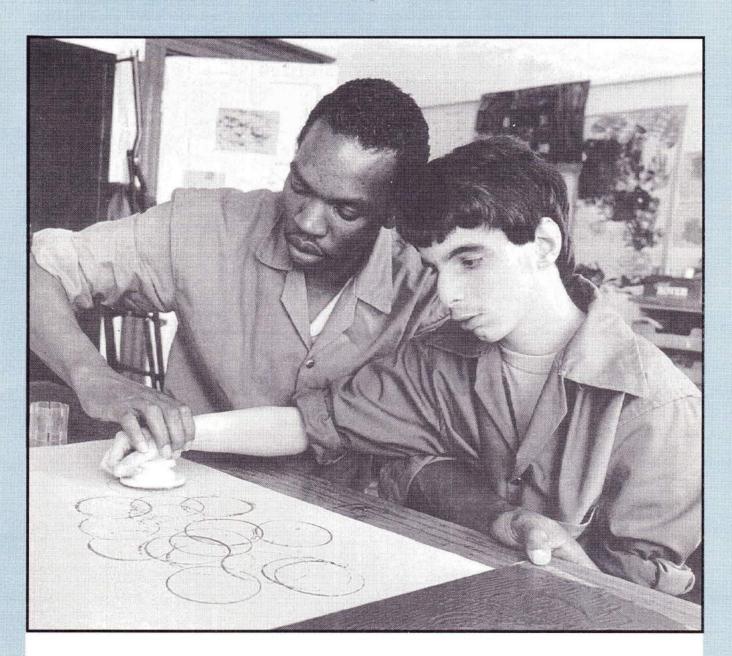
# **Deafblind Education**

THE JOURNAL OF THE INTERNATIONAL ASSOCIATION FOR THE EDUCATION OF DEAFBLIND PEOPLE

### No. 9: January-June 1992



## Learning Together

## **CHAIRMAN'S REMARKS**

Our last executive meeting was held in Potsdam on the 10th and 11th of April. Although most of participants were from Europe, we managed to get information from all over the world. We are very grateful to Friedrich Pape and his staff for welcoming us to Oberlinhaus. The mood of the meeting was very friendly because of the quality of the hospitality as well as the active and sensitive participation of the delegates. In spite of the fact that most of the attendants were not English native speakers, it seems that the access to the floor was equal.

The main topics which were addressed during this meeting were the following:

- definition of the policy of IAEDB during the next years
- location of the next World Conference in 1995.

After discussions in working groups, it became obvious to all of us that many countries would need to be supported by 'position statements' of IAEDB when they have to define their policies towards deafblindness. One of the main concerns at the moment is the situation of adults, since a lot of needs are expressed and many different policies are being set up. So, it was decided that before the next Executives meeting (which will probably take place at Perkins) a short seminar would be organised for the executives in order to address the situation of the adults all over the world and to agree on a statement expressing the principles according to which plans towards the adults should be defined. This seminar will be short, but it will be efficient since some members of the executive committee are charged with gathering information and to process it before the meeting itself. All the members can send reports on the situation of the adults in their countries to the secretariat as of now.

We also had to decide on the location of the next Conference. On the basis of the reports by the Chairman and Secretary Treasurer who went to Argentina to investigate the possibility of organising the conference there, and after discussions with Lucia Piccione (Director of the Helen Keller Centre in Cordoba), we decided that the next World Conference in 1995 would be held in Cordoba. We expect a lot of support of the professionals from there. Graciela Ferioli and Lucia have already done a lot of work with their colleagues and the local authorities. So, we can expect that this event in Argentina will be an opportunity for the people from South America to exchange ideas with professionals from other parts of the world. We must admit that the cost of the travel will be more expensive for the European participants. But, for once, people from South America will be in a more favourable situation, which is fair. In this way, our Association is really an international one.

**Jacques Souriau** 

In the Chairman's Remarks Jacques Souriau outlines the IAEDB's plans to produce position statements or policy documents that outline our beliefs and agreed approach to aspects of deafblind education. Such documents will be useful for members who are developing services or who wish to promote services in their own country. It may help give greater credibility to an initiative in one individual country if it can easily be shown to be part of a much wider and internationally recognised movement. A short clear document on deafblind education is being prepared for use in influencing other agencies and to assist people working to introduce deafblind education in countries where little exists.

For some other topics, the process of producing material and a position statement and the discussion and debate generated will be of considerable value to the participants. The first such topic to be debated will be services for

## EDITORIAL

congenitally deafblind adults and a small working group is preparing a seminar for the next IAEDB Executive Meeting. The seminar will then be an opportunity for all to share and learn but will also contribute towards producing a policy or position statement which can be used to help people with the design of services and help with lobbying for appropriate and quality service provision.

In order to help this process I hope that the next Deafblind Education will focus on adult services. Please let me have information, reports and articles on the situation of deafblind and congenitally deafblind adults in your country. Some information can then be printed in Deafblind Education and every contribution will be passed on to the IAEDB secretariat to aid the work of the working group preparing for the seminar.

I felt that the recent Executive Meeting was a very positive step forward for IAEDB. The new constitution enables the association to further develop its activity. The promotional activities now being worked on should be of benefit to existing and future members. The specific consideration of adults follows naturally from the need to see achievements in school built on in adulthood and is I think an increasing priority for many of us. Also we must not forget those people who have not had an education that meets their needs, for whom a service or support could now be provided based on the principles of deafblind education.

Other topics in future are likely to include focussing on communication, interpreters and human aids to communication, mainstreaming, and the centralisation or decentralisation of services issue.

I look forward to working with you to further promote and develop deafblind education.

## Portugal hosts deafblind conference

Portugal held its first course on deafblind impairment in April. It was organised by the Instituto Jacob Rodrigues Pereira, Casa Pia de Lisboa, under the supervision of its Director, Carlos Pinto Ascensao and teachers Maria da Graca Pereira da Silva and Antonio Rebelo.

One hundred and twenty participants from all over Portugal attended the conference, which covered topics ranging from the deafblind individual to methods of assessment.

Right: Maria da Graca Pereira da Silva at the conference.

### Helen Keller deafblind awareness week

Organisations from all over the world were invited to participate in the Helen Keller Deafblind Awareness Week from 22nd–27th June.

The week, hosted by the Helen Keller National Center in the USA, focussed on deafblind people making the transition from school or institution to life outside. It stressed the continued need for accessible housing, employment and recreational opportunities within the community.

