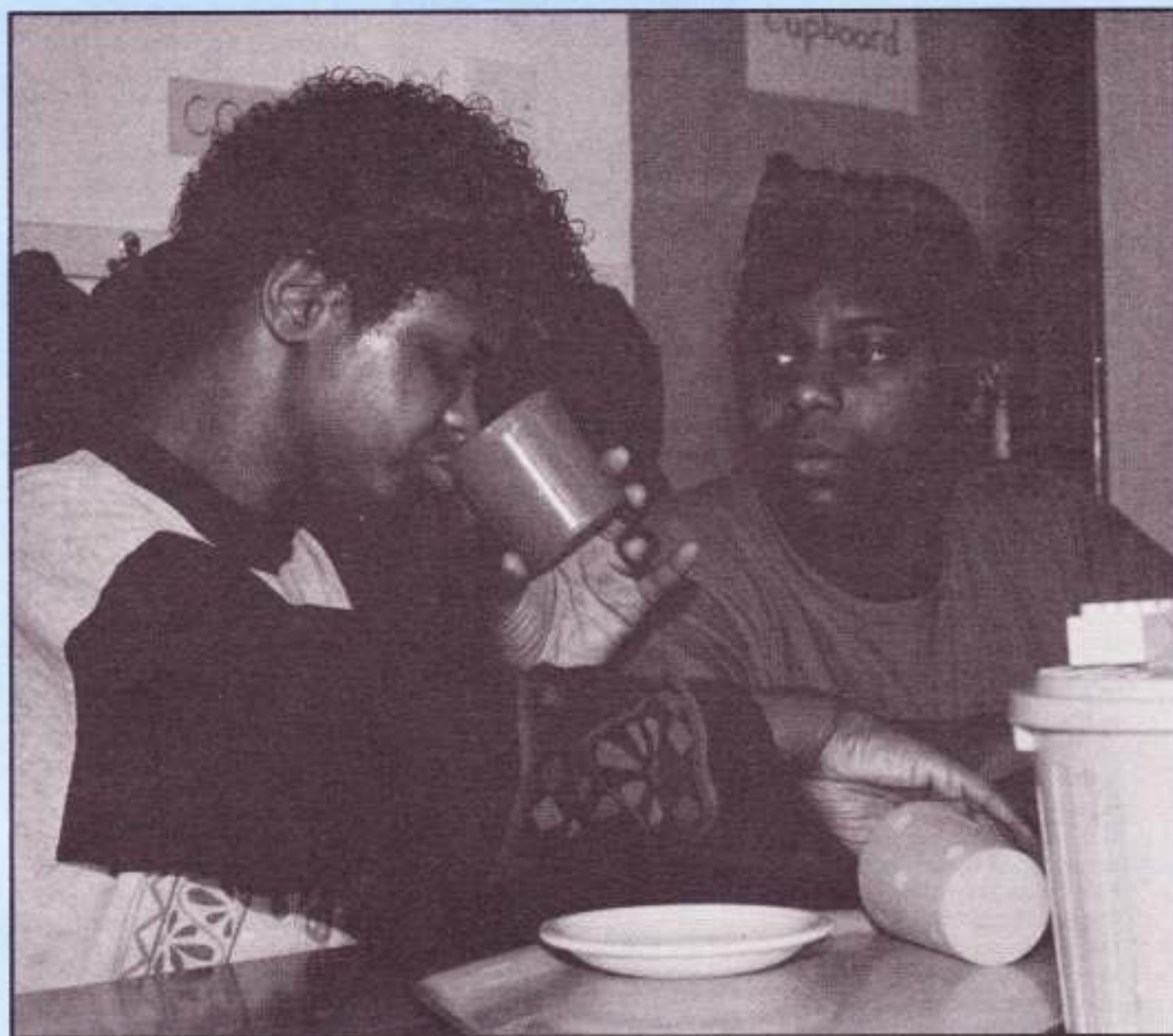


# Deafblind Education

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

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**Congenitally deafblind adults**  
– principles for a quality of life



I A E D B

## CHAIRMAN'S REMARKS

As most of you know, the last executive meeting of our Association took place in the United States in April. All the participants were hosted in the Perkins School for the Blind.

We are very grateful to Kevin Lessard, Mike Collins and the Perkins staff for allowing us to be together in a place known all over the world because of the Helen Keller and Ann Sullivan story, as well as for its support to many developing programs for the Blind or the Deafblind.

As decided during the previous executive meeting, a two day symposium on post-school services for the congenitally deafblind took place before the business meeting.

This symposium had been very well prepared by a committee (Anne Nafstad, Bob



Snow, Barbara Mason, Klaus Wilhemsen, Jean-François Guerineau and Gini Cloke) which chose lecturers and distributed and processed a questionnaire geared at getting a feed-back from all parts of the

world. Thanks to the work achieved by the symposium, the executive meeting was able to agree on a position statement about the principles which should be the basis for the development of services for congenitally deafblind people. Everybody agreed on the fact that the symposium was a success. It is a new way of working together at an international level and to support initiatives for the benefit of the deafblind.

It was decided that the next executive meeting could take place in Poland, and that the theme of the symposium should be deafblind people with "emotional disturbances".

**Jacques Souriau**

## EDITORIAL

This edition of Deafblind Education has as a main topic quality of life for congenitally deafblind adults. We include the results of a questionnaire on this subject, some of the papers presented at the recent seminar held before the IAEDB Executive meeting in Boston, and the paper produced at the meeting from the work of the different workshops. The next issue will include two further papers from the seminar. Our thanks to Anne Nafstad and the other members of the subgroup who prepared and analysed the questionnaire and organised the seminar. Also thanks to all those who contributed both on paper and at the meetings.

The seminar was very stimulating and useful for the participants and hopefully the outcomes such as the document



included in this Deafblind Education will be of use in many countries. The IAEDB plans to hold other seminars on important subjects with the aim of producing material that will help the promotion and development of quality services for deafblind people.

A new development discussed at the Boston Executive meeting is the European Staff Development Unit. The Unit is producing a newsletter and as an experiment we are including it within Deafblind Education.

Also in Europe the conference in Potsdam, Germany will introduce new friends and colleagues from Europe to IAEDB. Planning is under way for the next IAEDB World Conference to be held in Argentina. Of course many people will not be able to be at these conferences. I hope that you will use Deafblind Education to keep in touch, exchange news and discuss developments in deafblind education.

Our very best wishes.

**Malcolm Matthews**

# Awareness seminar on deafblindness

**Athens 3 - 6 March 1993**

During the IAEDB's Executive Meeting in 1987 in London, we wrote a list of countries where we had no contact-person. Greece was one of them. Since that meeting, a big change occurred: a seminar on Deafblindness, held on 3rd to 6th of March in Athens, gathered 300 people. This event happened because Mrs Karanicola, step mother of a deafblind child, and Argyro Raptou, blind teacher in the Elementary School for the Blind in Athens (KEAT) got in touch with French professionals. They informed them about a group of people wishing to develop a program for the deafblind in Greece. Helios Money was applied for supporting that project.

In March 1992, two French professionals went to Greece (Dominique Bonneau, geneticist, paediatrician, and Jacques Souriau) in order to carry out a project mainly planned by Frosso Zafiri (a Greek psychologist, working in a preschool centre for the Blind): assessment of deafblind children, meetings with families, conferences, discussions and interviews with professionals and members of the central administration.

## Awareness seminar

In December 1992, 3 Greek professionals went to Poitiers for 2 weeks for a visit and a short course.

In the same period of time, in October 1992, a Greek association of families and friends of the deafblind was set up. This association raised money in Greece in order to organise an Awareness Seminar in March 1993. The KEAT (Centre of Education and Rehabilitation of the Blind) took over the responsibility of this event. The program was decided on by Frosso Zafiri, Eleftheria Blaxogiannaki, Jacques Souriau and his staff.

This seminar was strongly supported by the Department of Special Education, the schools for the deaf and for the blind, the universities, and many individuals



(friends, professionals and families).

It was decided that the seminar should take place in a hotel, in order to make it more open and to draw general public attention. The purposes were to motivate the department of Education, to stimulate special interest from the professionals, and to show the necessity of a policy for the deafblind in Greece.

The Seminar actually took place from 3rd to 6th of March 1993 in Athens. 300 people came together: teachers for the Deaf and for the Blind, social workers, specialised educators, psychologists, specialists in sign language, professors of the University, deaf and blind people, etc ... For the first time in Greece, the world of the deaf and the world of the blind met. The press coverage was very good (the main TV channel reported about the seminar). Professionals came not only from Athens, but also from the main other big cities (Thessalonique and Patras). Key persons from the Departments of Education and Welfare attended the meeting. The interest of most of these people was very high. The main topics were:

- History of the programs for the deafblind (mainly in Europe);
- Definition and demography;
- Psychology of deafblindness;
- Communication;
- Individual Educational Planning;
- Specific approaches (pictographic communication, mimicry);
- Cultural aspects of deafblindness.

Jacques Souriau and his staff lectured (G. Gimenes, M. Souriau, R. Gimenes).

## Stepping stone

This event seems to be a stepping stone for future plans:

- Staff development: visits to different centres in Europe and organisation in Greece of a basic course on deafblindness (maybe this course could be arranged in collaboration with the European Coordinating Unit).
- A meeting of the schools for the Deaf and for the Blind in order to make a decision on which kind of dactylogy should be used in Greece.
- An inquiry about where are the deafblind people would allow to evaluate the services needed.
- School provisions for the deafblind in connection with the schools for the Deaf and for the Blind.
- Sheltered workshops: very few deafblind adults have a place where to work at the moment.

On the whole, it seems that very positive things are happening in Greece, which will be a very good opportunity for developing European Cooperation.

**Effrossini Zafiri  
Jacques Souriau**

# 3rd international Cochlea-Implant conference

Innsbruck April 4 - 7 1993

Three hundred delegates representing thirty-two countries met in the Congress House in Innsbruck for the 3rd International Cochlea-Implant Conference.

Four different types of implant were exhibited and there was a presentation on one other. The majority of UK implants are made by the Cochlea (Nucleus) Company, but a growing number of Smith/Nephew and Med-el devices are in use. There was much discussion on the inter-variability of these products, a project at Iowa University comparing implants is due to come out soon. A package containing the implant surgery and rehabilitation in the UK cost approximately £25,000 each. It is hoped that once competition between the companies picks up, this price will go down.

It is now accepted that implants are an effective strategy to use in deafened adults and children. They provide enough coded signals to be relayed up the auditory nerve to be interpreted as speech. They may, in some cases, give enough information to enable people to use them for telephone communication and some people find they still retain a musical appreciation. Those children who are born deaf or have become deaf very early in life do not have, or have a limited memory of speech sounds, so have to learn the meaning of sounds after they have been implanted. It takes them much longer to understand and use speech, but they are capable of using sound meaningfully and there were reports of some of these children reaching normal language acquisition for their chronological age. It is accepted that these children may not understand speech until 5 years after implantation. This, of course, is much better than with any hearing-aid.

## Deafblindness - implantation in children

There were a number of presentations on deafblind implantees and a few anecdotal reports. A pre-verbal Spanish child, three years old at implantation, is now recognising speech sounds and uses these as his main form of communication. A congenitally completely blind child in Iowa (L.T.) who was deafened by a bout of Meningitis, is also recognising speech, without lip-reading, five years after implantation and his case has been reported in a recent ASHA Journal. There is no doubt that implantation in these cognitively able children has prevented them becoming extremely highly dependent, handicapped deafblind individuals.

The Iowa child (L.T.) was reported as not being responsive to sound, withdrawn, combative and insecure. His social and developmental skills regressed and he was only at ease in a structured environment, which was familiar to him. He interacted in a limited way, generally with only one person at a time. Two years after his implant he could correctly repeat 54% of actual words and 76% of phonemes. He uses intonation in his speech and prefers speech to gesture. He can now answer who, what and where questions. His language development is still delayed, but he is still improving and hasn't "levelled off". He is far more outgoing and interacts with people much more and is a happier child.

## Implantation in deafblind adults and teenagers

Manchester has a great deal of expertise in this field. They gave a number of papers on types of patients and rehabilitation. One on the use of the telephone was



particularly outstanding. Some implantees are able to have conversations over the telephone - a skill never achieved by those with a comparable deafness who wear hearing aids. Manchester would like to extend their service to deafblind children in the near future.

The largest Usher Syndrome Group\* of implantees are in Melbourne, Australia and a Group in Holland has just secured funding to implant more Usher syndrome clients.

## The future?

As more companies grow, then the monopoly held by the Nucleus Company will erode. Different coding strategies and more 'user friendly' equipment will mean there are more options open to Audiologists.

As time goes on, more and more clinicians will be willing to "move the goalposts" and selection criteria will inevitably be expanded to include groups who have other special needs, such as blindness and physical impairments.

How an individual's quality of life is enhanced by wearing an implant is difficult to measure. Implants are expensive, but what price can be put on hearing the birds again? Cochlea-implants are here to stay.

## Rose Hays Rehabilitation Audiologist May '93

\*Usher syndrome is an inherited condition which manifests itself in various forms of sensori-neural deafness and progressive Retinitis Pigmentosa, causing blindness.

*Cochlea Implant use by a child who is Deaf & Blind ... A case study.* Holly Frynauf - Bertschy et al. AJA March '93, 38-47

# Integration

The topic of Integration is a difficult one for me to address because I am not quite sure what the term "integration" means. In 1980 I was given the opportunity to head up a team to develop support services for the integration of deafblind infants and children into their home communities in the province of Ontario. By 1984 the mandate was enlarged to include congenital and early adventitious deafblind youth and adults. It is because of the many examples and definitions of programs and support services with the label of "Integration" attached that I am not sure what it means.

The term seems to have a variety of meanings depending upon whether it is being used by officials from the fields of education, social services, health, housing or local government. In most cases when the term is used by educational officials they are referring to which class the child is registered in. When used by other bureaucrats it seems to mean where the individual lives. This has been particularly evident as governments close institutions for mentally, physically, and sensory challenged individuals. These individuals are considered institutionalized or integrated according to where they live or what is politically expedient. In one well-documented case a house with two handicapped individuals receiving government support was considered a mini institution (group home) and could not be located within 500 meters of any other such setting. The same situation in another case will be held up as an example of integration.

## Two examples

Perhaps two other examples will better illustrate my dilemma.

Several years ago, I was requested to aid a local government to develop services for several congenital and early adventitious deafblind adults who were graduating from education. After two weeks they had established the framework for services and began to implement it.

