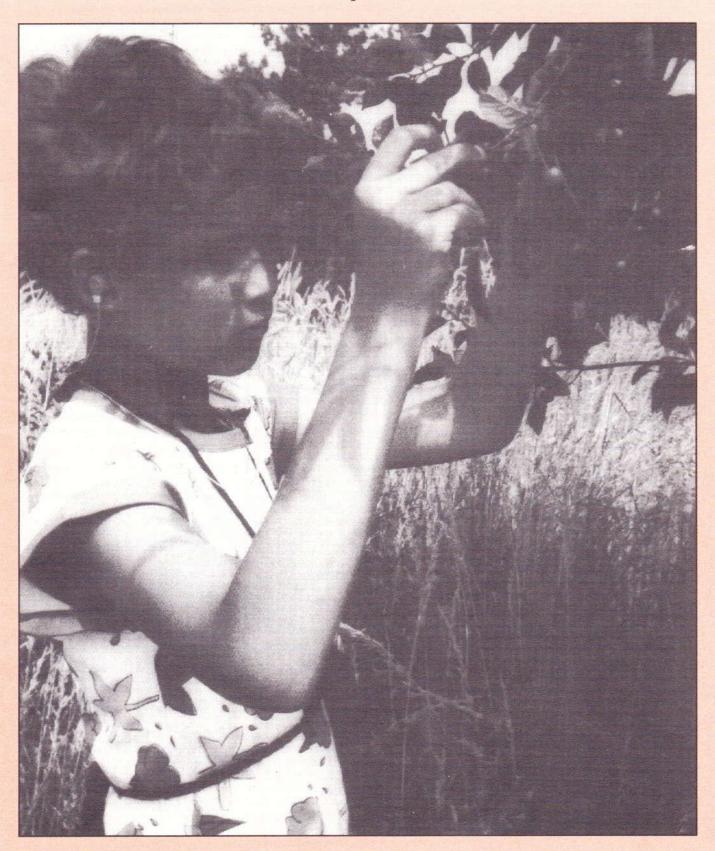
# **Deaf-Blind Education**

THE JOURNAL OF THE INTERNATIONAL ASSOCIATION FOR THE EDUCATION OF THE DEAF-BLIND

No. 5: January — June 1990



# **CHAIRMAN'S LETTER**

#### 26th March 1990

I am on my way back to London after a weekend in Sweden. My thanks to Sonja Jarl, Elisabeth Abouda and Kent Lundkvist for such a well organised visit to their school at Ekeskolan and the chance to see some of the work they do there.

At our Executive Committee meeting held there on Saturday 24th March, we heard the first plans for the World Conference to be held next year in Orebro. The Planning and Programme Committees have done a lot of hard work already and their ideas were much approved by the rest of the Executive Committee present. We also had time to visit the Grand Hotel where the delegates will stay and the Conference Centre, which has truly magnificent facilities. It all looks very exciting and worthwhile.

During the weekend there was also a meeting of the Constitution Committee: my congratulations to Bryndis Viglundsdottir and Rodney Clark who have progressed well with the revision of the Constitution.

The plans for the next European Conference in Potsdam in 1993 were also discussed by Friedrich Wilhelm Pape and all is going well. More news of this at a later date.

Don't forget to return your application form for a place at Orebro '91. I look forward to meeting you there.

> John McInnes Chairman

# Editorial

So now the barriers between nations are beginning to fall. As we watch the political world changing every week, we can believe that impossible things can happen. In Europe it becomes ever easier to build contacts between East and West. In other parts of the world we are seeing long-established political systems changing every week.

A time of change is a time for dreams. When we first planned the next European Conference to be in Potsdam, did any one of us believe that it would take place in a united Germany? If this can happen, then perhaps other dreams also can be realised. Perhaps now is the time for us to be braver about the changes that we believe are needed.

Is it foolish for us to dream that all deaf-blind children could receive schooling by the year 2000? That we will see specialist teachers in every country in the world? That we will eradicate rubella from the world? That all deaf-blind school-leavers will be able to find further education and employment?

What are the dreams that you have for deaf-blind education in your country? Share them with us in this journal. Or come to the World Conference in Sweden and show us.

And my dreams? That the next issue of Deaf-Blind Education will come out in time. Now, that is an impossible dream!

#### **Paul Ennals**

Apologies for the late appearance of this edition. The next issue will be published in January 1991, and we aim to be back on schedule therafter.

# Next European Conference — 1993

The International Association for the Education of the Deaf-Blind (IAEDB) decided at its last European Conference, held in 1989 in Warwick (GB) to host the next European Conference in Potsdam in 1993.

The Society for Rehabilitation in East Germany has taken on the responsibility for organising this Conference.

The Planning Committee met for the first time in February 1990 under the chairmanship of Pastor Pape of the Oberlinhaus, to start planning the Conference. The dates set for the Conference are 2nd-7th August 1993. Up to 400 participants are expected. A Family Camp for parents with deaf-blind children will run parallel with the Conference.

The Conference will be located in The Touristes and Congress Hotel in Potsdam, near the Oberlinhaus Centre. The palaces of Potsdam make the city an attractive tourist location, and it is surrounded by beautiful woods and lakes.

With the moves towards the reunification of Germany it is impossible to predict the prices of the Conference.

#### Friedrich-Wilhelm Pape, Pastor Oberlinhaus, Rud.-Breitscheid-Str 24, Potsdam, 1590. Tel: 763 221

Every year in the United States one week is designated as Helen Keller Deaf-Blind Awareness Week, and efforts are made to increase the awareness of the general population about the effects of deafblindness. This year they concentrated on elderly deaf-blindness, and this poster was widely shown.

Cover photo: Tomas, one of the young pupils at Oberlinhaus, previously East Germany.

# Teaching Strategies for Deaf-Blind Students

Barbara Miles has been working with deaf-blind students for 20 years. She is Language Specialist at the New England Centre for Deaf-Blind Students, Perkins School for the Blind, USA. Here she explores a very important aspect of teaching method — the relationship between the teacher and the deaf-blind student.

I want to talk mostly about my relationship with one deaf-blind student, who I am calling Paul, who recently graduated with a highschool diploma from Perkins School for the Blind. But before I tell you about Paul, and about some of the instructional strategies I used with him, or discovered with him, I want to say a little bit about the theoretical basis for the kind of relationship I am advocating. This theoretical basis is something that I have discovered in some literature about student-teacher relationships and which confirms the experience which I have had over my years of teaching. In other words, the theory did not precede the experience for me; it was the other way around - I interacted with the students, and taught for years, and then I happily discovered some theories which confirmed things that I already knew to be true.

One of the thinkers who has said most clearly what I believe about the nature of the teacher-student relationship is not himself primarily an educator, but is a Swiss psychiatrist and Jungian analyst. His name is Adolf Guggenbuhl-Craig, and the book which contains his thinking on the subject is called *Power and the Helping Professions*. In that book, he is writing primarily about social workers and clients, and about doctors and patients, but he also has a chapter about teachers and students.

# The teacher-student relationship

The essence of what he says has to do with the fact that there is an archetype, or kind of basic psychic structure in each of us, which determines the nature of the teacher-student relationship. What is significant about this archetype is that it has two poles, two sides: without the student, there is no teacher; without the teacher there is no student. The interesting thing that Guggenbuhl says about this relationship is that he sees a danger arising when the poles become split from each other and unrelated. The danger is that one pole will assume power over the other; power is the way in which the relationship between the two poles is maintained *if there is no relationship in any other way*.

In the case of the teacher-student relationship, if the teacher is out of touch with the student-pole of the archetype within himself or herself if in other words, the teacher cannot also conceive of himself as a learner — then the teacher will end up relating to the student only by means of power. It is as if the power fills a vacuum. It is in the nature of the archetype for the two sides to be related, and without a mutual, interactive relationship, both between individuals and within each individual, then power appears as the way to establish this necessary connection between teacher and student.

It is important, Guggenbuhl says, to conceive of this archetype of the teacher-student relationship as existing within both individuals who are involved in the actual relationship in the classroom, as well as between the individuals. Part of our success as teachers will be in our ability to evoke the teacher-pole of the archetype within our students. This is especially true, it seems to me, for older students, when they will soon be leaving school and will in fact have no teachers in an official capacity in the years to come, or at any rate will have fewer teachers than they have had during all their years in school. If we want them to go on learning past their school years, we will have to help them establish within themselves the capacity to teach themselves, to identify not only with the student pole of the archetype, but also with the teacher pole of the archetype. They will have to feel themselves competent to ask themselves and others the right questions in life, the questions to which they really need answers.

They will need to sense something of their ability to evaluate for themselves the answers they find to those questions. They need to know whether the answers they find are adequate, and if not, they need the motivation and the confidence to go on asking questions. For is this not, after all, what a good teacher does? He or she asks good questions, important questions, and knows where to help the student look for answers, and knows how to evaluate the answers, and has confidence in his or her ability to have useful knowledge about the world and to impart that knowledge.

