

## **Cordoba Conference Report**

***pages 6-11***

**Young deafblind people  
as decision makers**

***pages 22-23***

**Communication through  
active music**

***pages 17-18***

**Family concerns have  
few cultural barriers**

***page 21***



# 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 language and may be edited before publication. It should be sent for publication to arrive by the date below.

Opinions expressed in articles are those of the author and should not be understood as representing the view of IAEDB.

**Editor** Malcolm Matthews

**Editorial Team** Anna Cartwright  
Richard Hawkes

**Editorial Office** Sense  
11-13 Clifton Terrace  
London N4 3SR  
United Kingdom

Tel: +44.171.272 7774

Fax: +44.171.272 6012

**LAST COPY DATE FOR THE NEXT EDITION: 22 MARCH 1996**

## MESSAGE FROM THE CHAIR

**W**riting this message to the members of IAEDB I feel very privileged to have been given this exciting opportunity to participate in international co-operation and development. I would like to thank you for the confidence shown in me when electing me as Chairperson of the organisation to succeed Jacques Souriau. During Jacques' period of office the activities of IAEDB diversified and the number of member countries increased significantly. We are very grateful for all the efforts he made and are looking forward to seeing the results of this effort in other fields of work with deafblind people.

I am very happy that Rodney Clark as Secretary/Treasurer and Mike Collins as Vice-Chairman are willing to continue with their roles and I am looking forward to good and successful co-operation with them. Their contributions so far have been tremendous and we should thank them for this.

The World Conference in Cordoba, Argentina was a great success. We cannot thank our colleagues in Cordoba enough for creating such a wonderful conference for us to be together and share knowledge and experiences with each other. The next



world conference is going to be in Portugal - we wish them luck preparing for this.

I have been asked many times what the first steps I am going to take and what the objectives for the future are. Again and again I have answered "ask me in May!". What happens in May? We are in the middle of a strategic planning process which is going to end at the Executive Committee meeting in Vancouver, Canada in May. The Strategic Planning Working Group have already identified the development areas. During the Conference in Cordoba these questions were discussed and all the members will now have

received a questionnaire on the future priorities of IAEDB regarding objectives, activities and organisation. I very much hope that everyone takes the time to give their views and opinions as this is very important if we are to develop IAEDB to meet the needs of members all over the world. The Strategic Planning Working Group will meet in January in Lisbon to prepare proposals for the Executive Committee.

International responsibility has grown in recent years and there are now many organisations creating services for deafblind people in developing countries. Initiated by Sense International there will be an International Partners' meeting in Lisbon in January. We hope to share experiences and co-ordinate resources so that they can be used effectively to meet needs in developing countries.

As far as IAEDB is concerned I do hope that we can create facilities for many more countries to participate in international co-operation. Contacts and sharing information and knowledge are so valuable for our work with and for deafblind people. The more that we do this in the coming years the more successful my term of office will be.

**Marjaana Suosalmi**

# CONTENTS

## NEWS

**First National Conference of Deafblind People in Italy** *page 4*

**Usher in the Deaf Community, Conference Report** *page 5*

**Young Deafblind People as Decision Makers** *pages 22-23*

**Second International CHARGE Association Conference** *page 24*

**Recent Publications** *page 25*

**Conference Notice** *page 26*

## FEATURES

### **IAEDB World Conference**

A review of the highlights of this international week-long event. *pages 6-11*

### **Conditions and Syndromes that can result in Deafblindness**

The first in a series of reports, beginning with a focus on Cytomegalovirus. *page 12*

### **Teaching Students who are Deafblind and Cognitively Disabled to Effectively Communicate choices at Mealtimes**

A pull-out step-by-step approach to developing the concept of choice through context cues. *pages 14-16*

### **Communication Through Active Music**

An insight into the use of music to stimulate interaction patterns *pages 17-18*

### **Community Services Re-examined**

Changes following a review of this service in Victoria, Australia, are examined. *pages 19-20*

### **Family Concerns have few Cultural Barriers**

Impressions from the Conference Focus Day. *page 21*

## COUNTRY REPORTS

**Czech Republic** *page 13*

**Nigeria** *page 25*

# EDITORIAL



If you were at the 11th IAEDB World Conference you will know that it was an outstanding experience. As my colleague Eileen

Boothroyd said:

*"In addition to the formal sessions the opportunity to meet and talk informally to so many people about our work and their work provided a fantastic experience for recharging the batteries and sharpening up ideas. The individual contact with delegates from so many different countries was just as valuable as the formal part of the Conference."*

The conference programme was very well balanced, which I know can be difficult to achieve. I hope this edition of Deafblind Education provides a useful account of the conference both to those who were present as well as to those unable to be there. In this edition and future Deafblind Education journals we will be focusing on some of the conference content.

The last three editions of *Deafblind Education* have also been produced in a more limited version in Spanish, and it was encouraging to hear at the conference how positively these newsletters had been received. I am therefore very pleased that the IAEDB Executive decided that from this edition on we can produce a complete version in Spanish to be printed in Uruguay. Please let us know which version you would like to receive.

We try to respond to requests regarding Deafblind Education. As a result of a request we have prepared the first of a series of articles on causes of deafblindness.

In the next edition we plan to focus on the issue of integration or inclusion in education for deafblind children. This was the subject of a plenary at the Conference and sparked off so much debate that we hope to follow this up. If you have any contributions to make on this topic do please get in touch.

Finally, one of the sessions at the Conference involved discussion on the future activities and structure of IAEDB. We hope to publish your responses to the questionnaire on this subject in the next edition.

With very best wishes.

**Malcolm Matthews.**

# First National Conference of Deafblind People, Osimo, Italy

17-24 June 1995

**T**his is the 30th anniversary of the Lega del Filo d'Oro and a series of activities has been organised to celebrate this important date in our history.

One of the events which has had an impact on our future work was the planning of the first National Conference of Deafblind People. The 'Lega's' role in the planning of this was more of a secretariat while the real input was from deafblind people themselves. The national committee of deafblind people were responsible for the programme and all the speakers were themselves deaf and blind.

Two days prior to the Conference we also hosted the EBU's European Committee on Activities of Deafblind People annual meeting.

The title of the National Conference was 'Out of Isolation' and all the themes discussed during the week had relevance to this main theme. Areas such as European and International collaboration, Interpreter Training and Services, Technical Aids, Sport and Recreation, Communication and the need for a Contact Person Network were some of the principle themes. Special attention was given to the needs of people with Usher syndrome and the need for formal recognition of deafblind people in Italy, as this is not the case at present. The need to conduct national surveys to understand the different needs of deafblind people was underlined. Recommendations were made concerning all these subjects and a proposition to a new law concerning

deafblind people is currently approved by 145 members of parliament.

In this respect the conference was considered a success, although it became obvious from the participants that more attention should be given to the development of services in the south of Italy.

The week was not all work and no play, as ample time was given to a series of courses and recreational activities. Sailing, ballroom dancing, computer use and art and creativity were daily courses while special parties were regular additions to the programme.

The National Committee of Deafblind People are evaluating this conference in order to prepare a second, which is planned for 1998.



Participants at the First National Conference of Deafblind People, Italy

# Usher in the Deaf Community Conference in Britain

4 October 1995

**F**our years ago two people with Usher embarked on a project which would revolutionise awareness of this condition in the deaf community. In 1991 Sense and the British Deaf Association, supported by the Department of Health, employed Sarah Reed and Nick Sturley to create awareness of Usher, which affects 6% of the deaf population worldwide. They started with nothing, and quickly found there was little existing material. The project was aimed at sign language users only.

