

## **A philosophy of education**

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## **Deafblindness, self-determination and mental competence**

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# DEAFBLIND EDUCATION

**Deafblind Education** 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 IAEDB.

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

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## MESSAGE FROM THE CHAIR

**M**y favourite word nowadays is PROCESS. I know that I am not alone - it is very modern to say that we work process-oriented. But still I think that processes in the field of deafblindness are something special and can be developed further.

I would like to mention two cases in which we can see the results of a long process. First of all I am very pleased to see new and exciting work taking place in developing countries and countries with emerging services. More and more organisations are becoming interested in working with emerging programmes in many different countries. I see this development as a process which often starts when people meet at a conference or other meeting. Representatives from countries needing help are able to transmit their needs in many ways. After some time, often years, somebody will pick up the idea, start to work together with financing and eventually



help to develop a new programme within the country.

Another nice result of a long process is the communication work in Europe. Initiatives at an individual, national and regional level have come together to form a European Working Group on Communication. Last summer they organised a course in

Paris for around 100 people, and they are currently preparing a report plus materials to share with those who were unable to participate.

As we develop the organisation and activities of Deafblind International I hope that we can strengthen our role as an organisation which enables these kind of processes to go on and grow between the people living and working with deafblind people. We hope to enable many different kinds of networks to be created; living networks that will give people the possibility to develop themselves and their work in a process with others all around the world, or maybe in the neighbourhood!

We are currently preparing the Madrid conference. I hope that it becomes a starting point for many new processes - even if it may take a while before we can see the results!

**Marjaana Suosalmi**



**Marco Vinicio Hernández,**  
*student at the Deafblind  
Program, San Josa, Costa Rica.*  
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# EDITORIAL



**S**ince the last Deafblind Education there has been a meeting of the IAEDB Executive in Vancouver. This discussed the strategic plan for the organisation

and the results of the consultation with members. Decisions were made about the future direction and structure of the organisation. As a result IAEDB is now Deafblind International (DbI) and is described as "The world association promoting services for deafblind people". Some of the changes are reported in the article "Getting DbI Going" in this edition but more work is required, for example, revising the organisation's Objects.

The cover of this Deafblind Education has been modified to incorporate the new DbI logo. However the change from IAEDB to DbI reflects a widening focus that reinforces the change in editorial policy of Deafblind Education to cover more than educational matters and to include content on all aspects and disciplines related to work with people who are deafblind. In other words, we are about all services for deafblind people, not exclusively education services. As a result DbI Management Committee proposes that a new name is also needed for Deafblind Education. I would like to suggest that we have a competition to decide on a new name for Deafblind International's journal. So please do think about this and contact me or Richard Hawkes before the end of March 1997 with your suggestions. The winner will receive a free subscription to this journal.

This edition of Deafblind Education includes interesting articles on self-determination and deafblind people prepared by Paul Andreoli for a seminar held by the European Deafblind Network earlier this year in Hannover, Germany. The issue of choice and self-determination for deafblind people who are not regarded as mentally competent is a very difficult one for practitioners, for example, those working in residential homes. Paul's presentation led to considerable discussion at the seminar and I hope that readers may want to continue the debate in Deafblind Education. Please do consider writing a letter or an article in response on this - or indeed on any topic relevant to services for deafblind people. While we can not guarantee to publish everything we receive, we are always very grateful for feedback on articles and contributions offered.

**Malcolm Matthews**

# Book reviews

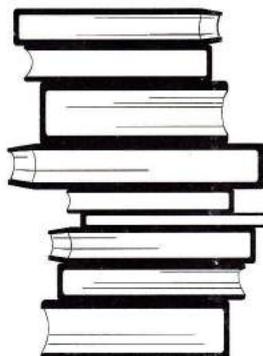
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## Addressing the communication needs of the individual with significant impairments: An ideas kit

by Louise Goold, Phyllis Borbilas, Annette Clarke, Carol Kane (Speech Pathologists, Communication Therapy Department, The Alice Betteridge School, The Royal NSW Institute for Deaf and Blind Children) in conjunction with Jodie Yates and Vale Mendelson.

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This Australian publication was written 3 years ago but only came to my attention earlier this year. It is only 37 sides but is invaluable if you are looking for ideas for communication with children with multiple and complex disabilities. To quote the introduction: "The way in which a person with intellectual, visual, hearing and/or physical impairments communicates can be distinctly different to the methods that a non-disabled peer uses. This kit contains some examples of different types of communication systems. The



communication methods pictured and described have all been used successfully... The key to successful communication with these systems is meticulous programme design and implementation which is specific to the individual. All systems are tailor-made to suit the user and his/her unique needs and preferences."

The booklet is in colour with lots of photos of materials used in communication and of children and young people communicating. Most of the aids used are low technology, for example, bells, buzzers and noise-

makers for use by students in gaining attention. Other ideas include a sound switch that reacts to vocalisation and operates a tape-loop on a cassette recorder to play the message, "Come and talk with me".

There are sections on non-symbolic communication including facial expression and natural gesture; on individualised gestures, including examples of a gesture dictionary and wall chart; on tangible symbols using ideas such as a neck or wrist display for portability and ease of access for a mobile person who uses object symbols. The final two sections are on two-dimensional symbols and conversation books.

This booklet is very well presented and easy to read with positive pictures of children and young people. It is probably particularly useful for family members and new staff. An excellent publication.

**Published in 1993, available from RNIB National Education Services, Garrow House, 190 Kensal Road, London W10 5BT, price £13.50.**

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## Games for People with Sensory Impairments

by Lauren Lieberman and James Cowart

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A colleague attended a session at the Canadian Conference on Deafblindness in May 1996 run by Lauren Lieberman on recreation and leisure for children who are deafblind. He was enthused and excited by her ideas and vowed to put some into practice in his work with congenitally deafblind adults. As a result I was pleased to receive a copy of Lauren's book and can confirm that it is full of practical ideas for games and activities for children and adults of all ages with sensory impairments. I shall certainly be trying a few out myself during next summer's holiday programme!

To quote a review on the backcover: "This unique and valuable collection of games and activities, developed by innovative practitioners, fills a long-standing need for a book about teaching students with sensory impairments

accompanied by multiple disabilities."

Some of the content is suited to experienced teachers in school situations and some is relevant for leisure time. There are two main sections. The first concerns adapting and teaching games and activities. Games can be adapted through changing the rules (a sighted guide runs with the player; being allowed to dribble a basketball by bouncing and catching the ball), modifying equipment (using an audible ball) or facilities (using a tug-of-war rope on the ground as a boundary for games such as volleyball), or by skill modification (a student with crutches uses one of his or her crutches as a bat). Instructional strategies forms an important section since students' usually gain information through sight and hearing. Instead, braille (meaning using tactile senses in learning), physical guidance, explanation and demonstration are used. For example, a boy with some residual sight and no hearing is taught dodgeball by an instructor and two volunteers. Two

volunteers are required to give an adequate demonstration and allow the instructor to give physical assistance and signed feedback. The instructor stays close to the student signing the appropriate action, physically assisting the student to dodge the ball, retrieve the ball, etc., and also providing immediate feedback related to the success of the student's efforts.

The second part of the book details 70 games including well known activities like Modern Dance, Body Painting and Beach Ball Volleyball and perhaps more unusual games such as Busy Bee and Sensational Ping-Pong. To find out what is sensational about this version of Ping-Pong you will have to buy or borrow the book!

**Published in 1996, the book is available by credit card order (Tel: US + 217 351 5076 or Canada + 519 971 9500), price \$US17/\$24.50 Canadian.**

**Malcolm Matthews**

## IAEDB Award for Distinguished Service

The occasion of the Canadian Conference on Deafblindness and the annual meeting of the IAEDB Executive Committee was an auspicious moment to acknowledge the unique contribution of John and Jacquelyn McInnes to the field of deafblind education over many years. Their responses are presented here, and they outline their philosophy towards deafblind education on pages 11-13.

### Response from John McInnes

"I would like to thank Michael Collins and Tony Best for their kind words. It is impossible to adequately express either my original surprise upon being notified of the IAEDB Distinguished Service Award or the appreciation of this honour that I feel this evening. I must say that the award is all the more special to me because I am receiving it in the same year that three very special individuals were also so honoured. Dr. Jan Van Dijk, Rodney Clark and lastly, but by no means least, my wife.

A wise man has said the most prized possession that an individual may possess is not gold and silver nor a brief spot in the sun. The most prized possession is, and will always be, recognition by one's peers. It is with this thought in mind that I thank you for the honour you have bestowed upon me. I will value this award for the personal honour it bestows upon Jacquie and I while at the same time recognizing it is an award which was made possible by the many parents and professionals in Canada and abroad who have supported and encouraged us during our professional careers.

