or against the counter force of flying upwards into the air. At its most lyrical the dancers move from stillness to barely touching, from resting and absorption in the moment, to slipping down and out of it, containing an energy and relationship that exudes intimacy and total communication and touches on issues to do with personal and wider social boundaries, taboos and prejudices.

For more information on the work of Touchdown Dance please contact Katy Dymoke; telephone: +44 1457 876770 or email: touchkate@aol.com.



Corrina Veesart



Chamber of Corrina

Paint me like I am
 Chocolate brown hair
 Wavy like the ocean swells
 Paint me shy as a koala bear
 But my shyness fades like dawn fades away
 to sunny day
 And I become as talkative as a blue jay
 Paint me curious to learn
 And eager to bring smiles to others
 Paint me with curious eyes
 Green as the wood
 Of Wisconsin
 Paint me cuddling a child
 So tenderly singing softly
 Why don't you touch your Wand to me and
 Paint me perky springing about jumping
 around,
 chanting my cheer to myself ...
 Paint me as loving as a mother gorilla to her
 young child
 I love my friends and care for them.
 Paint me surrounded in a room of roses and
 angels
 All whispering glory and
 Singing softly
 Just paint me as a cheerleader
 Though I'm not yet one
 But want to be
 Paint me kicking my legs from side to side
 like a Kangaroo

Corrina Veesart is a 16 year old deafblind teenager who lives in a small coastal town in Central California. Corrina is a member of the American Association of Deafblind and has attended their national conferences since she was 11. Corrina has written a letter to *Dbi Review* and talks about her life and interests which include writing and dancing. Corrina's poem *Chamber of Corrina* was published in a recent issue of *National Family Association of the Deafblind* newsletter.

Dear Dbl Review

I am an active regular teenager and I attend a typical high school. I am among two other deaf girls who go to my school. I am a fluent signer using ASL signs. I am eager to learn in school and get very good grades.

I am profoundly deaf. I can hear some very loud sounds if nearby. I cannot read lips since my vision is not good enough for me to see the movements of the lips. I can see from about five to six inches from my face. Beyond that length is blurry. It's hard to see the signs clearly so I often use tracking. I can make out shapes ahead of me but it is almost impossible for me to make out what they are until I come up close. I also have a hard time telling if the ground is flat or sloping. For example, I can't see steps very well. I hate to use my cane though. In the dark I can see nothing.

I enjoy making up stories. I usually write names and then make up stories related to the names, often about a group of teenage girls who are best friends or sisters who never argue. I have a wild imagination and love to invent stories and characters. My ability to write came naturally. My teacher urges me to write down my stories so others can share my imagination, and learn some of the secrets that my mind is hiding from them.

I also enjoy reading. I carry a book almost everywhere I go along with my magnifier since I can't see small print. I can also read Braille. I am known as 'bookworm' since I LOVE books. My mother can hardly drag me away from my books when I need to go to bed or other small matters.

I also love the sense of rhythm. I love dancing. It gives me a feeling of freedom. I just found out I succeeded in making the cheerleading team at school. I also take ballet at a dance studio with a whole class. I have an interpreter with me. My dance teacher tutors me after class or once in a while on Sundays to help me understand the movements. I know I can do anything I put my mind to.

Sincerely,

Corrina



NOTICEBOARD

The Sense Scotland Helen Keller Award 1998

For the most exciting submission in any art medium on the subject of deafblindness

This Award is made to the author of the best submission on the subject of deafblindness. The brief is as open ended as that and is open to anyone wherever they may live in the world.

Entries from people with a dual sensory impairment will be especially welcome.

The Award will be a trophy and £250, and two further awards of certificates and £50 will be made. Commendations may be made at the discretion of the judges.

This year the Glasgow School of Art has agreed to act as host of the awards ceremony. The ceremony will take place during the first week of November and it is hoped that all entries will be displayed at the Art School during the following week.

The closing date is **3pm Friday 30 October 1998** and judging will take place by a panel of independent judges. If you intend to submit an entry of an exceptionally large nature you will need to notify Sense Scotland beforehand.

For rules and an entry form please contact either Bill Mitchell or Ian Murray at:

Sense Scotland, Helen Keller Award, 5th Floor,
45 Finnieston Street, Clydeaway Centre,
Glasgow G3 8JU.
Tel: 0141 564 2444 Fax: 0141 564 2443
Text: 0141 564 2442.

CONGRATULATIONS!!!

The Editorial Team of Dbl Review send their congratulations to Kaiiopo Karanicola who suggested the new name of *Deafblind International's Review* in our What's in a Name? competition in the last issue of *Deafblind Education*.