#### Reciprocity

One of the most interesting things about the very nature of this teacher-student relationship, which Guggenbuhl points out, and which I have sensed myself for many years, is the reciprocal nature of these two roles, both within an individual and between individuals. This reciprocity is such that if I wish to evoke the teacher capacity in another to whom I am relating, I must myself become the student. By becoming a student myself, by getting in touch with my own curiosity, and my own capacity to learn, and the fact that there is much that I do not know, I evoke the teacher capacity in the other. The other then is stimulated to question, to evaluate answers, to get in touch with his or her own authority as the one who knows the answers.

I find it interesting that in recent studies of the origins of language in young children, researchers are finding that exactly this mutuality of relationship is what makes it possible for a child to learn language. Language is not learned because the mother explicitly teaches the child, but it is learned as a result of an interactive relationship between the care-giver and the child, in which the child gradually senses more and more his or her own power as a

communicator. It is the care-giver's responsiveness to the child's language, however crude or approximate that language is, which gives the child the confidence to go on using language, and eventually to develop a rich means of expressing himself or herself. Without this responsiveness of the care-giver, the child will learn nothing. If you are interested in reading more about mutual, interactive relationships as they apply specifically to teaching deafblind students, I refer you to work by Charity Rowland, Kathleen Stremel-Campbell, Ellen Siegel-Causey and June Downing. In all of their work they talk about the importance of mutuality, of viewing the teacher as not only the own who acts upon the child, but also as the one who is acted upon by the child. Or, I would say, as the learner as well as the teacher, the responder as well as the initiator.

#### **Teaching Paul**

Let me talk now about Paul, the student I told you about earlier, who recently graduated with a high school diploma from the department here at Perkins. I want to tell you something about the history of my relationship with him and the things I learned about how to teach him most effectively.

I first met Paul in the summer of 1973 when I was asked to tutor him at home. He was then nine years old and had just lost his vision as a result of retinal detachments of unknown origin. He was scheduled to enter Perkins in the fall, and his school district wanted someone to begin to introduce braille to him during the summer. Another teacher and I divided the tutoring job that summer, and I worked with Paul for two days a week during most of the summer.

What I found when I first met Paul was a bright boy who was quite confused and depressed by his recent blindness. He was rebellious, and had to be cajoled into learning anything that summer. (Braille, of course, was the last thing that he wanted to learn, because it reminded him of his blindness.) The method which the other tutor and I developed for teaching him braille consisted, among other things, of letting him choose the words he wished to learn and entering them into a dictionary which we made together. The method was crude were I doing it now I would elaborate it with braille experience stories and exercises in reading longer chunks of written material. (I think we paid the price years later in having to remediate Paul's braille reading skills). But, as I look back on it now, I see that the method did have one important advantage, and that was that it did establish a genuine mutual relationship between myself and him; it allowed me to learn from him what he already knew and was interested in, and it allowed him access to some of the power in that situation, which might otherwise have been unbalanced in my favour, especially if I had decided all the words he would need to learn.

I remember reading that summer a book by Sylvia Ashton-Warner called Teacher and being fascinated by the success she had teaching Maori children to read by using a similar method. She used to ask each of the children, every day, to tell her individual life-experience stories, and she would write the stories for them, and would give them each their most cherished words to carry around on big pieces of cardboard for the day. She found that if she truly listened to their concerns and found words that really were important to them, they would learn the words quickly and would go on to become interested in reading and writing as a way of interacting with the world. Often this listening on her part required her to write words which she might not have chosen herself as the most pleasant or apparently useful words for the children; words such as 'drunk' and 'fight' and 'fire' came up more than once in these children's stories, because what was on their minds was what was happening in their homes where life was far from easy

I don't remember many of the words that Paul chose that summer, but the ones I do remember had to do with power and vision: most of his favourite words were names of vehicles - car, truck, fire truck, ambulance - vehicles I realised (but he did not yet believe) he would never be able to drive because he could no longer see. As I look back now on that summer with Paul, I think that the fact of his having lost his sight was so painful to me that I could not help him as much as I might now be able to, given my further experience with children who have lost their sight and given my further experience with my own inner blindness. The way that I perceive that I might have been able to help him more would have been for me to have been more receptive to the metaphorical resonances of these words ('car', 'truck', fire truck') that he was choosing. I see now that they were in some sense representative of the power which he had lost in losing his vision, and of the hope he still had of finding

some power and some adequate way of moving about in the world despite this loss. (This is what these vehicles do, after all: they move people about in the world and, as we can see on TV every day, they are one of the ultimate symbols of power in our culture.) Merely reflecting back to him some of these feelings of desire for power might have helped him a bit; even without any reflection, my own realisation of his desire for power, and his frustration at the lack of it, and his hope of finding it, might have allowed him to contain those feelings in himself a bit better. Of course doing that would have required that I be in touch with my own frustration at my own blindness. Seen metaphorically what I mean by my own blindness is my own lack of power, my own limitation and consequent dependence on others.

I did not teach Paul again until many years later. I had been away from Perkins for a number of years, and had returned to teach a class of students who were working on highschool diplomas. Paul was the youngest of the four boys whom I taught that year, and he was 17 at the time. What I remember most about that year with Paul was my own frustration at what I regarded as his stubborn denial of his blindness and his consequent limitations. He was obsessed during most of that year with fantasies of becoming an airline pilot. It is only in writing this now and looking back to that first summer that I see the continuing theme: he wanted to be master of a powerful vehicle, he wanted to feel powerful and in control of his life, the way an airline pilot must feel. But during that year of teaching, I still could not see the metaphorical resonance of this wish to be an airline pilot; all I, and my fellow teacher, could think about was how absurdly unrealistic it was for a boy who was totally deaf and blind to be wanting to be a pilot. 'Impossible!' I thought. 'Why can't he see how ridiculous this is?"

#### Learning from him

But, in fact, I needed to learn from him. I tried to argue him out of this desire, rationally. But when I did this, it turned into a power struggle — he became convinced that it was a question of his will against mine; he thought that I was the one preventing him from becoming an airline pilot. I see now that Guggenbuhl was right — power rushed in and filled the vacuum left when there was no relationship going on here. Slowly it began to dawn on me that I was just as blind

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as he was. I was blind to many things in this situation - blind to his feelings of frustration, blind to the real desire behind this literal desire to be a pilot, blind to my own limitations as a teacher. What I finally realised was that I could not teach him as much as he could teach himself and as much as the world could teach him. If he wanted to be an airline pilot he would have to try, absurd as that was. He would have to write letters to the Air Force and to airlines and ask about the qualifications, the training required. He would have to be the one to ask the questions and decide for himself if the answers were adequate. (I wonder even now if my initial resistance to letting him write these letters, or to even thinking of the possibility of writing them, was born out of a desire to protect him from the pain of the inevitable answers.)

Paul did write the letters. They were full of grammatical mistakes and what, from my sighted and hearing perspective, I considered to be incredibly naive questions. But he sent them. And he got answers. And it was only when he had the answers in his hands, in print (and after we had brailled them for him) that he really believed the answers. He had to be his own teacher, and my teacher, in this situation. And after that year of writing letters (the next ones were to the Army if he couldn't fly he wanted to fight) and getting similar answers (no, the Army could not accept someone to fight who could not see because it was too dangerous), Paul finally reached a new level of acceptance of his own blindness. And a new confidence in the fact that when he had questions, he could ask them and he could get straight answers. It seemed like a paradox, but it was true, that in accepting his limitations more fully, he became more aware of his own power. And I feel as if I learned along with Paul that year; I realised that there were lots of things that I couldn't teach him, things that he would have to learn for himself.

## The story

I taught Paul one more time, several years later. By this time he was nearing graduation, and was finishing his requirements for a high-school diploma. Two important things happened during that year regarding my relationship with Paul that influenced the kind of strategies I used in teaching him. One was that he and I discovered together a story which we both loved and which we worked on together for a long time, and which came to be of benefit for both us us, I think. I came upon the story — an Irish fairy-tale called 'Conn-eda' while I was searching for a way to work on braille skills with Paul, a way which would be motivating for him. What I knew I had to teach him was something tedious. An evaluation by a learning disabilities specialist had revealed that Paul had difficulty reading because he had difficulty 'chunking' - putting words together in meaningful clusters - and difficulty with shortterm memory. (The fact of this difficulty I consider to be partially due to my failure to put language into the context of sentences for him during that first summer that I taught him. The difficult remediation that I had to do later I considered to be partially my own karma.) I had to design a remediation curriculum which would require him to read in proper chunks and to develop his shortterm memory.