The IAEDB, now Deafblind International, has played an important part in my professional growth during the past twenty years. The knowledge I have gained and the many friendships that have evolved from my association with its members have often sustained me when I was not sure I could explain one more time "Mary is not a deaf child with visual problems nor is she a blind child with hearing problems!! She is deafblind and this is a unique handicap requiring a completely different approach for her education and overall development."

The partnership of parents and professionals has been one of the corner-stones of this organization since the adoption of its charter in Australia in 1976. It has provided a strength, a flexibility, a knowledge base, and a point of view that neither group could have developed on its own. I have drawn on this resource many times and have always found the members willing to share their knowledge and to offer their unstinting support.

I wish each and every one of you success in your future work with persons who are deafblind. The outstanding work of the executive during the period since the conference in Sweden under the guidance of Jacques Souriau and Marjaana Suosalmi, and in particular the work of the Strategic Planning Group and their professionalism in the preparation and presentation of their recommendations, illustrates the depth of human resources available to each of you as members of Deafblind International. I know that you will use these resources to establish new and improve existing services for all persons who are deafblind and the parents and professionals who support them day to day.

Again, I wish to thank you and all members of Deafblind International for this honour. I hope that I will see many of you at the Deafblind International Conference in Portugal, if not before. Until we meet again let me hear from you on the Internet. My address is [jmmadb@hookup.net](mailto:jmmadb@hookup.net).



*Marjaana Suosalmi presenting the IAEDB Distinguished Service Award Certificate to John and Jacquelyn McInnes at the Canadian Conference on Deafblindness (Vancouver, July 1996)*

### Response from Jacquelyn McInnes

"Words cannot express the feelings of appreciation that I have as a recipient of the IAEDB Distinguished Service Award. My association with each of you here tonight and the many other international peers I have met over the years has greatly added to the joy and satisfaction I have always felt when working with and for deafblind individuals, their families, and the many people in each of their communities. This award is made even more special as I accept it here in British Columbia, Canada, as this province sent four of the seven children to the Deafblind Unit at the W. Ross Macdonald School in Ontario when we opened the program in September of 1971. It will make the last few days we have spent together as members of the International Planning Committee and the next few days of the 1996 Canadian Conference even more memorable in my life.

My association with an international group of people began as I entered the world of people who were deafblind in 1968. On my arrival at the Perkins School for the Blind I met students, fellow teacher trainees, as well as staff members who had come from many different countries and I still count many of these people as valued friends.

On my return to Canada, we who were charged with beginning the work in the field of deafblindness turned to the only true experts we had - the families of and the children who were deafblind. My gratitude goes to all of these people throughout the world who have taken time to accept me into their lives and to interact with me thus enriching my life beyond words. Without each of them there would be no reason for IAEDB to exist. I thank them also for lovingly reminding me of this each time I strive to be of service to them.

Thank you all, once again, for this most treasured honor. I will continue to "strive for excellence" and to live up to the great responsibilities which goes with it. I will leave you all with this thought 'ALL PEOPLE SMILE IN THE SAME LANGUAGE'. Let us all do our best in the coming years to ensure that people who are deafblind and their families have much to smile about!"

# DbI Update

## ● **DbI seeks Treasurer**

Deafblind International intends to separate the functions of Secretary and Treasurer from 1 January 1998. We are seeking an organisation to manage our finances and provide us with a Treasurer to join the Management Committee. Currently the finances are managed by Sense, the UK organisation, and the income and expenditure varies between \$15,000 and \$30,000 per annum. It is anticipated that this will increase substantially from 1998 onwards. Any member organisation that is willing to undertake this work is asked to contact Rodney Clark at Sense as soon as possible.  
Sense, 11-13 Clifton Terrace, London N4 3SR, UK. Tel: +44 171 272 7774. Fax: +44 171 272 6012. Minicom: +44 171 272 9648. E-mail: rodney@sense.org.uk

## ● **Next Meeting of the Executive Committee**

The next, and perhaps last, meeting of the Executive Committee of Deafblind International will take place at the European Conference in Madrid on Saturday 19 July 1997 at 4.00pm. The location will be the conference venue, and the exact details and any change of time will be included in the Conference Book. The Management Committee that was established in Vancouver in May 1996 to develop the new structure of DbI and to implement a strategic plan will be reporting to this meeting. Please see the article on page 22 for an update of the Committee's work.

## ● **1997 Membership Fees**

The Management Committee has decided that there will be no change in the membership fees until the new constitution is introduced, hopefully on 1 January 1998. Membership fees therefore remain the same for 1997 i.e. £10 sterling or \$US20 for individual members and £100 or \$US200 for corporate members. Reminder notices will be sent out shortly.

In addition, we are pleased to inform you that it is now possible to pay your membership subscriptions by credit card. It is very difficult, indeed impossible, for some countries to pay small amounts of money overseas, and we hope that this new facility will make it much easier for members. Please see the membership form for further details.

*Celebrations around Assumption Cathedral, Cathedral Square, Moscow, May 1996*



# Russian Experiences

Russia has a long history of recognition of deafblindness, with the first recorded unit for educating deafblind children opening in 1909. Soviet respect for science and education allowed the development of innovative research and teaching approaches over a long period of time. Individuals such as Dr Valery Chulkov from the Institute of Special Education, Moscow, have helped to build DbI.

But the current situation of political uncertainty and a fragile economy poses a major threat to the continuation of work with people who are deafblind. The changes affecting Russia impact upon every aspect of daily life and professional practice.

## **Institute for Special Education**

We were introduced to the work of the Institute and particularly that of the 'Deafblind Laboratory', led by Dr Valery Chulkov. The Institute's role seems to be research and development in relation to special education.

Dr Nikolai Malofeev, Director of the Institute, outlined the development of special education in Russia. Children with profound congenital deafblindness have traditionally been considered 'ineducable'. Although the principle of education for all is now widely recognised, in practice it is very difficult to develop services when even mainstream education has suffered badly from the lack of resources. Similarly, there is an official

commitment to integrated education, and although the residential schools are closing as a result, there are few resources to support local schools in meeting these additional needs.

The impact of the economic difficulties cannot be over-emphasised. The Institute has experienced severe cuts, to the extent that even salaries can no longer be guaranteed. Families can afford nothing beyond the basics for survival, and anything which can be cut has been. Professionals are routinely taking second and even third jobs to try to maintain enough income for food and necessities.

Despite the difficulties, Dr Malofeev identified clear priorities for the

Developing links with Russia was one of the early priorities established for Sense International. In May 1996 Vanessa Davis, of Sense's Policy and National Services Department, and Kate Thomson, who had researched into deafblindness in Russia, undertook a study trip to Moscow.

The aims of the trip were to gain further knowledge of services and issues relating to deafblindness in Russia, to identify possible areas for cooperation and to develop Sense International's relationship with potential partner agencies.

The following is an extract from Vanessa Davis' report...

Institute, including:

- research in relation to early intervention;
- raising the profile of life and vocational skills in the curriculum;
- working with children with compound impairments;
- developing IT support for special schools.

Tatiana Basilova, senior researcher at the Deafblind Laboratory, undertakes specialist assessments of children who are deafblind. She and her colleague, Irina Salomatina, are working to identify children who are deafblind via contacts with schools



(Left, below and opposite page) Staff and students at the Sergiev Posad School

and clinics for deaf children. They have a particular interest in Usher syndrome.

The Laboratory was established 40 years ago and developed programmes with an experimental group which are now used at the Sergiev Posad School. The current group consists of three children aged 10 - 11, and there are practical barriers to its growth. A key issue is the lack of new teachers coming forward to learn about deafblindness.

Olga Kukushkina, the Institute's International Officer, introduced us to a computer programme designed to assess a child's level of development and define problems in learning.

**It is very difficult to develop services when even mainstream education has suffered badly from the lack of resources**

#### **Sergiev Posad School**

Sergiev Posad (formerly Zagorsk) School has achieved an international reputation. Several years ago it moved to a new larger site, though building work has yet to be completed. Plans include the provision of

accommodation for adults, as some young people are unable to move on at 18 as they have nowhere else to go.

The School was established for children assessed as being of normal intelligence, though with dual sensory impairment. However the school now accepts referrals from children who have more severe disabilities, including some with learning disabilities. Jan van Dyjk established a link with St Michielsgestel to provide a three-year training programme to help staff respond to these new needs. St Michielsgestel and Hilton/Perkins have also been generous in donating equipment, which has enabled the school to establish a computer room.

