

Deafblind Education

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Congenitally deafblind adults
– principles for a quality of life – Part 2



CHAIRMAN'S REMARKS

First of all, I would like to address my best wishes for the new year to all IAEDB members from all parts of the world. I am sure that all of you (families, friends or professionals) will do your best to improve the quality of life of the deafblind people to whom you are related.

I would also like to tell the deafblind persons who belong to our association as well as to all the other ones that IAEDB will go on supporting all the actions aimed at making their needs met and their initiatives encouraged and implemented.

Our next Executive Meeting will take place in Poland thanks to the very efficient help of our Polish colleagues. This meeting will be an occasion for us to exchange about the many events, actions and projects which are taking place all over the world.

During the two days before the Executive Meeting, a symposium will address the problem of mental illness in deafblind people, a



question we all come across, although there has been very little attention given to it during our previous meetings or conferences. I am sure that these two days will be an occasion to improve the awareness and the quality of intervention concerning this very specific topic.

Our next years will be very Spanish, since the world conference will take place in Argentina in 1995 and the European conference in Spain in 1997. Please, do your best to learn Spanish if you want to fully profit from these two events. No doubt the quality of the scientific content will equal the quality of the social events which will surely be of high standard, knowing the organisers.

My last words will be for the IAEDB secretariat which, inconspicuously, type, look after the money, keep the books, answer the phone, edit our newsletter, dispatch the information, prepare the meetings ... in a word work hard for the benefit of our organisation and for deafblind people. On behalf of IAEDB I would like to express our gratitude for the good job they are accomplishing, making possible the amazing development of the activities carried out by our ever growing network.

Jacques Souriau

EDITORIAL

This edition of Deafblind Education includes the two final papers from the seminar held in Boston, USA in April 1993 on the topic of quality of life for congenitally deafblind people.

Another symposium is being held in April 1994 in Bydgoszcz, Poland on the topic 'Behaviour and Personality Difficulties Approaches in Care and Services for Deafblind People'. This will result in some very interesting papers on perhaps controversial topics - for example 'Only an Ostrich is Against Drugs' is the title of a plenary session - which I hope we will be able to cover in later editions of Deafblind Education. Workshop topics planned are 'Autism and Deafblindness - Relation or Mislabelling', 'Depression and Reaction in Congenitally Deafblind Persons', 'Sexuality - Our or Their Problem' and 'Self-Abusive and Aggressive Behaviour. Different Approaches in Treatment'.

The European Conference in Summer 1993 in Potsdam, Germany was very successful. I was a member of the Programme Committee and it was a very



satisfactory experience to see our ideas come to fruition. One of the highlights for many people was the plenary presentation by Daniel Alvarez Reyes. Daniel is himself deafblind and is the Counsellor on Deafblind Affairs at the Organizacion Nacional de Ciegos, Spain. A short version of his paper 'Access to Context: A basic need for deafblind people' is included in this Deafblind Education".

Other recent activity in Europe has included a meeting of the European Usher Syndrome Study Group and publication of proceedings. The committee on Acquired Deafblindness in Adulthood is continuing its work with a seminar in March 1994. The sub-committee on Staff Development is also continuing and will be helping develop the newly formed European Coordinating Unit for Deafblind Services.

There is so much happening at the moment often in difficult circumstances. At Potsdam a workshop on the major developments in the Czech Republic indicated the importance of sharing information and materials. I hope that Deafblind Education will be used as a tool for the further development of quality education and services for deafblind children and adults around the world. I look forward to receiving your contributions to help make this happen.

Malcolm Matthews

Music Research Project - Norway 1992/93

I was conducting a Music Research Project at the 'Aks Hjemmet for Dove' (AKS) (Home for Deaf), in the small village of Andebu in Norway, for a period of a year (Aug 1992 - June 1993). The students were deafblind and deaf multiply handicapped. My priority was to see how music could assist them to relax and enjoy a 'New Musical Experience', using a specially purpose built 'Music-Floor'.

I was working with 14 children and three adults who had a broad range of disabilities including autism, brain damage and deafblindness. The techniques using 'Touch, Communication, Relaxation using Music and Movement' (TCRM) appeared to assist the students to feel more relaxed and to respond positively to the different styles of music. More importantly they were able to enjoy the experience of feeling the vibrations through a 'Music-Floor'.

The centre had a specially purpose built 'Music-Floor', which had a music hi-fi centre linked through the floor. This included the use of a keyboard and microphone through the 'Music-Floor'. The vibrations from the music appeared to relax the students' bodies and made them feel more confident in being able to move around. It appeared to assist some students in their daily living skills, as in one case a boy was able to control his toilet much better at regular times because his body became more relaxed.

This was a joint project with the Special Teachers at the school who became actively involved and were able to use the 'TCRM' techniques within their own teaching environment. The Music Research Project identified the 'Styles of Music' applicable to use with deafblind and deaf multiply handicapped students. A report was produced for ARS which identified various techniques one can use and identified methods of applying 'Sound and Rhythms' for these types of students.

A condensed version of this report is currently being prepared for future publication. If anyone is interested please contact Russ Palmer at the following address:

Music Research Project - Norway,
RPL Associates,
30 Critchfield Road, Old Bosham,
Chichester, West Sussex PO18
8EH, England. Tel: (0243) 572393.
Price £4 (add £1 p&p).

Russ Palmer



Tanzania is one of the three sister countries of East Africa. In the South it is bordered by Malawi, Mozambique and Zambia. Uganda and Kenya are on the Northern part while lake Victoria, Burundi, Rwanda and Zaire are found on the Western part. On the Eastern coast lies the Indian Ocean.

It has a population of about 30 million people of which ten percent (3 million people) are disabled.

In general, the situation of deafblind people in Tanzania is very disappointing due to the fact that until now there was no programme whatsoever established to cater for them. They are the poorest of the poor, most illiterate, ignored, neglected and jobless.

National Committee

It was in the light of such an appalling situation that a call was made to establish an organ which would be involved in the provision of services for the deafblind people. Therefore the Tanzania National Committee for the Deafblind was born in February 1993 as a brain child of the two seminars held in Kenya and Uganda to discuss issues pertaining to deafblind people in East Africa.

This is a Committee of its own kind which expresses continuing concern for the rights of the deafblind people, in which case it acts as a pressure group to draw the attention of the Government and other interested parties to the plight of deafblind people. The Committee aims at promoting employment, technical assistance, prevention of deafblindness and any other aspects that might be important for the well being of deafblind people.

To start with, the main focus has been on children, although the aim is also to take into account the adults depending on the progress of the committee after its take off. Until now

30 school-age children have been identified, for whom plans are being made to look into the possibilities of establishing a unit.

In its efforts to promote services for deafblind people; the Committee has tried to prepare a plan of action that stands as a pilot project in Dar es Salaam city whose evaluation will determine the future situation. This pilot project is worth Tshs 41,091,600 in total or equivalent to (US dollars) 117,406,5714. However, the implementation is yet to take off due to lack of funds.

Some of the major problems the Committee faces are:

- Firstly; the absence of a building; both for the Committee Office and for the Unit.
- Secondly; a lack of transport. This makes it difficult for the Committee Secretary who is a blind person to reach the already identified deafblind children as they live far from one another. More often than not this Secretary has to go on foot from office to office in an attempt to advocate the activities of the Committee.
- Thirdly; lack of funds in general. The Committee so far has no funds at all. All Committee plans have remained just a mere dream and wishful thinking. There is no office equipment, such as typewriters, filing cabinets, tables, chairs, telephone services, computers, fax and the like. Hence, the Committee faces a serious communication block. The Committee has therefore failed to recruit any personnel for its various plans.

At this juncture may I please make an appeal for international support of whatever kind; financial, equipment, advice or other. I hope that having learned of the real situation that deafblind people are facing in Tanzania, and of the difficulties that hit the Tanzania National Committee for the Deafblind in its efforts to render a service for the people so concerned; you will sympathetically respond to our cry. Remember deafblind people are full human beings just like you and me. They have feelings and wishes that need recognition and acceptance.

Lastly the Committee wishes to express its inner felt thanks for those who in one way or another feel the call to support the Tanzania National Committee for the Deafblind, either materially or morally.

The Tanzania National Committee for the Deafblind

Cordoba '95

It was about 10pm when Graciela and I left the hotel to go out for an evening meal. We walked through the streets in the centre of Cordoba to the restaurant. Even during the cooler months of July and August it is delightful to stroll through the pedestrian area. The old streets are full of shops selling quality leather shoes, stylish clothes, colourful knitwear, silverware and local wooden craft objects. Food stores have appetising displays of oils, sauces, meats and chocolates. There are many cafes and restaurants, for Cordoba is a regional capital but also a tourist centre attracting visitors from many parts of Latin America.

The restaurant was a large room with high ceiling. It didn't open until 9pm - Argentines tend to eat late in the evening - but by 10.30 was full of noise. Families of seven or eight people were discussing, laughing and enthusiastically attacking large plates of food. At another table, a young couple both dressed casually but elegantly in white silk shirts, were enjoying bowls of colourful ice cream with rich sauces. Four older people, well known to the restaurant owner, were tasting the local red wine - far nicer than the drink they export. They were dressed formally, in suits and ties with both women wearing embroidered dresses with more than a hint of sparkle on them. The music was Spanish, the atmosphere Mediterranean, but the food was Argentinean. And the people, although of Spanish descent, were proud of their own identity and the history of that region of South America. What seemed common to everyone was enjoyment. You felt that if an excuse could be found, people would get up and dance. Life was meant to be enjoyed.

We met some friends, ordered several bottles of wine and then went into the cooking area to look at the meats for our main course. There were enormous portions of really high quality meat - vegetarians are catered for although the national enthusiasm for eating is really based on a love of the superb quality meats. This restaurant had a central barbecue at which you could select the pieces you wanted which would then be cooked to your order. The staff, who willingly spoke English, were keen to ensure you had all the

information you needed to make choices. Precisely what part of the animals were being offered, which sauces would complement the flavour best. To the English eater, it was rather more explicit than expected.

I was in Cordoba for a meeting about the IAEDB Conference in 1995. Graciela lives in Cordoba, works for the Hilton/Perkins Programme and is chair of the programme committee. She had picked me up from the hotel after we had put in a full day of meetings and visits. We had spent some time at the university where the conference will be held. The campus is quite new with plenty of rooms for workshops as well as a large central hall and dining room.

Just along the road from the university is the Helen Keller School for the Deafblind. Graciela has an office there and Lucia Piccionne, chair of the conference committee, is the headteacher. There has already been a lot of discussion between them and the university staff. The university has hosted large conferences before but they see this as rather a special project which reflects well on their town. They want to do the best for the School, of which the town is proud, and for the visitors who will judge the region by their efficiency and welcome.

The programme committee has met twice and made all the major decisions on conference format and content. Plenary session speakers have been confirmed; themes for the workshop sessions have been agreed; a timetable for announcements and call for papers has been finalised; a budget has been drawn up and sponsorship targets set. The main themes were announced in September 1993 and are strategies for integration; multi-disciplinary approaches; recreation, play and leisure programmes; adaptation of the environment and materials. A call for papers on these themes will be sent out in September of this year. One day of the conference will form a 'break-out day' when we will hold a number of mini-conferences. Participants can choose one topic to explore in depth for the whole day. We now have experts in each of the topics who have agreed to put together a programme.

Back in the restaurant we discuss the social programme. Some

The 11th World Conference of IAEDB

will be held in
Cordoba, Argentina
on 9-14 July 1995.