From my previous teaching of Paul, I realised that it would not be easy to get him to do this kind of tedious work, and that if it were to get done, the context of what he was reading would have to be extremely motivating both to him and to me. So the task was to find something to read together that we would both be very interested in. (I include myself in the equation, because I have learned from my years of teaching that if what I am teaching is something that is not interesting to me, I cannot keep up the energy and enthusiasm necessary to keep the lesson going well over a long stretch of time.) I had learned from Paul that he was very interested in Ireland because he has ancestors from Ireland, and he had travelled there the previous summer with a priest who was a friend of the family. In fact, Ireland was a subject which was numinous for Paul. By numinous, I mean that it held a fascination of an almost religious nature. (Most deaf-blind students that I know have one or more topics or objects that hold this kind of numinous 'charge' for them, one has to just mention a particular word, and they get really excited.) I, for one, believe in using this interest to its full educational advantage - taking this topic and expanding it in order to open it out further, all the while being assured that I will have the child's full attention as long as this topic is the centre.

For Paul, Ireland was such a topic. And for me, fairy tales are such a topic. So my solution to engaging both of our interests was to find an Irish fairy tale, which I did. Fortuitously, the fairy-tale was the story of an initiation of an ancient Irish prince, so it contained many themes which were appropriate for Paul, who was himself about to set out into the world to make his way. Paul and I worked on this story for the better part of a year, and it held our interest the whole time. The work we did was laborious, I required Paul to memorise whole sentences as he read them, and to sign them in rhythmical chunks, so that the phraseology of English would become more natural to him. I was surprised at the extent to which he was willing to persevere in this tedious task. I attribute his perseverance to the fact that the story was about one of his favourite topics in the world, and to the fact that it was an excellent story, one full of suspense and heroism and pain and victory. I'm not one to remember stories very easily, but I don't think I will forget that one, and I think that my experience with Paul's excitement about that story taught me a great deal. And his persistence in spite of the great difficulty of that task paralleled the persistence of the hero of the story, and therefore imprinted the story on my mind. One detail about that story stand out now in my mind: the hero prince had a shaggy horse who was his guide on the journey. Paul was especially enamoured of that character of the shaggy horse in the story. During that year he himself had an opportunity to learn to ride horses as part of a recreation programme at school. He loved the experience. It was as if he had found an adequate vehicle after all those years.

### Sharing

The other thing that happened that year was that during this teaching of that story and the teaching of other things to Paul, I began to share with him more of the personal details of my life than I ever had before. I did this consciously, aware of how few adult models he had in his life, and wanting to give him some honest and straightforward stories about some of the difficulties and successes I had experienced, in order to help him imagine for himself more possibilities in life. When I thought about the nature of his handicap — the fact that he has never seen a movie or watched television or overheard a conversation between other I realised how much he needed access to stories of other people's lives, and how hungry he was for them. Our class, as a whole, began

to read 'Ann Landers' and 'Ask Beth' (newspaper advice columns for adults and teenagers) that year. The students loved reading these, and always had a million questions. And I told Paul, whenever it seemed appropriate, stories from my own teenage years and stories from my present life that I felt might be of interest to him. He asked me questions which, from one perspective, might be considered naive - certainly they were questions which no sighted and hearing person his age would be likely to ask. But they were questions which, if I took them seriously, would almost always end up teaching me something about myself. Often the questions would be as simple as, 'Why did you do that?' - asked perfectly genuinely and demanding an honest answer. Having to answer him in a way that he could understand forced me to look at events in my life with a fresh eye, and attuned me to a kind of blindness and deafness in myself of which I had been unaware.

I guess in the end what I want to say is that I feel that it is in learning from our deaf-blind students that we become their best teachers. The longer I teach the more I am aware that they have so much to teach us — about accepting limitations, about fighting limitations, about tenacity, and fear, and courage, and humour, and about a simple, unencumbered view of the world, in which success is measured in minute and precious steps rather than in megabucks or star wars or super powers.

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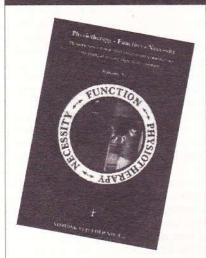
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## **BOOK REVIEW**



# Physiotherapy – Function – Necessity

Physiotherapy with deaf-blind and young people is a very specialised field. This new book, produced by the Nordic Staff Training Centre and translated into English, provides valuable information and ideas.

Marianne Vester is physiotherapist at Aalborg School in Denmark, and has many years experience with deaf-blind children. Her book, emphasises how the range of physiotherapy skills can be most effective as part of an integrated training programme. Using the Bobath Concept model of assessment and analysis, she examines the development of deaf-blind children and identifies the areas where deafblindness can impede normal child development. Her ideas for therapy are aimed at physiotherapists, other staff and parents.

'Physiotherapy - Function -Necessity' provides a positive approach to work with deafblind children, with or without other disabilities, and encourages the belief that the use of simple techniques can enable deaf-blind children to function at a higher level and achieve a greater degree of independence.

An accompanying video is also available. Book and Video can be ordered from: Forlaget Nord-Press

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# **Record Keeping**

# Effective tools for disseminating information to parents and other professionals

Phillippa Clark is educational psychologist at the Royal School for Deaf Children in Exeter, UK. Here she describes some of the systems of record-keeping used with the deaf-blind children at the school.

#### Introduction

The importance of keeping records of children's progress in school is widely accepted in mainstream and special education. In many schools there has been a development in the type and quality of records being kept. This change has been strongly influenced by curriculum-referenced assessment procedures and the acceptance that records and testing of children need to be directly related to teaching.

However, evaluation and recordkeeping must not become a meaningless routine for the teacher. It must be relevant to the children's learning and provide teachers with information from which they can make decisions with regard to Individual Educational Programmes.

The purpose of evaluation and record-keeping is not to prove but to improve.

## Curriculum and Assessment must be Individually Based

Professionals and parents involved in the education of the deaf-blind accept the premise that the curriculum must be maximally relevant to the pressing needs and disposition of the individual children. A major emphasis must be placed upon the idiosyncratic conduct and problems which the children encounter in their own lives.

Accepting this, it is then evident that the process of recording a child's progress must also be unique to that child. A school or department system of recording information/progress may not fully take into account the individual differences between the children.

At the Royal School for the Deaf, Exeter it is our aim to be flexible in our assessment and recording progress of our deaf-blind children. We do use some standard types of assessment, as it is important to measure children's progress against what is generally accepted to be the norm. However, we also develop systems of recording to meet the individual development of our children.

Evaluation and record-keeping in this way is our process of collating information for us to make decisions about curriculum and teaching strategies. It also provides us with reasons for parents as to why new ideas and methods are being developed. The records should reflect what is being taught and how it is being taught.

I will explain some of the processes we use to record different curricular areas. It is important to remember that we are flexible and systems of record-keeping are adapted according to the needs of individual children, teachers and families.

However, our record-keeping processes do serve three main functions:-

- to help teachers (and parents) to select appropriate learning experiences.
- to communicate to others (parents, professional and child) what is expected
- to give parents and professional standards for evaluating progress.

Used in this way, the records are used by teachers to appraise their own classroom practice and ensure they are providing effective learning experiences for the children.

## 1 Checklists of Attainments

If checklists of attainments (e.g. the number of words a child can read) are used sensitively they can provide information about a child's rate of learning and an insight into the child's strengths and weaknesses in one particular area.

However, we have found that by systematically observing and recording one child's school responses in a reading test we have measured the number of words known, but also we have learnt about his self-confidence. By carefully observing the child it was possible to identify three types of response he gave when asked to read/sign a set of written words:-

a) he quickly produced the sign

- b) he hesitated, but when shown the initial position of the sign he completed the sign before the adult
- c) he did not attempt to make any sign but pointed to the adult as an indication "you do it" He then copied the sign and if he was not happy with his own attempt would present his hands to the adult for co-active guidance

It would have been easy to miss the distinction between the child's responses if the only record being kept was a simple tick-list of success.

Instead, the records have provided useful information on the child's learning processes and this understanding is much more important than simply knowing the size of his signing vocabulary.

## 2 Checklists of Self-Care/Independence Skills

Checklists of Self-Care/ Independence Skills are very common in the education of the deaf-blind. There are many commercial checklists and perhaps more appropriately many schools and teachers have developed their own with specific regard to the children in the school.

The format of such checklists tends to be written objectives, which can be broken into small steps, and which can be readily used on a criterion-referenced basis. The skills a child has already acquired can be checked off and the next teaching area (skills the child has not yet achieved) easily identified.

Those adults in direct contact with the deaf-blind child are the best people to complete such checklists — they have the details and vested interest to help him/her develop.

The difficulties of generalising skills between home, classroom and residential setting are often very apparent in the Self-Care/ Independence areas. It is therefore important to identify the different skills children demonstrate in each setting.

At the Royal School for the Deaf, Exeter three sets of Self-Care Skills are completed on each child, by: i) parents

ii) teacher and classroom assistants

iii) carestaff in residential setting

The similarities and differences in achievements have provided a good basis for negotiating between a child's various carers. Agreement can be reached on which skills to teach and practice.