We were introduced to the teaching system, using a case study of a young woman with rubella syndrome who had arrived at the school when she was four. We then spent some time in classes, including those with the most disabled children. Different communication models are used simultaneously, including speech, sign, written word, pictures, objects of reference. Exercises include sorting by colour, pre-writing skills such as copying patterns and forming letters from sticks. The development of literacy is an important goal, and we were introduced to an innovative education programme which promotes reading and writing skills.

#### **VOS: the All-Russia Association of the Blind**

Sergei Sirotkin and his partner Elvira Shakenova lead the work of VOS in relation to deafblindness. Sergei Sirotkin, himself deafblind, was one of

the first deafblind people to become a graduate of the programme developed by the Institute.

VOS is a national agency with centres across Russia providing a range of services to blind adults, including some who are deafblind. Services include housing, employment schemes, rehabilitation and holidays. Sergei and Elvira have also established a small fund to provide financial help to deafblind people.

While VOS receives some government funding, it also finances itself with the profits from its enterprises, for which it previously received tax concessions. Now it no longer enjoys such favourable treatment, and is experiencing cuts. The work traditionally undertaken by employment schemes is being taken over by the private sector, leaving disabled people disproportionately affected by unemployment.

Elvira and Sergei accompanied us to Volokolamsk, a rehabilitation centre in the Moscow region, which began working with people who are



deafblind two years ago with their support and encouragement.

The centre has a total of 80 trainees who live-in (many coming from long distances). Programmes last for up to 5 months. There are only two or three deafblind trainees at a time, because of the need for one-to-one support. Teachers felt that the biggest challenge in working with deafblind trainees was to learn communication skills.

Trainees are generally mature, and there is an emphasis on skills for employment, including crafts which can be practised from home. Workshops included making items from paper and bark, woodwork, dressmaking and knitting, macrame, typing, Braille, and there is a strong gender bias in allocating these. The centre has its own farm which provides food and gives agricultural experience to trainees. Staff were keen to gain ideas for new activities.

The centre has a gym, facilities for mobility training, and medical rooms. Causes of sensory loss are investigated and treatment carried out, including acupuncture and a new system which sends electrical impulses through the eyes (or ears). There is also a resident psychologist.

The centre is planning to move to a new and much larger site, and the shells of buildings have already been completed. However, building work has now stopped because of lack of money.

### Union of Parents and Children

Larissa Zelentsova is the founder of the Union, a registered charity which works with people with congenital disabilities, some of whom have sensory impairment, and their families. The Union supports families to develop and campaign for services, and has so far established around 20 groups in different cities. The organisation runs entirely on a voluntary basis and running expenses, such as stationery and phone bills, are a problem. Larissa's son Denis has cerebral palsy, and she has had to overcome considerable barriers to secure any form of education for him. Teaching at home or residential schools are usually the only options for children with physical disabilities, which leaves them very isolated. Families who choose not to accept a residential placement for their child have no social services to support them, and home teaching and even health care are only available to families that can pay.

The Union is active in trying to improve conditions in the 'internaty' (residential institutions) for children



## Home teaching and even health care are only available to families that can pay

and adults. Conditions in these are such that most families see them as a last resort. They have been able to rehouse 30 young people from one such establishment with American aid.

The Union is working to overcome the fragmentation of services, to promote early intervention (including scanning for pregnant women), and to encourage a wider curriculum to be available to disabled children, since their education often stops at primary level, regardless of ability. The Union is involved in a new school for 'ineducable' children in Moscow, set up as a partnership between a voluntary group and the local education department. Support, such as training and materials, would be welcomed.

### Rainbow Club

The Rainbow Club was originally based at Sergiev Posad School to provide practical help and activities for children from the school and elsewhere at weekends and holidays. It has now relocated to Moscow and linked with a computer club. Irina

Salomatina is a leader and founder of Rainbow, as well as working at the Institute. Rainbow is self-financing (for example through type-setting and the sale of books) and hoping to become a registered charity to aid fundraising.

Rainbow works with a wide range of children and young people, encouraging them to take responsibility for running the club and providing a range of activities and support. Young people who are deafblind are encouraged to attend, and where appropriate to develop computer skills. Rainbow has a particular commitment to children who have been through residential schools, recognising that this leaves them disadvantaged. It hopes to establish a newsletter for the schools, but lacks the costly equipment as well as running costs to undertake this.

*The information and contacts resulting from our visit are being used to identify ways in which Sense International can support the development of services in Russia. We were pleased that Irina Salomatina and Larissa Zelentsova have been able to visit the UK, and are sure this will result in a long and productive partnership.*

*We would like to extend our thanks to everyone we met, and particularly Irina Salomatina for being such an attentive guide.*

Vanessa Davis, Sense

**First  
Announcement**

## Second European Family Conference

**The Role of the Family in the Process of  
Self-Determination of Deafblind Children and Youngsters  
18 - 21 September, 1997**

The Parents organisation of the Rafaël Centre for Deafblind Children is organising, in co-operation with the Instituut voor Doven in Sint Michielsgestel and the European Deafblind Network, the Second European Family Conference.

The First Conference was held in Madrid in 1995 with great success. The initiative for this Second Conference was taken by the Parents section of the EDbN during this event, when participants unanimously decided to hold a Family Conference every two years.

The Conference will be primarily for, and run by, parents, although there will be a few places available for professionals and other interested people. The main theme will be "Self-Determination and Communication of Deafblind Children". A preliminary programme is as follows:

- Morning Plenary Sessions held by guest speakers of parents and professionals.
- Afternoon Workshops and Discussion Sessions, to debate issues presented in the morning.
- Opportunity to visit the Rafaël Centre and the educational setting for young deafblind children.
- Social programme for parents on Saturday evening
- Final Plenary Session, Forum and Conclusions on the Conference on Sunday.

Each European country is invited to send a maximum of three participants. The Conference language will be English and participants are requested to bring their own interpreter if required.

An official announcement of the Conference, with the final programme, will be available in early 1997, from:



The Organising Committee  
Second European Family Conference  
Theerestraat 42  
5271 GD Sint-Michielsgestel  
The Netherlands

Tel: + 31 (0) 73 558 8329  
Fax: + 31 (0) 73 551 2157

## IAEDB Distinguished Service Awards

At each of Dbl's major conferences awards are made, if there are suitable candidates, to people for Distinguished Service within the deafblind field.

There are no set criteria for these awards other than that the recipients have made a significant contribution, usually with an international impact, to services for deafblind children or adults over a substantial period of time.

Previous recipients have included Joan Shields, UK (Poitiers, 1987), Dr Edward Waterhouse, USA (Örebro, 1991), Jan van Dijk, Netherlands, Rodney Clark, UK (Cordoba, 1995), and John and Jacquelyn McInnes, (Canada, 1996).

Submissions are now sought for consideration for the awards to be made at the European Conference to be held in Madrid, Spain in July 1997.

Please send names and information in support of the submissions by 31 January 1997 at the latest to the Secretariat, Dbl, 11-13 Clifton Terrace, London N4 3SR, UK.

### **Report from the Dbl Acquired Deafblindness sub-committee meeting**

**Birmingham, England 12 - 15 October, 1996**

To date this sub-committee has been active in arranging two European Seminars on various aspects of acquired deafblindness, with latest one held in Poitiers, France, earlier this year. During the sub-committee meeting, held at Birmingham in October, it was decided that the next special topic for its work will be a focus on people who are elderly and have acquired deafblindness. The committee's first steps in this will be to undertake an international audit of existing services for, and material on, people who are elderly deafblind. It is hoped that the results of this will form the basis of an international event, probably to be held in early 1998, and lead to the first international publication on elderly deafblind people.

**For more information, contact:**

Anneke Balder, Stichting Doof-Blinden, Professor Bronkhorstlaan 10, 3723 MB Bilthoven, The Netherlands  
(Tel: + 31 (0) 302 250 604; Fax: + 31 (0) 302 291 884).

# A Philosophy behind Education

**Following receipt of their IAEDB Award, John and Jacquelyn McInnes agreed to share the observations and beliefs they have developed over the years which have led to their pioneering work in the field of deafblind education.**

## An Introductory Note

When we were asked to summarise our philosophy we were somewhat at a loss. While we frequently discuss various aspects of our work we have never attempted to summarise our beliefs before. It would be pretentious to call the following a philosophy. We have simply listed under various headings some of our assumptions which we have applied over the last twenty-five years. Please be charitable when reading this attempt to summarise these assumptions. As we re-read them, two things are obvious. Such assumptions are not static but rather continue to evolve. Secondly, we have left out more than we have included.

## Deafblindness

- 1 Deafblindness is a unique low incidence handicap. Because of its low incidence, in most communities no pool of community knowledge or appropriate expectations exists.
- 2 This lack of knowledge may result in an infant, child, youth or adult with deafblindness being inappropriately placed in a program designed to ameliorate problems caused by other handicapping conditions.
- 3 Persons with congenital and early adventitious deafblindness share many of the same problems that are faced by individuals who are adventitiously deafblind but differ significantly in at least two aspects, the development of language and the development of the most advantageous learning style.

