

STEPS / Lidingö

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FROM INTERVIEWS WITH TWO FAMILIES IN THE STEPS PROJECT

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BACKGROUND

The STEPS project is part of a programme initiated by EU to bring attention to the issue of discrimination, an important part of the EU charter given attention in article 21. To take steps towards finding methods which counter discrimination, the STEPS project was formed together with a number of other projects in Europe.

Within the STEPS project a series of European conferences work to collect information to form a common approach to the issue of discrimination. Some of these have taken place, others will be organized. A conference is therefore coming up where discussions will take place on legal and financial matters in relation to discrimination. To be able to discuss these, experiences will be gathered from persons with a disability.

This memo contains material from two interviews, here naturally presented briefly, which have been carried out in the Swedish national project. The question to be answered for this study has focussed on the family's striving for a good life for a son or a daughter with intellectual disability. Attention will be given to whether there has been, or whether there are at present, experiences which can be seen as an expression of discrimination.

The two persons in these interviews participate in the STEPS project. Those being interviewed are the parents of each person. The reason for choosing parents as informants is obvious as the persons do not communicate fully through speech. Another reason is the fact that possible discrimination is a phenomena identified and experienced by family members.

As these interviews will be made public, without any possibility for us to retrieve copies which are handed out, we have chosen not to go into aspects regarding personal matters concerning the person and his family, and details of services which have been mentioned in the interviews. The two persons have naturally been given names, Adam and Ben, which are not their real ones. In spite of this the reader is requested to handle this memo with due ethical considerations. After these two interviews a comment is given by the project managers.

ADAM

Childhood years

Adam was born in Lidingö, in 1980. At birth he was initially identified as a child with a heart condition commonly termed "blue baby". The implications of this condition

dominated his early life and at 2 years of age he had the first of several heart operations. Gradually a picture emerged of a child with a multiple disability. This included, in addition to his heart condition, one-sided paralyses, hearing impairment, epilepsy and intellectual disability. During his early childhood he was cared for in his own home and most of the support or treatment he required was provided by local health authorities.

School years

At pre-school age it became necessary to choose an adequate form for early education. This came to be the start of an extended period of lack of clarity, and consequently, indecision as to what were Adam's primary needs, and how, where and by whom they should be met. His parents recall this period as one of "fumbling in the dark". They describe this as a frustrating period when they were expected to make demands as well as decisions regarding their son's conditions and needs, without having received information enough about these matters.

This was exemplified by the account of their wishing to visit a primary school to assess its adequacy for their son and being told that first they must make the formal application before being allowed to make a visit. From their point of view this natural request illustrates the bewilderment of authorities they met when trying to assist their son to a good life.

At a later stage in his life, when Adam's needs had become more clear and it was established that he had an intellectual disability as well as a hearing impairment, it was found that the only provisions for such a child involved a placement at a residential school, localized to another province, a place at a considerable distance from his home. As this was presented as the only alternative it "had" to be accepted and a period of distress began.

Adam expressed a clear protest on the occasions of returning to school from a stay in his home over a week-end. By the staff of school this behaviour was described as disruptive and a normal part of his disability. By his parents, his behaviour was seen as an expression of his dislike of his being sent away. No other form for education was suggested until he was old enough to attend another school.

Another approach was however applied when Adam reached secondary school level. He was then able to attend a comprehensive school, still in another province, with a flexible curriculum, allowing for education with a personal content. He then also got the opportunity to live in a group-home for children. In spite of the school being a long distance from his parental home, his parents to-day regard this as a positive development. This was the first time a personally planned programme was made available. It was seen as a contrast to the previous "placement" which they regarded as being based on legislative factors rather than personal needs.

The approach to provide services based on personal needs, was also applicable in the planning of Adam's adult life, and this began 4 years prior to his leaving school. The parents recall that the social worker at the school, already on Adam's admittance, contacted the local authorities in his home community and informed them that it was time to start planning for Adam's adult life: *"He is going to need housing with support and meaningful daily activities - be prepared!"*.