The conference in October was the culmination of four years intensive

work and was opened by the Minister for Disabled People. During these years Sarah and Nick developed a programme for training deaf advocates using their own specially designed aids, such as blurred glasses to show what

people, they found after research that a comic book format was best for getting the message across. Eventually a leaflet 'What is Usher?', four booklets and a poster were produced. The hardest booklet to write, which has just come out, concerns the genetics of Usher.

A new video was launched at the Conference called 'Oh Really, You Have Usher?' made by people with Usher in sign language but with a voice-over and subtitles. The video demonstrates what it is like to have Usher and what people can do to help. Worldwide interest has been shown in all the leaflets and the video, as such material has never been available before. Even new signs had to be invented, as signs for 'retina', for example, did not exist.

Social workers, educationalists and health workers formed the bulk of the 150-strong audience, and the two Project Officers, Sarah and Nick, did most of the presentation. The Minister for the Disabled spoke of the new Disability Bill going through Parliament, and said he had not been



## HOW did I get USHER?

USHER SYNDROME IN THE DEAF COMMUNITY



an Usher person sees, set up training sessions and visits to deaf clubs, and travelled to different countries giving workshops. In 1995 six deaf advocates received certificates after training, and another group are currently being trained.

Everything had to be developed from scratch, and because both Sarah and Nick are profoundly deaf, they were able to produce unique material specially designed for deaf people. Because born-deaf people tend to think more in picture form than hearing

aware of Usher before the Conference, but now their needs would definitely be taken into consideration in the Bill. Both Austin Reeve, Vice-Chair of the BDA and Mary Guest, Usher Services Sense, spoke of the background to the project, which has succeeded beyond their wildest imagination.

The leaflets and video are available from the British Deaf Association, and from Sense, London. A review of the genetics leaflet and video will be in the next edition of Deafblind Education.

Sue Sturley

# IAEDB World Conference

**The 11th World Conference of the International Association for the Education of Deafblind People took place in Cordoba, Argentina from 9-14 July. A total of almost 400 delegates from throughout the world attended the Conference. The World Conference takes place every 4 years and is perhaps the most important activity of the IAEDB as it provides a unique opportunity for all those involved in providing services to deafblind people throughout the world to come together to share and learn from each other.**

**T**he location of the World Conference is extremely important as services in the host country often receive much stimulation and support. This was the first such conference to be held in Argentina and the first in South America. The venue was the University in Cordoba in North Central Argentina. Although it was winter the sun shone warmly for the first few days much to the surprise of the

**The IAEDB Distinguished Service Award recipients are Jan van Dijk (Netherlands), Rodney Clark (England) and John and Jackie McInnes (Canada). Jan was presented with his award in March '95 as reported in the last Deafblind Education. Rodney's award was presented in Cordoba. John and Jackie McInnes will be receiving their award next year when the IAEDB Executive meet in Canada.**

Argentinians and the delight of the visitors.

There were many very enthusiastic South American participants and a real feeling of excitement and advancement. There was so much enthusiasm and commitment - and reminders that it is a privilege to be involved in the deafblind movement. The conference was a revitalising, enjoyable and educational experience and the

## Renowned Educator of the Deafblind Passes Away

It is with sadness and regret that we announce the recent death of a well-known and widely loved deafblind educator, Nice Tognosi de Saraiva Loureiro of Brazil. Just after the close of our international conference in Cordoba, Argentina, Nice suffered a major stroke at the airport, and was hospitalised. Her immediate family, a daughter and a son, were with her in the hospital in Cordoba when she succumbed a week later.

Those who attended the IAEDB Conference will remember Nice's happiness and excitement during her last few days, particularly her obvious joy at having the world conference in South America, and also her pride in having been awarded the prestigious Anne Sullivan Medal for her lifetime of contributions to the deafblind field. It is with ultimate respect that we remember this special lady.

Nice was born on November, 1925, in Botucatu, in the state of Sao Paulo, Brazil. Later, her family moved to Sao Caetano do Sul, another town in the same area, but closer to the city of Sao Paulo, where she studied at the primary level at the Santo Andre school. Her father was the director of this school. After graduation, she

studied at the Normal Padre Anchieta School, where she received her teaching degree.

Nice started her professional life as teacher at the Paroquial Sao Caetano School. At this time, many of the young teachers in the city were quite impressed about a recent book which described the story of Helen Keller and Anne Sullivan. This book planted in Nice the seeds of ideas which would later germinate into her lifelong career path. When Helen Keller visited Brazil in 1953, Nice ensured she was appointed as Helen's guide throughout the visit. She was very impressed with Helen's communication abilities throughout this visit, and she loved to recount her experiences with Helen through all of her years in the deafblind profession. She was working as teacher at the Padre Chico School for the Blind at this time, and she began to formulate her plans to teach deafblind people in Brazil.

Nice went on to take a course on deafness at the Instituto Nacional de Educacion de Sordos in Rio de Janeiro. She then came to study with us at the Perkins School for the Blind in Boston, at the invitation of Dr. Edward Waterhouse. Upon return she started a class for deafblind children at the Instituto Padre Chico, and another for adults at the Fundacion para o Livro do Cego no Brazil. Many barriers

# CORDOBA CONFERENCE

Deafblind Education  
July - December 1995



**Opening of  
the IAEDB  
World  
Conference**

conference programme planners and organisers are to be congratulated on their significant achievement.

The Conference plan was rather different from previous years. Every day, except Thursday, started with plenaries, when major speakers gave presentations on fundamental issues such as: "The Unique Nature of Deafblindness and Resulting Fundamental Considerations", given by Kurt Vinterhøj from Denmark with responses from Ton Visser from St. Michelsgestel and Gricelda Callegari from Argentina.

Kurt talked about the different needs of individuals and four main groups of deafblind people: congenitally deafblind people, those who are born deaf and become blind or are born blind and become deaf and those who become both deaf and blind, mostly in old age. He referred to the new populations of deafblind people with various syndromes and a range of disabilities in addition to their deafness and blindness. He stressed the need for a definition of

presented themselves to make her dreams of deafblind service delivery appear to be impossible, but she persisted. Finally, she started the first school for deafblind children in Brazil, at the Escola Residencial para Deficientes da Audio-Visao; in 1977 the name was changed to the Escola de Educacao Especial Anne Sullivan, as it is still known today.

Nice continued with graduate level training at the university of San Marcos. She has held many different positions in Brazil. She has been a teacher of deafblind children; she has served as consultant to begin new programs throughout Sao Paulo State; she was Coordinator at the Escuela Municipal de Deficientes Auditivos in Sao Bernardo do Campo; and she served as a member of the Executive Committee of the Anne Sullivan School right up to her death.

Nice will always be remembered in our field for having helped to put deafblind education on the map of South America. More importantly, she will always be remembered for her kind and gentle ways with deafblind people, and her infectious enthusiasm with her professional colleagues. Even in later years her energy and enthusiasm were boundless. We will always remember her as a very warm friend.

**by Michael T. Collins, Vice-Chair, IAEDB**

## **IAEDB Executive Committee news**

**The IAEDB Executive Committee met and elected Marjaana Sousalmi as the new Chairperson. Mike Collins and Rodney Clark were re-elected as Vice-Chairperson and Secretary-Treasurer respectively. The Committee also decided to hold the next World Conference in 1999 in Portugal.**

deafblindness recognised by the United Nations. Kurt also talked about the need to recognise the culture of deafblind people, though there may be subcultures that vary according to whether people have been born deaf, like those with Usher syndrome whose culture may be based on deaf culture and sign language, or born blind, in which case their culture may be influenced by that of blind people. In studying communication between deafblind people there was a clear culture which was not observable when hearing sighted people were communicating with deafblind people. They gave each other social signals which each recognised, their turn-taking was different and other aspects replaced facial expression. We therefore need deafblind people involved in what we do when developing communication with children and adults so this culture can be transmitted to them.

