

## **Publication nr. 1**

### **Towards Independence for Lower Functioning Young Adults**

#### ***Plenary presentation at the 9th IAEDB World Conference, Poitiers 1987***

Towards independence for lower functioning young adults

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*The article below only covers congenitally deaf-blind people who are defined as being deaf-blind according to the Nordic definition of deaf-blindness. ?The article mentions some of the points of view and trends that concern family and staff of congenitally deaf-blind individuals at an early stage of development.*

### **VIEW OF MAN AND SPECIAL EDUCATION**

The legislation in our countries reflects a belief in what persons can do and what influence they are to have on their own lives. Think only of the legislation for school programs and the rules for both parents' and students' influence as well as our social legislation and its rules - or the lack of such - for the clients' influence on how to run the institution or group home in which they live. The legislation varies with the countries because they, among other things, express ideologies that again influence the view of man.

In our daily activities we are not very conscious about this. But if we work with congenitally deaf-blind people at an early stage of development, the injustice becomes very apparent when the congenitally deaf-blind individual is to have his or her natural share of the resources in society.

Many deaf-blind people still live in institutions for mentally retarded persons without sufficient staff, and without staff with the necessary qualifications. The housing facilities are not adapted to the needs of deaf-blind people and the staff is not trained in deaf-blind services. As a result, the deaf-blind persons' possibilities for development are not as good as they could be.

The majority of the congenitally deaf-blind people will not during their youth receive any continued education so that their communicative skills, influencing all other development, can continue to develop. In youth they will not have the same opportunities for accommodation, education and vocational training as other young persons.

Adulthood offers the same lack of possibilities for new impressions and possibilities for interaction, which is the basis of development.

In some countries they try to make up for this inequality. There are countries where the special legislation for impaired persons is abolished and the legislation e.g. for education and for social affairs is changed instead, so that the current legislation also meets the needs of handicapped people.

And there are countries where parents and staff fight hard for the equality for the law and thus argue that persons at an early stage of development, too, shall have the same opportunities for a place to live, leisure time activities, work and lifelong education, the same as other people in the society.

In this way they argue for a dynamic view of man based on the idea that all individuals have potentials for development if the possibilities for interaction are provided. And they argue against a mechanical view of man, based on the idea that human potentials and qualities cannot be changed and that a person will remain the way he was born.

We should be very aware of these fundamental views because in many areas they will determine deaf-blind peoples' possibilities. And they too, influence the way special education is practiced, for instance applying special methods to solve behaviour problems. In the Nordic countries the deaf-blind rubella child has made out the majority of the known congenitally deaf-blind population. In schools and in homes they have been educated and have developed due to working methods inspired by the programs for the deaf and the programs for the blind, which were strongly moored in European humanist philosophy.

As the integration of disabled people took place in other parts of society, congenitally deaf-blind people at an early stage of development were offered education in schools and homes for deaf-blind persons. This new group had other requirements for education and development because of their retarded development in the social, emotional, motor, cognitive and linguistic areas. Young and adult deaf-blind individuals with considerable behaviour and communication problems brought about a change in the concept of education, and new psychological theories were introduced or were practiced thoroughly and consistently. One tried for instance to solve the behaviour and communication problems using therapeutic principles derived from American scientific behaviourism.

The therapeutic principles have contributed with the inclusion of a large group of severely handicapped persons in the education and development programs around the world. The question is, however, if this principle is not only a new expression of a mechanical view of man, considering human development only as a result of environmental conditions where behaviour and language are controlled through punishment and reward.

The Soviet psychology has made considerable contributions to the understanding of the more sophisticated mental processes, including the functions of language as a means to control behaviour and thinking. The contributors to this understanding

emphasize that a person develops because of an interaction with his social and physical environment. This is a dynamic view of man.

When working with congenitally deaf-blind people at an early stage of development, it becomes evident that we work with a combined psychological model using different methods, which reflect different ideologies. This Eclectic psychological model consists of American scientific behaviourism, Soviet socially oriented psychology and European humanist philosophy focusing the individual.

Therefore we must be aware that the concept of society, the concept of man, the psychological theories and the practice in special education are based on different ideological philosophies. And congenitally deaf-blind people at an early stage of development must have their equal share of the resources in society. They must be treated equally in homes, at work and in education due to the legislation and the view of man existing in the society where they live.

## **THE DEFINITION OF DEAF-BLINDNESS**

Since 1980 the Nordic countries have applied a common Nordic definition of deaf-blindness. It is of great importance that this definition is functional and it is not conditioned by any minimal loss of hearing or vision. The individual potential of using the residual hearing or vision varies a lot. If all other conditions were the same, a young person would be able to use his residual hearing or vision a lot better than an elderly person, and a person without mental retardation will be able to exploit his residual hearing or vision better than a person with mental retardation.