Art on the Internet

Khaled Alvi has Usher Type I and is an artist living and working in London. Khaled has a "gallery" of his work on the Internet. To view Khaled's work simply visit his website:
<http://ourworld.compuserve.com/homepages/KAlvi/art.htm>



SOUTH AFRICA

Sandra Tyler, Chairperson of Deafblind South Africa, recalls the meeting and events leading up to the formation of Deafblind South Africa.

'On Saturday 20 July 1996, a meeting of 30 deafblind individuals with intervenors, from two well-established Friendship Groups, was held at Cape Town International Airport.

After the presentation of two papers focusing on the problems experienced by deafblind people, from both a

personal and professional perspective, a motion was submitted for the formation of a National Association. Following the election of a committee comprising a Chairperson, Vice Chairperson, Secretary/Treasurer and two additional members, Deafblind South Africa was founded.

Since my attendance at the World Helen Keller Conference in Italy a few years ago, I have begun addressing the needs of the deafblind. The inauguration

of **Deafblind South Africa** was therefore incredibly meaningful to me and I hope that during my office as Chairperson, I will be able to make a worthwhile contribution to the lives of deafblind people in South Africa.'

For further information about Deafblind South Africa please write to Sandra Tyler, Chairperson Deafblind South Africa, c/o Natal Society for the Blind, 194 Umbilo Road, Durban 4001, Natal, South Africa.

HONG KONG

The Hong Kong Society for the Blind provides a wide range of services for the blind, visually impaired and deafblind people. These services are provided in order to meet the wide-ranging needs of clients and are kept under constant review.

1997 was a year of significant change in Hong Kong with China resuming sovereignty over Hong Kong after 155 years. Amidst all these changes the Society will continue – in co-operation with other organisations in Hong

Kong and other countries – to develop quality and comprehensive services for visually impaired people in Hong Kong.

The Society celebrated its 40th anniversary in 1996 and in the last decade the Society has completed two Five-year Programme Plans with detailed evaluation and assessments.

The first Deaf-Blind Rehabilitation Service in Hong Kong commenced operation in 1992 and before the service was planned, the officers-in-

charge of the Deaf-Blind Project had been sent to Singapore and USA to receive specialist training related to deaf-blind people. The Rehabilitation Service provides training to adults who are visually and hearing impaired. It is a pioneering project amongst the Chinese speaking community of Hong Kong. A handbook on tactual sign language is currently being developed to facilitate communication of people with dual sensory loss.

EAST AFRICA

Thanks go to Mrs Penny May Kamau editor of Deafblind News for sending information on activities in East Africa.

For further information please contact Mrs Kamau, PO Box 63168, Nairobi, Kenya or email:

shiapmk@africaonline.co.ke

Workshop for Administrators

Officials from the head offices of the Ministry of Education, District Education Officers, Headteachers and heads of deafblind units from all the deafblind programmes in East Africa converged on Hotel Milimani in Nairobi for two days in July 1997 to learn more about deafblindness and how to improve services for deafblind children in the region.

During the workshop participants assessed the needs of deafblind children and how to access resources, looked at partnership of parents and family, and also worked out a plan of action for the coming year for each programme. A follow-up seminar for the same group is planned for early next year to assess how far the plans have been implemented and discuss any problems that have arisen. ▶▶▶



Kenya

The school programme for deafblind pupils in the country has continued to expand with several children identified and placed in appropriate education programmes. At the primary level there is a full school for deafblind children at Kabamet in Baringo district and units at Kwale School for the Deaf at the coast and Maseno School for the Deaf in Nyanza. In addition to this there are a number of deafblind pupils following individualised programmes in various schools throughout the country.

As these pupils graduate from primary level of education it has been necessary to place them in higher institutions of learning where they can acquire the skills necessary for the transition to an independent life after school. Two institutions: Mumias Secondary Vocational School for Deaf Girls and Sikri Agricultural Training Centre for Deaf and Blind Boys, have accepted deafblind students and have put in place programmes to prepare them for future life. In order to facilitate the work of these schools The Association of the Swedish Deafblind (FSDB) has assigned Mr Joseph Shiroko to assist in planning with parents, teachers, pupils, government departments and the local communities to ensure that the deafblind students follow appropriate training courses and are fully prepared for the transition to life after school. This kind of co-operation is vital if the students are to be accepted as full members of society.

Nakuru Project – social workers in the Nakuru district are still busy following up the possible cases of deafblindness which came about as a result of the screening exercises in the district. In several cases it is proving difficult to trace some people as their exact place of residence is not known while others have moved away from the area. However, progress is being made and several people have already been assisted to get appropriate medical assistance or placement in educational programmes. The awareness programme is also continuing and local seminars have been arranged for community leaders and the general public.