Full details will be
announced in
September 1994.

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time during the day was spent visiting local places of interest and talking with city officials. A reception in the town hall with the local band seems likely and an open air barbecue would be possible. The town, on the edge of the Pampas, is surrounded by countryside with rivers, waterfalls and lakes. A coach trip round part of this would be appreciated - the talk turns to visitors that have been taken round and what they found interesting.

Many participants will come from overseas but a number are expected from Latin America. The growth in services for the deafblind has been remarkable. In the past eight years, six new schools have opened up, staff training was been carried out and a support network established. The presence of the conference should help the development of those services and is a marvellous opportunity for staff and managers to find out more. We talk a little about the needs of these participants to make sure they can be met alongside those of more experienced professionals.

I notice Lucia's shoulders moving. The music has changed; this is clearly for dancing to. I don't believe an Englishman is made to move to these rhythms - certainly not this Englishman. But Lucia is already standing up and reaching to me across the table. She asks, 'Are you good at this? I hope so!' Oh well, there's still enough time left to practice. See you there in July 1995!

Tony Best

Access to Context

A basic need for deafblind people

Daniel Alvarez Reyes, Organizacion de Ciegos, Spain.

The access of a deafblind person to the "real" context, to the world which surrounds him/her, is determined by his/her ability and expertise in overcoming the barriers and voids created by lack of sight and hearing.

This characteristic of a lack of immediate connection with the environment and the need to use the sense of touch in order to receive information and communicate makes deafblindness a single disability which cannot be contemplated as the sum of two.

From this, the need arises for specific strategies, techniques and quality services, both in the education of deafblind children and in assisting adults who have become deafblind to adapt to their new situation. We must first of all learn and understand the context.

The role played by those close to us, by the professionals working with us, and general social acceptance are fundamental: we deafblind are not in a position to undertake, on our own, the task of building

bridges between the limits of our perception and the outside world, and we require the support of all.

I would now like to explain some of the most serious difficulties faced by the deafblind within an environment which "hears and sees". Afterwards, we will analyse some of the resources we have available and which we will need to develop with the aim of attaining an independent and integrated lifestyle.

1 How does deafblindness affect our relationship with context?

According to the age at which deafblindness occurs, its characteristics differ greatly.

At birth, we make contact with our surroundings by means of the stimuli we receive through our five senses and links with the world occur thanks to the social and cultural inter-relationship of the person with everything which surrounds him/her.

Without an intervention to compensate the lack of perception of external stimuli, deafblind children will be unable to develop a model of behaviour or have a relationship suitably adapted to the environment.

Referring to the example of Anne Nafstad, it could be said that deafblind children "do not have maps which are good enough to prevent their getting lost. They need maps or charts to show the shifting character of the landscape through they are travelling; (...) we can see where they have the most need of help, to be carried, led and held by the hand".

On the other hand, deafblindness acquired in adulthood affects people who have already acquired a stock of knowledge and who possess visual and/or auditory experiences,

as well as a clear awareness of the loss they have suffered, since they have lost the sense they relied on to compensate the lack of another sense, or both at the same time.

As a result of the loss of the sense of distance, the relationship with the surrounding reality is momentarily restricted to the information supplied by touch through outstretched hands and feelings through the skin. The only information available beyond the fingertips is possible exclusively through smell, the only sense of distance which remains ... outside imagination.

Even after going through a period of rehabilitation, difficulties inherent in the disability itself remain, but also due to a world which is barely prepared to accommodate us. Let us take a look at some of the most important of such difficulties:

1.1 Connection with the environment and communication with others

In order to re-integrate ourselves into the world, we need to develop other skills by which to gather information, and to learn to communicate through a new channel - that of touch: our hands become our greatest treasure.

Therefore, at communication

level, a radical change occurs for those accustomed to oral communication, and to a lesser degree for those who already used alternative systems before, such as Sign Language or Dactylogy.

As affirmed by Stig Ohlson, a deafblind person feels that the new system is not natural for him/her - it is something external, something learned, and its greater or lesser usefulness will depend, among other factors, on practice and the level of expertise of each individual.

It also requires the presence of other people trained in the same system and who have sufficient interest and patience- to approach the deafblind person and relate to him/her.

All of this is closely related to the need of the deafblind person to have access to the world which surrounds him/her, to be aware of what is happening around him/her. One can touch objects and things and obtain direct information by touching them, but: how can we perceive something which is happening in front of us?

The inability to know immediately what is happening and not to understand what is being said produces a radical change in all the dimensions of the individual: physical, psychological, social and cultural.

Furthermore, there are a series of factors which are outside the control of the individual, provoked by the characteristics of the environment in which he/she is immersed:

- **Speed**
Owing to the slower transmission of tactile communication, messages which are excessively rapid or complicated are difficult to grasp.

Frequently, deafblind people find themselves having conversations with people whose communication is quicker than their own. The deafblind person always asks at the beginning for the speaker to talk more slowly, to respect his/her rate of communication. However, little by little the speed of the conversation and the succession of events increases, making it difficult for the deafblind person to participate.

The latter may ask for the message to be repeated, but if this situation is prolonged it will result in tiredness, loss of concentration and a blocking of the tactile receptive process of the messages for both the deafblind person and the interpreter. In addition, there is not always enough time to request a repetition.

The deafblind person has to constantly try to guess the information he/she has not grasped. Very often he/she may misinterpret or completely lose the sense of what is being said, causing uneasiness, a passive reaction and a sense of frustration.

- **Single channel of information**

Frequently, information is lost as a result of having to receive via a single channel (touch) that which is normally received via two channels (sight and hearing): it is not just a case of transmitting the linguistic content – what is being spoken about – but rather a question of situating the deafblind person with respect to the physical space in which he/she is located and with respect to the other people present (who his/her interlocutor is and who is talking), so that he/she may find his/her place, control the environment and interactively taking his/her own decisions and initiatives.

The context, probably, "will have to wait" until the deafblind person understands what is happening; frequently, he/she will find himself/herself immersed in situations which are totally unknown and outside his/her control, although it

may affect him/her directly.

If a deafblind person is left in an unknown place, without being given any information – even if it is for his/her own good – it could cause a passive attitude or a state of anxiety, according to the situation or even if the person in question has not developed skills of adaptation and communication with the environment, it could cause an irreparable harm.

It is true that very often, the person accompanying the deafblind person has to act quickly, without time for any explanations. However, it is clear that we cannot influence or change an event if we only know about it after it has happened.

In order to overcome this difficulty, the deafblind person needs ANTICIPATION: to have advance information, whenever possible, of the situation he/she is going to face.

- **Concentration and tiredness**

The effort of "seeing and hearing" by means of touch is constant and has its price. From time to time, a rest is needed in order to recover concentration and energy.

Moreover, undertaking an activity alone (reading, working, etc.) requires the use of the hands and the maximum concentration possible. This means that nothing else can be done with the hands and that one must "isolate oneself" from the environment in order to be "inside" what one is doing. If somebody interrupts you, you need a certain amount of time to memorise where you have left off and to get back there without difficulty. This is why, erroneously, it is believed that a deafblind person gets annoyed when he/she is interrupted.

- **Loss of expressiveness**

This is closely related to the loss of information. If you are unsure as to what is happening or what is being said, you do not know whether to laugh, smile, become serious or merely to put on a face to suit the occasion.

If they are not kept alive, the natural expressions we had beforehand can be lost, and it generally happens that deafblind people become not very or not at all expressive.

It is essential to maintain expressive habits: to look at people when one speaks to them, to smile during an agreeable conversation, to accompany what we say with suitable gestures. Looking at people when one talks to them creates a much greater bond than looking at the wall; the latter makes

communication shorter. Looking elsewhere seems to give an impression of lack of interest.

- **The need for good interpreters**

It is not easy to find people with whom one can establish satisfactory communication, except perhaps with certain interlocutors or interpreters on whom one can rely and with whom one can develop it. It is hard to find people with a good understanding of their role, who know how to put themselves in your place, be in the background or remember that you cannot see.

Normally, interpreters are scarce and one often has to resort to people who "know how to communicate", but who do not know how to connect you with the context.

Your interpreter should possess expertise and speed within your system of communication and have a good capacity for synthesis in order to select the most important information. It is very important for us to feel assured that our interpreter will react in the face of unexpected situations or provide us with the information we may lose. Explanations which are objective and real are vital for us.

1.2 Access to information and culture

The severing of the contact with the environment makes it difficult to participate in cultural events.

The problem has a direct effect on collective activities. It is difficult for a deafblind person to join in with a cultural event aimed at the public in general, since it will have a quicker pace and will always be backed up by audio-visual elements.

At this point the Associations of and for the deafblind play a fundamental role, organising specific activities for our group: -the use of touch, explanations through an interpreter, selection of entertainment which involves movement and other types of sensations which are agreeable to and can be perceived by the deafblind.

1.3 Mobility

The disconnection of the deafblind person with his/her environment is present in all of his/her movements; i.e., although he/she may be well trained, there is always a risk that something may happen which he/she may be incapable of grasping or controlling.

Things happen around one in which one feels implicated but will never know exactly how they

happened. One needs to have great self-control and a sense of calm, the ability to deduce and resolve problems and a strong practical sense. However, in important situations and in unfamiliar places, such as: a visit to the doctor, travel, attending a lecture, etc., it is better to rely on a guide-interpreter.

1.4 Other Problems:

- **Loss of identity** Everybody needs to feel identified with a particular social group. One needs to know that one has one's own world, which is shared and in which everything is comprehensible.

The deafblind person tends to think that he/she is the only one with such a disability. This feeling increases the sensation of isolation.

Small groups of deafblind people within the organisations for the deaf or blind, or organisations created by them themselves assist in the recovery of this loss of identity and in stimulating the desire to do things.

- **Over-protection** There are many cases in which overprotection by the family, although well-intended, results in the deafblind not being informed or being given information which is toned down and far from real.

Whilst not a detailed list, I believe that these are some of the most significant examples of the difficulties faced by a person entering the context minus two of the most important senses.

2 Interaction with the environment: basis for an independent and integrated life-style

The inability to see or hear means, above all, a loss of contact with distance. Furthermore, the loss of hearing implies the loss of a valuable means of rapid and efficient communication with others. Outside physical contact, there is no communication. Obviously, this causes serious problems which have to be resolved.

Once we have decided to face reality, we have to use all our inside and outside resources, either by ourselves or with the help of professionals, as in the case of deafblind children.

We all know how the processes of motor, cognitive and communicative development of the deafblind child work.

A deafblind baby retains its contact with reality thanks to the sensations it receives through

touch, smell and taste. At first, it is unable to identify them, just as other babies are unable to recognise the first auditory and visual stimuli they receive.

Later, by means of structured strategies, the child learns to establish these bonds of affection and to explore the environment from a vital core in which it feels safe and to which it knows it can return, creating little by little a comprehensible image of the world within its mind.

The greater the quantity and the quality of the sensorial stimuli and the information received from the environment and those close to the deafblind child, the more its world will grow.

For example, there are children whose ability to use their sense of touch to recognise people and to move around the school is superior than the mine, although I am considered to be a very skilled adult.

These responses are so extraordinary that they reaffirm our conviction that the stimuli and information which we give to deafblind children day by day, month by month and year by year leads to surprising results.