Adult years

Today Adam lives in Lidingö, in the same community as his family. There he also lives with other persons with whom he is acquainted since his childhood - he has returned "home". He has lived in his present home for three years and has views as to how well it meets his needs and wishes!

In his apartment he receives the support he needs from a staff-group. This is made up by 4,37 staff who have the responsibility of providing support to a group 8 persons, all

with an intellectual disability, living in their own apartments in a house in the central part of Lidingö. Adam has lived in this way since June 2000.

He attends his activities on a daily basis. The activity group to which he belongs goes under the name of "The Craftsmen". His activities of the week includes the production and sale of wooden handicrafts, as well as other associated activities, for example the care of public notice boards in the community. In this group he has got a personal program which has been agreed upon between himself and the staff-group which is responsible for providing daily activities.

Participation in the ongoing STEPS project has had positive consequences for Adam. He has brought up issues of improving his housing. He has for example expressed the wish to live in a house which would make it possible for him to have a flagpole, and if not that at least a balcony to his apartment where he can hang out the flag! This request stems from his childhood living in a villa with a garden and a flagpole.

As the traditional group-home has been located to apartments, this could be interpreted as a discriminatory factor. There is however no formal legal or financial hinders to the ownership of a house becoming a reality. There are several experiences of persons with an intellectual disability having acquired a mortgage or becoming the owner of one's own home. Adam's parents also refer to positive experiences of their son's contacts with the bank and the personal support he has received through the appointment of a trustee.

Adam begun his adult life in circumstances which his parents now regard as satisfactory and which provide him with a good life. They emphasise the complexities of his disability and consider that the public services, for example the local health clinic, are supportive and cooperative in facilitating his wish to live on his own while receiving help from the district nurse when required, for example concerning medication.

The parents also consider that their son is a respected citizen and member of the community. He is well known as an active cyclist in his neighbourhood. His daily journey includes his having to cross a railway line at which he once had been witness to a pedestrian who had caught her shoe heel on the rails. Adam had reported the incident to the local rail authority which had taken measures to prevent such an incident recurring. His parents told of this episode as an example of "a non-discriminatory attitude" which they think is representative for the attitude towards persons with disability in Lidingö.

BEN

Childhood years

Ben was born in Lidingö, in 1969. At birth Ben was identified as a child with Down's Syndrom. For his parents his condition was something with which they had no previous awareness and were not familiar. The mother recollects this time as one when she received much information but which lacked any indication as to the long term consequences of his condition. She laughingly recalls how she associated "a chromosome deviation" as being the cause of criminality and wondering how this would affect her child!

One aspect about which she still feels a deep regret was that she was advised not to breast feed her son "in case" she should decide to place him in an institution. She says that such placement was never an alternative which the family considered, but that they felt bound to heed the advice of the "specialists". She was also told that she herself would be better able to cope with her situation if she did not tire herself by breast feeding, a view she says she still does not understand. Ben remained in the family and was cared for at home. In 1972 he was admitted to the local nursery along with other children of his age in the neighbourhood.

School years

On reaching school age Ben was admitted to the local primary school. There he attended a special class for children with intellectual disability, located in a separate building but in the grounds of the school. The class consisted of 6 children with individual programmes. The leisure and play activities and meals took place together with the other children from the school. This period of Ben's schooling is recalled as satisfactory and free from any complications based on his disability. To the extent that his family required support after school hours this was provided through his previous nursery school which also had the function of providing after-school leisure.

Ben's secondary schooling was a much more problematic period of his life. He was admitted to a special school 30 km:s from his home, involving a long journey daily in a special school bus (in Sweden children are expected to join a local school). This meant that he had new class-mates, but not necessarily from his own community. Apart from that the distance between home and school made the school less accessible for his family, creating difficulties for the family to maintain contact with his schooling.

When he became a teenager, in 1986, it was discovered that he had got an infection and had to be treated regularly with injections, something which had an extremely traumatic effect on Ben. Ben's fear of receiving injections by force lead eventually to his refusal to attend school and finally he was discharged.