Ton Visser also stressed the importance of interactions, say between mother and child, and the mother learning to recognise and respond appropriately to the child's communications.

Adult deafblind people in a group of hearing sighted people are hampered by the slowness of the communication, the lack of simultaneous conversation and therefore of synchronisation and gearing between the participants. They need good interpreters and activities appropriate for their interests and tempo.

## CORDOBA CONFERENCE



**Lucia Piccione, Conference President**

Tuesday's first plenary was by Paul Ennals with the support of Stuart Aitken (on video) "Values and Value Changes in Society Impacting on Deafblind Individuals". Carlos Picasso, a parent from Argentina responded. Paul talked about our own need to confront our value systems and conflicts within them and to recognise the value systems of others. He discussed different attitudes in different countries or societies towards disability. For some it may be shameful and should be hidden away, while others believe the disabled child is given to test their love and should be happy, leading to an emphasis on "care" rather than "education". For others it is a question of "equal rights" and may result in a policy of full integration or even a belief that to cure by medical intervention is wrong. Paul talked about education and curriculum reflecting the value systems of educators and the political views of countries, and about what is acceptable and desirable social behaviour. This will differ in families, societies and cultures, for example, the way people eat, hug and kiss, and, the most problematic area, sex, where personal values have to be confronted. Parents and carers have power over individuals and a responsibility to recognise all different values and to learn to respect the value system of the deafblind person. He suggested a programme of staff development working towards an agreed statement of values.

Paul was followed by Susana Podesta, a lecturer on philosophy and ethics, not specifically connected with deafblindness, who spoke on "Ethics and Dilemmas". She explained that what we do in a specific situation is a moral issue, while the reason why we do it is an ethical one. Morals regulate relationships in a social system. We have the freedom and the responsibility to decide on our personal moral code. *"I am not free when I do what I wish but I am free when I weigh decisions and decide. Without freedom there is no responsibility."*

Wednesday's first plenary was about integration: "A time for Transformation" by Maria Bove who spoke very volubly about the values of full integration as it was practised in her area of the United States. She was supported by Anna Nafsted from Norway who showed a video of a deafblind child who goes to the local school in a rural community which is very ready to support both child and family. Michael Collins from Perkins School gave a very measured response looking at the wider needs of children and whether they could all be met satisfactorily in the mainstream system in all circumstances or when specialist provision might be appropriate.

The second session considered: "Alternatives for Young Adults" with Jean-Francois Guerneau from France speaking.

Tony Best addressed the final plenary on Friday morning on "Goals and Desires for the Next Few Years".

### Workshops

The afternoons of Monday and Tuesday were given to workshops, three separate sessions each day with a choice of up to 10 for each session. There was a very wide range of topics, from a specific area of creativity such as sculpture or music therapy to philosophical studies such as 'Deafblind user of services: a child for ever' or "From many different grains a loaf is created" to practical ideas "Assessing Deafblind Children: Difficulties Arising from this" and "Reading and Writing". It would be impossible to discuss them all and it was equally difficult to choose which ones to go to with such a variety. However, here is a brief outline of a few of the 50 workshops to give an idea of the range and quality of presentations.

Jacques Souriau's workshop on Reading and Writing demonstrated working through objects of reference, going



on to pictures then to symbols of the pictures plus the written form, and eventually to the written form by itself for those for whom it was appropriate.

Greta Berlau from Norway gave a workshop on growing into culture and how difficult this is for some deafblind children who have communication difficulties. This leads to a poor knowledge of the social world and more idiosyncratic behaviour whereas a growth of understanding of the culture leads to less idiosyncratic behaviour. Parents and professionals must try to mediate between the child and the environment on a social plane. To demonstrate how deafblind children can develop a feeling for the national

## **"Intervention is the only way to integrate deafblind people into society"**

culture by experiential learning, Greta showed a video of a group of deafblind children and their families having a "winter sports festival". Winter sports are very much part of the Norwegian culture and by involving the village and the families, holding an opening ceremony with a trumpet and flag waving, having skiing and tobogganing competitions, eating out in the cold in the snow, being part of a crowd and having a presentation of certificates at the end, the children were introduced over several years to an awareness and involvement in their national culture and they enjoyed themselves!

Patricia Curtis gave a workshop on "Intervention" which originated in her home-country, Canada. She is Director of the New Brunswick chapter of the Canadian Deafblind and Rubella Association and is the parent of a deafblind adult. "Intervention", she said, "is the only way to integrate deafblind people into society". Intervention provides the means to communicate, learn, work and socialise. It means not doing *for* but doing *with*. The intervenor is the human vehicle who provides access to all available opportunities. The qualities of the person and the relationship with the deafblind individual and the family are more important than training, though this too is important and is now a two year course. It is the parents who select the intervenor, after careful screening by professionals who will subsequently support the person. The number of paid hours required is recommended to the social worker who usually agrees. More hours are provided by family and friends and further hours are added over time as the deafblind person is able to use them.

William Green presented a workshop about Training for Interpreters for Deafblind People. He is on the European Coordinating Committee on the training of interpreters and spoke about its meetings in Lisbon. It was very apparent how varied the training is and that many places still have very little training, and that what there is, is haphazard. Some of us were asked to describe briefly what was provided in our countries. William hoped that the network would be joined by people from other countries and would ultimately produce a recommended curriculum with guidelines. He listed some of the aspects that should be included in a training pack.

## **Preconferencia LatinoAmericana**

**T**he weekend before the Cordoba Conference, forty people, mostly parents, met at the Instituto Helen Keller to think about ways that parents could get together and work in Latin America. The weekend was arranged and hosted by the Argentine parents association (Asociacion de Padres de Personas con Sordoceguera) and there were parents present from Argentina, Brasil, Chile and Uruguay.

I was privileged to be there to share experiences drawn from Sense's development, and Clara Berg from the National Family Association for Deaf-Blind in the USA, and Stan Munroe from the Canadian Deafblind and Rubella Association joined me in discussing ideas.

The main stimulation and impetus of course came from the Latin American parents and I came away excited and humbled, as I always am on such occasions, by the constant evidence of love, dedication and sheer energy shown by the parents gathered there.

It is astonishing how much has been done from a position of so little advantage, and this must be remembered as we think of how much still needs to be done. I do not know how much value my contribution was but I do know how much I brought away with me to feed memory and motivation. I was among many in the Conference proper who stood and cheered as Carlos and Alicia Picasso were awarded the Anne Sullivan Medal; a worthy recognition of two parents' achievement and in a way a recognition for all parents in Latin America as well as the rest of the world. I wish you had all been there.

Of the Focus Day run by the families in the International Conference, Stan Munroe writes elsewhere. But, for me, one of the abiding memories of the families' pre-conference and the international conference was the reality and power of the families' involvement.

**Norman Brown  
Sense, London**

## **Focus Groups**

Thursday was entirely given over to Focus Group Sessions. This meant different speakers presenting papers on chosen topics throughout the day. There were 10 different topics to choose from: Staff Development, Programmes in Latin America, Usher Syndrome, Families and their Concerns, Adventitious Deafblindness, Early Childhood, Pre-Linguistic Communication, Functional Programme for School Age Children, Services and Rehabilitation for Adults, Examining a Deafblind Child's Behaviour and How to Direct or Shape it.