## The Individual With Deafblindness

- 1 Every infant, child, youth or adult with congenital or early adventitious deafblindness faces their own unique set of challenges.

- 2 Each may have no or some degree of both residual vision and hearing. In most cases each individual will have to be taught to assimilate information from these distance senses with input from the other senses.
- 3 All will be born with, and will continue to face problems with communication, socialization, orientation and the development of an appropriate individual learning style.

**We have rarely, if ever, met parents who did not have a clear idea of what their child could and could not do**

## Communication

- 1 The concept of communication is much broader than simply the exchange of language.
- 2 Communication embodies every interaction with the environment and includes everything from the breeze blowing on a child's face to his or her using a computer to interact with others throughout the world.
- 3 Communication skills will have to be adapted to accommodate individual differences using the unique total approach required to meet the challenges presented by his or her deafblindness.
- 4 The major problem faced is obtaining sufficient non-distorted information from all interactions with the environment.

- 5 Communication must be the most important part of every activity and must take place before, during and after it.
- 6 The Total Communication Approach, as defined in Deafblind Infants and Children, provides a basis for successful interaction through the use of an Activity Based Program.
- 7 Communication is best fostered in a Reactive Environment and its development is often hampered in a directive one.

## Parents

- 1 The one thing parents do not have to be told is what their child can't do on the basis of some test or scale. We have rarely, if ever, met parents who did not have a clear idea of what their child could and could not do.
- 2 Parents may be disbelieved by professionals when they explain what their child can do at home in a safe environment simply because the professional is unsuccessful in having the child perform the action for him or her on demand.
- 3 Parents may be hesitant to share their information because professionals have disbelieved them.
- 4 Parents often need professional assistance to understand their child's handicap and to learn appropriate techniques and methods to use in day to day interaction with their child.
- 5 Parents also need assistance to form reasonable expectations of their child's present and future progress, and thus have a basis to participate in the development of long-term goals until such time as the individual with deafblindness is able to participate in, and

eventually, take responsibility for setting such goals.

- 6 Members of the nuclear and extended family must have pre-eminent roles in the development of the infant, child and youth with deafblindness. Parents and the professionals must make a conscious effort to involve these people.
- 7 Appropriate support is needed for the non-educational hours. Educational programs often only support the child for approximately one half of the number of days in each year and in the case of community-based educational programs, only a few hours per day. Information about this support must be available when the family requests it and family members must know such support is available if they are to be expected to provide for their child.
- 8 In communities where parents do not have contact with a local specialist in the area of deafblindness, a specialist consultant should be available to the family and community professionals at least once every two weeks.
- 9 Evaluations, particularly initial evaluations, should be done by a trained team and should take place in the infant or child's most familiar and safe environment.
- 10 Parents of children with deafblindness should also be supported by specialists in deafblindness and organizations such as the Canadian Deafblind and Rubella Association in their efforts to contact and interact with other parents.
- 11 Care should be exercised in suggesting that these same parents attend meetings for, and interact with, parents of children with other handicapping conditions. Without appropriate support such interactions can result in discouragement and even despair.
- 12 Professionals, and the organizations they represent, should be ready to support parents who wish to advocate for appropriate support for their child; support individuals who are deafblind who wish to advocate for themselves; and when necessary, advocate actively for the infant, child, youth or adult and their family.

## The Role Of The Specialist In Supporting Individuals Who Are Deafblind

- 1 Because of the low incidence of the handicap and the lack of a pool of community knowledge, the specialist in deafblindness must educate and work with a variety of medical, therapeutic and educational professionals as well as with the extended family.
- 2 The educational aspect of the role is never ending and as each new individual replaces one that has received such information the process must begin again.
- 3 The role of the specialist teacher of the deafblind in a dedicated setting, either residential or community based, must extend beyond the classroom. He or she must accept responsibility to educate other members of the staff, school administration, community workers and parents; develop, implement and evaluate a personal program for each child; and support the carrying out of the child's program in the school, home and community.

### **The personal program must cover twenty-four hours a day, three-hundred and sixty-five days a year**

- 4 Where the child with deafblindness is placed in a regular classroom in the local school, it should not be the responsibility of the classroom teacher to develop the child's overall program. The classroom teacher is a specialist in understanding the needs of children who are in a particular grade and the educational program required to best meet those needs. The teacher should not be expected to become a specialist in deafblindness also.
- 5 The placing of a child with deafblindness in a class designed to meet the needs of children with other handicaps because of a low teacher-student ratio is usually inappropriate for the reasons outlined in 4 above.

- 6 It is the responsibility of the specialist consultant to develop a program which will incorporate those aspects of the classroom and school program which can benefit the child with deafblindness into the child's broader Personal Program.
- 7 The specialist consultant must be specifically trained in the area of deafblindness.
- 8 The pooling of knowledge from the areas of deafness and blindness cannot be substituted for the trained specialist consultant. However, individuals with previous training in these or other fields can, and do, make excellent specialists in the area of deafblindness after receiving appropriate training.

## The Personal Program

- 1 Regardless of who develops the personal program, it must cover twenty-four hours per day, three hundred and sixty-five days a year.
- 2 The Personal Program must incorporate into a single comprehensive whole educational plans, therapeutic programs, developmental programs, recreational programs, parental concerns and lifestyle requirements and, where appropriate, requests and concerns of the individual with deafblindness.
- 3 The Personal Program should contain a history of medical, developmental and educational progress, a summary of the present level of functioning, long-term goals and short-term objectives.
- 4 The individual with deafblindness must be encouraged to take part in the planning and implementing of his or her personal program, beginning with the choosing of specific activities and moving eventually to identifying long-term goals and short-term objectives and discussing his or her progress toward their accomplishment.
- 5 It is inappropriate to judge an individual with deafblindness by the standards and needs of the general population but it is even more inappropriate not to develop an alternative comprehensive program which will allow him or her to reach full potential.

## Learning

- 1 Each individual must be supported to develop a learning style that best suits his or her interaction with the environment.
- 2 Professionals who are not experienced in the field may mistake the individual's inability to gather sufficient non-distorted information from the environment for an inability to process information.
- 3 The major problem faced by the individual with deafblindness is obtaining sufficient non-distorted information from all interactions with the environment. Obtaining such undistorted information will enable understanding of the results of interactions with the environment, facilitate the making of and the carrying out of actions arising from decisions, and to understand the effects these actions have, thus promoting the assimilation of such information so that existing concepts and future actions may be modified.
- 4 As our understanding increased, we supplemented our original TRY, NEED, LEARN, FORMAL model with three additional models to stress the relationship between what the person working with the individual with deafblindness is doing, the techniques and methods used to do it and the expected reaction from the child. We feel that an understanding of this inter-relationship will assist individuals working in the field.
  - *Presentation Model:* awareness, acquisition, application, transfer
  - *Interaction Model:* Jacque's math  $1+1=1$ ;  $1+1=1\ 1/2$ ;  $1+1=2$
  - *Reaction Model:* resists, tolerates, co-operates passively, enjoys, responds, leads, imitates, initiates
- 5 When we are teaching an individual with deafblindness, regardless of age, the highest level of functioning is not when the skill can be performed successfully, it is when the individual knows when to ask for, and asks for, assistance appropriately.
- 6 The individual working with the infant, child, youth or adult with deafblindness must constantly strive to have age appropriate decisions made by him or her concerning all daily activities. Such decisions should include the right to say "NO, I do not want to ..." or "more please" appropriately.

## Intervention

- 1 Intervention is a process designed to provide sufficient non-distorted information to enable the individual with deafblindness, regardless of age, to gain an understanding of his or her environment and make decisions. The intervenor will provide appropriate support to enable the individual to act upon his or her decisions and to receive sufficient non-distorted feedback to understand the result of his or her actions and thus to promote development in the cognitive-conceptual, affective and psychomotor domains.
- 2 Many other terms are used for intervenor such as communicator-guide, special support person [SSP] or special interpreter guide. The function of the intervenor, whatever the label, will be defined by the needs of the client not the title, training or skills of the person providing the support.
- 3 As the level of functioning of the individual with deafblindness increases more, not less, support will be required.
- 4 Gradually the role and number of intervenors will be modified from one intervenor providing basic overall support to the individual with deafblindness having several intervenors with specific interests and skills in addition to a key intervenor who provides a general level of intervention.
- 5 One of the goals of all programs for individuals with deafblindness should be to educate the individual to be able to hire, train and, if necessary, fire his or her intervenor. This can start early by encouraging the child to choose to do specific activities with a particular family member; graduate to planning daily and weekly activities and choosing a specific intervenor to do each with, to sitting in on hiring; then to asking one or two questions during the interview and discussing the replies received with a trusted individual; to expressing a preference from among the applicants; to planning and carrying out the interview according to suitable standards; and finally learning how to discuss an intervenor's performance on the basis of an agreed upon job description such as found in the Intervenor's Self Evaluation Guide.
- 6 It should be an underlying goal of every program to increase the

opportunities for the individual with deafblindness to decide *what* he or she is *going to do, when* and *with whom*. Every effort should be made to decrease the imposition of activities or the intervenors by an individual or agency. Even an infant should be encouraged to choose a specific activity from a number of activities and to choose the particular family member to do it with.

