

# DEAFBLIND EDUCATION

THE JOURNAL OF DbI - THE WORLD ASSOCIATION PROMOTING SERVICES FOR DEAFBLIND PEOPLE



## Focus on Inclusion

**SPECIAL EDITION**

*pages 7-19*

## Elderly Deafblind People

*pages 20-21*

No. 19 January-June 1997

# 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 Dbl.

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

**Editor** Malcolm Matthews

**Production Team** Emanuela Brahamsha  
Anna Cartwright  
Yvette Gallegos  
Richard Hawkes  
Asuncion Snow  
Judith Varsavsky

**Editorial Office** Sense  
11-13 Clifton Terrace  
London N4 3SR  
United Kingdom  
Tel: +44.171.272.7774  
Fax: +44.171.272.6012  
E-mail: dbi@sense.org.uk

**LAST COPY DATE FOR THE NEXT EDITION: 10 October 1997**

## MESSAGE FROM THE CHAIR

**D**uring the process of our strategic planning we asked members which mechanisms they considered to be the most important in the international work of DbI. You answered: the conferences and the Newsletter. You are now holding the newsletter in your hand, and many of us Europeans are on the way to Madrid. The main theme of the conference, 'Discovering the wor(l)d together', has appealed to me from the very first moment that I heard it. What clever people to have succeeded in including four so very important words in a short sentence: discover, world, word, together!

This certainly is a year when we in the deafblind world can really discover the world together. This year not only do Europeans have an opportunity to meet others, but two other big conferences are also taking place. The 6th Helen Keller Conference, the conference of deafblind people themselves, will be arranged for the first time in Colombia, Latin America. For DbI, it was a great experience to have a conference in Argentina two years ago. We wish the same kind of 'discovering of the world' to all the participants of the Helen Keller Conference. One of the decisions of the meeting of the DbI Management Committee in May was to propose to the World Blind Union and the European Blind Union that there



should be meetings between their deafblind committees and DbI representatives to see how we might better work together in the future to our mutual advantage.

In June the American National Conference will gather together around 700-800 deafblind people, professionals and parents in Washington, USA. The conference will focus on the rights of deafblind people and stimulate discussion from many perspectives.

I am aware that there are thousands of people who cannot participate in these conferences, but I am sure that, if we all take the responsibility for it, the discussions, new knowledge, ideas and contacts gained from these can be conveyed to the whole field and we can

all benefit from promoting the rights and services for deafblind people.

Finally, you may remember that in the last edition of Deafblind Education there was an article about the ways in which we are proposing to continue to develop and change our international organisation. The Management Committee has been very busy developing the thinking behind these changes in preparation for the meeting of the Executive Committee which will take place in Madrid on 18-19 July. A new Constitution is to be presented, together with a transition process that will take us from our old systems to the new, and which will culminate in a General Assembly of members at the World Conference in Lisbon in 1999.

As part of this new constitution our Information Officer and Editor of Deafblind Education, Malcolm Matthews, has written some new 'objects' for DbI (this is legal English for our purposes) which are published on page 23 of this edition. We very much welcome any views that readers may have on these objects, so please do write to Malcolm if you have any comments. The next edition will publish a much fuller report of the transition process, plus a copy of the draft Constitution, and report on any decisions made at the Madrid meeting.

**Marjaana Suosalmi**

# CONTENTS

## NEWS

**The development of communication. What's new?**  
Highlights from the international communication course

**pages 4-5**

**12th World Conference, Portugal page 5**

**Book Review page 6**

**Sense International (India) page 10**

**Sixth Helen Keller World Conference, Columbia  
page 22**

**Proposed Dbl Objects page 23**

## FEATURES

### INCLUSION

**'Inclusion' - What matters?**

The contribution of inclusion to the development of effective interaction skills is examined.

**pages 7-8**

**Inclusive Education: Meeting the needs of a child who is deafblind**

Practical suggestions from one family's creative approach to inclusive education.

**pages 9-10**

**An experience of integration in Canada**

The contribution of parents and professionals to the success of integration is examined.

**page 11**

**Inclusion of a deafblind student in a primary classroom at his neighbourhood school: A case study**

Curriculum subjects are re-examined to facilitate inclusion.

**pages 12-13**

**Inclusion in life: Living and growing with Maya**

Two approaches to education are contrasted through the struggle to gain appropriate teaching for Maya

**pages 14-16**

**Integration of deafblind children: The need for a thoughtful process**

A case for a reasoned debate on the merits of integration is considered

**pages 17-19**

**Conditions and syndromes that can result in deafblindness**

Focus on Toxoplasmosis

**page 19**

**Elderly deafblind people: An audit of ideas and experiences**

Current ideas and materials from seven countries are outlined.

**pages 20-21**

## COUNTRY REPORTS

**Greece page 22**

**Brazil page 16**

## EDITORIAL



This is my last *Deafblind Education* as editor.

I have been editor for issues eight to 19 over a period of six years.

Looking back over those issues I am pleased to see the changes that have been made. We are now commissioning more articles rather than relying on material gathered at conferences and we have extended the content to focus on much more than education and congenital deafblindness. We are now relevant, I hope, to the whole field of deafblindness from children to elderly people, and cover developments in education, social and welfare services.

Although there has been change there has also been continuity. We have continued to reflect the interests of the International Association for the Education of Deafblind People, now Deafblind International, and changes in *Deafblind Education* have mirrored changes in the deafblind field. The children that many professionals were working with have grown up and become adults and this is reflected in the articles on residential and other services for congenitally deafblind adults. Also, as the field has expanded to include people working with acquired deafblindness and people working in areas other than education, the content has reflected this.

We have continued to try to focus on issues and approaches from all over the world and to avoid promotion of approaches developed in northern Europe and America. However in this issue our main articles relate to inclusion and draw from experiences of countries in these regions. Inclusion was the most enthusiastically received topic at the Cordoba world conference but it was also the most controversial. As a result, rather than seek a definitive description, I have asked a number of parents and professionals to write about inclusion from their perspectives. I hope this will be illuminating and that others will want to contribute their views.

*Deafblind Education* is still a relevant title for this journal as its aims are to promote life long learning and to be a tool for the education of professionals and policy makers concerned with deafblindness. The last six years have certainly been an education for me.

Eileen Boothroyd from Sense is to be the new editor of *Deafblind Education*. In the next edition she wants to include articles on the subject of employment. Please do write to Eileen with comments and contributions. I have recently taken on the role of Information Officer for Deafblind International and will remain a member of the editorial team of *Deafblind Education*. However, I will be concentrating on the development of a forum on deafblindness through a world wide web page on the internet, and I hope to continue communicating with some of you through that medium.

Best wishes

**Malcolm Matthews**

## 'The Development of Communication. What's New?'

### Report on the International Course

Ton Visser

#### Introduction

From 23 to 26 June 1996, the DbI Working Group on Communication, comprising Marlene Daelman (Belgium), Anne Nafstad (Norway), Inger Rødbroe (Denmark), Jacques Souriau (France) and Ton Visser (The Netherlands), organised an international course under the title 'The development of communication. What's new?'. The aim of the course was to illustrate how current knowledge of the socio-interactive aspects of communicative development can be applied in professional work with congenitally deafblind persons and persons with related communication handicaps (such as congenitally blind children without language, persons with autistic problems and persons with multiple handicaps). The course was divided into three parts:

#### Plenary sessions

Current insights into the socio-interactive aspects of communicative development in children and adults with and without a handicap were summarised by Jacqueline Nadel (Directeur de Recherche CNRS Paris, France), Luigia Camaioni ('La Sapienza' University, Rome, Italy), David Goode (Associate Professor at the College of Staten Island, USA), Gunilla Preisler (University of Stockholm, Sweden) and Bertil Bjerkan (University of Tromsø, Norway). The presentations by these researchers made an overwhelming impression on many of the course participants. In the first place this was due to the wealth of theoretical material which has been generated on the basis of the recent research findings. Secondly, much of this theoretical material - provided it is developed adequately - appears to be highly suitable as a theoretical framework for supporting our everyday practical activities. Does the way in which we interact with deafblind children and adults have the impact on their development and quality of life which we imagine? Which aspects of communication development are open to influence? One of the reasons for the overwhelming impact of the

researchers' papers was the fact that many of us attempted in our discussions to make this translation into everyday practice directly.

#### Information video presentation

The video produced by the Working Group on Communication was shown and given to all participants, together with two articles. The first of these explained:

*'The video has been realised on the basis of a joint effort by five professionals ... Video clips from many countries were collected and analysed in order to discover the underlying principles of well functioning interactions ... This video will illustrate how promising it is to apply these principles as strategies for interaction'.*

The second article examined the history of the working group, and summarised the insights its members developed during their research. The study of a large body of literature, and in particular Nadel and Camaioni's book 'New perspectives in early communicative development' (1992), together with an analysis of many clips,

led to a number of important findings.

The first of these findings relates to the role which the conscious use of 'immediate imitation' can play in the establishment and regulation of mutual and joint attention, the building of a joint repertoire of expressive acts and a joint repertoire of interactional themes: The fact the adult decided to 'follow' or 'mirror' the child ensured that the child took the lead in the interaction. Imitating the congenitally deafblind person proved to be an efficient strategy in cases where he did not have a spontaneous repertoire of social acts, where he had developed autistic-like behaviours, passivity or withdrawal, as a consequence of enduring disruptions and deprivations with regard to social interaction'.

A second important finding was the gradual uncovering of those aspects which appear to play a crucial role in social interactions. The ability to recognise and regulate these aspects correctly in the interaction process is a decisive factor in enabling a genuine interaction to develop between a deafblind person and a hearing-seeing partner. This can make a major contribution to bringing about a permanent improvement in the quality of interactions and the prevention of severe communication and development disorders. Regulation of the following aspects of the interaction were perceived by the working group as highly important:

- proximity
- rhythm
- intensity
- tempo
- timing
- affective state
- expressive units
- attention
- novelty
- modality

The ability to recognise and regulate these aspects correctly will ensure that the most natural development possible of social and communicative interaction between people with congenital deafblindness and their seeing-hearing adult partners is able to proceed or be restored. This skill will genuinely enable the deafblind child or adult to become both the initiator of interactions and to make a continuous contribution to

The course proceedings, video and papers are available from CNEFEI to anyone who did not take part (price on request). If there is demand the members of the working group will be willing to help colleagues set up a course on 'Development of mutual interaction' within their own working environments. The use of a video is essential to this work, since only through distancing ourselves from our work by viewing video recordings is it possible to discover what our own role in the interaction process is and note how it can be improved.

The working group would like to thank all participants on the course for their extremely intensive contribution. This not only made organising and presenting the course a very enjoyable experience, but also made it a very inspiring event for every one of us.