If you, or your organisation took part in any of the week's events, or held your own to celebrate Helen Keller's birthday on 27th June, why not write in to Deafblind Education and let other readers know?

### Views on adult services

Educational provision for deafblind children has progressed rapidly over the last few years in most parts of the world. Now, many countries are turning their attention to adults, recognising the need for education beyond school.

Deafblind Education would like to run a special feature in the next edition on services to adults which include education. If you would like to contribute to this feature, please contact the Assistant Editor, at

Sense, 311 Gray's Inn Road, London WCIX 8PT.



The International Association for the Education of Deafblind People announces:

#### 1993 European Conference

"Equal and Exceptional: Access to Culture for Deafblind People"

July 31 to August 5, 1993, Potsdam, Germany

hosted by Oberlinhaus, Taubblindenarbeit

(Usher syndrome seminar: 29-31 July 1993)

The conference refers to people who despite being deafblind have needs for communication with other people, interaction within the community, close relationships, and access to culture.

#### Osimo proceedings available

The proceedings of the European Conference on Staff Development in Services to Deafblind People, held in Osimo, Italy in 1990 are now available.

> If you would like a copy, contact: Lega del Filo d'Oro, Via Montecerno 1, 60027 Osimo (AN), Italy

## **IAEDP** Membership

The strength of IAEDP lies in its membership, both individual and corporate. The objects of the Association are to promote the recognition of deafblindness as a unique disability throughout the world, to promote services, to gather and disseminate information and to promote research.

Membership is open to individuals and corporate bodies wishing to further these objects. Please complete and return the form below if you would like further information.

Please tick as appropriate:

□ I am interested in individual membership of IAEDP

□ I am interested in corporate membership of IAEDP

Name\_

Address \_\_\_\_

Pease send to: Membership, IAEDP, 311 Gray's Inn Road London WC1X 8PT, United Kingdom.

## **News from Potsdam**

In case you didn't know, the 1993 IAEDB European conference "Equal and Exceptional: Access to Culture for Deafblind People" will be held in Potsdam, Germany. The conference's host, Oberlinhaus has prepared this short introduction.

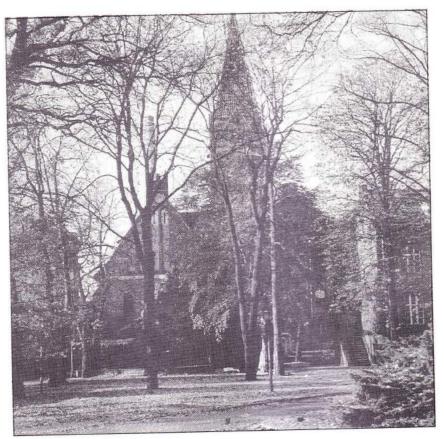
On 14th January, 1887, Herta Schulz, born on 30th July 1876, was the first deafblind child to be taken in by the Oberlinhaus. Herta was brought here for rehabilitation because her constant cries were proving unbearable for the families and neighbours in her Berlin rentcomplex.

With a regulated daily programme and qualified help in accessing her environment, her disturbing behaviour was quickly altered, and by the end of 1888, the then director of the Oberlinhaus wrote:

"Herta is an unusually gifted child. Her dexterity is wonderful. At first, she valued only her dolls. Gradually, she expanded her circle of trust. Piece by piece, she has completely achieved what a fully visual and hearing child of her age would seldom have accomplished."

Who could have know what changes were about to occur when the decision was made in Warwick, UK, in August 1989 to accept the offer of the Oberlinhaus to host the 1993 European conference in an eastern-block nation on the doorstep of Berlin?

Who could have forseen the possibility that Potsdam, the host city of the 1993 European conference, would no longer be "behind the wall" in 1993? That the wall would be forever gone? That so many walls in Eastern Europe



The Oberlinhaus, Potsdam

would be falling? That so many incredible governmental and social changes would be impacting the lives of the entire populations of all the former eastern-block nations?

Freedom Bridge, the Glienicke Bridge spanning the Havel River, connecting Potsdam with West Berlin, symbolises the beginning of a process that began on 9th November 1989, when the wall opened and the bridge was crossed freely again, a preamble to so many

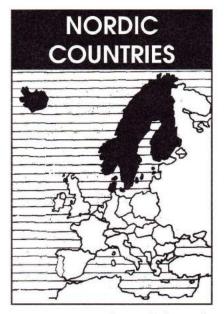


profound changes in east-west relationships since that date.

The IAEDB's European conference site selection for 1993 is highlighted even more by the opportunities brought about by the elimination of all political barriers to the east, and the permanent opening of freedom's bridge. Special programme emphasis and participation by the eastern European nations will be a programme feature in 1993.

Potsdam will be celebrating its 1000th birthday in 1993. As the cultural capital of the Prussian dynasty of the Hohenzollerns, the city promises to be showcased for this historic birthday celebration. The city's cultural menu will be long and varied, and all visitors to Potsdam in 1993 are promised an exciting stay.





Marjaana Suosalmi and Elin Østli have sent this report.

As many readers will know the Nordisk Uddannelsescenter for Døvblindepersonale (NUD) is the Nordic Staff training centre financed by the Nordic Council of Ministers and serving the five Nordic countries Denmark, Finland, Iceland, Norway and Sweden, Our task is staff training and development through course, workshop and conference activities, a resource service and development work, the working formats given priority in this order. The services are given to all categories of staff working with deafblind persons of all ages and with all types of deafblindness.

### Recent developments

Even if some of the working formats are quite stable, evaluation, change and development take place all the time. This is necessary, because the role of the NUD is to support work with deafblind people by supplementing the staff development activities provided at the national level. All changes in the Nordic countries have to be reflected in the work at the NUD. And we are, of course, also influenced by our European and other international contacts.

The staff development activities of the NUD have for the past ten years focused on basic courses, where several topics relevant to the service in question (to persons with acquired deafblindness, to congenitally deafblind children or congenitally deafblind adults) are covered. Our basic courses, which last six weeks, are divided into two three week periods. This new format is to be evaluated by the end of this year. Already now it seems clear that it makes it easier for people to leave their work and their families to come to our basic courses. The interval between the two course periods also gives the students an opportunity to work on the things which were taught during the first part and see how they apply to practice, and, if necessary, to discuss problems which arise during the second part. Furthermore it gives the NUD an opportunity to plan the details of the second three week period in co-operation with the students.

