



# **Sense**

## **International**

### **India**

# **National Expert Meeting On Deafblindness**

11 - 12<sup>th</sup> September '98  
YMCA International  
Mumbai

**Working with deafblind people  
throughout India**



**DbI**  
**R**

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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**W**e 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 Gärd.

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

**W**elcome to the first edition of *Dbl 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 Dbl 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' perspective on both the visual arts and dance.

The Dbl 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 Dbl 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

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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.

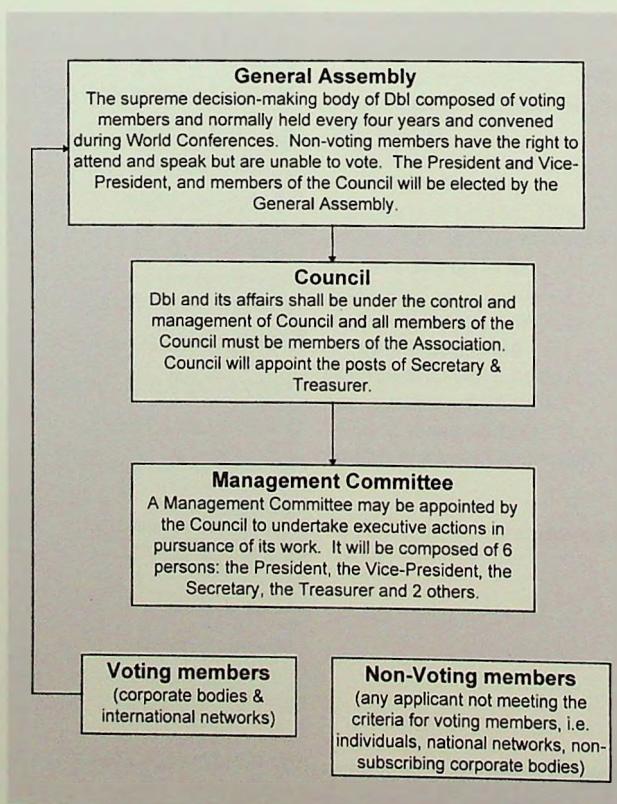
## Network Recognition

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**



## Dbl Conferences

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

## Dbl 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 Dbl conference and would like further information and an application form then please contact Tamar Underhill, Assistant Secretary Dbl, telephone +44 171 272 7774 or fax +44 171 272 6012 or email [dbi@sense.org.uk](mailto:dbi@sense.org.uk).

As a reminder of past and planned Dbl 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	Orebro, 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 Dbl 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 Dbl for any financial obligations for the conference. Financial assistance from Dbl 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 Dbl 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 Dbl 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?



## CONFERENCES

### **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](mailto: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](mailto: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: [cpi.educa@mail.telepac.pt](mailto:cpi.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



# COMMUNICATION

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 your 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@inet.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.

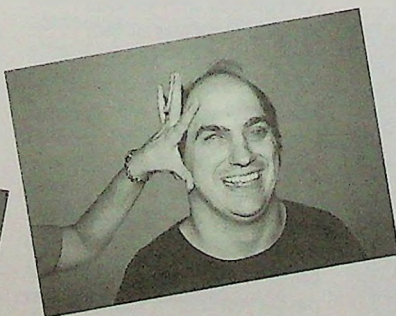
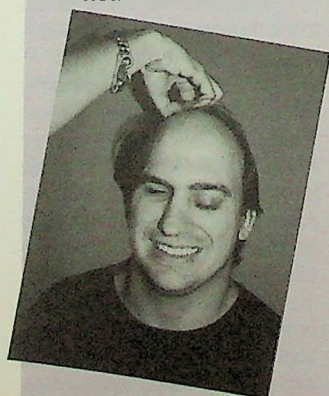
Perhaps the greatest advantage of Body Signing and its strategies is that it provides a better and more precise warning system. This allows the student to know exactly what is about to happen to them, or anticipate what they are about to eat or drink. The confusion of day to day activities and the fear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

**T**he 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.**



## AWARDS

### Beroz N Vacha



**B**eroz 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 Mohanial 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"

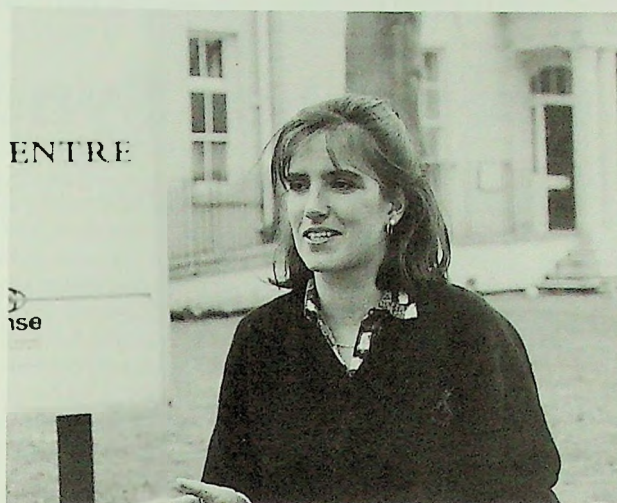
No one can be more deserving than Beroz. Beroz never assumes personal acclaim but considers herself a representative of the school and her colleagues, whose patient work and caring dedication overcome seemingly insurmountable challenges and problems. Beroz's late husband Nari was supportive of her work 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".**



**T**he 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.



## FOCUS ON THE ARTS



*'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'



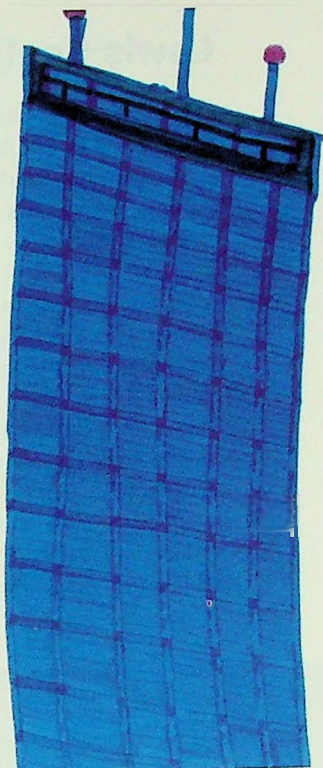
## Sasha Gyori

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



▲ 'Hancock Building'



▲ 'Jimmy'



▶ '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."*

GALLERY





## GALLERY



▲ '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.



GALLERY

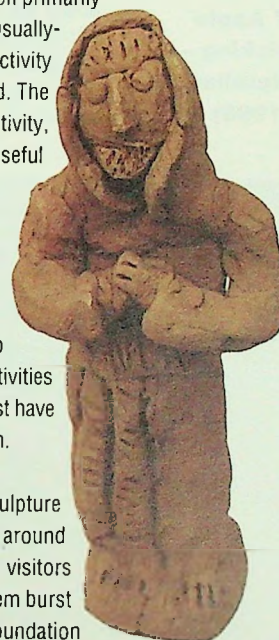
In 1945 the family were able to return to their home town of Vilnius. Ivanas went to the school for the deaf, became the best student and was considered to be highly gifted. He was offered the chance to study in Moscow but instead worked in a shoe factory for 30 years. Suffering from glaucoma and cataracts, 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 Sarišská, 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 skilful 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)**



**D**ance 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

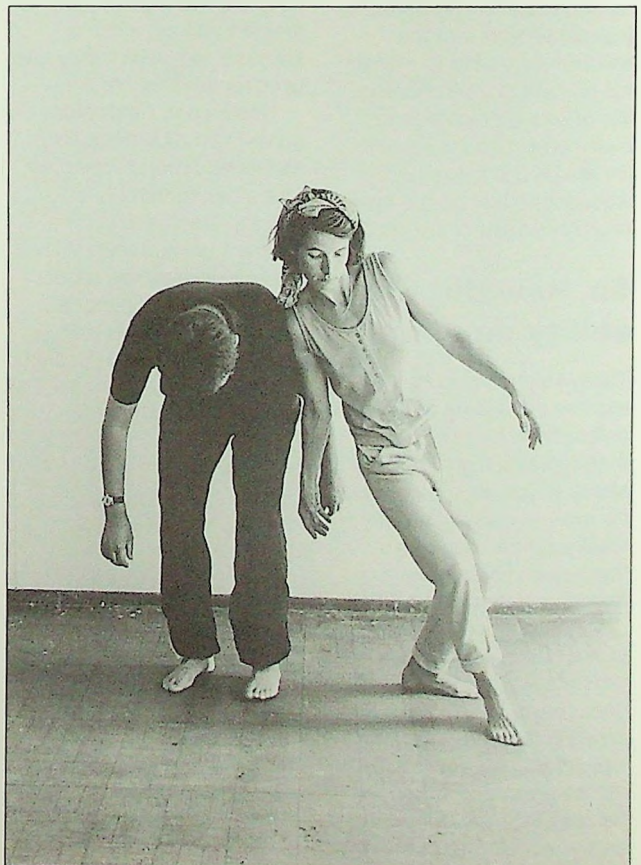
# Touchdown

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 form to 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.

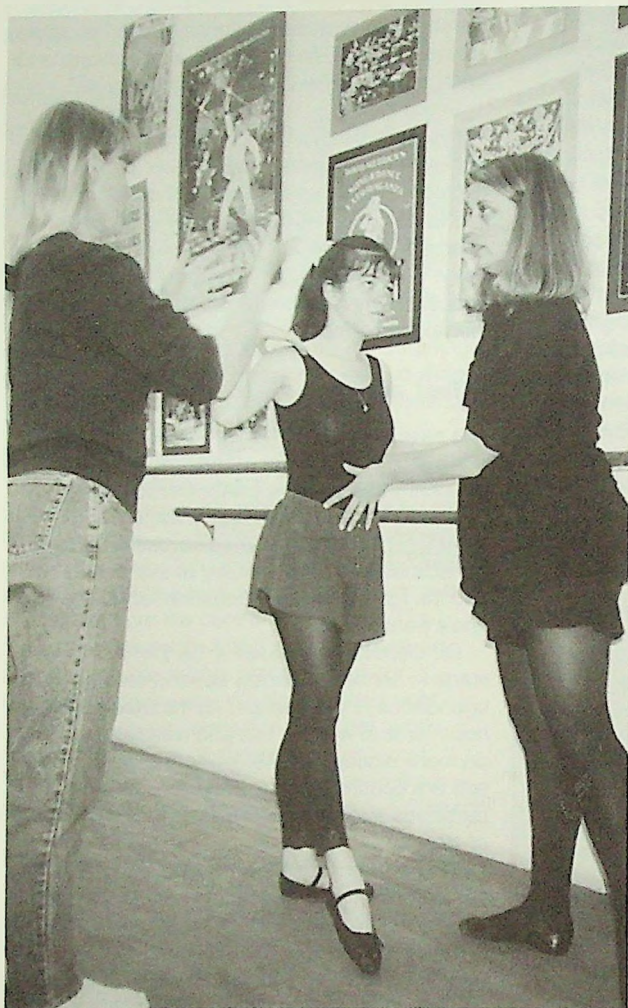
Contact Improvisation transcends form and technique to find a dance style that expresses the meeting of two people, the meeting of two energy sources, and the consequential effervescent movement that carries their bodies through space, with or against gravity, and with or against the counter force of 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 Kalliope 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 Kabarnet 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.

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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 Morrissey 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.

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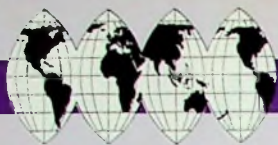
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### WEST AFRICA

#### 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, Ajtósi 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

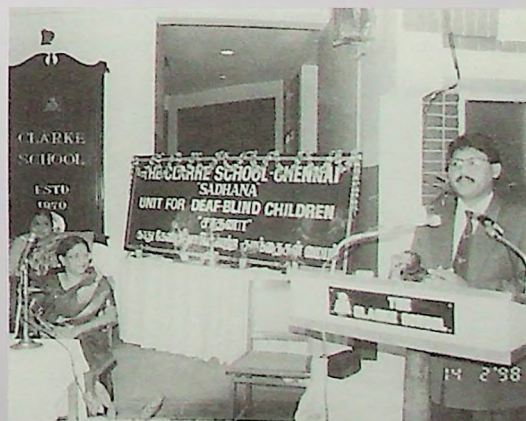
diverse range did not prevent proactive ideas for integration and involvement.

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](mailto: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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### USA

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Overbrook School for the Blind  
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Fax: +1 - 215 - 877 2466  
Email: bmkb@obs.org

## Networks

### ACQUIRED DEAFBLINDNESS NETWORK

c/o Anneke Balder  
Stichting Doof-Blinden  
Professor Brauherslaan 10  
3723 MB Bithoven  
THE NETHERLANDS  
Tel: +31 - 30 - 2250604  
Fax: +31 - 30 - 2291884

### COMMUNICATION NETWORK

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

### CONGENITAL DEAFBLINDNESS IN ADULTS NETWORK

c/o Bob Snow  
Sense North  
122 Westgate  
Wakefield WF1 1XP  
UK  
Tel: +44 - 1924 - 201778  
Fax: +44 - 1924 - 366307  
Email: bobsensen@aol.com

### EURO UNIT/STAFF DEVELOPMENT NETWORK

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

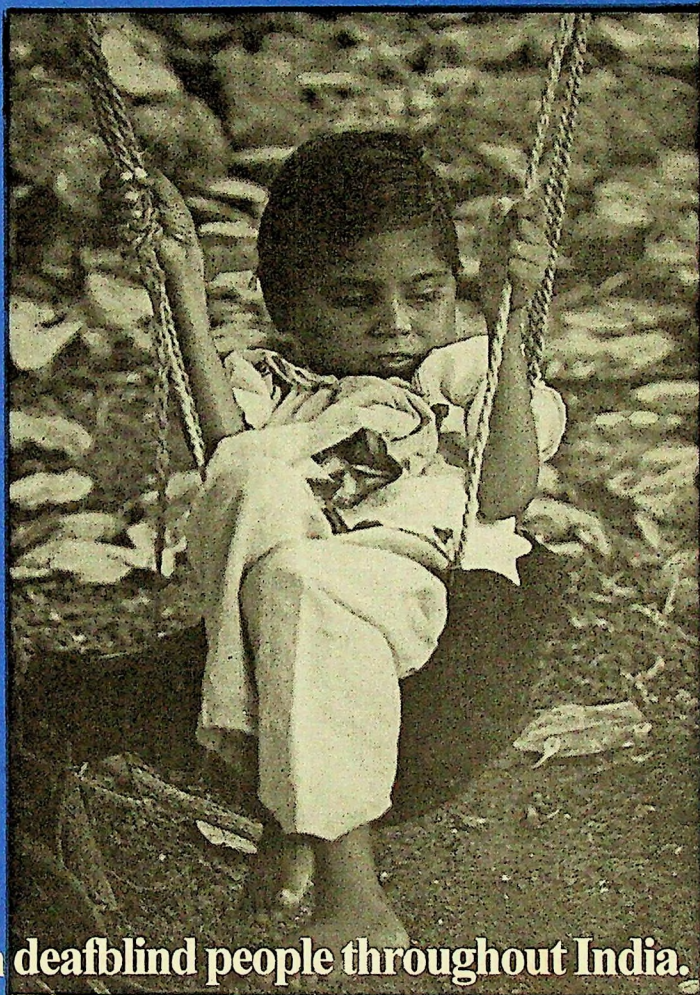
### EUROPEAN USHER SYNDROME STUDY GROUP (EUSSG)

c/o Mary Guest  
Sense  
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**Sense**  
International  
India



**Working with deafblind people throughout India.**





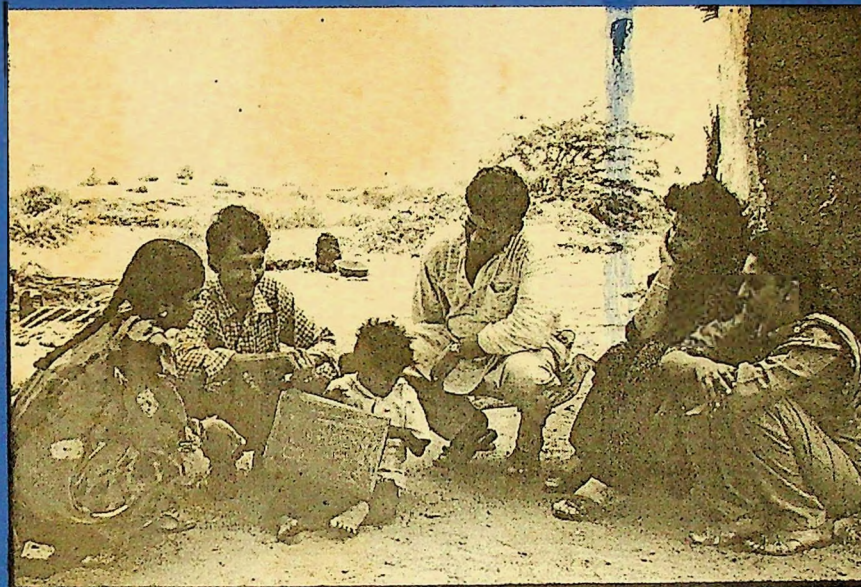
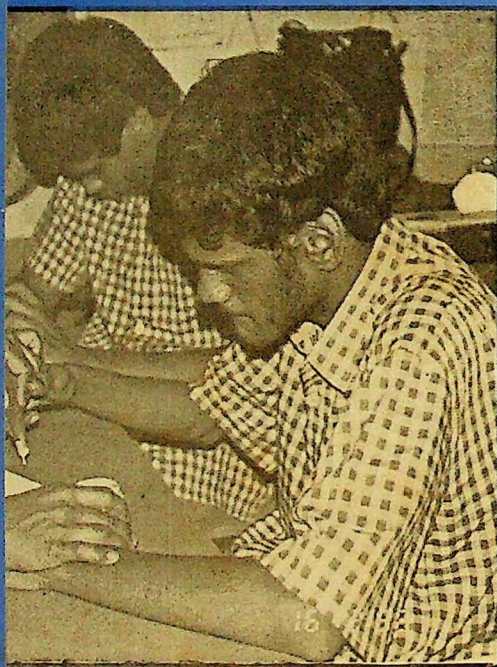
#### MISSION...

Sense International (India) was created in 1997 to support the development of services for deafblind people in India. The role of Sense International (India) is to act as a catalyst to stimulate these developments by offering support, training and experience.

Its mission is "to stimulate developments that will be sustainable in the long term by working with partner organisations who will ultimately assume responsibility for the services for deafblind people."

impairments and comes in varying degrees. Because 95 per cent of deafblindness is acquired, deafblindness causes unique problems in communication,

now and his or her experience of the world extends only as far as the experience of others. These challenges are by no means insurmountable and deafblind people have achieved an excellent quality of life.



#### PARTNERS....

Sense International (India) works in partnership with organisations wishing to support deafblind people. Sense International (India) supports the following:

Helen Keller Institute for Deaf and Deafblind, Mumbai : a Vocational Training and Rehabilitation project for young deafblind adults.

Blind People's Association, Ahmedabad (formerly known as "Blind Men's Association") : a deafblind unit on their campus and an outreach programme in the villages in the neighbouring districts and

National Association for the Blind, Mumbai in a home based programme. Initially the project will provide services for five deafblind children but gradually expand services through the vast network of NAB State/

#### OTHER ACTIVITIES...

Deafblindness is such a unique disability that professionals working with deafblind people have to look to peers for support, training and information.

Sense International (India) organises conferences and workshops that focus on issues related to deafblindness which aim to improve services and reach more deafblind people. Sense International (India) organised a two day National Expert Meeting in September '98 in which professionals, parents and policy planners from all over India, UK, Holland and USA participated.

To increase the knowledge and skills in a specialist area relating to multi sensory impairments, Sense International (India) recommends professionals to attend the Professional Development Programme at Sense International UK for a period of six weeks.

Sense International (India) further aims at developing teacher training programmes with partners.