**Contact address for course proceedings and video: CNEFEI, 58 Avenue des Landes, F-92000, Suresnes, France**  
Tel: +33 1 47 727 053  
Fax: +33 1 45 063 993

interactions. The interaction will then be truly shaped by both partners and will be characterised by a fluent response to each other's input/reactions. This will often naturally lead to a high degree of involvement with each other and a genuine sharing of each other's experiences and feelings. On the basis of adequately developing interaction processes, deafblind children (and also deafblind adults sometimes) will be able to achieve good communication development, which is then not characterised solely by repetition within a known situation of fixed action/reaction patterns with a very high degree of predictability.

### Workshops

Five workshops were led by members of the working group and focused on video clips of their working situations. Participants analysed these with the aim of determining whether it was possible to recognise which aspects of the interaction need to be regulated and to discuss alternative forms of intervention which may have been more useful. The following discussions all proved to be extremely lively and often intense. It was clear that this aspect of our work with and for deafblind children and adults is seen by many as its most fundamental element.

### Conclusion

A panel of participants was formed at the end of the four days to give their reactions to the course. The majority of the course had provided a great deal of clear, directly applicable information and focused on learning to understand the most essential aspects of communication. It was agreed that this fundamental insight can help in offering the people we work with a better chance to 'really be someone in their own right'. It was moving to see in the videos how often this approach can succeed, despite the very difficult circumstances.

## 12th World Conference 1999

At the meeting of the Executive Committee held at the 11th World Conference in Cordoba, Argentina in July 1995, it was decided that the 12th Conference should be held in Lisbon, Portugal in summer 1999, hosted by Casa Pia de Lisboa. Casa Pia is a large, Government child care agency, providing residential, education and other services for more than 4,000 children, both disabled and able-bodied, throughout Portugal.

This has been a very popular decision, especially since education for deafblind children only began in Portugal in the late 1980's. It recognises the great progress that has been made since that time, when Antonio Rebelo and Maria da Graça attended the European Conference at the University of Warwick in the UK in 1989.

Support from the Instituut voor Doven in the Netherlands and from Perkins School in the USA, plus regular contact with DBI friends and colleagues which Antonio has assiduously maintained over the years, has seen a healthy development from the first small class in September 1996 to the opening of a new, purpose-built school in the heart of Lisbon for 17 deafblind pupils, the Colegio A.A. Costa Ferreira. Marjaana Suosalmi, Chairman, and Rodney Clark, Secretary/Treasurer, had the privilege of visiting the school and meeting with the staff shortly before its official opening.

Their purpose in Lisbon was to discuss plans for the 1999 Conference. Three full days were spent, visiting potential sites,



**Signing of the Formal Contract between Casa Pia and DBI. From left to right: Antonio Rebelo, Director, Colegio A.A. Costa Ferreira, Lisbon; Luis Rebelo, Director, Casa Pia de Lisboa; Rodney Clark, Secretary/Treasurer, DBI; Videira Barrelo, Deputy Director, Casa Pia de Lisboa.**

considering the proposals for the various committees and agreeing a basic strategy for the management of the event. These agreements were constituted as a Formal Contract between Casa Pia and DBI, and the signing of the contract took place in the Board Room of Casa Pia last December. The signatories were Luis Rebelo, Director of Casa Pia, and Rodney Clark for DBI. Antonio Rebelo proposed a toast (using the finest Port, of course) and promised that the 1999 Conference would be the best ever. Luis, who is Antonio's brother, said that Casa Pia would ensure that the conference received whatever support it needed to make it a success. Present at the ceremony were 13 senior representatives from Casa Pia who all expressed their enthusiasm for the event, in addition to their pride at being successful in bidding for it. It was felt that the conference would substantially

enhance the development of services for deafblind people in Portugal.

The venue has not been decided, although the front-runner is currently a fine Conference Centre in Estoril, close to Lisbon, where hotel and catering staff are trained, so the food should be wonderful! The Planning Committee is being chaired by Isabel Amaral with the involvement of Luis Silvera, Director of Resources for Casa Pia. The Committee has already begun its work, notably the identification of the venue and the establishment of the management for the conference.

The Programme Committee will be under the chairmanship of Antonio Rebelo and its membership is being finalised at the time of writing (January). It is hoped that its first meeting will be held towards the end of February.

**Rodney Clark**  
Secretary/Treasurer, DBI

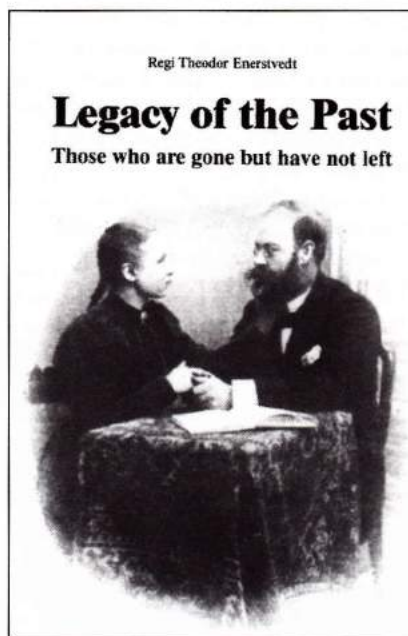
# Book review

**A**lthough the author sub-titles his book 'Some aspects of blind education, deaf education and deafblind education with emphasis on the time before 1900', Professor Enerstvedt's book is neither restricted in the 'aspects' chosen nor relevant only to investigation into history. It is both a scholarly study and a provocative discussion of issues of great significance to present provision and education affecting the lives of people with impairment of either distance sense or both.

Professor Enerstvedt not only presents a wealth of historical evidence and surmise from around the world, but examines the ideas current at the time in those cultures and, in doing so, challenges many views which still hold adherence today. Professor Enerstvedt is particularly alive to the effect that beliefs, dreams and wishful thinking have had on the treatment of those not able to compete on equal terms in a sighted and hearing world. For future policy, he reveals a burning concern that reality should be faced and that knowledge should be advanced, regardless of intense desires that all people should function, or be seen to function, as nearly as possible like the sighted and hearing majority. In espousing recognition of diversity and difference without placing social value judgements upon degrees of difference, Professor Enerstvedt dares to challenge our ideas of 'normality' as 'being like us' and asks the reader to reconsider which aspects of 'like us' are 'normal'.

Regi Enerstvedt is a Professor of Sociology at the University of Oslo and also Senior Research Officer at Skådalen Resource Centre for Special Education of the Hearing Impaired and the Deafblind. It must also be of significance that Professor Enerstvedt deliberately sought periods of practical work experience among deafblind people in different countries during the course of his lengthy research.

The book is divided into three chapters, each serving as separate volumes considering in sequence the development of educational theory and practice for blind education, for deaf



## Legacy of the Past. Those who are gone but have not left

Regi Theodor Enerstvedt.  
Dronninglund, Denmark: Nord-Press, 1996.  
399 pages.  
Reviewed by Norman Brown

people and for deafblind people. Each chapter in itself is therefore an invaluable study of changing attitudes and educational approaches for the unique impairment but much delight comes from dipping into all three to see how common or cross influences operated or did not operate. Such enquiries are aided by the detailed table of contents, which lays out clearly what can be found in each chapter's subdivisions, while Professor Enerstvedt himself aids the reader in considering cross-influences because it is one of his own considerations. Many and detailed footnotes throughout enable the scholar to check exactly what is being offered, while enabling the general reader to keep to the main text without the diversion of additional explanations.

It is a rare opportunity to have three such studies in one binding. The book

is therefore something of a treasure house with three adjoining chambers, where the visitor will find not only well-remembered, half-remembered or long-lost treasures but will also come across new ones to intrigue and enjoy.

The author's admittedly individual style also adds to the fascination of the book, moving as it does from dispassionate exposition to personal examination and challenge, culminating in the proposition in the Epilogue. It is also welcome to have the perspective of a scholar from northern Europe, when so much available in English has inevitably come from English-speaking countries.

It is a book which, once acquired, will be returned to again and again, either as an excellent first door of enquiry leading to further sources of study, or as refreshment of the mind concerning alternative views on significant issues.

Although Professor Enerstvedt claims 'the time before 1900', in the education of deafblind people he certainly covers new thinking up until 1990. It is only the most recent research and thinking on the development of early communication that is missing from his broad coverage and one cannot criticise him for that. Had he waited to see its effects, the present book would still be in manuscript form and we would have been the losers.

I fully expect to find the book upon the shelves of every library claiming coverage of sensory impairment, and also in the study area of every teacher and student of education for learners with sensory impairment. For those interested in deafblindness, the book is a unique source, gathering in one volume as it does, the history of influence and inspiration that gives perspective in a way that was not possible before.

**Norman Brown is Joint Course Co-ordinator of the Distance Education Programme in Multi-Sensory Impairment at the University of Birmingham, UK, and Specialist Adviser in Congenital Deafblindness for Sense The National Deafblind and Rubella Association.**

**At the world conference in Cordoba in 1995, Maria Bove gave a plenary presentation on inclusion that created great excitement and enthusiasm in the audience but also raised many questions and concerns. Deafblindness is a unique disability with a low incidence. For years professionals and others have argued, especially in Deafblind Education, about the need for specialist dedicated provision for deafblind children. For some inclusion is perceived as potentially resulting in the end of appropriate education for deafblind children. For others it is the beginning.**

**Parents and professionals, mainly but not exclusively from North America and Canada, were asked to write about their experiences of inclusion related to deafblindness. It is hoped that this approach will give a broad picture and lead to further debate and discussion both within the field and in Deafblind Education.**

## 'Inclusion' - What matters?

**Anne Nafstad, Skådalen Centre, Oslo**

### **It matters to belong**

My colleague Inger Rødbroe showed a video in Cordoba of a young congenitally deafblind boy who lived on a farm in the countryside. We saw him with his mother and father, with cows and tractors. The child goes to the local school. What does this child gain? He has access to a context that gives meaning to his life and he shares events and experiences with his family. He is 'himself' and 'one of them' and a 'farmer's son'. The family wants the community to include him as he is what they call a 'special variation'. They want to expose this child and give him a future in a community in which he is not a stranger. Gradually, people will learn

to interact with him and communicate with him because he is 'one of them'. He belongs there.

The Cordoba story was very special. There is something in that story that makes me optimistic when I think about the future of congenitally deafblind children. Parents and families can think differently from professionals, they see other options and other solutions. The solutions they imagine are not constrained by the policy of an institution or by the ideology of a professional. For that reason my own 'philosophy' as regards 'inclusion' is primarily to support parents and families in their ability to interact and communicate with their child. In this way they are free to be

the experts on their child. Only then can they become free from institutional policies, disagree with professionals and decide what is right for their child. I do not think professionals and institutions should be involved in that kind of decision. Modern professionals like myself are not sufficiently personally accountable. I can give advice today, have a good idea tomorrow, change my mind the day after and leave in a week.