Another innovation is our "open house" arrangements. Twice a year the house is open to larger groups who wish to work on any problem relative to deafblindness. The groups make their own program and schedules and benefit from the facilities at the NUD, including the library, the working rooms and the accommodation facilities, for the price of 100 Danish kroner per person per day.

### Non-Nordic visitors

Non-Nordic colleagues are welcome to contact us if they wish to come here and study during these "open house" weeks, maybe to combine it with visits to deafblind services in the Nordic countries. Although priority must be given to Nordic staff, we will offer you any vacant accommodation capacity, and will be able to agree on the final details with you two to three months ahead of your visit. And by the way, we remind you that it is possible to host individual visitors or small groups during our course periods. Please remember that the course activities take place in Nordic languages. Contact us for further details.

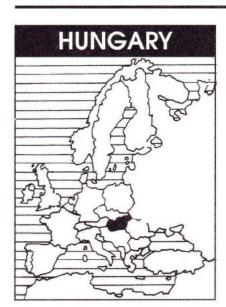
## Changes in the field

Like in other countries, changes in the way educational and social services are organised have a major impact on most aspects of day-today deafblind work. In the Nordic countries the decentralisation process has dominated the picture. The NUD pays very much attention to the changes brought about by this process.

## **Nordic directory**

The collection of material for staff development which we call the Nordic Directory for Staff in Deaf-Blind Services is becoming steadily bigger. The series now contains 14 books (two with accompanying video tapes) and 21 articles.

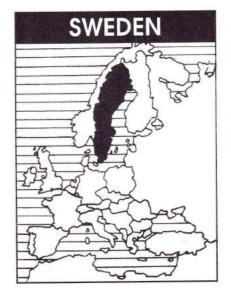
With people from five different countries, the Nordic material is produced in different languages. The Scandinavians understand each others' languages quite well, but as Finnish is a very different language, systematic translation to and from Finnish is required. In addition to this we translate some foreign material to include it in the Nordic Directory. We feel that work is sometimes duplicated because people are not sufficiently informed about each other's productions. If any of our material seems interesting, and you would consider translations into your language, we will be very happy to give you a more complete summary and more specific information.



#### Friedrich Pape, from Germany, visited Hungary recently and brought back this short report.

There is a small group beginning. There is a school for multiply handicapped blind children from the Catholic Church. They have two or three deafblind children and were willing to develop this area. So, we have addresses from this other region and we are very hopeful that they will come to the 1993 European Conference in Potsdam. We are battling to develop education for deafblind children, young people and adults in this part of Germany, and I am very optimistic.

## Art for deafblind people



Karin Tiberg of Sweden reports on a new project to enable deafblind people to enjoy art.

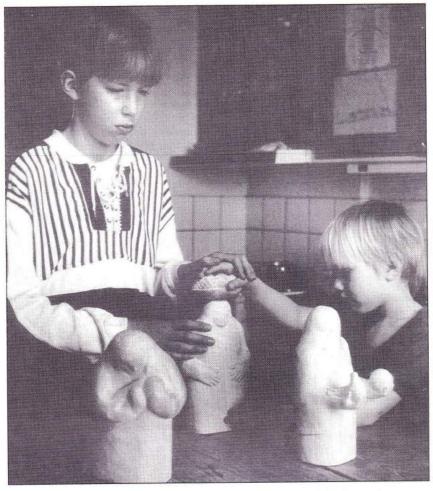
Deafblind people have two languages: sign language and braille. These languages restrict them to communicating with a limited number of people.

The association for deaf people in Orebro, Sweden, has started a project to give deafblind people a third language - the language of art. The artist and deafblind people have questions in common. They must often ask themselves, "Am I understood?" or, "Have I expressed myself clearly enough?" In the project a group of deaf and visually handicapped people in Orebro work together with a sculptor. The will to communicate and strengthen their languages is the base for their work.

The aim of the project is to give deafblind people access to culture, and to the possibility of sharing some of the emotions and experiences that art can give. In Sweden today, deafblind people have few opportunities to enjoy culture offered by society.

The project has three phases. The first, which is taking place at the moment, is a co-operation between the group of deaf and visually handicapped people and the sculptor. They work together to create sculptures that "talk".

The artist learns to adapt her sculptures to the needs, functional limits and resources of the group. The artist learns to speak clearly, and the group learns to be sensitive



to the "language of art". The goal of this work is to produce a series of sculptures that can be distributed via the libraries of Sweden. People who live in isolated places or have difficulty in visiting a library will have the possibility of a home delivery service.

The sculptures will be presented in boxes of three. For every box there is a theme, ie birds, the beach, emotions, or female qualities, like the ones shown in the photo which represent caring, fertility, growing and peace. A theme can also be treated in different artistic ways. For example, a leaf can be shaped in a naturalistic manner and in various abstract forms.

For contrasting effects, different boxes are made of different materials, such as bronze, wood and stone. Wax, tar and spices are used to activate the sense of smell.

#### Second stage

The second phase is to search the museums in Sweden to find pieces of art that they will allow people to touch. An inventory will be made of these objects, which will be made available to deafblind people. Another aim is to persuade one or more museums to open rooms for "touch sculptures" and to arrange an exhibition of "touch art" that will circulate among the libraries of Sweden.

#### Third stage

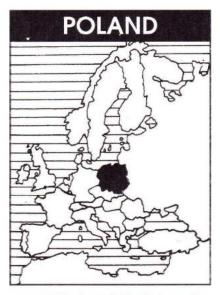
This stage aims to create a centre, or an art school for deafblind people, where they can learn to work with clay, plaster, wax and wood. The "touch sculptures" in the libraries and museums will act as inspiration for the pupils as they continue their work at home.

The first phase of this project began in February 1992 and will be finished in the autumn. During this short period of time, the members of the deaf and visually handicapped group have shown a remarkable ability to discover and understand the "language of art" and to find ways of expressing their feelings.

The first part of the project will be presented in the ONCE Foundation Pavilion at Expo '92 in Sevilla, and will include the three sculptures in the photograph.

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## **Teaching in Poland**



In 1986, the Polish Ministry of National Education established a special class for deafblind children in the Educational Centre for Blind children, in Bydgoszcz. Krystyna Klugiewicz, a teacher of deafblind children reports.