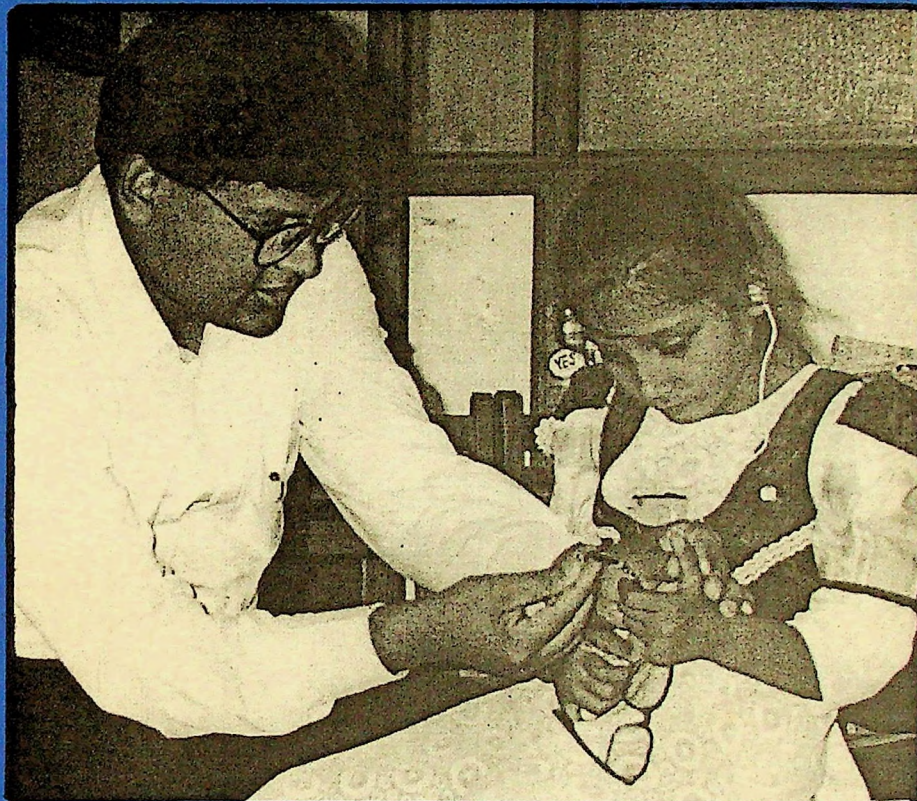


## FUTURE...

Sense International (India) looks ahead to a fruitful relationship with ongoing partners and projects, further identification of new partners and looking into possible ways of raising funds in India and working on new project possibilities.

We look forward to continue working towards the involvement of government and the possibilities of extending deafblind services to neighbouring countries like Nepal, Sri Lanka, Bangladesh and Pakistan.

Our ultimate aim is to ensure that there is a whole range of services for deafblind people throughout the country. We have a dream of having at least one service for deafblind people that is easy to access in every state of India.



Sense International (India)

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Home Page: [www.indoweb.com/sense](http://www.indoweb.com/sense)



## The deafblind population: policy and planning- Malcolm Matthews

### **What is deafblindness?**

Definition: UK, Nordic and "child centred" definitions

The functional service focused definition

Why functioning is so important

A scatter graph showing the different combinations of sensory impairment

The multiplication effect of combinations of impairment

### **Causes**

An overview

Numbers by age profile

The changing deafblind population

### **The different deafblind groups**

The congenital / prelingual distinction

(and how this relates to the child centred definition and Nordic definition)

Blind becoming deaf

Deaf becoming blind

Deafblind in later life (including elderly)

### **Policy**

The UN Rules make specific mention of deafblindness

The services proposed within the UN rules

*What is special about deafblind services*

### **The policy requirements for significant development of services**

Champions

Recognition

- of 3 sensory impairments and the importance of multiple disability)
- of the need to specifically address deafblindness

Identification (registration)

Expertise / training

Philosophy / aims (in the UK independence, in India economic contribution?)

Changing attitudes (increased focus on economic contribution in UK)

Deafblind centres or within services for others?

### **Meeting needs**

- mobility
  - access to information
  - communication
  - personality / behaviour
- (in UK one to one support is seen as a major part of meeting need)

### **Issues**

- small numbers
- within different populations
- often have other disabilities
- heterogeneous population
- but same needs / approaches but maybe different methods?

### **Planning**

Think Dual Sensory

Recommendations to government

"A deafblind person in a service for others gets left out"

What needs to be done by- national government

- local government & - service providers



## **Acquired Deafblindness- Malcolm Matthews**

### **What is acquired deafblindness?**

The comparison with congenital deafblindness. Post-lingual meaning after developing language (spoken or sign) being the most useful concept. People with acquired deafblindness and learning disabilities may respond more like people with congenital deafblindness.

The similarities with congenital deafblindness. For example If no intervention at the right time and a modified or new approach to communication is not possible then methods may be similar.

### **Subgroups**

Blind becoming deaf: tactile skills; fingerspelling and block

Deaf becoming blind: lipreading; sign – restricted visual frame – hands on – sign language community (pride in signing and visual ability)

Elderly:

**Causes:** accident, illness, genetic e.g. Usher, ageing

### **Issues**

Sudden traumatic loss

Gradual loss: need for regular input

Psychological effects:

Need for information for the individual (and their family)

### **Effects**

On identity

Isolation

Spiritual needs

Contribution to family / society / work

Time

The individual – acceptance, desire to learn; meeting others; groups and mentors

### **Services**

Rehabilitation – taster days

Timing the input – don't leave until can't communicate (but not too early either); quote or video

Learning communication

Working with the whole family / community

Staff awareness

### **Back to the definition:**

Mobility – individual skills – mobility skills, learn routes

- modify environment: lighting, trails, outline doors, hazard tape

Access to information (including from environment)

Communication – lighting, position, don't cover face

- modify methods
- new methods e.g. hands on, objects

**Guidelines on maintaining (or developing) communication skills** (if time allows)

Nine points proposed by a Europe wide expert meeting on older people with vision and hearing loss as the key to maintaining or developing communication

### **A casestudy** (if time allows)

Bill had been deaf and blind for 35 years and had lived alone with his wife until she died. He has no other family. He could speak – and would speak to the "voices in his head" but nobody could communicate with him and he had no reading or writing skills. As a result of diabetes he had tactile discrimination problems and was tactile defensive. A relationship was built with Bill through playing the game of dominoes. He now communicates using objects of reference and a few signs.



## **SENSE INTERNATIONAL AND THE ROLE OF INGOS – RICHARD HAWKES**

The aim of this presentation is to give details of the international organisations that exist within the deafblind field, specifically focusing on Sense International and the other INGOS which support the development of services throughout the world.

The presentation will cover:

- Relevant international networks / bodies

DbI, ICEVI, WBU, WFD, HKI, World Organisation of deafblind people

- INGOS in the deafblind field

Hilton / Perkins, Sense International, Instituut voor Doven, CBM, ONCE, NUD, FSDB, Lega del Filo d'Oro, Sightsavers

- INGOS working in India

Hilton / Perkins, Sense International, Instituut voor Doven, CBM, Sightsavers

- Sense International

- Aim
- Summary of programmes
- Policy and practice
- Relationships with partners
- Nature of support
- India

- Relationships between INGOS





# NEWS

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## Working with deafblind people throughout India Issue - 1 August 1998

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### BEGINING OF A NEW ERA

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This is the first newsletter of Sense International (India). We were established in March 1997 with the aim of supporting the development of services for deafblind people in India by working in partnership with Indian Non Governmental Organisations (NGOs), International NGOs, governmental bodies, schools, centers and professionals.

Sense International is UK based organization, created in 1994 to support and develop services for deafblind people throughout the world. It is a part of Sense, the National deafblind and Rubella Association in the UK, and now has projects in Latin America, Africa and Eastern Europe.

As a result of constant pressure from people in India, such as Mrs. Beroz Vacha, Sense International made India its top priority programme. In January 1997, Akhil Paul became Sense International's first ever non-UK based member of staff when he was appointed as Development Manager of Sense International (India).

Sense International (India) does not seek to develop its own services. We work with partners and assist them as they develop deafblind services. Our ultimate aim is to enable them assume full responsibility for the services for deafblind people. News of some of our projects can be found in this newsletter.

Our role is to act as a catalyst to stimulate these developments by offering support, expertise and experience.

In addition, we arrange activities that support our partners such as national meetings on deafblindness, training courses and exchange of information.

For the last twenty one years, the Helen Keller Institute for Deaf and Deafblind, Mumbai has been the only center in India providing specific service to deafblind children and now we are supporting new developments in the Institute.

Sense International (India) has been able to develop a large network of experts, consultants who have rich experience in working with persons who are deafblind. It is with this experience & commitment that Sense International (India) is initially supporting three projects that cater to deafblind children and young adults in Maharashtra and Gujarat.

We are delighted that even at such an early stage in our development we already have a project supported by the British Government, through its Department For International Development (DFID). The prestigious National Lottery Charities Board is giving funds for another substantial project for young adults who are deafblind.

The purpose of this newsletter is to provide information about deafblindness and developments at Sense International (India). We will circulate it widely throughout the country and will be pleased to publish information that is sent to us. Please contact Binali Suhandani, Assistant Development Manager, if you would like to include anything or if you know of people who should receive this newsletter.



## WHAT IS DEAFBLINDNESS?

Deafblindness is a combination of visual and hearing impairments and comes in varying degrees. Because 95 per cent of all we learn comes through our eyes and ears, deafblindness causes unique problems in communication, mobility and accessing information.

For the young child who is deafblind, the world is initially much narrower. If the child is profoundly deaf and totally blind, his or her experience of the world extends only as far as the fingertips can reach. Such children are effectively alone if no one is touching them. Their concepts of the world depend upon what or whom they have had an opportunity to physically contact.

As far as the developing world is concerned, there are not enough resources to provide health care and education for everyone. Disabled people, especially people who are deafblind, may have little access to these services because lack of awareness. In many countries, there has been little research, although we can assume that there are large numbers of deafblind people. But no one really knows how many deafblind people there are, where they are or what happens to them. This means that deafblind children may be put in institutions, or left uncared. In India, we do not have any research or survey conducted regarding the population of persons with deafblindness but the Community Based Rehabilitation Projects have hinted that there might be around 2,50,000 persons with dual sensory / multi - sensory losses.

Though deafblindness presents many unique challenges to both those who have visual and hearing impairments and to their families and friends, these challenges are by no means unsurmountable. Many persons who are deafblind have achieved a quality of life that is excellent.

## THE PARTNERS IN PROGRESS

### HELEN KELLER INSTITUTE, MUMBAI

Established in 1976, Helen Keller Institute for the deaf and deafblind is a pioneering institute in India that creates, builds and develops services to allow the disabled person to become a contributory, functional and accepted fellow human being within his own society. The institute since its inception has helped educate and train 32 deaf blind children.

Sense International (India) has assisted Helen Keller Institute in developing a vocational training project for young adults who are deafblind. The project aims to develop vocational skills in deafblind adults in order to ensure their employment and independence. This project is being funded by National Lottery Charities Board, UK



Pradip & Annie making candles at HKIDB

### BLIND PEOPLE'S ASSOCIATION, AHMEDABAD.

The Blind People's Association (formerly known as "Blind Men's Association") is a registered trust working for the past 40 years for the comprehensive rehabilitation of persons with blindness, deafness, mental retardation, Locomotor disabilities and multiple disabilities. They have initiated Community Based Rehabilitation (CBR) programmes for the disabled people in villages.

In these programmes, Blind People's Association identified deafblind people but was unable to provide services to them due to lack of specialised expertise in this field.

With the help of Sense International (India), the Blind People's Association has started a unit for deafblind children and will impart training in communication skills, parental training program, human resource development, program for teachers and vocational training program for selected deafblind persons.



Apart from these services, the Blind People's Association will strive to develop & initiate services for deafblind people in the whole of Gujarat through their Community based rehabilitation programs and like minded organizations.

The Project of Blind People's Association is being supported by British Department for International Development (DFID) and the Sylvia Adams Trust.



Richard visiting a deafblind child in Kapadvanj

### **NATIONAL ASSOCIATION FOR THE BLIND, MUMBAI**

National Association for the Blind, India established in 1952 is the largest voluntary Organisation in India working in the field of welfare of blind. It is involved in prevention, education, rehabilitation, training, employment and research.

The National Association for the Blind (NAB) carries out its activities through a network of 17 State and district branches all over the country. The NAB Education department has initiated a home based programme for children with multiple disabilities. At present 25 children living in Mumbai & its suburban areas are receiving these services

Sense International (India) is supporting National Association for the Blind to initiate a home based programme for deafblind children under their existing project. With further assistance from Sense International (India), the National Association for the Blind plans to identify five locations in India,



Kaushik with his mother & brother in Mumbai

where the National Association for the Blind has a strong State/ District branch which will work towards development of services for deafblind people in their areas.

### **PROFESSIONAL DEVELOPMENT PROGRAMME**

To increase the knowledge and skills in a specialist area relating to sensory impairment and additional disabilities, Sense International UK offers a Professional Development Program (PDP) for professionals from all over the world to increase their skills.

This is a specialized program, structured and designed specifically for individual participant that gives opportunity to observe classroom, daily care and educational activities of deafblind children and adults in educational and residential settings in UK for a period of six weeks.

Sense International (India) deputed Br. George from the Montford Center for Education, Meghalaya, Ms. Sheela Sinha from Helen Keller Institute for the Deaf & Deafblind, Mumbai, Ms. Meena Nikam from National Association for the Blind, Mumbai and Ms. Vimal Thawani from Blind People's Association, Ahmedabad to undergo an exposure training in the UK under the Professional Development Program (PDP).



## CLARKE SCHOOL FOR THE DEAF, MADRAS

The Clarke school was founded in 1970 for children who are deaf and mentally retarded. It is one of the few successful schools in the country imparting high standard of education to hearing impaired and mentally retarded children.

The School showed willingness to respond to the needs of the rural community by starting a rural outreach programme, which would provide a special school for the deaf, speech and hearing lab, hostel for children, pre - vocational center in rural arts and home training program.



A Grandmother's gratitude in Chennai

On 14<sup>th</sup> of February, a new deafblind unit at the Clarke school in Madras was inaugurated by Akhil Paul, Development Manager of Sense International India.

## PANORAMA OF OUR ACTIVITIES

### Sense International (India) Office!

Since its inception, Sense International (India) invested its resources in assessing the situation for deafblind people throughout India and identifying potential partners. Throughout these 18 months, the Development Manager operated from home. With an increasing number of projects to support, and addition of a new member of staff, it was no longer possible for Akhil Paul to be home based and we therefore felt the need for opening an office.



Richard Inaugurating the SII Office

Finally, on 13<sup>th</sup> June, 98 Richard Hawkes, Head of Sense International, UK inaugurated the new office of Sense International (India). At the inauguration, Richard explained the need for starting the India program and the current status of services for deafblind people in the country.

We take this opportunity to invite you to our office whenever you are in Ahmedabad.

### Sense Team Strengthens

Binali Suhandani, the eighth member of Sense International has joined the Sense team as Assistant Development Manager of Sense International (India).

Binali has experience in Policy Research and Documentation. She volunteered for National Association for the Blind, Mumbai, while in college. She worked for the Women's World Banking where she was responsible for training organizations, studying and preparing case studies of organizations, preparing training manuals and publications.

### Expert Assistance!

Gerard Swan, Deputy Headteacher of the Kingsley School, UK is in India to provide training and assist the staff of deafblind unit of the Blind People's Association in Ahmedabad to set up and run the unit as an integral part of Blind People's Association.

Kingsley school provides education for 107 children with special needs and 28 mainstream nursery aged children. Gerard with 16 years of experience, both in the



mainstream primary school and special school has the direct responsibility for deafblind children of infant age (5-7 yr.), the IT department which looks at using the micro technology and various adaptations to allow access for children with learning and physical difficulties.

While in India, Gerard has visited the Helen Keller Institute for the deaf & deafblind and Home Based programme of NAB Education Department at Mumbai and is now busy with the staff of BPA.

### **National Expert Meeting**

Deafblindness, though a low-incidence disability area, requires a lot of attention from the planners, practitioners, and parents. With this in view, Sense International (India) announces a "National Expert Meeting on deafblindness" on 11<sup>th</sup> and 12<sup>th</sup> of September, 1998 in Mumbai.

This is for the first time that experts and committed practitioners from all over India and UK, the Instituut voor Doven in the Netherlands and the Hilton/Perkins International Program, USA will be participating in the meeting.

The aim of this meeting is to bring together experts/ professionals/ parents/ policy planners and organizations, who will be involved in the development of services for deafblind persons in India in the near future.

### **RICHARD SAYS..**

I am delighted to have been asked to contribute a few words to this first newsletter of Sense International India. Sense International was created in 1994 to support the development of services for deafblind people. In the first two years we consulted many people in India for advice on the most appropriate strategy.

The overwhelming advice, which we were very pleased to follow, was that everything in India should be implemented by Indian people on the advice and recommendations of India people. As a result Akhil Paul was appointed Development Manager in January 1997 and all subsequent actions have been a result of his work.

Akhil will be too modest to say anywhere else in this newsletter how well things have progressed. So I will take the opportunity of doing so! In 18 months a tremendous amount has been achieved - we have projects with the Blind People's Association, the Helen Keller Institute and the National Association of the Blind, with a number of other possibilities currently being considered; excellent relationships have been developed with many people and organisations who have expressed an interest in supporting deafblind people; and very importantly, the infrastructures of the operation in India are now in place with the opening of an office in Ahmedabad and the appointment of Binali Suhundani as Akhil's assistant.

Overall we could not be more pleased with the way that things have progressed to date. With the ongoing support of those of you who will be reading this newsletter we are extremely confident that services for deafblind people India will continue to increase throughout the country. Thank you for your support.

Richard Hawkes  
Head of Sense International, UK

**DEAR FRIENDS** I am very happy to present to you the first ever newsletter of Sense International India. For a long time we have wanted to start a newsletter, that would give an opportunity to the organisations working with persons who are deafblind to share their experiences, achievements and problems. We welcome your comments and look forward to your contributions for the next issue, which will be in November 1998.

This newsletter became a reality with arrival of Binali Suhundani, Assistant Manager of Sense International (India) as she willingly took up the challenge and produced this newsletter in record time.

With best wishes,

Akhil Paul

Development Manager

Sense International (India)

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# **Conference Pack**



## **National Expert Meeting On Deafblindness**

**11-12 September, 1998  
YMCA International House  
Mumbai**

**Working with deafblind throughout India**



## **Conference Pack Contents**

- ☛ Welcome sheet/ Workshop Information
- ☛ Programme
- ☛ About Sense International (India)
- ☛ Mission Statement
- ☛ Leaflet of Sense International (India)
- ☛ August Newsletter of Sense International (India)
- ☛ Expectations from the Meeting
- ☛ Biographies of Participants
- ☛ Summary of Papers to be presented



## **WELCOME SHEET**

### **DETAILS OF ARRANGEMENTS AND LOGISTICS**

Dear Friends,

Welcome to Sense International (India). For your convenience, we are putting down the details of the arrangements and logistics during the workshop.

The workshop will be held, on all days, at the YMCA Conference hall. Accommodation for all outside participants has been arranged at YMCA which is comfortable and excellently located.

Your breakfast will be ready at 7.30 a.m. Please be on time, if not the entire day's programme gets thrown out of gear. Lunch break generally will be between 1.00 and 2.00 p.m. Beverages (Tea & Coffee) will be available at the end of each session in the Dining Hall.

The visit to Helen Keller Institute for the Deaf & Deafblind and National Association for the Blind are on the 10<sup>th</sup>. The HKI vehicle will pick you up at 9.30 a.m. from YMCA to take you to Helen Keller Institute and at 12.30 p.m. transport will be available at the HKI to visit the NAB programme.

The Sense International (India) team will be staying in YMCA. You can get in touch with us in case you need anything.

The hotel location is convenient for those among you who are keen on morning and evening walks. The weather is pleasant at this time of the year.

For the rest, we wish you a productive, interesting and pleasant stay!