It is very important not to forget that the majority of information is received through the child's hands. It is more different to do this through the child's hands than through the rest of its body. For example, if we inform the child by means of a tap on its foot that we are going to put a woollen sock on it, we are providing less information than if, for example, we put the sock on the child's hand and without letting go, we run it over the hand and down the child's body until reaching its foot and then put it on. Prior to this gesture, a mother may place her baby's hand on her throat and talk to it, making the sign which symbolises the sock and then following the process described.

It is also very important to talk to the deafblind baby, to establish a communication with it just as if it could hear us, sing it a lullaby, placing its hand on our throat and also transmit our laughter to it.

I hope that with these examples I have been able to explain how important it is for the deafblind child to learn to "see" and "hear" through touch. Possibly we sometimes forget that with it, we are substituting two senses.

Those of us who are close to the deafblind child should feel confident that with more time and in another way, he/she will also become part of the context in which he/she lives.

In the case of adventitiously deafblind adults, if they have

developed to a maximum their interior skills and resources, they may inter-relate with their environment without too much difficulty, to obtain all the necessary information, either directly or through assistance.

Let us look at some of the resources which may help this connection with the environment:

2.1 Development and maximum utilisation of our senses

First of all, we must learn to take maximum advantage of the senses we still have, because for certain, they have wider and more surprising possibilities than we had believed and feel confident that we are being informed about the world around us.

Let us examine some of the characteristics and peculiarities of these senses:

- **Smell**
Smell is also a sense of distance. Generally speaking, the human sense of smell is not well developed, since we have relegated it to second place, owing to the greater importance we give to sight, hearing and touch.

It brings us smells and fragrances which inform and warn us of danger or help us to recognise people and places.

Smell is the first sense to appear at birth and the last which accompanies us when we die. Many investigators believe that the maternal smell is our first impression of the world.

From birth, smell conditions us with respect to our perception of the outside world, our relationship with others. In general, it plays a very important part in human relationships. No other sense is so closely linked to our affective life as smell.

- **Taste**
Taste is a sense which is developed precociously. At four or five months, the foetus is already capable of "tasting" the amniotic liquid on which its mother feeds it. Children have an inborn love of sweet things and reject anything with a bitter taste. The rest depends on education and the social context in which they live.

The influence of taste on education is very important from the time that it helps us to adapt to the environment. It is the function which makes the organ, and not the reverse. It helps us to learn how to choose, distinguish, select. It is not imposed but transmitted.

- **Touch**

Touch is of great importance in social relationships and for the intellectual development of the child.

The function of touch is not just limited to a single organ, as is the case with the other senses, but rather it is extended over the entire skin: it is the sense which keeps us in permanent contact with reality.

The first communications of a newborn baby reach it through its skin. No-one can doubt the enormous importance to a baby of its mother's caress. These are vital aspects in the development of emotional links.

A child not only explores with its hands, but also with its sense of taste, for example by taking objects to its mouth.

The sensitivity of the fingertips and the hands become the most valuable treasure in the life of a person who is both blind and deaf. Through that sensitivity, he/she will become aware of his/her environment and develop alphabetic and sign systems in order to communicate expressively or receptively. The potentially useful positions which can be made by the fingers of the hand are very numerous. The proof exists in the fact that not just one but several different manual alphabets exist in the world; Sign Language even varies from one country to another.

Through touch, we can also read in such brilliant systems as Braille and other technical means.

Constant use of touch in order to obtain information from the environment develops nervous, cerebral and muscular habits which improve the capacity of access to context information and also because such important factors as mind and memory participate in the process.

The processing of the information increases the ability to distinguish, deduce and resolve problems with more and more confidence and speed of reflexes.

- **Other senses**

One always speaks of the five senses. However, we also have another sense known as kinaesthesia, which is the sense mediated by muscles, by movement.

We can feel how we move our arms and legs, how our muscles tense, relaxation, stretching, reflex impulses.

For example, if we are sitting with one leg crossed over the other, it is our kinaesthetic sense which lets us know (although we cannot see it) our own position within space. Our kinaesthetic sense sends

us messages without the participation of the other senses.

Another sense is that of "balance". It is our sense of stability which enables us to remain standing with confidence. Since this sense is connected to delicate mechanisms in the ear, many deafblind people may have problems of balance, but often this is simply due to lack of physical exercise. These senses are vital in mobility training.

We could complete the list with sensations such as hunger, thirst, pain and others, all perceived through the organic senses.

With practice, we learn to meticulously process the information we receive and deduce from this process the next step we are to take.

The ability to reach conclusions will depend to a large extent on the amount of experience required by a particular situation. Personal experiences and knowledge acquired in the past will help us to interpret the observations we make in a particular situation and to come to conclusions.

The ability to resolve problems is one of the greatest contributions made by the mind and is a specifically human trait.

2.2 Communication and intervention: key elements for access to context

- **Communication**

We are all aware of the fact that communication is the key to learning, knowledge and a way of access to people. A very important part of the Rehabilitation Programmes consists of the strengthening of communicative skills through teaching the greatest number of communication systems possible.

In order to achieve a rapid and satisfactory communication when translating and following the normal pace of oral messages, use of a manual alphabet is not sufficient: we need to incorporate signs or symbols to achieve more speed.

In this respect, I consider myself very fortunate, since I have developed a system which combines the manual alphabet with mimic symbols. It is a form of communication which occurred spontaneously and was developed through daily contact: it is the communication I have with Asun, my wife, and it is the best that I could wish for.

It is not just a linguistic communication, but also includes the expression of feelings and moods. One day, this

communication gave me a very special gift: it was the moment she transmitted her laughter to me. Thanks to this small but vitally important connection, my sense of humour remains intact.

- **Intervention**

It is vital to understand that deafblind children, teenagers and adults only join the world when we can understand it, when we receive the necessary information to act for ourselves.

Whilst there is no system by which the deafblind person can directly obtain the information he/she needs, the support of an intervenor or a guide-interpreter is the key to his/her interaction with and participation in any environment.

We are all aware of the efficient role played by the intervenor in individualised programmes for deafblind children, which results in a faster construction and understanding of the world, because it permits him/her to relate events and to act when the latter occur.

Moreover, a good guide-interpreter service is the key to the fuller independence and social participation of deafblind adults. Clear proof of this is that this support, whether voluntary or professional, has been the basis for the creation of independent Deafblind Associations.

We can live without sight and hearing, but we cannot do without them. We also have to learn to "use the eyes and ears" of those around us. This learning is fundamental, and we therefore need, in any training programme we take part, the help of an intervenor.

If the context allows for a time adjustment in order to follow events, there is no doubt that a deafblind person will have the fullest possible access to and become an integral part of that context.

2.3 Psychological adjustment: clarity of thought

One of the key factors we rely on for our rehabilitation and rejoining the world is the maximum development of our internal resources.

At first, a period of difficult psychological adaptation is required in order to accept reality and recover our self-confidence. This acceptance will lead us away from the idea that "the world ends at the fingertips" towards a new concept: "the world begins again at the fingertips".

This change of attitude supports what Richard Kinney described as "clarity of thought". Clarity of thought helps us to distinguish between the possible and the

impossible: one cannot fly just by moving one's arms, nor be aware of the colour of an object just by touching it.

It also helps us to face reality relying on what we have, forgetting what we lack. As in the words of Tagore, the Indian poet: "If you cry because the sun has gone, your tears will prevent you from seeing the stars".

It is essential to replace each old objective with a new one: a person who liked painting before can find a new outlet in manual arts or poetry, for example.

Deafblindness does not necessarily mean that a person cannot lead the life he/she had before: in fact, it is very important to "live the same life as before", replacing what is impossible with what is possible.

This clarity of thought is not only vital for us, but is also essential for those around us.

The clarity of thought was essential in my case, but I acquired it over time and owe it to my wife: she never let me leave reality and presented it to me just as it was. Naturally, this was no easy task, but her courage brought out my courage, and I started to experience a decisive mental change: I began to look upon each problem as a challenge.

Also, you have to understand that you are living with people who can see and hear. Your "leisure" time is fully occupied, but those close to you also have their preferences and want to share them with you.

When you recover your self-confidence and assurance, you feel

that your regular world has become too small for you. It is then that you experience the need to go out into the outside world and start building again within it: this was the start of the long road we have travelled until today and reason why I am here with you now, in such a beautiful and impressive context we are now talking.

Conclusion

It is obvious that when one is deafblind, access to context presents serious problems, but solutions and resources exist for solving them.

If we are given time to follow events, as well as the essential supports, there is no doubt that we can connect and integrate in a satisfactory manner.

Achieving clarity of thought, whilst at the same time developing to the maximum our senses, our mental ability and our communicative skills, and learning to "understand" the context, are important keys to our access to the latter. However, it is clarity of thought which will permit us to attain, in the end, a sense of freedom: freedom within what is possible.

However, equally certain is the fact that it is essential to remember that when talking of "access to context", it is very important that the "context" in question should also adapt to the needs of that group. It is the process of adaptation and the efforts made to bring individuals and society closer together which are paving the way for the evolution towards a context in which we will all play a full part.

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An examination of the relations between an individual's autonomy and social integration

Autonomy and Social Integration

A basic objective upon which everybody can agree is the need to create conditions enabling deafblind people to live in their chosen environment. Our aims in working with deafblind young adults should include targets such as:

- developing autonomy
- developing independence
- developing possibilities for taking an active part in social life.

These plans relate to a trend which aims to allow disabled people to be recognised as 'adult', and which arise from a consideration of ethics and the view of the person as someone constantly evolving.

Declared purpose: integration

We know that deafblind persons require special aids and adaptations to learn about and organise their life, but what impact do these have on their access to appropriate conditions for a social life?

Those working with deafblind people stress specific aspects such as their communication and mobility skills. But these can amplify the idea of their inevitable separation from the 'normal world', and the idea that it's impossible to provide for them in a non-specific and non-separated manner.

Through using different approaches, various countries have aimed to provide systems which approach integration. In France, an important bill, passed in 1975, said that the 'prevention and detection of handicap, care, education, training and career advice, a guarantee of a minimum of resource, social integration and access to sports and leisure for every disabled child and adult are a national obligation'.

However, when we want to develop integration and socialisation, it's necessary to look at the persons' relations with social others to understand how the person, a system in itself, links with the social system.

For deafblind people education

and communication need special adaptations. These can produce particular and specific relationships with social others, which in turn can make people think that developments may only be organised in such special environments, and that there is no possibility of social integration except in such circumstances.

So, how could we discuss autonomy?

Autonomy, personal development, socialisation

Autonomy: definitions

The word 'autonomy' is very rich in representations: for educators and teachers it can mean a lot of wishes and a lot of hopes.

If we make reference to etymology, autonomy comes from Greek ('autonomia') and means the power of an individual to make rules for himself ('nomos' in Greek means 'rules, norms') and to be able to live by them (in English autonomy can mean something like 'self-government').

Greek can offer further insights into a definition of autonomy. 'Autos' refers to the subject, but in his relation with the other: 'autos' means 'himself', but 'to autos' can mean 'the same', the other like me.

*autos myself self-centred
to autos the other relationship*

A social dimension is now apparent by including the idea of relationship in the meaning of 'autonomy':

- relationships with other people, and relations within a group
- relationship with the way other people relate to the environment
- relationship with culture,
- maybe relationship to social norms and to language.

'Autonomy' may imply the individual and society are interrelated.

Autonomy and development

Within the field of psychology, psycho-analytical approaches have stressed ways of building autonomy through the process of separating/strengthening 'the self'. A failure in this process can lead to distorted and pathological development.