At first, I worked alone with a class of five students: two girls and three boys. Then, a friend of mine helped me to lead it. Using a special method of teaching, I began working on breaking down the students' passivity and making them interested in learning. As the children were not completely blind I was able to use their residual sight. It was useful to acquaint them with their immediate surroundings: the classroom, corridors, school, dining rooms and bedrooms. Step by step I started to teach them about their families, relatives, homes, names and so on. Their parents brought family photos which helped in my work. I also tried to explain changes in their surroundings, for example the cycle of the seasons. We went walking though parks, forests and vegetable gardens. I did my best to familiarise the children with events going on around us.

During my lessons I used a lot of real objects, pictures and texts. I slowly introduced speaking by signs and by touch. It was hard work, not only for me, but mainly for the students because they were not used to working and they soon felt weary and discouraged. I had to teach them how to work, eat, dress and undress, go upstairs and downstairs and so on.

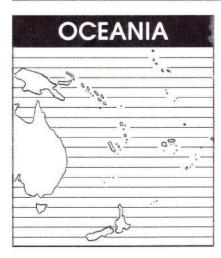
Today, we have three groups of deaf and blind students in our centre. The first is for beginners and has four children in it. The teaching methods are similar to those I have described above, but the students are also learning some Polish, mathematics, and physical education.

The second group contains four children with residual sight and hearing. There are many differences between them, so we have to use individual teaching methods. I take care of the third group, which contains five students at different levels of ability. They are learning Polish, mathematics, biology, geography and history. Three hours a week they have special lessons to prepare them for their future careers. All of the children have to train to do manual work.

All the students can take dictation from signed speech. They can also understand what they read and pick out special words or signs in a long text. My students have started to be interested in many things around them and now they ask a lot of questions.

Our children come from all over Poland. Some of them live very far from school, so they board. Cooperation with their parents is good, although there are a few cases of children being rejected. Twice a year, all parents have the opportunity to take part in our lessons. They are instructed in how to help us in our work. Of course, they can also comment on our methods and may have their own requirements.

As an institution, we have a lot of financial problems. The school also lacks equipment. However, despite our difficulties we know that our work with deafblind children is a necessity. We must teach them about the world around them and prepare them for living on their own.



Oceania (The Pacific Region) has been busy developing services. Currently an excellent research project is being undertaken in the region via a combined effort of the Ebenezer School for the Blind (Hong Kong), The Melbourne University and The Victorian Association for the Blind to devise a low vision assessment test suitable for use in developing countries. A training package will accompany the test and it is hoped that it will also prove to be a useful tool for multihandicapped blind children. The project officer is currently visiting many institutions and organisations throughout the world to collect relevant information.

A new body has also been formed in the area. It is the Pacific Island Council and has representatives

from all the developing islands in the Pacific including Fiji, Western Samoa, Vanuatu, Tonga, the Soloman Islands, Papua New Guinea and the Cook Islands. It is hoped that this body will be a coordinating body for training and international projects and so help to avoid unnecessary duplication of services and training programmes. As there are only very low numbers of multi-handicapped blind children including those who are deafblind, much of the focus of training in the Pacific Islands will be across disabilities. Thus a very good interpersonal network is rapidly becoming established between professionals working in the area of visual disability and those in other disabilities.

## **Canadian developments**

## Recent achievements

It took ten years to make government officials understand the special needs of deafblind children and adults in Canada. Only in the past two years has deafblindness been recognised as a unique handicap here in Canada. This has prompted studies on the integration of deafblind children in community schools, independent living facilities and on the delivery of social programmes to ensure deafblind Canadians have access to the fundamental elements of daily life. One-on-one intervention has been recognised as the indispensable communication link between the environment and a deafblind person. To meet this requirement, intervention service programmes have been instituted in educational establishments, at home on weekends, during school breaks and the two month summer holiday. These intervention programmes are now being provided in most regions of the country.

## No programme

A very special programme has recently been approved by the Social Services Ministry of the Province of Ontario. This programme has been tailored to the needs of one 22 year old deafblind person. She is provided with her own flat, intervenors and computer equipment. It is a model for other deafblind people. Volunteer help is also provided from friends. This individualised programme emphasises independent living, education and employment. It was designed by the young woman's mother who also supervises the programme.

Since the beginning of the inauguration of the first group home or supported independent living facility in 1985, six more were opened last year in three regions of the country. These seven homes are located in communities where the young deafblind residents share amenities and collective resources with their peers. This integration has created a chain reaction of awareness of the abilities of deafblind people. Some of these young adults have also found gainful employment. Others are



The Canadian Deaf-Blind and Rubella Association (CDBRA) was formed 17 years ago by parents whose children attended an educational faculty in Ontario. It was established out of concern for the future of their young deafblind children and the desire to assist parents. Stan Munroe, President of CDBRA brings readers up to date with the latest in deafblind education in Canada.

enrolled in a continuing education or vocational programme taking the challenge of a university degree. A group of adventitious deafblind adults have succeeded, with the financial help of rotary Clubs, in acquiring a specially designed apartment building.

### **Intervenor** course

The CDBRA, in collaboration with the Canadian Institute of the Blind, has promoted the establishment of a college diploma course for intervenors. The first group of 29 students will complete the first year of the two year course in June 1992. The course includes students from Canada and the US. Another twenty part-time students are following a four year weekend programme.

To promote high performance of intervenors a special award competition has been opened across Canada. This competition is being promoted through the Andrew Love Memorial Fund founded by Andrew's parents in September 1991. The fund can also be used to assist deafblind persons pursuing vocational or university courses.

The CDBRA has also instituted a National Intervention Fund to help parents and deafblind adults in emergencies or in situations where intervention services are not provided.

Canada has gained more recognition on the international scene through its participation in world conferences. This is also evidenced by the requests for information and assistance which comes from various parts of the globe.

The recent publishing of the book Vision in Children, Normal and Abnormal has enhanced the reputation of the CDBRA. The Association is also recognised as one of the world leaders on the concept of intervention and the development of intervention programmes tailored to the special needs of deafblind individuals.

Our most gratifying achievement is to have continually improved the quality of life of many deafblind Canadians and succeeding in having deafblindness recognised as a unique handicap.

## **Future activities**

We have developed a 'Global Plan of Action' to be implemented over the next 3-5 years with a 'Specific Plan of Action' for each year. One of the short term goals is to intensify awareness of the needs of deafblind individuals through various media available at both the national and regional levels.