## CORDOBA CONFERENCE

### The Focus Day on Families and their concerns

Apart from Stan Munroe from Canada and Norman Brown from England, all the speakers were from South America. It was interesting to hear exactly the same problems referred to by both professionals and parents. Parents went through the trauma of diagnosis with consultants who made remarks like "Take care of her at home". The parents needed help and they were "Two years calling in the darkness". One consultant said "Remove the eye" because the child had glaucoma. A younger and more perceptive consultant treated the glaucoma. One parent said: "They take the facts with a lightness they should not have. We need psychologists to support us through the time of shock. They should come down from their professional pride and listen to parents, since we can help them as they help us".

A psychologist spoke very thoughtfully about the changes in attitude, expectations and feelings on the birth of a deafblind child both in the parents and their environment of family and friends, neighbourhood and wider society and the ways in which professionals can support and help families through these traumatic changes. A parent reiterated what the psychologist had said about the expectations of the new

**The world over, it is usually the parents who start the relationship with professionals and show how it can work**

born baby and "the sadness of a lost paradise". Parents feel different from other parents because of the lack of communication with their child through the normal distance senses. "A child nourishes from word, then from bread". It was the same feeling, spoken of many times during the Conference, that the transmission of language and culture and values through sight and hearing is suspended. The use of sign language can begin to restore the communication and culture.

Norman Brown also talked about the importance of early intervention. A baby initiates two thirds of interactions with its carer through sight and hearing. These interactions are essential building the relationship in between them.

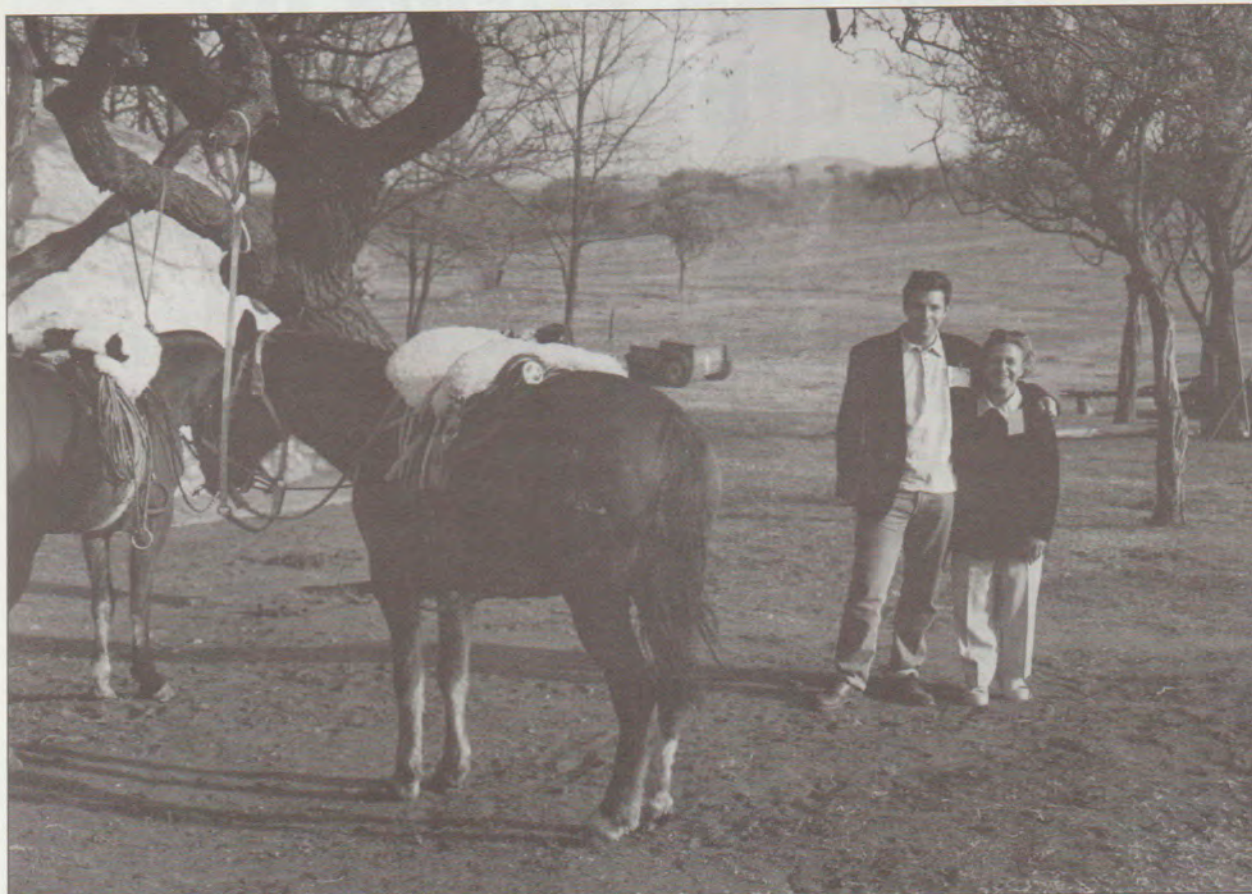
Teachers and parents spoke about finding the right schools and building relationships with staff. Carlos Picasso, who founded the Fatima School in Buenos Aires for his daughter, spoke about the economic effect of chasing round trying to find schools, losing and changing jobs and having to move the other children in the family from their schools. His family had moved 5 times in Fatima's 20 years. He said: "What we don't do no one will do. Parents are always in a fantasy looking for something better. It's like climbing a mountain, always one more step to the real top with lumps and boulders on the way. Families aim to reach the highest point that can be reached together, not leaving any behind". Stan Munroe and Norman Brown concluded with guidelines for supporting families and children and providing services and for the partnership between parents and professionals. As Stan said: "The impossible is the untried".

The Focus Day was good because it demonstrated not only what the problems were but how they were being dealt with, what support should be available, and how to achieve it. It was a well planned day demonstrating the cooperation there already is in South America between parents and



# CORDOBA CONFERENCE

Deafblind Education  
July - December 1995



**Richard Hawkes (Sense International) and Clara Berg (USA)**

professionals and showing that, the world over, it is usually the parents that start the relationship and show how it can work. What is clearly lacking is support from many of the Governments because of the general financial situation. Much needs to be done there. Stan writes more about this Focus Day on page 21.

## The Focus Day on Staff Development

The Staff Development Focus Group had a number of formal presentations and dedicated a considerable amount of time to a problem-solving group exercise which proved to be fascinating. One group tackled a serious and genuine training problem from a Kenyan delegate, another group produced a solution for a Latin American country and the third looked at a European dilemma. It was a thought provoking and enjoyable team exchange with everyone having to consider a cultural context and local difficulties that were different from their usual range of problems! This all seemed very appropriate at an international conference as it also enabled us to work together towards consensus.

## Culture and Celebrations

The Conference was not all work, however interesting and enjoyable that might be. As ever a lot of the fun was in meeting people, and there were lots of new people to meet. We had one afternoon off when we were taken out in

buses into the hills to a ranch where there were gauchos and dancers in the national costumes. We had a typical Argentinean meal, which means a lot of meat, salads and maize. The dancing was lovely, especially some amazing little children of four or five upwards who did several dances in a mixed Spanish/Indian style, remembering all the steps and really catching the style and grace of the dances. They were dressed in long Spanish dresses and the boys in smart Spanish tight trousers and waistcoats over loose shirts. Outside we saw the gauchos careering round on horseback demonstrating their accurate riding skills. It was a lovely day and we had a drive back through the hills and gorges to Cordoba.