From,

Sense International (India) Team



**SENSE INTERNATIONAL INDIA PROGRAMME**  
**NATIONAL EXPERT MEETING ON DEAFBLINDNESS**

**Mumbai, 11th & 12th September 1998**

**PROGRAMME**

**FRIDAY 11th SEPTEMBER**

9.00	Inauguration
9.00 - 9.30	Introduction and welcome Richard Hawkes - Sense International
9.30 - 10.30	The Helen Keller Institute - history and development Beroz Vacha, Director
10.30 - 11.00	Tea / Coffee
11.00 - 12.00	Keynote introduction Dr. Tony Best - Royal National Institute for the Blind, Condoval Hall School, UK.
12.00 - 13.00	The deafblind population: policy and planning Malcolm Matthews - Director Policy and National Services, Sense UK
13.00 - 14.30	Lunch
14.30 - 15.30	Presentations from:  <ol style="list-style-type: none"><li>1. National Association for the Blind, Mumbai</li><li>2. Jai Vakil School, Sewri, Mumbai</li><li>3. Blind People's Association, Ahmedbad</li><li>4. Clarke School for the Deaf, Chennai</li><li>5. Spastic Society of Tamilnadu, Chennai.</li></ol>
15.30 - 16.30	Congenital deafblind children Ger van Rijn - Instituut voor Doven, Sint Michielsgestel, the Netherlands
16.30 - 17.00	Tea / Coffee
17.00 - 18.30	Workshops - what is deafblindness / deafblindness in India  Co-Chairs (Tony Best, Ger van Rijn, Marianne Riggio, Lieke de Louw, B. Punani, Beroz Vacha, D. Nagarajan, Dr. Menon)  Reporters (Richard Hawkes, Eileen Boothroyd, Malcolm Matthews, Sue Turner)
18.30 - 19.00	Report back



## **SATURDAY 12th SEPTEMBER**

- 9.00 - 9.30            Deafblind International  
Rodney Clark - Secretary, Deafblind International; Chief Executive, Sense
- 9.30 - 10.00        Sense International and the role of INGOs  
Richard Hawkes, Sense International
- 10.00 - 11.00       Acquired deafblindness  
Malcolm Matthews - Director Policy and National Services, Sense UK
- 11.00 - 11.30       Tea / Coffee
- 11.30 - 12.30       Parents and families - a personal experience  
Sue Turner - Sense Council and parent of two deafblind children
- 12.30 - 13.30       Partnerships and their importance in the deafblind field  
Eileen Boothroyd - Director of Education, Sense, Editor of DBI Review
- 13.30 - 14.30       Lunch
- 14.30 - 16.30       Workshops - "Parents and partnerships" or "INGOs and future strategies"  
  
Co-Chairs (Eileen Boothroyd / Sue Turner, Tony Best, Marianne Riggio, Richard Hawkes, Aloka Guha, Nandini Rawal, Mr. S. Datrange, Mr. B. Venkatesh)  
  
Reporters (Malcolm Matthews, Lieke de Leuw, Ger van Rijn, Kirk Horton)
- 16.30 - 17.00       Tea / Coffee
- 17.00 - 17.30       Report back
- 17.30 - 18.30       Conclusions  
Dr. Tony Best - Royal National Institute for the Blind, Condover Hall School
- 18.30 - 18.45       Closing remarks  
Beroz Vacha (Helen Keller Institute), Akhil Paul (Sense International India)



## ABOUT SENSE INTERNATIONAL (INDIA)

Sense International (India) is a registered trust which supports the establishment and development of more services for deafblind people in India. It aims to stimulate developments that will be sustainable in the long term by working with the local partner organisations who will ultimately assume full responsibility for the services for deafblind people. The role of Sense International (India) is to act as a catalyst to stimulate development by offering support and expertise to the partner organisations.

There are approximately 2,50,000 deafblind people in India. Till 1997, Helen Keller Institute in Mumbai was the only established service available for deafblind people in India. This situation led to constant requests from India to Sense UK. Sense is the largest voluntary organisation in the world providing services to people who are deafblind. In January 1997, Sense & Sense International UK stepped into India for developing services for deafblind people.

In the last year, Sense International (India) has been closely involved in the establishment of three new services. In Ahmedabad, the Blind People's Organisation is developing a comprehensive programme for deafblind people which involves a specialist unit and community based projects; In Mumbai, is assisting the Helen Keller Institute for Deaf and deafblind to develop vocational skills in deafblind adults in order to ensure their employment and independence and, the National Association for the Blind, Mumbai, has now extended its home based programme to cover deafblind children. In Chennai a new deafblind unit at the Clarke school for the deaf was recently inaugurated.

These projects can be initiation of academic unit for the deafblind, Community Based Projects, research and development, Family/ Parent training Programmes, Vocational training and Manpower development.

Sense International (India) raises funds in the UK to support the India programme but will also establish a fund raising operation in India. Sense International (India) will have time limited agreements with each partner and the partner will be able to make an increased input to the partnership each year. Sense International (India) will also work closely with each partner and develop its capacity to do this by offering support in areas such as fund raising, management and administration in addition to support in developing a quality deafblind service.



## **MISSION STATEMENT**

Sense International (India) is a registered trust which works for people who are deafblind. Deafblindness means severe impairment of both vision and hearing resulting in unique and special needs. We provide advice, support, information and services for individual people, their families, carers and involved professionals.

### **Our values**

Sense International (India) believes that everyone:

- ◆ has rights and responsibilities and is entitled to dignity and respect
- ◆ has the right to quality services to meet individual needs
- ◆ has the right to opportunities which will promote individual development
- ◆ has the right to information
- ◆ has the right to make choices
- ◆ should be able to contribute to the development of services directly or through a representative or a family member.

### **Our aims and objectives**

These are to:

- ◆ Work to develop new projects and new services in partnership with partner organisations
- ◆ Help to develop their capacity by offering support in areas such as management and administration to maintain the service for deafblind in the long run.
- ◆ To provide more sustainable services for deafblind and multiply disabled people in India
- ◆ To involve parents and families of deafblind people in developing services for deafblind
- ◆ Establish a fundraising operation in India to support its programmes.



## **EXPECTATIONS OF THE PARTICIPANTS FROM THE NATIONAL EXPERT MEETING**

1. A specific model for promoting education and training to deafblind people and training to specific teachers.
2. To know what's happening around the globe for the rehabilitation of deafblind people.
3. To know about issues, data and programmes concerned to deafblind people.
4. To learn about the present scenario of children with deafblindness.
5. To get familiarized with the ideas and technology of rehabilitation of blind and deafblind children, the new avenues of CBR for un reached.
6. An action plan with particular emphasis on the beneficiaries in the rural areas.
7. To know about the prevention programme for deafblind people.
8. To know about the service delivery model for deafblind people for different age groups.
9. To know about the employment opportunities for deafblind people.
10. To understand newer approaches to comprehensive rehabilitation of the persons with deafblindness.
11. To identify and locate sources of information and strategies for planning services for deafblind people on local, regional and national level.
12. A meaningful interaction with experts.
13. Preparation of groundwork and environment for future co operation in the field of deafblind services.
14. To know and understand this field better.
15. To get knowledge on recent trends and advancements in the field of services, training and research of deafblind people.
16. To learn about the work done by different organisations and formulate strategies for developing services for deafblind in India.
17. To listen to experts from all over the world and get a global picture about deafblindness which would enable us to apply and develop concepts in India.
18. Get the latest information on deafblindness, rehabilitation methods and new approaches.
19. To share and exchange views with experts and help the deafblind and multi handicapped children to become independent
20. To know the modalities for implementation of PWD act, making integration a reality, circular adaptations as a tool.
21. To know more about the teaching methodology for deafblind.



22. To gain more technical know how about applying of deafblind.
23. To know the syllabus of the teacher training for teachers of deafblind.
24. To get information regarding the list of reading materials, research reports etc. available in India and abroad.
25. To know about the causes of deafblindness.
26. To get information about setting up and running a deafblind unit – the mode of functioning, techniques, infrastructure for the unit of deafblind, training of staff and fund raising.
27. To know about the area where emphasis should be given by Rehabilitation Council of India.



## ***LIST OF PARTICIPANTS***

**NAME : MR. K.R. RAJENDRA**  
**ORGANISATION: ACTION AID**  
**DESIGNATION : PROGRAMME MANAGER (DISABILITY DIVISION)**

Mr. K. R. Rajendra, Programme Manager of the Disability division in Action Aid, has 19 years of experience of work for rehabilitation of persons with disability. He has served the Ramanan Maharshi Academy and has contributed a lot to the field of sports for the blind. Action Aid, India is an international development agency and a registered charity of UK working in 25 developing countries in the world. Community Based Rehabilitation is the thrust area of Action Aid India's work.

**ORGANISATION: BLIND PEOPLE'S ORGANISATION (FORMERLY KNOWN AS "BLIND MEN'S ASSOCIATION")**

The Blind People's Association is an NGO that works for the comprehensive rehabilitation of visually and hearing impaired peoples and people with learning and multiple disabilities. The Blind People's Association has 40 years experience in implementing programmes for people with single category disabilities and for the past seven years it has been working with multiply disabled people in an institutional programme as well as in community based settings.

**NAME : DR. BHUSHAN PUNANI**  
**DESIGNATION : EXECUTIVE DIRECTOR**

Dr. Bhushan Punani, Executive director of Blind People's Association is a professional in the field of visually impaired. He is a member of the Rehabilitation Council of India (RCI) committee, Member of General Council of National Institute for visually handicapped and member of Expert committee of various schemes of Government of India. He is also a rehabilitation consultant of Sight Savers International.

**NAME : MRS. NANDINI RAWAL**  
**DESIGNATION : PROJECT DIRECTOR, BLIND PEOPLE'S ASSOCIATION**  
**SECRETARY, INTERNATIONAL COUNCIL FOR EDUCATION OF PEOPLE WITH VISUAL IMPAIRMENT (ICEVI)**

Nandini Rawal has been involved in the field of development and empowerment of persons with disabilities for the past 18 years. Her interests lie in infusing professional inputs in the field of disability and her particular choice is in the conceptualization and initiation of contemporary and modern rehabilitation programmes.

**NAME : MRS. VIMAL THAWANI**  
**DESIGNATION : PROJECT CO- ORDINATOR, BLIND PEOPLE'S ASSOCIATION**  
**SECRETARY, SADBHAVANA RURAL DEVELOPMENT TRUST FOR THE BLIND AND DISABLED**

Vimal Thawani is a professional Social worker. Before joining Blind People's Organisation, she worked as a Lecturer in M.S. University, Baroda as a faculty of Social work. She is interested in working directly with children and persons with disabilities, assessment and individualized planning for such persons. In addition to the above, she is also a trained counselor for which she works with persons from all categories of disability. Vimal has also participated in the Professional Development Programme (PDP) of Sense International, UK.



**NAME : DR. LEELAVATHY PATRICK**  
**ORGANISATION: CLARKE SCHOOL FOR THE DEAF AND MENTALLY RETARDED**  
**DESIGNATION : DIRECTOR**

Dr. Patrick has many years of experience in the field of disability. She was conferred Doctorate Honors Cause by Smith College, Massachusetts, USA for outstanding work in the field of Special Education and for starting and sustaining a school of the statute; the Clarke school for the deaf and mentally retarded in Chennai since 1970.

The Clarke school offers a school for hearing impaired, mentally retarded, multiply handicapped and a unit for deafblind. In addition to the above, it offers teacher training for teachers of the deaf, mentally retarded, Psycho diagnostic services, parents counseling and Vocational training.

**NAME : MRS. J. VIJAYALAKSHMY**  
**ORGANISATION: SADHANA SCHOOL FOR DEAFBLIND (UNIT OF CLARKE SCHOOL)**  
**DESIGNATION : MEDICAL DOCTOR & SPECIAL EDUCATOR OF DEAFBLIND**

Mrs. Vijayalakshmy has been associated with the Clarke school sine 3 years. She is presently working with deafblind children. Sadhana School is the deafblind unit of the Clarke school. At present there are 14 children of whom two are totally blind and profoundly hearing-impaired. The school has distant education programmes, Home training programmes and training programme for the teachers. The school also conducts free diagnostic clinics twice a week that is open for public. In addition, the school organises camps for detection of handicaps.

**NAME : MR. A. B. KASOTE**  
**ORGANISATION: COMPREHENSIVE RURAL DEVELOPMENT PROJECT**  
**DESIGNATION : EXECUTIVE SECRETARY & DIRECTOR**

Before establishing the school for blind, Mr. A. B. Kasote, used to work in the mission organisation as social worker. The Comprehensive Rural Development Project offers a school and home for blind and deaf blind boys and girls. They arrange medical camps especially of eye and cancer. They have Community Based Rehabilitation programmes for blind and deafblind parents. They provide community wells, Contour building, land leveling etc. They also have scholarships and small amounts of stipends to children whose parents are blind.

**NAME : MS. KAMAKSHAMMA MURTHY**  
**ORGANISATION: DIVINE LIGHT TRUST FOR THE BLIND**  
**DESIGNATION : TEACHER**

Ms. Kamakshamma is a teacher who has had a special training in Low vision and Hearing impairment. She has experience of 20 years as a teacher in the same organisation. She also has experience in Co ordinating teacher training programmes.

The Divine Light Trust for the Blind is involved in many activities. Some of them are preparing children who are blind, have low vision, or are hearing impaired for Integrated Education. They train children with multiple disabilities. They also impart training to teachers for integrated education. Apart from these they support NGOs in rural areas for the services to children with disabilities.

**ORGANISATION: HELEN KELLER INSTITUTE**

The Helen Keller Institute for deaf and deafblind is a school which helps educate and train deafblind and deaf children. The vision of the organisation is to create and develop services for deaf and



deafblind, deaf/multiple handicapped children and young adults through day care – residential facilities and other ancillary services.

The institute since its inception has helped educate and train 32 deafblind children and 130 deaf children, since its inception in July 1977.

**NAME : MR. SURESH AHUJA**

**DESIGNATION: PRESIDENT, ADD, VICE PRESIDENT, HELEN KELLER INSTITUTE.**

Mr. Suresh Ahuja is the Honorary President of ADD India and also Vice president of Helen Keller Institute for the Blind. He is the founder member of National Association for the Blind and has worked there as Executive Director for 25 years.

**NAME : MRS. BEROZ VACHA**

**DESIGNATION : DIRECTOR**

Mrs. Beroz Vacha, one of the founder members of Helen Keller Institute of Deaf and Deafblind, is currently the Director of the institute. Her career spans a little over 30 years beginning as a teacher, to a principal and then a Director. She is on the board of the Central Government, Ministry of Welfare and Human Resources Development for work for the Deafblind and Multiply Handicapped.

In 1983 she became the first editor of the International Newsletter for the Deafblind under the U.N.E.S.C.O. projects. From 1987 to 1995 she was a member of the Executive Board of I.E.A.D.B. She is also functioning as the educational consultant to SENSE INTERNATIONAL. Mrs. Vacha has received several national & international awards, the important ones being the following :-

1. "The Ann Sullivan Medal " in August, 1991 at Sweden.
2. The National Presidential Award on December 3rd 1997.

**NAME : MRS. REENA BHANDARI**

**DESIGNATION : PRINCIPAL, DEAFBLIND UNIT**

Mrs. Reena Bhandari has 20 years of experience in educating deaf and deafblind students. The last five years have been in the deafblind section first as a coordinator and currently as principal. Ms Bhandari holds a diploma in teaching the deaf from Bombay University and has subsequently secured a diploma in teaching the Visually Handicapped children with additional disabilities from Perkins school for the blind U.S.A.

**NAME : MRS. SHEELA SINHA**

**DESIGNATION : COORDINATOR, DEAFBLIND UNIT**

Mrs. Sheela Sinha has been in the field of deafblind education for the last ten years. She is a postgraduate in Psychology and was working as a lecturer prior to entering this field. She is currently working as a coordinator of deafblind section of the institute and apart from teaching has also been involved in the training of teachers from various organisations.

She has been to Helen Keller national Centre, Long Island, New York, for a short term International Training Programme and was a participant of the first International Professional Development Programme conducted by Sense International in 1994.



**NAME : MRS. SHUBHANGI BANDEKAR**  
**DESIGNATION : PRINCIPAL, DEAF SECTION**

Mrs. Shubhangi Bandekar is the principal of the deaf section of the institute. She has 15 years of experience as Special Teacher of deaf. She has a diploma in deaf education from Pune. She has attended seminars in Ahmedabad and Goa on education/vocational training of multiply handicapped.

**NAME: :PROF. S. PRABHAKAR**  
**ORGANISATION : HOLY CROSS SERVICE SOCIETY, TRICHY**  
**DESIGNATION : EXECUTIVE DIRECTOR**

Prof. S. Prabhakar was the Professor and head of the Rehabilitation Science department in Holy Cross College, Trichy. He took a voluntary retirement to assist the disabled through direct services by providing training programmes and offering consultancy services.

Now he is Director of Holy Cross Service Society, Trichy, which offers education, Prevention and Rehabilitation services to all categories of disabled. Presently, the society is assisting nearly 2700 disabled people. The other activities include Consultancy services, Research studies, training programmes and personnel development.

**NAME: MRS. RANU BANERJEE**  
**ORGANISATION: INDIAN INSTITUTE OF CEREBAL PALSY**  
**DESIGNATION: PRINCIPAL**

Mrs. Ranu Banerjee is the principal of the centre for special education. She has a MS from Purdue University (USA) and her area of specialisation is the mangement and education of children and adults who have severe to profound multiple imparments.

**NAME : MR. L. SHANMUGUM**  
**ORGANISATION: INTEGRATED EDUCATION IMPLEMENTATION COMMITTEE,**  
**MADURAI**  
**DESIGNATION : SECRETARY**

Mr. L. Shanmugum has 15 years of experience in teaching the blind. He is the Secretary and Promoter of the organisation that offers Integrated Education for the disabled, hostel facilities to the visually impaired, vocational training to the blind, identification of disabled in rural areas and education to the blind with other disabilities.

**NAME : MRS. HEMA UDESHI**  
**ORGANISATION: IMPACT INDIA FOUNDATION, MUMBAI**  
**DESIGNATION : NATIONAL CO-ORDINATOR**

Impact India provides free surgical intervention to restore sight, mobility and hearing to the patients in the rural areas of India through the "Lifeline Express" – the world's first mobile hospital on wheels. The foundation supports the Malaria Control programme in Mumbai. It is involved in the National Pulse Polio Immunisation Programme to eradicate polio. Impact India organises multi specialty surgical camps in different states.

As a National Coordinator, Hema Udeshi works closely with the Ministry of Health, Ministry of Railways, UN and interacts with several NGOs and government bodies.



**NAME : MRS. BHARATI VIKAS PALKAR**  
**ORGANISATION: JAI VAKIL SCHOOL FOR EDUCATION, MUMBAI**  
**DESIGNATION : PRINCIPAL**

Mrs. Bharati Vikas Palkar, Principal of the school has experience in teaching, training and rehabilitating Mentally Retarded children with handicapped as well as multiply handicapped children. She has been working for this school since 1993. She is a member of A.W.M.H., Makaton India and is a life member of the Psychology Association of Bombay.

The Jai Vakil School for Education has two branches in Bombay and the other rural branch in Pune. It runs a vocational training center, residential section, research center, teacher training course center and a MIND college of special education.

**NAME : MRS. KUSUM MEHTA**  
**ORGANISATION: SHRI K.L. INSTITUTE FOR THE DEAF, BHAVNAGAR**  
**DESIGNATION : PRINCIPAL**

Mrs. Kusum Mehta, Principal of the school for the deaf has 21 years of experience in the field of deaf. The school offers programmes like rehabilitation for the deaf, training college, mothers training program. The sister concerns of her institute include the blind school, the school for the Mentally Retarded, unit for Cerebral Palsy, Polio Operations and equipments and a physiotherapy center. Her main interest is in language and speech development of the hearing handicapped and rehabilitating them in normal society.

**NAME : FR. GEORGE KUNNATH**  
**ORGANISATION: KUTCH VIKAS TRUST, BHUJ**  
**DESIGNATION : MANAGING TRUSTEE**

Fr. George Kunnath is the Managing Trustee of Kutch Vikas Trust that works for the rehabilitation of the blind and handicapped, integrated education for the Blind, Prevention & Cure of blindness, Organises Eye camps , provides free medical aid, conducts eye operations. Kutch Vikas Trust is seriously considering to setup a unit for deafblind in their campus.

Fr. George has been serving the poor, needy people in Kutch district of Gujarat, He has started schools, hostels for blind and handicapped children and eye and general hospitals.

**NAME : MRS. M. SHARMILA**  
**ORGANISATION: L.V. PRASAD EYE INSTITUTE, HYDERABAD**  
**DESIGNATION : CONSULTANT FOR VISION REHABILITATION SERVICES**

L. V. Prasad Eye Institute is a non profit charitable organisation committed to provide eye care of the highest quality to all segments of population irrespective of their economic status. 50% of the service are reserved to the economically under privileged at no cost. The activities comprise of medical care, eye banking, research, training for eye care, low vision and rehabilitation services.

Apart from being a consultant, M. Sharmila is a member of Rehabilitation wing of the Holy cross college , Tamil nadu and Task force representative of a District in Andhra Pradesh for "Implementation of PWD Act". She also conducts training programmes for parents , teachers(primary level),and Community Based Rehabilitation for Coordinators and Workers.



**NAME : MR. CHAPAL KHASNABIS**  
**ORGANISATION: MOBILITY INDIA, BANGALORE**  
**DESIGNATION : EXECUTIVE DIRECTOR**

MR. Chapal Khasnabis has 20 years of experience in the field of disability. He is also a member of International Society for Prosthetic & Orthotics (ISPO) and Orthotic & Prosthetics Society of India (OPSI).