Other goals include: campaigning extensively to heighten the profile of multisensory impaired people; encouraging federal and provincial ministries to recognise the individual needs of a deafblind person and urging employers to accept the potential of deafblind people.

Because of frequent demands from organisations both in Canada and abroad we have formed a Consultative Committee whose responsibility will be to facilitate workshops on various aspects of deafblindness that is education, intervention, parents' assistance, independent living facilities, and so on. These consultative services will be offered in Canada and the US. As the Centre for Deafblind Children at Mampong-Akwapim, Ghana, continues to grow, we aim to demonstrate qualitative developments in our operations. Such development includes healthy relationships with all our working partners and other clients of the Centre, in addition to improvements in our strategies for effective job performance.

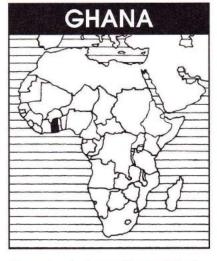
There are currently nine deafblind pupils at the centre, with varying degrees of ability. The staff includes ten teachers and two house-parents.

All our programmes are designed to help the deafblind students acquire daily living skills and vocational skills which will be useful to them in their future lives. We place great emphasis on orientation and mobility training, in addition to training in local handicrafts. Other subjects include language development, number work and religion.

### Seminars

A number of training seminars were held during 1991 at the centre, aimed at teachers, parents and house-parents. In June, a group of teachers got together to improve their efficiency and discuss ways in which they could keep themselves abreast of changes in their profession.

In July, a workshop was held for parents of deafblind children to determine the most appropriate ways of involving them in the centre's activities. The three major



discussion topics emphasised that education must never create a division between home and school; that parents have knowledge which should be used as a basis for planning school programmes and that the biggest problem faced by many parents is stress, which needs tactful and professional handling.

The third seminar, in September, was organised by the Special Education Division of the Ghana Education Service and brought together 40 house-parents from schools for the disabled across the country. The group examined the role of the house-parent and the ways in which educational programmes can be continued outside the classroom.

All three seminars proved extremely popular and useful. In the future, the centre hopes to collaborate with others in the area to make training accessible to all.

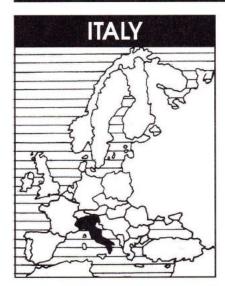
## Problems

Two major problems for the centre in recent months have been lack of accommodation and transport. The centre had only one room for teaching which could not house its nine pupils and ten teachers, so temporary accommodation was found at the Demonstration School for the Deaf. However, that school is also facing accommodation problems, so the solution was inadequate. A new classroom annexe is now being built at the centre which should resolve any further difficulties.

The centre's minibus has broken down and is beyond repair, which has made it difficult to visit the students' homes for counselling and follow-up visits. It has also been almost impossible to take the students on educational visits to places of interest. We hope that another bus will be available soon.

During 1992, the centre intends to build upon relationships with the students' families, to improve cooperation between the home and school. All staff are keen to encourage greater parental involvement in the programmes running at the centre.

Once the classroom annexe has been completed, three more teachers will be recruited in September. This will mean that the three deafblind children currently on our waiting list can take their places at the centre.



This year is a very important one for the Lega del Filo d'Oro, and we have a very interesting programme of collaboration with other countries. These activities include deafblind people themselves, their families, teachers and specialists.

In July, we will be welcoming six students and their teachers from Aalborgskolen, Denmark for a week's holiday here in Italy. The holidays continue in August when 12 families will be given the opportunity to rent summer cottages in Denmark by the Danish Association of the Deafblind.

Our work with Denmark carries on in September. One of our specialists, who will head our new Diagnostic Centre will be visiting the Audiological Department at Aalborgskolen, to find out about the latest technology and discuss future work.

Two deafblind people will be attending the Weekend Away, in Great Britain, which is Sense's annual conference. Their visit will be in recognition of their presentations on the future role of the Lega del Filo d'Oro.

As ever, 1992 promises to be a busy year for the Lega del Filo d'Oro. Watch out for futher reports in future editions of Deafblind Education.

## Spanish statistics

In 1985 in our country we began to work towards the development of services for deafblind people, within the structure of the Spanish National Organisation of the Blind (ONCE). However, for about 40 years there has been a unit devoted to the education of deafblind children.

One of our first steps was a screening campaign to get a better knowledge about our deafblind population. We have always been guessing at figures and we go on doing so by comparing statistics from other countries where they have been working in favour of this group for many years.

As you may know, a general study of the population is a very difficult task. In 1986, we implemented our first survey and as a result we identified 180 cases at that time. By the end of 1987 we already knew of about 340 people.

At present, our register includes about 700 people. This figure is increasing continuously and we estimate that according to various countries' statistics, the total amount of deafblind people in Spain, which has a total population of about 40,000,000, must be somewhere between 3,500 and 4,000 persons.

We know, for example, that in Sweden, where they have one of the best surveys of the deafblind population, they have identified 1,200 cases among a total population of 8,500,000 people.

We have done an aetiological study of the 700 cases we have registered up to now, because this provides very important information when it comes to planning services in the fields of education and rehabilitation.

Another way of approaching statistics was to make an estimation taking into account figures from the Spanish National Federation of the Deaf. It considers that in our country there are about 120,000 deaf people. If from 3 - 6% of these have Usher syndrome, we would have from 3,500 to 4,000 cases. Supposing that they represent 50 of deafblind people, then the deafblind population would be twice as big as we have estimated, ie about 8,000 people.

These figures were talked about at the eleventh Spanish National Congress of Teachers of the Deaf.