Our final evening was a banquet. We had speeches and presentations of the Anne Sullivan Award by Perkins School to six teachers who had given long and valuable service to the education of deafblind children. Jacques Souriau, Head of the Poitier School and former Chair of IAEDB, received one. We were all delighted when Rodney Clark received the special award of the IAEDB for his outstanding services to education and IAEDB itself. He has been the Secretary and Treasurer for some years and as Jacques Souriau said: "*Rodney has really made the IAEDB what it is today, a fully international organisation*". After some lovely food and lots of wine we all danced the night away led by the exuberance and inexhaustible energy of the South Americans. The music never stops!

*Contributors to this article were Jessica Hills, Eileen Bootbroyd, Richard Hawkes and Malcolm Matthews.*

# Conditions and Syndromes that can Result in Deafblindness

At a workshop in Cordoba it was suggested that a series of articles on conditions and syndromes that can result in deafblindness would be of value. Malcolm Matthews had illustrated data from the UK which shows the changing nature of deafblindness in Britain and the wide range of conditions that may result in deafblindness.

In each edition of Deafblind Education we shall consider one or more potential causes of deafblindness. This edition will examine prenatal causes, focusing on Cytomegalovirus. In the next edition the subject will be CHARGE Association.

## CYTOMEGALOVIRUS

Various syndromes and congenital conditions affect both the eye and the ear. This can be attributed in part to the development in the embryo of the eye and ear during the same time period, during the first 12 weeks of pregnancy. There are also similarities between the two organs, such as their common origin. As a result there are many diseases and symptom complexes which affect both sense organs and result in dual sensory impairment or deafblindness. It follows that prenatal causes of deafness may be associated with visual impairment whereas with postnatal causes there will be hardly any association.

Prenatal causes of deafblindness include rubella, cytomegalovirus and toxoplasmosis. Congenital rubella syndrome consists of deafness, cataracts, glaucoma, retinopathy and heart defects. Rubella is well known but in countries with effective immunisation programmes the number of newly diagnosed children is very low. A survey of 666 people known to Sense in Britain included only 2 children with congenital rubella syndrome under the age of 5.

However there are many young people and adults with congenital rubella syndrome and their education, continuing education, quality of life and health issues remains the major concern for many readers of Deafblind Education. A later edition of Deafblind Education will include an article on the possible delayed effects or manifestations of rubella.

Cytomegalovirus or CMV is a

potential prenatal cause of deafblindness. In the UK Sense's Head Office database records 7 people deafblind through CMV compared to at least 280 deafblind through rubella.

Cytomegalovirus means 'large cell virus', and is a commonly occurring virus. It belongs to the herpes virus group which includes chicken pox, cold sore and glandular fever viruses. Frequently the infection passes unnoticed or there may be mild flu-like symptoms. Very occasionally it is more serious and lasts longer, such as with glandular fever. Once infection has taken place the virus remains dormant or harmless within the body - usually with no ill effects. The virus can become active again at intervals. CMV is so common that by the age of 30 about half the people in Britain have already caught it and most people are likely to pick it up at some time in their lives. The virus is spread by saliva, urine and other body fluids. CMV is very difficult to avoid; it is usually caught from someone you are close to who shows no signs of being ill.

If a woman catches CMV during her pregnancy the virus may sometimes be passed on to the foetus. If this happens some babies may be damaged but perhaps only 10% of affected babies will display symptoms and in only half of these children will the disability be serious.

CMV, like the rubella virus, can cross the placenta and affect the developing foetus. It is only the first, or primary infection of a person during pregnancy which can cause problems. It is very

rare that reactivation of CMV in pregnancy causes damage to the foetus.

Problems resulting from congenital cytomegalovirus vary but may include jaundice, bloodspots on the skin, enlargement of the liver or spleen, spasticity (disordered control of movement), intracranial and other calcifications (the deposition of calcium within organic tissue), mental retardation and seizures. In some cases hearing impairment may be the only sign of the CMV infection while others will have severe sight problems as well.

Estimates suggest that of 600,000 babies born in England and Wales perhaps 2,000 will have congenital Cytomegalovirus and of these about 200 have problems as a result. Most children with congenital CMV are healthy and if not tested for the virus at birth would not be suspected of having it. It is not known why some babies are affected and others are not.

Pre-natal diagnosis is not possible as at present there is no test available. There is no vaccine.

## References

- CaF (Contact A Family) *Directory of specific Conditions & Rare Syndromes* (updated Dec 93).
- Tooke P *Cytomegalovirus in Talking Sense* (Autumn 87).
- Admiral *Rare genetic syndromes associated with visual and hearing defects in Deafblind Education* (July - Dec 89).
- Best & Brown *The Population of Learners with Multi-Sensory Impairment* Distance Education Course: Multi Sensory Impairment: University of Birmingham.

# Working with Deafblind Children in the Czech Republic

**U**ntil 1992 the Czech Republic was a country which had no special provisions for the education and upbringing of deafblind people. Deafblind children lived with their families and if the family could not or were unable to look after them they were placed in homes of social welfare for retarded. In such homes, of course, deafblind children were not provided with the special care they needed.

In 1992 a team at the Pedagogical Faculty of Palacky University in Olomouc was established. This team began to work on the conception of education and upbringing of deafblind children. At first they gathered all the available information referring to the life of deafblind people, tried to enter into relations with countries that had experience of deafblind children and studied literature from abroad.

The following stage aimed to seek out deafblind children. The situation was complicated by the fact that there was no survey of deafblind children in the Czech Republic, and that doctors had to keep all medical records secret. In spite of these problems the team slowly succeeded in identifying some deafblind children. After members of the team located such a child they would visit the family and make the first diagnosis. Then the parents and child were invited to an ambulatory stay, during which the special pedagogues worked with the deafblind child and showed the parents how to set about bringing up their child.

At the end of the stay the parents obtained a pedagogic-educational programme that was specially designed for their child and they were to follow the instructions until the next ambulatory stay. These children made progress and this encouraged



the team to establish systematic pedagogic-educational care of children with dual-sensory impairments.

This programme was assisted by the teachers and directorate of a school, on Svaty Kopecek, near Olomouc, for children with hearing impairments.

In April 1993 the University team succeeded in setting up the first experimental class for deafblind children at this school.

There are a maximum of 4 children in the class, with two pupils to one teacher. The teachers and educators work according to individual pedagogic-educational programmes made for each child in the class. These programmes are prepared by members of the University based team in Olomouc.

Since 1994 there has been a special pedagogic centre for deafblind children in the school at Svaty Kopecek. Its main task is to help deafblind children who live at home or in an institution. A pedagogue of this centre visits the children regularly and designs an individual programme for each that is practised until the next visit. The children are periodically invited together with their parents to a weekly ambulatory stay at the experimental class. During this the pedagogue is able

to make a complex diagnosis of each child and recommend a programme of further care.

We have met with a number of problems since we established the independent educational institution for deafblind children. It was necessary to work on a programme of further care of deafblind people in the Czech Republic and to secure special staff and technical equipment. New problems were solved with great effort and enthusiasm by everyone involved: special pedagogues, technicians and students of special pedagogics at Palacky University. We also co-operate with the Ministry of Education in the Czech Republic, and, under the auspice of this Ministry, work out the programme of upbringing and educating deafblind children.

In conclusion it is necessary to state that our work is still at an early stage, in spite of the indisputable progress we have made. Our team is aware of this fact and so we would be grateful for any help that could assist our efforts.