Mobility India, established in Bangalore in 1994, is an Action Aid India partner and provides support to NGOs in India working for disability rehabilitation. The main activities and programmes of Mobility India include awareness for the need of Mobility and rehabilitation aid and to create these facilities in rural areas. It also promotes appropriate technology with focus on Community based Rehabilitation and simple therapeutic techniques to prevent/ correct deformities and avoid surgery wherever possible.

**NAME : BR. MICHAEL MATHEW KALAPURACKAL**  
**ORGANISATION: MONTFORD CENTRE FOR EDUCATION, TURA**  
**DESIGNATION : VICE - PRINCIPAL**

Br. Michael has been a teacher of deaf and blind. He is member of the society of the Montford brothers of St. Gabriel who run institutions for deaf and blind in 27 countries.

The Montford Centre for Education offers regular and vocational education for blind and deaf. There are trainings for teachers of deaf, integrated education of the disabled and are looking forward for setting up deafblind unit in the school. The Montford Center is the only institution of its kind in North - East India.

**NAME : MRS. SUDHA BALACHANDRA**  
**ORGANISATION: NASEOH, MUMBAI**  
**DESIGNATION : EXECUTIVE SECRETARY AND DIRECTOR GENERAL**

Mrs. Sudha Balachandra has been working in the field of disability since 1975 as a professional and Administrator. She has been a part of various committees promoting rehabilitation of disabled in Maharashtra.

The National Society for Equal Opportunities for Handicapped (NASEOH) conducts early intervention programmes for special children, Integration of deaf to normal schools, Vocational training of all categories of disabled, Placement service, provides Aids and Appliances, Organises rural Camps, adopted slum colonies for health awareness programmes, trains women volunteers, conducts research activities and Organises sports for the disabled.

**NAME : MR. RAJENDRA SINGH SETHI, MUMBAI**  
**DESIGNATION : MEMBER, STANDING COMMITTEE ON ACTIVITIES OF DEAFBLIND OF WORLD BLIND UNION**

Mr. Rajendra Singh Sethi is a person who is totally blind and severely hearing impaired. He is on the standing committee on the activities of deafblind people of the World Blind Union. He has presented various papers and is a consultant for the international newsletter published by deafblind committee.

**ORGANISATION: NATIONAL ASSOCIATION FOR THE BLIND**

National Association for the Blind, India established in 1952, is the largest voluntary organisation in India, working in the field of blind welfare on national level. It has multifarious activities - prevention, education, rehabilitation, training, employment, research, etc. the work is spread throughout the country through a network of State/ District branches of the Association and voluntary agencies engaged in rural development. The association is represented on important committees of Central State



government and has contributed greatly in framing policies and programmes for people with disabilities.

**NAME : MR. SUBHASH DATRANGE**  
**DESIGNATION : EXECUTIVE DIRECTOR**

Mr. Subhash Datrange, Executive Director of the National Association for the Blind has set up India's first research and development workshop for aids and appliances, first museum of the equipments for the Blind, developed India's first white cane for the blind.

He has raised considerable sums of money through fund raising programme and project assistance from national and international funding agencies. Mr. Datrange is also the member of Advisory Committee of Sense International (India).

**NAME : MR. RAJENDRA VYAS**  
**DESIGNATION : HON. SECRETARY GENERAL**

Padamshri. Rajendra T Vyas is the founder and honorary secretary general of the Asia office of the Royal Commonwealth Society for the Blind. He also is the founder of National Association for the Blind(India), President of the Blind graduate's forum, NAB talking book and Braille Press Project. The President of India – Neelem Sanjiv Reddy, awarded him the Padamashri in 1982.

**NAME : MR. M. K. CHOUDHARY**  
**DESIGNATION : DIRECTOR (EDUCATION)**

Mr. M K Choudhary has experience in the field of education of the Blind over 30 years. His special interests are in developing Integrated Education Programmes and family centered Home-Based programmes. He is a member of State & National Committees for Education of the disabled.

**NAME : MRS. MEENA NIKAM**  
**DESIGNATION : SPECIAL EDUCATOR**

Meena Nikam has experience in teaching the blind, deafblind and the multi disabled blind children-of over 15 years. Her special interests lie in developing home based programmes for blind children with additional disabilities, arranging and conducting training programmes for families of these children. To enhance her experience and make her interests a reality, She was deputed by Sense International (India) for the Professional Development Programme(PDP) in UK. for a period of six weeks.

**NAME : MRS. SUMITRA MISHRA**  
**ORGANISATION: NATIONAL ASSOCIATION FOR THE BLIND, DELHI**  
**DESIGNATION : CO- ORDINATOR, MULTI HANDICAPPED UNIT**

Sumitra Mishra, co-ordinator of the Multi handicapped unit of National Association for the Blind, New Delhi is a qualified rehabilitation consultant for people with learning disability. She works towards the psychosocial intervention for Multi handicapped people and children having multiple special needs.

The multi handicapped unit caters to children between three months to 20 years of age having a combination of multiple special needs. It looks after their developmental, therapeutic, social, educational, pre- vocational, behavioral and orientation and mobility needs. The unit also looks after parental guidance and counseling and family support needs.



**NAME : DR. NEERJA SHUKLA**  
**ORGANISATION: NATIONAL COUNCIL OF EDUCATIONAL RESEARCH AND TRAINING, NEW DELHI**  
**DESIGNATION : PROFESSOR AND HEAD OF DEPARTMENT OF GROUPS WITH SPECIAL NEEDS**

The National Council of Educational Research and Training (NCERT) conducts research, training, development and extension programmes in the area of school education including special education. Dr. Neerja Shukla has been providing leadership to a group of faculty members working in the area of special education. She has been a resource person for helping the Ministry of Human Resource Development in the area of special education.

**NAME : DR. D.K. MENON**  
**ORGANISATION: NATIONAL INSTITUTE FOR THE MENTALLY HANDICAPPED, HYDERABAD**  
**DESIGNATION : DIRECTOR**

The National Institute for the Mentally Handicapped is committed to develop models of care for the mentally handicapped persons, conduct research in the area of mental handicap, promote human resource development and work with mentally handicapped persons. The institute offers diplomas in Mental retardation, Vocational training and Employment. It also offers degree in Mental retardation , refresher and short term courses.

**NAME : DR. B. RAMESH AVADHANI**  
**ORGANISATION : NATIONAL INSTITUTE OF REHABILITATION TRAINING & RESEARCH(NIRTAR), CUTTACK**  
**DESIGNATION :DIRECTOR(NIRTAR) AND ACTING DIRECTOR OF NATIONAL INSTITUTE FOR THE MULTI DISABLED**

The National Institute of Rehabilitation training and Research has been serving the disabled from rural Orissa at Olatpur, 35 kms from Bhubaneshwar/ Cuttak, since 1975. The main objectives of the Institute are to undertake, sponsor or coordinate training programmes for the rehabilitation personnel for the orthopaedically handicapped, to conduct research on bio medical engineering, surgical or medical procedures for orthopaedically handicapped.

**NAME : DR. S.R.SHUKLA**  
**ORGANISATION:NATIONAL INSTITUTE FOR THE VISUALLY HANDICAPPED, DEHRADUN**  
**DESIGNATION :DIRECTOR (IN-CHARGE)**

The institute was established in 1979. The institute has a model school for the Visually handicapped which provides education to the blind, partially sighted and low vision children. The training center for the Adult Blind imparts vocational training to the adult blind men and women. The institute has a national library for the print/ visually handicapped.

**NAME : DR. M.N.G.MANI**  
**ORGANISATION: SHRI RAMAKRISHNA MISSION VIDHYALAYA COLLEGE OF EDUCATION, COIMBATORE**  
**DESIGNATION : PRINCIPAL & DIRECTOR & ASIA CHAIRMAN OF ICEVI**

Dr. Mani has done his Doctorate in education of children with multiple disabilities. He is the principal of Shri Ramakrishna Mission Vidhyalaya College of Education and also director of a resource centre which has large computerised braille production facilities.



**NAME : MR. J. P. SINGH**  
**ORGANISATION: REHABILITATION COUNCIL OF INDIA**  
**DESIGNATION :MEMBER SECRETARY**

Mr. J. P. Singh has been working in the area of disability since 23 years. He has designed , fabricated products for locomotor handicapped. The Rehabilitation Council of India regulates the training policies and programmes in the field of rehabilitation of people with disabilities. It grants recognition to the institutions running the training courses for professionals dealing with disabled persons. It also maintains a Central Rehabilitation Register of the Rehabilitation Professionals.

**NAME : MRS. ALOKA GUHA**  
**ORGANISATION : SPASTICS SOCIETY OF TAMILNADU, CHENNAI**  
**DESIGNATION : DIRECTOR**

The Spastics Society of Tamilnadu was founded in 1981. In its institutional based rehabilitation, it offers special education centres, vocational training centre, Human resource development centre, workshop, orthotics centre and a food processing unit. In its non Institutional based rehabilitation, it has mobile extension services in 15 blocks, 23 newborn screening clinics in hospitals, CBR programmes, State level network, Material development and short term courses for government and NGO personnel.

Mrs. Aloka Guha is a special educator by training, generalist by choice and administrator by force of circumstance. Her main interests are in early intervention, CBR and Inclusive education.

**NAME : DR. LINA KASHYAP**  
**ORGANISATION: TATA INSTITUTE OF SOCIAL SCIENCES**  
**DESIGNATION : PROFESSOR AND HEAD OF DEPARTMENT OF FAMILY AND  
CHILDCARE**

Dr. Lina Kashyap is a Professor and head of the Department in Tata Institute of Social Sciences which offers the Masters degree in social work, personnel management, industrial relations, health studies, administration and hospital studies administration,. The department of family and child welfare also offers a certificate course in Rehabilitation counseling.

Dr. Kashyap networks with organisations working with people with disability. She also is a member of National standing Committee of CAPART( Disability Division) and a member of general council of the Ali Yavar Jung national Institute for the Hearing impaired.

**NAME : MRS. SANDHYA LIMAYE**  
**DESIGNATION : LECTURER , TATA INSTITUTE OF SOCIAL SCIENCES**

Mrs. Sandhya Limaye, Lecturer in Family and Child Welfare Department has an experience as a social welfare officer in AYJNNH for 11 years. Her paper on facilitating integration of a deaf child in a regular school has been accepted by IIM rehabilitation Conference, Hongkong that was held in August, 1988. Mrs. Limaye herself is hard of hearing.

**NAME : MR. A.K.CHAUDHARY**  
**DESIGNATION : JOINT SECRETARY, MINISTRY OF WELFARE**

Mr. A. K. Chaudhary is the Joint Secretary in the Ministry of Welfare. He has always shown his interest in the field of disability. He did some commendable work, while he was Joint Secretary of the welfare wing.



**NAME : MR. B. VENKATESH**  
**DESIGNATION : CONSULTANT (DISABILITY & DEVELOPMENT), BANGALORE**

Mr. B. Venkatesh is a Consultant of Disability and Development. He has been involved in organising Disabled people in rural communities for social Action for the last 11 years. "Venky" as he is popularly known has been the Director of the ADD India.

**NAME : JESSICA HILLS**  
**DESIGNATION : CHAIRMAN, SENSE COUNCIL**

Jessica Hills has been involved with Sense for almost 40 years. She was a teacher of deaf children who started working with deafblind children during the rubella epidemic in the UK in the late 1950's. In 1963 Jessica became Secretary of what was very much a Parents' Group with no staff members. By the late 1970's Jessica had become Head Teacher of Braidwood School for Deaf Children in Birmingham and in 1981 she became Chairman of Sense Council. In 1998 Sense has almost 1,500 members of staff and Jessica remains Chairman of Council. She is also a Trustee of Sense International and has attended many seminars and conferences throughout the world.

**NAME : DR TONY BEST**  
**DESIGNATION : HEADTEACHER, RNIB CONDOVER HALL SCHOOL**

Tony Best is Headteacher of RNIB Condoval Hall School, an all-age residential school for children with visual impairments and additional difficulties. He has been involved with special education throughout his professional life, having trained and worked with hearing impaired children and visually impaired children.

Prior to this appointment, he worked at the University of Birmingham, where he was a tutor in education of visually impaired children and in multi-sensory impairment. In addition to writing a number of articles about visual impairment and deafblindness, he is the author of 3 books on the education of children with visual impairments. He has worked extensively overseas and during 1990-91 worked on secondment to the Hilton\Perkins International Program, based in the USA, developing staff training services in visual impairment and deafblindness in a number of developing countries.

**NAME : SUE TURNER**  
**DESIGNATION : MEMBER, SENSE COUNCIL**

Sue Turner is married with four sons, now all adult, two of whom have sensory impairments and learning disabilities. They both live locally in (separate) houses designed specifically for their needs.

Sue has been involved with Sense for about ten years. She is a member of Sense Council and is the Chairman of the Kent Family Branch. The Branch's main achievement so far has been negotiating successfully with Social Services to set up a home for five multiply disabled young people in Maidstone. Sue is also a Non-Executive Director of the local Priority Care NHS Trust.

**NAME : EILEEN BOOTHROYD**  
**DESIGNATION : EDUCATION OFFICER, SENSE**

Eileen Boothroyd is Sense's Education Officer working as part of the Policy and National Services Department. Her role involves representing Sense at national and local government level on issues related to the education of children and young people. She also supports the work of teachers and schools, and works with families to secure appropriate educational provision.

She is the Editor of DbI Review, the journal of the world organisation for deafblind people and has delivered papers at conferences and seminars in the UK and abroad.



**NAME : MALCOLM MATTHEWS**  
**DESIGNATION : INFORMATION OFFICER FOR DEAFBLIND INTERNATIONAL, SENSE**

Prior to his joining Sense in 1989, Malcolm Matthews had 16 years experience in the voluntary sector, including the post of regional manager for Scope (formerly The Spastics Society) in the South East. He has worked at Sense for nearly 9 years and during that time has been Director of Welfare and Information, Director of Services and most recently Director of Policy and National Services. He has responsibility for Sense's national services of Education, Acquired Deafblindness (including Usher syndrome), Voluntary Services (including holidays, advocacy and branches), Policy & Quality and Campaigning.

Malcolm has much experience of international work. He is the Information Officer for Deafblind International (DbI) and a former editor of the DbI Review. He is also the professional representative from the UK on the European Deafblind Network council.

**NAME : DR LIEKE DE LEUW**  
**DESIGNATION : HEAD OF INTERNATIONAL DEPT. OF INSTITUUT voor DOVEN**

Lieke de Leuw is the head of the International Department of the Instituut voor Doven (IvD), the national deaf institute in the Netherlands.

She is one of the most experienced professionals in the deafblind field in the world. She was principle of the deafblind department of IvD for 7 years and head of their early intervention department for 8 years. She has many years international experience, and has delivered speeches and presented papers at conferences and seminars throughout the world. For 2 years she was a special expert for functional rehabilitation from the European Union, and in addition she is the co-ordinator of the European Co-ordinating Unit for professionals working with deafblind children.

**NAME : GER VAN RIJN**  
**DESIGNATION : ASSISTANT DIRECTOR, INSITUUT voor DOVEN**

Ger van Rijn is the assistant director of the deafblind school at the Instituut voor Doven (IvD), the national deaf institute in the Netherlands. He has worked in the deafblind field for over 20 years and has much experience working with deafblind children and their parents. As assistant director, Ger has responsibility for the smooth running of the school which includes supporting the teachers and staff, and keeping up to date with changes in deafblind education.

He has experience of the international field, and has helped to develop training programmes for educators of European schools for deafblind children.

**NAME : RODNEY CLARK**  
**DESIGNATION : CHIEF EXECUTIVE OFFICER, SENSE**

Rodney is the Chief Executive Officer of Sense, the National Deafblind & Rubella Association (UK). He is also the Secretary of Deafblind International, the World Deafblind Organisation which now has members in 100 countries world wide. In 18 years he has taken Sense from a small NGO with 2 members of staff to one of the largest NGOs in the UK with more than 1,500 people working for it.

Rodney has vast experience of international work in the deafblind field and has worked with colleagues in every continent in the world. It was his decision to create Sense International in order to respond to the needs of developing services for deafblind all over the world.



**NAME : RICHARD HAWKES**  
**DESIGNATION : HEAD, SENSE INTERNATIONAL**

Richard is the Head of Sense International. For more than 10 years he has worked for a variety of International organisations, including many INGOs and the United Nations. He was appointed Head of Sense International when it was created in 1994 and since then has overseen the development of projects in India, Latin America, Eastern Europe and Africa. There are 8 people working for SI in various parts of the world and it has recently become an independent registered INGO.

Richard has also been securing funding from the British Government and European Union and other International bodies for supporting the International work.

**NAME : MARIANNE RIGGIO**  
**DESIGNATION : EDUCATIONAL CONSULTANT, HILTON PERKINS PROGRAMME**

Marianne Riggio has a Masters Degree in the Education of Deafblind/Multihandicapped children from Boston College. She is currently an Educational Consultant for the Hilton/Perkins Program. Her responsibilities include the providing technical assistance to programs serving infants and preschool children with visual and multiple disabilities and to programs serving children who are deafblind throughout the United States. Also, she collaborates in the coordination of services for children with visual and multiple disabilities and children who are deafblind throughout Asia and for programs serving deafblind children in East Africa.

**NAME : MR. KIRK HORTON**  
**DESIGNATION : REGIONAL REPRESENTATIVE, HILTON PERKINS INTERNATIONAL PROGRAMME, USA**

Mr. Kirk Horton is a well known name in the field of services for the rural blind. He worked for Helen Keller International and developed many community - based programmes for visually impaired in Malaysia, Indonesia and Philippines. Mr. Kirk Horton has to his credit the first ever training manual for field workers of community based rehabilitation programmes. He is a qualified mobility expert and he has used his experience quite extensively in this training manual. He has also written a book on education of Blind children in regular schools which has been published by UNESCO. Apart from the above expertise, Kirk is also expert in low vision and early intervention. At the moment, he is based in Thailand as the Regional representative of Hilton Perkins International Programme of Perkins School for the Blind, USA.



## **SUE TURNER: MEMBER OF SENSE COUNCIL**

Sue Turner will give a personal view of what it is like to have deafblind children. The talk will include the following:

### **Working with professionals:**

- This will include diagnosis, dealing with medical professionals - doctors, health visitors, nurses, dentists etc.
- The involvement of social services and their understanding and participation in solving problems.
- Dealing with schools and education professionals, teachers, specialist teachers, educational psychologists.

### **The family:**

- The disadvantages of having deafblind children in the family
- How they decided on their own family philosophy of dealing with all their children.
- The involvement of other family members and friends and how it has affected the family as a whole and individually.
- Looking at difficulties encountered on reaching adulthood and the ongoing involvement of the family, especially the difficulties of acting as an advocate versus acting as a parent.

### **Involvement of Sense:**

- How the family came to hear about Sense and the difference it has made to their lives.
- How the Sense Kent Family branch came about and the role of the branch including the involvement of parents in mutual support.
- How Sense encourages family involvement.



**EILEEN BOOTHROYD, EDUCATION OFFICER, SENSE**

**Partnerships**

- \*Characteristics of successful partnerships
- \*Why partnership approaches and co-operative working are relevant to the field of deafblindness and multi-sensory impairment
- \*Professionals sharing across disciplines
- \*Policy development and service delivery
- \*Examples of successful working practice some of the difficulties encountered

**RODNEY CLARK, CHIEF EXECUTIVE OFFICER, SENSE**

- History of International Co-operation
- Formation of DBI and developments
- Current situation - corporate membership, networks etc
- Activities: magazines, conferences, network activities - holidays, study tours, seminars, expert meetings, family activities, campaigning, bilateral outcomes etc
- The Future.



## African visits

*In March, Emanuela Brahamsha, Assistant International Officer, visited Ghana and Nigeria to assess the possibility of supporting deafblind developments in these countries. The visit was prompted by Sr. Justina Obiajunwa, the Principal of the Pacelli School for Blind and Partially-Sighted Children in Nigeria. Sr. Justina was one of the participants on our Professional Development Programme and as a result of her participation she has set up a unit for deafblind children within her school. On her return to Nigeria she visited the Deafblind Unit of the Demonstration School for the Deaf in Ghana to seek advice on setting up her own unit.*

*Sense International is looking to support the developments of both these services and to encourage the exchange of expertise between Ghana and Nigeria.*

### First Stop Ghana

The Deafblind Unit at the Demonstration School for the Deaf in Mampong-Akwapim in Eastern Ghana was set up in 1978 by Marion Obeng

with one student. To this day it continues to be the only service for deafblind children and young adults in the whole of West Africa.



Raising awareness about deafblindness in rural Ghana



The teachers at the Deafblind Unit in Ghana

The primary focus of the Deafblind Centre is of course the education of their 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 able to earn a living or contribute to the family. The Deafblind Unit also has an exciting outreach programme to raise awareness about deafblindness and of the needs and abilities of deafblind people.