For more information on the work in Kenya please contact Mrs Penny May Kamau at the above address.

Tanzania

Education Programme – The number of deafblind children receiving educational services has increased to eleven. Of these, two are full time pupils at Uhuru primary while the others are on a home based programme. Two other children have passed away due to illness. Teachers are still waiting to see the completion of a dormitory for the deafblind children at Uhuru primary which will enable all the children to receive full time education.

Adult Programme – Mr David Shaba, a deafblind adult living in Dar es Salaam, has through the local media appealed to other deafblind adults to come forward and join his newly registered group. The group is call

Tanzania Deafblind Traders and membership is open to all deafblind persons in Tanzania. The group aims to start a small scale business in order to uplift the well being of its members. Mr Shaba attended the Helen Keller World conference for the Deafblind which was held in September 1997 in Paipa, Colombia and was selected to be the deafblind representative from Africa in a proposed world federation of the deafblind.

For information on Tanzania Deafblind Traders please contact: Mr David Shaba, P.O. Box 36792, Dar es Salaam, Tanzania.

Uganda

The education programme for deafblind children in Uganda is still expanding. The unit at Buckley High School, Iganga, now has six deafblind children, six teachers and two housemothers. Other deafblind children have been assessed and plan to join the unit when funds are available. The unit now has its own dormitory.

In addition to the unit at Buckley, some children in Kampala were identified and it was decided to start a Saturday school for them. This was made possible by the kind co-operation of Mr Joe Morrisey at the Uganda School for Deaf who allowed the programme to run in his school. Two teachers from Buckley have been running the programme together with two teachers from the school for the deaf. They currently have three children in the programme. This programme has also helped to bring together parents to share experiences and ideas concerning their children.

If you need more information on the deafblind movement in Tanzania please contact: The Executive Secretary, Tanzania National Committee for the Deafblind, P.O. Box 22408, Dar es Salaam, Tanzania.

For more information on the Uganda National Association for the Deafblind please contact: Mr Ebrahim Kizito, P.O. Box 30227, Kampala, Uganda.



WEST AFRICA

Ghana

On 15th March, Princess Anne, the Patron of Sense, visited the Deafblind Department of the Demonstration School for the Deaf in Mampong-Akwapim, Ghana. This was the first time Princess Anne had visited a deafblind unit outside of the UK. The Deafblind Department was set up in 1978 by Marion Obeng with one student and to this day continues to be the only service for deafblind children and young adults in the whole of West Africa.

The primary focus of the Deafblind Centre is the education of deafblind students. There are different

programmes for the younger students and the older students. The younger children's programme consists of sensory training, orientation and mobility, daily living skills and vocabulary development. The older students continue with this programme but spend a great deal more time learning vocational skills such as mat weaving and wool work. Greater emphasis is placed on enabling them to become independent and to earn a living or contribute to the family. The Deafblind Department also has an outreach programme to raise awareness about deafblindness, and the

needs and abilities of deafblind people.

The Princess had the opportunity to see the students at work and to discuss their programmes with their teachers. She was also treated to a dance performance by the students of the Demonstration School. The visit was highly successful and the Princess said she would be keeping herself informed of the progress of the Department.

This was a very significant visit for both the Deafblind Department and Sense International as it marked the beginning of a future collaboration between the two organisations.

LATIN AMERICA

Since September 1995 the Hilton Perkins Program has been developing a project with universities from Latin America. Two meetings with Universities from Costa Rica, Mexico, Colombia, Brazil, Chile and Argentina took place in order to establish curriculum and certification requirements.

Also, consultation in Costa Rica and Chile assisted work on subject areas to be developed in the courses. Representatives from both Costa Rica and Chile, were also in Boston to work with university Professors from Boston College.

"Working together Professionals, Families and Community in the Integrated Approaches to the Visually-Impaired with additional disabilities"

This conference is to take place on October 8-12, 1998

in Bahia Blanca, Buenos Aires State. It is being organised by ASAERCA (Argentina Association for Educators for the Blind). The main topic of the conference

will be on people with visual impairment with additional disabilities and in addition to Argentinean speakers, will have speakers from USA, Chile and Brazil.

II Latin American Parent Meeting

A parents meeting was organised by the Argentina Parents Association in Buenos Aires in May 1997. Participants came from Chile, Bolivia, Brazil, Guatemala, Mexico, and Argentina. It was made possible by the Conrad N. Hilton Foundation in co-operation with the Hilton Perkins program.