For the child, this process of separating and strengthening the self may be built in a setting of dependence with the mother, or mother figure, which can lead to separation being safely established.

Through alternating distance and proximity behaviours with the mother the child will learn to take some risks and to confront reality for himself. Guiding, closeness, and then distancing behaviours permit the individual to separate himself and to build his own identity.

The paternal, or father figure, introduces a third party (the outsider?) into the relation between mother and child. This presence can create a new definition of personal space for the child. Autonomy may then be understood as a definition of personal space for the child.

When acquiring social rules later on, an individual learns to join society's collective law, and assist the development of a true personal autonomy.

This developed personal autonomy will be realised through awareness of himself, his capacities, and his limits. Awareness of necessary dependencies is also related to the process of developing autonomy, as it always takes place in a limited space, which must be first be conquered and built through differentiating and relating to other people.

If a contradictory term to autonomy is 'dependence' (or 'enslavement'), another is 'disjunction' (separation): to be autonomous presupposes to be in a relationship, to 'live with' (cf. in Latin 'cum vivere': conviviality, social interaction).

Access to autonomy and to independence

A common question for educators and teachers is *how can we enable people to achieve more independence and autonomy?*

Firstly, answers can be searched for in the handicap itself. What are the consequences of deafblindness? An evaluation of sensory capacities, medically and functionally, is necessary, as technical aids may enable the maximum use of personal capabilities.

The second consideration concerns the individual himself, his interactive and emotive life, especially in the context of his 'separation', as this will play an important part in determining his autonomy.

A third level concerns the way in which the environment itself (ie family, institutions and society), relates to the handicapped person's particular situation. To what extent can this environment further the development of autonomy?

In working with disabled people, deafblind or other handicapped people, and when discussing preparation for independence and development of autonomy, plans clearly have to consider the necessity of special aids, particularly those that can help the person to relate to the environment, such as meditation.

Contents of autonomy

Recent research on autonomy showed that for many teachers, autonomy is primarily perceived as a value to be developed and an attitude to life (M. Agnes, Hoffmann-Gossett).

But autonomy is also about indulging in ego, 'being', and 'doing'; autonomy is connected to independence, to liberty, awareness, responsibility and sociability.

Action is of course something important, it's a question of doing for oneself, of deciding for oneself or of organising oneself.

Socialisation is also important, as it is concerned with becoming freer and more responsible. This could not be achieved without showing our differences and our similarities. There is no singular subject without the social background from which we can be distinguished.

Another aspect is evolution; if we consider autonomy as an attitude, then it is a way of being, of existing, an aim in life.

To conclude, autonomy is organised around:

- the presence of others, of Law

(Law as a set of rules), and self-awareness;

- around the contradictory interaction (dialectic in French) between dependence and independence;
- and around the idea of surpassing the apparent contradiction of independence and socialisation. It is a matter of living as a separate adult person, whilst surrounded by interdependence.

Handicap and adult status

Many countries over the past twenty years have planned special policies for disabled people and tried to promote their place in society. This has often involved organising special services, education systems and rehabilitation systems, while declaring the promotion of integration.

Clearly these policies are necessary.

However, the real purpose of rehabilitation often means that people have to adapt themselves to the proposed solution. An aim we can promote to surpass this idea of rehabilitation is the concept of 'adult status'.

To become an adult

The following are possible stages we can examine in becoming an adult:

- 1 socialisation and peer groups
- 2 to leave parents
- 3 to leave an institution?
- 4 sexuality and living within a relationship
- 5 working

Step one: socialisation –

Socialisation is partly determined by belonging (or feeling to belong) to a group with whom we share norms and values. Sociologists show how important this function of integration is in building an identity. It is also a very important aspect concerning deafblind people.

The relationship between deafblind people is, from this point of view, a necessity. The presence of peers is an essential element of personal development which implies that special schools, homes and associations, have a clear responsibility to provide this opportunity.

Step two: to leave parents – for every young person, access to personal autonomy and independence relates to 'leaving home'. But for disabled children we

observe that parents can have different attitudes: some accept their child as he is, some over-protect him, whilst others reject him ... whatever the parents' attitude, the child has to be separated from his family for his education.

Step three: role of the institutions –

Do the institutions put obstacles in the way of achieving autonomy? One of the most difficult obstacles concerns what we could call the 'total institution'. This is when work, leisure, eating, sleeping and relationships with others happen in the same place, inside the same walls, and with the same staff. Of course this holistic dimension affects the way relationships are built.

Living in an institution is very often characterised by an absence of private life. Alternatively, an institution can also be a support system geared towards allowing people to go out.

Step 4: sex and relationships (or 'couple life') – sexuality is of course an important dimension of social life and of access to adult life. In an institution though, pressure exists in a way which denies full sexual identity.

Step 5: access to work – work is a very important component of social life. It is a constituent of adult status because it is perceived as overtone's right. In terms of sociological and psychological development, work is a criteria of social participation. When working, we create something, provide a service which has a real value. Work leads to social relationships and to social reality.

The place itself where people work, be it a workshop or factory, is itself considered an important place for socialisation and personal development, as it can foster exchanges and interactions.

Employment is therefore an important part of social life, as it can give the individual:

- a sense of personal identity: self-respect, responsibility, dignity, and the feeling of being accepted as a member of society
- a feeling of contributing towards a collective life
- an opportunity to vary his own links with others
- a regular and structured pattern to daily life
- a pattern of social life which can be used in other contexts (eg placing oneself in a team, accepting the lead ...).

Disabled people's rights

Usually, the first criteria for access to adulthood and adult status is chronological age. But some people, especially people with disabilities, are deprived of adult status through a process which gives authority to a guardian. While this is generally recognised as protecting, it should not constitute 'locking up' a person for all of his life without the possibility of development and social integration.

Integration

Definitions

In a dictionary, we find the following definition:

'... *integration: the action of integrating, to be integrated, to be assimilated...*

This (common) definition seems to mean an action which aims to remove differences between individuals or groups. In fact, if we consider that to 'integrate' is close to 'assimilate' (similar), then integration would be the process designed to perceive people as identical to each other. This can refer to two ideas:

- to be a member of a group
- and to look like the other members of the group.

Within sociology, integration means first and foremost the relationship of the individual with the environment. It means access to a network, to belong to a system which has a purpose, and to carry out a function.

In other words integration is a process which makes different elements play together in order to produce an effect.

If we refer to psychology, integration means for an individual:

- to internalise norms and values which govern the group;
- to identify with the group and its members;
- to feel that he belongs to the group;

If to be integrated is to be in relationship and to be the same as others, what about people who are not so 'ordinary', for instance those with disabilities, such as deafblind people?

When considering their relationship with society, how is it possible to take into account, whilst simultaneously deny, these differences?

So, two dangers exist; one is to deprive deafblind people from any peers, which means loneliness; and the second is to create a 'ghetto'

which means the lack of relationship with other social groups or society.

Educational projects and social policy for people with disabilities usually mention the terms 'insertion' or 'integration'.

A French sociologist, Pierre Tap, proposes two dimensions of integration:

- the first is 'insertion', which means to insert, to include one group within another (To include 'A' in 'O')
- the second dimension is 'articulation' between 'O' and its sub-system 'A'. In this idea there is the concept of 'joint' and of 'coordination'.

So a true integration would be a successful graft, as opposed to:

- 'assimilation' (when 'A' is diluted in 'O');
- and opposed to 'encystment' (if 'A' has no relation at all with 'O', which would be the 'ghetto' situation).

Real integration would occur in a situation where a group which is taken in can participate in a common purpose and carry out a unique role in a complex entwining of communication and interaction.

Evaluation of social integration

Following on from this perspective, we can consider integration as a phenomenon highlighting individuals and groups as systems within an interaction. Integration into society may be achieved through the mutual adjustment of diverse individuals and groups, and through allowing society to organise itself.

Integration is also the reciprocal adjustment of the components of a civilisation. In recent research evaluating social work and social integration, a French sociologist (J M Dutrenit) considered that the smaller units of a group are *social norms* and *individuals*.

He then tried to evaluate possible degrees of integration on three levels:

- normative integration, concerning the relation between norms and individuals;
- communicative integration, which is the degree of communication with the environment;
- functional integration, which is the degree of dependence. This assumes that functional integration is very strong, as it is in developed societies, where

agriculture, industry, trades and services are very much dependant on one another.

These levels appear basic for a relationship between the individual and the environment. Social work therefore focuses on their mutual adjustment. It centres on the development of an individual's relationship to their environment through the development of personal strategies.

Social integration would then mean *social participation*, instead of passive agreement and conformity. This approach led Dutrenit to observe the effects of social work through the idea of 'status'. Status being the ratio of *contribution to remuneration*; what I bring to the group, and what the group gives to me.

For example within the concept of 'contribution' exists work, training and social participation; in 'remuneration' exists salary, others' esteem and allowances.

What about deafblind people?

All of this seems to be very far from our daily practice with deafblind people. However, I think that even when working with people who have real difficulties in social communication, we cannot forget this dimension: we are moving in a larger group, a larger system, than the group or the system we can touch or see. This includes the family, other institutions, different groups or organisations we are in relation with, and with whom we influence and are influenced by. We can assume that this is all related to social norms, and that they can be valued in terms of 'status'.

I think it would be interesting to consider the way the concepts of 'insertion' and 'articulation' function for deafblind people, and how the concepts of 'contribution', versus 'remuneration' operate.

This would involve considering how deafblind people, just like everybody, are confronted with the process of social integration.

Jean-François Guérineau

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Education and Social Factors as a Basis for a New Physical Learning Environment

Marleen Janssen of the Rafaël School for deafblind children in Sint-Michielsgestel, the Netherlands.

The school for deafblind pupils at the Instituut voor Doven in Sint-Michielsgestel, the Netherlands, has been in existence for 30 years. From the beginnings of our work in the sixties right through to the present day, we have made a continual effort to develop educational and teaching strategies which meet the children's needs. As you may be aware, the work carried out by Professor J. van Dijk has had a great influence on the development of this school. Our work over the years has been based consistently on a particular 'philosophy', a holistic approach which has been regularly updated to accommodate new theoretical accents. Over this period, our work has also been carried out in a number of 'physical teaching environments'. Our philosophy has naturally always been that the building (the physical learning environment) should support the attainment of educational goals. The original Rafael pavilion, built in 1967, had become much too small by the eighties, as the number of pupils had doubled, from 34 to 68. In addition, the composition of the deafblind population has changed: we are seeing a steady increase in the number of pupils with multisensory impairments as a result of rare genetic syndromes.

We were therefore naturally delighted when the Dutch Ministry of Education and Science gave the go-ahead in 1990 for the construction of a new school building and for the rebuilding of the existing combined school-living homes (integrated units) for the youngest pupils.

First of all, I should like to discuss three theoretical models which enable us to look at the assessment, the education and the intervention programme for congenitally deafblind children. On the basis of these theoretical models, I will attempt to formulate a number of essential educational and social needs of the pupils. I



shall then explain the main aspects of our programme on the basis of these needs and try to illustrate how we have translated the educational and social demands of the programme into the physical demands placed on the building.

Theoretical principles

The theoretical principles are described extensively elsewhere, as is the use of diagnostic tools (Van Dijk, 1982, 1991; Visser, 1988), and I shall therefore restrict myself here to a brief discussion of the main points.