The collaborative use of checklists have also provided an insight into how different carers view one particular child. It may be that in one setting, either home, classroom or in residence, the child is allowed to be much more independent than in another. Our human tendency to do things for multi-handicapped children can be a great hindrance to them developing autonomy and independence. We must learn from, and encourage, each other to stand back and let the deaf-blind child achieve things for himself.

One mother told us that if she had completed a checklist before it would have given her more ideas of how to help her fourteen year old Rubella-damaged son, who is a bright independent child. Many items on the checklist (e.g. changing an electric light bulb), mother had done for her child whilst he was at school — never thinking of the value of doing this exercise with him.

Completing the checklists and discussing the findings have also led parents to comment that they feel more valued by the teachers. Parents have found they have many contributions to make to their child's learning programme.

## 3 Developing Autonomy in the Deaf-Blind Child

If we want deaf-blind children to develop their own powers of judgment and discrimination we must give them opportunities to exercise judgment and discrimination.

It is for this reason that we provide a free-play area for our younger deaf-blind children. An activity room with a variety of play facilities e.g. trampoline. rocking horse, climbing frame, sand and water play.

However, children, both those with some residual vision and the totally blind, tended to remain on/at one favoured activity. This appeared to be for two reasons:

- a) adults tended to place the child at the same activity
- b) the child was unaware of the variety of activities and that they could make a choice

We set out to teach the children both the mobility skills they required to find the various activities and also to teach them to choose between activities.

To record progress we linked the various activities in the room and each day we observed the children and ticked in red if a child approached and stayed at one particular activity (we were not at this stage concerned with the quality of play); we gave a black tick if an adult had directed a child to a particular activity.

The early records were a clear indication that the children had a very limited experience of the various activities available to them. However, as we continued with the teaching and recording we found a marked improvement in the number of activities a child chose.

The parameters emerged from the records:-

- the number of black ticks both increased and was better spread across the chart The adults became more aware of the experiences each child was missing and endeavoured to widen the range of activities they directed children to
- ii) The number of red ticks (selfchoice) also increased. As the children experienced a wider range of activities and could link this with their mobility skills, they themselves became more adept at selecting activities.

From these records it was possible to see, in objective terms, the children developing their autonomy and demonstrating a favouritism for certain activities; this was not a favouritism linked to lack of experience but a real enjoyment of some activities more than others.

It was interesting to note that even when activities and apparatus were re-arranged in the room that the children maintained their favourite activities. This re-assured us that their choice was not limited to their mobility skills.

This is a good place to emphasise that record-keeping of different curricular areas need not continue for ever. We are no longer keeping detailed records of this particular activity; there is no need at present. Records can be made trivial by completing them just for their own sake and will not then lead to an improvement in teaching.

We must reflect on our teaching practice at all times and adapt our record-keeping to help us select appropriate learning experiences for the children

### **4** Self-Recording

As deaf-blind children develop it may be possible to involve them in self-recording. To involve them in monitoring their own progress helps them to develop self-worth and responsibility for their own actions.

In our senior school a housemark system operates, where all children can be awarded good marks for good work and behaviour. Each child is in one of three house-groups (Red, Blue or Green) and their marks at the end of the term has a day's outing e.g. to the theatre or fun-fair. The system works very well for the mainstream children and leads to the correct form of peer-group pressure to encourage each other to get good marks.

We wanted the deaf-blind children to be seen as equal participants in this process. Hence we developed a token economy system whereby the children could earn ticks for work completed and then exchange these ticks for good marks.

The children recorded their ticks on a weekly chart, using a different coloured pen for each day. At the end of the week they totalled their ticks and exchanged them with the classteacher for the appropriate number of good marks. It did not take them long to learn that the harder they worked the more ticks they could award themselves. They realised the importance of the good marks and were pleased to be praised in the weekly assembly for achieving lots of good marks. Indeed three of the boys also enjoyed trips out of school for being members of the winning houses.

Perhaps most important was that the children learnt the idea of negotiation. The "exchange rate" of ticks for good marks was different for each child. The rate might also vary from week to week, if six ticks earned a good mark one week the teacher encouraged the child to get seven ticks the next week for the same good mark.

It was evident that the children enjoyed this self-recording of their work and began to see that they could improve their own work-rate. We were impressed when the children worked out for themselves that by writing down extra activities (playing ball, going to church) on the chart they could award themselves with even more ticks.

### 5 Record-keeping must take into account the whole child

It is easy to make errors of judgment about a child if we do not consider him/her as a whole. For example, we had an on-going problem of wetting with one of our older children. We drew out a toilet chart, set time for toiletting and recorded when the child was sent to the toilet and when he was wet.

The only pattern that emerged from these results was one of repeated wets occurring immediately after the boy had been sent to the toilet. This seemed crazy to us, so we decided that we must observe him in the toilets. And what did we find:-

a) He has a poor posture at the urinal, he leans his right elbow on the wall and continues with the stereotypic head-rubbing.

b) With his left hand he is careless in holding himself, has difficulty in directing the flow of his urine and often allows the urine to run down into his trouser leg.

Hence, when he had appeared wet, and we recorded him as wet, it was in fact an error. He had performed in the toilet and we had failed to praise him for this.

This instance highlighted that we must consider the child as a whole, and not always take our observations (wet trousers) and draw the immediate conclusions. We must be vigilant in our observations and ensure we are recording what is actually happening, not what we think is happening.

It is good to report that since these observations have been made we are now teaching the child to stand upright at the urinal and to hold himself correctly. The records indicate that the new toiletting programme is very successful.

### Conclusions

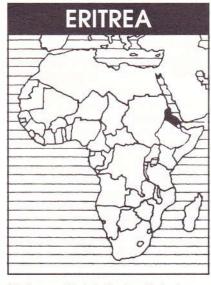
It is very important to keep records of the progress of each deaf-blind child. The records should be clear, concise, easy to use and directly related to the child's learning experience. If records are too detailed or difficult to complete then they will only increase the workload of busy teachers, parents and carestaff. Simple charts that can be completed in the classroom are always the most effective.

The value of this type of recordkeeping is evident when it comes to the time of making decisions about children, or writing reports. The objective data is all collated and this information will help you in planning Individual Educational Programmes — ensuring that the child makes maximum progress and wastes minimum time in failing.

A further advantage to a good record-keeping system is when you want to communicate with parents and other professional regarding a child's progress and your teaching programme, the information is readily available to you. This sharing with parents of the records is often very useful at the Royal School for the Deaf, Exeter.

Through having objective data available we can talk with parents about specific progress. We can tell them exactly how their child has progressed, rather than simply saying "We think he can eat/dress/ write better now". The records provide evidence of progress even when this is in small increments. This evidence encourages parents and teachers to continue in their often unrewarding task of educating deaf-blind children.

> Mahmoud's letter scroll



Mahmoud is totally deaf-blind as a result of a bullet wound. He is an Eritrean, and was shot by soldiers of the Ethiopian army. Now he stays in a rehabilitation centre run by the Eritrean Relief Association, learning to rebuild his life.

His close friend, Tesfai, constructed a letter chart. Their language, Tigrinya, contains 196 letters, so Tesfai cut 196 shapes out of leather and attached them to a



scroll. To speak to Mahmoud, his friends take his finger to one letter at a time.

Mahmoud is now learning Tadoma, the system of understanding speech by feeling the vibrations of the throat and the lip movements of the speaker. His own speed is still good, and this should help him to learn to understand the speech of his friends.

In the centre, Mahmoud is the only

resident who can walk, so he helps with the tasks that involve walking and standing; using his cane he finds his way outside to hang up the clothes. In this community of disabled people, everyone has a role. No-one can be useless when there is a war in your country.

In a land where there is famine, disease, poverty and war, there are still people who will face up to the challenges of deaf-blindness.

Next year the 10th IAEDB Conference will take place in Sweden. We want to celebrate this important event. Since the first conference in 1962 at Condover Hall, U.K. we have got new groups interested in the conferences e.g. parents or families, staff working with adventitious or young adult deaf-blind and people with Usher Syndrome. There has been a remarkable development of standard for and attitudes to the deaf-blind.

The conference will provide a forum for active exchange of opinions and review of the latest developments under the three main themes, as well as an opportunity for promoting cooperation between the participants from all over the world. We hope you also will enjoy the social programme of various events, which give opportunity to get to know each other and to get experiences of the Swedish landscape and culture.

On behalf of the local committee I have the great pleasure to welcome you to participate in the World Conference on the theme "Quality of Life — Lifelong Enrichment".

Looking forward to seeing you in 1991 in Orebro.

Sonja Jarl

## EUROPEAN USHER SYNDROME STUDY **GROUP MEETING**

The 6th meeting of EUSSG will be held in Örebro from Friday 2 August to Sunday 4 August 1991. One of the residential schools in Örebro for special education will host the meeting and accommodation will be provided in the students rooms.