A second meeting was planned for May 1998 in

Montevideo, Uruguay, with the objective of providing parent training leaders; 35 parents participated. This second meeting was made possible by ONCE (Organización Nacional de Ciegos Españoles) in co-operation with ULAC (Union Latin America de Ciegos), Conrad N. Hilton Foundation - Nevada, USA and Hilton Perkins Program.



INDONESIA

Wonosobo – our first start to educate the deafblind

In July 1993, Mr. Paul van Woesik from the Helen Keller Foundation in the Netherlands, visited the Institute Dena-Upakara for deaf children with an idea to sponsor the Institute to open a new deafblind unit. The Institute's staff accepted this idea and acknowledged the need to address the challenge of educating deafblind children.

A year later the co-operation of the Foundation was confirmed. Advice was sought on deafblind education within Asia and Mrs Beroz N. Vacha of the Helen Keller Institute in Bombay was approached. During 1995

correspondence was exchanged with Mrs Beroz and Mr Kirk Horton in Bangkok, who sent books, video-cassettes with guide-books and brochures. Kirk Horton also introduced the Institute to the work of Deafblind International and networking with Dbi members proved very beneficial.

Sr. Agatha from the Institute was accepted onto a training course at the Helen Keller Institute in Bombay (January-April



1996). Although the teacher's knowledge of deafblind education is growing at the Institute Dena-Upakara, much still needs to be learnt. In September 1996 Sr. Agatha and Sr. Agnes attended a course in Malang sponsored by the Perkins Program. This valuable course also enabled contact with colleagues from Indonesia.

In July 1996 the Institute gained its first deafblind student, 6 year old Brigitta Natalia Yuwono who is profoundly deaf and has only one functional eye. Her mother suffered from rubella whilst pregnant with Brigitta. Then in July 1997 another student joined, 5 year old Stanley Halim who is blind



and moderately hearing impaired.

In July 1997 Marianne Riggio visited from the Perkins school, USA. This visit has further strengthened motivation.

The Institute very much appreciates the support and encouragement they have received through good networking.

Sr. Antonie Ardatin

SLOVAKIA

Opening of a New Building at Evanjelicka Pomocna Škola Pre Hluchoslepe Deti, Cervenica, Slovakia

On Saturday 15th November 1997, the only school for deafblind children in Slovakia officially opened a second building, doubling the schools capacity. The original building has two

classrooms and staff quarters on the ground floor and bedrooms, bathrooms, kitchen and dining room and a gym upstairs. Staff will move into rooms in the new building creating more classroom space. A new large well appointed gym, kitchen and large dining room are welcome additions to the facilities. The new dining

room is large enough to be used as a function room in the evenings; for example the parents self-help group. All this can only add to the already high standard of education and care provided at the school.

Simon Phillimore, Sense International volunteer



HUNGARY

"Dear Friends,

Let me introduce to you the Hungarian Deafblind Association, and the present state of affairs of the deafblind in Hungary.

According to foreign statistics, (since in Hungary no record is kept of the deafblind population) there are about 500-600 deafblind people, out of which 70-80 are prelingually deafblind. About 50 out of the whole deafblind population are children, but only 8 of them attend special education. The education of deafblind children started only 4 years ago, therefore the available places are limited. Unfortunately, many families with deafblind children are still without proper help and guidance.

The Hungarian government is not in the position of being able to help deafblind people. Deafblindness is only one of many social spheres that is still not properly organised and supported.

The Hungarian Deafblind Association was formed in 1994. Its members are

deafblind adults, children, their relatives, helpers and specialists. We employ a principal contributor, who is undertaking all the work of the association. The secretary-general is the father of a deafblind child, the president is a deafblind person and we have two special educators and another parent as members of the governing body. Our specialists, who regularly attend international courses and conferences, provide the parents with special literature and help them to cope with the problems experienced in bringing up their child. Each year we organise a summer camp for the families, where they can not only relax, but also attend some lectures (given by Hungarian and foreign experts) on topics they are interested in.

We help the adult deafblind people by interpreting for them at medical examinations, in public offices and represent their needs at various social agencies. We supply schools that take part in deafblind education with auxiliary resources. Generally, we are

trying to support all activities that would help the deafblind.

The association gets its financial support partly from the Hilton/Perkins fund, and partly from money won at various competitions. Luckily, all our previous competitions were judged favourably, which enabled us to organise the summer camps, to have our own introductory brochure, and to buy computers."

If you would like further information please contact Szmolka János, President, Hungarian Deafblind Association, Budapest, Ajtösi Dürer sor 39, 1146 Hungary

Creativity and Social Integration

This event was organised by Sense International (UK) and Lega del Filo d'Oro (Italy) and hosted by the European Youth Centre in Budapest in November 1997.