Deprivation

As we all know, the congenitally deafblind child has a very difficult start in life. Having impaired vision, or no vision at all, during the first years of life, often in combination with other adverse physical and neurological factors, has a major impact on the formation of abnormal behaviour patterns.

In addition to the vision loss, the child also has to cope with an auditive handicap. Although the visual deprivation plays the most important role in explaining the typical behaviour patterns, auditory

deprivation from birth also has far-reaching consequences for the child's development, particularly as regards interaction with the social environment.

The total or partial absence of the distance senses seriously impairs the deafblind child's ability to assimilate senso-motor information. The child has difficulty in localising and associating the multitude of stimuli which he or she receives, often in a fragmentary fashion, from the environment. The child reacts to this difficulty by shutting itself off from particular stimuli and/or by seeking refuge in a one-sided type of stimuli in which he or she becomes completely absorbed. For example, a severely visually impaired child may go to great lengths to catch the full rays of the sun in his eyes, or to place his ear on a soundbox in order to receive particular sound signals or vibrations.

An impairment of the distance-senses is always accompanied by delayed motor development. For a deafblind child, the challenging effect of the environment acting as a stimulant to movement is less strong, since the child lacks visual and auditory feedback. Moreover, a large number of congenitally deafblind children have problems with coordination or lack the skills to perceive, memorise and perform movements. This condition, known as dyspraxia, makes it difficult for the child to express itself through communicative codes such as sign language or speech, as well as creating problems in the performance of daily living skills.

Children with dual sensory impairments can be described as deprived in the truest sense of the word. As a result of a complex interplay of sensory and social deprivation phenomena, sometimes compounded by neurological disorders (e.g. spasticity), the world in which these children live is very lacking in stimuli. Given an extremely deprived situation such

as this, the human organism responds in a specific way. It does everything possible to achieve a sort of equilibrium (homeostasis) with its environment, and seeks compensation from self-stimulating behavioural forms (Van Dijk, 1982). When a child becomes repeatedly involved in these one-sided, habitual behaviour patterns, this has an enormous negative impact on learning and overall development.

Attachment and competence

It has been found that children who enjoy a secure attachment in their early years not only function more competently in later years in social relationships with adults and peers, but are also better able to explore, discover new associations, control their emotions, react flexibly and persistently when performing tasks, and take part in varied symbolic play with their peers (Riksen-Walraven, 1977; 1989; Lamb et al. 1985; Sroufe, 1988).

Competence can be defined as 'the commitment to achieving an effective interaction with the environment' (White, 1959). If a child is successful in its attempts to control the environment, this creates positive feelings of effectiveness, which are a source of pleasure to the child. The child realises that he himself is the cause of his behaviour and the results of that behaviour (Bandura, 1986; Riksen-Walraven, 1989).

It is assumed that there is a mutual influence between the competent behaviour of the child and the presence or absence of supporting responses to that behaviour from the environment. Sensitive, responsive reaction of carer and child to each other is an important condition for building up a secure attachment. As the carer responds consistently, rapidly and adequately to signals from the child, the child develops a concept of accessibility and predictability, which in turn leads to positive feelings towards the reliable person of the carer. In addition to the sensory impressions, the memory plays a role in this. The routine and regularity of the daily care helps the child to learn how the carer will respond in particular situations. The child constructs an 'internal working model', a concept of the style of interactions and the emotions of the carer. At the same time, the child constructs an image of its own responses and their effects. In this way, the child learns that it is able to influence the adult through certain signals and behaviour (Lamb et al. 1985). It will be clear that deafblind

children and their parents experience many difficulties in establishing a secure attachment. The visual impairment, in particular, has a major impact: eye contact, 'reading someone's face', mutual looking at the same object or action, are all virtually impossible. This has a serious effect on the natural synchronicity, the mutual attunement of mother-infant interaction. The child's behaviour can be so 'abnormal' that there are virtually no points of contact through which the carer can build up a secure attachment. Conversely, it is extremely difficult for the child to 'read' the signals coming from the carer. Certain typical behaviour patterns, such as stereotyped jumping, clapping and rocking, can be regarded as expressions of the compulsion for proximity seeking, which can sometimes persist throughout a child's entire life (van Dijk, 1982). Competent functioning is seriously threatened in such cases, due to the frequent experiences of failure. The child often develops strong feelings of dependence and helplessness in its relationship with its environment. The child has learned that behaviour and its results exist independently of each other (Abramson, et al., 1987; Van Dijk, 1982, 1991; Broesterhuizen, 1992) and continually reinforces positive behaviour. This coactive technique is also used for teaching new skills to older children. A child who is initially entrapped within his own physical situation to this extent will not come into contact with other children spontaneously. As a result, the child misses a crucial behavioural model for social learning. Play, and particularly social play, does not develop naturally. It is frequently necessary to teach social skills, even when the child is older, through reinforcement learning and behavioural rules. The ability to empathise sensitively with another person can be regarded as a talent which can only be developed in those deafblind children who reach a high level of linguistic communication (Van Dijk & Janssen, 1993).

Educational and Social Needs of Deafblind Children as Underlying Principles of the Programme

What are the needs of these children with dual sensory impairments? They express certain

essential educational and social needs in an indirect manner, and we try to gear our programme as far as possible to meeting these needs. The main aims are to create the basic conditions for the development of communicative skills on the one hand, and for the development of independence on the other.

The need for structuring and expanding the living environment

The child does not learn of its own accord on which stimuli it can orient itself, nor how to interact with the people and objects in its environment. When confronted with the outside world, there is an extremely high risk of confusion. A crucial question which the child then indirectly asks his carers is that they help him to make his living environment surveyable. He needs help in constructing images and conceptions of objects and people, and of the interactions with them, as well as in learning to discover associations. This forms the basis for the further learning of daily living skills, as well as for communicative development. Structuring or ordering the environment - making events predictable - is therefore a key principle in our programme. Essential key words in this structuring are the elements 'persons', 'time' and 'place'.

Daily routine

We begin with our young pupils by creating a predictable daily routine. In the context of the physical environment, this means an integrated school-living setting, i.e. living and learning in one and the same building.

In an intensive relationship involving 'acting together', the carer guides the child through the normal daily activities. It is always the carer or teacher who creates structure in the child's environment and makes connections clear, precisely adjusted to the needs of the child. This will initially be in the area of vital needs, such as eating, drinking, bathing, sleeping, the need for contact and movement. By carrying out these recurrent daily activities consistently at the same time, the same place and, as far as possible, with the same persons, it is hoped that the child will begin to develop an understanding of this fixed routine. For example, the child will gradually become aware that, after dressing, he/she always has a drink in the living room at a particular place at a particular table and with a particular person; or else the child becomes aware that, after

having a drink, it is always allowed to choose between two favourite activities, walking or cycling.

Building up a routine in this systematic way leads to the development of habits. The most motivating moments for the child can then serve as fixed points of recognition in the day. In order to meet the need for predictability, it is also important that all activities carried out during the day are announced in advance and that it is made clear to the child when an activity is finished. In addition to systematic planning of the daily programme and the creation of a related and clearly set out weekly programme, a number of other aids are used here, in the form of 'calendars'. Naturally, each child is given a place where he/she can keep his/her calendar and communication cupboard.

We believe that these calendars and other aids can be invaluable, not only in creating an overview of the environment but, in particular, in developing and stimulating communication. The child is given an opportunity to express its wishes and to make known conversation topics.

Expanding the living environment

As the deafblind child develops further, builds up conceptions about its surroundings, and discovers more and more associations, the living environment should be gradually expanded. As soon as a child has an overview of his environment, changes are made and new challenges created.

This includes the situation, for example, when the child has reached the stage that the small, surveyable world of the school-living home gives way to living in the residential home and 'learning' at school. By following a short, surveyable route, the child learns to go to school independently.

At school, just as in the integrated unit, certain activities are linked to particular rooms and particular persons.

At fixed times, the motor circuit is exercised in the gymnasium with the specialist teacher. There is also time for relaxing motor activities.

It is essential that the programme is put together for each individual child in such a way that what the child learns is integrated with earlier experiences. Although this may seem obvious, as stated earlier it is the most crucial problem within deafblind education.

Integration of experiences and the building up of an overview are a

primary requirements, including for older pupils.

This means that a pupil, for example in the context of the subject 'General Techniques' learns how to plant, weed and harvest lettuce, and learns to make a box in which to store the vegetables. Subsequently, the child may learn during the 'Home Economics' lesson how to prepare the lettuce. During mobility lessons and excursions, the pupil is accompanied to the greengrocer or supermarket to buy lettuce or salad and all the other ingredients necessary for preparation.

The classroom teacher fulfils a coordinating function here by further clarifying, during the conversation lessons, those matters which have not yet been sufficiently understood, and setting these down on paper. In order to promote optimum integration of learning experiences, it was decided to group the practical subjects together in a single, separate practical building.

The need to develop attachment relationships and competence

Good relationships are not only important for the social and emotional development of the child, but also for communicative development and the development of competence. We attempt to deal with these issues in our programme.

Characterising people by means of referential objects for persons and activities

Before a child is able to develop an attachment relationship, it must first realise that it is dealing with another person and not an extension of itself. It is important that the carer characterises him or herself in a special way which distinguishes him or her from other people. We create specific recognition activities in our programme to this end, in which so called 'referential objects for persons' are used. The child is made aware of a particular characteristic of the carer's external appearance (e.g. long hair, a moustache), or of something which that person always wears (e.g. a necklace, an earring) whenever he or she interacts with the child. By carrying out recognition activities such as these at a fixed time and place, for example when greeting or parting, it is hoped that the child will be able to build up an impression of that person. Affective moments also play a role in the mutual contact between carer and child; examples

of such moments include a caress or a kiss. As the child becomes more aware of this reliable, predictable person, the referential object gradually becomes linked to a 'natural gesture' for that person, for example moving the brooch from side to side, which can act as a means by which the child can actively express its desire to come into contact with the carer.

Mutual responsiveness

It is only in the context of an intensive one-to-one relationship involving 'acting together' during the daily activities that a secure attachment can develop. The child begins to develop confidence in the carer and learns that it is able to influence the adult by means of certain signals and actions.

For example: Teacher and child perform greeting actions together. A fixed sequence is built up, for example rocking backward, backward somersault and sitting on the teacher's lap. After a few repetitions, the child suddenly gives a signal, by putting her hands together. It is then the teacher's task to pick up on this signal and to make clear to the child that she has received the signal, by responding to it immediately, with a familiar clapping-game.

Through this intensive contact, the carer attempts to stimulate the synchronicity between carer and child. The carer learns to 'listen' to the child, and vice versa.

Transfer to parents

Using the method described above, an attempt is made to create a bond between the child and a number of specially nominated persons. The parents are closely involved in this process from the beginning. If this attempt is successful, the parents are 'brought in' to the programme in an ever clearer way. 'Referential objects for persons' are developed for the parents which make it possible to 'talk' about the parents even when they are absent. The school should also be a place where parents feel at home and are able to join in.

The feeling of competence and independence

One potential danger of such an intensive individual approach is that the deafblind child becomes too dependent on the hearing and seeing carer. The majority of deaf blind children, on account of their dual sensory handicap and/or their dyspraxia, have undergone many

negative experiences in their interaction with objects and people (Van Dijk, 1991). Such experiences of failure have a far-reaching effect on their competent functioning. Frequently, the child perceives itself as unable to control its own actions and their consequences. It feels dependent on and is controlled by its environment.