**Padr Libuse Ludidova**  
**Mgr Eva Souralova**

# Teaching Students who are Deafblind and Cognitively Disabled to Effectively Communicate Choices During Mealtime

by

**Carole R. Gothelf**

Director, Education Services  
The Jewish Guild for the Blind

**Patricia A. Finocchiaro**

Coordinator, Day Treatment Program  
The Jewish Guild for the Blind

**Caren A. Mercer**

Principal, Guild School  
The Jewish Guild for the Blind

**Daniel B. Crimmins**

Director, Department of Psychology  
Westchester Institute for Human Development  
and New York Medical College, Cedarwood Hall

**Individuals who are deafblind and have a cognitive disability may not effectively communicate their desires and choices even when provided with the opportunity to do so, in part because of their frequently limited communication skills. The ability of these individuals to make choices may be further constrained by instructional staff and caregivers, who anticipate their wishes and make choices for them. These caregivers and instructional staff may be acting with only the best intentions for these individuals, perhaps in the belief that they are unable to make a meaningful choice. Often, however, these individuals have not been taught how to make a choice. For students who are deaf-blind and cognitively disabled to achieve valued life outcomes, it is essential that they are able to effectively communicate personal choices.**

**G**iven the essential nature of the ability to communicate choice and the potential barriers to choice-making, it is necessary to focus on teaching students who are deafblind and cognitively disabled the process of making meaningful choices and to develop a flexible curriculum in which they have opportunities to practice making choices within the context of their daily routines. Mealtime is ideal for this instruction. It naturally occurs on a consistent, daily basis, in school, at home and in social environments. The act of communicating what one wants to eat or drink and receiving what one has chosen results in natural consequences that are highly motivating, thus reinforcing the power of clear communication.

The table that follows offers a set of practical guidelines for teaching students who are deafblind and cognitively disabled to make choices during mealtimes. It is offered as an aid to instructional staff and caregivers to illustrate the ways in which a typical daily activity can be utilised to teach choice-making within the context of a natural routine. In addition, it has implications for how the skill can be increased in complexity as the student progresses. We offer this as an example that can be applied in other settings and activities, which include selecting something to do, choosing with whom to do it, choosing where to do it, choosing when to do it, or choosing whether to do it at all (Brown & Gothelf, in preparation; Crimmins & Gothelf, 1994).

## Choice-making Instruction

Guiding Principle	Example	Considerations
<p>People typically make choices in the environments in which the outcomes of their choice are available.</p>	<p>Choosing what to eat should take place where the student normally eats. Teaching choice-making in an artificial environment removes many of the naturally-occurring cues to the event.</p>	<p>Administrative policies and procedures should ensure that the choice-making process can take place. This may involve working with the cafeteria staff or revising lunch-time schedules.</p>
<p>The boundaries in which the choice-making activity takes place should be defined through the use of appropriate aids and cues. Providing boundaries minimises the visual/motor and cognitive requirements of orienting and reaching.</p>	<p>A dycem placemat can be used to secure a cafeteria tray on a table, or on the lap tray of a student's wheel chair. A second dycem mat can be used to secure the plates and glasses on the tray. (Dycem is a non-slip plastic that is helpful in stabilising objects on surfaces. It comes in reels or sheets that can be cut to size. It is portable, easily cleaned, inexpensive and available from adaptive aids catalogues).</p>	<p>If cafeteria trays are not available or necessary, the plates of food can be placed on a dycem mat directly on a table. For students with vision, the colour of the dycem should be selected to provide contrast with the tray or table and the plates.</p>
<p>Individual preferences play an important role in enhancing motivation for the activity.</p>	<p>The student is presented with two food samples, one at a time. The items from which a student is choosing should be two things which he or she is likely to want to eat.</p>	<p>Administrators should work with cafeteria staff to ensure that appropriate alternatives are made available. (E.g., if two hot meals are not available, a choice between a hot meal and sandwich, or between two sandwiches should be substituted). Be aware that food preferences are influenced by a student's cultural and family background.</p>
<p>The student is made aware of the food through tactile/kinaesthetic cues (guided or paired movements between the teacher and the student), visual, verbal, gestural and object cues. The teacher must assess the conditions that facilitate comprehension (e.g., with gestures/without gestures, etc).</p>	<p>For each sample of food, the student is moved through touching the plate, touching the food, smelling the food, and tasting the food. A staff member will say the name of the food, sign it, and shape the student's hands to sign the name of the food.</p>	<p>The student's receptive vocabulary may be limited. Natural routines should be maintained within the normal context of mealtime in order to help the student comprehend the expectations for his or her behaviour.</p>
<p>Choices should be presented consistently in order to reinforce the physical structure within which choosing occurs. Placing the choices in the same locations in relation to the student's body each time they are presented helps the student to anticipate where the sample is likely to be.</p>	<p>The first sample is presented on the student's left, tasted with the left hand, and then removed. The second sample is then presented on the student's right, tasted with the right hand, and then removed. Care must be taken to ensure that the individual is not always choosing the sample on the right or the sample on the left.</p>	<p>The student's ability to reach, grasp, and manipulate utensils or the food itself, may be influenced by poor muscle tone, stability, or coordination, as well as limited visual functioning. Generally, proper postural alignment can be attained through the use of adaptive positioning equipment. Grasping and manipulating utensils can be assisted through the use of adaptive aids such as special spoons, plates with lips, or slant trays. (Campbell, 1987).</p>
<p>Establishing routines within instructional sequences enables the student to anticipate the next step and encourages self-initiated choice-making. A pause or time-delay in a sequence (hands in the lap) may serve as a prompt to the student to initiate an interaction or make a selection (Siegel-Causey &amp; Ernst, 1989).</p>	<p>Both samples are then presented to the student. The student touches the left plate with the left hand, and the right plate with the right hand. As the student touches each sample, he or she is reminded of its name. The student is then directed to place both hands in his or her lap (using verbal and/or physical prompt as needed). The student is then instructed: "It is time to pick what you want for lunch." Language input should be provided at a level and in a mode that the student can comprehend.</p>	<p>If a student does not respond when the question is repeated, the teacher communicates: "That's OK, if you don't want the meat or the rice, I'll ask you again soon". Language input should be provided at a level and in a mode that the student can comprehend. The teacher should always return and provide the student with another opportunity and additional prompting if necessary.</p>

Continued

## Choice-making Instruction (continued)

Guiding Principle	Example	Considerations
Reliable communication of preference depends upon a foundation of consistent responses to the student's non-verbal behaviours. Non-verbal behaviours need to be acknowledged by the teacher on the assumption that the individual is attempting to communicate meaningful dialogue. This provides a basis for communicating shared meanings (Guess, Benson, & Siegel-Causey, 1985; Williams, 1991).	The student chooses the desired food by touching one of the samples, by looking or facial gesture, by starting to eat, by vocal sounds and/or body movements, by signing or in any way indicating his or her preference.	If the student reaches for both, or neither, the teacher must repeat the previous procedure, and reinforce that the student must choose one sample. The teacher must acknowledge any form of communication. If the student repeatedly reaches for both, he should be given some of each for lunch.
Components of everyday routines should be used to establish relations between words and their meanings. Routines enable students to take an active part in the activity and to communicate with the teacher.	The staff signs "finished" for the undesired plate and moves the student through the sign "finished" and prompts the student to move the plate away.	Initially, the student may require the teacher to move his hands for him. Subsequently, the teacher and the student should cooperatively move their hands together, the student's hands riding on top of the teacher's. The teacher should pause in the pushing action, and allow the student to communicate a desire to continue by moving the teacher's hands.
In addition to establishing correspondence between words and their meanings, the process of systematically using routines in the choice-making process must be established.	The teacher signs "eat" and the name of the desired food, and prompts the student to do the same. This procedure must follow the previous one.	The teacher may choose other ways to communicate the same message, such as signing the student's name followed by the signs for "wants to eat" and the name of the food. Language input should be provided at a level and in a mode that the student can comprehend.
Appropriate communicative behaviour is reinforced by getting the requested item. The student communicates through an action or a signal to indicate his preference.	The student is served a full portion of the food that was selected.	The student must join the cafeteria line to obtain the full portion of food.