More than 40 young people from throughout Europe came together to look at the concept of social integration and explore in

INDIA

New Deafblind Unit In India

On 14th February 1998 Akhil Paul, Development Manager for Sense International (India) inaugurated a new deafblind unit at the Clarke School for the Deaf in Madras. This is now the second specific service for deafblind people in India, the other being the Helen Keller Institute for the Deaf and Deafblind in Mumbai.

The Clarke School was founded in 1970 for children who are deaf and mentally

retarded. It is one of the few successful schools in India imparting a high standard of education to the hearing impaired with cognitive impairment. Apart from the academic education, the Clarke School has programmes for the mentally retarded, teacher training programmes giving Diploma in Education of the Hearing Impaired and one year Diploma in Education of the mentally retarded. Clarke school has also trained teachers from Vietnam, Uganda, Sri-Lanka and

adjoining countries through involvement of Commonwealth Society for the Deaf, London and the Instituut voor Doven, Netherlands. The Clarke School proposes to start a teacher training programme for teachers of children who are deafblind.

The deafblind unit, called "Sadhana", was initiated with an intention of giving services to children with deafblindness in the city of Madras and neighbouring areas. At the moment Dr. Vijayalaxmi, who is a paediatrician and mother





creative ways exactly what it means and how it affects people. This event was a follow-up to a previous Mobility International event held in 1995 that was specifically for young deafblind people. At that meeting the participants decided that they did not want specific activities just for deafblind people – they wanted to participate in events that all young people are involved in.

At this study session there were 14 deafblind people and their interpreters; the other participants were from a variety of youth organisations and disability organisations. It was particularly pleasing to have representatives from a number of Central and Eastern European countries – Czech Republic, Hungary, Poland and Russia were all represented.

Speakers and presenters included Cathy Nolan from PHAB Northern Ireland who looked at the concept of social integration and used examples of inclusive art; Klaus Vilhelmsen from the Institute for Deafblind people, Denmark, who discussed the



Peter van Houtte of Belgium communicates with Aneta Swiercz of Poland

role of culture and the effects on social integration of both culture and creativity; and Gilberto Scaramuzzo, a professional clown from Italy, who ran sessions on theatre and movement.

There was a wide range of disabilities among the participants and this particularly affected social integration and communication. For example there were deaf people, blind people, people who are both deaf and blind, wheelchair users and people with cerebral palsy – but this

diverse range did not prevent proactive ideas for integration and involvement.

The most successful result of the seminar was when the participants insisted on having an input into the decision-making process of the event. They elected a group of four young people to contribute to the process and to consider what activities will be appropriate in the future. This group has since been in touch with each other and will be in contact with Mobility International to discuss future possibilities.

of a deaf child, is co-ordinating the unit with support from 3 Assistant Special Educators who are trained to deal with deaf & mentally retarded children. There are 14 children who are getting intervention and training in the unit. Among the 14 children, about 9 are deafblind due to rubella and pre-matured birth.

The Clarke school is very steadily progressing in the able hands of Dr. Leelawathy, who is a trained teacher of Deaf. She did her Diploma from the Clarke

School for the Deaf in USA. Due to her hard work and contributions to the field of education of the deaf, the Smith College in Massachusetts, USA, awarded her with the Honorary Doctorate. The School has shown willingness to respond to the needs of the rural community by starting a rural outreach set-up which has a special school for deaf, speech & hearing laboratory, hostel for children, prevocational centre in rural arts and home training programme.



Akhil Paul, Sense International, opens the new deafblind unit

Nellie Girard 12 September 1920 - 18 November 1997

Many of Dbl Review's readers will have met or heard of Nellie Girard. For the past 30 years, her presence, along with her husband Gwinn, has been almost guaranteed at international conferences on deafblindness. The following are tributes in memory of Nellie's life and contribution to deafblindness.

When a lovely flame dies, smoke gets in your eyes

Nellie Ruth Girard (née Henry) was born on a farm near Clinton, Oklahoma. She learned her family values from her mother, father, four brothers and two sisters.

One day when Nellie was nine years old, she was at home while her parents were in town. A man came to visit her father. She had learned that when visitors came, you entertained and fed them. She caught a chicken, killed it, cleaned it, fried it and fed the man before her parents returned. He was a United States Senator.

This work ethic she brought to her nursing career and eventually her marriage to a young Marine. She and her husband raised four of their own children and adopted two more boys.