As a result of this danger, we try as far as possible to create activities which succeed for these children. The learning activities are divided into such small steps that the child's chance of success is extremely high and the risk of failure minimal. Initially, activities are carried out together with the child (coactively). In order to teach the child not to become too dependent on his or her carer, it is important that the carer knows when to draw back and leave the child to itself. It is important that situations are created in which the child is able to function completely independently, without any intervention by an adult. This can be achieved, for example, by providing suitable, self-rewarding toys, or by presenting simple tasks in which the activities are immediately rewarding for the child. It is important that separate, clearly laid-out rooms are set aside for the carrying out of such tasks.

Initially these are separate, small classes next to the classroom, so that the teacher can keep an eye on the pupil. The child is prepared in this room for tasks which he or she learns to carry out later in the more complex environment of the practical room. For a limited number of pupils, simple construction or packing activities such as those learned here will continue to form a useful way of spending the day in the future. All the activities are geared to enabling the child to function as independently as possible. For these children, too, being able to take pride in their own achievements, being able to do things for themselves, has a major impact on determining the quality of their life. In this way the child, by receiving 'practical training' two mornings per week in his or her final school year is prepared for his/her future 'working environment'.

Building up communication and the selection of a suitable communication code should also be geared to creating a feeling of competence.

When dealing with a child with dyspraxia, the carer does not use complex sign language or finger-spelling, but chooses rather for body signals, a reference book containing drawings or concrete referential objects.

Relationships with other children

A second potential danger for which we need to be alert when adopting the individual approach is that the child has little contact with its peers. The child will therefore have to learn social skills and social play through reinforcement learning and behavioural rules.

Naturally, the physical environment should offer an opportunity for social activities, such as circle games and playing outside with other children, as well as social activities involving all those concerned with the school, such as parents, teachers, houseparents and other children, for example at annual celebrations such as Christmas, Easter, Carnival or, at the opening of the new school building.

The need to develop anticipation and generalisation skills

Learning to anticipate (expecting what is going to happen) and to generalise (applying what has been learned in different situations and settings) are important skills, on the one hand for developing communication skills, and on the other for building up independent living skills and social skills.

Creation of anticipatory situations

Learning to link a signal to a reaction or type of behaviour is an essential condition for learning in general and for communication in particular. As indicated earlier in the section on social learning theory, it is extremely rare for deafblind children to spontaneously develop orientational reflexes and discover associations. An important principle in our programme is therefore that the child must continually be given opportunities to develop its own initiative. This is stimulated by the creation of so-called 'anticipatory situations' - situations within which the child is able, as it were from the basis of habitual events, to guess what the following step will be. For example, the child gets used to taking a bath and then going to the dining area and there, together with the carer, pouring and drinking milk. At a particular moment, which is carefully determined by the carer, the child is given the jug of milk but not the beaker. As soon as the child starts looking around, or gives a signal, the carer quickly gives him the beaker and rewards him for his alertness or response. Consciously failing to meet the built-up expectation pattern and breaking the fixed routine challenges the

child to produce an active response. Situations of this kind are to be found at all levels in the programme. The ability to anticipate is not only developed in the context of activities such as bathing and eating, but also in a motor circuit and when preparing a child for a subsequent event using the calendar.

Transfer to different situations, people and settings

Another key principle in our education programme is that the independent living skills and social skills are taught coactively and are exercised in situations which are as natural as possible, by means of reinforcement learning or, if possible, via model behaviour and instruction. The independent living skills include such things as getting changed, laying the table, making a sandwich, needlework, etc.; the social skills include waiting for each other, asking for help, and handing something round to others. Once these skills have been learned, we try to transfer them directly to other situations/living environments in which the child is involved: the class, the living group, the practical room, the parental home. It will be clear that this demands consistently good coordination between the various environments.

A certain group of deafblind children, i.e. those with dyspraxia, are only able to learn those skills which involve little motor complexity and which are routine in nature. Rather than teaching these children how to prepare a complete meal, it is better to show them how to bake biscuits step by step. Instead of teaching them how to make complex tapestries, it is better to teach them simple rug-pegging techniques, and so on. Transfer takes place via the practical teacher to the relevant class teacher, houseparent and/or natural parent. For example, once a child has learnt to peg rugs, this can develop into an important hobby which can also be carried out in the residential home or parental home.

If a child has learnt to bake apple turnovers, for example, during a home economics lesson, he or she is also taught to hand these round to other children and adults in the practical room, in the classroom and in the living group. Moreover, once the child has learnt to bake apple turnovers, he or she is also taught to perform this skill at home or in the residential home.

In constructing our new school, we created the possibility for a number of pupils to take part in practical training placements within their own

Deafblind course in Colorado

The Colorado Department of Education and the University of Northern Colorado are co-sponsoring a second Kephart Symposium graduate course on deafblindness. The course, "Assessment into Intervention: Effective Strategies for Students with Deafblindness", will be held in Vail, Colorado on July 25-29, 1994. The course instructor will be Dr. Kay Alicyn Ferrell.

Presentation topics will include:

- Psychological Views of Deafblindness" by Dr. Barbara McLetchie
- The Infant, Toddler, and Preschool Child" by the Colorado Hilton Perkins Early Intervention Assessment Team
- The School Aged Child" by Dr. Barbara McLetchie
- Social Interaction/Inclusion/Intervention" by Dr. Madeline Milian-Perrone and Dr. Nancy Sall
- "What Professionals Need to Know" by a panel of parents and consumers.

For more information about course content, please contact:

Tanni Anthony, CDE, 20t E. Colfax Avenue, Denver, Colorado 80203 (tel: 303-866 6681).

For information on course registration, please contact:

Marsha Woodruff, UNC, Division of Special Education, Greeley, CO, 80639 (tel: 303-351-2893).

school. This involves them carrying out work which was previously performed by domestic staff. The tasks involved are mainly of a routine nature, such as making coffee and taking the coffee pots round to the various buildings; washing, ironing and folding towels, etc.

This, then, briefly sets out the educational and social principles which form the basic conditions for the development of communication on the one hand, and of independence on the other. I hope it has become clear how a physical learning environment can make a positive contribution to this development.

Over the years, the development of communication, in particular, has been a strong focus of attention within our programme; this is partly as a result of the fact that the deafblind department is attached to the Instituut voor Doven. The development of certain aspects of independence has received relatively less attention compared with a number of sister organisations which are attached to centres for the visually handicapped. The rebuilding of the integrated units and the new school building have enabled us to create greater opportunities for the more successful development of independence within our programme (Visser, 1992).

The school building

In conclusion, I should like to mention a few technical details. As I said earlier, the physical learning environment should be supportive rather than distracting.

The school has been built in such a way that direct entry of light, which would be disturbing for these children, is avoided as far as possible. The south-west side of the buildings is covered by an overhanging roof, and a light-reflecting film has been placed in front of windows where undesirable light could still enter. Artificial illumination, designed to produce optimum lighting strength, is provided throughout the building from hidden light sources. The paint used on walls, doors and ceilings has been chosen for optimum light intensity.

A uniform system of marker points has been installed throughout the whole school to designate the various rooms and routes.

Seen from the children's point of view, the new school has a simple overall structure, with simple, clearly laid-out rooms and with clearly defined routes.

In many respects we can say that

the physical learning environment meets the main educational and social demands. The school now has a very clear layout, and is genuinely a place where the children can feel secure and where they are sufficiently challenged to learn and to live in a competent way within the scope of their individual capabilities.

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Ideals and Realities

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This article has to be seen as a contribution to the discussion about services for deafblind adults. It is not a blueprint but includes goals and contents for a service for deafblind adults, and I will try to emphasise some main points which I find important in relation to the title of this discussion.

Ideals

The main goal for our pedagogical work with deafblind people is that they obtain quality of life. We think that an important condition for quality of life is identity. And we think, too, that an important precondition for identity is creativity.

If we are going to talk about a deafblind culture, the concept of identity is very important. You cannot be given identity, it is a personal process. But what we can do is to give peace, space and nourishment to deafblind people to initiate and motivate the process. We must give a special space of life and space of action, where cultural possibilities are available to stimulate this process. As a consequence of this way of thinking about the identity process, deafblind people must be given the possibility (medbestemmelse, selvstændighed, selvforvaltning) self-management, independence and participation in decision making.

Further I would like to underline that we work together with deafblind people in equal companionship and with respect for them. And we think that deafblind people, like other human beings, will develop in interaction with the physical and the psychical environment. And both the physical and psychical environment will develop, too, in this interaction with deafblind people.

In order to help deafblind people create a continuing quality of life, it is our goal also to develop fundamental competencies. The pedagogical way to develop these competencies is based on pedagogical planned activities. To put it in another way - we could say a functional way of learning.

The competence of language is the most important. In our work we use the total communication philosophy.

Total communication is more than having different possibilities of

expression to choose from. It is a basic attitude to communication which opens up a flexible and non-traditional use of linguistic expressions in an equal communicative relationship.

We find that in relation to all this the concept of deafblind culture

can be used as a frame, or a common denominator.

The concept of deafblind culture is used in a resolution which was decided at the Nordic Conference in Finland in 1992. I will end the first part of this article by introducing the ideals of this resolution:

RESOLUTION - Adopted at The Nordic Conference in Finland, 1992.

Deafblind workers in the Nordic countries must intensify their efforts to secure human rights for congenitally deafblind people to be respected.

This is necessary, speaking from our experience of the lack of possibilities available to deafblind people to develop their own culture.

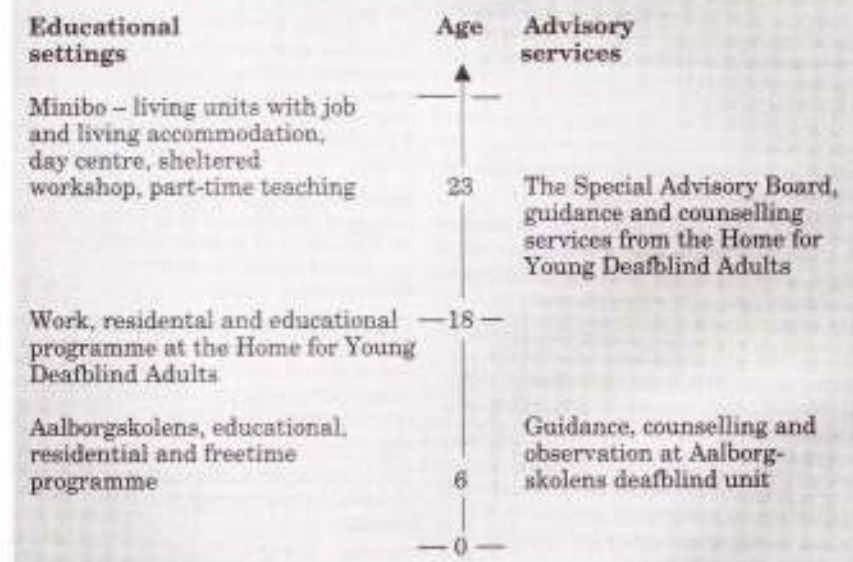
These possibilities are being reduced further by an absolute and one-sided implementation of decentralisation.

The main point in this resolution is that deafblind people are not regarded as a minority group, but as a sub-culture based on a different language.

Realities

And now to the realities.

The Institutional Services for Congenitally Deafblind in Denmark



The framework for quality of life in Denmark is lifelong provision for a person born deafblind.

There is an advisory service from birth to death. From birth until 18, this kind of service comes from Aalborgskolen, and after that from The Institution for Deafblind Adults.