Table 1: More frequent causes of deafblindness in the group 0-18 years old

Total number of cases:	120
Rubella	50
Premature babies	11
Usher syndrome	10
Congenital malformations	6
Encephalopathy by virus	3
Hydrocephali	2
Polymalformation Syndrome	1
Congenital Encephalopathy	1
Retrolental fibroplasy	1
Exantematic contact	1
Retinoblastoma	1
Meningitis by bacteria	1
Meningitis in newborn baby	1
Brain tumour	1
Marfan syndrome	1
Pierre Robin syndrome	1
Toxoplasmosis	1
Down syndrome	1
Goldenmar syndrome	1
Golft syndrome	1
Parents' consanguinity	1 1 1 1 1 1
Demos Gustant syndrome	
Unknown etiology	1
No data available	13

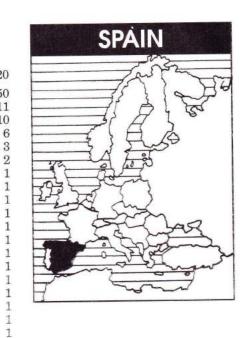


Table 2: More frequent causes of deafblindness in the group 18+	
Total amount of cases	571
No data available	22
Age distribution	
18-35	151
35-65	247
65+	151
Etiology distribution	
Usher syndrome	176
Meningitis	45
Accidents, traumatism	21
Rubella	15
Premature babies	2
Typhoid fever & no identified fever	7
Diabetes	2 7 9 1 1 1 4 1 5 1
Cerebral palsy	1
Cerebral damage	1
Marinesco syndrome	1
Noonan syndrome	1
Lawrence Moon Bield syndrome	4
Behec syndrome	1
Wolfran syndrome	ð
Ruckhinghansen syndrome	1
Polymalformation syndrome	1
Other pathologies not directly related to either deafness	
or blindness (measles, scarlet fever etc.)	25
Other pathologies that cause either blindness or deafness	100
(cataracts, glaucoma, tympanum performation)	102
Unknown etiology	80
No data available as regards etiology	51
Usher syndrome incidence in siblings	05
2 siblings	25
3 siblings	42
4 siblings	10
Families with no Usher syndrome cases	10

Asuncion Leyton, Co-ordinator on the deafblind programme at ONCE, has sent Deafblind Education these photographs showing work with children in the organisation's deafblind unit.





## Deatblind Education January-June 1992

## **Fighting for services**

Tony Best, of the Hilton Perkins National Program, at the Perkins School for the Blind in the USA has been investigating services in other countries. This is his report.

#### Latin America

Hilton Perkins has been involved in Argentina and in Cordoba, where one of our staff works and where there has already been an assessment of needs carried out by Hilton Perkins. Staff training was identified as a major problem, and the countries that are involved -Argentina, Chile, Columbia, Brazil, Peru, Equador and Bolivia - are organising a series of training events taking place in May, June and September of next year. All the countries are working together to provide training for staff and to exchange information.

#### India

Hilton Perkins is also working in India, with staff visiting Nepal, Bombay and South India where there are children of five years old and programmes beginning to be set up. They have asked for technical assistance, support and advice.

#### South East Asia

Quite a number of children have been identified in this area, and a number of programmes have been set up. In Korea, Singapore, Hong Kong, Thailand, Malaysia and Indonesia all have programmes for deafblind children and are struggling against some difficult situations. Twenty-five people from 13 different programmes for deafblind children asked for some training and for the opportunity to meet with other people working in the same field.

The people on the course are now working on projects in curriculum development, assessment procedures and models of service delivery. They are all meeting again soon to discuss the development of work within South East Asia. They have been given a modified curriculum, but it needs changing for it to be appropriate for South  $\overline{T}$  at the transment.

I am ming to shand some time

so that these countries can develop services beyond the few children they are already dealing with to try to meet the needs of identified children within their own countries, which is a far greater number.

All these countries are developing services and are supporting themselves or each other. Sometimes they receive external help - for example, Hilton Perkins has a staff member in Bangkok who networks people and enables them to communicate with each other.

It is very encouraging to see so many countries developing services. They are all solving problems with geography, language differences and stage of development. In some of these countries, only half the children go to primary schools anyway, and they are working in very different cultures with different expectations. They will be finding solutions which are mindstratching for those of us in richer

countries - overcoming incredible

## Let's play

Last June, Deafblind Education featured a report on the ways in which deafblind children play, written by Tatiana Basilova, Senior Scholar at the Institute of Defectology in Moscow. In this edition, Jane Brodin, a PhD student in the department of education at Stockholm University investigates play as a means of communication and learning.

In this article I describe the communicative interaction between six profoundly mentally retarded children and their parents/ caregivers. The children are multiply handicapped and function at an early developmental level. The function of play in these children's interactions with their mothers is also examined.

Children with severe disabilities are a relatively small group of the total population in Sweden. The living situations of families with children with severe handicaps have changed considerably during the last twenty years. One reason for this is the changing attitudes in Swedish society towards people with disabilities. There has also been a change in ideology in the area of care for the mentally handicapped. Efforts have been made to offer all citizens the same legal rights and opportunities in order to secure fellowship and participation in activities in society. Children with disabilities, according to law, must no longer be placed in an institution, except in extremely special cases. This has resulted in an increase in family support programmes. Today most children live in their homes and grow up with their parents and siblings. As a consequence, parents have started to formulate demands for integration and different kinds of family support. The living situations of the parents in this article have a great influence on their children's possibilities for play, communication and development. Play and communication, I find, are of great importance for these children's total development.

## Methods

My study looked at six children; two girls and four boys, between one and 10 years old. All six children are at an early developmental level, are profoundly mentally retarded and have five or six additional handicaps in addition to the profound retardation. They are all motor disabled, have communication disorders and are incontinent. Four of the children are visually impaired, and four have epilepsy. The study was based on parental interviews, observations (naturalistic and video-recorded) and naturally-occurring conversations with parents, personal assistants and teachers. Data collection began in autumn 1985, was intensified in 1988 and finished at the beginning of 1990. A quantitative compilation was done of the childrens' communicative abilities, that is turntaking and initiatives, which gave information about the child's ability to influence the communicative interaction. I chose to describe these children in their daily environments. The empirical data was presented as case studies, along with compilations of the results of all six children. I visited the children in their homes and at their preschools or schools on five to six different occasions. During each visit I video-recorded the child during a meal and play time for between 15 and 40 minutes.

## Context

Play is often considered to be important for child development. As a starting point I asked: 'What function does play serve for profoundly mentally retarded children?' There is a general opinion that severely multiply handicapped children are extremely passive and take few or no initiatives by themselves. Many researchers have supported this hypothesis. However, I find that these children do not show passivity in all situations. If they can participate in play, they become more active. Context seems to be of great importance for the child's passivity/activity. These children are very dependent on adults in play situations. Play often means that an adult person activates the child and plays with him. Profoundly mentally retarded children have few natural contacts with playmates, and are more often referred to play with adults. Profoundly mentally retarded children are fond of singing and listening to music, of physical body play and of games that stimulate their senses. They prefer to be physically close to the mother/ caregiver, and they prefer games that offer visual, auditory and

tactile stimulation. The three oldest children in my study liked to sit and watch (with great interest) when other children played. They were not interested in playing with traditional toys, and most of the children preferred to play together with their parents/caregivers. The six children communicated with natural reactions and signals, that is body language, gestures and facial expressions. Only two of the children used signals consciously. They all used gaze/eye contact, sound/vocalisations, facial expressions, body position and breathing to show what they wanted. Five of the children laughed and smiled when they felt comfortable, and four cried when they felt sad. The youngest child, a girl, was very quiet. She often slept and never laughed, smiled or cried. All the children showed when they were tired, four when they were hungry and three when they had had enough food. The children indicated when they were happy, sad or dissatisfied. Four of them also showed when they were interested in different objects. Some of them could attract a person's attention. They all used their communicative ability to show feelings and needs.