Nellie got involved with the deaf-blind when taking a young boy of eight months with a heart problem and found that he was also blind and deaf. Never one to give up on a child, Nellie searched for help and by the time the Rubella epidemic came to our part of the US, she was one that was considered an expert in the field. She had taught Chris to talk with the help of the John Tracy Clinic and California School for the Blind.

With the help of her husband and doctors that she hand-picked, she eventually was taking care of nine deaf-blind Rubella children. She attended every Deaf-Blind seminar she possibly could, always trying to learn more and trying to help others.

I can truthfully say "She cared".

Gwinn Girard

I first met Nellie and Gwinn when they came over to England in about 1971 and came to stay with me in Birmingham. They were trying to find information and ideas about working with deafblind children and, of course, we were doing the same in what was then the National Deafblind and Rubella Association. The deafblind children Nellie and Gwinn were looking after following the Rubella epidemics in the 1960's were so similar to all the children and their families that we were trying to support in this country.

We learned a lot from each other and remained in touch ever since.

Whenever we went from Sense to an international Conference, we could be sure that Nellie and Gwinn would be there, always ready to learn more and always contributing their knowledge and vast experience.

More than this, however, was the love, care and kindness that both Nellie and Gwinn ooze wherever they go. In spite of frequent serious illnesses Nellie carried on coming and was an example and inspiration to everyone who knew her. She will be greatly missed, not only by Gwinn and their large and lovely family to whom we send our love and sympathy, but by all who knew her in the international work with deafblind people.

Jessica Hills, Chairman, Sense



Valery Chulkov 9 September 1939 – 4 December 1997

Tatjana Basilova, reflects on the life and work of Valery Chulkov who lost his fight against cancer at the end of last year.

Many colleagues from different countries knew and loved Valery Chulkov, who represented modern Russia. He was the first constant representative of Russia in the Executive Committee of IAEDB and did a lot for the development of international exchange in the sphere of deafblind teaching and for the international recognition of the achievements of the Russian science and practice in this field. His personal charm, ability to communicate in German, French and English earned him love and respect from colleagues worldwide.

Valery Nikolaevich Chulkov was born on 9th September 1939 in Moscow. He became an orphan at a very early age; his mother died when he was just 3, and his father died when he was 6. Valery was adopted and brought up by his cousin, whom he took care of till the end of his own life. He was a bright student at school where he was influenced by a well-known specialist in teaching deaf children, Alexandra Gozova, who taught psychology at Valery's school. From her, Valery learnt about the educational problems facing deaf people. After a successful career at university, Valery decided to study in the department of teaching deaf children at a Teachers' University.

After successfully graduating in 1964, Valery was sent to the Moscow region where he worked for three years. First he was a speech therapist at the school for children with learning difficulties, and then as a teacher of Russian and mathematics at a school for the deaf. After that, Valery spent some time working as



a teacher of the deaf in various Moscow schools.

In 1968, Valery went to the Institute of Defectology, which, since 1992, is now known as the Institute of Special Education, where he worked till the end of his life. He started research work in the sphere of general and vocational education of the deaf.

He wrote a number of articles and worked out programmes, methodological recommendations and teaching materials to intensify the effectiveness of teaching mathematics, mechanical drawing and vocational teaching of people with hearing impairments.

For many years Valery taught psychology and many former students will remember his interesting lectures and seminars which were filled with knowledge of deaf children and their problems, relating to their personalities and to their language.

From 1981 until 1996, Valery was the Head of the Laboratory of Teaching Deafblind Children, which in 1992 became the Laboratory of Teaching Children with Compound Impairments. Under Valery's supervision, modern programmes were created. These programmes are still successfully being used in the teaching of

partially sighted, deaf and deafblind children. Valery also initiated the introduction of a new approach to teaching children with severe sensory impairments - *social-everyday-life orientation*. Under his supervision, research and practical work was undertaken in Zagorsk at the Sergiev Posad Home for deafblind children and in Moscow in an experimental group home for deafblind children.

Those teachers who worked under Valery's supervision always observed his attention, enthusiasm and tact which helped them in their own work. Valery Chulkov was the supervisor for several doctoral students in psychology and teaching deafblind children. These people are now the leading specialists in this field. More than 40 scientific works, including three methodological books and articles, were published by him.

Valery was a very tender father to his children: his daughter Sophi, works as a speech therapist, and his son, is currently a student at a Theological College. Throughout his life, Valery was also very fond of the fine arts and poetry.

In the last two years of his life, the terrible illness which was to kill him, dramatically changed Valery's life. Despite overcoming a very complicated operation, Valery was plagued by severe pain. His ability to draw helped him to overcome the hardships during the last year of his life.

We lost in Valery a kind, true and trusty friend; attentive, talented and intelligent researcher, and scientific leader who was always ready to give a helping hand.