## Concerns

As we have watched individuals with deafblindness graduate from preschool, move through educational programs into adulthood, two concerns have emerged. First is the problem of Learned Helplessness. In some programs, at some stage, it is decided a sufficient level of functioning has been reached. The focus of the individual's program appears to switch from continuing development to maintaining his or her present level of functioning. No more is expected and thus little more is achieved. New work, a greater say in running his or her life and new experiences must be constantly and consciously stressed if Learned Helplessness is to be avoided.

Secondly is the apparent lack of appreciation the role of incidental learning plays in everyone's development. Failure to provide for the decreased ability of the individual with deafblindness to benefit from such learning, either because of its absence or because of the distortion of the information received, must be compensated for in programming particularly in the areas of communication, social-emotional development and cognitive-conceptual development.

## A Final Word

We are sure that many will disagree with some of the above assumptions. They are based upon our experience and the experience of those parents, professionals and individuals with deafblindness with whom we have worked closely. We ask you to understand that these assumptions have provided only a starting place from which to work with each individual infant, child, youth or adult. Many of these assumptions will be modified when assisting a particular person or family. If you wish to question, or discuss them with us we can be reached by Email at [jmmadb@hookup.net](mailto:jmmadb@hookup.net) or by "Snail Mail" at J & J McInnes, 20 Scotia Ave., Brantford, ON, CA, N3R 5R1

# Deafblind benefit from Costa Rica Program

The first Deafblind Program in Costa Rica began at the Centro Nacional de Educacion Especial Fernando Centeno Guell at San Josa, in 1994.

Gloria Rodriguez-Caicedo, the program's Teacher-Coordinator, discusses its achievements and her hopes for the future of deafblind services in Costa Rica.

**M**arco Diego was three years old and inspired great tenderness in me when I met him on a March morning in 1994. I quickly realized that he did not show any interest in his environment. He kept in constant motion, did not have any independent behaviour and did not demonstrate affection. He seemed immersed in his own private world.

I decided to effect a change in his destiny, and accepted him as one of the first pupils of the Deafblind Program at Centro Nacional de Educacion Especial Fernando Centeno Guell in my birthland, Costa Rica.

Created in 1940, the Centro offered educative services to deafblind children since 1960. The care, however, was not grounded in theory since the staff working there had not undergone specific training to care for deafblind children.

In 1994 things took a turn for the better: the Center received the support of the International Hilton-Perkins Program and began the first deafblind program in the Central America region. The objectives were simple: to search for education services more in accord with the particular traits of the deafblind population and their particular needs. In order to achieve this goal other related professionals were trained in the field of deafblindness.

The development of the Program was supported by donations from the Organizacion de Ciegos from Spain and the Union Latinoamericana de Ciegos (ONCE-ULAC), as well as from the Dutch Embassy in Costa Rica and the Damas Voluntarias de Escazu, a local Costa Rican organization.

The Deafblind Program has 11 students aged between two and 15 years, placed in several classrooms according to age, developmental level, degree of sight and hearing



*Gloria and Marco Diego Cubillo (5 years old - student)*

impairment, communication skills and some other parameters. They enter either the Visual Deficiency Department, the Language and Audition program, or the Total Communication program.

The Teacher-Coordinator of the Program arranges different services for the children, according to their individual needs, such as communication development, visual stimulation, parent orientation, multi-sensorial stimulation and cognitive development.

The Program advises, individually or through teamwork, the staff who take care of deafblind children. It organises training activities at a national level for educators who work with deafblind children and assists the creation and organisation of a national group of parents of deafblind children.

## What happened to Marco Diego?

Two years after receiving him on the Program, Marco Diego has achieved great things. Good results have followed from the introduction of

**The Program should extend beyond the walls of the Center and give counselling to educators of the deafblind across Costa Rica**



**Elizabeth Camacho (teacher). Leonardo Mor (7 years old - student)**

the Center should have more staff dedicated exclusively to deafblind children care. For her part, the Teacher-Coordinator should be able to dedicate more time to parent orientation, staff training and guidance, teamwork and the search for more resources, both human and material. Lastly, the Program should extend further than the walls of the Center and, at the very least, give counselling to the educators of the deafblind across Costa Rica.

The aims for the improvement and growth of the Deafblind Program are difficult to achieve in these times when the country's economy is suffering a contraction. As a result the special education services are suffering a similar situation. Special education is public and free in Costa Rica, although there are a few services offered privately. I believe that for the near future, if there is to be a real concern for quality and excellency in deafblind education, a combined public-private model is needed, so that national and international resources can be tapped effectively. This way, perhaps Marco Diego and his classmates can have a brighter future ...

**Gloria Rodriguez-Caicedo**

routines, key-objects, continuity and consistency in treatment, the use of a curriculum tailored to his needs and level of learning, as well as from the dedication of his mother.

Today Marco follows the class routine with independence, recognizes the meaning of key-objects (eg. the cup for snack time, the keys to go out, the glue bottle to create handcrafts, etc.), has more interest in his surroundings, has begun to demonstrate affection, is capable of taking people to where he wants to go, can undress alone and put on his clothes with a little help, keeps attention and eye contact for short periods and can be felt to be in an altogether more serene state.

But there is still a lot to do. Diego gets only two, two-hour sessions each week. This is caused by the budget and time limitations of the Centeno Guell. Marco Diego, despite his progress, is still showing the traits of an individual immersed in his own world, rather than those of someone who functions in a social group.

### **The Future**

For the time being it cannot be claimed that the students at Centro Nacional de Educacion Especial Fernando Centeno Guell are receiving optimal educative care. The children should attend the school for more hours per week and



**Marco Vinicio Hernández (5 years old - student)**

**ANNOUNCEMENT**

## Sense International

# Second Professional Development Programme

**Sense International, created in 1994 to assist in the development of services for deafblind people throughout the world, is pleased to announce details of its Second Professional Development Programme to take place on**

**15 September - 24 October 1997**

**at Sense West, Birmingham, UK.**

Sense International will be repeating its successful Professional Development Programme (PDP) next autumn. The PDP gives professionals working in countries with developing services the opportunity to increase their knowledge and skills in a specialised area relating to sensory impairment. In April 1996, Sense International welcomed five colleagues from Argentina, Colombia, India and Uganda to take part in its successful first Professional Development Programme. It brought together 80 individuals from 20 different organisations to work on a common project.

The PDP is a unique programme which offers:

- ▶ An individually designed training programme according to the needs of each participant
- ▶ The opportunity to visit different specialist services throughout the UK
- ▶ Access to professionals experienced in similar work
- ▶ The chance to produce a project related to the participant's work at home with the support of specialists in the UK and elsewhere

The PDP is a long-term partnership between Sense International and the participants. The PDP will consist of not only 6 weeks formal training in the UK (including 3 weeks individual placements) but also a programme of follow-up support to enable the participants to carry out their projects.

#### **What some participants said:**

Sheela Sinha, Senior Teacher of the Deafblind Unit at the Helen Keller Institute for the Deaf and Deafblind in Mumbai, India:

*"Five of us had come here from different corners of the world with different professional problems and different goals in our minds. The beauty of this programme was that each one of us could get enough out of it to suit his / her perspective and needs. We learnt a lot, gathered a variety of literature, materials and useful ideas along the way and got a chance to test our own professional techniques and beliefs against the knowledge and expertise of highly qualified and experienced educators we met during the six weeks."*

Brother George Velicakathu, who will be setting up a deafblind unit in Northeast India:

*"We had the opportunity to listen to and interact with some of the top professionals in the field of deafblind education in the country and in the world and to visit, observe and live in some of the best centres and programmes for deafblind people. It was also an opportunity for us to take in, reflect, assimilate ideas and techniques and critically evaluate the programmes in our own countries."*

Ximena Serpa, the Coordinator of POSCAL in Colombia, came on the PDP to learn more about setting up services for adults. She wrote to us recently saying:

*"I am training my staff members with the excellent information I got on the PDP. I am also sharing it with other programmes in Colombia and have already started working with adults."*

Further details of the Second Professional Training Programme will be available from Sense International from January 1997 and will be sent to DbI members.