#### Royal Visit

This visit, fortunately, coincided with a Royal Visit by Sense's Patron, HRH Princess Anne, to the Deafblind Unit.



This was the first time Princess Anne had visited a deafblind unit outside of the UK. 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 everyone at the Deafblind Unit felt honoured to receive such attention. In her turn the Princess said she would be keeping herself informed of the progress of the Unit.



## Nigerian Connection

The next leg of the visit was to the Pacelli School in Lagos, which is the second oldest blind school in Nigeria. It was established 36 years ago and offers primary education, rehabilitation and vocational training to congenitally and adventitiously blind and partially sighted children. It was set up and run by the Catholic Church for the majority of its existence. There was a period of a few years where the government took over the financing and overseeing of the School. However, it was recently handed back to the Catholic Church and is now autonomous of government control. It is a non fee-paying school and funding is dependent on the Church and donations from NGO's and local businesses.

There are currently 88 students at the Pacelli School (50 boys and 38 girls). 84 students are in the primary section. They are divided into reception class and primary classes 1 – 6 and follow the National Curriculum in addition to mobility and orientation

◀ *Making traditional 'red-red' during a life skills class in Mampong-Akwapim*



▲ *Simeon learning Braille in Nigeria*

and braille. Four students are in the rehabilitation section. This section was set up to rehabilitate students who recently become blind or partially sighted and need training to enable them to continue their education.

Students come from all over Nigeria. Given Pacelli's excellent reputation and achievement of past



▲ *Tolpe and his teacher in the deafblind unit at the Pacelli School*



# Romania

*Following the visit to Romania undertaken by Sense International in October 1997 a number of follow-up activities were recommended. We are pleased to report that funding has been secured to enable these activities to take place.*

From 26th May to 2nd June a team of six people will be going to Romania for a variety of meetings and projects. This is the first time ever that a group of specialists from the deafblind field have worked with Romanian experts from a variety of fields to concentrate on possibilities for developing services for deafblind people in Romania.

The activities include:

## National seminar on deafblindness

This is the first ever national seminar on deafblindness in Romania. The UK team will cover issues such as congenital deafblindness, acquired deafblindness, services for children, services for adults, communication and the international situation. It will provide the opportunity of bringing together all those in Romania who have expressed an interest in developing services with experienced professionals from the UK.

## Regional seminar – Iasi

The Director of the governmental "State Secretariat for the Handicapped" in the region of Iasi, in north-east Romania, has expressed a great interest in bringing together experts from blind schools, deaf schools and a variety of other specialist services to consider deafblindness. We have therefore organised a one day seminar for this region.

## Specialist staff training

The experts from Sense will visit three different centres to deliver two days of specialist staff training specifically designed to meet the needs of each centre. This will also enable a more detailed assessment of future needs to be made. The centres are a kindergarten for deaf children in Bucharest and schools for deaf children in Sibiu and Bucharest.

## Other meetings

In addition to the other activities there will be various specialist meetings. These include the Director of Special Education in the National Ministry of Education and the National Association of Blind People.

## UK team

The delegation from the UK is Rodney Clark (Chief Executive), Richard Hawkes (Sense International), Ciprian Gimbuta (Andlaw House), Eileen Boothroyd (Head of Education), Mary Foster (Training and Consultancy, Sense West) and Liz Duncan (Head of Acquired Deafblind Team).

# Croatia

Following the initial visit to Croatia undertaken by Richard Hawkes in November 1997 it was agreed to consider ways of supporting, where possible, the Croatian Association of Deafblind People.

From 28th June to 4th July Joff McGill and Graham Hicks will be participating in the first ever Summer Camp for deafblind people and their families in Croatia. Joff is providing advice and expertise relating to the organisation of such activities, activities that bring families together and other suggestions concerning respite; Graham will be demonstrating how independent a deafblind person can be, discussing the support that is necessary to enable this independence and talking to Croatian deafblind people about how deafblind people can organise themselves.





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Students come from all over Nigeria. Given Pacelli's excellent reputation and achievement of past



students, there is a long waiting list to get into the School.

### The Deafblind Unit

Sr. Justina has just set up a deafblind unit or special class within the primary section of the School. It has its own classroom with four students aged from 9 years old to 19. These are students who were not benefiting by being in the regular primary section and had never 'graduated' from the reception class. In addition to these students, there are two more children who are likely to join the unit.

People are aware that Sr. Justina is setting up a deafblind unit and she believes there will be no shortage of children wishing to attend the unit.

**This African visit was very significant for Sense International as it marked the beginning of a future collaboration between the three organisations. We are currently negotiating a training programme with the Units in Ghana and Nigeria to take place in November. Watch this space!**



▲ Tolpe and his teacher in the deafblind unit at the Pacelli School

# Akhil Paul opens second deafblind unit in India

*After only one year in office Akhil Paul has already helped double the number of deafblind units in India! On 14th February 1998 Akhil 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.*



Akhil officially opens the Sadhana Unit for Deafblind Children

The Clarke School was founded in 1970 for the children who are deaf and mentally retarded. It has programmes for deaf children, children with learning disabilities, teacher training programmes giving Diploma in Education of the Hearing Impaired and one year Diploma in Education of the mentally retarded. For many years they have had a strong relationship with Sense International's partners from the Netherlands, the National Deaf Institute in Sint Michiesgestel.

The deafblind unit, called

"Sadhana", was initiated with an intention of giving services to deafblind children in the city of Madras and neighbouring areas. At the moment Dr. Vijayalaxmi, who is a paediatrician and mother of a deaf child, is coordinating the unit with support from 3 Assistant Special Educators who are trained to deal with deaf children with additional disabilities. 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-mature birth.



## Other news from India

### Blind Men's Association (BMA)

Plans are now firmly in place for the BMA's substantial project aimed at developing centre-based and community-based services for deafblind people throughout the state of Gujarat. There will be a deafblind unit at the BMA campus in Ahmedabad which will be the centre of the overall project. A deafblind dimension will then be added to all the work of the BMA – Community Based Rehabilitation, Urban Rehabilitation, vocational training and specialist schools services.

As part of this project Sense International has arranged for Gerard Swan, Deputy Head Teacher at Kingsley Special School in Northants, to spend six weeks at the BMA this summer advising on the establishment of their deafblind service.

We have applied to the Department for International Development (DFID) for support for this project and are currently waiting to hear from them.

### Helen Keller Institute (HKI)

HKI have now finalised their plans for developing a vocational training project for their older deafblind students. We have applied to the National Lottery for support for this project and are currently waiting to hear from them.

We are also making arrangements for Caroline Dunn, a Senior Physiotherapist with 20 years experience working with multiply disabled children, to spend three weeks at HKI in September.

### Meena Nikam

Akhil has had a number of meetings with Meena Nikam (participant in the last Professional Development Programme) to put together a follow-up programme for her. This has now been finalised and will include training to be given by Sue Turner to families of deafblind children in Mumbai.

### National Expert Meeting

Taking up most of Akhil's time at the moment is the organisation of the first ever National Expert Meeting on Deafblindness in India. This meeting

will take place in September and will bring together about 50 experts from a variety of fields from throughout India to consider deafblindness and discuss ways for developing services in the future. A team of experts from the UK will be addressing this meeting and participating in other activities whilst in India; they are Rodney Clark, Richard Hawkes, Tony Best, Sue Turner, Eileen Boothroyd and Malcolm Matthews.

### New office

For one year Akhil has been working from his dining table! This is because Akhil did not want to spend valuable resources on an office until a clear strategy had been identified and an appropriate location for an office agreed. We have agreed that the time has come to set up our own office. This is in the centre of Ahmedabad and in addition to an office for Sense International (India) it will also have a guest room for visitors to stay in.

## Horizon project

### *New Opportunities in Working Life for Deafblind People*

#### Transnational Meeting, Sweden – April 1998

The first meeting of the transnational partners took place in Norrköping, Sweden, in April to coincide with a seminar the Swedes had organised on the theme of Employment for Deafblind People, specifically focusing on legislative issues. The seminar was addressed by a representative from the "Disability Ombudsman" – a government run department concerned with the rights of disabled people – who outlined plans to introduce new legislation for disabled people in Sweden. Amongst other things this will cover discrimination in the workplace and will give the Ombudsman the right to go to court against employers.

During the transnational meeting

the UK delegation were joined by our partners from Portugal, Italy and Sweden. Decisions and progress were made on all of the transnational areas of work and responsibilities for undertaking different areas of work were agreed. Possibly more importantly substantive discussions were had on subjects such as the whole concept of employment for deafblind people and how this group should go about promoting this concept in the coming years. It was agreed that future transnational meetings would benefit from more thematic discussions of this nature in addition to reviewing and planning the work programme.

The next meeting of the transnational group will be in Birmingham in September.

#### UK project

The project in Birmingham is about the establishment of new workshops, the recruitment and subsequent training of people with sensory impairments to act as support staff in these workshops and, the overall aim, the development of the skills and abilities of deafblind people to enable them to work in the workshops and, thereafter, in a more open employment environment.

Sensory impaired people to act as support staff for the deafblind people have been recruited and undertaken a detailed training programme. In July the Princess Royal will formally open the new workshops. There will be a major UK conference on the employment of deafblind people in Birmingham in September.



EUROPEAN SOCIAL FUND GB



# Romania

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## Welcome to Tamar Underhill

We are very pleased to welcome Tamar Underhill to Sense International. Tamar joins us as the International Projects Administrator. She comes to Sense International after 2 years as the Africa Grants Administrator at Comic Relief, helping to distribute money to UK registered charities working in Africa under 5 grants programmes: women, disabled people, people living in towns and cities, people affected by conflict and pastoralists. Before that she worked at Action on Disability and Development for 8 months as an Assistant Fundraiser. She also worked in Bangalore, southern India, as a volunteer teacher of drama in the Association of the Physically Disabled's integrated school for disabled and non-disabled children. Tamar will be working with Richard and Emanuela in the London office.

## Fundraising News

### Talks

**18 June** – Doug Scott and Friends will give a lecture on Nepal – Its mountains and People.

**3 November** – Bill Bryson and Friends will be talking about travelling and travel writing.

Both talks will take place at 6.30 pm at the Royal Geographical Society in London. Tickets cost £10 or £6 concessions. Tickets available from Stefan Meigh at Sense International – 0171 272 7774.

### Trek

We are pleased to say that so far we have 90 Trekkers and 3 companies involving an extra 30 Trekkers. We are predicting 130 participants in all who will be raising much needed funds for Sense International's work worldwide.

## Working with BOND

*Sense International is playing an active role in two Working Groups of BOND, the umbrella organisation for UK NGO's working in development.*

Emanuela Brahamsha has been helping to co-ordinate the Disability and Development Working Group which involves about fifteen organisations which either have a specific disability focus (such as Sense International) or are more general organisations with an interest in disability (such as Save the Children Fund). The last meeting of the network took place at Sense and was very well attended.

Richard Hawkes is on the Steering Group of the East European Working Group and was responsible for co-ordinating the most recent meeting which focused on funding opportunities for organisations working in Eastern Europe. About 35 organisations attended a meeting which was addressed by representatives from the Charity Know How Fund and the European Union's PHARE and TACIS programmes.

## Recent visitors to the UK

In recent months Sense International has hosted and arranged programmes for a large number of visitors from overseas. This has included people from India, Netherlands, Romania and USA. We are grateful to all those members of

Sense staff, and colleagues from other organisations, for the time that has been put into ensuring that all these colleagues have been made to feel welcome and excellent programmes have been facilitated for them.

**We hope you enjoy the new format of Sense International News. If you have any comments or queries, please contact Emanuela on 0171 281 4373.**

**SENSE INTERNATIONAL was created in 1994 to enable SENSE, the National Deafblind and Rubella Association in the United Kingdom, to respond appropriately to the many requests for support being received from overseas, particularly from developing countries. It is our aim to assist in the increase of services for deafblind people throughout the world.**

**Sense International, 11-13 Clifton Terrace, Finsbury Park, London N4 3SR, United Kingdom  
Tel: 0171 281 4373 or 0171 272 7774 • Fax: 0171 272 6012 • E-mail: si@sense.org.uk**

**A Company Limited by Guarantee Registered in England and Wales Company No: 1825301 Charity No: 289868**

**Patron: Her Royal Highness The Princess Royal**





## Major Developments in India

*Another new deafblind service*

*Support secured from DFID and the National Lottery*

*Assistant Development Manager appointed*

*Sense International (India) moves into new office*

Recent months have seen further major developments in our India programme, reflecting the tremendous work being undertaken by our Development Manager, Akhil Paul. At the start of the year there was only one specialist deafblind service in the country – now there are three, with a number of others being discussed and planned. The programme was also given a tremendous boost in June with the news that applications for funding to



*Vimal Thawani at the official opening of the new deafblind programme at Ahmedabad*



*Richard Hawkes inaugurates the BPA's new deafblind programme*

both the Department for International Development and the National Lottery had been successful.

On 15th June Richard Hawkes was privileged to be at the official inauguration of the new deafblind programme of the Blind People's Association (BPA) in Ahmedabad Gujarat. Over one hundred people were present and the event was reported on national television and in a number of national newspapers. This programme includes a specialist deafblind unit at the BPA campus and a substantial community based element reaching deafblind children in villages around Ahmedabad. Four specialists with a variety of backgrounds in disability have been recruited to work in the programme, which is under the overall

▶▶▶ continued ▶▶▶



## Major developments in India

continued from page 1

co-ordination of Vimal Thawani, a participant in our last Professional Development Programme. These staff are undergoing a detailed training programme which includes placements at the Helen Keller Institute for the Deaf and Deafblind in Mumbai and with the National Association of the Blind. We were absolutely delighted to hear that the Joint Funding Scheme of the British Government's Department for International Development have decided to support this programme for three years.

We were also thrilled to learn the news that the National Lottery Charities Board had agreed to support the vocational training project for young deafblind adults at the Helen Keller Institute in Mumbai. After receiving this news the Helen Keller Institute, with the support of Akhil Paul, Sense International (India) Development Manager, started the process of recruiting a manager and specialist staff for this project, the first of its kind in Asia.

## New Office and Staff

On 13th June 1998 Sense International (India) officially moved



Akhil Paul demonstrates fingerspelling to villagers in rural Gujarat

into a new office in the Memnagar district of Ahmedabad. More than seventy people attended the official inauguration of the office, demonstrating the tremendous support that exists to do something

for deafblind people. At the beginning of July we were delighted to welcome Binali Suhandani to the team as Assistant Development Manager. Binali worked for Women's World Banking where she was responsible for training and preparing organisation case studies. She is now Sense International's eighth member of staff.

## New Projects

A number of exciting activities and projects are being planned for the future. Most immediately a team from Sense will join experts from the USA, Netherlands and from throughout India at the first ever National Expert Meeting on Deafblindness in Mumbai on 11th and 12th September. During this visit the Sense experts will also visit a number of centres in different parts of India to discuss the establishment of deafblind services. This will include discussions with the National Association of the Blind about a national deafblind project which would aim to replicate the fantastic home-based work in Mumbai co-ordinated by Meena Nikam. With the kind support of the Nuffield Foundation, Meena has been implementing a programme to support children with visual impairments in their homes; she is now reaching more than thirty children.



Vimal Thawani, deafblind co-ordinator at the BPA, with a deafblind child in rural Gujarat

# Visit to Croatia

**Joff McGill, Sense's Voluntary Services Officer, reports on his visit to Croatia:**

Is International work glamorous – you bet your life it was!

"Would I like to go to Croatia and take part in a summer camp and international symposium for deafblind people and their families?", asked Sense International.

There was a time on my journey out when the answer was quite clearly "No", but having made a whistle stop tour of three International airports all in one day, I did make it to Split. From there I went to Baska Voda, a further 50 km south, where the summer camp was to take place. I never really looked back from there.

The event was organised by DODIR, a young association of deafblind people. Deafblind people are involved throughout the organisation and a number of key professionals (teachers, professors and psychologists) are interested in developing services for deafblind people. For the summer camp, DODIR brought together deafblind people, their families, interested professionals, volunteers and international practitioners. The aim was to increase knowledge and awareness of deafblindness, to share information and experiences and to have an enjoyable week!

A typical day involved lectures and seminars, perhaps some meetings discussing various issues related to deafblindness, a swim in the sea and plenty of social time.

Sense International was represented at the camp by Graham Hicks, Sense's Development Manager and Consultant on Services for Deafblind People, Siobhan Richardson and Carol Byrne (two interpreters), Jacinta Yeaman from Sense Scotland's Family Resource Centre and myself. Our role was to work in partnership with DODIR, to share ideas about bringing families and deafblind people together and to identify potential for future collaboration.

There were some amazing people involved with the summer camp with a huge range of skills. The conference was being interpreted into English, sign language, relay interpretation, hand over hand sign and at least two forms of deafblind manual – quite a sight! Remember this is a young organisation, with no paid staff and already they are organising major conferences, influencing government and supporting deafblind people in many ways.

Everyone enjoyed the week. For some it was what they could learn at the lectures and the mutual support and friendship available. For others it was the new opportunities the week provided. As one deafblind man said "I have never been to the sea before – this week has been great".

As a young organisation DODIR has many ideas about how to develop. Because of this we faced a barrage of questions. Not only did we not have all the answers, but in many ways it was not appropriate for us to answer them. Instead they needed ideas on which where the most important questions and the confidence that they do have the skills and the right people involved to find their own answers.

After a week, I found that I learned many things myself:

- In terms of my own development the trip was a great opportunity to meet so many people and I learned from their experiences.
- There are many ways that Sense can continue to support organisations like DODIR as they seek to build and sustain themselves and develop services for deafblind people.
- Sense International's work is very much valued by its partners abroad.
- Watching Croatia reach the semi-finals of the world cup while I was there was great – but couldn't quite make up for the disappointment of that Argentina game!

# New Deaf



Richard Hawkes with inaugural members of Romania's new deafblind association

On 1st June 1998 Liz Duncan, Joint Head of Sense's Acquired Deafblindness Team, participated in the very first meeting of a new deafblind association in Romania. During deafblind awareness training at the Eminescu Kindergarten for Deaf Children in Bucharest Liz identified a significant number of deafblind children. At a meeting with the parents of these children Liz discussed the vital role that parents play in the UK and how Sense itself was founded by parents more than forty years ago. The next day these parents told Liz that they had met late into the previous evening and decided that they wanted to create a new association for Romania. Three days later more than fifty people (parents and professionals) had signed up as members and a draft constitution was being prepared. This group of people are as determined to do something for their children as Sense's founders were forty years ago – and Sense International will do everything possible to support their development and activities.

## National Seminar and Training Activities

The training at Eminescu followed the first ever National Seminar on Deafblindness in Romania. Organised by Professor Vasile Preda, Head of the Department for Special Education at the University of Cluj in Transylvania,





in rural Gujarat

blind people. At the beginning of July we were delighted to meet Binali Suhandani to the Assistant Development Officer. Binali worked for Women's Development where she was responsible for training and preparing case studies. She is now Sense International's eighth member.

## Projects

A range of exciting activities and projects are being planned for the future. Most immediately a team from Sense will join experts from the USA, India and from throughout the world for the first ever National Expert Group on Deafblindness in Mumbai on 11th and 12th September. During the visit the Sense experts will also visit a number of centres in different parts of India to discuss the development of deafblind services. The visit will include discussions with the Association of the Blind, the national deafblind project which aims to replicate the home-based work in Mumbai initiated by Meena Nikam. With the support of the Nuffield Foundation, Meena has been running a programme to train children with visual impairments in their homes; she is now training more than thirty children.

# Visit to Croatia

*Joff McGill, Sense's Voluntary Services Officer, reports on his visit to Croatia:*

Is International work glamorous – you bet your life it was!

"Would I like to go to Croatia and take part in a summer camp and international symposium for deafblind people and their families?", asked Sense International.

There was a time on my journey out when the answer was quite clearly "No", but having made a whistle stop tour of three International airports all in one day, I did make it to Split. From there I went to Baska Voda, a further 50 km south, where the summer camp was to take place. I never really looked back from there.

The event was organised by DODIR, a young association of deafblind people. Deafblind people are involved throughout the organisation and a number of key professionals (teachers, professors and psychologists) are interested in developing services for deafblind people. For the summer camp, DODIR brought together deafblind people, their families, interested professionals, volunteers and international practitioners. The aim was to increase knowledge and awareness of deafblindness, to share information and experiences and to have an enjoyable week!

A typical day involved lectures and seminars, perhaps some meetings discussing various issues related to deafblindness, a swim in the sea and plenty of social time.