The local government officials wished to show me that they had excellent programs in place to integrate individuals with other handicaps into their local community before I left the area. Government representatives of the Social Services Ministry and I



**John McInnes (above) is a past Chairman of IAEDB and a leading figure internationally in deafblind education. This paper is his presentation to the Boston 1993 IAEDB meeting.**

travelled by car approximately 100 miles to see a young blind man who was living in "his" own home.

The young man was totally blind with no other significant handicaps. He was gifted in music and had a large repertoire of piano pieces memorised. He lived with a young husband and wife team of social workers who were paid to provide support as part of their professional responsibilities.

During the more than four hours I spent in this integrated setting the young man never was able to complete an answer to any question I asked him because one or other of the non handicapped adults jumped in to complete his answer. I asked if he would play the piano for me. He began to play a selection of pieces (loud, rhythmic, and contemporary). He was stopped and told that he might play parts of three pieces named by the non handicapped staff with the comment "He'd play the piano all day if we let him."

During lunch he was told what and how much he could eat and drink and when finished to go to the bathroom before changing his shirt for the one that they had laid out for him. When I suggested that there were techniques that he could learn to pour his own milk and organize his own clothing, I was told that it was not necessary and would only further complicate his life.

He may live in the community but he represented one of the worst cases of institutionalization I have

ever had the misfortune to see.

A second case comes to mind that further increases my confusion. I know of a gentleman with whom most of you are familiar. He has lived in an institutional setting for more than ten years. Individuals sharing his accommodation influence and sometimes make decisions for him and most of his work is done without leaving the institutional setting.

His name is Mr. Kevin Lesard and he is the Director of Perkins. He is fully integrated into his family, professional and social groups at the local, national and international levels.

The only conclusion that I have been able to reach is that:

**It is not where you live, but how you live that defines your level of integration into society.**

The number of congenital and early adventitious deafblind adults sharing accommodation or living in proximity of each other does not seem to be a significant factor in promoting or preventing integration unless it is used as an excuse to institutionalize the use of staff. During the last few years I have had the opportunity to visit many programs for congenital and early adventitious deafblind adults. While I hesitate to identify individual programmes, such as those found at Minibro in Alberg, Brock House at Birmingham, the programs in Hanover and Ontario are excellent examples of individuals in multiple unit settings who have a degree of freedom and ability to control their own lives that is in keeping with that exercised by the general population.

You should be aware that certain basic assumptions underlie and influence my comments. The most influential of which are my perceptions of:

- the dignity of man and his right to self actualization regardless of his or her level of functioning.
- the need for the availability of support by another human being to permit each individual deafblind person to seek self actualization.
- the effect of Multi-Sensory Deprivation (the reduction or loss of non distorted information from the distance senses of sight and hearing) on learning and development.

The first two topics have been more than adequately addressed elsewhere in Deafblind Education. The third topic may need some further elaboration.

In the late 1960's and early 1970's much thought and energy of those working in with congenital and early adventitious deafblind infants and children was directed toward generalizing a definition of what was meant by the term deafblind and the investigation of how it affected development in areas such as communication, motor development and living skills. While it is often stated in different ways, a consensus appears to have developed that defines a deafblind individual as one who has a severely reduced capacity to receive non distorted information through the distance senses and who may, or may not, have additional handicaps.

In the last few years, we have begun to work with congenital and early adventitious deafblind adults who, as infants and children, have been in excellent programs designed to ameliorate problems arising from deafblindness and to support their growth and development. We can no longer blame present shortcomings on inappropriate treatment during the early stages of development.

These congenital and early adventitious deafblind adults with whom we are now working have basic skills but often appeared to be immature, naive, lack adult social skills, and may exhibit unusual behaviours which can appear to prevent their successful integration into society. It has become obvious that it is not sufficient simply to look at what should be learned, but also to investigate how multi sensory deprivation effects learning.

## Learning

There are many theories to explain learning. However, when you narrow the query to how information is obtained from the environment there does appear to be some basic agreement.

Information is obtained by the average non handicapped individual from three types of sources. Primary, or direct learning; Secondary, or learning through formal and informal exchanges of information; and Tertiary learning, that which we absorb from the environment without conscious, directed effort. Additionally it is stated that between 8 and 12 percent of our accumulated knowledge is learned at a primary level, between 10 and 20 percent at a secondary level, and the

remaining 70 to 80 percent at a tertiary level.

The implications for what we teach and how we work with congenital and early adventitious deafblind infants, children, youth and adults is monumental. Congenital and early adventitious deafblind persons of any age do not spend a great deal of time observing and absorbing what is happening about them when it has not been directly brought to their attention. We must compensate for that seventy to eighty percent that the non handicapped person learns at a tertiary level when designing programs. In addition special provisions must be made to promote learning in formal group instructional sessions and to promote discussion and interaction in informal settings. All this must be in addition to the excellent job that most programs do in supporting primary learning experiences through the use of techniques specifically developed for working with congenital and early adventitious deafblind persons.

A paper on Integration is not the place to pursue this topic in further detail. It is however, necessary to consider briefly what types of learning is affected. Some educational psychologists such as Benjenime Bloom have classified learning as falling into three domains; cognitive, affective, and psycho-motor. Put more simply - knowledge, attitudes, and skills. Learning in each of these domains is profoundly influenced by the reception of distorted and/or limitation of information concerning the individual's interaction with the environment. The reduction or elimination of a continuous stream of non distorted information will greatly reduce the ability to learn effectively in each of these domains.

Some areas in which the need for specialized training may be overlooked when developing and promoting an integrated environment include decision making, personal control and interpersonal relations with staff and others. Each of these areas exist on a multi level continuum. One level is influenced by the age of the individual, another by the individuals interaction with society and a third by society's expectations of him or her. It is an interactive, multi level continuum because there are few, if any, clearly defined stages with sharp divisions between them and because what is learned as appropriate is influenced by society's general view of age appropriate behaviour and also society's view of the handicapped person within it.

## Decision making

Decision making is a skill that must be learned. The decisions which will be made will be influenced by what you know at the time when the decision is made and the attitudes that you think important people in your life hold and by what you think is acceptable, or to use the current phrase, politically correct, towards the results of any thing you will do as a result of the decision.

Non handicapped individuals rarely make decisions without recalling the past experiences of themselves and others. They may discuss possible alternatives with friends; take courses, pay professionals for advice and conduct polls prior to making decisions. You and I can take courses to prepare us to make financial decisions, buy a house or car and even on how to choose a mate. These courses are designed to supplement or modify the information, attitudes and skills that we have acquired each day of our lives.

The skill of decision making must be taught to the congenital and early adventitious deafblind person as he or she grows up in a carefully developed program that is designed to compensate for the lack of secondary and tertiary learning and the severely reduced amount of feedback received about the results of decisions made. Decisions must not stop at "milk or juice". The importance of the decisions must proceed to, and beyond, what type of work will be undertaken and social relationships formed, with whom they will be formed, which individuals will provide support for day to day activities and when the activities will be undertaken.

The ability to make decisions implies

- an understanding of the results of a decision,
- the ability to carry out the decision,

and

- an understanding of the responsibilities incurred as a result of making and carrying out a decision
- as well as the ability to decide if the results of your actions are satisfactory.

Before you indicate that this is fine in theory but you work with congenital and early adventitious deafblind adults labelled "low functioning" I will add so do I. I will also point out to you that Burner states emphatically that you "can teach anything to anybody at some

level in an intellectually honest manner". The challenge each of us faces as professionals is to constantly teach decision making skills and to continually seek to turn over more and more of the daily decisions to the congenital and early adventitious deafblind adults with whom we work.

If we need assistance to develop our decision-making skills, do not our congenital and early adventitious adults need even more, and do we not have an obligation to provide it? Most professionals attending this seminar will agree that we should at an intellectual level. It is because the ability to make decisions implies the ability to take control of the situation that there is often some reluctance to go beyond "milk or juice".

## Control

As we encourage the congenital and early adventitious deafblind adult to make more and more important decisions and to accept more responsibility for his or her life, we must consciously also turn over control. The ability to make and carry out decisions and thus to take control of his or her life is not something that can suddenly be thrust upon the youth or adult simply because they have changed the location in which they live. Nor, is it something that can be given and taken away at the whim of some higher authority.

The ability to exercise control infers both responsibilities and limits for all of us and these, like those of decision making, are influenced by both age and social expectations. They change according to many factors including the role we are fulfilling at the moment, the people we are interacting with and the expected outcomes. The congenital and early adventitious adult cannot gain an understanding of these responsibilities and limits as we do through tertiary learning supplemented by a few formal instructional and informal "bull" sessions. They must be taught, not caught.

This transfer of control takes place on a limited basis in many programs and on a broad basis in a few. In most programs areas of real control are avoided or given up grudgingly to congenital and early adventitious deafblind clients. I would encourage you to examine your individual programs to identify the degree to which your program structure supports the turning over of control to the deafblind client and/or his or her advocate.

## Programs

The development of the content, the strategies of implementation, and the methods of evaluation of the client's individual program must be the property of the congenital and early adventitious adult and/or his or her advocate. We have a duty and an obligation to offer the best advice, outline all the alternatives and support the decisions of the client or advocate.

We do not have the right to assume control of the person's life. Our responsibility is to obtain informed consent before we begin to implement a program and to assist the client or his or her advocate to evaluate its success. If the client or advocate does not have sufficient information to give such informed consent or to make the evaluation then we have a professional responsibility to supply it in an understandable form.

In the approach we use, the individual program's goals are written in terms of 5 year Goals and 12 month objectives. Once the program has been approved by the congenital and early adventitious deafblind adult and/or his or her advocate, the next step is implementation. This has two distinct parts. What activities will be undertaken and who will provide the intervention necessary to permit the deafblind adult to carry out the chosen activities.

Through the use of a variety of well known techniques, it is both possible and desirable to have the deafblind adult choose both what activities they wish to pursue and when they plan to do them. Most programs provide this type of choice. The major differences among programs seems to be in the response to the situation when a congenital and early adventitious deafblind adult indicates that he or she does not wish to engage in the activity at the time indicated on the plan.

The specific response to this situation often gives a clear indication as to the individual intervenor's perception of his or her primary role. We feel the intervenor's role is to support the deafblind adult and in supporting him or her ensuring that he or she is aware of the realistic alternatives available at this time and of the probable consequences of the actions that he or she has decided to take.

The number of options open to the deafblind adult will vary according to a number of things including his or her level of functioning. It can never be viewed as appropriate to force the deafblind

adult to partake in a particular activity simply because "it is in the plans". If a particular alternative is desirable but not viable for a specific individual at this time, it is our responsibility to develop a program that will make it so regardless of the length of time that it will take to reach that goal.

## Staffing

Each of us choose who we prefer to have as a companion when pursuing a chosen activity. In the work place, we probably have the least amount of choice and flexibility. Even there we can exercise a degree of choice. We exercise a far greater control when choosing a friend with whom we will participate in specific recreational pursuits or carry out maintenance activities such as shopping. This ability to choose and control is important to us as a integrated member of society. It is possible to permit the congenital and early adventitious deafblind adult to learn to exercise these same options.

You must decide whether the approach to supporting the congenital and early adventitious adult will be paternal, co-equal or master-servant in approach. If the approach is to be anything other than paternalistic then the approach must accommodate and promote the ability for the deafblind adult to have the amount of control over individual relationships that is available to the general population.

The approach that is used to integrate the congenital and early adventitious deafblind infant into the family works equally well with adults. The primary caregiver [usually mother] establishes routines and bonding with the infant. As the child develops individual family members are integrated into the routine as it expands. Father is initially identified with specific activities as eventually are other family members. Once the infant begins to show anticipation of different activities according to the person interacting with them then some switching can occur. Family members become individuals with their own personalities and relationships with the deafblind infant.

When staffing programs designed to support integration for congenital and early adventitious deafblind adult, the same sequence should be provided. The following sequence has proved beneficial in our experience. Unfortunately, in many programs, the sequence is aborted after the second step.

- 1 The intervenor establishes a bond with the client.
- 2 The client makes choices of activities and of the order in which they will be carried out with the intervenor.
- 3 Additional intervenors are introduced to carry out specific activities, usually outside of the core group of activities.
- 4 Individual clients are encouraged to choose which intervenor they wish to have accompany them for leisure and recreation activities.
- 5 Individual clients are asked What activity that they wish to do When and with Whom. When the choice is made the client then negotiates with the intervenor for the intervention services.

The term "negotiate" encompasses an extensive range of knowledge, skills and attitudes that must be carefully developed within the activities through the support of the client's primary or "key" intervenor. This type of learning will never cease. Just as you and I continue to learn new social skills, modify attitudes and recognize trends, the deafblind adult must have the same opportunity. Regardless of the excellence of the program, each congenital and early adventitious deafblind adult will continue to be limited in the new learning that can take place unless human support is available to supply immediate feedback and dialogue.

- 6 Individual clients extend their ability to "train" their intervenor. "Extend" because usually, starting in the area of communication, such ability should have begun when the client was a child and must continue until the client can show an intervenor, in a non offensive manner, how to support him or her as they carry out the tasks of daily living.
- 7 Individual clients participate in staff hiring and ongoing program planning.

We have attached the label of "Supported Independent Living" to the whole concept. One of the most important outcomes of the application of this concept has been that when staff view the congenital and early adventitious deafblind adults as clients with their own range of individual abilities rather than "charges" and view their underlying objective as being to make their client as independent as

possible we have found little difficulty in building a client's feeling of self worth.

## Problems

The following represent some of the problems that seem to continually rear their heads as we establish adult programs for congenital and early adventitious adults as they integrate into the community.

- 1 Educating the planners that transition to living as a congenital and early adventitious deafblind adult in an integrated setting encompasses three separate things, each of which must be programmed for if successful integration into the community, as distinct from simply changing where the deafblind adult will live is to take place.
  - change of location
  - change of people (friends, companions and intervenors)
  - change of lifestyle patterns
- 2 Recognition that existing support systems for other handicaps (including those designed to meet the needs of the adventitious deafblind) will not provide adequate support for the congenital and early adventitious deafblind adult.
- 3 Too great a focus on communication expertise rather than on the total ameliorating the problems caused by vision and hearing may result in a staff far better suited to meet the needs of a deaf client than the needs of a congenital and early adventitious deafblind client.
- 4 A recognition by bureaucracy that success for the congenital and early adventitious deafblind adult requires human support to facilitate the deafblind adult's integration into society. Successful integration is not represented by a congenital or early adventitious deafblind adult abandoned in an invisible cell of sensory isolation, repeating mindlessly the daily routines of existence. Existing is not integration.