For details of the EUSSG meeting apply to:

Mary Guest Head of Usher Syndrome Services SENSE 311 Grays Inn Road London WC IX 8 PT England

Telephone: 071-278 10 05

10<sup>TH</sup> IAEDB CONFERENCE ÖREBRO SWEDEN

#### 4 - 9 AUGUST 1991

#### "QUALITY OF LIFE -LIFELONG ENRICHMENT"



## **Suggested Topics for Workshops**

#### **Quality of Life**

- general working approach focusing the quality of life for a deaf-blind person - psycho-social aspects of a challenging environment
- appropriate physical environment for a deaf-blind person — the deaf-blind in the family and in the community
- transmission of culture and the culture of the deaf-blind themselves
- meaningful activities improving the quality throughout life: play, work, art, hobbies, learning
- methods in helping the deaf-blind person to find and develop his/her own motivation, creativity, curiosity
- the development of the identity of a deaf-blind person
- focus of control e.g. a deaf-blind person should feel that he is in control of his situation

#### Assessment

- genetic syndroms causing deafblindness
- new knowledge on specific areas of assessment (visual, audiological, neurological, psychological etc.)

- assessment as a guideline for intervention and education
- assessment as a basis for planning individual services for deaf-blind adults - identification and assessment in developing countries
- strategies related to holistic, coherent and meaningful approach in assessment
- follow-up studies

#### Communication

- development of communication and language skills
- alternative and augmentative communication systems
- · play, symbolic play and cooperative play
- social aspects of communication in life-long perspective
- communication of the adventitious deaf-blind
- communication in the family
- communication in newly started programmes
- alternative communication systems in developing countries
- specific devices or techniques used with the deaf-blind for developing communication and language
- computers in communication

Further details from: IAEDB Conference Bergsmannen konferenscenter Box 328 00 S-701 35 ÖREBRO Sweden

# Parental involvement in residential programmes

Susan Allen, Jake Allen Centre, Florida, USA

Parents whose children attend residential programmes face difficult emotional issues, different than those parents who's children live in the home on a everyday basis.

We as parents have made decisions that are sometimes hard for us to accept even if we feel it is the answer to educating our children.

We at the Jake Allen Centre have strived to design an innovative programme that will provide the best of both home environment and the stability of a residential school. This is not only for the deaf-blind child, but the parents and family as well.

Here is how it came about and why it continues to.!be so effective: After 9 years of living with my deafblind son, it became evident that Jake's needs were not being met in the public school programme. He had been shifted from one exceptional programme to another. Without much success in communication or acceptable behaviour, I became convinced that the importance of a consistent environment that would provide language every waking hour was the only answer.

I visited typical residential programmes throughout.the country, but felt disappointed in the amount of parental contact and involvement I saw. But an even greater disappointment was the over-all progress I saw in congenially deaf/blind children and the acceptance of their entire family.

As I spoke to parents of young multi sensory impaired children, I began to ask questions like "if you were designing the perfect school placement, what would it be?" and out of that thought the Jake Allen Centre was born.

How does it involve parents in residential placement? It doesn't involve them, it is them and here's how. . First, upon entry parents write out what they want from their child when they reach adulthood. These adult goals are discussed in length to establish what each day in the coming years will accomplish. The idea is,then to establish that each day - counts on meeting the ultimate goal, whatever that may be...

From that day on the parents basic desire is followed with guidance from properly trained staff. Basically there have been few problems. The family then begins to join the team from the first day, knowing that they are respected and still remain in control of their child.

For example: If a family has a routine of eating dinner at a restaurant each Friday evening and that activity is a critical part of their family life, that would be the activity that the Centre focuses on in the programme.

Second of all, the children go home each weekend all over the State. Parental involvement here is never a question. (If there are no parents, foster parents are established.) Giving the family 5 days to function as a "nonhandicapped" family, helps the entire unit to survive and continue to be a healthy unit and not a totally dysfunctional family.

The staff must never forget, these are not "our children" but have simply been loaned to us during the five day school week. Staff members and administration are never to comment on parents emotional steps or behaviour. If you have never been a parent of a deaf/ blind child you cannot comment on how you would or how they should behave, how they should think or conduct their household or spend their weekends with their child.

Parents are required to spend 1 week each year in classes. Each Spring *all* students, intervenors and families go away to camp and spend a week together in classes, group sessions and social events, getting to know each other and forming the bonds that make intervention work to it's fullest

This week is spent educating parents on the communication methods used, sharing triumphs and disappointments as a family would and accepting each other. These times together help prevent jealously between the parent and the intervenor.

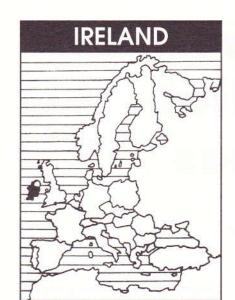
Mom realises that just because the child has begun to communicate with the intervenor does not mean her child doesn't love her or that she is inadequate. It simply means the stage has been set to promote communication in the residence and it made it possible for the first formal communication to happen there. Soon communication begins to take all forms of life. In and out of the residence.

Intervenors must be an extension of the family. Mom, Dad, Siblings, teachers and intervenor working and functioning as a team to bring the worid alive not only during the 5 day school week, but on the weekend as well.

For me, my family and my son, residential placement has been the answer for him and his education.

Each Friday I meet with his intervenors and go over what has happened the past 5 days. I follow as much as possible throughout the weekend what has happened at the Centre and on Monday we again meet to plan the coming weeks events. The intervenors are his tools to reach the worid, we are a team.

Residential programmes must not resist change and evolution of the family in the 90s. Active, participating families must join the educational forces to produce full, dignified adults. With families who have had every chance to learn, grow and develop with their disabled child, typical programmes must redesign.



# The Anne Sullivan Foundation for Deaf-Blind

On 27 April, 1989 a group of people held a meeting in St. Joseph's House for the Deaf in Stillorgan, Co. Dublin, Ireland. The group included a doctor, social worker, speech therapist and teachers, all of whom have worked with deaf-blind children and some parents of these children. They decided to form a National Organisation and to call it The Anne Sullivan Foundation for Deaf-Blind.

### The Miracle Worker

Anne Sullivan was the daughter of a Limerick couple who emigrated to the USA. She trained to become a teacher of the blind. Those who have read anything or seen the film about Helen Keller will know why Anne Sullivan became known as The Miracle Worker. She was Helen Keller's teacher and then her friend and companion for fifty years.

## The Anne Sullivan Foundation

People who have partial visual and hearing impairments and who can learn to use oral or manual communication are well provided for by the special schools and organisations already established for this purpose.

Higher functioning deaf-blind children are catered for at Marian

School, Dominican Convent, Cabra, Dublin 7.

There is another group of people who are prelingually deafblind who have very little or no means of communication and who may also be mentally handicapped. These people are termed low functioning deaf-blind.

It is to improve the quality of life for the latter group that the Anne Sullivan Foundation has been formed.

## Workshop for Low Functioning Deaf-Blind

In November, 1988 a workshop was held in St. Josephs House for Adult Deaf and Deaf-Blind in Stillorgan. Co. Dublin to establish techniques for working with low functioning deaf-blind young people.

It was organised by the Union of Voluntary Organisations for the Handicapped and Mobility International under the sponsorship of the Commission of the European Communities. The project brought together all the groups involved with deaf-blind people. Included were children, parents policy makers, teachers, social workers. care workers doctors, nurses and other professionals.

The major roles were played by four specialists, two from Britain and two from Denmark who have considerable experience with the subjects of Assessment, Educational Techniques, Mobility and Communication Skills. The new thinking on teaching methods and technology which they introduced should benefit our low functioning deaf-blind children, through those who work with them.

The conclusions and recommendations arrived at by those involved in the Project, included:

## 1 Professional Coordination

There is a need for a more coordinated and better organised service for low functioning deafblind.

## 2 National Agency or Coordinator

There is a need for a National Agency, with comprehensive information on all those who suffer from low functioning deafblindness so that resources may be more efficiently used, and for the development of a National Comprehensive Plan.

## **3 Residential Centre**

There is a need for a residential centre where experts from the different professions could concentrate all their efforts to the education and improvement of the quality of life for the low functioning deaf-blind. Weekly or fortnightly home visits would be encouraged. If the national immunisation campaign, organised by the Department of Health continues to succeed in eliminating or greatly reducing the incidence of Rubella, the residential centre could, in due course, become a Home for Life for those being trained. It is not acceptable that People with severe sensory impairment must live in Psychiatric hospitals.

These were the thoughts which triggered off the idea of establishing The Anne Sullivan Foundation.

### Progress

The first meeting of the Anne Sullivan Foundation was held on 25 May, 1989 and five meetings of the Management Committee have been held since then. We have become subscribers to and we have established links with SENSE. the National Deaf-Blind and Rubella Association of Great Britain. We have also joined the European Group of Organisations for the Deaf-Blind. Our representative on this body is Joan Kelly, teacher of the deaf-blind. Joan also attended a Conference held in Warwick University in August, which was organised by the International Association of the Deaf-Blind and in November she went to Denmark on an educational visit. This journey was largely financed by a grant from the Commission of the European Communities through the good offices of Mobility International. Denmark is probably the most advanced country in the world in its attitude to and its treatment of handicapped people.