Diagnosing deaf-blind persons becomes a team-work where conditioning functions like communication, social life, physical condition, work ability, daily living skills, housing conditions, economy etc. must be taken into consideration, as well as for congenitally deaf-blind people, also the information available on the cognitive, the emotional and the motor development. As opposed to a medical definition, a functional definition will still be valid as the progresses in special education and in medicine make it possible to include deaf-blind persons even with massive additional handicaps in the habilitation and rehabilitation programs.

This is where the large group of young and adult deaf-blind persons at an early stage of development belong. Years ago they were wrongly diagnosed as mentally retarded, and today they do not receive the help they need for an optimal development.

This group of young and adult deaf-blind persons is probably much larger than the group we know of today. A considerable part of this group of persons will be at an early stage of development cognitively and linguistically and have severe physical handicaps. Many will have behaviour problems because of the lack of language and the lack of mastering and comprehensibility in their daily life.

These persons must necessarily be included in the provisions that already exist and that are planned for deaf-blind people.

Due to the functional definition it is difficult to distinguish between congenitally deaf-blind people and multihandicapped people who do not use their hearing and vision functionally. In the Nordic countries we begin to interpret the definition of deaf-blindness in the way that persons who do not use their hearing and vision in a functional way are also defined as being deaf-blind, even though one cannot identify loss of hearing or vision when using the current medical methods.

Even if we do have problems doing it, we try to define this group from other handicapped people. They have a strong need for habilitation or rehabilitation, and they must therefore be taken into consideration when provisions are planned for young and adult congenitally deaf-blind people.

The expression "lower functioning" used about deaf-blind persons is at best meaningless and at worst discriminating. In most cases it refers to individuals at an early stage of development in the cognitive, linguistic, social, emotional and motor area. It would be more current in future to say "persons at an early stage of development" expressing belief in continuous step by step development, provided we can create possibilities for interaction.

By referring to the cognitive development as Piaget describes it, a common reference can be created applying the six sub-stages of the sensory motor period. A large number of the persons requiring improved services in youth and adulthood will in their cognitive development have reached a stage corresponding to the pre-operational period, and can hardly be considered as individuals at an early stage of development.

## **FURTHER EDUCATIONAL PROGRAMS IN YOUTH**

The first 18 years of a congenitally deaf-blind person's life is of crucial importance for the functions later in life. This period covers perhaps only one fourth of the entire lifetime of a person. It is therefore an urgent task for parents, professionals and politicians to plan and to realize provisions for young people and for young adults, which can offer possibilities for a meaningful adulthood as close to the normal standard as possible. The youth period is the bridge over the gap between childhood and adulthood and should intentionally contribute to the preparation of the young person for its adulthood. During their education it should be possible for them to:

1. Live together with other young persons
2. Have hobby and leisure time activities
3. Have further school education
4. Have a vocational training.

Congenitally deaf-blind youth have a strong need for help to be able to manage in adulthood. It will therefore be natural to offer all young persons 3 - 5 years of further education. This continued educational program should be offered to all persons regardless of the stage of development, and it must be adjusted to the individual young person's possibilities for housing, leisure time activities and work in adult life.

This means that the continued educational program will prove its efficiency only when a range of possibilities is built up for adult life. It includes housing facilities with its social life, leisure time activities, and work and at an early stage of development in the cognitive, linguistic, social, emotional and motor area. It would be more current in future to say "persons at an early stage of development" expressing belief in continuous step by step development, provided we can create possibilities for interaction. By referring to the cognitive development as Piaget describes it, a common reference can be created applying the six sub-stages of the sensory motor period. A large number of the persons requiring improved services in youth and adulthood will in their cognitive development have reached a stage corresponding to the pre-operational period, and can hardly be considered as individuals at an early stage of development.

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This means that the continued educational program will prove its efficiency only when a range of possibilities is built up for adult life. It includes housing facilities with its social life, leisure time activities, work and possibilities for further education also in adulthood. Thus provisions for youth and adulthood must be planned in a coordinated way.

There are many reasons why the years of youth are such an important period of life. The young person will experience an emotional and practical liberation from his or her parents, which enables both parts to prepare for separation later in life and to establish new emotional relations. And during the young person's education the family, parents and siblings can visit him or her when needed.

In establishing the continued education programs it is important to maintain the holistic view on man where the interdisciplinary team provides overview and coherence in the daily life.