We have tended to reserve the capability of interacting and communicating with congenitally deafblind children for professionals. How come? There may have been good reasons for that in the past, but the good reasons are gone.

## The basics of inclusion – The knowledge we did not have

As regards communicative development, a paradigm shift has taken place both outside our field and inside the field. This paradigm shift is reflected in the work of the European Working Group on Communication and Congenital Deafblindness (see pages 4-5).

Modern infant research has revealed that the human infant is a socially interested being from the start. He does not have to learn to be interested in being with other persons. The human infant is precoded to learn and grow within the context of interpersonal togetherness. The idea of 'symbiosis' from which an 'I' and a 'you' gradually matured and emerged is declared dead. The infant is ready to enter into a dyadic space consisting of 'we-here-now'. The 'we' is not symbiotic, but rather immediately rhythmically harmonised, affectively tuned, reciprocal and symmetrically patterned. A Norwegian spokesman for this paradigm shift, Professor Stein Bråthen, talks about 'companion space'. I understand this metaphor to denote the expectation that the child is born with precoded attention to typical aspects of inter-subjective events within a space meant to contain a companion. This inter-subjective dyad is our smallest species-specific ecological niche, within which we grow as a part interconnected with other parts into dyadic, triadic and gradually more complex human systems and networks. The moment the midwife cuts us off from our mothers, we are disconnected from the primitive symbiotic system, but with a very strong biological guidance towards being immediately reconnected within another much more advanced and adaptive system, the interpersonal human dyad.

Congenitally deafblind infants easily become unconnected or only partly connected little beings in the postnatal interpersonal system. With the knowledge we have today, we can prevent this happening. We know how to support the co-construction of the dyad so that these infants are included

in the primary spaces of human togetherness. It is a big step forward. The knowledge is simple and rather solid. Simple and solid enough to be transferred to families and family-based networks around individual congenitally deafblind children wherever they live.

The co-construction of a primary social-interactive dyadic space does not happen 'by itself' in cases of congenital deafblindness despite this kind of event being biologically guided. Even if

## It is necessary that deafblindness is acknowledged as a unique handicap

parents and children have a close relationship from the point of view of attachment, it can be that the social interactive dyadic relationship is not established or that it is very weak.

*Without the primary reciprocal inclusion of the congenitally deafblind person and his primary partners into a shared dyadic space of affective-social togetherness, more advanced forms of human togetherness (cognitive, communicative and linguistic) in which the natural process of learning and development take place, cannot emerge.*

The co-construction of a shared cognitive and communicative space occurs along the same lines, but the processes are increasingly more complex, and there are many more individual variations. Current knowledge about how to include

## The change towards an open and inclusive society is a change towards the better

congenitally deafblind children in communicative spaces of shared meaning is not very strong yet, but it is coming. Something will probably come from the European Working Group on Communication, and there is also a Norwegian study into the subject. So far we can say this:

*Congenitally deafblind children need to be included in the co-construction of their own communicative spaces. They need take an active part in events that nourish co-construction of the topics of their conversations. They*

*need to be active participants in co-constructing a first vocabulary of shared meanings, and they need somebody who is willing to listen to their stories. Somebody who understands, but does not teach.*

## What matters on a system level

The situation may easily occur where congenitally deafblind people are included into larger and more common handicap categories, and thereby made invisible. A basic prerequisite for any step towards inclusion is that congenitally deafblind people are identified and treated as congenitally deafblind people; as belonging to a subgroup within the group of deafblind people. It is necessary that deafblindness is acknowledged as a unique handicap, in particular in relation to communication and language. Congenital deafblindness needs special attention by definition.

## The old story

When I started work in the field 15 years ago, it was common for professionals to construct parents as 'clients' or 'victims of an unfair fate' along with their congenitally deafblind children. Representatives of local community agencies were often regarded as ignorant and unable to see the needs of the deafblind person. In our own stories, it was common to construct local agents as 'enemies'. We also constructed congenitally deafblind people as so special that they could only live and learn in very special,

extremely marginalised (and hidden) institutional environments where the architecture, activities and lifestyle were planned and made sense only to the heroes (ourselves). But it is easy to be critical when times have changed. I do believe, however, that the change towards an open and inclusive society is a change towards the better. We are free to connect in interpersonal networks across all former boundaries. These complex networks of people create flexibility and multiple and individualised options. Networks or reciprocal relationships also create reciprocal personal accountability. There are many more facets to inclusion.



# Inclusive education: Meeting the needs of a child who is deafblind

by Nancy Hartshorne

**A**t the time we are writing this article we are going through a tough time with the education agency serving our son. Although we have always felt that Jacob's education has been excellent, and are very proud of our efforts at inclusion, we are beginning to run into some obstacles that are difficult, although not insurmountable.

Jacob is eight years old, and has CHARGE syndrome, a condition that often results in some degree of hearing and/or vision loss. He currently attends his neighborhood public school and is a member of the second grade classroom. He has a profound sensorineural hearing loss, and is visually impaired, although he uses the vision he has quite well.

When researching deafblind education a few years ago, I found that a growing trend in some parts of the United States is to educate these children in the mainstream, with their same-age non-disabled peers. The reasons for this are 1) to ensure that what the child learns is functional for them in an inclusive community setting, as opposed to only being functional, or comfortable for them in a segregated setting, and 2) to ensure that the child becomes socialized, or a part of, his or her natural community. Inclusive community living and employment are aspects of life that we value for our son, and so this seemed the way to work towards achieving these goals.

Many experts in deafblindness agree that there are three main components that contribute to the necessary education for a person who is deafblind. These are:

- 1 teaching communication skills,
- 2 teaching orientation and mobility skills, and
- 3 using a functional curriculum.

Anyone who reads this journal probably already understands the importance of the first two components. Children and people who are deafblind need to be able to make their needs, wants, and feelings known, and to physically navigate the world around them as well

as possible. Both of these components give them a degree of freedom they would not have otherwise. A functional curriculum refers to teaching a person skills used in everyday life, or skills that will enhance the person's ability to get along in the world, as independently as possible. For example, instead of teaching a person a sorting task involving screwing nuts onto bolts, (a task often assigned in a segregated workshop setting and taught in isolation) a person could be practising sorting and fine-motor skills by placing the same piece of mail into many mailboxes. The person could be responsible for setting out cups for snack time at school, or taking tickets in the lunch line. These are all skills that are functional, that is, they are skills that are accepted as valuable in the general community, and to some degree they encourage socialization with non-disabled peers.

This brings me to a fourth component I would add to the list: socialization skills. Friendships are important for Jacob because his current friends are the people that will grow up to be leaders in our community, people who may assist him, teach him, and hire him. They are also people who will continue to socialize with him.

So, how do we bring all of these components together in an inclusive setting? Let me define what I mean by inclusive. Jacob receives all of the supports and services he would receive if he were in a segregated classroom in a segregated school. He merely receives them alongside his peers without disabilities. He has a full-time assistant to help him through his activities each day, to interpret others' communications to him, and to facilitate his socialization with friends. Jacob does not spend his entire day in the general education classroom however. He has speech and auditory training with a speech and language teacher for one-half hour per day, and leaves the second grade room to use the toilet four times a day, which can be a time consuming task. He attends physical education with his

classmates and receives physical therapy in the context of what is going on in the class. He receives occupational therapy to work on feeding skills during lunchtime in the cafeteria. He goes outside for recess with the other children, and to art and music classes as well.

Jacob receives communication instruction from his assistant throughout the day in functional settings. She communicates with him constantly, and encourages him to make choices about activities when possible. He currently uses an object/symbol communication system, which he carries with him in a pack wherever he goes. His assistant is very creative when it comes to making communication opportunities for him.

## We have adapted the curriculum areas to meet Jacob's needs

Even though this sounds chaotic, Jacob does follow a daily schedule and routine that he is comfortable with. The fact that he must move around the school building for so many varied activities lends itself well to orientation and mobility training. He is now expected to locate different rooms he goes to based on a symbol cue given him and is becoming more and more adept at this.

As stated before, we are trying to use as functional a curriculum as possible with Jacob. Of course, this makes things difficult at times when the other students in the room are doing things that are highly academic, but this is something that can be overcome. For example, if a goal for Jacob is to learn to write his name, or even the first letter of his name, he can work on this activity while the other children are working on penmanship or language arts. In this way we have adapted the curriculum areas to meet Jacob's needs. When the other

## FOCUS ON INCLUSION

children are working on multiplication tables, Jacob may be learning to label groups of blocks by number, or just stack them, to enhance his hand-eye coordination skills.

This type of program takes a great deal of planning, and I am the first to say that it has not always been successful. But there are certain vehicles that can be put into place to help ensure success. The two most important are:

- 1 an educational team of people that share a philosophy, are enthusiastic, and willing to meet on a frequent basis to plan, and
- 2 a Circle of Friends.

The importance of a collaborative team cannot be emphasized enough. The cohesiveness of this group of people can make or break a program's success. We have come very close to losing this cohesiveness many times, and it is usually because someone on the team does not understand the "why" of Jacob's program being inclusive. Sometimes we win over that team member, and sometimes we struggle with making it work. This is what our current struggles are all about. It has by no means been easy. It takes a dedicated team to work through this.

Circles of Friends are groups of

people that form around a person with a disability to support the person's inclusion into his or her natural community. For Jacob, this means that his age peers meet on a monthly basis, and help to identify problems and plan fun activities for Jacob and his friends. When problems arise that the circle can give input to, this is, in a way, listening to Jacob's voice about what he would like to see happen. In other words, eight-year-olds know what other eight-year-olds want, think, feel, and dream about, and many times are more able to identify these things for Jacob than we, as adults or service providers can.

A circle of support need not be a formalized group, but could just be peers that care about and interact with a child with a disability. Jacob has many friends that interact with him who aren't part of his formal circle. This is because he started attending the general education setting at the age of five, when all the children started. These kids have never known that it is unusual for Jacob to be at their school, and they have always accepted him wholeheartedly. A formal circle of friends is almost a necessity for a child who enters a general education setting at a later age, however, as the circle of support can help facilitate the

transition into new classrooms and friendships.

As stated before, our experience and trials with Jacob at school in an inclusive setting have by no means been easy, nor has everything always gone the way we would like it to go. But we feel strongly that if we continue to work toward the ideal program, things can only get better.

What about the future? Our hope is that Jacob will stay in the inclusive setting until the sixth grade (twelve years old). Beyond that, there is a different system in place to contend with, the middle school. Whether we continue to ask for an inclusive school setting, or request that the school begin providing vocational training in the community at that time, remains to be seen. It will depend on Jacob's skills and rate of learning, and on what new developments have been made in the field of deafblind education. Unfortunately we live in a rural area that is somewhat 'behind the times' educationally. For this reason it will never be a matter of availability of suitable programs. We created this program for Jacob and we will continue to create appropriate programs for him throughout his life, if that is what it takes for him to achieve his potential and still be a happy, accepted, and contributing member of his community.