## Census

The Primary objective of The Anne Sullivan Foundation is the establishment of a residential centre for training and teaching the younger low functioning deafblind and a Home for Life with trained staff for the over 20s. We cannot plan or negotiate with the various Public bodies concerned unless we know the extent of the needs of those we plan to help. For this reason a census or enquiry form was sent to the parents of all the young deaf-blind known to us.

# Supported Employment for Students with Deaf-Blindness

Betsy McGinnity is Supervisor of Vocational Services for the Deaf-blind Program of Perkins School for the Bind, USA. Here she looks at some different approaches that the School has explored for supporting their young adults in employment.

In the late seventies a large number of students in the deaf-blind program at Perkins were hearing and visually impaired as a result of the rubella epidemic of the midsixties. This entire group was scheduled to leave school systems and enter the world of adult services between 1986 and 1987. Preparing them for that transition became a major focus of their educational programs.

At that time many graduates who were academically capable ended up in sheltered workshops or unemployed when they left school. In 1979 Perkins was awarded a federal grant designed to offer these students training to prepare them for competitive employment. The project was based on the premise that, with experience in community based competitive work sites, certain students with hearing and visual impairments could avoid being placed in sheltered workshops when they graduated. Many students who participated in that project made a successful transition to competitive employment upon graduating. Certain students could not make the transition to total independence at the work site.

Those students who did not make a successful transition to complete independence at the work site often experienced considerable success on the job. It was clear that they would not be well served by movement to a more restrictive setting like a sheltered workshop program but needed something more than was currently being offered.

In 1987, Perkins was awarded a federal grant to develop supported employment opportunities for students with dual-sensory impairments. The focus of the grant was to prepare the students to function as independently as possible in the world of work as adults. The overall goal of the project was to provide an employment focus for deaf-blind

youth directed toward the achievement of the same goals sought by non-handicapped workers, ie., security, mobility, quality of life, and appropriate income level.

In order to do this the project established the following objectives:

- To work with private industry to establish a variety of supported employment sites
- To appropriately address the training needs of 33 students with deaf-blindness by providing them with training and on going support in community based employment settings
- To work with the primary adult service agencies in the state to advocate for the establishment of supported employment options for persons with deafblindness
- To disseminate information about the project and the viability of supported employment for youths with deaf-blindness.

The project participants ranged in age from sixteen through twentytwo. All met the federal definition of deaf-blindness. Eleven students have no functional vision, four students have extremely limited

fields of vision <10 deg., and the remainder tested at 20/200 or worse. Twenty-three students have severe or profound hearing losses, and ten students have moderate hearing losses. Fifteen students have test results that indicate severe to profound mental retardation, twelve have test results that indicate moderate mental retardation , and the rest function within normal ranges. Five students function as totally deaf-blind individuals.

The Supported Employment grant has utilised a variety of models. These models include:

Individual Competitive — in which a student is trained at a job site to perform specific job responsibilities with the expectation that the student will be able to function independently at some point. This option is often called "transitional employment. Training is individualised and the training time may be extensive. The student is hired by and supervised by the employer. The project has utilised a variety of competitive jobs including dishwasher, warehouse worker, and assemble at a braille printing press.

Supported Competitive — in this option the student is hired directly by the employer, in some instances for sub minimum wage. A job coach provides ongoing training and support but supervision is also provided by company staff. Often more than one student is placed in the worksite in order to best utilise the job coach's time. The supported competitive jobs utilised by the project include laundry worker, food preparer, coin teller, and greenhouse labourer.

Work Crew — in this option students work as a group and are primarily supervised by Perkins staff. The employer subcontracts with Perkins and Perkins pays the students. The work crew jobs developed by the project all involved custodial and cleaning services.

The Supported Employment project completed its last year of funding. To date thirty-one students with hearing and visual impairments received training in ten supported employment' sites in the community. During the project, seven project participants have completed the transition out of school into community based transitional and supported employment sites.

Further information about the project is available by writing to:

Betsy L. McGinnity, Coordinator of Vocational Transitional Services Deaf-Blind Program, Perkins School for the Blind, 175 North Beacon Street, Watertown, MA 02172

## LETTERS ... LETTERS ...

From 1987 to 1989 I was a teacher at the Kabarnet School for Deaf-Blind children. Now I am a student at the Kenya Institute of Special Education. I am doing research into the characteristics of rubella deaf-blind children, and teaching strategies for working with them. This area of deafblindness is very new in my country and I am asking if anyone can send me some information on this topic. I hope that you can help me. Yours sincerely **Zipporah Kumen** P O Box 48413 Nairobi **KENYA** 

We receive many letters such as this, from all parts of the world, and we seek to provide information. We hope that our readers also will respond, so that we can help each other.

In Italy we are going to change the way we refer to deatblindness, by removing the hyphen that usually separates the words 'deaf' and 'blind'. So, we will no longer refer to deaf-blind or blinddeaf, only deafblind. Why are we doing this? Because

Why are we doing this? Because deafblindness is not just the sum of deafness and blindness. Deafblindness is another entity. A Deafblind person is a person with special difficulties, a different communication, a different way of life.

So I now propose to use the word deafblind in all literature; if you also agree, then gradually we can bring about the change in all languages (in Italian it is Sordocieco and Sordocecita).

Yours sincerely Dr Salvatore Lagati ITALY

Do other readers have any thoughts about this? Do you have a different way of describing deafblind children and young people in your country?

I have received with great pleasure and interest the magazines you have sent me with connection to the problems of the instruction and life of deaf-blind people. In Romania there are, just like in any other country of the world, such impaired people, and in my town, Cluj-Napoca (the Department of Psychology of the University, the School for the blind) we have gained a valuable experience in the difficult work or recuperation of deaf-blind children.

The best known case is that of Mr Vasile Adamescu, who has been blind and deaf since he was two and a half years (as a result of a cerebrospinal meningitis) and whose recuperation was started when he was eleven years of age. So, he was deaf-blind and mute for about 8 years, thus remaining nearly undeveloped from a psychological point of view. In spite of this huge handicap, through intense and competent educational work. Mr V Adamescu succeeded in gradually recuperating the respective impairment of his psychic development: he got his high school graduation and then attended college in the field of psychopedagogy, a field in which he is now a teacher in the School for the Blind in the city of Cluj-Napoca.

I have personally worked and cooperated with him for nearly 35 years and will continue to do so permanently in all fields (research, didactic work etc). I consider that such problems are of a great scientific interest (in psychology, pedagogy, biology, sociology etc.) and so I will dedicate the greatest portion of my time to these studies.

Yours sincerely, Professor Valeria Mare ROMANIA

Our first letter from Iran. I hope some of our readers can help.

I am an Occupational Therapist at a Rehabilitation Centre. I would be grateful for any written material concerning the education of the deaf-blind. Yours sincerely **Mehrzad Ghodsi** 9, 111 Street Golsar Place

Golsar Place Rasht, IRAN

We hope to more into the new school for deaf-blind children in October 1990. We will leave the city of Zurich and will go to the Langnau am Ablis, a suburb of Zurich. Also on the site there will be a new centre for deaf-blind young adults. Our previous centre for young adults was small, in the centre of Zurich, and there was no room for the new students who wished to enter the centre.

This is an exciting time for deaf-blind children and adults in Switzerland. We will give you more information soon. Yours sincerely Esther Frei Teacher, Stiftung für Taubblinde Freiestr. 26 CH-8032 Zurich SWITZERLAND

# Young, Deaf and Visually Impaired

#### An introductory film by and of deaf Swedish young people who suffer from RP (Retinitis Pigmentosa)

Vision impairment strikes even the deaf. Some deaf people have a special impairment known as RP (Retinitis Pigmentosa). An hereditary combination of deafness and RP is usually called the Usher Syndrome.

This film is an attempt to give the viewer some insight into what life with the Usher Syndrome is like.

The film is semidocumentary. Helen and Hans are themselves. Jan (who actually also has RP) plays a curious deaf man with no vision impairment.

The dialogue is in Swedish sign language and has been interpreted into spoken English by Frederic Love. The voice belongs to Björn Sandberg.

This film is intended first and foremost for the parents and families of children suffering from the Usher Syndrome. It may also be of value to other groups of people interested in information about RP, the Usher Syndrome, and their consequences.