Sense International was represented at the camp by Graham Hicks, Sense's Development Manager and Consultant on Services for Deafblind People, Siobhan Richardson and Carol Byrne (two interpreters), Jacinta Yeaman from Sense Scotland's Family Resource Centre and myself. Our role was to work in partnership with DODIR, to share ideas about bringing families and deafblind people together and to identify potential for future collaboration.

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# New Deafblind Association in Romania



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## National Seminar and Training Activities

The training at Eminescu followed the first ever National Seminar on Deafblindness in Romania. Organised by Professor Vasile Preda, Head of the Department for Special Education at the University of Cluj in Transylvania,

the Seminar brought together approximately fifty people from throughout Romania. This included professionals from the deaf and blind fields, associations of deaf and blind people, governmental representatives and deafblind people themselves. Sense staff Eileen Boothroyd, Mary Foster, Liz Duncan and Ciprian Gimbuta all gave detailed presentations on different aspects of deafblindness and the seminar was brought to an excellent conclusion by Rodney Clark.

Following the seminar the Sense group split up and contributed to a number of other activities in different parts of the country. In Iasi, in north-east Romania, the Director of the governmental "State Secretariat for the Handicapped" organised a one day seminar for experts from that region. More than thirty people participated and were very keen to consider future developments, all of which Sense International will be prepared to consider and, when appropriate, support.

## Awareness Raising

In addition to the training at the Eminescu Kindergarten there were other deafblind awareness events organised at schools for deaf children in Sibiu and Bucharest. In Sibiu more than twenty members of the teaching staff participated in a two day event



Vasile Adamescu, a deafblind man, with Professors Mare and Preda at the opening of the National Deafblind Seminar

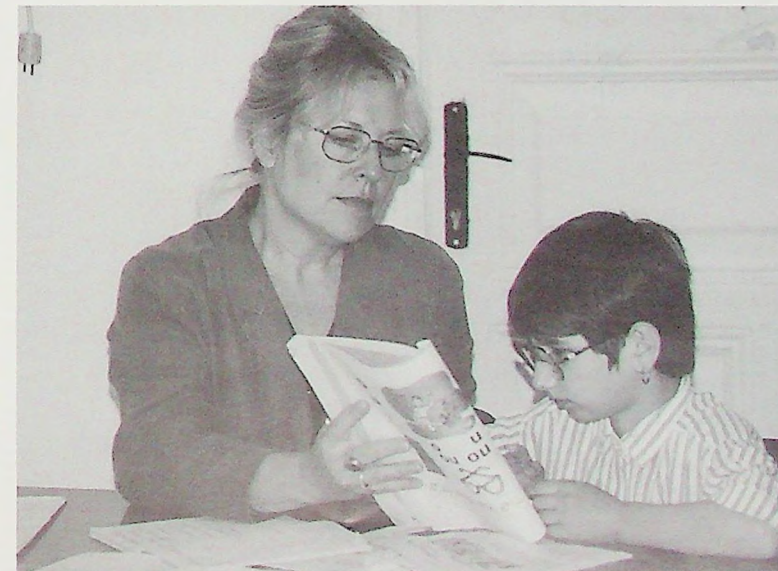


Participants in Romania's first ever National Deafblind Seminar

led by Eileen Boothroyd and Mary Foster. In Bucharest Liz Duncan followed the success at Eminescu with further training at a specialist deaf school and urged the parents there to link up with the new association. The visit also saw a very successful full day of presentations to the staff and students of the Special Education Department of the University of Cluj and meetings with representatives of various associations and organisations, including the Director of Special Education in the National Ministry of Education.

Overall this was a tremendously successful visit. The aim was to

respond to requests for more information about deafblindness and to identify individuals and organisations keen to work in this field in the future. That this led to the creation of a new deafblind association is extremely pleasing. Even more so is the level of enthusiasm that has been generated and the genuine desire on the part of so many people to start providing services for deafblind people. Sense International is committed to supporting these developments and will hopefully be working closely with friends and colleagues in Romania for many years to come.



Mary Foster with a deafblind child at Sibiu School for the Deaf



## HORIZON project goes from strength to strength



Things continue to progress well with the HORIZON funded project, New Opportunities in Working Life for Deafblind People. HRH The Princess Royal officially opened the UK project's workshop in Birmingham on July 16th. The workshop will develop the skills and abilities of deafblind people supported by a team of trainers, themselves with sensory impairments.

As part of the HORIZON Project, Sense West will be organising and hosting the following conference:

### European Conference

A two day conference is being held in Birmingham on 23 and 24 September 1998 on making the meaningful employment of disabled people a reality in the workplace. The conference will cover many aspects of UK and European policy, support and initiatives to create employment opportunities for disabled people, especially those with sensory impairments. Topics covered will include:

- EC and the UK Government initiatives to help disabled people into meaningful employment.

- Support available to employers to facilitate the employment of disabled people.
- Disability Discrimination Act.
- Job coaching, mentoring and training for disabled people.
- Current initiatives in creating employment opportunities for disabled people.

Speakers will include Richard Howitt MEP who will give an MEP's view of employing disabled people and Michael Barrett of the UK Forum on Disability for Europe who will discuss European legislation on disabled people in the workplace.

The conference will be especially useful to employers (particularly Human Resource managers), employers organisations and trade unions, organisations involved in supported employment for people with disabilities, Employment Service (PACT teams), local authority staff and disability organisations.

**For further information about the conference, please contact Jane Harding at Sense West on 0121 - 687 1564. For further details of the HORIZON project contact Tamar Underhill at Sense International.**

## New work in Bulgaria

We have recently received funding for an exciting chance to work with various deafblind organisations in Bulgaria. Last year Richard Hawkes and Ges Roulstone from Sense East visited Bulgaria to participate and speak at a meeting of disability organisations. During this time they met with different deafblind contacts and held discussions about working together in the future.

Charity Know How have agreed to fund two professionals from Sense East to visit Bulgaria for a period of 10 days. This will allow them to work closely with the Rehabilitation Centre for Blind Adults in Plovdiv to assess their needs regarding work with deafblind adults. They will also meet representatives from the Association of Deafblind People to discuss their aims and needs and identify possible ways of supporting them in the future. The trainers will also meet with the Faculty of Primary and Pre-School Education to discuss ways of assisting their special education teachers' course develop a module of practical work with deafblind adults. Watch this space for a report of the visit!

## Sense-India Conference

Plans are underway for a Sense conference aimed at raising funds for the work of Sense and Sense International. The two day conference, due to take place in February '99 in London, is based on 'Project Finance and Investment in India', and is targeted at corporates from both the UK and overseas who have business interests in this area.

A number of high profile figures will be invited to speak including foreign ministers and financiers, as well as experts from the fields of banking, law and economics. Through the sale of delegate tickets and sponsorship, Sense hopes to raise a significant sum to further the work with deafblind people in India and the UK.

**Any comments or sponsorship queries to Jill Houston at Sense on 0171 272 7774.**

**If you would like to comment on our Newsletter or make a contribution, please contact Emanuela on 0171 281 4373. The deadline for receiving copy is 1st December.**

## 1999 Dbl World Conference Lisbon

From 20 - 25 July 1999, Casa Pia de Lisboa will host the 12th World Conference of Deafblind International, the world-wide network promoting services for deafblind people. The conference will bring together professionals, deafblind people and families to discuss issues around the theme: "Developing through relationships: celebrating achievement." Sub-themes will include

- Relationships between congenitally deafblind children and young deafblind adults and sighted hearing people,
- Relationships between deafblind people,
- Relationships between families and professionals, and

■ Relationships across borders. The deadline for registration is 30th April 1999 and the deadline for submitting papers is 30 September 1998.

For further information, please contact Tamar Underhill at Sense International. Alternatively you can contact the organisers direct on:

XII World Conference of Dbl, Planning Committee, Casa Pia de Lisboa/CAACF, Av. do Restelo 1, 1400 Lisbon Portugal.

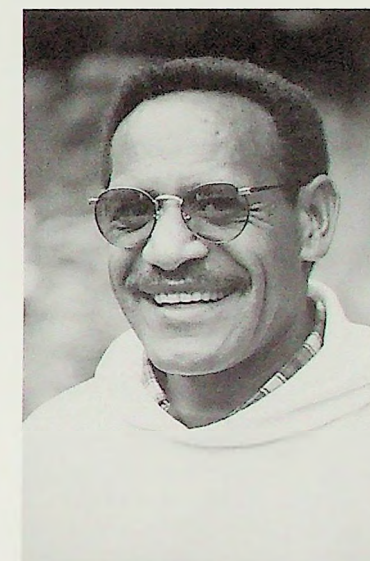
Tel. +351 - 1 - 362 7135.

Fax. +351 - 1 - 363 3448.

Email: cpl.educa@mail.telepac.pt

## News from Papua New Guinea

Many of you who have been reading Sense International News may recall that last year we had a participant from Papua New Guinea on our Professional Development Programme. We have received many concerned requests over Don Waipé's welfare following the devastating tidal wave that hit Papua New Guinea recently. I am pleased to say that Don and his family are well. He says: "I am very well. The tidal wave that you have heard about was in the coastal part of the country. I live and work far away from there. Thank you for all your well wishes."



Don Waipé

**SENSE INTERNATIONAL was created in 1994 to enable SENSE, the National Deafblind and Rubella Association in the United Kingdom, to respond appropriately to the many requests for support being received from overseas, particularly from developing countries. It is our aim to assist in the increase of services for deafblind people throughout the world.**

**Sense International, 11-13 Clifton Terrace, Finsbury Park, London N4 3SR, United Kingdom  
Tel: +44 - (0)171 281 4373 or +44 - (0)171 272 7774 • Fax: +44 - (0)171 272 6012 • E-mail: si@sense.org.uk**

**A Company Limited by Guarantee Registered in England and Wales Company No: 1825301 Charity No: 289868**

**Patron: Her Royal Highness The Princess Royal**

Design and print: Intertype

## Borneo Cycle Challenge

Following on from the Himalayan Challenge '98 we have organised a new challenge that is unrivalled for its excitement and adventure. A cycle ride across the island of Borneo. Borneo is the third largest island in the world, has the highest mountain in south-east Asia, tropical rain-forests with varied inhabitants of orangutan, the rare proboscis monkey, orchids and Rafflesia, the largest flower, and the famous head-hunters of Sabah. All this and much, much more.

The cycle ride takes ten days out of Britain and covers a distance of 250 miles. Through February and March 1999, 200 cyclists will be crossing Borneo from coast to coast, starting in the capitol Kota

Kinabalu and ending in exotic Sandakan relaxing on the beaches of the South China Seas. There will also be the opportunity to climb Mt. Kinabalu, 13,455ft, dive amongst some of the most beautiful coral reefs, white water raft the great rivers of Sabah and see orangutan, the wild man of Borneo, in its only remaining habitat.

All this will cost a personal contribution of £215 and a pledge to raise a further £2,000 for Sense International. We had an overwhelming response of 130 Sense people involved in Himalayan trek. Funds raised from the cycle challenge will go to the much needed work of Sense overseas and in the UK.



**For further information contact Stefan Meigh on 0171 - 272 7774.**





# The Helen Keller Institute for Deaf & DeafBlind, Bombay - India

Founded in July 1977

## *Your support is our Strength*

"Human needs exist from conception to death. However just as each individual differs from all others so do one's needs vary from infancy to old age – to a sensitive observer the presence within the community of many such children having different needs is a reality that cannot be ignored."



Blessed with SIGHT and HEARING, we the fortunate ones, rarely pause to picture the world of the DEAF & DEAFBLIND.

To experience – SHUT your EYES and PLUG your EARS.

Now TRY and imagine what it is to live like this in a Soundless, Sightless world.

NEVER truly hearing the sound of laughter –

NEVER truly able to express thoughts and feelings through the clear spoken word –

NEVER seeing the face of a loved one or nature's beautiful storehouse of sounds and sights.

Such is the world of Deaf & DeafBlind..



**Our Philosophy of  
Total Communication.**

This revolutionary approach has stood us the test of time. We believe that ...

"In an atmosphere that encourages free & honest self expression & full participation by one and all persons involved - children will through interaction experimentation, trial & error not only develop but will thrive & grow confident."

Dr. David Denton  
(U.S.A.)

Thus the Philosophy of Total Communication which encourages all forms of communications....

Oral & Aural, Manual, Print, Mime & Dance helps to quickly develop cognitive levels (thinking & reasoning) thus enabling free modes of self expressions....

Our high functioning DeafBlind children are able to communicate with intelligent Deaf as well as the hearing sighted people from different walks of life.

Total communication is a communication Philosophy & not a teaching method as very often confused by the advocates of a single system.

It was with this very idea to serve the severest handicap groups of Deaf Children with / without an additional disability and the DeafBlind multiply handicapped child for whom no services existed in the past that The Institute - The Helen Keller Institute for Deaf and DeafBlind was established in 1977 by a few visionary teachers supported by the Executive Committee. Our faith and belief that: "NO ONE IS INCAPABLE OF BEING TAUGHT - THAT NO ONE CAN DO WITHOUT EDUCATION AND IT IS THE FUNDAMENTAL BIRTHRIGHT OF A CHILD TO BE LOVED AND EDUCATED" has served and strengthened us over the years.



*Enjoying the creative & Rhythmic Art of Dance-Music,  
Drama despite the handicap..*

*"Give to every other human being every right that you claim for yourself" - R. Ingersol*



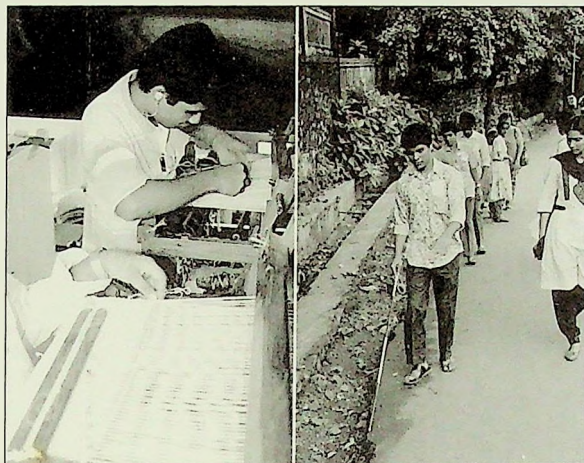
*A Birth right - developing communication skills and allowing  
the child to communicate.*

We are the pioneers in India, in fact in South East Asia, to establish on a scientific basis an educational programme for the DeafBlind Multiply handicapped child. Today, we can proudly say that through our work and services for this cause we have gained recognition nationally and internationally. And all this has been possible through the efforts of so many people from the local voluntary agencies, philanthropist, INGO's Individual donors, State Government and Ministry of Welfare, New Delhi.



Yet, so much more needs to be done and, therefore, this appeal seeks the opportunity to enlist your active support in making their lives more meaningful and contributory for themselves, their families and the community at large.

The DeafBlind child is one you may have never seen or heard of. Struggling, working, happy just like any other child inspite of their handicaps. A DeafBlind child is one who because of the combination of his hearing and visual handicaps is unable to work in a regular programme and needs a specialized individualized programme to be able to function at his/her level. Often one teacher can handle no more than one child or two children of this type at a time. Come and see them being educated.



*The red & white cane – symbol of the DeafBlind.  
My ability and the responsibility to earn a livelihood, to move  
freely in my environment and make people aware of my  
abilities to be independent inspite of my handicap.*



*The talking hands of my teacher keep me in touch  
with the world.*

If only all the hands that see me  
reach out & touch – FOR MINE IS  
A WORLD OF TOUCH through my  
talking hands.

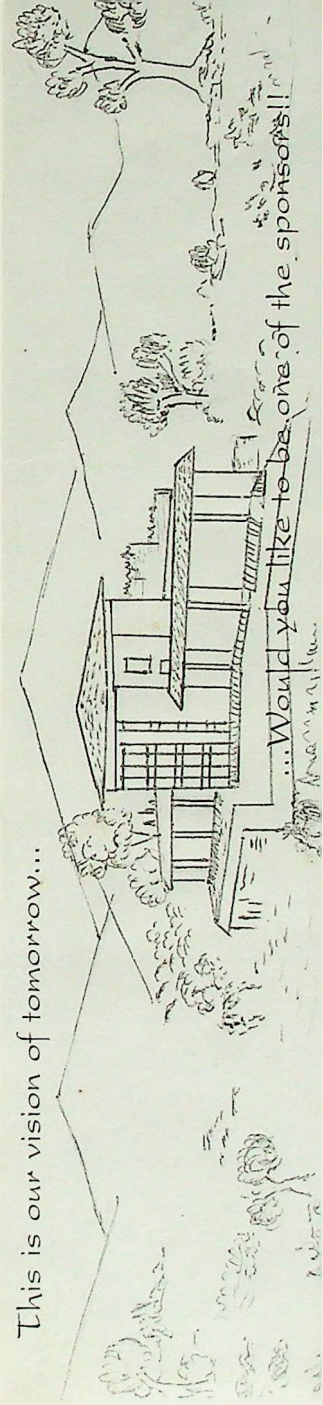
"Your fingers can be gentle firm or  
kind  
or fierce when anger surges  
through your mind.  
Or they can trace with exquisite  
grace,  
the tenderness love mirrors in your  
face.

Oh when I reach to take you by the  
hand  
it is because I need to understand  
that

I am not alone in this broad land".

**Robert Smithdas** –  
a living legendary DeafBlind per-  
son (U.S.A.)

This is our vision of tomorrow...



...Would you like to be one of the sponsors!!



You can reach out to our existing services by

- Sponsoring a DeafBlind / Deaf child & Educational Projects.
- Donation towards Educational Equipment.
- Strengthening the Nutrition & Health Care Programme.
- Transport – Donating a Bus.

M.I.D.C. contributed 1 acre of land at Thane - Belapur to The Helen Keller Institute to expand full range of Services for the Multiply Handicapped on a National Level. You can donate from a class room, an audio visual room, a gymnasium, a wing, to a building etc.

For information contact

The Director, The Helen Keller Institute for Deaf & DeafBlind, Municipal Secondary School Building, South Wing, Ground Floor, Near 'S' Bridge, N.M. Joshi Marg, Byculla (W), Bombay - 400 011.

Tel : 3087052

Fax : 91-22-2872735



Late Helen Keller and her teacher Anne Sullivan  
June 27 1880 – June 1 1968 (U.S.A.)

Late Dr. Helen Keller, the prodigy and genius who opened the doors of educating Deaf and DeafBlind, was herself deafblind. She has said – "A person who is severely handicapped never knows his own hidden source of strength until he is treated like a normal human being and allowed and supported to shape his own life – for life is either a challenge and an adventure or nothing at all!"

Your contribution in shaping the life of this little being will go a long way in the annals of The Helen Keller Institute for Deaf & DeafBlind.

*In the service of*  
**The Helen Keller Institute for Deaf & DeafBlind**

*SC Dalal*

**Mr. Suryakant C. Dalal**  
President & Trustee

*Beroz N. Vacha.*

**Mrs. Beroz N. Vacha**  
Director

The Society is registered under the Societies Registration Act 1860, Bombay Public Trust Act 1950 and Exemption of Income Tax under Section 80-G Income Tax Act, 1961. All cheques to be addressed to the Society for Special Education for Deaf or The Helen Keller Institute for Deaf & DeafBlind



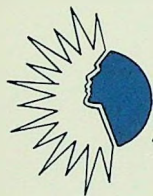
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WE TOO  
SHALL  
CONQUER

## The Helen Keller Institute for The Deaf & Deaf Blind, Bombay - India.

A Pioneering Institute in Asia in the Education of DeafBlind established in July 1977.  
Our strengths come from Helen Keller's Legacy

"....The one who walked the distance of a lifetime without fear,  
that darkness is a challenge to the soul,  
and silence has a language we must learn,  
that we are tested in the crucible of circumstances to know our inner strengths,  
to break our own paths that will mark the way,  
from small beginnings to still greater things."

Robert J. Smithdas



### DEAFBLIND SECTION:-

We offer individualized instruction from Early Intervention to Rehabilitation of the person.

1. Infant – Toddler to Pre School – thrice a week to every day – followed by a monthly home visit for family orientation. For all age groups.
2. A graded functional curriculum catering to each individual from self help skills to Academics to pre vocational & independent living skills to job rehabilitation.
3. Co-curricular activities – swimming, camping, mobility, domestic science, mime, dance etc.
4. Hostel facilities for children residing outside Bombay.

### DEAF SECTION:-

Toddler to Preschool to primary education to integration programmes.

Full range of co-curricular activities – swimming, camping, hiking, dance & mime, art & craft, domestic science, pre-vocational training.

FREE EDUCATION, BOOKS, HEARING AIDS, NUTRITION, MEDICAL FACILITIES AND SUBSIDIZED TRANSPORT.