In some places in the world further education is provided for congenitally deaf-blind youth and in other parts such provisions are planned. We must be aware that we do not once again segregate the persons at an early stage of development, but plan for all deaf-blind persons.

## **NEEDS IN ADULTHOOD**

In adulthood the basic needs are the same as in youth, and it is natural to see to that adulthood is built up on:

1. Housing facilities that allow for optimal independence in the daily activities, with the possibility for social activities
2. A possibility to maintain and develop hobby and leisure time activities to make leisure time meaningful.
3. Work or occupation activities that give satisfaction and optimal use of capacities and skills
4. Continued education and information for the continuous development of communicative skills as a tool for social development and for the understanding of society.

These basic needs must of course also be met in the large number of people who have not previously been educated in the schools or homes for the deaf-blind, but who today live in the institutions for mentally retarded persons. To support these people the following measures should be planned:

1. Habilitation and rehabilitation centres that offer training and education within the four areas mentioned above. The centres should function as resource centres and should also do field-testing and adjustment of aids and devices. In addition to this they should offer training activities for staff from other programs for the deaf-blind or from the institutions for mentally retarded persons.
2. Counselling and advisory services should be established to guide and instruct staff and deaf-blind persons.
3. A decentralised system of homes, jobs and further education programs adapted to the individual needs should be established. This system must be established to ensure that the individual gets the optimal possibilities for development, and must maintain and extend expertise within the field.

Systematically we should compile the experience acquired on housing facilities and possibilities for jobs or occupational activities for persons at an early stage of development. How many persons should live in the ideal group home to meet the individual needs for social contact, leisure time activities and so on? And how big should these units be to allow for vocational growth among staff? How do we create a model for integration that exceeds administrative integration and allows for social integration as well? How can we develop jobs for deaf-blind people at an early stage of development so that they also can work or have work activities which are different from the occupational activities in the home?

In the years to come it will also be an important task to develop adequate services for elderly congenitally deaf-blind people, so that the provisions are coordinated with the rhythm of life. So it happens to us and so it should happen to elderly deaf-blind people.

## COMMUNICATION

Cognitive and linguistic development is conditioned by the interaction with other persons and with the environment. According to Piaget the development of schemes and the coordination of schemes is the basis for the images that later on will be symbolised when using linguistic medias.

Adult persons at an early stage of development must therefore continue to take part in social and practical activities that offer new perceptual possibilities, and that are functional. In this way the basis for language development is formed.

Many persons will not reach a stage of development where they have a rich expressive language, which is often what we go for. But is the expressive language not only the top of the iceberg, the tenth that can be seen above the water? The rest of the language system, which we cannot see, is as important and it consists among other things of:

1. The creation of concepts
2. An inner language
3. A receptive language.

The concepts are created through sensory motor experience in establishing schemes, which are changed through assimilation and accommodation. They can continue to develop and form an important basis for adult persons' independent participation in daily life activities. The adult person without expressive language will demonstrate his or her creation of concepts and inner language in concrete action.

During sensory motor activity we create images, which are the beginning of an inner language. The inner language will control a person's actions depending on the memory for temporal sequences, and it is in this way also an important tool for independent living as an adult.

By using total communication in social and concrete situations it is possible to build up a functional receptive language, which will be of great value for daily communication. Our strong wish to develop an expressive language must not let us underestimate the value of other language elements, which are basic for other skills.

The use of total communication and structuring of persons, time and place have helped many deaf-blind persons at an early stage of development. But no matter which linguistic medium we apply, the main problem consists in attaining generalisation with spontaneous use of communication. This is perhaps due to the fact that communication often takes place at the staffs' initiative and therefore does not get an immediate function and leads to generalisation. Therefore we must be aware of the deaf-blind persons' to initiatives that are functional and thereby quicker lead to generalisation.

The strong structuring is often necessary to create comprehensibility and anticipation towards activities, and also to reduce the clients' fear and uncertainty. The structuring normally takes place at initiatives from the staff, but the deaf-blind person's signals can decide when a new activity is to be started. In addition to this, the staff must take care to interpret the signals from the deaf-blind person during the activities.

At this early stage of development the communication will depend on an established interaction where the staff interpret the deaf-blind person's pre-symbolic signals and attribute communicative value to these. The pre-symbolic communication takes place in eye-contact, following of the glance, mimics, touch, movements of the hands, sound productions etc. Later in the communication development other medias from total communication can be applied. It can be medias like concrete objects, 3-dimensional models, photos, drawings, pictogrammes, natural signs and sign language.