### Sense International (India)

**Sense International has appointed its first overseas based member of staff and has created Sense International (India).** On 1 January, Akhil Paul became the first Development Manager for Sense International in India. Akhil has considerable experience of working with people with visual impairments and those with multiple disabilities. He previously worked for the National Association for the Blind - India (NAB) and the Blind Men's Association (BMA). He is also on the Asia Regional Committee of the International Council for the Education of People with Visual Impairment (ICEVI).

India currently has only one specialised school for deafblind children - the Helen Keller Institute for the Deaf and Deafblind in Mumbai (formerly Bombay). This school provides a service for 23 children - an excellent service but simply not enough for a country which could well have more than 300,000 deafblind people. Whilst no national assessment of the deafblind population has ever been undertaken, figures for people with single disabilities are as follows:

- Visual impairment - 4.597 million
- Hearing impairment - 3.995 million
- Learning disabilities - 19.800 million

Following an extensive training and induction programme that included



**Akhil Paul, Development Manager, Sense International (India)**

detailed visits to the Instituut voor Doven in the Netherlands, Perkins School for the Blind (USA) and centres throughout the UK, Akhil's immediate priority is to undertake the first ever nationwide survey of the situation for deafblind people in India. This will identify organisations willing to work with us, possible project partners and initial estimates of the

deafblind population. We intend to identify projects to develop and support which will become sustainable services for deafblind people in the long-term. These may include schooling, pre-school support, family support, immunisation programmes, the development of residential and non-residential services for adult deafblind people, and vocational training for young adults. However, we will wait for the results of the national assessment before deciding on the specific areas of development.

**Richard Hawkes  
Sense International**

# An experience of integration in Canada

by Julia Downs

**"Hi, my name is Mark, and I am 13. This June I will graduate with the class of '97 from Manoad Steves Elementary School in Richmond, British Columbia, Canada. I have been at Manoad Steves for eight years since Kindergarten. It is my local school. My younger brother goes there too and all the kids I know in our neighbourhood.**

**My favourite subjects are gym and music. I find most of the academic subjects pretty boring and prefer recess and lunch when we get to play hockey or basketball. Last year in Grade six I really enjoyed going away to Outdoor Education Camp for a week. We learnt about life outside - lakes, forests and mountains. We had a great time canoeing on the lake, hiking through disused tunnels, eating and being away from our parents!"**

**T**his is a fairly typical account of life at elementary school in Canada. The only difference is that Mark is deafblind. He is fully integrated into his local school with the help of a one-on-one intervenor provided by the school district. A Provincial Resource Teacher for the Deafblind visits the school on a regular basis to help adapt the curriculum. She offers suggestions on what is meaningful for Mark to participate in. She assists with training new staff and does simulation exercises for classmates of what it is like to be deafblind in the classroom. The Provincial Resource Team has been a central part of the success of Mark's integration.

Mark's school program has been flexible and changed each year. In Kindergarten Mark did exactly the same activities, with assistance, as all his peers. A highlight was graduation when Mark walked into the classroom with his classmates wearing a mortar board. Both walking and wearing a hat were great achievements and celebrated by all present.

**This is what integration means. Being able to participate to the best of your ability and be accepted for who you are**

In later grades when Mark could not sit or focus for any length of time he had a three-fold program: a classroom based component, a school based program, for example, watering the plants, passing out notices, and a community based program, which included shopping, swimming and traffic safety. The school based team met on a regular basis to plan this program. As parents we always participated fully in these meetings and

also in the Individual Education Plan meetings which were held three times a year for the whole team. Outside therapists would join these and they often comprised 12 people.

Mark's eight years of elementary schooling have flown by. Upon reflection the majority of those years have been good ones for Mark. Naturally there have been ups and downs. Grade six was by far the best. Mark had been at school for seven years. The staff were all comfortable with him. He had an excellent male intervenor and the two of them just clicked. Outdoor Education Week was amazing. We heard wonderful stories from all concerned - including other parents whose children attended. To us this is what integration means. Being able to participate to the best of your ability and be accepted for who you are.

We truly appreciate all the wonderful staff who have been involved with Mark from the principal to the janitor. All were equally important to Mark's participation in school life.

Coyne is an eight year old boy who attends Charlie Lake Elementary School, along with his younger brother and the kids from his neighbourhood. He is currently registered in a grade two classroom. He continues to delight his classmates, teachers, and family with his remarkable progress.

When Coyne first arrived at school, almost three years ago, his attention span was about 2-3 minutes. He could not be encouraged to stay with any task. Now it is not uncommon for Coyne to spend 30-40 minutes engaged in preferred activities. During the first few months at school, Coyne seemed unable to make any sense of his visual world. Now he has begun to establish eye contact with people and objects in his environment and to develop visual attending behaviours.

The casual observer in Coyne's classroom would be startled to learn that he is deafblind. Coyne is diagnosed with cortical visual impairment caused by a severe seizure disorder during his infancy. He also has a moderate to severe conductive hearing loss, bilaterally, due to recurring middle ear infections and scar tissue on the ear drums. As a result, Coyne has generalized developmental delay. Despite these difficulties, he interacts with his classmates and follows routines in the classroom.

Coyne's success is due, in part, to a support team comprised of family members and educational personnel, and a carefully planned transition process. Coyne's support team includes his parents, school based staff (Classroom Teacher, Teaching Assistants, Principal), itinerant staff (Inclusion Support Teacher, Teacher of the Hearing Impaired, Speech/Language Pathologist, Physiotherapist), and provincial support staff (Deafblind Outreach Program Consultant, Special Education Technology Regional Representative). Although we do not have a Teacher of the Visually Impaired in our school district, we were able to contract this service from a neighbouring region. The teacher is able to travel to our district twice each year, and has become a visiting member of Coyne's team at these times.

The transition process developed for Coyne began several months before his first day at school when he entered the Kindergarten program. It involved a series of steps including school and



*Coyne participating in circle time activity with his classmates*

support staff observing Coyne at the preschool and meeting with the parents and preschool staff; Coyne making four visits to his new school accompanied by his Teaching Assistant from the preschool; Coyne's mom and the school principal interviewing applicants for teaching assistant positions, and the newly hired teaching assistants (T.A.s) spending the first two weeks of school observing Coyne and working with him in the home environment. He began attending the school program on a part-time basis and, over a period of one month, his participation was gradually extended until he was comfortable with a full day.

Keeping in mind the demands and intensity of working with a deafblind child, and recognising Coyne's high

activity level, we decided to request two part-time teaching assistants for Coyne instead of a single full-time position. This has proven to have had many benefits. The two T.A.s find it very helpful to be able to communicate, on a regular basis, with someone else who has in-depth knowledge of the student. They appreciate being able to do a lot of collaborative problem solving and sharing of insights and successes. They confess that they are tired at the end of a shift with Coyne, and are better able to find the energy and enthusiasm to work with him again after some time off.

Once Coyne began attending school we quickly found that we did not have enough, or the right kind of, activities prepared for him. We had been offering Coyne a variety of table activities using manipulatives which he rejected. With the help of our Deafblind Outreach Consultant, we began to search for different materials, develop modifications, and create new activities. He needed more movement and motor experiences that allowed the T.A.s to establish a bond with him and work through the early stages of imitative play (resonance and co-active activities).

Coyne would only tolerate classroom activities for very short periods of time, so we developed a hall pass for him. By clipping the hall pass to his shirt (a picture symbol for walk in a reusable conference name tag holder), he quickly learned that he could leave the classroom for a short period of time to explore the halls, ramps, and stairways.

**Coyne's classmates include him as a member of their class, volunteering to help out when he is having difficulty and celebrating with him when he is successful**

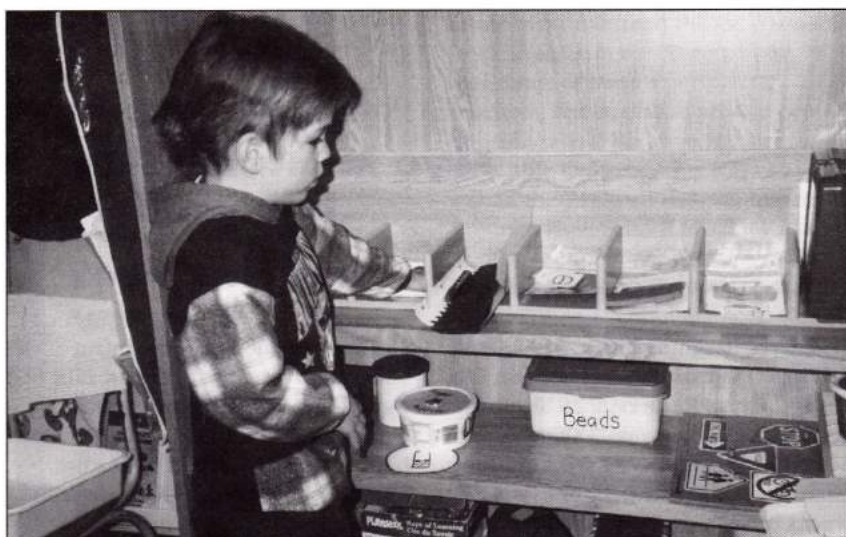
# Inclusion of a deafblind student in a primary classroom at his neighbourhood school: A case study

## Lesley Lahaye

He enjoyed his walks, and was then able to come back to class and be introduced to other materials.

We also set up a station for Coyne on the gym stage. We used portable blackboards to block off an area and arranged a rebounder, stairs, bench, and mats into a small obstacle course. The key to the stage door on a brightly coloured ring became his cue, and he could choose to do motor activities even when a class was using the gym. During Coyne's first months at school, he spent a great deal of time with his T.A.s in the hallways or on the stage. Gradually he began to tolerate table and centre activities in the classroom, and to imitate play with his preferred materials. Now he seldom uses his hall pass and his obstacle course activities have been included in the regular gym program.

We have used the Michigan Scale to track Coyne's development in key areas, and used this information as a basis for his Individualized Educational Plan (I.E.P.). We have been able to adapt or modify some of the classroom activities for Coyne (e.g. journal, calendar, buddy reading, computer



**Coyne checking his morning routine using his communication calendar box**

class, gym). When the class receives instruction on specific academic skills from which Coyne cannot benefit, we provide alternate activities (on the same theme) targeted to his developmental level.

Although Coyne is registered in a regular classroom program, he does not spend all of his day working within the confines of the class. He leaves the room for a thirty minute auditory training session (with the Teacher of the Hearing Impaired) twice each week. He participates in a swim program (accompanied by his teaching assistant) at the community recreation centre one afternoon each week. He also leaves the classroom for a daily snack routine in the afternoon. These activities provide opportunities to work on self-help skills and personal safety. Often Coyne chooses a buddy from his class to join him.