## Variety of support structures

When interacting with representatives of social services in Canada, there is almost a fanatical devotion to the notion that not more than a specific number of handicapped individuals (usually 3 and always under 10) be allowed to live in one setting. When this is

applied to the congenital and early adventitious deafblind, it completely ignores the nature of the handicap, the concept of freedom of choice and realistic financial considerations. Our experience has shown that no one specific organizational structure or staffing pattern provides a distinct advantage over another as long as the pattern provides for integration as it is described in this paper. When appropriate intervention has been available, we have successfully used all of the following *when appropriate levels of intervention were available*:

- 10 or more congenital and early adventitious deafblind individuals living in a residential setting.
- four to nine congenital or early adventitious deafblind individuals living in a group setting.
- one to three congenital or early adventitious deafblind adults living in a house or apartment as a small group.
- one congenital or early adventitious deafblind adult living with his or her family as an adult with shared responsibilities within the family.
- one congenital or early adventitious deafblind adult living with non handicapped peers who provide intervention in non scheduled hours.
- one congenital or early adventitious deafblind adult living in his or her own apartment with scheduled intervention from individuals who live elsewhere.

## Conclusion

Integration is not where you live but how you live and relate to the world about you. As professionals we have a responsibility to continually provide and encourage the stretching of personal control of his or her life for each deafblind person. We must not set some preconceived limits for either bureaucratic or other reasons beyond which we assume that the individual cannot progress. Our assumptions must form goals toward which we strive, not limits which we cannot exceed.

Even the most successful congenital and early adventitious deafblind adult will continue to need human support throughout his or her life. It does not matter whether we call that supporting person an intervenor or by some other name as long as their role is clearly defined and their goal is to foster the growing independence of the congenital and early adventitious deafblind adult.



Not all deafblind children will reach adulthood, yet death is seen as something of a taboo. Walther Tibosch, of the Instituut voor doven in the Netherlands, offers guidance on supporting the terminally ill deafblind child, and on comforting relatives, carers and staff.

# Within the limits of education

## A contribution to inner growth

Children who are very ill can die. Fortunately this comparatively does not occur often. Parents, teachers and staff seldom bear this in mind. Matters stand differently when the diagnosis shows clearly that we are talking about sick and dying children. Against knowing better one still hopes against hope for a miracle, but soon it is obvious that a fatal course is possible or probably unavoidable. The progress of medical science has led to great improvements concerning these illnesses. Children who used to be "doomed to death" now sometimes stay alive longer than was assumed until recently.

"The Instituut voor doven" is asked increasingly to educate children with a limited perspective in life. The admission of these children puts great demands on all fellow-workers involved in the guidance of and the co-operation with the child as well as the parents. More is demanded than know-how, dedication and experience.

Suddenly death seems nearer in one's own life. The limits of one's own existence seem tangible, just at the moment when so many answers are expected to various difficult questions. The intensive process in death support and loss experience begins, in which it is not just the dying child who needs attention but also the relatives and staff who take care of the child on a daily basis.

In this article I want to talk about the support offered to those who are professionally involved in the last phases of life of sick and dying children.

## Five phases

Work on the subject of sick and dying children is still fairly recent. With the book published in 1969 "On death and dying" Elisabeth Kübler-Ross has made a significant contribution in gaining more insight

in to the process of dying and the support of loss-experiences. Her merit especially lies in her approach to the dying and in creating surroundings which invite the dying and their relatives express their fears. Kübler-Ross distinguishes in the processes of dying some specific behavioural characteristics which can be globally expressed in five phases: denial and isolation, anger, negotiating, depression and finally acceptance.

These are the phases which can more or less be applied to all kinds of human situations in which huge misfortune, losses and disappointments must be coped with. These are the phases which relatives and other close friends of the dying also experience, during the process of dying.

These phases can be successive, alternate and coexistent.

## Step by step

In the Dutch situation these phases have a preceding phase of ignorance and uncertainty. After the diagnosis a period follows in which the child itself gradually discovers the truth. Dutch doctors seldom choose to confront children abruptly with reality. Finally telling the truth is part of the support of me dying. Bringing out "the message" is one of the first subjects which has to be discussed by the staff, teacher and a still to be formed multi-disciplinary team.

In all phases, it is less important for the staff to give answers to the many questions, but to listen to them. It is important for the sick and dying child that it has the feeling that it is being heard. Often questions are answered by the child who poses them, or the answers are more or less known. It is a process of following, not of controlling.

The phase of ignorance and insecurity is filled with great doubt. All professionals involved with the sick and dying child are inclined to spare the child and in so doing to suppress all their own feelings of

grief, fear, aggression and so on. Support must be focused on giving these people the chance to vent their feelings and emotions.

The ignorance which begins this phase gradually makes way for uncertainty. In this phase the sick and dying child is inclined to withdraw from reality and to deny the seriousness of the syndrome. The staff will often have to be lenient with the denial, provided that the negation of it does not go too far. The full truth cannot be coped with yet.

When the truth becomes increasingly obvious, the phase of rebelliousness and protest comes next. This anger is directed at people close to the child most of the time. Nothing and nobody seems right any more. It is important for the teacher and counselling group to know that the protests of the child and its parents are not directed at them personally, but at the situation.

This makes it easier for them to show the parents and the child that they are respected and understood, despite their anger and despite their reproaches.

The protests gradually die down and the phase follows in which a compromise with God or life is achieved by negotiation. The child tries to preserve life or at least tries to postpone dying for a while by making promises or vows. This helpless struggle gives the counsellors a strong feeling of abandonment and sadness. Gradually they realise that they have to continue life alone. Sometimes this period is marked by a feeling of guilt.

It is important to let teachers and staff know that they can talk about these feelings and that they are a normal part of this intensive guidance process.

When the child realises it is going to die of its illness, a feeling of terrible and definitive loss comes about. It is not only the child who develops this feeling but also relatives, staff and teachers. In this

phase of depression contact with each other is difficult. Everyone feels helpless about handling the child and at the same time they have to cope with their own depression.

In this phase it is of the utmost importance that, despite rejections, the teachers and staff remain patient - that they do not push on, but show their availability. Being near all the time is important to lay foundations of confidence for the child and its relatives.

Given sufficient time and support a phase of acceptance of the illness and its ending may be achieved in some cases. The moment may arise when the child disengages itself from its environment, even from its closest relatives. This can be a very painful experience. In this phase, relatives and staff need more support than the dying child. Another aspect of this difficult phase is that the relationship between all people concerned becomes stronger. It is therefore important to talk about death and its consequences. This makes it easier to go through the process of mourning.

In the final phase contact becomes more non-verbal than verbal. Being present at the last moments of a beloved person is seen to be very important by the child and its relatives. The capacity to be there is an important aspect of the relationship with the dying child. Missing these moments may be the cause of feelings of regret and failure in the carer.

## "Hearing"

It is important in the support and guidance of all those concerned in the last phase of life of the sick and dying child that they know they can vent their emotions, feelings, confusion, helplessness and fears. Within "Rafaël" a unit of the "Instituut voor Doven", where deaf and blind children and adolescents are educated, this support of staff takes the form of intensive interdisciplinary co-operation between the team and staff, nurse, psychologist, parish-worker and management. Management takes care of the organisation so that the staff have a free hand in the guidance of the children, the parents and each other. The psychologist and the parish-worker take care of personal and group support. They also turn their attention to staff questions in connection with the guidance of the child and the parents. They discuss this with the parents. As a team they look for practical answers to concrete and abstract questions

which are put by the child.

The uncertainties which occupy their minds are reflected upon in full detail and also they consider how far they are able to persevere this intensive guidance.

"How can we make the child participate as normally as possible to life in class and peer-group?"

"What answer is going to be expected from me, when the child asks what happens when you die?"

"How can I see if the activity which I am doing with the child is not too strenuous?"

"Is there a heaven, or what does heaven look like?"

"In how far must a sick and dying child know that it is going to die?"

In answering all these questions active participation of those relatives and professionally involved staff is of utmost importance. Practical answers and solutions are looked for by everyone involved in mutual discussions. Within these discussions it is necessary that there is enough room for personal convictions and respect for one another's opinion and beliefs.

There must be the possibility for staff and teacher to indicate that they no longer can pay a contribution to this intensive process of guidance. The limits of someone's possibilities can be overstepped.

The support of sick and dying children is not a matter just for professionals. Relatives and those involved in the daily care of the child are also involved in this important task during this intensive process.

## Dilemmas

It is not simple to set up curricula for deaf and blind children and it sometimes requires difficult choices. These become dilemmas when sick and dying children are involved.

On the one hand you want to give the child the chance of an education and you want to prevent putting the child in an oppressive "glass house" long before its death. On the other hand, it is almost unbearable to see the child's potential reduced, especially when the learning programme is strongly focused on the development of cognitive and other abilities.

You have to work to encourage trust and personal attachments, but eventually the child is forced to let go of all the things it holds dear. Such attachments can have a profound effect on the support of the child in its final phase of life and

the staff's experience of loss afterwards.

Staff want to tell the child where it stands, and how badly things are going, but there is a taboo on helplessness in our culture. As a result, feelings we cannot handle are put away, concealed, hidden, tucked away. Because of this taboo on helplessness, there is also a taboo on dying and death.

On the one hand, we want to prepare the child for death and we want to reassure it by telling it about Heaven, but on the other hand, words, language and understanding are beyond the intellectual and communicative faculties of the child. We will have to try to descend to the level of understanding of the child: a language without words, drawings, just touching each other, being close at hand and letting the child experience all this.

The dilemmas mentioned above are part of a wider range of difficult situations and choices to which staff are put during supporting the sick and dying child. It is therefore important to give special attention to preparing and giving training to staff involved with the dying child. This helps not just to gain and insight into the feelings of the dying child, but also into the staff's own psychological and physical reactions to the child and to the process of dying.

Finally, I want to touch on a dilemma of a totally different nature. In the Netherlands we live in a culture of man without God and in a society in which the church has become a minority. The present staff have little time and attention for really understanding the Roman Catholic religion, and the comfort to be gained from religion has not yet been fully explored. Undoubtedly during the process of dying, a young child will ask many questions. Not only just by listening, the priest or parish worker does not just stand for support but he or she also pays a contribution to answering these questions.

As I reach the end of this article, I would like to bring the Chinese proverb to your attention: "A gem is not polished without rubbing, and no man is perfect without tribulations."

The process of supporting a sick and dying child calls for extraordinary devotion and a certain maturity that can only be obtained through experience. When you have pulled through this painful experience, you can transform it into a positive attitude to life.

# Communication with congenitally deafblind persons

## A Nordic development project has resulted in training activities and a collection of articles

A project to develop the work with communication and congenitally deafblind people has been carried out in the Nordic countries over the past few years. Till now, the project has resulted in a training material – a collection of articles on the prerequisites for communication and conferences and training courses on the same topic ... The quintessence of the project is that the prerequisites for the development of communication in a deafblind person are the same as for any other person. Communication will develop along the same lines, due to the same principles. Only, it is necessary, in all situations, to compensate for the deafblindness. This is not to say that it is easy, but it is a fundament that has proved very fruitful. If the project and perhaps some of the thinking is Nordic, the principles for the development are not Nordic, and perhaps interesting for other colleagues.

### Communication with congenitally deafblind persons – its prerequisites

Communication is the crucial factor in all deafblind habilitation and holds a central position in all staff development activities. The authors of the book on the prerequisites for communication, Karl Jacobsen, Harald Martinsen, Anne Nafstad, Inger Røbroe and Klaus Vilhelmsen have all been engaged in staff development activities at the NUD and contributed with their respective aspects on the

development of communication in congenitally deafblind people. Although different, their contributions are all based on the same view on human development and deafblind habilitation.

The following is a brief summary of the book they have written together.

### Key concepts

*The biological basis for development* is the activity in the baby – reflexive behaviour for a start – which triggers reactions in the adult caretaker because he or she has the *illusion that the activity observed is communicative*. In severely handicapped babies these activities may not occur or may be deviant and unexpected, and the activity reaction chain which forms the *learning process* and which seems to be the onset of development, is not activated. The learning process causes emotional and cognitive changes in the two parts in the interactional unit. The mutual exchange and bilateral change are called *transactions*. *Security* is the emotional basis for new activity and development. Only with sufficient security is the child able to approach the unfamiliar and unexplored. The feeling of being understood and responded to gives security. *The complexity of human development* must not slip the attention. The social interaction which triggers development has both emotional and cognitive aspects and affect learning and behaviour, which in turn affect emotions and cognitions, which in turn ...

### Normal and deviant social development

"The human being is born social" is postulated when explaining early child development as a result of social child-parent interaction. Subsequently the following is attributed to the baby and seen as basic to social development: Babies are more attentive to social stimulation than to others. The small baby's behaviour is normally relatively regular and this, in addition to the fact that the adult really wants to cover all the needs of the baby, provides the caregiver with sufficient extra-situational cues to be able to give adequate responses to the child's behaviour. Giving adequate responses implicates interpreting the baby's behaviour as messages; it is conceived as signal behaviour. The feeling of success in giving adequate responses attaches him emotionally to the baby, and the baby is predisposed to develop an emotional attachment relationship with his caregiver. Although most of the early child activity is reflexive and state related behaviour, the – illusionist interpretation the caregiver gives to the behaviour really is the trigger and the motor of further social, emotional and cognitive development in providing genuine learning opportunities for the child. The learning opportunities are optimal because the learning is based on the child's own activities and the responses are instant.

The interaction between babies born with severe handicaps and

their caregivers is likely to be in strong contrast to the picture just painted, especially if the baby is blind or deafblind. Most of these children show little activity to interpret and the activity which occur may easily be unexpected and unusual. Adult persons' intuitive reactions to babies' activities will not always be appropriate. Only when knowing enough about the mechanisms of usual development as well as about the handicap or combination of handicaps, the caregiver can have success with the responses and expect a transactional relationship.

Studies of visual preferences strongly support the statement referred above that babies prefer social stimulation to other stimulation. Even very small babies are attentive to a human face (in nature, photo or drawing) over longer periods of time than to other visual stimuli of corresponding complexity. The baby also shows more attention to the human voice than to other sounds. They prefer complex, contrasting and moving visual stimuli and sound with varying patterns and intensity and high frequency. This is a result of very early learning experiences, but can still be seen as preprogrammed because there is the biological basis for the babies' early environment of human faces and (female) voices providing it with these learning experiences.