**THE DEADLINE FOR APPLICATIONS IS MARCH 31ST, 1997.**

Since 1995, health service organisations in the Netherlands have been obliged, by law, to enter into a 'care-contract' with their individual clients or their representatives.

This 'care-contract' deals with matters such as information, client-consultation, informed consent, privacy, inspection of personal files, competence and complaints procedures.

In this article we would like to discuss some implications of this individual care-contract in relation to self-determination and restricted mental competence.

# Deafblindness, Self-Determination and Mental Competence

by Paul Andreoli,  
Kalorama Centre for Deafblind Adults,  
The Netherlands

Care-contracts are arranged so that even when a person is placed under guardianship his/her choices should be respected in the areas where the person is considered competent. It is the responsibility of the actual professional care-giver to consider a client's competence in every situation.

Self-determination is one of the pillars of the basic philosophy of Kalorama, Centre for Deafblind Adults. The Kalorama approach is based on enabling a deafblind adult to influence his/her quality of life by reacting to environmental circumstances.

Rehabilitation is seen as the professional supported process that enables a person to function to their own satisfaction in all chosen areas and situations. The methodological guidelines that guide this process comprise a three E's strategy:

- Exposure to the chosen situation
- Experience of the situation
- Expertise based on the impact of their personal experiences

In other words, the person learns by experiencing exposure to the situations of their choice. The role of the professional is to support the actions of deafblind people by simply reacting, within their professional capacity, to the person's demands without arguing the rationality of the demands.

For us professionals this is not an

**We often do not realise how difficult it is for a client to reject the advice of a professional to whom he/she is partly dependent**

easy task: socialised in a "we know what is good for you" culture we often have to suppress making decisions for our clients, even when they are fully competent. And if we succeed in refraining from making decisions for clients, we still overload them with "good advice" and warnings of the negative consequences of their actions. In these situations we often do not realise how difficult it is for a client to reject the advice of a professional to whom he/she is partly dependent due to his/her needs for help and support.

Let me give an example of this situation. When we were presenting our 3-E's approach at a conference, a colleague described the following situation: a 38 year old deafblind man, financially well-to-do, decided to buy a

new 6-person camper. He argued that with such a camper it would be easier for him to find a woman to marry. He chose such a large vehicle because he supposed that this would be a clear signal to his future partner that he was in for a real family with three or four children. Our colleague suggested that in this case we would not agree to "exposure to the situation" of buying the expensive camper. Before we could respond to this position, one of the attendants reacted spontaneously, "I have just had a bad bargain concerning a camper, which I bought three months ago against the advice of some of my friends who are experienced campers". It had cost him a lot of money! After that reaction there was a lively audience discussion about how harmful it would be for the deafblind man involved to have the quite predictable experience of owning a camper without the fulfilment of his wishes concerning a partner and family.

In the Netherlands, the State Inspection of Health Services recently made a clear statement about this issue: clients should be protected against life threatening and severely harmful events. This also includes situations which are "slow-onset" but life threatening or severely harmful in the long-term, such as cases of lack of care and neglect of self-care, which may lead to a deplorable personal mental and physical condition. In all other

## Self-Determination and Sexual Activity in a residential setting for deafblind adults

**S**exuality belongs to a person's private life and should, in most cases, not be a target of professional intervention, unless the person himself seeks help for sexual problems or information. Yet we have formulated some criteria for rules concerning sexual activity in our residential setting. The reason for this is that for some residents their level of "sexual development" does not match their calendar age. Sexual education for these residents implies more than just information; on the one hand they need to have a safe space to discover this own sexuality, on the other hand they need to learn boundaries and values concerning this exploration. In sexual education it is important to avoid confrontation with undesirable situations, such as abuse, or confrontations with sexual activities of others which are not appropriate to the level of sexual development of the resident.

Concerning 'boundaries and values' we make use of the concept of "most accepted values in our general culture". This means that we try not to favour our own values concerning sexuality, be they liberal or conservative, but try to use those values which are most frequent in the general culture the client will experience outside the institute.

### What does this imply for the residents at Kalorama?

We have different group-homes for residents with different levels of development. In those group-homes with adults who have an age-appropriate level of development, residents are, in their private rooms, free in their sexual activities under the condition that these activities are not harmful to others.

In group-homes with adults who are still in a stage of 'sexual education', sexual activities between residents are

not allowed. How strict we maintain these rules depends on the estimated "age-of-sexual-development" of the residents concerned. A deafblind person with an estimated age-of-sexual-development of about sixteen years will be allowed more room for experimentation than a person with an estimated age-of-sexual-development of eight years.

In groups with residents with different levels of sexual development we always ensure that the living environment offers protection for the resident with the lowest level of sexual development.

Sometimes we are in conflict with representatives of residents who want a more restrictive sexual policy for their relative. As professionals we try to judge the competence of the resident to make his/her own choice on the issue concerned.

cases the client should have the "benefit of the doubt" at least.

So in the instance of our 'camper-case' it can not be presumed, as far as we can be aware of the entire ins and outs of the situation, that the purchase will be of real harm to the person. As professionals we are therefore not allowed to interfere with the person's decision-making.

Although clear as a frame of reference, the statement is not easy to practice for professionals in their daily work due to feelings of common sense about the management of situations.

Even more difficult are situations in which "important others", such as parents or partners, are involved in the decision-making process of adult clients. A recent example of this comes from our outreach-support program, of a 34 year old man with Usher syndrome Type I who lives with his parents in a small village. The support program for this man offers what we term "professional prothese help". This is professional support concerning functioning which is only possible with

the handicap-compensating help of another person. (Notice that availability of professional and non-professional prothese-help will be a life-long need for most deafblind people!). Due to this offer the client asked his professional ambulant companion by text-phone to assist him in getting a nice golden ring in the jewellery shop in town. When the companion arrived at the client's house, his mother was informed of their plans to go shopping. "Okay" she said, "but don't buy any jewellery. Wait, I shall tell my son that too!". Her son agreed with her and they set off. The client directed his companion directly to the jewellery shop and bought an expensive golden diamond ring! The companion felt himself swimming into a net! He asked his client what his mother would say if she discovered his purchase. He answered that she would not discover it because he had saved the money in small amounts and argued that "I have more than 100 guilders in my bank account and I really want to buy this ring". The companion did not interfere in this

purchase but felt himself unsure of his professional handling of the situation.

During the supervision of this he realised that most of his professional conduct was in accordance with the philosophy of our approach and the statement of the State Inspection for Health Services. If he had tried to prevent the bargain he would have surely lost his credibility as ambulant companion for this client. Reflection on his feelings of "swimming into a net", he noticed that this feeling began the moment he could not find a satisfactory response to the mother's "order" not to allow the purchase of any jewellery. Afterwards, during his supervision, he thought that a better reaction would have been to inform the mother of his role: to follow the client's directives in order to provide the support appropriate to his wishes and goals.

We realise that there will be a lot to discuss with parents and partners who really want the best for their deafblind relatives in situations where we, as professionals, must follow the choices

of clients even when the important other wants the opposite. We also realise how difficult it can be for professionals to follow the client's choice in situations where they consider partners or parents to have a more realistic view.

In residential settings it is even more difficult for professionals to

optimise individual autonomy and self-determination due to their multiple roles in relation to individuals in groups where there may be incompatible interests amongst the members.

Despite these difficult aspects it should nevertheless not distract us as professionals from realising the most

favourable conditions for self-determination by deafblind people, even if they are not fully competent to make all their own choices!

**Paul Andreoli, Kalorama Centre for Deafblind Adults**

## Deafblindness, Self-Determination and Care-Program Influence

**T**he advantage of a volunteer is that it is easier to direct his supporting actions in comparison with a paid professional contact-person who always has a professional boss".

The deafblind person who formulated this statement was not arguing for modern slavery and assuming that the volunteer should do everything the deafblind person wants. But he was trying to deal with the problem of patronising professional care-givers and feeling that clients should fit in with care-programs instead of care-programs following the client's demands.

In my reaction I said that we at Kalorama had noticed this problem and had therefore rejected the idea of supplying fixed programs based on a client's initial demand. Instead we provided a more continuous individual program construction following client's initial and subsequent demands.

To illustrate this I gave him the following example: A deafblind man lived with his 80 year old mother. He requested a visit to Kalorama because he hoped to find a female professional there who would marry him. We informed him that we could not guarantee that he would find a future partner at Kalorama, but invited him to visit. During the visit he met a client who is severely deaf and blind and who lived independently. It surprised him that such a person cooked his own meals, so he asked for training in cooking at Kalorama, rather than his own home, so that he could meet other deafblind

people regularly.