Table adapted from Gothelf, C.R. Crimmins, D.B. Mercer, C.A. Finnocchiaro, P. A., (1994). *Teaching choice-making skills to students with dual sensory impairments*. *TEACHING Exceptional Children*, 26(4), pp13-15. Copyright 1994 by The Council for Exceptional Children. Reprinted with permission.

## References

- Brown, F. & Gothelf, C.R. (in preparation). *Teaching Choice Diversity: A Curriculum For Individuals with Severe Disabilities*.
- Campbell, Philippa H. (1987). Integrated Programming for Students with Multiple Handicaps. In L. Goelz, D. Guess, & K. Stremel-Campbell (Eds.), *Innovative Program Design for Individuals with Dual Sensory Impairments* (pp. 159-188). Baltimore: Paul H. Brookes.
- Crimmins, D.B. & Gothelf, C.R. (in press). *Examining The Communicative Purposes Of Behavior*. American Foundation for the Blind: Deaf-Blind Project. New York: American Foundation for the Blind.
- Guess, D., Benson, H.A. & Siegel-Causey, E. (1985). Concepts and Issues Related To Choice-making and Autonomy Among Persons With Severe Disabilities. *The Journal of the Association for Persons with Severe Handicaps*. 10 79-86.
- Siegel-Causey, E. & Ernst, B. (1989). Theoretical Orientation And Research In Nonsymbolic Development. In E. Siegel-Causey & D. Guess (Eds.), *Enhancing Nonsymbolic Communication Interactions Among Learners With Severe Disabilities* (pp. 17-51). Baltimore Paul H. Brookes.
- Williams, R.K. (1991). Choices, communication, and control: A call for expanding them in the lives of people with severe disabilities. In L. Meyer, *The Lives Of People With Severe Disabilities* (pp. 543 544). Baltimore: Paul H. Brookes. C. Peck, & L. Brown (Eds.), *Critical Issues In*



# Communication Through Active Music

**A Swedish / English collaboration on Music and Communication describes how music can be used as an educational tool for developing social interaction patterns with congenitally deafblind adults.**

**This is a joint project between Sweden and England on music and communication.**

Inger Rodbroe and Tony Heyes met by coincidence first in England and later in Sweden. Inger has worked with deafblind children at Alborgskolen, Denmark, for 14 years. She has been involved in Nordic and European projects on assessment and communication and been a consultant on deafblind adults in Sweden for 18 months. Inger is currently Principal of the Deafblind Department at Aalborg School, Denmark. Tony worked for several years as a professional musician, with drums as his main instrument, and later studied dance / movement. For the past 5 years he has been working as Music and Movement Instructor with deaf multiple disabled and deafblind adults at Poolmead, Bath, England.

Music and sound and pre-linguistic communication became the theme of the meetings that followed. A number of workshops lead to the joint project which is expected to be completed and published in 1996.

The two project workers, Inger and Tony, have combined their expertise and professional knowledge - on the one side music and on the other the development of communication - and

**In music sessions the deafblind person is an active contributor to the development of his/her own style of communication**

used video analysis to learn from their joint experiences.

The joint work developed into a collaboration project between the Royal National Institute for Deaf People Poolmead Centre, Bath, England and the Swedish Resource Centre,

Finspang, Sweden. The two institutions believe that the contributions offered by the two professionals were so valuable that they ought to be available to other deafblind workers.

The collaboration began in 1993 and has resulted in workshops on this topic in the United Kingdom and Sweden, video material, a leaflet promoting a proposed teaching pack, and a workshop at Cordoba entitled "Music, sound and prelinguistic communication with congenitally deafblind adults". The proposed teaching pack will include a book/manual and video. It is being prepared for educators, care staff and professionals working in the field of communication development with congenitally deafblind adults. The first edition of the pack will be produced in English.

The pack will focus on how to establish and re-establish social interaction patterns with congenitally deafblind adults. The theoretical sources are:

- knowledge of early interaction of able-bodied children and their parents, and
- knowledge of clinical experiences of the specific conditions needed for deafblind people to develop interaction and communication.

The natural way of learning the social rules needed in communication for a child is through play. Play is very much initiated and controlled by the child. It is characterised by shared affections, curiosity and discovery through exploration.

In order to recreate the natural learning conditions for communication,

**Tony and a client experimenting with music**



Caroline Penn



**Tony and client using drums together**

Tony and Inger have looked for relevant ways in which to “play” with congenitally deafblind adults. This is where music comes in.

Music and music therapy are well known elements within work with deafblind people. Similarly, the importance of recognising the potential communicative competence of deafblind people and the value of early interaction in the development of this is well known to us. Also, the use of video analysis has developed to be an indispensable tool in the continuous development of teachers and other workers with deafblind people. The project combines these three elements together with an understanding of deafblindness. This has led to new understandings and ways of working.

In the music sessions the participants are congenitally deafblind

Compiled from:

RNID leaflet *Communication through active music* leaflet.

Lastrup, Birthe *Theme day on Music, Sound and pre-linguistic communication in Deafblind News* 1995 (Denmark).

Hills, Jessica *Report on Cordoba conference* (unpublished).

adults with severe communication problems. The deafblind person is an active contributor to the development of his or her own style of communication through choosing tempo and particular interests.

These music sessions have helped professionals develop the courage to use music as a tool to establish interaction patterns in their own work even if they were not experienced in the use of musical instruments.

Birthe Lastrup described her experience at a theme day as a ‘Musical Journey’:

*“Initially the lecturers had promised to take us on a musical journey based on the perspective of the deafblind person. For the participants who listened to this it became an exceptional and inspiring journey, with the deafblind person as the tour guide. We experienced simple musical effects auditorily, visually and tacitly. We experienced how a 54 year old deafblind person, who had never before in life been heard, seen or understood by the people in his social environment, by collaboration around a drum with an empathetic partner, for the first time in his life experienced the environment to be reactive to his emotions and activity. This developed into a dialogue between the two of them. A beautiful*

*and touching experience for all who were privileged to be present.”*

At the Cordoba conference, Tony Heyes and Inger Rodbroe spoke about their work and presented a video of the workshops that had been held at Mo Gard, Sweden and Poolmead, England.

Jessica Hills thought this was the most moving workshop she attended. She writes:

*“Tony Heyes and Inger Rodbroe have been working together and researching the effects of developing turn-taking and sharing in a musical conversation using percussion instruments chosen by the deafblind participants. Turn-taking is an important step in the development of communication. There was a beautiful video sequence which did not leave a dry eye in the auditorium, of a man in a wheelchair in Sweden starting with hand clapping and turn-taking and gradually beginning to explore Tony’s hands and arms, shoulders, head and face while Tony in response explored his. Both were totally absorbed in the experience and Tony found it quite difficult eventually to withdraw from the situation and leave the deafblind man happy and not feeling deserted. It was their first encounter.”*

# Community Services Re-examined

**A recent review of the Deafblind Association, Victoria, Australia, has led to a restructuring in its Community Service Program. Sue Hymus, Community Services Coordinator, outlined this in a paper at the National Deafblind Conference in May.**

I first outlined the role of the Community Support Worker during the Melbourne conference two years ago. I was then a very recent recruit to DBA, one of only 1.5 generalist community workers.