FREE COUNSELLING SERVICES FOR STUDENTS, PARENTS AND STAFF FOR THE ENTIRE INSTITUTE.





*The Helen Kessler Institute for  
The Deaf & Deaf Blind, Bombay - India*  
**Founded in July 1977**

Municipal Secondary School, South Wing, Gr. Fl., 'S' Bridge,  
N. M. Joshi Marg, Byculla (W), Mumbai 400 011.  
Tel. : 308 7052 • Fax : 91 22 287 - 2735



"I feel the capacity to care is the thing which gives life its deepest significance"..... Therefore.....

"Give to every other human being every right that you claim for yourself"



## *Your Support is our Strength*

### **I. Introduction**

The purpose of this document is to introduce The Helen Keller Institute for Deaf & DeafBlind - Bombay India, to various International Charities and National Charities for raising funds to develop our 1 acre of land given to us in April 1994 by the Maharashtra Development Corporation.

Our vision is to create, build and develop services for the Deaf/Deaf Multiple Handicapped/DeafBlind children and young adults through Day-Care/Residential Facilities and other ancillary services. This then allows the handicapped person to be a contributory, functional and an accepted fellow-human being within his own society - The society which recognizes its joint responsibility!!

"For the responsibility to assure and guarantee the birthright of Deaf and DeafBlind children rests with us. There can be no greater test of the measure of a human being, a society or a Nation, than the way in which we individually and collectively care for our children".

### **II. WHO ARE WE?**

The Helen Keller Institute is a school managed by an Executive Committee which is an administrative body titled as, the Society for Special Education for the Deaf. The Society is registered with the Charity Commissioner under the Societies Registration Act 1860 and the Bombay Public Trust Act of 1950 and with the Commissioner of Income Tax under Section 80-G of the Income Tax Act 1961.

It all began in 1977 when three experienced teachers of the Deaf asked themselves a question: "WHO IS A DEAF MULTIPLY HANDICAPPED / DEAFBLIND CHILD?", for at that time no services existed for such a child.

Thus we established, The Helen Keller Institute for Deaf and DeafBlind on July 11, 1977 with 2 DeafBlind children, 1 Deaf child, 3 teachers, a group of Committee Members and Rs.150/-, in the home of one of the teachers. It is now a pioneering institute in India, in fact in Asia, to start a programme for deafblind children. Its commitment came from the belief that, "NO ONE IS INCAPABLE OF BEING TAUGHT AND NO ONE CAN DO WITHOUT EDUCATION. IT IS THE FUNDAMENTAL BIRTHRIGHT OF EVERY CHILD TO BE LOVED AND TO BE EDUCATED". It is also the first institute in India to follow the philosophy of "TOTAL COMMUNICATION" in teaching the Deaf, Deaf Multiply Handicapped and DeafBlind.

### **III. AIMS AND OBJECTIVES AS AT PRESENT :**

Our thrust is towards the community's acceptance as a JOINT PARTNERSHIP responsibility with the child's family and educators. This is how we try to achieve it by



preparing our own children. As envisaged in the Memorandum of our Society we offer the following services to provide a Quality of Life to every deaf and deafblind child :

1. Free/subsidized education, transport, nutrition, hearing aids, medical facilities, uniform.
2. Counselling services for children, teachers and parents.
3. Pre-vocational training and every effort to rehabilitate him in the society.
4. Free/subsidized residential facilities for deafblind children residing outside Bombay.

The Institute has helped educate and train 32 deafblind children and 130 deaf children, since its inception in July 1977. At present we have 25 deafblind and 64 children on our roll. The institute is now recognized nationally and internationally and is aided by the Ministry of Welfare, New Delhi and Women, Child and Handicapped Development Office, Maharashtra State. It has two separate schools - one for deaf, another for deafblind children, and a special residential unit for deafblind children residing outside Bombay. The deaf and deafblind schools are housed in two separate wings of a Municipal School building where we have no possibilities of acquiring more space for expanding our Educational and Co-curricular activities - Our corridors are gymnasiums, we share a play ground with hundreds of Municipal School children. WE JUST CANNOT EXPAND ON THESE PREMISES. The new land is our Hope of a better Education / Rehabilitation facilities. Yet in a modest sense it has all the necessary and special infrastructure to educate and rehabilitate deaf and deafblind children at a minimal level.

#### **IV. SCHOOL FOR THE DEAF :**

In the deaf section the medium of instruction is English and Hindi. The admission starts from pre-school to primary.

**EDUCATIONAL GOALS** stress : the all round growth and personality development of the child through the philosophy of total communication. The philosophy of Total Communication is the right to express honest communication in any form that encourages and allows the child to think, discover and express himself! The child is inducted into language, speech, formal subjects e.g. Science, Maths, Social and Environmental studies together with co-curricular activities - Art and Craft, Music, Dance Drama, Yoga, P.T. Sports, Swimming etc. They also participate in joint activities with regular school students for girl guides, camp outings etc.

On completion of primary school our deaf children are main streamed/placed in a secondary school for deaf children. Some of our deaf children are now studying in regular colleges, while others have gone in for training in job orientation courses. We have also been successful in finding job placement for some children.

It is our experience that the older deaf children are able to communicate with our deaf



blind children and thus a strong peer group partnership is formed. They are the eyes for our deafblind.

#### **V. SCHOOL FOR DEAF BLIND :**

"A person is deafblind when he or she has a severe degree of combined visual and auditory impairment. Some deafblind people are totally deaf and blind, whilst others have residual hearing and residual vision. The severity of the combined vision and auditory impairment means that deafblind people cannot automatically utilise services for people with visual impairments or with hearing impairments. Thus deafblindness entails extreme difficulties with regard to education, training, working life, social life, cultural activities and information".

The child who is visually and auditorily impaired is devoid of any language, communication, speech, awareness of its family or the world outside. To bring such a child out of his isolation and loneliness, our program offers individualized teaching carried out through strategies to meet the child's personal needs. All teaching is rooted in each child's individual experience in its early stages. Its other activities are oriented to focus on self care and self-help skills, opportunities for improving communication, cognitive and fine motor skills through academic skills, for practical training in fundamental living skills, recreational and leisure skills pre-vocational skills thus paving the way to live in a community.

Our 4 Usher deafblind are exceptionally clever children with tremendous potential for education and work opportunity, they are currently working in a workshop for the handicapped. So far we have rehabilitated deaf/deafblind children into job placements.

#### **VI. OUR AIMS AND OBJECTIVES THROUGH DEVELOPING OUR 1 ACRE OF LAND :**

It is a virgin green belt on the fringe of an industrial complex with no educational facilities for either normal or handicapped children at the moment. We plan to build in phases:

1. The children are educated and housed on the same complex, which will avoid the unnecessary burden of travelling 70 kms. per day - (the distance at present between our hostel and day school).
2. To create further facilities for our young adolescent DEAF AND DEAFBLIND students who will need different types of services in their teens. Some of the different industries coming up in the vicinity have the possibilities of taking up our 17 years and above students into training and job opportunities, thus paving the way to community awareness and support for our own clients.
3. To create group home system where our students - adolescents and adults can live independently, yet supported by us and the local community. Inviting their friends for week-ends/going away with them from the campus - is a step to



integrated independent living.

4. We feel the need to support the parents of our outstation students. We, therefore, want to create FAMILY ADVISORY SERVICES where families of students can stay with us for a period of a weekend to a week to tune into the kind of programme that is viable for the child and learn how best they can help the child not only during the holidays but as part of the child's growing up programme.
5. To create parallel educational opportunities for non-handicapped and handicapped children from the nearby rural area. True integration should be inculcated into the early years of the children and hence we envisage these possibilities.
6. To create, at a further date, facilities of a multi-advisory-cum-training centre where the trained teachers, guests, visitors, parents and other interested workers can come and stay to avail of the educational services for such a group of children.

#### **VII. WHO ARE THE BENEFICIARIES :**

1. Some of the ancillary services that support the handicapped child in the school programme will be used here to support its family. Early effective Intervention and Interaction are the key factors.
2. Different personnel involved in different learning areas, eg:- the parent advisory Centre - The parent can interact with the other parents, the care takers, house parents, the staff, the other deafblind children of different ages, the voluntary workers, the trainee teachers, the community worker etc.
3. The participants involvement in the Dorms, group home system at different levels will add to the dimensions and awareness of the Life of a Deafblind child outside the wall of a classroom.

#### **VIII. HOW THE SERVICES WILL BE DELIVERED :**

The beneficiaries will also be catered to :

1. At every level the importance of communication with the deafblind, its involvement and interaction in its immediate environment and extending it towards and into the community will be emphasized.
2. Care and education provided by the trained professional and the voluntary workers as assistance.
3. Need based supportive environment for leisure skills, job opportunities, access to job placement that take into full account their potential and abilities as against the handicapped disabilities.
4. Developed concepts of its rights and its uses.



## **IX. AGE RANGE & DISABILITIES :**

0-3 years accompanied by parents/guardians/social worker with facilities for Family Advisory Services which will include instruction, counselling, opportunities to be useful/supportive in programme.

3-20 years. The institute hopes to rehabilitate the children with supportive help. Deafness with additional handicaps e.g. sight impairment, no communication skills, challenging behaviours and additional physical disabilities.

## **X. STAFFING :**

The staffing pattern will depend on the different services available to our clients.

## **XI. FOR THE EXISTING RESIDENTIAL STAFF PATTERN :**

We have to be realistic in the context of our local Indian situation.

Due to space limitation, at present our services are for 14 deafblind children in residence. Age 4 yrs. to 16 yrs.

Some children can manage all daily living skills and help in the kitchen, dorm, and support younger deafblind children. For the younger deafblind kids we have caretakers, cook women, matron. Apart from this the school provides educational and medical support. We have so far maintained an adequate staffing pattern and in the near future with better financial resources and space, more support services will be available.

Some of our boys, (17 plus) now live in a nearby boys hostel of sighted hearing people. They are now learning to commute and interact with the community they live in and work with.

## **XII. TIMESCALE AND INTENDED OUTCOMES :**

The awareness that will come through the involvement of the people from the community with our clients will generate positive influences on other voluntary agencies. Once such a base is established the importance of education for the deafblind and equal opportunities will be a reality to be believed and experienced by many.

1. Programme will be time-bound according to the needs of the client and the onset of the disability structured as and the requirements of the Adult will be so very different from the children. Therefore programmes will be short term / long term goals. We will try our level best to allow the client and its family every opportunity to be integrated into larger community.
2. Eventually life education, job opportunities should become complementary for an adequate quality of life.



### **XIII. TIMETABLE :**

THE RESIDENTIAL UNIT BUILDING is due to commence after the monsoon i.e. October '96. It will be developed in phases and the target goal of completion is 1998-99. December. THE SCHOOL UNIT should commence 1997 and again it will be built in phase over a period of two years.

### **FINANCE :**

The Construction cost of the Residential Building as well as the School buildings is outlined in the enclosed information.

We are hoping to raise funds through local charitable organisations, Government Agencies and other I.N.G.O.'s. (International non-governmental Organisation).

We have been assured/already obtained fees/low cost consultancies/assistance by Architects, Engineers, Surveyors, suppliers for building structures wiring etc.

### **XIV. GOVERNANCE AND MANAGEMENT :**

The governance and management of the project will be done by Mr. Suryakant C. Dalal, the President and Chairman of the Fund Raising Committee and the Executive Committee of the Society for Special Education for the Deaf; and Mrs. Beroz N. Vacha the Director of the Institute. Since Mrs. Vacha is the co-ordinating factor she has been authorised to sign all documents jointly with Mr. Dalal or sometimes singly in absence of Mr. Dalal.

In the final analysis, the Helen Keller Institute for the Deaf and DeafBlind envisages to be a National Centre where equal opportunities for this group of handicapped people becomes a reality as covered in preamble of the Vth Helen Keller World Conference and also under the laws enacted by the Government of India.

In the service of  
The Helen Keller Institute for Deaf & DeafBlind,

*Beroz N. Vacha*

Beroz N. Vacha,  
Director



# Emerging from the valley of silent darkness

Gustasp Irani

The founder of The Helen Keller Institute for the Deaf and Deaf Blind, Behroz Vacha believes in the handicapped child's right to education



*Finger movements effectively used in communication with the Deaf Blind*

Let's play pretend; pretend that you are deaf, dumb and blind; pretend that the dimensions of your world are defined by touch alone. Into this world a lady intrudes. Gently she takes your hand in hers and caresses away any resistance you might have to her touch. Then, slowly she starts to communicate with signals. Repeatedly she sits and rises, makes you sit and rise, and through her touch and signalling alone reaches across the void to you. Next, she signals she cares, that she is there to guide and love you. Welcome to the world of silent darkness; Ms. Behroz Vacha,

founder, director and motivating force behind The Helen Keller Institute for the Deaf and Deaf Blind, Bombay, the first and only one of its kind in India, demonstrates that it is not as despairing or hopeless as it might seem at first.

In recognition of her role as a beacon of light in the bleak dark world of the deaf-blind, Vacha was presented with the Anne Sullivan Medal at an international conference in Sweden on August 8, 1991. The award, instituted in 1966 to commemorate the birth centenary of Ms. Anne Sullivan, the teacher of the world renowned deaf-blind Ms. Helen Keller, comprises five medals presented every four years. Vacha is the first Indian and Asian to be so honoured.

The same year (1991) she was presented with the Rotary Club of Bombay Public Service Award and selected as the Woman of the Year by the Zonta Club International (Bombay III Branch). A year earlier she was conferred the prestigious Rustom Merwanji Alpaiwala Memorial Award by the National Association for the Blind, India.

Recognition, it appears came in a rush to Vacha who started her pioneering work for the deaf-blind in 1977. She welcomes it, for to her it is a recognition of the needs of the deaf-blind and the people around her, volunteers and professionals who work selflessly to meet these needs. "I am just a part of the Helen Keller Institute. Any



award I receive is on behalf of the institution", says Vacha, adding as she takes us around, "To know me is to know my children".

There is a little girl of six just learning how to walk; her parents had unwittingly cocooned her, fearing she might get hurt because of her multiple handicaps. Vacha aids the child's teacher with the exercise; one hand firmly but gently across the small of the girl's back and the other hand working the legs up and down. "It is painful for her", Vacha informs us. The girl winces, but playing among the pinched features is a smile; she recognizes the familiar loving touch.

The foundations of the deaf-blind Institute, Vacha explains, are rooted in patience, caring and dedication. We see it reflected in the smile of a mother who sits observing her daughter interact with the teacher and learns how to reach out and touch the hidden crevasses of her daughter's life. At a neighboring table, a little girl leans forward (she recognizes people by their smell), her hands seeking out Vacha who is then drawn into a great big affectionate hug.

There is a great deal of activity at the table where two teenaged boys sit with their teacher; hands darting around in furious conversation. Nearby another teenager interacts with his counsellor, both sporting wide grins. "They have a great sense of humor. They joke about a lot," says Vacha. Later she calls the boys over to meet us and we realize that if there are any inhibitions about their handicap, they are within us. But soon they draw us across the barrier and briefly we are communicating, sharing each other's worlds. One boy gently runs his hands over our body, exploring its physical form, strangely the touch is not an intrusion on our physical form, no more than someone looking at us is, for the hands are, in effect, his eyes.

"Anyone whose grey cells are ticking can be treated as a normal child no matter what his or her handicap. It is often the way we, the society, think and feel about them which is the real handicap," says Vacha, adding that every child should have a right to an education according to his or her ability.

At the deaf-blind Institute the right to education is offered at present to 23 deaf-blind students. Because of the nature of their handicap the teacher-student ratio is high – one to one for the young and one to two for the more advanced students. Qualified counsellors help the older children. "Many of them are reaching their adolescence and must deal with the problems that the age brings," Vacha explains. In addition the Institute has its own residence quarters in Borivli where 16 of the deaf-blind students reside.

It all began in 1977, with three students, a meager Rs. 150 in the coffers and a whole lot of courage, caring and determination that a handful of determined women started work from one residential abode. According to Vacha, the starting was important for she believed that assistance from well-wishers would follow. "I believe that people



have a lot of goodness in them and it is for me to reach out and tap it. Often what I get may not be what I want, but I know that it will eventually help the Institute and the children," says Vacha who does not hesitate to ask for a good cause. "I even fight with my God for my children," she confesses.

And miracles, small and big, do happen. Vacha shows us an unsolicited letter she received from the Gulf Refugee Relief Fund. In it they state that their primary objectives have been met and from the surplus funds they are donating a part to the deaf-blind Institute. There are companies which have donated furniture when refurbishing their offices. Then there are people who have supplied transport, the qualified and dedicated teachers and staff, the volunteers who have donated their skills and time to the Institute and of course there is Vacha's husband Nariman (formerly a secretary of the Bombay Parsi Panchayat and of the RN and R.N. Wadia Trusts); "He has not only allowed me unhampered freedom in my work but has actively supported me in my task."

According to Vacha, there is a difference between pity and sympathy. With pity, one gives and forgets. Sympathy, however, is the true foundation of philanthropy. "Philanthropy is to give of yourself not just your wealth." Vacha derives part of her inspiration from the lines of an unknown author who observed: "A hundred times a day I remind myself that my inner and outer life depends on those living and dead and that I must exert myself in the same measure that I have received and am receiving and pass it on to posterity."

The last part 'and pass it on...' Vacha informs us, is her own addition. It is something she is constantly doing. On the walls of her office almost all inspirational lines have handwritten tailpieces. It is a reflection of her drive to give a little more and inspire those around her to do the same.

Vacha recalls instances from her childhood that were to influence her commitment to the deaf and deaf-blind in her adult years. "As a young school girl in Bulsar I had a deaf boy in my class and I noticed that people and other students picked on him only because he was so timid and handicapped." Years later when she revisited Bulsar she noticed a grave in front of the school and was informed that it was the last resting place of that same deaf boy. To Vacha, the grave was symbolic of a muted spirit that was denied the right to education for no fault of its own.

After qualifying in the education of the deaf from Bombay and the University of Manchester, Vacha started her career as a teacher to the deaf. In 1965 she met a 17 year-old girl Shyama Mehta who was born deaf and progressively lost her eye-sight till she was totally blind by the age of 16. "Her courage, her sense of humour, her sharp memory amazed me. She was instrumental in showing me the true spirit of courage. Indeed, she changed the entire pattern of my life," Vacha records. From then on Vacha started to think increasingly about deaf-blind children.



In 1971 she took a seven-year-old deaf-blind boy Persy, diagnosed as mentally retarded too, under her wing. She believed in him and his mental abilities. This was certified by Dr Edward Waterhouse of the Perkins Institute of the Blind and Deaf-Blind in the USA who on one of his annual visits to India, diagnosed Persy as a deaf-blind boy with retarded milestones and not as a retarded boy. In 1974 Dr Waterhouse invited Vacha to participate in a program of the deaf-blind at the Perkins Institute - BOSTON MASSACHUSETTS - U.S.A.

Vacha returned to India and, despite the odds, ventured into the country's unexplored valley of silent darkness. And in this valley there was self enlightenment too. "I learned that ideas may come from others sometimes, but I am responsible for my own decisions," says Vacha. To Vacha it was a discovery of the true Zoroastrian teaching of choice based on good thoughts, good words and good deeds. Vacha sees a disturbing contradiction within the Parsi community. Parsis are renowned for their charity and philanthropy but when it comes to sharing their best gift, their religion, they are selfish. "Nowhere does Zarathushtra talk of non conversion. He in fact asked his followers to spread his message to all corners of the world."

And spreading goodness, in her own way, is Vacha as the story of Ashok illustrates. When only one year old, Ashok, a deaf-blind boy, was referred to Vacha by an adoption agency as they did not know how to handle a child with his kind of handicap. The Vachas, who have no issue of their own, took the little boy to their home and cared for him for four months, until such time as he was adopted by an American couple. Vacha shows us a letter from Ashok's new parents. In it they mention the medical treatment and operations the child has undergone as doctors try to retrieve his vision. They end by thanking the Vachas for giving them Ashok, stating: "He certainly has brought a lot of joy, love and happiness into our home."

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### *Acknowledgements*

No task is ever completed without Acknowledgements....

It is said that one Swallow may announce the arrival of Summer but does not make the summer.... It is a whole flock of Swallows flying together in a direction that makes the summer.