After a long period without schooling he was provided with some home tutoring from a visiting teacher. This was later withdrawn as it was assessed that Ben was not "receptive to education" and therefore "excused" from schooling.

Adult years

For a long period following his exclusion from school Ben lived in his family home and was dependent entirely on his family for support. His behaviour became more that of a recluse, refusing to leave the home or meet with other people.

When it had become clear that Ben was considered as no longer being entitled to schooling, daily activities were offered in the form of a personal assistant, provided by the disability services of the municipality. A team of assistants then began a process of "socialisation", encouraging and supporting Ben to leave his home, to meet others and to participate in activities of his personal choice. As part of this process he made his first contacts with the activity group, "The Craftsmen", in which he now participates.

Today

Now Ben lives in a group-home and the days of the week are spent in daily activities outside his home, both services provided by the municipality as an entitled right in current legislation.

The group-home is a house which is shared by 4 persons, each having his own bedroom but otherwise sharing facilities such as kitchen, sitting room and two bathrooms. The support he needs in his home comes from a staff-group of 7,27 who are responsible for providing services to the men resident in the house. Ben has lived in this way since 1996.

During day-time he is a member of an activity group, "The Craftsmen". There he has a personal program which has been agreed upon between himself and the staff group. The activities of the group include the production and sale of wooden handicrafts. Ben's main interest and occupation concerns birdlife and the making of wooden nesting boxes. These are sold to members of the public who attach them to trees in urban areas (a common phenomena in Sweden). "The Craftsmen" also have a responsibility in the community as they take care of the public notice boards, maintaining them and clearing them regularly of notices which have become out of date.

DISCUSSION

On the major question of whether discrimination of persons with intellectual disability exist, there are of course limitations to identify this through two interviews. But in spite of this there are some tendencies which could be given attention.

Adam's parents do for example discuss whether the problems they have faced could be seen as an expression of discrimination. They point to the intricacies of special legislation regarding children with a disability. Which "legislation" and "regulations" are applicable for a child with a multiple disability: those for children with a hearing impairment or those for children with an intellectual disability? During the interview they were not prepared to describe this issue as necessarily being a legislative and a discriminatory problem but saw it merely as an expression of human inadequacy.

Is it that we are unused to the use of discrimination as a concept and therefore we don't see this phenomena if and when it appears?

Both interviews point to major problems for these persons arising during school years, problems which had major implications for them later in life. It is not possible from this material to state that the educational system for person with this disability does contain discriminatory practices. The school years mentioned here are from a period some decades ago, a time when the knowledge of today was not at hand. It is difficult to judge past work, from present position.

But these children had received their education at residential schools, that is at institutions. As such they are an expression of discrimination of persons as their function is to separate persons with a disability from the mainstream of everyday life. It is quite clear from these small glimpses of the background of Adam and Ben that these school institutions used practises which had negative consequences for them.

Another tendency in these interviews is represented by the adult years. Adam and Ben lead a good life in Lidingö. No expression is found of discrimination. Instead they are respected members of this town, at the same time as they have contributions to the community. Can the reason be that their needs are seen, recognized and responded to?

With the acceptance in the disability services of Lidingö for present ideology of legislation, respect is shown for the needs of these persons. The democratic basis of the Act of Parliament has been brought into everyday life leading to major attempts to find services which contribute to the citizenship of these members of community.

As regards the financial side of these services a well differentiated system of economic support has been developed leading to a variation of housing and daily activities. In this way a basis has been laid for meeting personal needs by means of giving a structure to economy, based on the ideology of present legislation. The idea that the needs of the person can be taken as a starting point for budgeting, is an expression of a non-discriminatory attitude. (More on the work of disability services can be found in the STEPS report from May 2003.)

Our conclusion from this little study is that legal and financial matters are important factors when working against discrimination. The legal framework of services must of course be based on the recognition of all persons with a disability as citizens, with the democratic rights which belong to this role. When the economic system is used as a means of realising this socio-political idea, it becomes a most potent tool against discrimination.