### **State conditioned behaviour**

State conditioned behaviour is physically activated behaviour, and is for a large part the early spontaneous behaviour that the baby shows. Babies react differently to stimulation in the 5 different states (according to Wolff). The states are defined according to certain manifested behaviour. The usual patterns in behaviour may not be manifested by handicapped babies, and therefore the babies are at risk of being misunderstood. Blind and deafblind babies have apparent inactivity as the expression of high attention level when listening. This is easily mistaken for passivity and lack of attention and interest. Blind and deafblind babies are less awake because they are less stimulated by visual input, they cry less and they move their limbs less. Some of the state related behaviour is typically interpreted as expressions for feelings, wishes or as reactions to sensory input, i.e. crying, smiling, other mimics. All this is behaviour which also occurs in adult

behaviour. The message this behaviour gives when observed in adults is attributed to the baby's behaviour, so most often, when a baby cries, it is interpreted as an expression of discomfort and distress, as there are reasons to believe that in reality it only expresses an activity level and is related to both positive and negative excitement. Extra-situational cues and even cultural conventions help the caregivers interpret the crying. There is, however, still a lack of specificity which seems to make it very important for the development of social communication. When blind and deafblind babies cry less than other children, they are deprived of the attention from the caregivers and the learning opportunities which are embedded in this.

### **Smile**

The smile is a reflex smile in the beginning, but normally the social smile, which also involves eye contact, occurs at the age of one month. As it is interpreted as an expression of satisfaction and affection, it is really stimulating for the caregiver. In blind and deafblind babies, the social smile may be delayed for perhaps 6 months. It can also be more vague in its appearance.

It is clear that in order to react, and react adequately to severely handicapped babies' activity, it is necessary to have all extra-situational cues available, and to know how the handicap or combination of handicaps, motor, sensory, mental, affect state dependent behaviour, stimulus input and reactions.

The dialogic character of even the very early interactions between baby-caregiver is based on the adult person's over-interpretation of the behaviour observed, which is possible because of the regularity in the child's behaviour and its apparent similarity to more grown-up behaviour. Imitation situations are examples of dialogue situations where the contributions are relatively equal; initially the adult picks up and imitates child behaviour, then the child learns the rules of the game and is able to imitate familiar adult behaviour, and later even unfamiliar behaviour.

Imitation situations are considered fundamental for development in general and for language development in particular.

The new baby needs to experience that its behaviour has an effect on the surroundings, and needs to be motivated to more

activity through this. The child and the caregiver mutually affect each other and these transactions and their patterns can explain how children develop. The activity level and the behaviour patterns are basic elements in the understanding of activity and reactions to activity. The activities must be interpreted adequately successfully -, and they must seem meaningful to the adult and also be rewarding. The activity level varies, but must match the expectations which the caregiver has. Being reacted adequately to has an important learning effect; learning promotes all activity, not only the activity reacted to, and has a cumulative effect on future mastering.

Blind and deafblind children are high-risk groups for developing mental retardation because of the lack of learning opportunities. 20 - 30% of congenitally blind or visually impaired children become gravely mentally retarded, the majority show autistic features. Congenitally deafblind children are at even higher risk for developing this kind of deprivation impairment. Their passivity seems to be the main problem. The lack of sensory input and subsequent passivity in addition to the misinterpretation of their attention reactions, results in a negative feed-back chain and stereotyped behaviour, repetitive activity and other autistic features dominate their activity repertoire.

Stereotyped behaviour has a place in normal development during the first year, and disappears as it is replaced by other attention seeking behaviour. In many severely handicapped children stereotyped behaviour loses its original attention seeking function and develop new areas of function like self stimulation or protection against stimulus input. To break this vicious circle it is necessary to intervene with reactive responsiveness, structuring and securing (structuring and combining it with initiative promoting ruptures in the structure). Succourance often occurs in the blind and deafblind persons with a good development. They are prompt dependent. Learned dependency, another form of passivity, has many appearances and can be un-learned.

### **Security**

When Simon showed very restless behaviour before the summer holidays, it was probably because he was insecure. He lacked the overview over the six week period that he knew was going to be different from school. He was fixating on plans and

schemes that were to be changed, and like a maniac he talked about anything that was related to his summer holidays.

Overview and the security it provides us with, are necessary to be able to use capacities like, for example, cognitive capacity. Security and attachment mutually condition each other, and the basis is contact. Without contact, the adult is not able to interpret the child's activity, without contact the child can not be satisfied in his physical and mental needs. Researchers like Bowlby, Mahler, Spitz and Winnicott have studied and discussed attachment during the past 2-3 decades. They all agree that attachment is necessary for a normal development. Bowlby focused on the biological basis of attachment. Normal children, through their biologically conditioned behaviour, are granted a kind of attachment and security. To have good attachment, the caregivers need to respond adequately to the activities. Bowlby called it attachment behaviour. It has become more clear that the earliest development of a child is less dependent on the quality of the care from the adult and relies more on the child's own contribution through its congenital competence for social interaction manifested in crying and smiling. The development of attachment to one or more persons normally takes place during the first three years, and it is critical for other aspects of development as well as for further development. Identity, knowledge and confidence in one's own capacity is important for the feeling of security.

## Interaction

The deafblind child is again at-risk due to the sensory impairments. It is not able to initiate the social interaction and to give rewarding feed-back to the caregiver, e.g. smile, give eye-contact, be comforted or calmed through visual and auditory stimulation. At the age of 6 months, the non-handicapped child acquires the motor skills to start exploring the world, and thus expand his space of interaction. When the deafblind child does not do these things, his motor and cognitive development will be delayed. Covering physiological needs is not sufficient for a good child development. It is necessary also to have the emotional care which comes with love and secure attachment. Damages to this development pattern will affect the social and emotional development, the cognitive development and the

development of language. Feeling insecure drains all energy in a person. In making a child secure, energy is released and can be spent on the capacities in the child for further development. To secure a child, it must have an overview, possibilities to recognise and possibilities to establish memory.

Structuring the child's environment and activities has been a well-known strategy in deafblind education for several years. The structuring of time, activities and localities is necessary for the overview and can prevent the development of stereotyped, self-injurious or aggressive behaviour. Structuring is not a goal in itself, but is the means by which the deafblind person can increase his feeling of security. As the world becomes more ordered, the deafblind person can find cues and references that help him to interact with the world. With this, the possibilities for communication increase. To, in the end, facilitate social communication the structure must be established, and then skilfully broken.

## Relating to the world

In deafblind work the primary aim is to prevent or to solve serious problems in the areas of communication, access to information and orientation and movement (cf. the definition of deafblindness). It is in communicating with the surroundings, exploring and getting information and moving freely that a person acquires an understanding of it. The units of function which define the person and his relation to the environment are communication, information, orientation and free movement, and if these units lack or do not operate properly, the person's relationship or interaction with the world will be dysfunctional and he will not be able to increase his understanding of it. The units have their basis in the early interaction between baby and caregiver. So it is necessary to include both contact and proximity in the series of units of function as they are the earliest forms of interaction.

The units of function or units of interaction are learned; transferred from adult to child. The transfer is likely to be suffering from the congenital sensory loss, and cannot be expected to be fully successful. Nearly all mothers to deafblind children report that they lack of contact or have poor contact with their baby. This is manifested through lack of synchrony in the child-adult interaction. Contact is a

result of the mutual attention and the ability to react to signals from one another, and is simultaneously the basis for proximity, attachment, exploration and communicative interaction, both coded and not coded. The pattern of interaction which is most threatened by congenital deafblindness, is the dialogue. The structures of the dialogue like turn-taking and give-and-take are very dependent on hearing and vision, the latter in particular. The dialogue between a deafblind person and a caretaker will always depend relatively much on the caretaker. It is crucial to introduce the patterns of interaction on the deafblind person's premises and accentuate the response effect of his spontaneous activity. Because the transfer of patterns is likely to take so long, there is no time to waste, and routine situations may well serve as training situations for the patterns of interaction, e.g. mutual imitation, give-and-take and turn-taking which are all basic for the mastering of dialogue.

Interaction patterns are prerequisites for social communication, and it is more important to understand these patterns and be able to use them in a flexible way than it is to have some look-alike language behaviour which is used mechanically.

The adult person's task is to facilitate the deafblind person's discoveries on all levels from interpretations of reflex behaviour to the most advanced communication with the environment. On the different levels there are elements which make the interactions possible and which can be called units of interaction. With the awareness of how the different units of interaction function, it is possible to facilitate self-discoveries which by far provide the best learning situation.

## Hearing and its impact on communication development

Hearing first and foremost is basic for the development of spoken language. Hearing input can also increase the comprehension of a message which primarily is conveyed through other sensory channels. Hearing can help in establishing contact, can guarantee security for a deafblind person when exploring and can help focusing on e.g. an object for communication. Hearing loss in a deafblind baby can scarcely be evaluated at an early age, and subjective hearing tests

will always give little specific information because of the skills required to respond to the auditory input. A brain stem audiometry gives information especially on the auditory capacity for high frequent sounds. A complete assessment of the hearing function is often difficult, and must for a large part be made upon systematic observations over periods of time. To exploit a hearing capacity, the auditory input must have meaning, must make sense to the child. Peter, who only reacted to >100dB sounds when in a formal testing situation, showed attention reactions to the sounds of a little sound toy he had. Functional testing is crucial and the sound must make sense. The caregivers must make them meaningful, and in addition give the child optimal hearing aid treatment, make sure the distance between sound source and microphone is correct and in all other ways grant optimal transmission of meaningful sounds, e.g. by presenting only one sound at the time in optimal acoustic environment.

Normally, hearing functions at birth, and has functioned even during the intra-uterine period. Just after birth the connection between auditory and visual input can be made; the baby can direct its glance to the sound source. The audiotively based attention radius, however, develops in the same pattern as vision and motor skills. Sounds play an important role in the early baby-caregiver interaction, and the baby is the initiating part. A deafblind baby with some residual hearing will use auditory input to establish contact, and it is important that the adult knows the adequate reaction to sound for this child. A slight turning of the head, ceased motor activity, quietness, changes in breathing, movements of the mouth and fingers are likely to be signals of attentive listening. Often signals are delayed. Children react more and more attentively to the human voice. Talking to the deafblind child provides the child with cues for recognition; the prosodic elements in the spoken language are relative both to the person speaking and to the state of mood he or she is in, and thus to the message conveyed even if the language as such is not understood.

Sound to establish contact and contract (guarantee the adult's presence) can well be used over longer distances as well, with e.g. a conference microphone or an FM device. To establish/use auditory input as other cues, it is important to give the child multiple experiences with sound. Sound as cues for orientation must be specific,

and all sound pollution should be avoided. Echoes are useful for orientation, but make requirements on the environment in general. Sound can be used to establish a common focus of attention, and again the sounds must be made meaningful and must be presented distinctively to give the caregiver cues to understand the child's attention behaviour. Sound effects from familiar situations can be used as mediator in a communication situation e.g. about going to the swimming pool, drive the car etc., or tell which persons he is going to be with during the day. Sound is also particularly relevant as response to spontaneous activity, confirmation of a shared focus of interest. Especially with good residual hearing it is important to support signed and other communication with language communication. With deafblind children, verbal communication will, however, never be the only medium.

### **Vision and its impact on communication development**

Vision is important for many of the child's activities which are interpreted as communicative behaviour; eye contact, glancing, smiling, grasping, crawling towards a person or an object etc. For example, grasping which normally occurs after three months, is likely to occur in the blind child six months later. As grasping is interpreted as communicative behaviour, the adults will start interacting with the child and give the child a learning opportunity. The adult reactions to child's behaviour is at first not very specific, but will become much more related to content and functions: they will call the objects by the proper name, they will show how to use the object in the right way etc. So the vision has a function in child initiated interaction in two ways; as indicator of attention and interest and for stimulus perception to trigger child activity. It is estimated that 70 - 90% of the child's activity is related to vision.

At birth, visual capacity is low. The vision function is optimal at 30 - 50 cm from the object. It is considered to be a facilitating factor for the cognitive development, as it reduces the amount of visual stimuli, and helps the baby focus on the important persons like mother and other caregivers who normally interact with the baby at this distance. The radius for visual attention will increase as the baby grows older and can add new visual

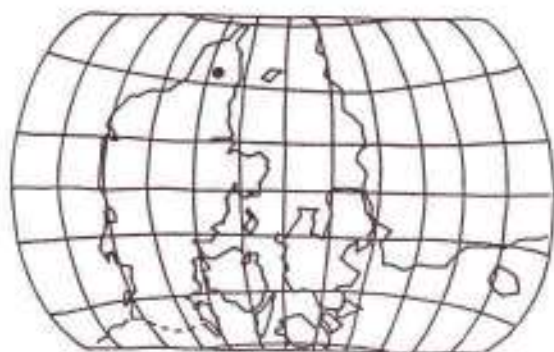
input to his collection of already familiar things/persons. Recent studies of babies' visual preferences show that the child, from birth on, focuses on what is the most pertinent stimulus in his visual field, the size of details, the contrast, the position and the movement. The baby's vision focuses, or is directed towards certain stimuli. This reflexive behaviour is not completely will controlled until the child is 2-3 years old. This reflex behaviour assures that the child is attentive to things of importance, objects that the adult will show him, important faces ... The limited visual attention radius and the attention directing reflex both facilitates cognitive development. They are likely to help in the development of concepts which, it seems, starts very early in normal development, at the age of 1-2 months.

Little visual input and few vision related signals make passivity a fundamental problem when the baby does not see. Means to reduce the risk of deviant and delayed development in blind and deafblind children will be to be aware of the different signals to expect. Thus the signals are not overseen or misinterpreted and can be reacted upon. Is also important to use special methods to create spontaneous activity. For deafblind children hearing aid treatment and visual aids help to exploit any residual capacity, in addition tactile and vibratory stimulation become important. The child needs extra and multimedia cues, and needs more time to process information.

Visual examination must be based on objective testing when the client is severely handicapped. The purely medical examination and refraction testing does not require active participation from the client. Nor does cover testing to reveal eventual squinting. Visual field can best be assessed through systematic observations in daily activities. Acuity is traditionally measured in subjective testing, but objective test materials have been developed recently for use with persons with special needs, e.g. gratings ... and testing of preferential looking. Often residual vision is discovered through this kind of testing, and obviously important potential for habilitation is revealed.