"Young, Deaf and Visually Impaired" has been produced by Björn Sandberg for the Usher Group of Örebro, Sweden. It can be ordered from:

> SIL-lagret Box 1833 S-700

# Nordic Staff Training Centre for Deaf-Blind Services

Our courses for the remainder of 1990 include the following:

20.08.90 - 07.09.90: Workshop on Aggressive and Self-Abusive Behaviour 16-18 participants

17.09.90 - 05.10.90: Basic Course on Adventitiously Deaf-Blind Adults. Part II 18 Participants

#### 22.10.90 - 09.11.90:

Basic Course on Congenitally Deaf-Blind Children, Part I 18 Participants

24.11.90 - 30.11.90: Conference on Administration and the Deaf-Blind

20 Participants max.

## Preliminary overview of the 1991 educational activities.

Staff working in services for congenitally deaf-blind children are invited to a basic course every year. The other basic course is designed for staff working with congenitally deaf-blind adults. The workshops will discuss the following:

- New perspectives in the most important disciplines in the work with adventituously deafblind persons.
- Approaches in communication with congenitally deaf-blind persons.
- Usher Syndrome, consequences for young and adult persons.

#### There will be a Nordic Conference on Ageing and Deaf-Blindness.

The IAEDB World Conference will take place here in the Nordic next time, the place is Orebro in Sweden, and the date is 4th - 9th August 1991.

# Foreign course participants

Our friends abroad often ask if it is possible for other than Nordic citizens to join in the courses. We would be very happy to see you as our guests for a period of time during one of our courses. It is then possible to stay at the centre to study in the library and to meet and discuss with Nordic colleagues in deaf-blind work.

However, if you want to attend a whole course, please bear in mind that with few exceptions only both the lecturing and the group work is in the Nordic languages. To be able to take part in this, eventual foreign participants would have to cover the expenses for travel and accommodation as well as the costs for an interpreter.

# Notice

Please note that The Nordic Staff Training Centre will have a new telephone number due to a change in the telecommunication service in Denmark: From May 15th 1990 you will have to dial + 45 98 84 34 99. We also have a telefax number: + 45 98 84 34 13.

> Marjaana Sousalmi Director of Education

Elin Ostli Secretary of Education

### **Russian visitors**

A group of Russian educators recently visited the deaf-blind department at Perkins School for the Blind, Massachussetts, USA. The visit allowed for a lively exchange of information covering a wide range of teaching approaches and innovations applied in USA and USSR.

The visit is just one of a number of examples of increased contact between the deaf-blind specialists in Russia and in the rest of Europe and USA. Following the presence of Dr. Valerii Chulkov at the IAEDB European Conference in Warwick, UK, a group from Britain representing Sense, the RNIB and the National Deaf-Blind League visited Moscow and Zagorsk. Dr. Chulkov and Svetlana Vishnevskaja have attended seminars and conferences in Dronninglund, Denmark and in Osimo, Italy. A programme of further visits and exchanges is now prepared.

# Deaf-Blind Education — the early years

Piet de Baere charts some of the beginnings of education and care for deaf-blind children. Piet wrote this article for the European Conference that was held in Bruges, Belgium in 1986.

Today the Spermalie Institute in Bruges is one of Europe's premier centres, providing home intervention, family support, education, and support for young adults.

Some years ago a young group of deaf-blind children were accepted once again at Spermalie. Now, as they become older, staff at the school are planning a new curriculum for them — a programme that will prepare them for their last years at school.

At the instruction of the Belgian government, a first statistical investigation was held in 1835 concerning the number of deaf and blind persons in Belgium. Three deaf-blind people were located in West-Flanders. Charles Carton (1802 - 1863), who in 1836 founded the institute for deaf and blind in Bruges, wrote in his first book on Anna Temmerman the following about this:

'Only one of the three could then get a proper education and schooling. The second was 'idiotic' at the same time, and the third was much too young. I thought that it was the appropriate time to prove that education and schooling were possible, and this against the opinion of those who theoretically claimed it to be impossible, but nobody ever proved the possibility with facts. I was restless until Anna stayed in my institution. I realised that without an example of a similar education and schooling method the plan would be very hard to achieve; I only had some principles to guide me. I believed in them because they were simple and because I had the Ladies at my disposal.'

Anna Temmerman was born blind, probably heard something for some time and became deaf at a very young age.

When Carton learned to know her, her parents were deceased and she was living with her grandmother.

'The grandparents and the aunt wouldn't separate from Anna. They didn't believe that a stranger would give her the necessary care with which they surrounded her; they were very attached to her.' 'When at last Anna was leaving home through the intervention of some members of the Commission of Civil Assistance, they said 'You are taking away the blessing from our home'. However I am glad that I can add they were happy when they saw the progress Anna made. They felt happy that they took the right decision after all.'

Anna stayed in Charles Carton's Institute for Deaf and Blind from the age of 21. She stayed there for 22 years until her death in 1859 at the age of 43.

### Anna Temmerman and Lavra Bridgman

What did Carton know about deafblind children and adults who received some kind of education, schooling or formation and who could have served as an example to him? In his 1839 and 1843 writings on Anna Temmerman, he studied what was known and being done at that time. As far as we can check, his inventory is quite complete. We restrict ourselves to some examples reported by Carton:

James Mitchell, born in Nairn, Scotland was deaf-blind (cataract) from birth. He didn't get proper education nor schooling. Mitchell was at that time, the living example for the idea that this was impossible.

Octavie Morisseau was deaf from a very early age and became blind when she was 13. As a deaf person, she already got education and schooling from 1832 onward at the Institute for the Deaf in Paris.

Julia Brace became deaf-blind at the age of four and as an adult stayed in an institution at Hartford (USA) from 1825 on. She didn't get a proper education and schooling.

These examples brought Carton to the following conclusion:

'The deaf-blind show us that despite the fact that they don't hear or see, they are no robots; but that they, even in their situation behave intelligently and that they think about their behaviour.'

Laura Bridgman (1829-1889)

became deaf-blind at the age of two, after a long disease. On October 4th 1837 at the age of eight, she was admitted to the Perkins Institute for the Blind (Boston, USA) by Samuel Howe, where she stayed until her death. She was the first deaf-blind child in history to receive a proper education and schooling. Carton already knew in 1839 that Howe had stared with the education and schooling of Laura Bridgman. He wrote in his work on Anna, that he was very optimistic about the developmental possibilities of Laura.

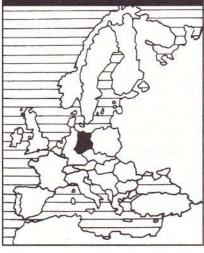
'It is hard to predict,' wrote Carton, 'but much is to be expected from the intelligence of the child, from her attention and great efforts made by her in order to learn new ideas.'

Carton and Howe also met each other at the Institute in Bruges. When visiting Carton, Howe received a letter from Boston in which was written that they had succeeded in making God known to Laura. Carton wrote that he and Howe had a different opinion on that issue. Howe believed that this shouldn't be taught to Laura; she should eventually have come to the knowledge of a Supreme Being by herself. For Carton however, being a priest, this was the goal of education and schooling. By achieving this, Carton wanted to show that also deaf-blind persons are human beings of full value.

It is a strange coincidence that at the same time in 1837, at two so far away places — Laura Bridgman in Boston by S. Howe and Anna Temmerman in Bruges by C. Carton — with a deaf-blind child and a deaf-blind 21-year-old, the history of the care of the deaf-blind takes a start.

Carton and Anna Temmerman were forgotten. Howe and Laura Bridgman remain known. This has several reasons. It is mainly the famous Helen Keller (1880 -1968) and her teacher Ann Sullivan, trained at Perkins, who have maintained the vivid memory to Laura Bridgman and Howe, who stimulated the care of the deaf-blind throughout the world.

# E. GERMANY



#### A time of change

As East Germany gets through fundamental and peaceful change, the entire concepts of education are being rethought and a new law on education is being prepared. The newlyelected government and regional delegates can draw upon a network of 14 special working parties and numerous sub-groups, consisting of over 2,000 educationalists and parents, in drawing up a new education policy.

The new education system will be more open, based on a pluralistic concept of society, recognising individual rights. There will no longer be a state or party monopoly on education. Key principles are likely to include:

- respect of the dignity of every individual
- prime responsibility of the family for education
- education and personal development as a life-long process
- public awareness of the importance of education

During this period of change, many associations and self-help groups are forming. Those involved in working with deaf-blind people are visiting. We are developing and change the curricula for educating deaf-blind children. We are planning a central organisation, to enable increased staff training. The planning committee for the European Conference, to be held in Potsdam in 1993, has been formed. We hope that this Conference will take place in a united Germany and an integrated Europe.

Fr Friedrich Pa-e

# The Education of deafblind children in the German Democratic Republic

Since 1985 groups of deaf-blind children have been formed in schools for the deaf at Berlin, Dresden and Halberstadt. That was almost 100 years (exactly 98 years) after the first deaf-blind child came into the Oberlinhaus in Potsdam-Babelsberg, an institution for education of deaf-blinds.

The care for the children in these new groups at Berlin, Dresden and Halberstadt is undertaken by qualified day nursery educators, kindergarten teachers, educators and teachers. Some of them studied in special schools for the deaf. Beside them work hospital nurses, night staff and other technical staff of the schools. All of them have entered a fresh line of research, and that was hard work.