Some of the children will come to Aalborgskolen if the parents want this educational, residential and freetime programme.

At the Home for Young Deafblind

Adults they will receive work, residential and educational programmes. The deafblind department at Aalborgskolen with 23 deafblind children, and the Home for Deafblind Young Adults (10), cover deafblind services for all ages all over Denmark.

Minibo is a living unit, a group home for deafblind adults, and it is placed in Aalborg too. We now have two living units for deafblind adults in Aalborg. In both group homes there is room for six deafblind

adults. At Minibo and Hojbo the deafblind students receive freetime activities and living accommodation, and in Skovhuset, an institution in the neighbourhood of Aalborg, the 12 deafblind students from Minibo and Hojbo will have provisions like a Day Centre, Sheltered Workshop and part time teaching.

Other group homes for six deafblind adults have now started in other places in Denmark. And the adult guidance has, as one of its aims, to be a red connecting line between the Institution for Deafblind Adults and the group homes spread around in the country, in order to keep the deafblind students in touch – and to supervise the staff.

Culture

In Aalborg with its concentration of about 50 deafblind students, representing nearly all ages, we have a great opportunity to try to create a deafblind culture.

In creating the provisions for deafblind children, young adults and adults one of the main points has been to look at the opportunities and public services for non-handicapped people.

The primary aim in special education and social work with deafblind children is through individual learning and meaningful social togetherness:

- to develop communicative competence in order to motivate the child for contact and active interaction with the environment.
- to have in view that the individual child develops his potential to reach the highest degree of self-management and self-reliance.
- to have the possibility for further education.
- to have the possibility for choice of profession or special training.
- to have the possibility for moving to his/her own home.

Implicit in this formulation we find a humanistic view of man. Showing that if development is going to take place, it must be based on the child's own activity - learning is an active and personal process.

At the home for the young deafblind adults the three provisions are inspired by the possibilities attainable by non-handicapped persons.

The main aims of Ungdomshjem for Dovblinde are to develop the young congenitally deafblind students to live as independently as possible.

The deafblind adult has the same possibilities as the non handicapped

adult - a place to live, freetime activities, a job and part-time teaching. The balance between these provisions for the deafblind adult is divided in a way, so that most of the hours of their working day are in a sheltered workshop/day centre/ group, and the part time teaching is only a few hours a week.

An example of the aims of the pedagogical work on a group home for deafblind adults would be those of the Minibo Institution.

At Minibo the staff want to work on following objectives:

- 1 The residents must have the opportunity for individual development, and experience fellowship and security. In the relationship between resident and staff there must be mutual respect and confidence in both positive and negative interaction.
- 2 The residents have a right to experiences which strengthen social relations, so that, for instance, fantasy and creativity can be displayed regardless of the functional level.
- 3 The residents must have a right to an adult life based on participation in decision making, emancipation, communication/information, freespace and private life.

These aims are based upon rights for deafblind as well as non-handicapped people and show the possibilities which an adult life can contain.

Only in one of these examples of the superior aims of three different Danish institutions was the concept of creativity explicit. In my private evaluation process, when I think of quality of life as a superior and common aim for the pedagogical work of the deafblind of all ages, the concept of creativity should have a central place not only in one, but in all three examples. In my opinion we need a common aim for the deafblind field in general, in relation to a life-long enrichment.

Self-determination

Another example is the concept of self-determination.

The aims for the home for the young deafblind adult need to be evaluated clearly.

This aim is from the time in Denmark where the welfare society wanted to ensure that handicapped people had a share in its material wealth. But this is just one side of a quality aspect. In a Nordic way of thinking it has been described in this way.

Quality of Life

- 1 External conditions/practical conditions
 - school
 - work
 - home/place of refuge
 (economy - social policy)
- 2 Interpersonal relations
 - emotional – relation to family
 - social – relation to friends
 - cultural – participation in groups
- 3 Internal experienced quality of life
 - basic mood
 - creativity
 - experience of meaning/coherence

Creative, identity, quality of life

I will now concentrate on the concepts of creativity, identity and quality of life. But of course in Denmark we also use the traditional pedagogic methods - such as work with structure in time, place and people, and work with sequences and so on. But I think that the work we have been doing with young adults and adults during the last 10 years has had its basis in the traditional work with children, and certainly we have learned a lot about what we can use, and what we can do without. But now the time has come where we need to think of the deafblind young adult and adult as young adult and adult persons, and to try, together with them, to create a young adult and adult content in their lives. The concept of deafblind culture will be important in this connection. And creativity, identity and quality of life too.

The theoretical background for the relationship between creativity and quality of life can be found in the theory of multiple competencies. In Denmark this is formulated by a neurobiological scientist, Kjeld Fredens, on the basis of the work by the American, Howard Gardner, - a theory called the multiple intelligences. The competencies are based on rhythm and the emotional and social foundation.

The main point in this theory is, that there is more than one intelligence or competence. A competence is a way of being connected with the surroundings - to give and to get impressions.

You have to be well trained in one competence, before you can be creative and before they can act together. Creativity can be described as being able to create oneself again.

This is an important theory in

The multiple competencies				
metacognition				
<i>Linguistic competence</i>	<i>Musical competence</i>	<i>Logical Mathematical</i>	<i>Spatial competence</i>	<i>Bodily competence</i>
Emotional and Social Foundation				
RHYTHM				

our work because according to this theory the value is not homogeneity and norms, but differences and individuality. This theory, too, can connect the biological side with the cognitive and social side, and can give a holistic view.

The theory also tells us that there are three levels in each competence. The concrete/enactive level, the iconic level, and the symbolic level.

We have to start our pedagogical work at the concrete level, where the deafblind person can manipulate the object, and make his own experiences. We need this representation before the real object can be represented as an icon. This can be a picture, a model or dramatising what we have done at the real level. And at last we can reach the symbolic representation.

This theory underlines that it is important that we not only see pictures or handle icons, but also get the opportunity to express ourselves in pictures or icons.

This theory underlines, too, that you have to experience life with and through your body.

A way to secure a language for deafblind people in which the content is experienced and by which they can express themselves can be to use the three levels as a three-phased planning and working model. And I would like to demonstrate this by an example.

Peter is a deafblind young man, who very easily gets frustrated, he can be very scared. He has no secure identity and has no self-confidence.

We want to give Peter some means by which he could support himself during the day, to help him get safely through the day. We chose an activity which we knew would motivate him - making scrambled eggs for lunch. And we put up some aims for the activity.

The aims were:

- 1 To develop his identity (by knowing that he could do this activity by himself).
- 2 To develop his language.
- 3 To teach him to make choices. (Because another activity he could choose when we made his daily programme, was to grill sausages).

4 To teach him what eggs are for.

5 To teach him the skill to do scrambled eggs.

The main idea was that because of the language connected to the activity and the confidence with the skill, he would feel no harm in doing it.

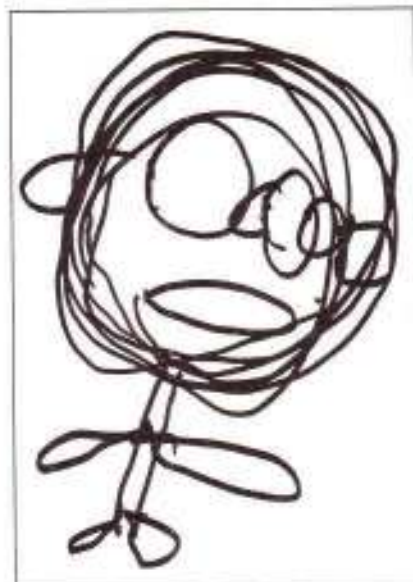
To reach the aims we used the three-phased working model mentioned before. First Peter had to make the scrambled eggs a number of times - that was the specific level. And after that we worked iconically with the sequence - we could look at a video and we could compare the video with pictures from his book.

We could train his memory by asking him, for instance, to put the picture in the right order and so on. There were eight drawings one for each part of the sequence. We finally tried to use very simple drawings instead of the other drawings, and by getting Peter to compare these drawings we hoped that he could end up using the simple drawings like a recipe and make the scrambled eggs by himself.

With this activity I think we ended up with Peter not being frustrated when we talked about making scrambled eggs, and he could take part in the activity, but he didn't reach the point where he could do it by himself.

We use this three-phased model in a lot of daily educational situations. We can use it in activities like Peter and the scrambled eggs. And we use it in connection with a topic-related work form. Such a topic will last for two-three weeks and can include all the hours of the day, where the different pedagogical staff groups will work in an interdisciplinary situation and try to give the deafblind students as many experiences related to the subject as possible. A topic, for example, can be - autumn, fish, my body, etc. And connected to the topic-related work form we use this three-phased planning and working model.

But let us look again at iconics and creativity. As I mentioned earlier, the theory about the multiple competencies mentions the importance of seeing pictures and expressing oneself through pictures. Many deafblind people will be able to be creative and express



themselves in an iconic way if we give them the opportunity. In this matter I would like to show two drawings.

The first drawing is titled 'The waterhose/gardenhose is being rolled up'. And regarding the drawing, I can imagine John with this waterhose where the problem arises when you wind this around your arm. I think that the frustrations of the waterhose impressed him so much that in his mind it felt that this waterhose was wound around his head.

John expresses something about himself, too, with this drawing. He is a small, stocky person. I think this is well expressed with the firm lines in the drawing. We can use the drawing to observe John too. He is very aware of his head, big eyes, big mouth and ears. The rest of the body could tell us about a lack of body confidence.



These two drawings are titled 'Robert walks on stilts' and 'Masquerade-Butterfly'. The young man Robert was dressed as a butterfly when we held a masquerade.

I think Robert expresses quite another mind with his drawing. And I think it suits his mind – he is a more gentle young man and very fleeting and light in his movements.

Creativity

During the last few years we have tried to work more with creativity. For instance, a year ago, there was a camp where one theme for a day was creativity, to which deafblind adults from the different institutions in Denmark were invited. The leader of the creative workshop was an art therapist. I feel that it is a very good idea to use professionals in a situation like this. The pedagogues tried, with her, to find the starting point for the deafblind students' different interests and different levels of functioning, so that they could have an opportunity to express themselves.

Some examples from this camp:

All the materials were placed in a yard and the deafblind students walked around touching and looking at them. The pedagogues tried to observe which materials the young people were interested in. One student, for example, was very interested in clay and made a lot of small figures.

Anne, a deafblind student inspired the camp. She liked to make sculptures of different and often very strange materials. This interest started with her having a lot of dolls and figures around her. As time went by she started to make her own dolls. The camp was also inspired by a workshop at IAEDB's World Conference in Örebro in Sweden in 1991, where a group from Poland showed sculptures.

Knud showed interest in painting. The art therapist showed him that one can produce a colour and a line by making a stroke with the brush, and after that Knud nearly made a picture on his own. In connection with the theory of the multiple competencies, you have to learn, or be taught, skills before you can be creative.

Casher is totally blind, and at a very early developmental level. He made a tactile picture and he got good tactile impressions by making the picture together with the pedagogue.

A sensory string was made in the middle of the first day. Before that the deafblind young people had not seemed very interested. But this string, as a social situation, was a success and gave inspiration for further work. The young people made one thing each for the string and the string passed through all hands. On the string there were

water balloons with small holes pricked in. The water dripped and splashed and it was great fun.

The young people created various shapes and strongly coloured things in different materials.

The picture workshop was a success where they worked with a great deal of concentration and creativity.