The European Coordinating Unit  
for Staff Development in Deafblind Services

PULL-OUT  
SUPPLEMENT



# QUALITY OF LIFE THROUGH QUALITY SERVICES

If you work with deafblind people, you will know:

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that deafblindness is a unique, rare and severe handicap;

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that the complexity of the dual sensory impairment often requires human services rather than technical equipment;

---

that deafblind services demand human resources and coordinated support and development.

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Upon the initiative of the IAEDB Sub-Committee on Staff Development in Deafblind Services, the European Communities' Deafblind Secretariat (ECDBS) has established a European Coordinating Unit for Staff Development in Deafblind Services. The main idea is to improve the services offered to deafblind people in Europe through increased quality of staff training and development.

### **What we offer**

is a coordination and information service.

The Coordinating Unit invites you/your institution, school or organization to subscribe to its services. With the subscription you will automatically become a part of the network which focuses on staff development initiatives in the deafblind field.

### **The aim**

is to support you in increasing your knowledge, and to make it easier for you to get in touch with those people and institutions closely involved in staff development that could help you to solve your problems.

### **Background**

The motivation for European coordination and the cooperation is the belief that the united efforts of a network will be more effective and give better results than solitary work.

No European country has specialized training offered to the wide range of staff in deafblind services. Therefore we have always looked to colleagues in other countries for new ideas and professional stimulation with the intention of improving the quality of our work. With European cooperation we can use our resources most productively and avoid duplication of efforts.

### **Past events**

The need for cooperation and coordination in the staff development activities in European services for deafblind people has been stated on several occasions during the past six to seven years.

The following pan-European events have taken place within this period.

#### **1986**

European Conference on Staff Training – a preliminary meeting exploring the need for cooperation. There was significant interest so the work continued with the biennial meetings of the "European Conference on Staff Development in Services to Deafblind People".

#### **1989**

The IAEDB Sub-Committee on Staff Development in Deafblind Services was created to initiate and coordinate other cooperation on staff development in addition to the biennial meeting of the European Conference.

#### **1988/1990/1992**

European Conferences on Staff Development: meeting discussing topics of relevance to staff development in deafblind services.

#### **1992**

The European Communities' Deafblind Secretariat puts forward a proposal about the establishment of the European Coordinating Unit for Staff Development in Deafblind Services.



The European Coordinating Unit for Staff Development in Deafblind Services  
c/o NUD, Slotsgade 8, DK-9330 Dronninglund, Denmark



## The Coordinating Unit starts operating now

– with a network and information service and coordination of staff development projects.

### The Unit and its services

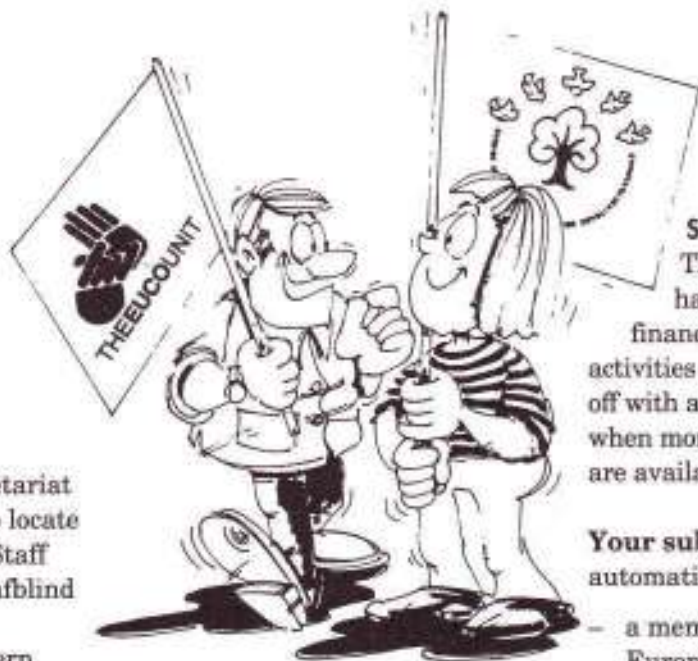
The EC Deafblind Secretariat (ECDBS) has decided to locate the Unit at the Nordic Staff Training Centre for Deafblind Services (NUD), in Dronninglund in Northern Jutland, Denmark.

The IAEDB Sub-Committee on Staff Development is appointed the governing body of the unit for the first two years. It consists of people from different European countries, all of whom have special competence in staff development.

### Aims and objectives of the unit

The aims and objectives of the unit will be:

- the establishment of a network and an inventory of organizations/institutions schools/persons involved in deafblind services in Europe
- dissemination of relevant information on actual and planned work in deafblind services in Europe
- coordination and initiation of projects on staff development
- identification of needs in staff developments in all the European countries
- coordination of activity in European countries without, or with, limited services to deafblind people
- coordination of actions in services to deafblind persons with no or little traditions for staff development
- initiation and coordination of



### Subscription

The Coordinating Unit has not acquired sufficient financing yet. Therefore the activities will be limited to start off with and can be expanded when more economic resources are available.

### Your subscription

automatically ensures you

- a membership in the European network cooperating on staff development in deafblind services
  - information on actual work and events of relevance to staff development through a biannual news bulletin
  - the updated bibliography of NUD's international library on deafblindness and related topics once a year
  - an updated inventory once a year. Here you will be able to find, at least as the network develops, the resource persons that you would like to contact, visit etc.
  - the most recent articles published in the Series of Nordic Directories for Staff in Deafblind Services which have been translated into English.
- translations and re-editions of literature, books and other publications of importance for staff development
  - development of a European library service with titles on deafblindness and related areas
  - programme of specific activities, eg courses, workshops, projects etc.
  - coordination of exchange programmes for deafblind people, their families and staff
  - assistance with fundraising for development work
  - stimulation of scientific developments of importance for European services to deafblind persons
  - policy making and implementation.

As you see, the aims and objectives of the unit are first and foremost to create a European fellowship in the field. The actual staff development activities will continue to be done by national institutions and professionals, and whenever required, with support from colleagues from other European countries.

**In addition to this,** you can contact the Unit in Dronninglund for more specific information, eg on things you find in the news bulletin, on the network, on staff development events or on how to get in touch with resource persons for the staff development activities you would like to take place in your own institution.

You can also order lists of specific references, and can get information on how to acquire those.

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## The International Association for the Education of Deafblind People

# Services for congenitally deafblind adults

In April, a two day symposium on post-school services for congenitally deafblind adults took place in the United States. A special committee had previously sent a questionnaire on the subject to members of the IAEDB. The results of these have led to the following Mission Statement. The principles it contains should provide a useful starting point for work with congenitally deafblind adults in any country.

### Principles

- 1 The International Association for the Education of Deafblind People (IAEDB) exists, amongst other purposes, to promote an improved quality of life for deafblind people, both children and adults, throughout the world.
- 2 The IAEDB believes that deafblindness is a unique disability and that within deafblindness there are distinct groups. Each group requires equal but different approaches for services. The group which is the subject of this paper are congenitally deafblind people, including early adventitiously deafblind people.
- 3 The IAEDB believes that all deafblind people require additional and specific external support if an improved quality of life is to be achieved.
- 4 The IAEDB believes that such support for Congenitally Deafblind Adults can only be achieved by an individualised service programme.
- 5 Such a programme must include services that adhere to the following principles affecting Quality of Life.

- 6 Quality of Life is improved according to a hierarchy beginning with factors relating to survival, through personal development and social development, to selfactualisation.
- 7 In each case, the principles are based on Equality of Opportunity and Access.
- 8 For Survival, this requires Equality of Opportunity and Access to Shelter, Warmth, Food, Clothing, Health Care, Communication, etc.
- 9 For Personal Development, this requires Equality of Opportunity and Access to family, education, communication, control of one's own life and age-appropriate activities.
- 10 For Social Development, this requires Equality of Opportunity and Access to a full range of emotional relationships, membership of social groups, work and recreation.
- 11 For Self-Actualisation, this requires Equality of Opportunity and Access to ongoing education and training, being respected as an individual and a sense of self-

worth and confidence through personal creativity at home, work and leisure.

- 12 When putting these principles into practical effect, it is inevitable that they must recognise the cultural context in which they will operate.

### The development of relationships

- 13 The congenitally deafblind person should have the opportunity to develop self-identity through relationships with family, peers, professionals and others.
- 14 The development of relationships for the congenitally deafblind person depends also on other people and he/she has the right to support in the continuing development of social and emotional skills.
- 15 The membership of a congenitally deafblind person's family is the same as that within the local/national cultural definition of family.
- 16 The relationship between the congenitally deafblind adult and the family should be allowed to evolve as the young

person enters adulthood and as both he/she and the family age.

- 17 There is a responsibility to offer education and continuing support to families in their changing roles.
- 18 Through interaction, congenitally deafblind people can enrich the lives of others.

### **Deafblind culture**

- 19 The possibility for Congenitally Deafblind people to develop in a specific cultural frame is a basic condition for Quality of Life. This cultural frame allows the person to develop individually and to access the common culture of the society in which he/she lives.
- 20 Opportunities to be creative are necessary for personal development and therefore must be afforded to the individual. Self-identity is a precondition for Quality of Life and for the ability to contribute to the culture. A cultural frame is necessary to support and stimulate creativity and self-identity.
- 21 Congenitally Deafblind people should have access to the common culture and should also have the possibility to create and have access to a culture of their own.
- 22 Two main dangers, when countries set up a policy for Congenitally Deafblind people, are excessive centralisation and excessive decentralisation, both of which diminish Quality of Life by impairing individual development and relationships. A wide set of options should be available so that Congenitally Deafblind people develop contacts which are adapted for accessibility and which offer choice.
- 23 **Deafblind culture is part of the common culture and can contribute to the development of this by**
  - producing specific cultural objects (works of art, means of communication, specific cultural events, etc.)
  - helping common culture to be aware of its own structure by comparison with Deafblind culture

- providing society as a whole, and non-deafblind people in particular, with experiences and models of relationships which can improve the Quality of Life for human beings.

### **Nature of Services and Empowerment**

- 24 **Professional services to persons with congenital deafblindness should consider**
  - the individual person in his/her right social context in all aspects of life and throughout life
  - that the primary characteristic of all services should be the conscious compensation of the effects of
  - congenital deafblindness on expressiveness and development of self in relation to the world.
- 25 **Adult services exist within a continuum from birth to death and should be realized through**
  - early detection
  - individualised early intervention
  - individualised special education
  - individually adapted contexts of social interaction
  - application of principles of special education to facilitate learning through life
  - continual availability of the human resources needed to realize social interaction with the environment
  - personalized general and psychiatric care when necessary
  - continual identification of the individual's capacities and potential and the provision of adapted environmental challenges geared at optimizing personal development
  - continual availability of all kinds of support needed to live as fully as possible as an individual, social and cultural being
  - conscious and continual awareness of the many and

varied risks of personal isolation and how to avoid them

- continual availability of highly qualified multiprofessional staff, particularly qualified intervenors.

### **26 Procedures for decision-making**

Decisions concerning life conditions for the individual, and particularly those concerning change or no change in life conditions should be taken in close collaboration between a team of qualified professionals and the family, with close regard to the preferences expressed by the Congenitally Deafblind person him/herself.

A personal advocate should be identified to take on the role of being the voice for the Congenitally Deafblind person when he/she is unable to represent his/her own interests.

When the Congenitally Deafblind person, for any reason, is not able to have access to interaction with other people, either through the use of personal intervenors or by him/herself, staff must be prepared to consciously switch between different roles, eg. staff member, friend, peer or others from within the prevailing culture.

### **27 Resources**

In order to prevent Quality of Life decreasing with age, increasing human and economic resources must be planned for and provided.

### **28 Quality Assurance Indicators**

The increasing autonomy of the individual will indicate that the effects of Congenital Deafblindness are being adequately compensated for.

During training, during their work, and subsequently, staff must be particularly taught to observe indications of autonomy/lack of autonomy through behaviour. Lack of autonomy or decreasing autonomy will require action involving changes in environmental conditions.

# Quality of life for congenitally deafblind (CDB) school leavers and young adults



In the last edition of *Deafblind Education* we looked at the UK response to the questionnaire on congenitally deafblind adults. At the seminar held in Boston it was agreed that the Canadian response should be published. This response on Quality of Life was prepared by John McInnes in consultation with The Canadian Deaf-Blind and Rubella Association, The Group Home for Deafblind Persons (Brantford) Inc., The Treffry Homes and the Ontario Chapter of the Canadian Deaf-Blind and Rubella Association.

When reading answers to this questionnaire take into consideration that Canada is geographically a large country divided into 10 provinces and two territories. Each province has jurisdiction over both education and health and therefore there are no definitive answers to many of the questions. The philosophy underlying the provision of service by the Canadian Deaf-Blind and Rubella Association is that each individual should be served according to his or her needs rather than forced into some delivery system designed to meet the needs of a hypothetical average congenital and early adventitious deafblind individual. Through the use of intervention we have been successful in providing a superior support system which allows the individual to use programs designed for the general population in a more economical way.

All replies to the questions assume that when satisfactory support services are indicated that there is intervention available. The intervenor is a individual who

- supplies the deafblind person with sufficient non distorted information to permit the deafblind person to make appropriate decisions.
- provides the support necessary to carry out the deafblind person's decisions in a reasonable amount of time.
- facilitates communication between the deafblind individual and the rest of the world.

It is also assumed that one of the goals of any program is to enable

the congenital or early adventitious deafblind adult to choose

- who will be his or her intervenor
  - how much intervention he or she wishes
  - when the intervention will be used
- and
- the activities that they wish to pursue, the job they wish to work at, and the life style they wish to adopt.

The fact that an agency or government supplies funds for support does not give that agency or government a right to dictate how the person will live.

## Continuing education

**Do congenitally deaf blind young adults and adults in your country receive adequate continuing education after school age? Yes/sometimes/ rarely**

Yes. Most congenital and early adventitious deafblind individuals, through the use of intervenors, have the opportunities available to the non handicapped population in his or her community.

**What is the focus of further education?**

The type and content of the program varies according to the needs of individual congenital and early adventitious deafblind adults. Academic, job oriented and life skills, and leisure/recreation programs are available to most clients.

**Do they receive adequate vocational training? Yes/sometimes/rarely**

Yes. Most congenital and early adventitious deafblind individuals, through the use of intervenors, have the opportunities available to the non handicapped population in his or her community. If intervention is not available, vocational training without an identified job placement, is a waste of time and money.