An individual 'supply fixed program' approach would have offered him training in how to date females and informed him of strategies like advertising and joining mixed activities. It is also possible that in such a 'supply fixed program' approach the professionals would have tried to convince him that his real need was not a partner but a need to live on his own in case his mother should die, which would have led to a program of independent living skills. In our 'continuous, individual demand-led program construction' we simply reacted within our capabilities to the deafblind person's demands without arguing the rationality of these demands.

"That is a good thing" reacted my deafblind partner in discussion, "but...as a potential client I still feel that I am very dependent on your professional philosophy, priorities, decisions and limits". He continued with, "I acknowledge your professional responsibility but, as a group of potential clients we can hardly influence policy concerning services for deafblind people". I could not and would not object to that point.

Nevertheless I was pleased to inform him about a pilot project of demand-orientated care programming of all the different providers of specialised services for deafblind people in two regions in the Netherlands. I was pleased because the quality features of this project concern the following statement:

"Quality of care should be determined by:

- an orientation to the desired situation for the client
- the co-operation of organisations with different provisions for care-supply
- offering opportunities to representatives of deafblind people to influence policy concerning care-supply and care-organisation.

The national organisations of deafblind people were invited to comment on the project proposals at the concept stage and there is also agreement on their participation in evaluating the project.

As professional organisations however, we still have a long way to go; from a position of professional "absolute power" to client participation in a process of balanced decision-making. This balance concerns interests about quality of life, quality of care and good employment practice.

Since the new legislation two processes have developed that stimulate the development of client-participation: one on the individual level concerning the obligation to have a care-contract; the other on the level of the service-organisation, as each is obliged to support the setting up of a client-council.

For Kalorama Centre it is not sufficient to meet these legal obligations. We will remain receptive to a continuous process of client influence about individual care programming and more general care-supply and care-organisation.

# Deafblind wo

## East Africa

The premises underlying the 'East Africa Model' for staff training are:

- that services in the deafblind field everywhere evolve by committed parents or individuals and not from a systemic level
- a concentration on in-service training
- a consideration of the cultural view on education for all children in Africa
- to provide training and support. Using hands-on and role-modelling to teach, combined with practical lectures from what has evolved in the classroom setting
- to "pull it all together" by giving workshops that are practical in a network model for teachers working with deafblind people.

All of the above aspects will help teachers build identities as deafblind workers.

The tasks of the deafblind consultants involved in the program are to:

- contribute to development work
- train and support teachers/staff
- educate teachers from the region who can be supervisors
- give workshops and conferences
- produce materials together with the staff involved in the East Africa Program.

The team consists of five consultants; Marianne Riggio and Rose Cieslo (USA), Auli Sowe (Finland), Inger Rødbroe (Denmark) and Evabritt Andreassen (Norway).

In July we were all working on different programs in Kenya and Uganda.

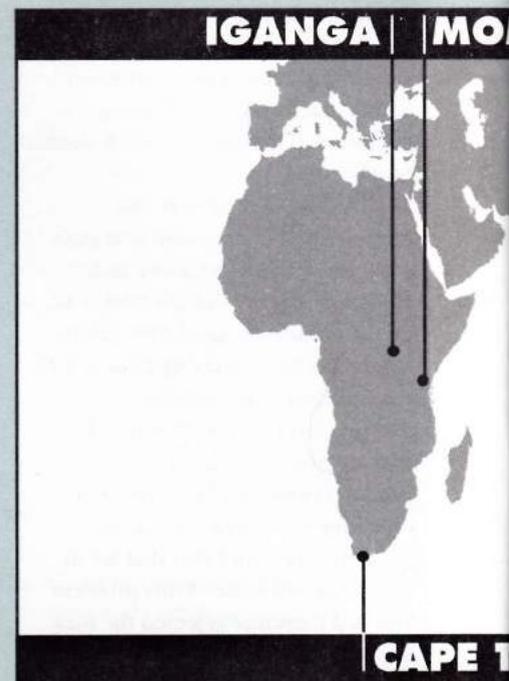
Marianne and Rose worked at the Kwale School for the Deaf (near Mombasa) in the Deafblind Program, which was established in May 1995. This unit has ten children and six teachers. The focus of the first phase

**The East African Program of deafblind projects has been working in Kenya, Uganda and Tanzania since 1994 with the aim of facilitating staff awareness in deafblind education. The projects are sponsored by the Swedish Organization of Handicapped International**

of work at the school was the assessment of individual children. The teachers were divided into two groups, with one consultant assigned to each. Two children were evaluated each day and individual educational plans were developed.

There were few educational toys and materials at the school, so time was spent working in the school workshop making such items as blocks, pegboards, activity boards and toys. All were made with locally available materials. The last day was spent organizing the combined classroom and living space and discussing activities that could meet the educational goals of the children on the programme. Activities were in the planned areas of communication, fine motor, gross motor and daily living skills. In the next phase of training (February 1997) they will engage in more in-depth training in specific areas.

Auli and Evabritt went to West Kenya. The Maseno School for the Deaf was the meeting venue for 14 teachers and 20 students from seven various schools for the deaf in West Kenya. This was our first meeting with students and staff, so our working format was different. We began by collecting information about the students' and teachers' needs before compiling a program. Students ranged from age 7 - 22, and most of them had Usher or rubella. Lectures were held in the mornings on specific issues, such as deafblindness, communication, sign-language, tactual signing, culture and how it effects language, mobility, pre-requisites for Braille and personal future planning. These were followed by practical work and observations, and concluded with a discussion and evaluation of the day.



The main issues for the teachers working at this vocational school were how to prepare their students for life after school; how to identify tasks that each individual could do in their home community; and how to teach them the skills they need to support themselves. We found it very helpful to use The Person-Centred Planning - Finding Direction for Change Using Personal Futures Planning (by Beth Mount). This produced a very nice and active process in the group; Auli and I didn't have the answers, the teachers had to teach us about their daily life, we acted as the facilitators, and we learned a lot about African daily life and culture during this process. A nice way to share and share alike!

We also had a parent session during our visit. Some parents arrived at Maseno who had never met before. A

# ork in Africa

**Aid Foundation and the Association of Swedish Deaf-blind, in collaboration with the Hilton/Perkins Program. Evabritt Andreassen, a Program Consultant from Norway, discusses the Program's approach and reports on work in Kenya and Uganda.**

**MBASA**



**OWN**

father of a deafblind boy, Mr Shiroco, attended the group and talked about parents' needs and the parent/professional partnership. This is not addressed much in Africa. He discussed with other parents how to pull together the different knowledge of parents and staff about each deafblind student. Mr Shiroco was elected by the parents-meeting to be their representative on the East Africa committee.

I was the fortunate one that got to work in two different programs on this visit. I left Maseno after six days and went to Iganga, Uganda to join Inger at Buckley High School. Inger started the work at Buckley in spring 1994, so this was her third visit. During this time they have identified students, built a deafblind unit on the premises and a boarding house is planned to be ready

in spring 1997, if all goes well. The Deafblind Unit is working very well, and Inger continues to follow up staff training, assess students, and evaluate and refine individual programs. One of the staff, Idah Bakusuka, participated in the six week Professional Development Programme arranged by Sense International. Inger also had the opportunity to meet Idah in England to support her in structuring and adapting her new knowledge, ideas and experiences, before returning to work in Uganda.

The working period culminated with a two day meeting in Nairobi. The consultants shared their experiences, planned for the next year and then updated representatives from the East African countries about the programs and what they need to arrange in each country. This was followed by a two day parents seminar with attendance from across Kenya, Uganda and Tanzania.

Tanzania was not visited this time although it is in the program. The plan is to return to Uhuru Primary School, in Dar-es-Salaam, in February 1997 where they are working to renovate a building to use as a deafblind unit.

Next on the agenda is a one week workshop in November 1997. The participants will be 15 - 20 teachers from different deafblind units. The Uganda National Institute of Special Education in Kampala will host the workshop, and Inger and Evabritt are the responsible partners.

The purpose of the workshop will be to focus on 'Starting Communication with Deafblind Children', and the format will be to address the topic both in theory and practice. The practical part will be to work with one or two children from

Kampala and to use video-tapes. Inger has video-taped the work at the deafblind unit at Buckley over the year, and these tapes will be the basis for analysing practical work with individuals who are deafblind. Part of the workshop will be to produce small pamphlets about essential aspects of the topic.

When the consultants return in February 1997 to give another two weeks in-service training, the session will be closed, with a two day seminar concerning information to administrators, and will include headmasters, District Educational Officers, District Directors of Education and other persons that are important for the program.