Creativity and identity

Creativity is of outstanding value for identity. As mentioned before, I see identity not as something you can be given, but as a personal process. To this process we can give peace, space and nourishment. So the process can be fulfilled and we can give lifespaces and action space in which there are cultural possibilities to encourage it.

When we talk about deafblind young adults and deafblind adults and identity, I think we also have to talk about what it means to be a grown up adult.

There can be several views on this subject:

- some things are decided by society and culture, eg work, free time, a place to live;
- some things are decided biologically, eg reproduction;
- some things are held in common by all human beings, eg you know more about who you are, you have experiences and you are more able to use them. You thereby have the possibility to realise yourself;
- in connection with this, an adult person can contribute to culture, and can take part in changing it.

Identity is a kind of active statement, where you can contribute to culture and this is a condition for being part of culture.

A consequence of this identity process has to be that deafblind people must be given opportunities to decide for themselves, to take care of their own lives and to be independent.

I would like to describe an example of how the deafblind students and the pedagogues at Minibo work with this process.

The two deafblind students, Lotte and Betty take part in council meetings, together with the pedagogues, and discuss and decide matters such as what they are going to eat for the next week, which colour they want for a wall and subjects like this which form the basis for their private lives.

Lotte and Betty are now very familiar with this form of meeting and enjoy them very much. The pedagogues try to help them to discuss the subjects.

There is a structured meeting form, starting with beer and an agenda. The first issue is information. They all take this meeting very seriously. For instance, at one meeting the pedagogues brought up the question of inviting a new deafblind member to these meetings. Lotte and Betty discussed this and finally they decided that Henrick, the new member, was welcome, but not until after Christmas. I think they hesitated because they felt that this was their meeting and it gave them status among the other deafblind people as a part of their identity. When we are talking about identity and what it means to be adult, I think that the content of our co-operation with the deafblind young people and the way we are working together is important. For a moment I will turn to what, in the Nordic countries, has been new and inspiring knowledge. This knowledge and research is about how language develops from the very beginning during the first three months in the interaction between the baby and the mother.

Anna Nafstaad describes in the book, 'Providing for communication with those born deafblind', the following three basic steps in early childhood development:

- nearness
- exploration
- interaction

as a basis for communication.

Most of the deafblind adults in Aalborg have not enough of the basics related to these steps. So we have to work with nearness, exploration, interaction as a basis for communication. But how do you do this when dealing with the young adult and deafblind adult?

Dramatisation

I would like to describe an example of this. As I mentioned before, we use dramatisation related to the iconic phase in the three phased method. Henrik and Dan had gone to the barbershop to get their hair cut. Some days later we dramatised their visit.

We planned a dramatisation which contained seven elements from the haircutting situation. To recall Henrik and Dan's memory of their real experiences from the barbershop, an adult played the part of the barber so that through imitation they could play the role of the barber. The difficulty of the dramatisation was gradually increased towards a non-verbal symbolic representation.

From my point of view there are

plenty of possibilities in a situation like this to train important things like different kinds of imitation, a shift in role and playing a role.

It is a pedagogical challenge to transform all the training they need to develop their language into a worthy adult way of living.

Sometimes you can solve the problem by giving things another name. For example, there was a discussion at the Institution about Anne, the young woman making sculptures. Can an adult woman play with dolls? But one day a colleague solved the problem by saying that Anne was not playing with dolls, she was making sculptures, and that was accepted.

Now I would like to turn to what I think is an important matter, when we are talking about pedagogical work with deafblind young people. What I am thinking about is the role of the professionals - the pedagogue's part in the co-operation.

I would like to tell you what the Danish philosopher, Soren Kierkegaard, wrote over 100 years ago about the teacher's role.

'Truly - to succeed in guiding a human being to a certain place, you first of all must be careful and find him where he is and start there.'

And Kierkegaard goes on to say that if you are unable to do this, you are unable to help another person. 'Indeed, in order to be able to help another, I must understand more than he, but first of all understand what he understands. If I don't do this, then my understanding more won't help at all.'

What Kierkegaard in fact is talking about here are the personal qualities of the professionals - like empathy, respect of the student and knowing the student's world and preconditions.

To secure a more precise and structured way of learning and to secure a more spontaneous way of learning, we need different professional identities.

On this subject, I would like to tell you about our experiences in Denmark where we, in daily co-operation with the deafblind students, have two professional identities - the teacher and the social pedagogue. These two professional categories do not have the same educational background, or the same experience. I think these two identities have to be aware of how each of them can cooperate with and help to develop the deafblind person. I don't mean that they should not work in an interdisciplinary situation together, but they have to know their own professional identity so that they can work together as well as

possible. No one group is more important than the other - they are equal partners, but they must contribute with different knowledge.

Teaching social-pedagogy

It is important that the deafblind students meet different kinds of professional identities to provide them with the best opportunities to develop the language, self-help skills, creativity and identity, as a basis for their quality of life.

Deafblind Culture

As mentioned at the beginning of this article, I think deafblind culture can be regarded as a

common denominator - a frame when we talk about how to secure opportunities for deafblind people to develop their own quality of life, and to secure their human rights. One of the problems will be how to help them to develop their own subculture instead of developing the subculture for them.

But what is culture? I think we need to discuss the concept of culture - we need to find a definition or a model.

The concept of culture is hard to describe. It is hard to see what is everywhere around you. And it is especially hard to describe your own culture. It is easier to describe another culture because of the differences.

The Extreme Differences between Teaching and Social-Pedagogy

Dimension	Teaching	Social-Pedagogy
Function	Qualifications and competencies, which parents cannot give the child	Relief of the parents - concerning upbringing, care and play
Process	Systematic planned structured	Spontaneous con amore impulsive
Focus	Narrow precise focused	Broad unprecise diffuse
Motion	Deductive from above and down	Inductive from below and up
Relation	Content - primary relation - secondary Teacher - outside the group Purely professional relation	Relation - primary content - secondary Pedagogue - part of the group Family like relation

Content relation		Content	
Teacher	Child	Pedagogue	Child
TEACHING		SOCIAL-PEDAGOGY	

The Cultural Sphere of Activities

relationship production reflection
communication emotion

Ways of Being Together	Modes of Expression	Musical Forms
<ul style="list-style-type: none"> • interaction • organisation • norms • social conventions 	<ul style="list-style-type: none"> • sign • linguistic • elements • codes • style • authenticity 	<ul style="list-style-type: none"> • creative capacities • musical capacities • aesthetic criteria • originality

'Det Kulturelle spring' Claus Jessen, Specialloverforeningen af 1981.

I would like to suggest a model of culture to be used in the discussion. This model is developed by teachers in Denmark who are working with different kinds of handicapped people.

In this definition, culture fulfils particular purposes and concrete functions in togetherness.

First they operate with what they call – *the cultural sphere of action* – in which the functions of the culture take place. These functions are – *relationships, communication, production, emotions and reflection*.

They explain the connection between these concepts in this way: Togetherness exists by relating person to person and group to group. The functioning of this relationship is based on *communication*.

In the first place the togetherness relationship and communication are the conditions for *production*. Production is understood as a necessity for life.

In the second place relationship and communication take part in arousing the *emotions*.

When emotions and production begin to influence the conscious behaviour, then it is based on mental and cognitive operations or reflections.

Instead of looking at the behaviour with the risk of being overwhelmed by a lot of unsystematic observations, we are now able to look at some relatively well-defined functions. And they are, again – relationship, communication, production, emotions and reflections. And as a whole we can name them the cultural sphere of actions.

The next level in the cultural model talks about FUNCTIONAL AREAS for the culture, ie how the culture appears.

We can't find the culture merely by looking for the categories in the cultural sphere of actions. Culture cannot be measured – it is more like a quality.

As mentioned, when I spoke about the multiple competencies, there is more than one competence/intelligence, and we are interested in the function and the quality of intelligence. It is the same when we are talking about culture, we are interested in the quality of human existence and we can try to look for the functional aspect.

The model operates with 3 functional areas – *ways of being together, models of expression, musical forms*.

Ways of being together – means simply how people are together. The *interaction* between the members in one group will be different from the interaction in

another group. There will be developed or imitated *norms* and rules for the group, which decide the social way of being together.

Modes of expression – solidarity and being together will be expressed and confirmed in different ways. It can be special *signs* when you say 'hello' and special phrases. The way the solidarity will be confirmed in a group can be with special *codes* only understood by the members themselves.

The group can be emphasised, too, by dressing in a special way and having special signs or symbols.

Lastly, the group's way of expression can be more or less *authentic* depending on whether the expression is genuine or imitated.

Musical forms – In being together and in the expression there can be elements showing a special *creativity*, indicating special aesthetic criteria, or there can be a production which is partly artistic in character or partly ordinary, eg jokes, battle songs for sports games and so on. These ordinary ways can be more or less *original*.

There will be overlaps between the three functional areas.

I think that a discussion about deafblind culture could benefit by taking this model as a starting point. It is good because it describes culture in a very broad concept.

I would like to mention some examples from Denmark from which we can describe deafblind culture. For instance, every year in Solund there is a music festival for two days where different kinds of groups of handicapped people from all over Denmark can listen to music and have fun. Well known bands in Denmark play and it is a very great experience for everyone to be there. Deafblind people from Aalborg and group homes around the country can be together again. It is important, too, that deafblind people can be together with other handicapped people.

Inspired by this Solund festival we started a festival last year at Skovhusets campus. We invited all the deafblind people in Aalborg and other groups of handicapped people in the area. Bands of handicapped musicians and other bands were playing too. This Skovhuset festival will continue.

Another opportunity for deafblind people to be together with old friends is winter games in Norway, arranged every year. These games are also for different kinds of handicapped people.

Another example is DKU, which stands for creative expansion for deafblind people. The DKU has a programme and deafblind people

can choose a workshop that they are interested in. The leader of the workshop is a professional. Last year there was a workshop where deafblind people could learn how to make sculptures and another where they could learn how to make flower decorations and another where a professional taught them how to use make-up.

Newspaper

Another example of deafblind culture is The Window, our newspaper. It is a newspaper planned for six editions a year. This newspaper will be sent to deafblind people around the country, to parents and others who might be interested in this paper. Deafblind people, parents, paedagogs and others can write in The Window – most of the deafblind people cannot write, but some of them can draw or use the paedagog to write for them.

Another example of how deafblind people can be together and create a social network is the young and adult deafblind people meeting at the cafe evenings in Aalborg. At the last cafe evening there were about 70 people together. The programme was music, eating, entertainment from two fairground performers and just being together.

Once a year we perform in a play. We started last year with Hans Christian Andersen's tale 'The Princess and the Pea'. We ended up with two performances for the Institution and other invited people. From the paedagog's point of view this was a good exercise for deafblind education. Much training was given in the process, eg imitation, learning to wait your turn, concentration, memory, learning to co-operate and to be in the social situation. The process was very funny for both the deafblind students and staff and for the audience, too, I think.

Things like The Window, Solund music festival, Skovhuset-music festival, winter games, DKU and cafe-evenings, theatre and others are very important for deafblind people. They are, thereby, given an opportunity to get in touch with each other again, so that the break they feel when they move to another Institution can be of less damage. They also get an opportunity to create their own culture.

I would like to be a little provocative. I think that deafblind people can take as great a part in the culture as non-handicapped people will allow them. And why not give this group, who don't need to have to work for their living, the opportunity to develop other creative sides of their nature, to be of benefit to the common culture too?