Meanwhile the collectives in these new school groups have stabilized and grown together. Children and all persons concerned with these deaf-blind children have learned. Knowledge and realization have been acquired, and people can look at their first successes. The deaf-blind children in the institutions from the Government live and learn there every week from Monday to Friday. The weekends they spend with their parents. Some of the children are brought from school to hometown and back together with an educator by taxi. The costs of transport are given from the Government.

Now I will tell you about the deaf-blind home of the Oberlinhaus in Potsdam-Babelsberg. The structure in this home is totally different. Children and grown-ups live together in the same house. At present the youngest child is six, and the eldest woman is 84 years old. Children and grown-ups live there all the time. Most of the children go home for holidays and red-letter days. So do some of the adults. The living together for these persons of different ages is familylike but not without problems. Most of the grown-up deaf-blind go through the house like seeing people. Little deaf-blind children disturb the grown-ups on their way and also are disturbed, when they try to find their own way

I have been working there since 1987. Within this time I didn't see any loving contacts from old deafblind people to the younger ones. I'm asking, if that has to be so or not? Should we try to create more contact between young and old? Deaf-blind people do have many problems with social behaviour, and it is very difficult to encourage them in social contact.

Not only deaf-blind children live in our school groups. I think, that is because of the lack of central coordination for years. At present 12 school and pre-school children live with us:

- one deaf, spastic, mentally retarded
- two blind, mentally retarded
- one mentally retarded
- two partially sighted and hard of hearing in a high degree, mentally retarded.

These children are not able to learn at schools for the mentally retarded. Six other children are deaf-blind. They are between six and 13 years of age.

Until now only one boy of them can be called a real schoolboy. Another boy is a day child. That means, he lives in Potsdam. Every morning he is brought by his mother and taken home in the afternoon. It is nice to see loving mother-child relationship. No holidays, no weekend, can give a child so much of normal family life as to be at home every day, for at least several hours.

I'm new in the work with deafblind children. I can tell nearly nothing about this field. I myself have a lot to learn.

One of the first goals in my new job was to change living and learning conditions for the children in our deaf-blind home. Lots of problems between old and young, old and new. This change to make it better for the children, only was possible by restraints for the deafblind adults.

A further problem is the reception of children. I think, it's too late when they come at the age of five or six years. At this age they already show a lot of abnormal behaviour. I think it would be much better if they came earlier. Maybe, we have to go with a baby-carriage then. But, don't the children suffer from isolation, from being separated from their family? I want to know your experience, your opinion.

> Rita Mietz Oberlinhaus Centre of Rehabilitation for Handicapped and Deaf-Blind Potsdam-Babelsberg, East Germany

# **Another View**

John McInnes, Chairman of IAEDB, interviews a young deaf-blind man on his hopes and ideas.

Paul Blais is a deaf-blind young man living at 360 Grey Street. He shares an apartment with Steven Kato another deaf-blind young man. Paul has no vision and a moderate to severe hearing loss when aided.

#### Where did you go to school? At the W. Ross Macdonald.

What kind of a school is that? It is a school for the blind.

How old were you when you started W. Ross?

Where were you before that?

Cedar Springs.

What was Cedar Springs like? Kind of a rough place to be living. They treated you like mentally retarded.

How long were you at Cedar Springs? Eight years.

#### How did you get to go to W. Ross Macdonald School?

I had a very fine teacher at Cedar Springs who fought very hard to get me out of Cedar Springs to W. Ross.

What was the difference between Cedar Springs and the deaf-blind unit at W. Ross Macdonald School? I would say the difference was at the blind school you had more freedom to take part in different things. If you wanted to go to the gym at night you could do that or swimming. At Cedar Springs you couldn't do all that.

# What do you do for work now Paul?

I work at Wood 'N Things – a store that I help to run, where I go and do furniture refinishing or make napkin holders and clocks.

Who else is there with you? Annie Mack and Helena Rooyakkers and Debbie Wardle.

Annie Mack is deaf-blind too. Are Helena and Debbie intervenors? Yes

When you say that you make napkin holders and finish things and refinish furniture, who decides what you are going to do? I work it out with Helena and decide for instance that this time of year is the busy time so lets get the ducks done for the people to buy for Christmas The slow time of the year pick up and work on whatever there that needs to be done.

#### Does Annie make decisions about the things she is going to do?

Helena and Annie talk it over together, I think Annie is starting to make some of her own decisions on what she thinks should be done.



Paul Blais working at Wood 'n' Things

#### What do you think you have learned since you started working at the store?

Well, I have learned how to look after the customers. How to figure out sales tax and make sure they get the right amount of change back and everything else.

# Why did you learn to refinish furniture?

I used to live in a foster home in Wallaceburg and I learned furniture refinishing while living in a foster home.

# How do you know how much to charge somebody for refinishing their furniture?

If I'm lucky, sometimes John Tripp who is a professional furniture refinisher comes in and gives me a suggestion of what the price should be, I estimate how long it will take me to finish the job.

What kind of things do you look for before you make up your mind? Is it worthwhile doing or is not worthwhile doing. For example, a customer brought in a frame this week that looked like wood but is was all plaster around the front. I said I am not going to muck around with this.

#### Why did you say that Paul?

I believe I had a frame once before that was a glaze like finish that had the black paint on it and we had to be super careful.

What else have you learned?

How to keep records or what has been sold and what hasn't been sold and how to order certain supplies such as ducks. How to estimate how many should be ordered and how to do night deposits, that is one thing I almost forgot.

# Does the store only sell things it makes?

No, we sell other things on consignment.

What do you mean by being on consignment? That means that the people will bring goods in and they would tell us what to charge so they get the money back. We get 25% and they get the other 75%.

# What do you thing you will be doing 5 years from now?

Hopefully, in 5 years from now I will try and get into radio broadcasting.

# That's interesting. How will you go about doing that?

I am thinking of completing schooling and probably go to college. Unless I could take

a night course through college for radio broadcasting, I don't know. Something I have to check into and see.

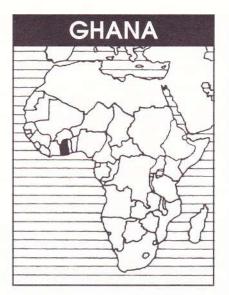
#### Do you see any problems you might have to overcome if you want to become a radio broadcaster?

Well, I know it would take a great deal of patience. The one thing I would have to do is have everything all brailled out. I wouldn't be able to read the sighted commercials, if I want to read the commercial it has to be done in braille.

If you don't become a radio broadcaster do you see any future in the store itself? Oh I think so, probably store manager or whatever.

#### Is there anything else you have to learn to be the store manager?

How to interview people. How to hire them and decide who should be hired.



The centre for Deaf-blind children at Mampong-Akwapim, Ghana, is part of the Demonstration School for Deaf Children. The Head of Centre, Miss Marion Obeng, has sent us these photos.



Two deaf-blind children with their housemother at a Christmas Party.



Classroom activities in sensory training.



Kwesi Owusu-Ansah, the senior pupil of the deaf-blind centre, among deaf children at the Demonstration School.

# Goals to achieve when working with the Deaf-Blind:

# **Communication** with the Child

Lucy Lugonzo has successfully established a service for deaf-blind children in Kenya. Here she talks about what she believes to be some of the most important principles.

Communication with the child is possible in every possible way, smiles, pats, nods, finger frowns, natural gestures, signs, speech, pictures, writing and finger spelling.

Try to be expert in the mode of communication used by the child in your care. Follow the directions of the child's teacher in regard to the development of language and communication.

#### **Parents**

Communicate understandably and professionally with the parents of the children. Take care that you realize and have consideration for their feelings. They may have, for example, frustration, hope, pleasure, anxiety. Try what you can to develop their confidence in you, not only as a warm caring person for their child. This point goes to care takers whom they can trust and respect. Write some letters to the parents who live very far from school.

Talk about their progress and the activities the child has done, whether they are of help or not. If a parent happens to visit the school, discuss problems concerning their child, together with the caretaker. It might be that the child has improved in sign language or clothing etc. The matter should be treated in a calm way. The staff caretakers should study the characteristics of the child.

Teacher and caretaker should work very closely if they want the child to be successful from morning until the time the child



goes to bed. The teacher and the caretaker can use the activities in the school compound and the child's experiences in the living unit as material for language development during the lessons.

If we want to achieve the goals of teaching deaf-blind children, we need more time in meetings concerning the individual child. Always give love to the child, learn all you can through discussions, observations, reading and getting as much as you can from parents.

With best regards, Happy Christmas and New Year

> Lucy Lugonzo Assistant Teacher Kabarnet School for Deaf-Blind PO Box 128 Kabarnet

# **Deaf-Blind Education**

Deaf-Blind 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 deaf-blind children and young adults. Photographs and drawings are welcome; they will be copied and returned. All written material should normally be in the

English language and may be edited before publication. It should be sent for publication to arrive by mid-January and mid-July for the first and second annual editions.

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

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