### Play and communication

In order to focus on the relation between play, communication and development I would like to stress the following. Play and communication are closely related to each other and take place in the same context. Like communication, play is a social process; participants influence each other. The child learns to communicate by social interaction and turn-taking in play. Feedback to children's signals is the foundation for the development of communicative ability. Even children at an early developmental level can learn turn-taking through play.

Adults have an important role in play and communication for these severely handicapped children. Play is a means of communication. The value of play, per se, is discussed. Can play be regarded as an aim in



itself and not only as a means for reaching competence in other areas? Play itself may be a reasonable aim for the parents and caregivers of the profoundly retarded children.

An interesting aspect of play and communication is training. Parents often request training programmes for their children and often participate in these programmes. The training usually involves stimulation of fine motor development of the ability to communicate and takes place in pleasurable play. However, there is a tendency to use normal child development as a basis, attempting to train children with disabilities to be as close to 'normal' development as possible. From my work it seems that children with severe disabilities may not follow the same pattern of development as normally developing children, because of their various additional handicaps. Each different ability develops to some extent but not as quickly and not in the same order as in standard child development. The combination of multiple handicaps seems to affect each child differently.

For parents this way of life consumes a great deal of time and effort. They often have to give up many of their own life projects. Despite all legal rules and laws, family support from society does not function as well as it could. Many children with disabilities are integrated in preschools and schools, but there are great difficulties as the integration seems to be physical more than social.

### Interpretation

The communication of the six children in my study was nonverbal. This meant that their parents must interpret their signals as if the child had a special intention. All parents interpret their children's signals, although they are not always aware of it. They look at the sounds/ vocalisations, body position, facial expression and gestures and interpret these signals from the child. The most common communicative actions involve the child's well-being and the child's wants and needs. Parents rely heavily on their own intuition and ability to interpret intention through the child's signals. However, their interpretation involves a great degree of guesswork. The repertoire of what the child can express is limited to only a few topics. One problem for the parents is to forward information about their child's communicative ability to other people in the environment. They often hear from other people that

they over-interpret the child and their comprehension is only an expression of wishful thinking.

Several researchers consider that the parent's ability to interpret a child's signals is genuine. The interpretation is to a great extent context-dependent, and the context in connection with common sense is used to judge the meaning of the child's intentions. Other researchers have shown that in normal child language development parents often say that their children can understand more than they do in reality. For parents of profoundly mentally retarded and multiply handicapped children the situation is almost the reverse. These parents tone down what they see and this can in some cases result in an underestimation of the child's ability. Parents have a unique competence in knowing their children and understanding their children's communication.

For these children's development it is absolutely necessary that parents answer them even when they give weak and limited signals. I would suggest that there are higher requirements in communication for parents of multiply handicapped children and that a positive and sensitive environment is a basic necessity for communicative development.

## Studying deafblind children with additional handicaps

Valeri Chulkov, of the Scientific Research Institute of Defectology, in Moscow, Russia, details the latest research into communication disorders in deafblind children.

According to L. Vygotsky's theory on child development, sensory impairment or mental deficiency may result in a series of developmental delays.

Studies by G Bertyn and other researchers show that amongst the deafblind population there are many children with primary additional handicaps: mental deficiency, motor disorders and underdeveloped physical structure. Understanding the developmental peculiarities of these children within the framework of special education has a twofold effect. It helps the teacher to respond adequately to the child's needs and stimulates research on specific ways of meeting these needs.

Figures compiled in this country in 1986 by M. Pevzner, G. Bertyn and R. Mareva show that 30% of mentally disabled children are deafblind. More accurate figures taken from a wider population place this number at 40 per cent.

According to our observations, adventitiously deafblind children usually have the intact potential for further mental development. We may speak about the developmental backwardness in these children as a secondary handicap caused by inadequate provision for the child's intellectual development.

Unfortunately, the exact number of children with motor disorders, including children with cerebral palsy among the population with multiple sensory impairments is not available. But our observations show that the number of these children among the deafblind population is significant and at the present moment our institutions for the deafblind are not really ready for training this particular category of children. The work with these children is only at its very beginning.

Theoretically, all types of primary handicaps known in special education may be reflected in the deafblind population. For these children to progress in their development, they must be given special provision and support. So, in deafblind education we must concentrate especially on the methods of educating deafblind children with mental deficiency, challenging behaviour, cerebral palsy and so on. Recently, we have been paying special attention to deafblind children with primary speech disorders and with severe autistic behaviour – so called communication disorders. In meeting the educational and developmental needs of this particular group of children, we try to use knowledge from the relevant adjacent branches of special education. Besides these, we look for specific educational methods which take into account this particular defect structure.

We have noticed underdevelopment of speech in some of our students in the Experimental Group at the Institute of Defectology and the Zagorsk Rehabilitation Centre. This could not be overcome, despite intensive remedial work with the children, who were all mentally able.

Special scientific investigation of this problem is now being done by the speech therapist M. Podoprigorova. Our hypothesis about primary speech disorders in these children is confirmed. We discovered that some children were suffering from a disorder of the morphological structure of the speech apparatus (the destruction of the dental jaw system) cleft palate and so on. In other cases we identified dysarthria, sensory alalia and childhood aphasia.

Here we need a very deep investigation and examination. The EEG test indirectly confirmed our diagnosis. In psychological educational diagnosis of this disorder it is very important to apply the test of speech memory in written and finger-spelled speech. The identification of aphasia and other speech disorders in the case of hearing loss is complicated, as the secondary speech disorders may mask the primary ones.