A major area of focus in Coyne's program has been the development of communication skills. We began in Kindergarten by introducing him to a communication calendar system using object cues. Gradually we paired tracings of objects with the objects they represented to help Coyne attach meaning to two dimensional symbols. We repeated the process with black

and white line drawings. We were then able to use the line drawings to help extend Coyne's receptive and expressive communication skills, along with sign language.

Perhaps one of the most exciting aspects of Coyne's program has been the opportunity for him to interact with non-handicapped peers. Coyne's classmates include him as a member of their class, volunteering to help out when he is having difficulty and celebrating with him when he is successful. They have begun to spontaneously use the sign language they have learned from short daily lessons with the T.A. when they interact with him in the classroom and on the playground.

Coyne is a well established member of the class and is comfortable in the regular classroom environment. The students are interacting more with Coyne and he is responding. There is no doubt that he will present us with many new challenges, but we are on our way! Coyne's successes will continue to fuel us in seeking solutions for the problems we meet along the road.

**Lesley Lahaye is an Inclusion Support Teacher, School District #60, Peace River North, Fort St. John, British Columbia, Canada.**



**Coyne completing an adapted calendar activity by lacing tactile markers in the square to indicate each school day**

# Inclusion in life: Living and growing with Maya

**Faye Manaster Eldar, MEd.  
Illinois, USA**

**O**ur daughter, Maya, who is now 15 years old, was born on 31 July 1981, at only 26 weeks gestation, weighing just 700 grams and 34cm long. She spent 14 weeks in the intensive care nursery (11 of those weeks breathing with the assistance of a respirator) and came home weighing almost 2,200 grams, able to breathe on her own and eat orally. Prior to her discharge, her eyes were examined by an ophthalmologist and she was pronounced to be blind due to retinopathy of prematurity. Having been a special education teacher prior to Maya's birth, I immediately asked the neonatologist to test Maya's hearing. I was told that it wasn't necessary because 'the doctors knew that Maya could hear' and 'Maya didn't act deaf'.

When I asked for a referral to an infant stimulation program, the neonatologist said that 'Maya didn't need that - those programs were only for families who left their babies lying in their cribs all day, and I know you won't do that'. Due to my training in special education (I have degrees in psychology and learning disabilities with behaviour disorders), I went to our local library to do research on Maya's problems. What I found were studies on infants with severe disabilities who had grown up in institutions and literature describing babies who were 'only' blind who had abilities that far surpassed Maya's at the time.

Maya attended a neonatology follow-up clinic monthly for the first year of her life, and received home visits from a visiting nurse as part of a follow-up program for high risk infants.

She also attended a private infant stimulation program in our area. In all these settings, I repeatedly stated that I felt that Maya had additional difficulties beyond being blind and premature. The professionals involved kept telling me that I was simply worrying too much and that Maya was doing fine. Also at that time, my mother, who was a physiotherapist, was becoming aware that Maya had some motor difficulties

## **The challenge of inclusion is how to provide disability-specific instruction in a 'normal' environment**

and had begun to work with her. Unfortunately, she was diagnosed with Alzheimer's disease shortly thereafter and lost the ability to articulate Maya's motor problems. Things changed after Maya's first birthday, when the regular neonatologist went on holiday, and was replaced by a new young doctor. He told me that he agreed that Maya had additional problems, and referred her to an audiologist, neurologist and physiotherapist for evaluations.

We celebrated Maya's first birthday with a big party, just as we learned that she was also deaf and had cerebral palsy. When we shared this information with the infant stimulation program staff, they responded by

expelling Maya from the program, stating that 'she was too severely handicapped to be helped'. Through our involvement in our local Lekotek (toy lending library for children with special needs) we learned of an infant stimulation program in Chicago's inner city that would accept Maya (after a six month wait), and also that our state has a federally-funded deafblind service center that provided direct services to infants in their homes. Unfortunately, these programs did not have year-round funding then, and were closed for the summer at the time Maya was diagnosed, so we had to wait until September for services. We were devastated and worried that Maya would never be able to learn anything.

When we look at Maya today and see a bright, capable young lady who has many abilities we wonder about the professionals who had written her off as 'too severely disabled' and told us to expect very little from her. We wish that they could see Maya today and realize how wrong it is to prejudice an infant's or child's abilities without providing services geared to their specific needs. In my opinion, this is the challenge of inclusion for children who are deafblind: how to provide disability-specific instruction in a 'normal' environment.

Maya has been in a wide variety of school placements, including a special public school in an adjacent town for students with 'moderate to severe disabilities with or without hearing impairments'. Maya attended this school for seven years, after the principal initially told us she was 'too

low functioning' to attend his special school. Maya made excellent progress while she attended the class for three - five year olds at this school, entering with only six expressive signs in her vocabulary and making 24 months of progress in language development in the first nine months. When she moved on to the primary class, however, things did not go well. Despite requests made by me, our consultant from the deafblind service center, and a consultant from our state's school for the blind, this school refused to adapt the curriculum specifically for Maya's needs, stating that they 'have an excellent program and they are not going to change anything for one child'. That statement marked the start of a three-year struggle with our home school district to accept Maya at our local primary school (only two blocks from our home!) and provide the necessary accommodations. It was also at this time that we learned about the 'inclusion movement' and the disdain in which some other parents held us because our daughter attended a 'special school'.

When Maya was finally able to enter the neighbourhood school, after seemingly endless meetings and negotiations which culminated in our district hiring the deafblind service center consultant themselves to serve as Maya's teacher as well as a facilitator for the staff, we were congratulated by other parents because she was 'included'. Maya's primary school experience was very positive, she made lots of social and academic gains and participated in extracurricular activities. Some of the students and staff learned sign language and enjoyed communicating with Maya. She loved walking home from school and being together with children from our block. She had a small circle of girlfriends, joined the Girl Scouts and loved her new school.

After two years, Maya had to transfer to our local middle school. This is where Maya's 'inclusive' placement began to unravel. Her 1:1 deafblind specialist teacher was replaced by an interpretive aide who had taken a crash course in sign language and told us that she 'didn't do the Braillewriter'. On paper, the specialist teacher was supervising Maya's instruction, but she was rarely available. When I complained to the principal, she told me that if I didn't

like the school, we should send Maya to the state school for the blind (a residential school in the far southern part of Illinois). Maya had three excellent peripatetic teachers for Braille instruction, hearing impaired services and orientation and mobility. They worked together to develop a curriculum and plan lessons for Maya, since she essentially had no teacher and spent a lot of time at a desk placed in the back of the library, or later in a separate little room that was a remodelled closet. Maya was assigned to a homeroom, but the teachers

## **We wish they could see how wrong it is to prejudge an infant's abilities without providing services geared to their specific needs**

basically ignored her. The girls who had been her friends in primary school, with one exception, also had no time for her.

Fortunately, Maya's peripatetic teachers rallied to the cause and complained to their respective supervisors that Maya's academic needs were not being addressed and that the middle school's administration seemed indifferent to her plight. Again, after many meetings with the school and special education administrators, our district agreed to hire a 1:1 teacher for Maya who has a Master's degree in deafblind education, as well as qualifications for teaching students with vision and hearing impairments. Maya's final year in the middle school was more productive academically. The principal and school staff basically accepted Maya as long as someone else was responsible for her. Maya did socialize to a certain extent with students in special classes for learning disabilities and for cognitive impairments, but was frustrated by their inability to communicate with her. Several times, she came home

from school complaining that 'hearing teens don't know sign language and don't care'.

After three years in the middle school, Maya graduated and had to start secondary school. We met first with officials from our local school district, who admitted that they had no knowledge or experience of deafblindness, but would be willing to allow Maya to attend the local school with an interpreter. Through the assistance of Maya's peripatetic teachers, her deafblind service center consultant and her own teacher, we were able to arrange for Maya to attend the Regional Hearing Impaired Program High School program at a regular school in another town. The Program has 32 deaf students who live in 50 different school districts. Our home district pays for Maya's tuition and bus transportation to attend this school. Maya's 1:1 teacher has transferred to this school with her. Maya is in a self-contained first year class with three other students (boys!) and two teachers, plus interpreters as needed.

Maya's academic achievements this year have been phenomenal, surpassing even the expectations of her teacher. Maya can read and write Braille independently, having become bilingual in pidgin sign language and Signed English in order to accomplish this. She is able to read fiction stories now, something we never imagined possible. Maya is now tackling Grade II Braille and is hard at work learning all of the contractions. Mathematics is still difficult for her, but she has made tremendous gains in her knowledge of facts and concepts in social studies and science.

Maya has friends at school now, both deaf and hearing teens who sign. She is the first and only deafblind student ever to attend her school, John Hersey High School, and the program did initially have reservations about accepting her. She also participates in the Junior Illinois Association of the Deaf, a social club after school. Several teachers have commented on their pleasant surprise that Maya is accepted by most of the deaf students and that they are willing to sign tactually with her.

Maya's school bus arrives at 6.20 am each morning for the long ride to school, and she willingly and cheerfully gets up, something that was not the

## FOCUS ON INCLUSION

case during her unhappy years in the middle school.

Maya had the opportunity to voice her opinion regarding where she would attend secondary school, and

### **School inclusion is not an end itself, but one means to help children reach their potential**

we are confident that we have made the correct choice. Academic considerations need to come first, and social considerations second whenever we select a program. I am puzzled and troubled as to why the growing body of literature pertaining to the inclusion of deafblind students never seems to address academic programming, curricular adaptations or Braille literacy. Maya's teacher has told us that some texts used in deafblind education teacher training courses imply that persons who are born deafblind do not read Braille or converse in sign language. Maya obviously has not read these books!!! I wonder how many other deafblind children are being denied the opportunity to reach their intellectual potential because of this sort of misinformation. Every family of a deafblind child will have to reach their own conclusions regarding their child's school placement and the balance of specialized academic and social inclusion that is needed.

It's important to remember also that inclusion is not something that begins and ends with each school day. Inclusion in family and community activities is just as important. Maya has attended regular day care and summer district day camp programs with the help of an interpreter. Deafblind children have the right (under the Americans with Disabilities Act) to a sign language interpreter provided by the program which they attend. We actually have found more barriers to her participation in generic 'special' programs, which often attempt to substitute an aide who knows a few signs for an actual interpreter, than in

'regular' community programs. If inclusion is ever going to work, all professionals who work with people who have disabilities must embrace it as part of the daily lives of themselves and their families. Are people with disabilities (of all ages and abilities) included where your children go to school or day care? Where you and your family play, worship, travel, work and live? What are you going to do to make this happen?

I am saddened when parents of children with disabilities criticize other families who, in their opinion, have not placed their child in a 'politically correct' school placement. I trust each family to make their own decision, as they are the expert on their own child. I expect that they will respect my ability to do the same.