Working in Africa is a very positive experience; it benefits both the deafblind units and the consultants who participate in the program. The feedback given show us that the East Africa Model is working.

**Evabritt Andreassen  
Regional Resource Center  
for Deafblind, Bergen, Norway**

## South Africa

On Saturday 20 July, a meeting of 30 deafblind people with intervenors was held at Cape Town International Airport. After the presentation of two papers, both dealing with the problems facing deafblind people from a personal and professional point of view, it was agreed to create a new national association. Hence Deafblind South Africa was born and a committee comprising a Chairperson, Vice-Chairperson Secretary/Treasurer and two additional members was elected.

The impetus for the creation of this organisation came from the Helen Keller World Conference in Italy a few years ago. The new Chairperson of Deafblind South Africa attended that conference and shortly afterwards began to address the needs of deafblind people in South Africa.

**Sandra Tyler, Chairperson  
Deafblind South Africa**

## Getting DbI Going

*In the last edition, Tony Best reported on the work of the IAEDB Strategic Planning Group and published its recommendations to the IAEDB Executive Committee which met in Vancouver, Canada in May. 36 members from 15 countries attended the meeting, at which a temporary Management Committee was established to put the decisions agreed at the meeting into action. The Committee met over 4 days and discussed the Strategic Planning Group's recommendations in detail, both in plenary and sub-plenary sessions. The recommendations were largely approved, but where modifications were made and further actions required, these are given below.*

The Management Committee (Mancom) is composed of Marjaana Suosalmi (Chairman), Mike Collins (Vice-Chairman), Rodney Clark (Secretary/Treasurer), Jacques Souriau (Immediate Past Chairman), Wolfgang Angermann (Deutsches Taubblindenwerk, Germany) and William Green (Lega del Filo d'Oro, Italy). Malcolm Matthews, currently editor of Deafblind Education, is to be invited to join the Committee in the new role of DbI Information Officer. Emanuela Brahmsha, Assistant International Officer for Sense, was Secretary to the Committee which held its first meeting in London during the weekend 11-13 October 1996.

The report below takes forward the 12 recommendations as given in Tony Best's article on Page 18 of the last edition of DbE. In each section, the words in quotes are the action recommended in Vancouver, followed by the decisions reached by the Mancom. It is proposed that the Management Committee will report to a meeting of the Executive Committee at the European Conference in Madrid, Spain in July 1997.

### 1 Individual Members

"Benefits and Responsibilities of membership need further definition. This should include a statement on access to representation on Council." The Mancom gave this matter a great deal of attention, recognising the importance of DbI to individuals in many situations throughout the world. In this respect, the importance of this journal was recognised as being the main contact with DbI for many people. The Mancom will be considering the Benefits and Responsibilities in greater detail at its next meetings. For representation on Council, see Section 5 below.

### 2 Corporate members

"Benefits and responsibilities of corporate membership need further definition. This should include a statement clarifying the difference between the nature of corporate and individual membership." Corporate membership is identified as the means of establishing a successful structure for the organisation, both

democratically and financially. The Council will be essentially composed of 2 groups, key funding members in one group and smaller corporate members and networks in the second. The first group will be composed of those corporate members paying a fee of \$2500 or more per annum, the second of those paying between \$200 and \$2000 per annum. Between this and the next Mancom meetings, it was agreed that a questionnaire should be sent to all Corporate Members to obtain their views to this proposal and to the reality of their adopting increased fees to underwrite the basic work of DbI.

### 3 Name

The new name, Deafblind International (DbI) was adopted at Vancouver and implemented immediately. "As well as a name, the association should have a strapline - a subtitle or phrase that explains what the association does. We recommend 'The world association promoting services for deafblind people'." This too was agreed for immediate implementation.

### 4 Structure

"The procedure and criteria for recognising a network needs to be established". William Green is to prepare a paper for the next meeting of the Mancom in May 1997. It was agreed that a network must be international and composed of at least 3 countries. Networks meeting the criteria to be agreed will be able to stand for election to the Council.

### 5 Council

"Principles and procedures are needed for council meetings and General Meetings, including frequency and definition of a quorum. Current practice in relation to Executive meetings should form the basis of this. The role of Country Representatives also needs defining". Wolfgang Angermann will produce principles and procedures for the General Meetings, Council, Management Committee and the Honorary Officers for the next meeting (see also Sections 6 and 7 below). Thereafter, Rodney Clark will produce a new draft Constitution and Bye-laws for presentation to the Executive Committee at the European Conference in Madrid, Spain in July 1997. The Vancouver meeting was concerned that country representatives should have a place within the formal structure of DbI. The Mancom recognised the importance of Country Representatives from the practical viewpoint of their being an initial contact point for members. However, it was unanimous in its view that the proposal that every country having individual members should have representation on Council was totally impractical, since there were already well in advance of 80 countries with members. The only possible solution is for the membership of the decision-

making bodies of DbI to be composed of the representatives of corporate members and networks and for DbI to work to ensure that every individual, wherever they may be, has the opportunity for membership of one of the other. One organisation in each country may be asked to be the initial DbI contact for that country, and one individual within that organisation be identified as the contact person. General Meetings for Corporate Members and Networks will be held every 2 years at either the World or the European Conference (this will be subject to modification as other regional conferences develop). It is further proposed that the Council be formed of a maximum of 25 members, divided between the key funding organisations and the small organisations/networks. The Council will meet as necessary between General Meetings, but at least once a year.

### 6 Management

"Decisions are needed on the composition of the Management Committee and details of an election process need to be determined. Their role needs further definition". This should be a small committee, not exceeding 6 people in number and meeting as often as necessary. Council will elect the membership but all Honorary Officers will be members.

### 7 Officers' posts

"Procedure for election of officers is needed. Further clarification of retirement and re-election." It is proposed that the Chairman and Vice-Chairman are elected by the General Meeting. The Treasurer and Secretary will be elected by the Council.

### 8 Finance strategy

"To implement this strategy, a budget and financial plan needs to be drawn up and presented to Council for every 4-year cycle. Procedures need to be established for achieving this". It was decided that the new constitution and all matters relating to it should come into effect as of 1 January 1998. It will be the duty of the Management Committee to draw up a budget and plan for the 4 year period starting from this date.

### 9 Administrator

"When this post is being filled, the management and employment conditions need further clarification". There was no discussion on this item, as the possibility of making such an appointment is a long way in the future.

### 10 Subscriptions

"Details need to be agreed on the principle of corporate subscriptions and the Treasurer should explore this with current corporate members. Levels of individual and corporate membership subscriptions need to be established, as do details of payment cycles". As stated above, a questionnaire is to be issued shortly.

### 11/12 Activities and Planning

No actions were recommended in Vancouver above what was recommended by the Strategic Planning Group.

# DbI

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.

## The objects of the Association as established are as follows:

- To promote the recognition of deafblindness as a unique disability throughout the world.
- To promote the education and development of deafblind people throughout the world in accordance with the educational and administrative requirements and with the socio-economic circumstances of individual countries, states and authorities.
- To guard and strengthen the civil rights of deafblind people and to ensure their equality of opportunity with other citizens.
- To promote continuing and life-long education and development for deafblind people.
- To promote and make known the variety and diversity of social support systems for deafblind people throughout the world.
- To promote interaction within the community of deafblind people.
- To promote interaction between deafblind people, their families, professionals and the wider community.
- To gather and disseminate information on research, staff development and programme methods.
- To promote research.

The phrase "deafblind people" is intended to encompass all age ranges, from childhood to old age, and all conditions of deafblindness, whether acquired congenitally or adventitiously.



The World  
Association  
Promoting  
Services for  
Deafblind People

**JOIN  
NOW!**

## Membership

There are two categories of membership: **individual** and **corporate**.

**Individual membership** is open to anyone and is without charge. An annual donation of £10/US\$20 is requested. Each country can have a representative on the Executive Committee for every 10 individual members. There is a maximum of three representatives.

**Corporate membership** is open to any school, association, institution, society or any similar organisation. There is an annual subscription of £100/US\$200. Each corporate member can have one representative on the Executive Committee. All members will receive *Deafblind Education* and may vote at General Meetings at the World Conference.

I wish to receive *Deafblind Education* in  English/  Spanish

I wish to become an **individual member** of DbI. I enclose £10/US\$20, or

I wish to become a **corporate member** of DbI. I enclose £100/US\$200, or

Please debit my Access/Visa/American Express card

Expiry date \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_  
Today's date \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_

Please return this to DbI, c/o Sense, 11-13 Clifton Terrace, Finsbury Park, London N4 3SR, United Kingdom.

[Please note that as Sense is Treasurer of DbI, credit card payments are made to Sense who then credits DbI]

Our corporate representative will be \_\_\_\_\_

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