**What is the focus of vocational training?**

The Canadian philosophy is to fit the program content to the needs of the individual rather than plugging the individual into the 'best fit' existing program. Formal community college and other educational programs are used in whole, or in part, according to the needs of the individual congenital and early adventitious deafblind adult with intervention.

**Describe the vocational training you know that works the best, and indicate what makes you say so.**

Community based programs are utilized where applicable through the use of an intervenor. Where there is no existing program that meets a particular client's needs, one is developed utilizing the program developmental guide.

**If you think continuing education and vocational training is not adequate, describe the main obstacles and barriers.**

It is neither practical or desirable to develop institutionalized continuing

education and vocational training programs restricted in focus to the congenital and early adventitious deafblind adult. This approach tends to remove responsibility from local communities, often leads to ghettoization and isolation of the deafblind, and tends to put limits upon the upper levels of their achievement through generalization of staff expectations.

Some problems that recur and which must be overcome are:

- 1 Obtaining funding for adequate levels of intervention. It has been our experience, however, that once funds are in place the successes of the congenital and early adventitious deafblind individual in the community setting leads to continued funding.
- 2 In some areas of the country inappropriate service models continue to be used. A medical model, [the most severe handicap] useful for treatment but not for development and support, or a combined approach model [there is no difference between congenital and early adventitious deafblind and adventitious deafblind] are in use. Experience has shown that when an appropriate delivery model [congenital and early adventitious deafblindness is a specific handicap] is put in place, even as a demonstration project, attempts to use less appropriate models are abandoned.
- 3 There are still pockets within Canada where deafblindness is not recognized as a distinct handicap. This is more common with adventitiously deafblind adults who were originally served as having some other handicap e.g. blindness, deafness, retardation, etc.] than with congenital and early adventitious deafblind individuals who are identified in early infancy and supported as deafblind with or without having additional handicaps. In addition, certain cultural expectations concerning the handicapped in general and deafblind in particular can shape the total governmental approach.
- 4 Initial and ongoing staff training for intervenors presents a problem. The low incidence of the handicap precludes the staff training support system available to other handicaps. When attempts have been made to utilize this network and modify

existing programs to train individuals to work with congenital and early adventitious deafblind individuals, they have been monumental failures.

- 5 The general public has a lack of knowledge concerning the congenital and early adventitious deafblind. All too often adventitiously deafblind people are looked upon as speaking for the individuals and services that are under the deafblind umbrella. Because of a lack of understanding of the congenital and early adventitious deafblind and their needs more damage than good often occurs.

## Policy

### Is there in your country an official recognition of deaf blindness as a separate handicap? Yes/no

See the beginning note. Each province has some formal recognition of deafblindness by all or some of the ministries of education, health, and social services. Recognition can take a variety of forms including funding of programs identified as specifically for deafblind persons, programs that pay for intervenors for deafblind persons in educational, community and work settings, and a funding grant for the Canadian Deaf-Blind and Rubella Association national office.

However, it must be reported that there is no specific act of the national government, nor of any provincial government that singles the deafblind out as a specific and distinct group. In addition, while The Canadian Deaf-Blind and Rubella Association and a number of provincial government ministries recognize the congenital or early adventitious deafblind as a distinct group requiring specific support and services that differ from the adventitious deafblind, this distinction has not been widely accepted by agencies that work with the blind, deaf or developmentally handicapped. This problem is increased due to the fact that many adventitiously deafblind adults seem to think that if a congenital or early adventitious individual receives appropriate programming that he or she will somehow become adventitiously deafblind and thus be appropriately served by programs designed for their support.

### Does the concept of deafblindness include congenitally deafblind adults (also multi handicapped)? Yes/no/unclear

Yes. As noted above in the reply to the previous question it is generally held by those working in the field that there are two groups of deafblind. [1] congenital and early adventitious deafblind and [2] adventitious deafblind.

### Who takes administrative and economical responsibility for the provision of services for post-school cdb and at what level?

- The Government
- Regional Authorities - Local Authorities
- Private organizations, e.g. charities, but financed by authorities
- Private organizations, but financed by fund raising - Parents' Associations
- Families alone
- Other

The Canadian Deaf-Blind and Rubella Association is made up of parents, family members, professionals and interested third parties without distinction as to original reason for joining. It is felt by all involved that the strength of the association lies in the acceptance of all members as equal partners.

### If there is shared responsibility between these groups, please indicate.

See initial note. Primary responsibility differs according to the geo-political location of the services. For example, the Ministry of Community and Social Services and the Ministry of Education in the province of Ontario works closely and Co-operatively with the Ontario Chapter of the Canadian Deaf-Blind and Rubella Association to provide support and services for congenital or early adventitious deafblind from age of identification onward. In other provinces the specific ministries involved and the level of co-operation may differ.

### Is the service differentiated according to need? Yes/no/partly

Yes. This is one of the basic precepts of the philosophy upon which the Canadian model stands.

**Are there any special plans for the provision for congenitally deaf blind adults in your country? Yes/no**

Services for the congenital or early adventitious deafblind began in the early seventies in Canada. Prior to that time individual children who were identified as deafblind were sent to programs in the United States.

Services in most jurisdictions start at identification and continue until the congenital or early adventitious deafblind child leaves education. Ages for school leaving varies from 19 to 24.

Programs for school aged congenital or early adventitious deafblind children are delivered either in both specialized settings and the child's local school or in a residential school setting.

In all cases, an essential part of the program is to introduce paid intervenors into the child's life and to teach him how to utilize this support service to enable him to utilize community resources.

The Canadian Deaf-Blind and Rubella Association, is concentrating on developing a range of support services for the congenital or early adventitious deafblind adult. This program will emphasize:

- 1 de-institutionalization of any congenital or early adventitious deafblind persons who have been inappropriately placed in institutional settings.
- 2 the development of a range of options for housing within the community that will include, but not be limited to:
  - a) transition homes
  - b) group homes for from 3 to 9 congenital or early adventitious deafblind who are individually supported by intervenors.
  - c) the congenital or early adventitious adult living in their own house or apartment by themselves or with a chosen friend with intervenor support.
  - d) the congenital or early adventitious deafblind adult living at home with full intervenor support.

In all cases the emphasis is upon supported independent living in the community and the utilization of community medical, educational, recreational, and vocational programs that exist for the non handicapped population. Employment will be as paid workers, or volunteers within the community rather than in a

workshop setting designed to offer sheltered employment for the deafblind or some other handicapping condition.

The Canadian Deaf-Blind and Rubella Association, in co-operation with various government ministries, is actively working to develop a network of training programs for intervenors to work with congenital or early adventitious deafblind individuals of all ages.

**Population**

**Is there an overview of the population of the congenitally deaf blind (excluding Usher people) in your country? Yes/no/partly**

Partly. However, Usher syndrome is not the only cause of adventitious deafblindness.

**Do you have any idea of the number of post-school congenitally deaf blind people (excluding Usher people) in your country today? Yes/no**

Yes

**If yes, please give the number**

There should be approximately 420 congenital or early adventitious deafblind over the age of 21. Of these, approximately 25% have been identified as deafblind and received services as such since the time of identification. Approximately 50% have been served using the medical model of the most severe handicap and are only now being identified and served as deafblind. In many cases, initially, existing service agencies are reluctant to either serve them as deafblind or to de-register them to a more appropriate support system.

**Do you have an idea about how many more post-school people there will be in five years time? Yes/no**

Yes

**If yes, please give the number**

51 +/- 10

**Has any survey of the needs of the population of post-school people been undertaken? Yes/partly/no**

Yes. An extensive survey was done on the needs of the deafblind in 1984. This committee took two years to travel across Canada and compile a report. Further needs assessments have been done in various provinces [Alberta 1985, Quebec 1983, Ontario 1992, etc.]

**Housing**

**Are there any units specially adapted to the needs of congenitally deafblind adults in your country? Several/some/one/none**

Does not fit overall philosophy, but such units are available when needed.

**Please describe the kind of units where you can find cdb. Underline the most common**

- Hospitals
- Institutions for the elderly
- Institutions for the mentally ill
- Institutions for the mentally retarded
- Schools of special education (day)
- Schools of special education (boarding)
- Special group homes for the deaf blind
- Units for other handicap groups
- Mainstreamed in local communities with support
- Parents' homes
- Other individual house or apartment

Those congenital or early adventitious deafblind adults that continue to be served under a medical model would be found in institutional settings of various kinds. Where such a service model is inappropriate, The Canadian Deaf-Blind and Rubella Association, in cooperation with other agencies and ministries of government continue to make every effort to have the congenital or early adventitious deafblind adult deinstitutionalized and placed in an appropriate community setting.

**The units you know, do they provide what you would call adequate living conditions for cdb according to the common norms of your country? Yes/in part/not at all**

Yes. That is the units designed to meet the needs of the congenital or adventitious deafblind adult.

**Which category of units are adequate?**

- Special group support facilities, with intervention. Local community settings, with intervention
- Family homes, with intervention
- Independent living with intervention

Two or three congenital or early adventitious deafblind adults sharing a house or apartment with intervention

Units [houses or apartments] clustered together with intervention  
Individual living at home as a fully participating adult with intervention

Individual living at home under parent direction, using allotted intervention

**What characterizes the best unit you know anywhere for congenitally deaf blind adults? (Describe on a separate sheet)**

[See the initial statement of philosophy.]

- 1 A reactive environment that emphasizes personal control by the congenital or early adventitious deafblind adult of his or her life to the same extent, and in the same way as the general population, through the use of intervention.
- 2 Any support system designed to economically use the existing community resources in providing a support structure.

For example

One congenital deafblind young lady lives in her own apartment and utilizes university students who share the apartment with her as intervenors. This arrangement provides both support and appropriate peer interaction. In the same city, another young lady lives in her own home as an adult who shares responsibilities for its operation with her parents, works in the community, and enjoys an active social life, all with appropriate intervention.

**Describe barriers and obstacles related to housing.**

The biggest barrier or obstacle, which has been largely overcome in many parts of Canada, is the concept held by some people that congenital or early adventitious deafblind must have modified housing rather than appropriate support to use existing housing. A second obstacle, arising from the treatment in Canada of the intellectually challenged, is the concept that they must live and work together in a sheltered environment. Fortunately, this concept is gradually being abandoned by individuals working in that field. However, it is prevalent enough that it must be taken into account when developing support programs for the individual

congenital or early adventitious deafblind adult. A third obstacle is the desire by many administrators to approach services to the congenital or early adventitious deafblind adult using a "best fit" mentality. Such administrators are trained to fit individual clients into existing programs and services. The concept of creating a new support structure is so threatening to them that it presents a serious obstacle that must be overcome.

## Support systems

**By support system we mean a service unit, organization of any kind or persons outside the units that provide consultant services to staff and families about what to do, how and why. This is different from housing, workshops, etc. and from direct economical support.**

The questions in this section presuppose a point of view that is diametrically opposed to the basic philosophy underlying our services. We hold that each congenital or early adventitious individual, regardless of age, should have access to the best medical and social services available to the general public. The Canadian Deaf-Blind and Rubella Association offers support to professionals who wish to gain more knowledge in the field of deafblindness through consultation, exchange of information, etc. However, the country is so large geographically and the incidence of congenital or early adventitious deafblindness is so low and individual clients are so wide spread that the concept of Units is neither practical or desirable.

**Is there in your country a general support system that serves units for cdb adults? Yes/partly/no**

Yes. The Canadian Deaf-Blind and Rubella Association is an advocacy organization that provides direct services where they are not provided by other agencies or by ministries of government.

**Is there an adequate medical support system? Yes/no**

Yes. Each congenital or early adventitious deafblind individual has his or her own network of medical professionals. Canada's health care system is such that all citizens have available to them the options as to which medical professionals they will consult, what services they will utilize, and which drugs they will take. These options

may be exercised without cost to any citizen. In addition, each congenital or early adventitious deafblind adult has his or her own drug card which permits him or her to receive free any prescribed drug.

**Is there adequate basic training for staff working with cdb adults? Yes/no**

Yes [both basic and advanced]

**Describe barriers and obstacles.**

Throughout this questionnaire we have indicated the barriers of:

- 1 Geographical distance
- 2 Funding limitations
- 3 Bureaucratic approaches
- 4 the low incidence of the handicap.

The Canadian Deaf-Blind and Rubella Association has been active in advocating for courses to train intervenors, has [and does] offer training through its provincial affiliates, and has supported both national conferences and training sessions for individuals working with, or responsible for services to, the deafblind.

## Work possibilities

**Do cdb adults have the possibility to work or engage in meaningful activities according to their capacities? Yes/maybe/hardly**

Yes. Each congenital or early adventitious deafblind adult has the opportunity to experience a variety of working situations which are chosen according to his or her interests and abilities. Following this type of exposure, which can last for a number of years, the individual is encouraged to choose a specific job that he or she wishes to do. Of course, individuals are free to change their mind and seek other opportunities for employment should they wish to do so.

**What is the most common kind of work-related activity?**

This is almost impossible to answer. See comment above. Activities include

- clerking in a store
- furniture refinishing
- office work, including but not limited to mail delivery, duplication, stock taking, etc.
- paper routes making and selling crafts - individual sales representative.



**Describe barriers and obstacles related to work.**

Initial acceptance by the employer, to low expectations by supporting agencies and individuals; fear of change; and the general economic outlook. [Canada now has 10%+, and in some areas 20%+ unemployment in the general population.]

**Social and cultural quality of life conditions**

**Do cdb adults normally live in an environment where people communicate with them according to their capacities and special communication systems? Yes sometimes/rarely**

Yes

**Do cdb adults have regular contact with their past? (old schools etc.) Yes/some/rarely**

Yes if they wish to do so. Some like to hold on to such links, others prefer new friends and family.

**Do they have regular contact with their families? Yes/some/rarely**

Yes, provided that they wish to maintain such contact.

**Do cdb adults have friends? Yes/sometimes/rarely**

Yes

**Do cdb adults have access to a common subculture? Yes/some/rarely**

Again, the question suggests an approach at odds with the Canadian philosophy. In most cases, the congenital or early adventitious deafblind adult chooses to become part of the local community and culture through the use of intervention and chooses friends from the community more often than other congenital or early adventitious deafblind adults.