For the sake of all deafblind children, I challenge activists for inclusion to move beyond rhetoric and philosophy and to address the issues of Braille literacy for users of tactile sign language and the challenges of making abstract academic concepts meaningful to people who are born deafblind. We need to join together to share resources and information to help our deafblind children and friends, truly a minority within a minority of people

### **I challenge activists for inclusion to move beyond rhetoric and philosophy**

with disabilities, have the highest possible quality of life. Despite my many years of professional training and experience in the field of special education, Maya has been my best teacher. Being Maya's mother is the most difficult thing I have done in my life. Our family depends upon the many caring and skilled professionals, with specific knowledge of deafblindness, Braille and total communication to help us navigate these uncharted waters. We need to put aside political ideologies, and focus on the skills and knowledge needed to best help all deafblind children learn.

## **Brazil - AHIMSA**

AHIMSA, the Associação Educacional para Múltipla Deficiência, is one of five deafblind centres in São Paulo. AHIMSA is a Hindu word meaning love and non-violence and this concept is carried throughout all their work. AHIMSA works with 40 children who are deafblind, blind or deaf with additional disabilities and mental handicaps. It has a specialised team of 18 teachers with skills ranging from psychology, pedagogy, social work, speech and music therapy and sign language instruction.

AHIMSA's main goal is to enable sensory impaired children to lead as independent lives as possible by integrating them more fully within their families and communities. They have also carried out prevention campaigns to raise

### **SÃO PAULO**



awareness of deafblindness among the community.

AHIMSA's future plans are to continue to provide services for multiply disabled children and their families and to provide training and information to teachers and professionals. They also wish to network more with similar organisations in Brazil in order to share information and experiences.

As with most centres in countries with developing services, AHIMSA survives with very few resources, which prevents them from expanding their work. As a result they cannot meet the needs of all the children that would like to attend AHIMSA. For this reason AHIMSA will continue to raise awareness among government officials and private institutions and campaign for a higher value to be placed on special education.



# Integration of deafblind children: The need for a thoughtful process

**Michael T. Collins, Director  
Hilton/Perkins Program, USA**

In recent years we have seen the emergence of a new value which we as a society have begun to adopt: that of assuring that the person with a disability is fully integrated into all aspects of everyday life. Many special educators share a passion for this value, and advocate that we implement best practices for integration.

In preparing this paper, I have spent a few minutes looking at some of the definitions of integration that we have struggled with. Webster's dictionary describes integration as 'incorporation as equals into a society or an organization of individuals of different groups (such as race)'. This is clearly a desirable outcome for deafblind people. It is hard to imagine a society which would, in this era, say that their community should not include those who are deafblind. If we assume that this applies to school, we can say that integration means that the deafblind child is accepted into the public school system as a student, and given the opportunity to learn. And furthermore, in the American version, that he must have all his schooling in this system.

But Webster also puts forth an alternate definition: 'The coordination of mental processes into a normal effective personality or with the individual's environment'. I would submit that this is an equally important and too often ignored aspect of integration for deafblind children. Yes, to be fully integrated is to be completely functioning as a member of society. But to do this, one must be internally integrated; that is, one must have had enough appropriate

instruction that one can have developed his own personality and be able to benefit from the advantages of being included in society; and one must have enough language and concepts that one can meaningfully interact with and profit from the environment.

I liked several of the things that John McInnes has said about integration. First, he pointed out that it is people who are integrated, and not spaces, housing or activities. He also indicated that successful integration does not mean homogeneity: '*A deafblind individual can be said to be integrated when he or she lives in a setting which provides compensation for the handicaps associated with multi-sensory deprivation, an opportunity to control his or her life through unlimited access to information upon which to base personal decisions, sufficient support to carry out those decisions and the right to choose with whom he or she*

**It is not enough to say that we have placed the deafblind child into a normal situation so that he can have normal friends**

*will associate within the same limits that are enjoyed by the non-handicapped population'* (McInnes, 1988).

In the USA at the present time, integration is an abandoned work, having been left behind in favour of the phrase 'full inclusion'. This typically means that the child is fully included in all aspects of regular education, with as many adaptations in place as are needed for this setting to be an appropriate learning environment for the child. In describing full inclusion, US educators have indicated that it is most critical, above all else, that the child be with his non-disabled peers all day. Unfortunately this has sometimes meant the abandonment of valuing the content of appropriate pedagogy. What the child needs to learn in his schooling and how it should be taught are often neglected in the rush to include. Maria Bove points out that '*integrated classrooms start with a philosophy, a clear vision and a mission*' ... and that '*in integrated classrooms, all students are acknowledged, valued and respected ... and that there is careful attention to what is taught and how it is delivered*' (Bove, 1995). I would suggest that these properties are not particularly unique to integrated classrooms, but are intrinsic to all good teaching, regardless of the instructional milieu. I would also suggest that these attributes are too frequently missing in classrooms that purport to be integrating children, with not enough attention on what the deafblind child needs to be taught.

In short, it is not enough to say that

## FOCUS ON INCLUSION

we have placed the deafblind child into a normal situation so that he can have normal friends. We must take some steps to assure that the deafblind child's communicative and cognitive abilities are expanded, so that the child can have meaningful, interactive friendships.

Let us examine briefly some of the problems which the integration movement has presented to us in the US in our service to deafblind children:

**In the current climate, the inclusion movement has definitely resulted in a much greater dispersion of deafblind children. While the children used to be served in more concentrated pockets, and in specialized programs, they are now served in a much greater number of schools, spread over a much larger geographic area.**

**This same phenomenon repeats itself in every state and region in the nation. Infrequently does one find two deafblind children served within the same building, let alone the same classroom.**

**As one might imagine, the population dispersion makes the State Coordinator or Consultant's job a much more challenging one. How does a consultant/specialist adequately assist and support programs for children who are in 138 different schools in a state or nation? These 138 schools definitely require a greater level of such assistance than in the past, since they do not typically employ specialists in deafblindness. In these school buildings we have a greatly increased number of special educators and general educators who need some basic training in the instruction of deafblind children.**

**The forementioned factors result in most states repeating training, again and again, in the very elementary instructional strategies known to be effective with deafblind children, for an ever-changing body of learners. The result is that very few educators are accumulating the larger body of knowledge which they need in order to conduct sound educational planning for the children.**

I observe that we have bought into a philosophy of integration and service at the local level without any attempt to build an infrastructure and support system to make it work. In stating this, I am not arguing that the philosophy is erroneous or misplaced. Certainly participation in one's family and community are values which we all hold dear for deafblind children, as for all children. Nonetheless, we must recognize that, at the local level, thousands of deafblind children are underserved or inappropriately served, for want of any local expertise about the population. Too often the deafblind children's needs are simply not recognized, let alone addressed in the IEP (Individualized Educational Plan).

I would suggest that deafblind children typically require certain educational content within their IEP, if their education is to be appropriate. I would submit that, all too often, the above specific content needed by the child, by way of his deafblindness, is altogether lacking. This is frequently true in small local programs of all types. Sometimes a specialist in one of the senses (teacher of the hearing impaired or visually impaired), or a resource person in moderate or severe special needs, will consult to the classroom on a regular basis. However, far too often, this is not a person with real expertise in assessing the child's needs and offering a curriculum which incorporates the above factors. The result is that the child receives a program which is only partially appropriate.

We must find a way for teachers with expertise in deafblindness to be employed as peripatetic and resource teachers to work directly with children, and with local building staff. We cannot expect teachers-to-be to train in deafblindness unless there is a likelihood of employment in the field thereafter. Just as a blind child is entitled to some minimum amounts of time from a trained vision professional in order to have an appropriate program, so a deafblind child needs regular input from a professional familiar with the concurrent sensory disabilities.

If there were an adequate core of peripatetic specialists, we might be able to more effectively use para-professionals or intervenors in local schools, under the direction of trained peripatetic teachers who periodically consult to the classroom staff. This

would increase the likelihood of the child's success in integration programs, and allow us to stretch our Masters-level specialists further.

In some parts of the world the concept of integration is beginning to be reinforced by the introduction of the whole concept of 'community-based rehabilitation' (CBR). If I might do this concept the injustice of a very brief synopsis: CBR alludes to training rehabilitation workers to work with

**We have bought into a philosophy of integration without any attempt to build an infrastructure and support system to make it work**

disabled children within their villages, rather than remove them and bring them to specialized schools. The model is especially applicable in situations where it is very rare for disabled people, and sometimes the general population, to go to school at all. The notion is that, while teaching the child skills in the village, we are teaching the skill in the place in which it needs to be used for the rest of the person's life, and we are teaching the village residents at the same time. So we end up helping the naturally nurturing environment of the village community to become even more helpful. And we are really helping that child to integrate into his home community.

Some dangers to this approach for our children:

- 1 Our population requires a depth of knowledge which is hard to bring to local village rehabilitation workers. There needs to be a senior person with in-depth knowledge as a regular resource to those who see the child on a daily basis, or the whole system is lacking.
- 2 Again, a child who cannot communicate with or interact with his village members is really not very well integrated. We must assure that children receive the

content and pedagogy they require, if we are to be offering an appropriate education.

- 3 In situations where it is the norm for other children to be in school, it can become convenient to say that our handicapped children are served 'well enough' by the occasional visit from the CBR worker. The issue of a deafblind child's right to access education must be viewed in the context of the availability of education to the general population.

In summary, I believe that we in the Western countries are 'selling' the concept of integration prematurely: we ourselves have a lot to learn about how to facilitate integration in a quality way. I think we need to slow down a bit and examine what things we are doing that benefit the children, and which actions of ours are resulting in deprivation for the children, before we sell the concept as the singular instructional approach in the new world order.

We lack institutional memory. We must not throw out everything we knew before in our haste to implement new ideas. When a new concept arises, not everything that went before is obsolete or irrelevant, and the same is true of integration. A scientific body of knowledge does not accumulate in this manner, and neither does a sound educational philosophy.

To quote F. Scott Fitzgerald: *'The mark of a truly first-rate intelligence is the ability to hold two opposed ideas in mind at the same time and still maintain the ability to function'*. We must begin to combine our values regarding the benefits of integration and the benefits of knowledgeable expertise. We have acted as though these ideas are diametrically opposed, when in fact specialization should be able to happen quite nicely in all settings. We have argued excessively about where children should be served, and not focused enough on what they should be receiving. We need integrated environments but we need specialized knowledge and methods, to assure that our children receive full and maximum integration.

## References

- Bove, Maria 'Inclusion of Deafblind Children'. A paper presented at the world conference of the International Association for the Education of Deafblind People, Cordoba, Argentina, 1995.
- McInnes, John 'Integration' in *Deafblind Education*, January-June 1988.