At that time the community workers were expected to be multi-skilled and extremely flexible in order to be able to respond appropriately to the wide range of client needs. As time went on it became obvious to me that it was not the volume of work per se but rather the extreme breadth of issues which obliged the workers to attempt to be "all things to all people", resulting in role confusion for workers and clients, inequities in service provision (eg some clients were receiving high levels of support and others receiving none) and a lack of empowering clients to take over or maintain control over their lives.

Workers experienced a high degree of stress in response to feeling fully responsible for all areas of client outcomes. Too much time was spent reacting to problems rather than proactively planning and preventing difficulties from arising. The sheer number and complexity of client issues could not have been foreseen when the programme was conceived back in 1988/89.

So ... What happened to change the service? A government-appointed consultant named Rod Harris came into the Association and scrutinised every aspect of our operations. He visited clients, interviewed staff and saw some of the issues first hand. Fortunately, we had kept detailed records of the numbers of clients being seen, their locations, the travelling time, the services provided, the outcomes - in fact every question our investigator asked was answered.

Interestingly, the new funding models being advocated by the Victorian Department of Health and Community Services (H&CS) coincided with the types of services offered by the community workers at DBA. These included:

1. Case management
2. Accommodation support



**Sue helping a client try out new equipment**

3. Therapy and skill development
4. Volunteer support
5. Recreation

Due to these service-divisions, we decided not to hire more generalist support workers, but instead divided the role up into several discrete positions, as described above, each with a single focus.

What emerged was a totally new staff structure. We now operate an interdisciplinary team approach where staff work collaboratively to meet the needs of clients with support from a Coordinator who oversees the programme and the allocation of resources. Each staff member is responsible for assisting the client to achieve their personal goals, within designated time-lines and agreed role boundaries.

The Case Manager's focus is on activities which are directly related to the planning, obtaining, linking and monitoring of services from a variety of agencies and professionals both with and on behalf of a client. This may include working face to face with an individual client or family; liaising with other service providers or community based resources; coordinating the various services or resources required by the client.

There is a continually moving caseload, as family difficulties arise and are resolved, and there is an expectation that case workers will attempt to assist families towards speedy resolutions. Case management services are currently provided by DBA's full time Social Worker and the Community Services Coordinator.

Three Family Support Workers work part time. Each supports a small number of deafblind people with daily living skills (e.g. reading mail, going shopping, to the hairdresser, or local department of social security). Although the workers aim to promote self-direction, and self-help skills, they focus on providing practical assistance without pushing skill development and "progress! progress! progress!". Sometimes people need only a sighted interpreter/guide/wheelchair driver to get them where they need to go.

It is a fact of life that some deafblind people want and need support forever. Thankfully, we can now offer drop-in home visits to a few people on a regular basis for an indefinite period.

In the area of Therapy we have provision to offer contracted (ie short term goal directed) communication and psychology services. Unlike their NSW, Australia, counterparts, deafblind

Victorians do not have to pay private service providers to develop their own individually tailored communication or behaviour intervention programmes. Both DBA and the Spastic Society of Victoria provide outreach assessment and intervention in the area of communication.

Physiotherapy, Occupational Therapy and specialist counselling can be purchased by DBA and offered to clients on a time limited arrangement. For some clients this may be one or two sessions, for others it may extend to 12 months.

Other new positions include the Volunteer Coordinator, who found to our surprise that most of the enquiries came *from* people with deafblindness who want to *be* volunteers, not passive receivers of this service! Our Coordinator has done a wonderful job establishing policies from scratch, and working closely with the client service staff to support all suitable applicants to participate in the program. This has been quite a challenge since there are many aspects that have to be considered when delivering a program for a relatively small number of clients in a city as large as Melbourne.

At present, H & C S does not fund recreation as a service type (although they are currently investigating this option, which looks promising). Early last year DBA was fortunate to receive a grant from the Victorian Department of Sport and Recreation for a recreation program funded over a three-year period, which promises to be a boon to the whole arena. We still have quite a way to go to fully develop this service, but it will focus on linking people with dual sensory loss into groups and activities of their choice, with appropriate support and training.

DBA's In-home and Recreational Respite Care program has continued to develop over the last two years, and a review of that program is currently being undertaken by the new full-time Coordinator/Worker, Allan Gale. The Respite Coordinator's main role is to plan and oversee the provision of temporary breaks for carers of people with multiple disabilities. Allan has been discussing with families how to alter the programme to offer care that meets the needs of families whilst conforming to the current Government service philosophies within budgetary constraints.

We serve 18 families in this programme, with the clients' ages falling between 4 - 65 years, with some children having *very* challenging behaviour. Anyone who is involved with people who have congenital

deafblindness will know how appropriate "in-home" respite is to a family who is feeling burnt out! Consequently we have been obliged to think very creatively to come up with solutions so carers can have *real* breaks from the task of caring. Therefore, *any* type of respite can be considered, ranging from one hour in the client's sitting-room through to a whole week at the beach.

## **Most of the enquiries came from people with deafblindness who want to be volunteers, not passive receivers of this service**

So much has changed in the Community Services area. What remains the same, you may wonder?

We continue to have close links with the Royal Victorian Institute for the Blind, the Victorian Deaf Society, the Association for the Blind and the Victorian School for Deaf Children. We are continuing to strive to form closer working relationships with other agencies, as we are still a small organisation and cannot possibly meet the needs of all people with vision and hearing loss. Many clients still complain that it is a puzzle to work out how best to navigate the maze of services "out there" so we will endeavour to establish clearer protocols to make it easier for clients to cross service boundaries.

Another aspect that has not changed is the size and location of DBA's office! In only a few short months, we found the offices brimming to overflowing with new desks and bodies when staff came in for meetings etc. Most of the time the place is pretty deserted however, because workers are mostly out in the community where they are needed.

More and more people with deafblindness are visiting the office in North Fitzroy, where we have improved the kitchen so that it is user friendly for people with low vision. Office staff have all achieved a basic level of mastery in Auslan, fingerspelling, and sighted guide techniques. We made good use of deafblind volunteers who were only too keen to share their knowledge and

thus make the initial entry point less harrowing for all concerned!

How have we achieved what we have in such a short time?

The answer is found in three parts.

Firstly, none of the changes would have been possible without funding. DBA has a significant income from fundraising, but the majority of funding comes from Government. There is an increased emphasis on the unit cost method of funding whereby we receive a predetermined amount of money in exchange for an agreed number of hours of direct client service, and this has allowed us to be very responsive to client needs. Whilst this arrangement has significant drawbacks, it also gives us fantastic flexibility. For example, we could offer support to deafblind people to attend the national conference by re-scheduling the support hours which would normally have been offered in Melbourne.

Secondly, we have spent a lot of time just *communicating* with people who have or who know about deafblindness and their carers, listening and taking on their suggestions, and complaints, about our service, and making changes wherever we could. We thank the Ushers and other deafblind people for keeping us in touch with local issues, and we appreciate Bob Segrave and Peter Tarrant chasing the latest news from around the world. Their personal correspondence with people in the UK at Sense, Canada and the USA, the distribution of videos, newsletters and now the ubiquitous Internet (!) helps to keep us moving forward.

Finally the third aspect with which I am sure everyone is all too familiar with is *bloody hard work!* We at DBA have dedicated hundreds of thousands of hours to improving the service and stretching ourselves to the limit, sometimes beyond in an attempt to develop and deliver a decent service to people who are living in their own homes with a dual sensory loss.

The theme of the Conference was *Accepting The Challenge*. And what a challenge it is for the community services program at DBA Victoria to continue to run a community based service within the constraints of a very tight budget, using lots of part-time workers, spread across a very large busy city.

The logistics of establishing and balancing all of the facets is a nightmare. However, when we see how much benefit individual people derive from it, we are more than willing to continue to meet and win this challenge.