**Do they have access to the culture of your country? Yes sometimes/rarely**

Yes

**Do cdb adults live in natural units according to the norms of your country? Yes sometimes/rarely**

Yes

**Do they have access to an equal family life according to the norms of your country? Yes/some/rarely**

Yes

**Describe barriers and obstacles related to realizing equal conditions related to social and cultural life on a separate sheet.**

See previous comments.

**Psychological conditions relating to quality of life**

**Do you think CDB adults have equal access to (for them) meaningful activities that nourish their personal development?**

What does "for them" mean?

Yes/sometimes/rarely

Yes

**Do you think cdb adults have equal access to non-linguistic ways of expressing their inner life? Yes/sometimes/rarely**

The identification and controlled expression of inner feelings is a learned response that must be taught. Most congenital or early adventitious deafblind individuals have limited secondary and tertiary learning abilities and these are the avenues that the non handicapped population use to develop the recognition, control, and expression of their "inner life". An adequate reply to this question is probably the substance of a university course or courses rather than an answer to a questionnaire.

**Do you think they have equal access to conditions that make them love and feel loved and needed? Yes/sometimes/rarely**

Yes

**Describe barriers and obstacles related to realizing equal conditions for psychological Q.o.L.**

The primary barriers to the development of an appropriate quality of life lie within the expectations of the service and support facilitators rather than within the congenital or early adventitious deafblind individual themselves. Such expectations expressed in terms such as:

"he is not capable of learning that!"

"she should not be exposed to that ...!"

"he will start in the ABC workshop next Monday, that is the next step"

"we will just fit her into our program for the [MR..., blind, deaf, etc.] it has a ...!"

"the approach we use with the mentally handicapped, deaf, blind, etc. should work"

etc. etc. etc.

A second barrier is the lack of national or international consultants that are available to support individual efforts to establish, modify, or evaluate existing services. It is unrealistic to think that the average worker in the field has the time, resources, or contacts to keep abreast of new developments in this rapidly expanding area of service to the congenital or early adventitious deafblind. A few countries or regions, such as the US, UK, Scandinavia, France, Germany and Canada have recognized centres of expertise. However, even these would benefit from a more formal program of information exchange.

**Vision for the future**

**What in your mind would describe optimal life conditions for cdb adults?**

Each congenital or early adventitious deafblind individual must be accepted as a person who has his or her own aspirations, likes, and expectations as well as level of functioning. Quality of Life means the opportunity to experience life as it is, not as some all knowing professional decides that it should be. Quality of Life means control with understanding, not compliance to imposed norms.

**Is there a shared vision on behalf of congenitally deaf blind post-school people among parents and staff?**

Yes

**What is this vision?**

The opportunity for each congenital or early adventitious deafblind individual, regardless of age or level of functioning, to participate fully in the local community according to the individual's interests and abilities through the use of intervention with sufficient financial support to make such an approach a reality.

## International discussion and collaboration

Do you think an international discussion/collaboration about Q.o.L conditions for cdb adults can be of any help?

Yes

If yes, how?

The sharing of ideas provides the basis for new approaches in individual countries and prevents re-inventing the wheel or repeating the same mistakes. [e.g. The concept was once held that if the educational system did a good job educating the deafblind child, he or she would not need special support as an adult. Upon reflection, it was being assumed that if the individual received appropriate education he or she would be a seeing or hearing adult or he or she would become an adventitiously deafblind adult and could be served by programs designed to meet the needs of the adventitiously deafblind, or he or she would be institutionalized, etc.] Through the sharing of information, such concepts are modified or replaced. Knowledge of programs and approaches used in one country can be used to reassure and even pressure bureaucrats in another country to initiate new programs and modify existing ones. Often, the knowledge that "we are not alone" provides comfort and new energy to tackle the job at hand.

## Further work

Is there any area concerning cdb adults that you think should be focused on particularly in further work?

- 1 The development of alternative support structures.
- 2 The application of learning theory to the continuing development of the congenital or early adventitious deafblind adult.
- 3 International staff training seminars and workshops.
- 4 An I.A.E.D.B sponsored exchange of information about specific topics and problems.

It is with great sadness that we report the death of Jaana Aro of Finland who represented Finland, along with Marja-Leena Saarinen, for a number of years. Jaana died on 31 May. Our sympathy is extended to her family and colleagues.

## Quality of Life for congenitally deafblind school leavers and young adults

# The Questionnaire - background, results, comments

## Background and Introduction

At the IAEDB executive meeting in Potsdam in 1992, some representatives especially interested in issues concerning quality of life for congenitally deafblind school leavers, young adults and adults, volunteered to form a programme committee to prepare an IAEDB symposium in Boston this year, dedicated to address this topic. In order to involve more people than those attending the symposium, and to get a more representative background for the questions addressed at the symposium, we decided to send out a questionnaire on the topic to the international network of IAEDB representatives.

In addition, a group of parents, organized by Gini Cloke in the UK, arranged a seminar where they reflected on the issue, and tried to give voice to their young adult children.

The information received is of course what it is, statements provided by people who are concerned about this issue.

I would like to share with the readers the one contribution which helped me to organize the rest. It was by a parent giving voice to her young adult child. The statement is as follows:

### "I WANT TO BE FREE"

Immediately I remembered the first word written spontaneously by a young girl in our school after 9 years special education. The word was "FREE".

Just before the symposium I went to see the film version of Steinbeck's novel "On Mice and Men". This author probably understood something essential about human loneliness. He may have felt that it is the responsibility of the strong to create a vision for the weaker, a vision which for the weaker becomes reality. In Steinbeck's novel the vision

contained a space of freedom, and a function within that space. In this case it was: "tending the rabbits". The total disruption of that vision may distort all possibilities for quality of life. Steinbeck went as far as to touch upon the relation between this vision and quality of death.

Maybe the only escape from naked reality is through fantasy about a separate reality, and the continual effort to realize shared visions without losing the dual consciousness you need to be responsible. This is of course nothing more than my point of view. But I appreciate the image I have that the international collegueship organized by IAEDB creates a professional space of enough freedom to be oneself, have a function and keep visions alive.

In my country and in the Nordic countries, policy for adults seems to be based on a concept of reality which to me seems very real, too real to be true. In the Nordic countries many colleagues are afraid that the ideology of normalization and decentralization, if not thought about very carefully, can become a prison of loneliness. We need to know what other people think, what is done, planned, thought, and envisioned around the world. At least one thing everybody agreed about in the answers; the need to discuss this on an international level, to share and to exchange questions and answers, ideas and experiences. This is in order not to repeat each others mistakes, and not to continually re-invent the wheel.

From the 24 completed questionnaires from all around the world, and from the other letters and reports received, it is clear that IAEDB has raised questions, which as yet, have no easy answers.

At least two responses to the questionnaires are being published in Deafblind Education. The first was the British response, pointing more to restrictions than to

answers. The second, published in this issue, is the Canadian. It is interesting, because the Canadian response was special in the way that the persons answering were clearly provoked by the philosophy underlying the questions. It is also interesting in the way that they come close to something like an answer. From the other answers, and from the discussions, especially about culture and sub-culture, it is also clear that the philosophy underlying the Canadian answer will promote considerable discussion.

## Results

Representatives from 24 countries/states/provinces answered the questionnaire. Two answers were too late to be counted in "the statistics".

This overview may make things easier for readers. Some countries seem to have come up with interesting, though different, total to partial solutions, which can be visited and seen. These include:

France: (contact Jean Francois Guerin in Poitiers) Focus: Workshops and realization of autonomy.

Denmark: (contact Klaus Wilhelmsen) Focus: Creativity/subculture/ educational principles in continual education, vocational training.

Canada: (contact John McInnes) Focus: The intervenor system. Integration and independence/equality.

Germany: (contact Dietrich Bunck) Focus: A differentiated service system. All areas of living conditions. A new "farm" for adults needing sheltered conditions.

UK: SENSE units. Units in villages administered by Jane Evans.

Norway: (contact Knut Johansen) Focus: Differentiated living conditions within a sheltered village concept.

Coming next year: Tromsø (still a vision) (contact Anne Nafstad) Differentiated mini- "village". Creative living and restitution of heavy deprivations (earlier institutionalizations)

Bergen: (contact Eva Britt Andreassen) Sheltered Village. In realization.

Sweden: Mo Gard (contact Marjaana Suosalmi) Focus: culture/subculture, restitution of heavy deprivations, vocational training. Psychiatry of deafness/deafblindness (specialized consultant). Communication

problems and selfinjury. (Specialised psychologist-consultant) Centre in rapid expansion.

Italy: (contact William Green) Focus: Differentiated partial integration within Osimo. Sheltered workshops.

US: Helen Keller Centre: Functional communication in transition programmes.

California School for the Blind: Transitional programmes. (Transition to integration in the community).

Poland: Deafblind Art.

Africa: Ghana & Kenya. (I do not know enough to specify the focus of the resources.)

Pacific: Resources exist, but I cannot specify focus further. (contact Heather Hewitt.)

## On the questionnaire

The questionnaire focused on different aspects related to Quality of Life (Q.o.L.), starting at the level of the system and moving closer towards the psychological level. All the 50% answers may indicate that many questions were unclear. People probably attributed different meanings to the words used in the questions. During the symposium, it was clear that a discussion around basic Q.o.L. related concepts is useful and necessary.

### 1 System level

Continuing education & vocational training

- More than 50% indicated the target group RARELY receive adequate continual education
- Around 50% indicated that adequate vocational training is RARE.

### 2 Policy

- 50% indicated official recognition of deafblindness as a separate handicap.
- 75% indicated the concept of deafblindness includes congenitally deafblind (cdb) adults, also multihandicapped.
- Generally, practical responsibility for initiating services to the target group is "private" or through associations, but funded generally from different public sources.
- 80% indicated the service is not, or only partly differentiated according to needs.

- 50% indicated there are no plans for provisions for this target group.
- 50% of the answers indicated such plans do exist.

### 3 Population overview

Concerning the whole population of cdb people:

- 30% indicated there IS an overview
- 30% there is, PARTLY
- 30% there is NOT.
- Concerning the target group of post school cdb people:
- 50% indicated there is NO overview
- 50% indicated there IS
- 70% indicated they do not overview the target population of the future.
- Concerning survey of needs of the target population:
- 50% indicated such surveys had NOT been undertaken
- 50% indicated YES, or PARTLY.

### 4 Welfare indicators

#### Housing

- 50% indicated NO units especially adapted to needs of the target group.
- The relevance of this kind of question may need discussion. The same goes for other questions touching upon "special" services and "units". Remarks were made that the use of such words is associated with a philosophy of institutionalization.
- Among the different "units" where one can find the target groups, all the listed options were mentioned. The most common were:
- Parents homes ( mentioned by 60%)
- Institutions for mentally retarded people (mentioned by 50%) - Schools for special education (50%)
- Special group homes for cdb people (40%)
- Units for other groups of handicapped people (40%)
- Other (35%)
- Support systems/service**
- 50% indicated NO support service serving units where the target group lives.

- 50% + indicated a NOT ADEQUATE medical service
- 70% indicated there IS, sometimes or regularly, collaboration between units
- 25% indicated REGULAR collaboration between units for children and adults. (35% sometimes, 35% rarely.)

#### Work possibilities

50% indicated there is hardly any possibility to engage in meaningful activities according to individual capacity

20% indicated there ARE possibilities.

#### 5 Social and cultural Q.o.L conditions

- 40% indicated the target group does NOT live in an adequate communicative environment
- 35% does SOMETIMES
- 25% indicated they DO.
- 65% indicated target group has NO contact with their past (old schools etc).
- 65% indicated regular contact with families.
- 50% indicated target group RARELY has friends
- 12% indicated they HAVE friends
- 38% indicated SOME have friends
- 70% indicated RARE access to shared subculture
- 20% SOMETIMES
- 10% YES.

*This question is interesting. The comments indicated two totally different philosophies represented in the answers. One philosophy wants to abandon the idea, another to promote it. This is a point of possible controversy. Interestingly, both views are promoted by countries with advanced services.*

- 50% indicated rare access to the culture of the country
- 20% indicated such access exists.
- 40% indicated access to equal family life is RARE
- 45% indicated that some have such access
- 10% indicated there IS equal access.

*Probably in this question living according to OTHER family norms than nuclear family / marriage was*

*meant. Maybe living at home in an extended child-role was meant as normal? The answers and question here are unclear, and this is a point for discussion.*

#### 6 Psychological conditions related to Q.o.L

- 50% indicated target group SOMETIMES has equal access to meaningful activities nourishing PERSONAL development.
- 10% indicated such access DOES exist.
- 50% indicated equal access to express inner life is RARE
- This point should be discussed
- 40% indicated SOMETIMES
- 10% indicated such access EXISTS.

*Important point of discussion. How do we know ANYTHING about their Quality of Life?*

*What are the cues by which we pass judgement on the adequacy of our support?*

- 10% indicated the target group has equal access to love and to feeling loved
- 50% indicated SOMETIMES
- 40% RARELY

*This is important for discussion.*

*There are positive experiences described, including philosophical and practical solutions. If we look at the social and cultural and psychological conditions, a low degree of suspected existential isolation in adulthood (cultural, social, psychological) is reported e.g. by John McInnes in Canada, by Sazarin and Souriau in France, by Klaus Wilhemsen in Denmark, and also by others. The four mentioned gave presentations in the symposium. Their approaches are not exactly similar.*

#### The main obstacles and barriers mentioned:

- the handicap itself, especially the problem of communication and access to information
- lack of trained staff
- lack of acknowledging attitude in society
- lack of knowledge about the target group and their needs and especially their potential
- bureaucracy
- lack of creativity in staff - lack of

human resources

- the political situation in general, especially the economy - the medical model
- decentralization/geography - size of population
- lack of access to social environments - the mechanistic nature of society
- lack of policy.

There seems to be 2 populations within the target group:

- 1 Those who are known and of whose needs there is awareness. This is because they were or are enrolled in special education programmes for cdb people.
- 2 The "hidden population", whose existence is only estimated and who were never enrolled in such programmes.

From what we know about these people, they suffer from very serious deprivation.

It appears to be the case that the (special) education system provides the greatest chance of recognition and for receiving adequate help.

Does special education take responsibility through a LIFE LONG PERSPECTIVE of adequate support?

Where is the CONTINUITY of responsibility, other than with the parents?

On the basis of the answers to the questionnaire, the information that came in, and the symposium, a position statement was written. This focuses on social and cultural conditions for quality of life, and on securing quality so that the increased risk of decreasing quality with age is counteracted.