## Conditions and syndromes that can result in deafblindness

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

# Toxoplasmosis

Toxoplasmosis is caused by a parasite called *toxoplasma gondii*. It forms cysts (hard-walled microscopic forms) which are passed in the faeces of its primary or main host, the cat.

In Britain, cats contaminate gardens and vegetables in their wanderings and even though they bury their faeces you can still come into contact with them, resulting in your eating the cystic form of toxoplasmosis. The infection is very likely to be contracted by children playing in sandpits, which is one reason why sandpits are supposed to be given new sand and sterilised each year.

Toxoplasmosis can affect almost all animals, including humans, but most animals carry it in their bodies. In pet-owning countries, humans can catch it from changing cat litter trays, gardening without gloves (in earth, cats' faeces may remain infected for 14 months), and even by eating unwashed garden vegetables. Cats alone are not the only reason for the incidence of this condition. Undercooked meat and the increasing consumption of unpasteurised goat's milk are two other potential causes. In France, the eating of raw or rare meat is considered a major cause of the spread of infection.

Luckily the infection that can result is usually very mild. It can be a glandular-like illness or produce symptoms of a mild flu. However, in a pregnant woman the infection, although not a risk to her, can cause congenic abnormality in the unborn child in up to 40% of infections. Of these, ten per cent are likely to be seriously affected.

If the disease is caught in early pregnancy it is less likely to cross the placenta to the foetus but, if it does, the effects are more serious. If the pregnant woman catches the infection later, it is more likely to cross the placenta but the effects on the foetus are less severe.

In France and Belgium the problem is considered to be so great that women are routinely screened as they are for rubella in Britain.

Babies that are born with toxoplasmosis (usually when infected between the third and sixth month) may develop severe symptoms. These include hydrocephalus, calcification in the brain and chorioretinitis (damage to the retina). Epilepsy and deafness can also result. Most worrying in this regard is that eye disease may not develop until the late teens.

The Public Health Laboratory in Swansea, UK, estimated in 1988 a rate of infection of two per 1,000 pregnant women. If the French figures of 40% passing infection to their babies is the same in the United Kingdom, it could mean that about 480 babies a year are affected in the UK.

Most adults recover spontaneously from toxoplasmosis without any treatment at all, although it is possible to treat the condition using sulpha drugs. Eye treatment of *toxoplasma* infections is more complicated, and pregnant women must be given a different drug since the usual one is too toxic. No treatment manages to eradicate all cysts. This means that an infection which may appear to have been cured can be reactivated later.

# Elderly deafblind people: An audit of ideas and experiences

Malcolm Matthews presents the main findings

The Acquired Deafblind Network (previously known as the Acquired Deafblind Sub-Committee) has recently undertaken an audit to identify current ideas, experience and materials relating to elderly deafblind people. In 1998 the results of this will be discussed by a working group to share and develop current practice in this field, and will provide materials for a conference on work with elderly deafblind people to be held later in the year.

In 1996 the Acquired Deafblind Network decided to focus its attention primarily on the needs of elderly deafblind people for the next two years. What were the reasons for this choice?

**In western European countries at least 25 out of every 100,000 people are deafblind and 75% of them are older than 65 years.**

Demographic changes in Europe indicate an increasingly ageing population. Last year the European Commission published a report setting out the scale and speed of the ageing process. According to the Commission, the number of Europeans aged over 60 is set to double by the year 2025. By that date there will be 113.5 million people aged over-60 in the European Union, comprising about a third of the total population.

It can be predicted that, as the majority of deafblind people are elderly, a significant increase in the elderly population means an increase in the deafblind population.

While we are only just beginning to recognise the extent of deafblindness



The Acquired Deafblind Network formed eight years ago as part of the International Association for the Education of Deafblind People (now Deafblind International). It has organised two European Conferences and provided information on acquired deafblindness to interested professionals.

The Committee members are professionals working in different European countries. They plan to publish and maintain a contact list of people working in the field, detailing their activities and current interests.

among the very elderly, we need to start planning for a probable doubling in the number of elderly deafblind people in Europe. The situation is similar in some other parts of the world.

So there is a great need to give attention to the elderly group. The starting point in doing this was to find out what is already happening and what materials exist that can be used by others. Hence the audit.

The audit process began with letters to our known international contacts asking if they, or others in their country, had ideas and experience of

work with elderly deafblind people. Information was requested on relevant materials such as videos and texts.

So far there have been 25 responses. Most respondents expressed interest in the topic but were not aware of work in the area or materials in their country. The following countries indicated that they were working or beginning to work with elderly deafblind people: Canada, Denmark, Finland, Germany, Italy, Netherlands, Norway, Spain, Switzerland, Tanzania, the United Kingdom and USA. Some of the responses are summarised opposite:

### Denmark

Video 'Contact persons for the deafblind', about the Danish service of contact persons, which is used much by elderly deafblind people. In the video one of the persons is an elderly deafblind man (English, 1997, for sale).

Report from a survey and investigation of 30 elderly deafblind people and ways to meet their needs within the existing system (Danish, for sale).

Booklet 'When Vision and Hearing Fail', giving advice to staff working with elderly people with a hearing impairment, vision impairment or a combination of both (free).

### USA

Helen Keller National Centre have five publications on older adults and deafblindness. For example 'Beyond Refuge: Coping with Loss of Vision and Hearing in Late Life' concerns a research study looking at the personal impact of vision and hearing loss in late life. Adaptive strategies and technology are also discussed. (For sale \$5).

### Netherlands

Brochure on elderly deafblindness in (Dutch, 1994, free).

An instruction book about elderly deafblindness (Dutch, 1994, for sale). Report about a survey on elderly deafblindness (Dutch, 1994, but English summary available).

Video 'The dying of the light' (English, 1989, 22 minutes, VHS PAL and NTSC, for sale).

Video '(Un)heard + (Un)seen' (English, 1994, 40 minutes, VHS PAL and NTSC, for sale).

Report of research into the circumstances of 10 deafblind residents in a home for the elderly deaf.

Pack on elderly deafblindness for workers in homes for the elderly (under preparation).

### Finland

Research to identify elderly deafblind people will be completed in summer 1997. Information on their quality of life will be available in 1998. This is the start of work to provide services to elderly deafblind people and education for staff.

### United Kingdom

The Department of Health are about to produce an updated version of a report entitled 'Think Dual Sensory: good practice guidelines for older people with dual sensory loss'. Aimed at local authorities, the content covers identifying and locating users and consulting them; devising a strategy for implementation; assessment and care management; specialist equipment; developing existing sensory services; making general services available to deafblind users.

Sense's basic information pack 'Deafblindness in Older People' details the causes of deafblindness, implications, practical information on communication techniques, mobility, environment etc. Aimed at anyone working or caring for an older deafblind person, particularly those with little or no previous knowledge of sensory impairment. (For sale £2.50)

### Norway

In Norway there is now a project concerning the elderly deafblind population. A report on a survey to find deafblind people who have not registered will be published in early 1998.

### Italy

An apartment for six elderly deafblind people has opened in Milan and it is hoped to produce a film of this in the near future.

## To join contact list:

I wish to be part of the Network. Please include my name, address, specialism and interests for circulation on the Network contact list.

Name \_\_\_\_\_

Address \_\_\_\_\_

Postcode \_\_\_\_\_

Country \_\_\_\_\_

Tel: (voice) \_\_\_\_\_

Tel: (text) \_\_\_\_\_

Fax \_\_\_\_\_

E-mail address \_\_\_\_\_

WWW home page \_\_\_\_\_

Organisation (if any) \_\_\_\_\_

Specialism (e.g. profession, activities, reason for interest in acquired deafblindness)  
\_\_\_\_\_  
\_\_\_\_\_

Interests (e.g. current concerns, problems or issues that you would welcome contact about)  
\_\_\_\_\_  
\_\_\_\_\_

I am a member of Deafblind International  Yes  No

Signed \_\_\_\_\_

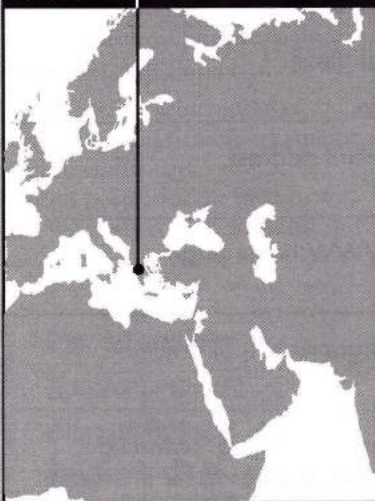
Date \_\_\_\_\_

Please return to Anneke Balder at  
Stichting Doof-Blinden  
Professor Bronkhorstlaan 10  
3723 MB Biltoven  
The Netherlands

## Greece

'Communication' is a non-profit institution founded in 1995 as the first unit in Greece to meet the needs of blind people with additional disabilities, particularly those with learning disabilities and mental handicaps. It is based in Athens and is a co-operation between the Association of Parents of People with Blindness and Additional Handicaps, the Centre for the Training of People with Blindness and the Panhellenic Association for the Blind. It is funded by the Ministry of Health and Welfare.

### ATHENS



The central aim of 'Communication', following the goals of the Parents' Association, is to provide individual educational programmes which increase the life skills and the quality of life of the students. The educational programme provides much needed services that were not available before. It consists of self-help skills, orientation and mobility training, learning from Braille, psychological support, occupational therapy, music therapy, therapeutic horse riding and physical education. The school provides individual programmes to cover the special needs of each student.

**For further information please contact:**  
**Communication**  
**Vouliagmenis Av**  
**(ex American Base)**  
**Athens, Greece**  
**Tel: + 30 1 964 4166**  
**Tel/Fax: + 30 1 964 2099**

# Sixth Helen Keller World Conference

## Rights and services for deafblind persons in accordance with the Standard Rules of the United Nations

Colombia, 13-19 September 1997

The Sixth Helen Keller World Conference on services to deafblind people will take place in Colombia, South America, from 13-19 September 1997. It is being organised by POSCAL (Project to create association of deafblind persons in Latin America), and the newly founded Colombian Association of the Deafblind, with support from the World Blind Union and the National Institute for the Blind and the National Institute for the Deaf.

The official conference language will be English, with Spanish translation available.

We invite three delegates from each country – two deafblind people with interpreters and one professional worker.

We also welcome observers.

The conference will be held in Paipa, a town 3<sup>1</sup>/<sub>2</sub> hours by bus from Santa Fe de Bogota international airport.

Delegates should arrive in Paipa on Saturday 13 September and depart on Friday 19 September.

The conference fee is US\$ 450 and includes board, lodging and transfer from the airport to Paipa. For single rooms there will be an extra charge of US\$ 100.