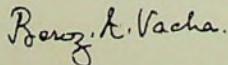
Things that were thought of as Impossible – with the passage of time have been made possible for the betterment of our children. And for this my very profound gratitude to :-

- I) Our own staff members and The Executive Committee whose remarkable enthusiasm and unstinting support at all times has been a source of strength and inspiration to me to go on with my work! This is most evident to all those who visit our Institute.
- II) To the State of Maharashtra – Directorate of Social Welfare and The Ministry of Welfare, New Delhi for their recognition and grant-in-Aid on a regular basis.
- III) To all the many voluntary individuals and donors, voluntary welfare organisations and Trusts from India for their contribution in terms of donations – groups activities / excursions / competitions teaching materials etc.
- IV) To the overseas International non-Governmental organizations (I.N.G.O.'s) for their generous funding in scholarships for our staff training / visits abroad for short courses and observations of programmes and valuable contributions towards developing our 1 acre of land in terms of an all comprehensive services for our Deaf & DeafBlind population.
- V) To the various national and international trusts and organizations for recognizing our services by conferring meritorious awards.
- VI) And, last but not the least, I owe a sense of gratitude to my friends and my family for their deep love and support, which is the basis for everything I do – especially my late husband Commander Nariman Vacha, the founder Trustee and Secretary of the Helen Keller Institute who encouraged me to go beyond myself.

Once again I thank you all for your presence and may God strengthen your hands.

Yours sincerely,

In the service of The Helen Keller  
Institute for the Deaf & DeafBlind,



**Mrs. Beroz N. Vacha,**  
Director.





**ANNOUNCEMENT  
OF  
TWO HANDS-ON TRAINING WORKSHOPS**

- I. Designing Toys for Active Learning
- II. Appropriate Paper Technology (APT.)

at

**The Spastics Society of Tamilnadu**

Opp. T.T.T.I., Taramani Road, Chennai - 600 113.

Phone : 2354651 Fax : 2350047

Email : [spastn@md2.vsnl.net.in](mailto:spastn@md2.vsnl.net.in)



## WORKSHOP I

### Designing Culturally Appropriate Toys for Active Learning (with specific relevance for children with disabilities)

- Dates : Monday 26th October '98 to  
Friday 30th October '98.
- Venue : The Spastics Society of Tamilnadu,  
Chennai.
- Resource Person : **Ms. Jean Westmacott**  
People Potential, U.K.
- Timings : 9.00 a.m. – 6.00 p.m.
- Course Fees : **Rs. 500/- only** (payable by DD in favour of  
The Spastics Society of Tamilnadu,  
Chennai)
- Residential Fees : Rs. 60/- day (boarding & lodging)
- Total Participants : 15 - 20 only.

#### Objectives :

- To make learning joyful, participative and stimulating.
- To assess the child's level of development.
- To enhance teaching competencies through the use of a wide range of low-cost toys and teaching materials.
- To equip participants with knowledge and skills in designing and making low-cost toys and games for children with disabilities.

#### Contents :

- ★ Assessment of stages of development.
- ★ Designing games / toys to enhance skill acquisition.
- ★ Exposure to different techniques and different materials for making toys.
- ★ Developing observation skills for determining effectiveness of toys and adaptations there of.

Contact Person : Ms. Astrid Udo  
The Spastics Society of Tamilnadu, Chennai.



## WORKSHOP II

### Appropriate Paper Technology (APT) (Fully residential)

- Dates : Batch I - Monday 16th Nov. '98 to Saturday 28th Nov. '98  
Batch II - Monday 30th Nov. '98 to Saturday 12th Dec. '98
- Venue : The Spastics Society of Tamilnadu, Chennai.
- Resource Person : **Mr. Timothy Gono** Harare, Zimbabwe.  
(Close associate of Beville Packer)
- Timings : 9.00 a.m. - 8.00 p.m.
- Course Fees : **Rs. 1000/- only**  
(Payable by DD in favour of  
The Spastics Society of Tamilnadu,  
Chennai)
- Residential Fees : Rs. 60/- per day (boarding & lodging)
- Total Participants : 15 - 20 only.

#### Objectives :

- a. To create awareness on the need and benefits of low-cost technology appropriate for Indian conditions.
- b. To understand the concept of "Appropriate Paper Technology" as devised by Beville Packer of Zimbabwe (the original APTer)
- c. To provide hands-on training in making assistive devices and special furniture from cardboard and paper, appropriate for persons with disabilities.
- d. To transfer knowledge and skills on APT so as to make each participant capable of becoming a "MASTER TRAINER IN APT".



**Contents :**

- ★ Identifying and learning to use paper, cardboard and paste.
- ★ Designing and making of stools, chairs, walkers, rocking horses, trolley, push carts, corner seats, cradle seats, tables.
- ★ Laminating and Decorating.
- ★ Group work.
- ★ Video presentations.
- ★ Theory work.

Contact Person : Mrs. Shalini Maburi  
The Spastics Society of Tamilnadu, Chennai.



## APPLICATION FORM

Name of Participant :

Qualification & Designation :

Name and address of Organisation :

Are you directly involved in CBR - Yes / No.      Rural / Urban

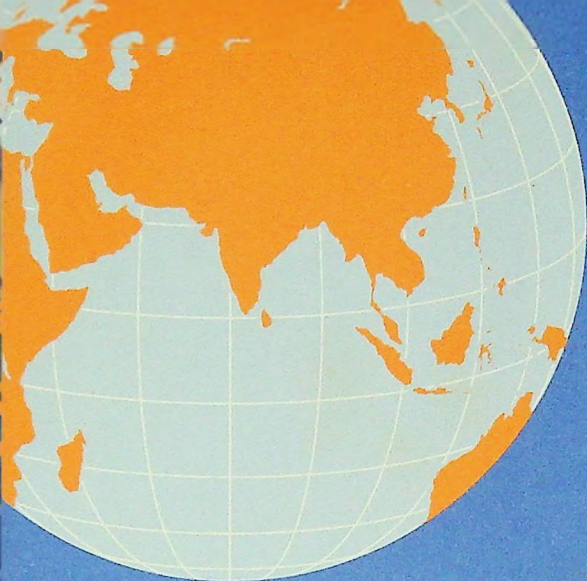
***(Please note that participants cannot be absent for even half a day during the training period.)***

**SENSE INTERNATIONAL (INDIA)  
AGENDA FOR THE ADVISORY COMMITTEE MEETING  
13<sup>TH</sup> September 1998, at 9.30 am.**

**AGENDA**

1. Welcome & Introduction by Jessica Hills, Chairman of Sense UK
2. Address by Mrs. Beroz Vacha, Director, Helen Keller Institute, Mumbai.
3. Election of Chairman of the Committee.
4. Apologies
5. Historical Summary and Relationship with Sense International - Richard Hawkes
6. Overview Report from Development Manager
7. Overall aims and objectives of SII
8. Sense International India Projects
  - BPA
  - HKI
  - NAB
  - Projects with IvD – Clarke
  - Forthcoming possibilities
9. Future Strategy and plans / strategic planning process
10. Finances and Fundraising
11. Sense International India Advisory Committee
  - Role of Committee
  - Roles of members
  - Reporting Mechanisms from Development Manager to Committee
  - Additional committee members
12. Frequency and Nature of Meetings
13. Any Other Business
14. Date of next meeting





# Sense **INTERNATIONAL**

working with deafblind people  
throughout the world



**Sense**  
The National Deafblind  
and Rubella Association  
**International**





## Sense INTERNATIONAL

working with deafblind people  
throughout the world



  
**Sense**  
The National Deafblind  
and Rubella Association  
International



## Sense International

works to improve the quality of life for deafblind people throughout the world by supporting local initiatives with training, advice and resources. It was created in 1994 in response to the many overseas requests being received by Sense, the National Deafblind and Rubella Association in the UK.

## Deafblindness

is a combination of visual and hearing impairments and comes in varying degrees. Because 95% of all we learn comes through our eyes and ears, deafblindness causes unique problems in communication, mobility and accessing information.



## The main cause

of deafblindness in children in the industrialised world used to be rubella contracted by the mother during pregnancy. This has now been substantially reduced through immunisation but



there are still many other causes, including premature birth, birth trauma and a number of syndromes.

## In the **developing world**

there are not enough resources to provide health care and education for everyone. Disabled people, especially people who are deafblind, have little access to these services because of lack of awareness. In many countries, there has been little research, although we can assume that there are large numbers of deafblind people. But no one really knows how many deafblind people there are, where they are or what happens to them. This means that deafblind children may be put in institutions, thrown onto the streets or sometimes left to die.



## For further information contact

Sense International  
11 - 13 Clifton Terrace  
Finsbury Park  
London N4 3SR UK  
Tel: +44 (0)171 272 7774  
Tel: +44 (0)171 281 4373  
Fax: +44 (0)171 272 6012  
e-mail: [si@sense.org.uk](mailto:si@sense.org.uk)

Charity Reg: 289868

Registered Company No: 1825301

Patron: Her Royal Highness The Princess Royal

with the kind support of:



**Colorgraphic**  
Direct Response Printers

  
**Sense**  
The National Deafblind  
and Rubella Association  
International





**In India** we think there are over 250,000 deafblind people, yet there is only one school in the whole sub-continent that specialises in deafblindness. The Helen Keller Institute for the Deaf and Deafblind in Mumbai (formerly Bombay) works with 23 deafblind children. While these children receive excellent education and support, we do not know what happens to the thousands of other deafblind people in India.

Sense International works with Indian organisations to develop services that will ultimately stand alone and have their own healthy development. We aim to enable deafblind people and their families to access services wherever they are in India, and to give them the chance to become full and active members of society.



## Central and Eastern Europe

saw little international exchange of ideas during the Communist years. In 1994 Sense International organised the first meeting in this region of people involved in services for deafblind people. A number of projects have developed as a result and co-operation has increased.



## In Latin America

services for deafblind people vary from country to country. In some countries there are one or two schools that have a small unit for deafblind children. Within these units there is often only one teacher who has received appropriate training. Sense International carries out training programmes in Bolivia, Brazil and Uruguay that aim to increase the awareness of deafblindness and to provide more teachers with the necessary skills.



**Training** is the most important way to help services grow. Because Sense has forty years of experience many people look to us for help. Our Professional Development Programme offers professionals from all over the world the chance to increase their skills. The programme is designed for each individual participant, according to their needs, and Sense International offers a strong follow up support programme. Past participants have gone on to develop vital services for their centres.





# Building a Future for Deafblind People

  
**Sense**  
The National Deafblind  
and Rubella Association





Patron: Her Royal Highness  
The Princess Royal

## What is Sense?

Sense is the national voluntary organisation supporting and campaigning for people who are deafblind, their families, their carers and professionals who work with them. People of all ages and with widely varying conditions use Sense's specialist services. Founded as a parents self-help group in 1955, Sense is now the world's largest organisation working with deafblind people. HRH The Princess Royal is Sense's Patron.

## What is Deafblindness?

The UK's 23,000 deafblind people have significant impairment of both their hearing and vision. Some are totally blind and deaf, but others have some remaining use of one or both senses.

People may be born deafblind or acquire deafblindness later in life. Rubella in pregnancy was once the most common cause of congenital deafblindness but is less common now thanks to immunisation. Meningitis, birth trauma, the effects of old age and the genetic condition Usher syndrome are now more frequent causes.

95% of what we learn about the world comes through sight and hearing. Despite the unique problems deafblind people face in communication, accessing information and mobility, many find help to develop and reach their potential through Sense's specialist support and training.







## Education, Family & Advisory Services

Early diagnosis and continued intensive educational support are key to a deafblind child's development. Sense runs a network of family centres, regional advisory services and branches to support both children and their parents. Intervenors, who work one-to-one to help children and adults develop and explore the world, are also trained and supported by Sense. Services include:

- specialist individual assessment
- nursery and school support
- training for parents and people who work with deafblind children
- help with writing and making an educational "statement"

## Residential and Training Support

Sense is committed to creating homes that allow deafblind adults to live as independently as possible. Residents live in homes ranging from single-person apartments to houses for up to six people, depending on their needs. Sense staff work intensively with residents to help them do as much as they can for themselves. Residents and other deafblind people in the community also receive specialised continuing education and individual training.



## Yes, I would like to learn more about Sense

I would like to receive information about (please tick):

- ☐ Supporting Sense at my workplace
- ☐ How Sense can work with my school, college or university
- ☐ Supporting Sense at my place of worship
- ☐ Making regular donations
- ☐ General information about Sense
- ☐ Sense's free guide to making or changing your Will
- ☐ Sense fundraising events

Name: \_\_\_\_\_

Address: \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

Post Code: \_\_\_\_\_

Telephone: \_\_\_\_\_

Please return this form to:  
 Sense, Fundraising (DM) Dept.  
 FREEPOST Licence No WC 4236  
 11 - 13 Clifton Terrace  
 London N4 3BR

Registered Charity  
 Number 289868

  
**Sense**  
 The National Deafblind  
 and Rubella Association



# I am happy to support Sense now

Any amount you would like to give would be appreciated.  
As a guide, here are some examples of what your  
donation can achieve:

- £15 could pay for half an hour of communication  
tuition for a deafblind child
- £35 could pay for materials for Sense's craft workshop
- £50 could go towards furniture for a Sense Group Home
- £100 would pay for one day of a deafblind teenager's  
holiday with Sense

Here is my donation of

☐ £15 ☐ £35 ☐ £50 ☐ £100 ☐ other £

Name: \_\_\_\_\_

Address: \_\_\_\_\_  
\_\_\_\_\_

Post Code: \_\_\_\_\_

Telephone No. \_\_\_\_\_

- ☐ My cheque / postal order is enclosed.
- ☐ Please debit my Visa/MasterCard/American Express/  
CAF Card

Card Number:

Expiry Date:

Signature: \_\_\_\_\_

## Regional addresses

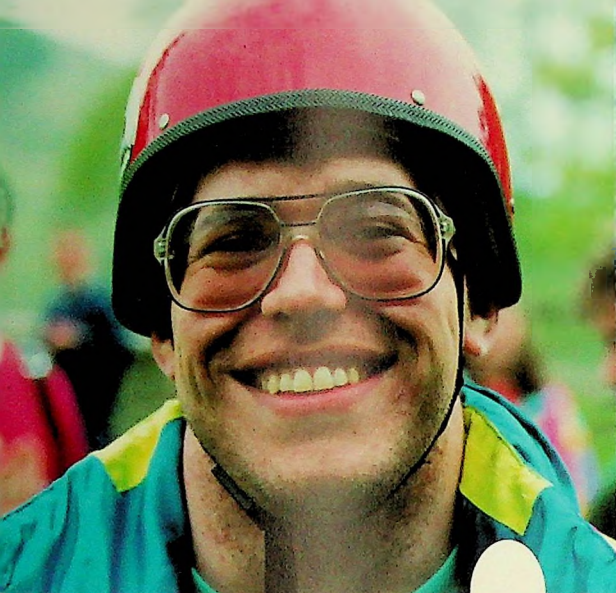
- **Sense, The National Deafblind and Rubella Association**  
11-13 Clifton Terrace  
Finsbury Park  
London N4 3SR  
Tel: 0171 272 7774  
Fax: 0171 272 6012  
Minicom: 0171 272 9648  
E-mail: [enquiries@sense.org.uk](mailto:enquiries@sense.org.uk)  
Website: [www.sense.org.uk](http://www.sense.org.uk)
- **Sense Northern Ireland**  
Sense Family Centre  
The Manor House  
51 Mallusk Road  
Mallusk  
County Antrim  
BT37 9AA  
Tel/Text: 01232-833 430  
Fax: 01232-844 236
- **Sense South East**  
Ground Floor  
Hanover House  
76 Coombe Road  
Norbiton, Kingston  
Surrey KT2 7JE  
Tel: 0181 541 1147  
Fax: 0181 541 1132  
Minicom: 0181 541 1938  
Modem: 0181 541 1856
- **Sense International**  
11-13 Clifton Terrace  
Finsbury Park  
London N4 3SR  
Tel: 0171 272 7774  
Fax: 0171 272 6012  
Minicom: 0171 272 9648
- **Sense North**  
122 Westgate  
Wakefield WF1 1XP  
Tel: 01924 201778  
Fax: 01924 366307  
Minicom: 01924 201778
- **Sense East**  
The Manor House  
72 Church Street  
Market Deeping  
Lincolnshire PE6 8AL  
Tel: 01778 344921  
Fax: 01778 380 078
- **Sense Scotland**  
45 Finnieston St  
Clydeaway Centre  
Glasgow  
G3 8JU  
Tel: 0141 564 2444  
Fax: 0141 564 2443  
Text: 0141 564 2442
- **Sense West**  
The Princess Royal Centre  
4 Church Road  
Edgbaston  
Birmingham  
West Midlands B15 3TD  
Tel/Text: 0121 687 1564  
Fax: 0121 687 1656

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## Acquired Deafblindness and Communicator - Guides

People who become deafblind in later life have very different needs than those born with sensory impairments. Sense helps people to live as independently as possible with assessments, training and advice on coping with sensory loss. Innovative Communicator-Guide services also work one-to-one with deafblind adults to provide assistance with mobility and daily tasks such as paying bills, shopping and visiting friends.

## Usher Services

Usher syndrome is a genetic condition affecting at least 3,000 people in the UK. People with Usher are born deaf or hard of hearing and usually begin losing their sight in late childhood.

Sense Usher Services provides information, training and support to help people with Usher live as independently as possible. It also backs new study of the syndrome.







## Sense Holidays and Voluntary Services

Every summer Sense takes deafblind young people on holiday to the seaside, activity centres and holiday cottages. In supportive environments geared towards their needs and interests, holiday makers enjoy themselves, gain new experiences and make new friends.

Sense also runs a network of local branches that act as mutual support and awareness raising groups for parents. People from within and outside Sense also work together to promote independence for deafblind people through the new Sense Advocacy Development Network.

## Campaigning and Sense International

Sense fights for the rights and needs of deafblind people through campaigns to Government, Parliament and local authorities. Sense branches and families also campaign locally.

Sense International, the charity's newest arm, helps Sense share specialist knowledge with professionals in other countries. Developing sustainable local services in India is the top priority. Training programmes are also underway in Latin America and Central Europe.





Patron: Her Royal Highness  
The Princess Royal

## What is Sense?

Sense is the national voluntary organisation supporting and campaigning for people who are deafblind, their families, their carers and professionals who work with them. People of all ages and with widely varying conditions use Sense's specialist services. Founded as a parents self-help group in 1955, Sense is now the world's largest organisation working with deafblind people. HRH The Princess Royal is Sense's Patron.

## What is Deafblindness?

The UK's 23,000 deafblind people have significant impairment of both their hearing and vision. Some are totally blind and deaf, but others have some remaining use of one or both senses.

People may be born deafblind or acquire deafblindness later in life. Rubella in pregnancy was once the most common cause of congenital deafblindness but is less common now thanks to immunisation. Meningitis, birth trauma, the effects of old age and the genetic condition Usher syndrome are now more frequent causes.

95% of what we learn about the world comes through sight and hearing. Despite the unique problems deafblind people face in communication, accessing information and mobility, many find help to develop and reach their potential through Sense's specialist support and training.







## Education, Family & Advisory Services

Early diagnosis and continued intensive educational support are key to a deafblind child's development. Sense runs a network of family centres, regional advisory services and branches to support both children and their parents. Intervenor, who work one-to-one to help children and adults develop and explore the world, are also trained and supported by Sense. Services include:

- specialist individual assessment
- nursery and school support
- training for parents and people who work with deafblind children
- help with writing and making an educational "statement"

## Residential and Training Support

Sense is committed to creating homes that allow deafblind adults to live as independently as possible. Residents live in homes ranging from single-person apartments to houses for up to six people, depending on their needs. Sense staff work intensively with residents to help them do as much as they can for themselves. Residents and other deafblind people in the community also receive specialised continuing education and individual training.



# Yes, I would like to learn more about Sense

I would like to receive information about (please tick):

- ☐ Supporting Sense at my workplace
- ☐ How Sense can work with my school, college or university
- ☐ Supporting Sense at my place of worship
- ☐ Making regular donations
- ☐ General information about Sense
- ☐ Sense's free guide to making or changing your Will
- ☐ Sense fundraising events

Name:

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Address:

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Post Code:

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Telephone:

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Please return this form to:  
Sense, Fundraising (DM) Dept.  
FREEPOST Licence No WC 4236  
11 - 13 Clifton Terrace  
London N4 3BR

Registered Charity  
Number 289868



**Sense**  
The National Deafblind  
and Rubella Association



## Teach yourself the deafblind manual alphabet



Kindly Supported by:

**Mr.Nareshchandra Doshi**  
Raipur (Madhya Pradesh)



**Sense International (India)**

405, Favourite Residency, Opp. St. Xavier's Loyola School,  
Memnagar, Ahmedabad - 380 052, Gujarat (India).  
Telefax : 91-79- 747 7185 e-mail : [senseind@ad1.vsnl.net.in](mailto:senseind@ad1.vsnl.net.in)