Australian National Deafblindness Conference 1998

Deafblindness Facing the Future

The lack of information about Australians aged over 65 years who have a significant dual sensory impairment was a cause for great concern, delegates to the fourth Australian National Deafblindness Conference were told.

The national conferences are held every two years. This year's was organised by the Australian DeafBlind Council (ADBC) under the auspices of The Deaf-Blind Association. It consisted of a training day, a social day and a meeting day, all of which were well attended. The Annual General Meeting of ADBC was also held.

More than 150 people, including 15 interpreters and a large contingent of parents and professionals from New Zealand attended the three-day conference which was held in Melbourne from Thursday 30 April until Saturday 2 May.

Other issues raised included the need for improved staff training, the unevenness of service provision for deafblind people around Australia, the need for a universal identifying symbol for deafblind people on canes and guide dog harnesses, and complications arising from the increasing automation of public transport.

Keynote speaker was consultant Mary Ward, author of two major reports on deafblindness in Australia. Other major speakers included Rod Macdonald, Vice-President of the Steering Committee of the World Federation of the Deaf-Blind, and Bill Jolley, Executive Officer of the National Federation of Blind Citizens of Australia.

Mary Ward included an outline of the various training initiatives currently being undertaken around Australia:

- A five-day post-graduate Winter School has been introduced at Renwick College in New South Wales in Developing Communication Skills in Students with Dual Sensory Disabilities. This is the first of a two-part program providing a range of professional development experiences for workers in the field of deafblind education. It will be offered from 5 to 10 July 1998 by Dr Deborah Chen, Associate Professor, Department of Special Education, California State University, and Sharon Barrey Grassick, Senior Training Officer with the West Australian Deafblind Association.
- The Deaf-Blind Association in Victoria has created the position of Training Officer, and a training video has been produced for residential care workers together with a manual.
- Restructuring of the Forsight Foundation in New South Wales has included an on-going training program for residential staff, and the Royal Blind Society in that state has created the position of Deafblind Consultant.
- In Queensland an intervenor package is being designed within the Education Department which is likely to be delivered through Griffith University.

Mary said another major area of concern in Australia was the situation of people over the age of 65 years who have



Some of the interpreters at work at the recent Australian National Deafblindness Conference in Melbourne

Information Session at Blindenheim Bern

significant dual sensory impairment.

"There is a growing body of evidence showing that misdiagnosis of significant dual sensory impairment leads to premature admission to hostels and nursing homes for people over 65... this misdiagnosis involves a diagnosis of psychosis, when the cause of the dysfunction is in fact a loss of contact with other people and the environment through the inability of professionals and staff to respond to the loss of both sight and hearing."

A submission has been made to the Federal Government for funding for research into this area.

The next conference will be staged in Perth, Western Australia, in 2000.

Bob Segrave, Australian DeafBlind Council

For further information about the proceedings from this conference please contact:

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Madrid 1997 European Congress of the Deafblind International and the Usher Study Group

On 10 January 1998, an Information Session was held in the Blindenheim Bern (Berne Home for the Blind) on the subject of the Madrid 1997 European Congress of the Deafblind International and the Usher Study Group.

The meeting was organised by the Support Centres for the deaf-blind and hearing-and-vision impaired of the Swiss National Association of and for the Blind (SNAB). The purpose of this meeting was to inform the results of the Madrid Congress and its consequences as they affect Switzerland, and to provide an opportunity for the exchange of ideas.

The meeting was attended by 67 people, an indication of the keen interest in this subject. The audience included specialist teachers for the blind and deaf, social workers, and the various specialised field of the Support Centres of the SNAB, deaf-blind persons and families, from both the German and French speaking areas of Switzerland. For the first time in this country, people from all these different fields were able to come together and discuss their interests and needs.

Toni Bargetzi, Division Head of the SNAB Support Centres for the deaf-blind and hearing-and-vision impaired, chaired the meeting and acted as MC throughout the day.

The meeting began with an overview of the existing institutions in Switzerland and the structure of the SNAB Support Centres for the deaf-blind and hearing-and-vision impaired. This was followed by an explanation by psychologist Norma Bergetzi

of the structures and committees at international level.

Christina Fasser, head of the RP Support Centre and President of the IRPA gave a summary report of the European Conference of the Usher Study Group. In her talk she expanded on the issues of research and science, education and training, areas of personal experience and the question of "where next?".

Anita Rothenbühler, who is herself hearing-and-vision impaired, Charly Lindenegger a social worker, and Norma Bergetzi, all of whom had attended the Dbl Conference on behalf of the SNAB, each presented from Madrid a chosen subject of personal interest. All their talks are available in black print in German and French from the central offices in Zurich or Lausanne.