Questions and registration can be addressed to:

**Ximena Serpa: Coordinator POSCAL programme,**  
**Calle 108 No 20A 13, Bogota, Columbia.**

**Fax: + 57.1.619 0337**

**E-mail: poscalxs@openway.com.co**

# 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.

## PROPOSED

### Statement of purpose

Deafblind International is the world association promoting services for deafblind people.

Deafblind International's objects are:

- 1 To promote the recognition and awareness of deafblindness as a unique congenital or acquired disability that affects children, adults and elderly people.
- 2 To support the civil rights of deafblind people and the equalisation of opportunities in all aspects of life.
- 3 To encourage the development of networks and opportunities for association and learning for professionals and to the benefit of deafblind people and their families.
- 4 To enable interaction between deafblind people, their families, professionals and the wider community.
- 5 To promote education and opportunities for development for deafblind people.
- 6 To encourage support and services for deafblind people that lead to self-determination and quality of life.
- 7 To promote quality in services for deafblind people by encouraging research, staff development and training, the promotion of policies that lead to good practice, and the dissemination of information.

**Please feel free to comment on these proposed objects. Contact Malcolm Matthews, Sense, 11-13 Clifton Terrace, London N4 3SR, UK.**



# DbI

DEAFBLIND INTERNATIONAL

**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 \_\_\_\_\_

Name \_\_\_\_\_ Signature \_\_\_\_\_

Institution \_\_\_\_\_

Address \_\_\_\_\_

Tel \_\_\_\_\_ Fax \_\_\_\_\_

**CHAIR**

Marijaana Suosalmi  
Resurscenter  
Mo Gard AB  
612 93 Finspang  
Sweden

**VICE-CHAIRMAN**

Michael Collins  
Perkins School for the Blind  
175 N Beacon Street  
Watertown, MA 02172  
USA

Antonio Rebelo  
Casa Pia de Lisboa  
Colégio A.A.C. Ferreira  
1700 Lisboa

**SECRETARY/TREASURER**

Rodney Clark  
Sense  
11-13 Clifton Terrace  
London N4 3SR, UK

**IMMEDIATE PAST CHAIRMAN**

Jacques Souriau  
CESSA Larnay  
Biard  
86580 Poitiers  
FRANCE

**National Contacts**

**ALBANIA**

Elida Cangonji  
Instituti Mediko Edukativ  
Tirana

**ARGENTINA**

Gricelda Collegari  
Instituto Helen Keller  
Av. Velez Sarsfield 2100  
Ciudad Universitaria  
5000 Cordoba

**AUSTRALIA**

Heather Hawitt  
University College  
University of Melbourne  
College Crescent  
Parkville 3052  
Victoria

**AUSTRIA**

Christa Heinemann  
Osterreichisches Hilfswerk für  
Taubblinde  
1100 Wien  
Humboldtplatz 7

**BELGIUM**

Marlene Daelman  
KMPI Spermalie  
Snoggaardstraat 9  
8000 Brugge

**BRAZIL**

Angela Ribeiro  
Escola de Educacao Especial  
'Anne Sullivan'  
Av. Conde de Porto Alegre 820  
S. Vaetano do Sul  
Sao Paulo 09500

**BULGARIA**

Vladimir Radoulov  
Research Institute for Education  
Cul. Tzakia 125 Fl. 5  
1113 Sofia

**CANADA**

Stan Munroe  
Canadian Deafblind and Rubella  
Association  
1658 4th Avenue West  
Owen Sound  
Ontario N4K

**CHILE**

Claudia Pumarino Cid  
Las Azuleas 181  
Las Condes  
Santiago

**CHINA**

Li Pan  
The Teacher Training Division  
The Education Commission of  
Hunan  
Changsha  
Hunan Province

**COLOMBIA**

Ximena Serpa  
Calle 108 # 20A - 13  
Bogota

**CZECH REPUBLIC**

Jan Jakes  
LORM - Society for the Deafblind  
K vodojemu 29  
150 00 Praha 5

**DENMARK**

Ole Martensen  
Information Centre for  
Acquired Deafblindness  
Generatorvej 2A  
DK-2730 Herlev

**EGYPT**

Father Youhana Henein  
Holy Mary Queen of Light  
Organisation  
PO Box 80  
Sidi Gaber  
Alexandria

**ESTONIA**

Olga Ilgina  
Estonian Federation of the Blind  
Lai Str 9  
EE0001 Tallinn  
Estonia

**FINLAND**

Marja-Leena Saarinen  
Rehabilitation Centre for  
Deafblind Children  
Kukkumäntie 27  
40600 Jyväskylä

**FRANCE**

Jacques Souriau  
CESSA Larnay, Biard  
86580 Poitiers

**GERMANY**

Dietrich Bunck  
Bildungszentrum-für-Taubblinde  
Postfach 710460  
30544 Hannover

**GHANA**

Marion N Obeng  
Centre for Deafblind Children  
PO Box 33  
Mampong-Akwapim

**GREECE**

Efrossyni Zafiri  
59 Messogiou  
Athens 11526

**HUNGARY**

Dorka Kiralyhidi  
Hungarian Deafblind Association  
Budapest 1146  
Ajtos Durer sor 39

**ICELAND**

Bryndis Viglundsdottir  
PO Box 5086  
Skiptholt 31  
105 Reykjavik

**INDIA**

Beroz N Vacha  
Helen Keller Inst. for the Deaf &  
Deafblind  
c/o Municipal School, Near 'S'  
Bridge  
NM Joshi Marg, Byculla (West),  
Mumbai 400011

**IRELAND**

Ray McLoughlin  
The Anne Sullivan Foundation  
40 Lower Drumcondia Road  
Dublin 9

**ISRAEL**

Ruth Rosenbluth  
Keren OR INC  
Abba Hillel Silver 3  
Ramot 01  
91234 Jerusalem

**ITALY**

Rossano Bartoli  
Lega del Filo D'Oro  
Via Montecerno 1  
60027 Osimo-Ancona

**JAMAICA**

Germaine Lynch  
The Salvation Army School for  
the Blind  
57 Mannings Hill Road  
PO Box 562  
Kingston 8

**JAPAN**

Sadako Imamura  
Yokohama Christian School for  
the Blind  
181 Takenomaru  
Nakaku, Yokohama

**KENYA**

Boniface Lentoimaga  
Kabernet School for Deafblind  
Children  
PO Box 128  
Kabernet

**LITHUANIA**

Irena Matuliene  
Lithuanian Association of the  
Blind and Visually  
Handicapped  
Labdariu 7/11  
Vilnius

**MALAYSIA**

Simon Rajendran  
St Nicholas Home  
Locked Bag No. 3031  
4 Bahan Jermal Rd  
10090 Penang

**MALTA**

Irene Schembri  
8 Mannarino Road, B'kara

**MAURITIUS**

Dr K Hazareesingh  
Mauritius Child Care Society  
The Oxford/Mauritius Child  
Care Project  
Phoenix

**NETHERLANDS**

Ton Visser  
Instituut voor Doven  
School Rafael  
Theerestraat 42  
5271 GD St Michielsgestel

**NEW ZEALAND**

Elsie Purdue  
Homai College, Browns Road  
Private Bag  
Manurewa, Auckland

**NIGERIA**

Chief Dipo Bailey  
Deaf-Blind Association of Nigeria  
PO Box 53271  
Falomo  
Ikoyi  
Lagos

**NORWAY**

Elisabeth Olafsen  
Norwegian Central Team for the  
Deafblind  
P.b. 8042 Dep.  
0031 Oslo

**PHILIPPINES**

Dante Capistrano  
Philippines National School for  
the Blind  
Galvez Corner Figueroa  
Pasay City 1300



**DbI**

DEAFBLIND INTERNATIONAL

**The World Association  
Promoting Services for  
Deafblind People**

**POLAND**

Jozef Mendrun  
Polski Związek Niewidomych  
Zarząd Główny  
00-216 Warszawa

**PORTUGAL**

Antonio Rebelo  
Casa Pia de Lisboa  
Colégio A.A.C. Ferreira  
1700 Lisbon

**ROMANIA**

Prof Valeriu Mare  
Department of Psychology  
The University Cluj-Napoca  
Str. Kogalniceanu Nr. 1  
3400 Cluj-Napoca

**RUSSIA**

Tatiana Basilova  
Institute of Correctional  
Education, Russian Academy  
of Education  
119834 Moscow  
Pogodinskaja str. 8

**SENEGAL**

Gilbert Tending  
EMMPI Centre Verbo-tonal de  
Enfants Sourds  
BP 3883 Dakar R.P.

**SINGAPORE**

Koh Poh Kwang  
Singapore School for the Visually  
Handicapped  
51 Toa Payoh Rise  
1129 Singapore

**SLOVAKIA**

Janka Sarisska  
Evanjelicka pomocna skola pre  
hluchoslepe deti  
082 07 Cervenica 114  
Slovakia

**SOUTH AFRICA**

Dr Johan van der Poel  
Pioneer School for the Visually  
Handicapped  
20 Adderley Street  
6850 Worcester

**SPAIN**

Pilar Gomez  
CRE Antonio Vicente Mosquete  
Programa de Sordociegos  
O.N.C.E.  
Paseo de la Habana 208  
28036 Madrid

**SRI LANKA**

Mr J S David  
Sri Lanka Churches' Council for  
Child Care  
490/2A Havelock Road  
Wellawatte  
Colombo 6

**SWEDEN**

Elizabeth Abouda  
Ekeskolan  
Box 9024  
S-700 09 Örebro

**SWITZERLAND**

Birgit Jentzch  
Stiftung für Taubblinde  
Heim Tanne  
Fuhrstrasse 15  
8135 Langau a A

**TAIWAN**

Frank Chang  
National Taiwan Normal Univ.  
Department of Special Education  
162 Hoping East Road, Sect. 1  
Taipei

**TANZANIA**

Elly Macha  
Tanzanian National Committee  
for the Deafblind  
PO Box 22408  
Dar es Salaam

**UGANDA**

Mbuusi Jackson  
PO Box 14278, Kampala

**UNITED KINGDOM**

Rodney Clark  
Sense, 11-13 Clifton Terrace  
London N4 3SR

**URUGUAY**

Carmen Cirintana  
Zufriategui 990, Montevideo

**USA**

Michael Collins  
Perkins School for the Blind  
175 N Beacon Street  
Watertown, MA 02172

**ZIMBABWE**

Robert Chimedza  
Ministry of Education and Culture  
PO Box 8022, Causeway  
Harare

**NORDIC REGIONAL OFFICE**

Elin Osti  
NUD  
Slottsgrade 8  
DK-9330 Dronninglund  
DENMARK

Partial funding for this publication was made possible by Perkins School for the Blind, Watertown, Massachusetts and the Conrad N Hilton Foundation, Los Angeles, California. The DbI is indebted to them for their support and would also wish to acknowledge the support received from the United Nations towards Deafblind Education and towards providing expert assistance to developing countries.