After the diagnosis, the speech therapist modifies his or her work with multiply sensory impaired children with primary speech disorders. This work consists mainly of special exercises aimed at training and the development of speech apparatus and correct pronunciation skills. In the case of aphasia the speech therapist uses sign language as a non-verbal form of communication, changes speech material in exercises and prolongs the period of its mastering by children.

Some years ago we paid our attention to the absence in some children of the need for communication, that is, autistic behaviour. Sometimes, this autistic isolation remained in adolescence, despite progress in cognitive and speech development. After examining some rubella handicapped children, the problem of communication disorders became clearer to us.

It is known that autistic children are characterised by problems in emotional relationships with the people who surround them, even their near relatives. They display stereotyped forms of behaviour, avoidance of new situations and fear of the unknown, narrow interests, withdrawal and mental retardation caused by decreased emotional contact with the environment. This is why studies on early child autism (V Lebedinsky, K. Lebedinskaja) are becoming increasingly important to deafblind education.

The scientists above have worked out an approach to the pathology of the emotional system based on a series of levels. The first covers field reactivity, the second stereotypes, the third expansion and the fourth emotional control. Deficiency in any of these levels determines the group to which an autistic child belongs. Since 1989 in Zagorsk School, teacher R. Burlakova has been carrying out experimental educational work on this problem.

## **Case study**

Lena, a girl aged 13, has been in Zagorsk School (see grey box) for six years. She is rubella handicapped, has congenital cataracts, aphasia and a hearing loss of more then 70Db.

She has mastered everyday living skills and self-care, and follows a timetable every day. Her level of academic achievements corresponds to the preparatory form and the first form of the special deafblind programme. In lessons she is willing to undertake only certain assignments, copying words and sentences, selecting tables with written words and matching words to pictures. She fulfils reading, writing and number assignments mechanically and indifferently, without showing any interest.

The girl seldom asks the teacher for help. If she wishes to gain her attention, she pulls the teacher's hand to the object she wishes to obtain or have removed. If the teacher turns her attention from Lena, she laughs quietly and shakes her palms and fingers in front of her.

Some time ago, she did not like school. She cried, counted the days before she could go home, liked to repeat the same signs, that is, "a day", "to sleep", "a car" and "a house". The number of words like " a day" and "to sleep" exactly corresponded to the number of days left before Sunday. The only person to whom the girl is attached is her mother, who now works at the school to help her daughter progress.

While working with the girl, we decided to change and modify the usual programme and fill the lessons with positive emotional experiences. Our work aimed to establish better contact with the teacher.

## **Changes in Russia**

With the break-up of the Soviet Union, there have been a number of changes affecting colleagues in deafblind education in Russia. Firstly, the Institute of Defectology now belongs to Russia. Secondly, the school and town where it was located (Zagorsk) now both have new names, in addition to a new building.

The building is now called 'The Rehabilitation Centre for Deafblind Children' and the town's new name is Sergiev Posad.

This was improved by imitating the child's contact with her mother, using touch, kindness and care. The girl was placed in more comfortable situations and in less unknown ones, the form of the child's treatment was changed from direct inducement to kind encouragement without pressure. In communication we returned to former methods – to signs instead of fingerspelling, because some signs had a personal meaning for her. We noticed that the girl was very interested in her baby brother, so we changed her reading texts to new ones devoted to her family. Lena started drawing pictures about her brother and other near relatives. In her pictures she tried to reproduce the furniture arrangement in her room and even the exact colour of her family members' clothes.

A year later we observed the positive results of our work. The girl's attitude to schooling was changed; her relationship with her teacher was improved. She stopped weeping and resisting schooling.

The next level, that is, the ability to expand upon this, is not yet accessible to Lena. The real obstacles are connected with difficulties in mastering painting, writing, reading, self-care and housekeeping. Lena still has no emotional relationships with other children, but her emotional status is changing very slowly, as we expected. The fact that these changes have occurred gives us great hope.

> Translated by Svetlana Vishnevskaja

## Assessment

Michael Collins, Director of the Hilton/Perkins National Program, at Perkins School for the Blind in the USA, offers some words of advice.

During the 1970's, with our societal focus upon attainment and scientific precision, we assessed deafblind children through standardised psychometrics, resulting in the assignment of an IQ. In the later 70's, practical developmental scales for assessing deafblind children were written, such as the Callier-Azusa and the Michigan Assessment Scales. These compared deafblind children against themselves, and against normal development. In the 80's, as the 'hippie' generation was entering their own adulthood, our assessments shifted focus toward assessing functional life skills, using assessments such as the Functional Life Skills Screening Inventory. Today, in the 90's, our focus is on the quality of life and our world environment, so it is not surprising that our assessments have shifted from the individual to looking at the whole environment, the 'ecological' approach.

In assessing ecologically, we consider the child's history,

residential environment, social spheres, closest relationships, and his various ways of communicating. We review what adaptations we can make in the surroundings, in the home schedule, in the school schedule, to better benefit learning. We consider the child's future. In short, we use the traditional assessments and tests to look at what the child can and cannot do, but then we look beyond the results and ask ourselves why.

One concern which I wish to raise is our 'bandwagon' approach to special education. We tend, in our enthusiasm for the latest strategies and practices, to jump on this new 'bandwagon' and forget that we knew anything previously. No science accrues knowledge in this manner, and our profession is then reduced to a series of changing beliefs, rather than increasing wisdom. In assessing, we need to integrate our ecological approaches of today with the best past practices of psychometry and functional scales, in order to be accurate and thorough.

As we think about the quality of life and apply this to assessment, I think it is helpful for us to consider the quality of life indicators as developmental. That is, quality of life indicators change as a person moves from infancy to childhood to adulthood. For infants, basic care, comfort and nurture are clearly the most relevant factors. In early childhood, education, choices, friendships, a sense of order and predictability to life, are all of high importance. However, we too often forget those things which we highly valued as children, such as wonder, surprise and fantasy.

I would offer one major caution: let us not develop another damned formula on what makes up quality! Quality for each of us is a reflection of our personal values, amongst professionals, and with families, if we are to understand each other's wishes for the child. We need to teach with our own values clear, and the values of our families respected. Values are not right or wrong, and change slowly, from within the person. We cannot impose our value systems on each other: we can only engage in dialogue, in order to gradually influence each other and gradually move toward those which are mutually held.

## Deafblind Education

Deafblind Education will appear twice yearly, the two editions will be dated January-June and July-December.

The editor will be pleased to receive articles, news items, letters, notices of books and 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.

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