#### Postscript.

FREEDOM was not mentioned by many. But it was articulated by the most important persons. FUN was mentioned by only one person. But that person is in line with the most famous of the Norwegian philosophers, professor Arne Næss. He is very old now, and he does not speak very often any more. When he's not climbing mountains, he takes time to repeat: "Adult life is too serious. Adults should play more." Of course, the old philosopher does not talk about congenitally deafblind adults. He talks about all human beings in our culture.

Anne Nafstad  
May, 1993

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# Deafblind services in New Zealand

**Lucy Addison**

I am the mother of a deafblind boy, who is currently 19 years old. I would like to outline our experience and compare the services we have received with services available now, and see what services are envisaged for the future in New Zealand.

Laurence was born in 1973, the first of our four children. I had rubella in the first few weeks of pregnancy and Laurence was born with cataracts in both eyes, a 'hole in the heart', and damage to his hearing and intellectual functioning. We were told that every cell in his body had been affected and that he would never develop normally. We were advised to put him in an institution as he would be a vegetable all his life. We disregarded that advice as we felt it ridiculous to write-off someone's entire life on the basis of their achievement at a few weeks old. At about eighteen months Laurence had meningitis and this was another major set-back to his development, and we felt it further damaged his hearing, as prior to that, he made pre-speech babbling noises.

For services to be of any use, one first needs to know they exist. Although Laurence had regular contact with many doctors, paediatricians, nurses, his ophthalmologist, audiologist, physiotherapist and so on, the only service agency we were advised to contact was the Crippled Children Society. The reason given for suggesting them was his multiple disabilities. I did not make contact with the Royal New Zealand Foundation for the Blind until Laurence was about two years and nine months. I was not aware that they had any services they could offer Laurence and none of the medical people we saw suggested it. When the field-officer enrolled him and asked if I would like Laurence to go to Homai College I was amazed because I had assumed Laurence was too badly handicapped to have even a remote chance of going there. For the first time I heard about the existence of the Deafblind Unit there and was assured that Laurence was no worse than some of the other children. When I visited the Unit with Laurence a short time later, I saw other deafblind children for the first

time. Until then we had not even heard of the term 'deafblind' and did not know that Laurence fitted into a recognised category.

## Education

Our experience with the Deafblind Unit at Homai College has been very positive. From the very first time I went there, I have tangibly felt the support of the staff. From the outset, the attitude had been - "It's not just your problem, we're all in this together." Sharing the load like this has been a tremendous help, as the burden of having had a child like Laurence would be difficult to over-estimate. The early years were very difficult and there were very few high points as his progress came in such minute degrees it was easy to overlook.

Until he was five, he attended part-time, and I stayed with him all the time, and after that he became a full-time student.

The six-monthly reports from the Homai staff were always a great encouragement to me as they always stressed what Laurence **could** do, and seeing improvements recorded in print seemed to give them added importance.

His school programme has always had a major element of teaching self-care skills, and for many years now Laurence has been independent in eating, dressing, bathing, etc. As he grew older his training included cooking, doing his washing, bed-making and basic shopping, etc. He began to walk when he was nearly three and a half and is very mobile. On the academic front, Laurence can write and recognise his name, and can count to about six.

He would never have achieved this level of independence if we had not had available to us the residential facilities and trained staff at Homai. Throughout his school years, he lived at a hostel at Homai College during the week and came home for the weekends. Each self-care skill, such as eating, dressing, toileting and so on, has only been achieved by adherence to a training programme with each task broken down into minute steps, and records kept to monitor results.

I believe it is essential that such facilities continue to be made available to those children who need them. I defy any family to follow such a programme effectively on their own and have a normal family life and raise other well-adjusted children, giving them all opportunities to participate in sporting and cultural pursuits, and to have a life that is now always dominated by the needs of the handicapped child to the exclusion of all other members of the family.

## Communication

From the beginning of our association with Homai College, Laurence has been taught Total Communication. The sign language used is the Australian Victorian sign system. As Laurence's understanding of signs increased there was a direct relationship with improvement in his behaviour as his frustration level was lower and he had a greater understanding of his world. The ability to communicate with those around him has been a major factor in him achieving what he has, and has enabled him to anticipate with pleasure those things he enjoys, e.g. going swimming, and to cope and adjust to difficult ones, e.g. hospital.

## Educational planning

Whilst at school, an IEP (Individual Educational Programme) was done every six months. For this a meeting was arranged with all of the professionals dealing with Laurence (teaching staff/ residential staff, Occupational Therapist, psychologist, etc) and parents, and together we discussed progress and problems and planned objectives for the following six months. In this way the programme was kept specific relevant and up to date, and has always been a collaborative effort.

## Staffing

The Deafblind Unit has always had an excellent ratio of staff to pupils. Throughout Laurence's time there it has been about one staff to two pupils. This has made it possible for the children to receive intensive attention and that, and the quality of staff, have made it possible for them to achieve fine results with their students.

## Integration

Laurence attended the local kindergarten and regular primary school for sessions with a teacher-aid as part of his programme, and when he was older he spent some time with other students within Homai College.

## Vocational

At present Laurence is attending an Auckland Protected Employment Trust (APET) workshop for four days a week, and spends one day at Work Options, a sheltered workshop administered by the Auckland Area Health Board. Both of these facilities speak very highly of Laurence's abilities and work habits, indeed the manager of APET says he is, the best worker in the workshop. The Deafblind Intervenor from the RNZFB has visited these workshops regularly since Laurence began, to instruct the staff in signing and without her active role Laurence would not have been as successful as he has.

While still at Homai College, Laurence developed his skills in the workshop there, and then spent a gradually increasing period of time at another APET workshop. As the time approached for him to leave Homai College, the staff there located various possible positions for him, and we visited these together and discussed the pros and cons and the final decision was ours.

At his most recent IPP (assessment), the staff member from a workshop expressed the view that Laurence is so able that she would like to see him have an opportunity in open employment, and she is currently endeavouring to find him a suitable position. The employment situation in New Zealand is difficult for everybody, with record numbers of unemployed, but we are hopeful that someone will be prepared to give Laurence a chance.

## Recreation

When Laurence was at Homai College he had many opportunities to try different things in the field of recreation. These activities included swimming, gymnastic activities, horse riding with Riding for the Disabled, music art and craft, roller skating, skateboard riding and regular outings on trains, boats etc, and visits to places of interest e.g. Auckland Zoo etc.

Since leaving the Deafblind Unit he has had a much reduced recreation programme. The reason for this is simply the fact that he needs someone to be with him and at his residential placement there are no staff to be spared. All of the activities he enjoyed at Homai he would still enjoy if it were possible for someone to accompany him. For a time the Deafblind Intervenor employed by the Foundation for the Blind arranged for a volunteer to take him out once a week for these type of experiences but that has not continued. As anyone working with

Laurence needs to be familiar with signing and know him well it places limits on the possibilities. We are currently trying to locate a 'buddy' for him who would be able to spend time with him regularly to extend his horizons in this area.

## Residential

When the time approached for Laurence to leave the Deafblind Unit the Deafblind Intervenor and Laurence's teacher collaborated in finding a possible placement for him. There is at present no residential facility tailored for the needs of the deafblind in New Zealand, so it was a case of finding him a placement in a home where he would fit in as well as possible. The Deafblind Intervenor visits the other graduates of the Deafblind Unit at their residences and was only too well aware of the difficulties involved. Together we visited the one she recommended and agreed to apply for a placement for Laurence there. He was accepted.

Once again the Intervenor has supported Laurence and given ongoing regular signing classes to the staff and has assisted them with catering to his special needs. e.g. When he moved in they found he was spilling drinks and messy at table, so she suggested they ensure he had good colour contrast i.e. not to give him milk in a white cup etc.

The present placement is not ideal. There are 13 residents with one staff member on duty at a time, so many of the ideas we have for extending him and keeping up the skills that were so hard-won are unable to be implemented. e.g. Laurence no longer has opportunities to do cooking. Because of the social immaturity and emotional needs of the other residents, they have been intolerant of Laurence, unable to grasp his difficulties and jealous of staff trying to give him extra attention.

The hostel has been refused funding for extra staff based on the needs of Laurence and the one other deafblind resident. It was established to provide a rehabilitation programme for disabled young adults and is a short-stay halfway house. There is no satisfactory long-term residential option at present for Laurence.

## Future residential

The other graduates of the Homai Deafblind Unit are also in residential placements that are inappropriate and do not provide a long-term answer to their needs. Many of them are regressing, losing

skills and their previous level of independence. To address this, a group of parents have banded together and are undertaking a new initiative. We are currently in the throes of establishing a Charitable Trust and have submitted an application to the Community Funding Agency for funding to set up a five bed house with a programme tailor-made to cater to the needs of our deafblind young adults. We have not had an official reply yet, but understand that our application is receiving favourable consideration.

Our mission statement is: "To provide a life long community house placement for a group of five Deafblind young people, staffed with personnel who are trained in the specialised needs of this group and who are able to support them to maximum independence, through considered intervention, in the home, workplace and wider community."

We want to have parents directly involved in decision making, improve the quality of life for our young people and to give them some security for their futures.

## Looking toward the future

To bring myself up to date in services available now for the deafblind I have made some enquiries.

The Deafblind Unit at Homai College is no longer in existence but the services continue as part of the general College programme. There are at present five deafblind students in the school programme, with ages ranging from 7 to 12 years. They have a separate programme in the mornings and are integrated with other visually impaired students in the afternoon. They are taught by two trained teachers of the deaf and one teacher-aide and the programme covers communication, cognitive skills, academic skills, daily living skills, recreation and leisure and pre-vocational skills.

Four of the students live in the Homai hostels and the effort to teach the children daily living skills continues as it was when Laurence was there. In Kowhai House, where three of the deafblind children are, there are six staff employed for the total of nine children, with three staff on duty at the times when the children are there. All of the staff are trained in signing and so input to the children is consistent and intensive.

Funding for education is limited and the impact of that reaches

everyone, making it difficult for staff to provide the service that they would wish. Staff feel that the deafblind children currently at the College are adequately provided for as the programme is still based on each child's IEP. For new children an IEP would be planned and staff would advocate for an additional teacher aide to provide the intensive programme required, but there is no guarantee that this would be supplied as cuts would have to be made in another area of the College to fund this.

Parents of new children are not considering a residential option because Homai are not able to offer it because of falling staff levels. When staff leave they are not replaced so the hostels will gradually reduce further and this valuable option will cease to be available.

In the mainstream education system funding is allocated according to the number of children on the roll, but this is not the case with our children - Homai do not receive more funds when they enrol new children, neither is the degree of need taken into account. The RNZFB receive a

bulk grant from the government and a portion of that is allocated to Homai College. Homai is now providing more services overall than it used to, e.g. the Inservice Advisory Research and Development team, without receiving more funding and staff are living continually with the threat of cuts to their funding. These days a greater proportion of visually impaired children have additional disabilities, so this is a growing area of need.

Current educational philosophy is not sympathetic to the very existence of special schools or special units in regular schools. Their philosophy is one of total inclusion and no other option is considered. They have total commitment to this ideology and refuse to acknowledge that this may not be in the best interests of some children and that other options should be available.

This actually contradicts the IEP system which is based on the premise that a child with special needs should have an educational programme based on their individual needs. The results of the

inclusion philosophy will not be known until this generation of special needs children have become adults, and in the meantime these children are guinea-pigs, losing forever their optimum opportunity to learn.

Parents of visually impaired children with additional disabilities who come through the assessment programme at Homai College are universally opposed to this total inclusion system. All of them wish their child to be educated according to their needs to give them the best possible preparation for life.

One wonders what the future will hold for the very young and as yet unborn deafblind children. Those of us who have benefited from the Deafblind Unit at Homai College hope that others too may continue to receive the specialised service previously offered and that mainstreaming and inclusion do not result in a watered-down and inferior service offered to these very needy children, for whom intensive specialised input at an early age would enable them to live full and satisfying lives as adults.

## Pacific Region

### UK expert in Australia

Doreen Woodford, a British authority on the education of hearing-impaired children, visited Melbourne late last year to deliver the inaugural Gorman Foundation Lecture.

Ms Woodford holds a number of senior positions in the disability field in the UK, and is on the advisory committee of the National Association for the Deaf Blind.

While in Melbourne she took the opportunity to spend time with DBCA staff and clients while visiting the family group homes. During a visit to the Association's Head Office, Ms Woodford was very interested to hear of recent developments in the Usher Syndrome field in Australia.

She said a very strong community feeling was developing among people with Usher Syndrome in the UK, and they were doing increasingly adventurous things together which a few years ago none would have imagined.

Groups have sprung up all around the world, and this has encouraged international travel.

There is a growing awareness of the way all vision-impaired people

who are also deaf are pushed to the edge of the deaf community.

Efforts are being made to make this community more aware of the role they should be playing in the lives of vision-impaired people.

This is a matter of education, and here the Usher group is taking the lead.

"Another move is to improve and enhance communication possibilities beyond what we call the use of the Deaf-Blind Manual. We are particularly looking at the use of an improved indigenous sign language, especially for those whose communication is limited," Ms Woodford said.

"A great deal of attention is being paid to sign systems in the world of education, but these do not have anything to do with spelling. Increasing numbers of young people are learning these systems, which involve signs representing ideas that have a much greater meaning than simply spelt words.

"The communication practices I have seen in Australia have been fine - it is simply the description I object to because it reveals confusion," she said.

It is important too that organisations liaise with teachers so they are up to date with the communication skills clients or

future clients with sensory disabilities are learning at school.

"New concepts are being developed for young deafblind adults in the UK who have reached the end of their schooldays, but whether these will all be translated into options I would not like to say because of the constraints of money and old-fashioned ideas."

The vision of options is greater than its reality but there are many opening up. Both people with disabilities and professionals are more aware of what might be possible outside the traditional fields.

"While I have not seen a person with disabilities supported by another person in open employment, I have seen many fellow workers being trained in such areas as sign language.

"Each UK county is supposed to have a specialist careers adviser available for every young person with a disability but many of them have not for financial reasons, and our concern is that often the advisers cannot communicate properly with people who are deaf.

"In the case of two sensory impairments the problem is even greater, and disability organisations themselves are employing people to provide career advice," Ms Woodford said.

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

The editor will be pleased to receive articles, news items, letters, notices of books and coming events, such as conferences and courses, concerning the education of deafblind children and young adults. Photographs and drawings are welcome; they will be copied and returned.

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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