In the afternoon 4 groups were formed to consider the question: "Where do we go from here?" This was followed by a plenary session in which the results of the group work were presented. The need for interaction, discussion about and participation in the work was strongly felt by all, as was the desire to pursue and identify co-operation.

The stimulating atmosphere that typified the day is proof of a general desire for greater and more intensive co-operation between professionals and deaf-blind persons.

SNAB will continue to work towards developing and increasing "horizontal spread", networking or professionals/clients. "Getting results" is the chief aim of this year's SNAB activities.

'Actual state of support for children and adults with severe impairments of hearing and sight'

The First Regional Science-Practical Conference, Moscow

This conference took place in the Institute of Special Education on 26 March 1998 and was organised by Sokoljansky's laboratory Head Dr Tatjana Basilova (the laboratory is known as the laboratory of teaching children with compound impairments). The main goal of the conference was to comprehend and gain an overview of the real situation and real organisation working on the problems facing deafblind people.

The conference was devoted to 75th Birthday of A. Mascherjakov and 35th Anniversary of the Home for deafblind children in Sergiev Posad.

Although the conference focused on the Moscow

region, representatives from 4 other Russian regions were present. There were 57 participants: researchers, directors and teachers of the deaf and deafblind, tutors from teachers' colleges and universities, deafblind people themselves and members of their families. 10 volunteers helped everybody to feel comfortable to enable concentrated work.

During the plenary session three talks by Tatjana Basilova, Galina Epifanova and Helen Goncharova showed traditional ties of the past experience in teaching and serving deafblind people in Russia and the present situation of co-operation between those who work in different organisations and

agencies. It was stressed that due to the recent and dramatic changes in the population of deafblind children, researchers and practitioners are interested in working together to establish new, effective methods of education and supervision of deafblind children and adults.

Eleven posters, three information stands and three exhibitions of handicrafts, illustrated the new approaches currently being developed. There were discussions on: the problems of using new technologies in teaching children with dual-sensory impairments; the problems of introducing new teaching methods for deafblind children in schools for deaf children, early family intervention and socio-psychological rehabilitation of older deafblind people; accurate physiological assessments and support of Usher people, and many other topics.

After the conference all participants completed a questionnaire. A willingness and desire to organise conferences on a regular basis was strongly expressed. It was decided to hold the second regional Moscow conference in March 1999 and devote it to the 110th anniversary of Ivan Sokoljansky, the founder of the Russian traditional approach to teaching deafblind children.

Irene Salomatina
Institute of Special
Education
Moscow
Russia



Photos by Tatjana Sherstuk

Delegates exchange ideas at the First Regional Science-Practical Conference in Moscow

DbI DISTINGUISHED SERVICE AWARD

The Dbl Distinguished Service Award was instituted in 1987 and is given to an individual who, in the opinion of the Dbl Management Committee, has

"outstandingly served the cause of deafblind education, both nationally and internationally, over very many years".

The award is usually presented during Dbl World or European Conferences, but *only* when a suitable recipient has been identified. Past recipients of this award have been:

Miss Joan Shields 1987 World Conference, Poitiers, France

Dr Edward Waterhouse 1991 World Conference, Orebro, Sweden

Dr Jan van Dijk, Mr John McInnes and Mr Rodney Clark 1995 World Conference, Cordoba, Argentina

Miss Sonja Jarl 1997 European Conference, Madrid, Spain

We are currently seeking nominations to receive this award in Lisbon in 1999. Please forward all nominations by **15 November 1998** to Rodney Clark, Secretary, Dbl, 11-13 Clifton Terrace, Finsbury Park, London N4 3SR or email: rclark@sense.org.uk.



Deafblind International, formerly known as the International Association for the Education of Deafblind People, was founded over 30 years ago to promote the education of deafblind children and young adults throughout the world.

The Association originally brought together professionals working with congenitally deafblind people. In recent years it has begun work with adventitiously deafblind people. Professionals, researchers, families, deafblind people and administrators are now involved.

Membership

There are two categories of Dbl membership: **voting** and **non-voting**

Voting members consist of corporate bodies and international networks. Corporate members are requested to subscribe an annual amount of between US\$300 and \$5,000. Corporates have the opportunity to sit on Dbl's Council and vote at the General Assembly. For further information and an application form for either Corporate or Network membership please contact the Dbl Secretariat.

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.

I wish to receive *Dbl Review* in English Spanish

I would like to receive *Dbl Review* on disc

I wish to become a non-voting member of Dbl. Please find enclosed my donation of US\$30

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

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