

A pamphlet on the European Year of People with Disabilities

Close the Institutions for the Intellectually Disabled

Everyone Can Live in the Open Society

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*"All human beings are born free
and are equal in worth and rights"
UN 1949*

*A society that discriminates its disabled citizens
is a disabled society.*

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Human Rights are Human Only if They Refer to Everyone

In the 1920s the philanthropic approach to care for people with disabilities subsided as ideas concerning racial hygiene changed the way in which people with disabilities were viewed. The institutional system was developed and people with intellectual disabilities were increasingly isolated from society.

Forced sterilizations were performed in large numbers throughout the western part of the world, and in Germany, under the Nazi regime, a large number of intellectually disabled children, teenagers and adults were murdered.

No other group of people has been subject to the same levels of encroachment on their integrity, as well as prejudiced abuse as children and adults with intellectual disabilities. Despite the fact that the human rights include people with disabilities, it is still considered acceptable to deny them access to the open society and confine them in institutions.

Today, the institutions are the last remaining manifestation of past, collective ideologies, that gave society the right, and the power, to separate certain people from the rest of the community and limit their freedom, influence and life conditions.

There is evidence that no people with disabilities need to live in institutions, no matter how profound their disabilities are. And more importantly: To live in the open

society leads to an increased degree of independence and personal development.

In Sweden and Norway all institutions for people with intellectual disabilities have been closed. As a result, destructive behavioral patterns have diminished or disappeared altogether to a degree that no one could have foreseen. Prejudices have been torn down, the solidarity with people with intellectual disabilities has been strengthened and the humanitarian forces in society have gained influence.

Inclusive living has had no negative effects or consequences. Furthermore, in the long run it is more economically sound, due to the good results.

As a result, the right to live like you and I do has become a political issue.

No one would want to live in an institution, the way many people with intellectual disabilities are forced to do.

No one would choose to live apart from his or her beloved ones and outside the fellowship of the open society.

No one would want to spend his life being dependent on persons he has not chosen himself.

Psychological Effects of Living in an Institution

A vast amount of research has been done on the psychological effects of living in an institution. In general, the negative effects are less severe when the institution is modern and small scale. But even in small institutions there is a marked difference compared to inclusive living.

The trauma of being involuntarily separated from one's parents, friends, and familiar home environment creates a fundamental conviction of being unwanted and powerless, of being an object, rather than a unique individual.

The institutional environment in itself creates additional handicaps that will mark the person for the rest of his or her life. It is primarily the emotional and social development that is hampered.

Emotional maturity is not dependent on the degree of disability. A person may be relatively intelligent, but emotionally immature, while someone with severe intellectual disabilities may be relatively mature, emotionally. The fact that a person with profound intellectual disabilities has difficulties in expressing his or her feelings does not preclude a developed emotional life.

The development of a normal emotional life is hampered when one is confined to a paltry and single-sexed environment, and suffers from lack of personal life, lack of

autonomy and lack of respect for one's personal integrity.

Emotional immaturity leads to a hampered and underdeveloped identity development and delayed sexual maturity. Furthermore, the development of language, as well as the intellectual development, is also hampered to a greater degree than was previously known.

Children and youth tend to develop ways of stimulating themselves, sometimes in self-destructive ways. Adults develop various psychiatric symptoms, aggressiveness and depression being the most common ones, although the symptoms may be different for people with intellectual disabilities than for non-disabled persons.

As a result of the research on the psychological effects of living in an institution, two terms have been coined: social deprivation and taught helplessness. Together, these terms reflect the results this research has led to.

Some institutions work better than others, but not even the best ones reach the same qualitative levels as adequately supported inclusive groups does. The reasons for this are that the groups who live together are small, they live in residential areas, the working conditions for the staff are better and the residents have more contact with their relatives.

Principles for Inclusive Living

The Normalisation Principle

The overarching idea is that children, youth, and adults with disabilities should be given access to living conditions and everyday routines that are as similar as possible to those of ordinary citizens.

Parents should be given support so that their children and teenagers can remain in the home. Only under inordinate circumstances should they be given the opportunity to live in a foster home or a pupil home.

Adults should be offered support so that they can live in a way similar to other adults or in a group home.

This way, persons with disabilities will avoid having their personalities shaped by living in an institution. Being part of the surrounding community will lead to new relationships and experiences.

By living like other people one will develop a personal daily rhythm as regards getting up in the morning, eating at regular hours, having work hours, leisure time, and bed time. In addition, this will lead to a normal weekly routine with opportunities to participate in cultural or other activities in one's neighbourhood, depending on one's individual interests.

A normal living situation will ease the contact with one's parents, relatives and friends, due to both social and geographical reasons. Having one's own apartment as part of the group home will make it possible to have control over one's own social life.

Just as for ordinary citizens, all residents of the group home and the pupil home should partake in daily activities-children should attend school and adults should have jobs to go to.

Children, youth and adults should live separately. Within larger districts there may be grounds for having special residences for young adults, as well as for older persons.

Within the frames for age divisions there should not be any divisions based on sex or degree of disability. In reality, this means that a group home should not house more than one person who has profound physical disabilities and is dependent on special aids for hygiene etc.

The only groups of people who should live together because they share additional handicaps, apart from their intellectual disabilities, are deaf people, because they need staff who master sign language, and persons with autism, due to special treatment programs.

In order for the individual to become socially integrated-that is, that he or she is given the opportunity to develop relationships and participate in the community-an inclusive living is a prerequisite. This demands support and guidance, as well as an awareness of the amount of time it will take to reach these goals.

The situation for the staff

The work structure of the staff at institutions is more task oriented and based on routines, than that of the staff at inclusive living facilities. This means that they are responsible for certain tasks, for example in the kitchen, the bathroom, as regards cleaning, etc. The staff is part of a hierarchical structure and seldom have the opportunity to develop and improve the support themselves.

The staff at inclusive homes feel greater responsibility for the living facility, they show more involvement, they like their work place and their work structure is focused on the individual. Each of them is responsible for one or more residents, concerning everything that involves these individuals in the home. Their input can be adapted to the needs of each individual.

The principle of the small group

A group of people with disabilities that live together should be no larger than that they can develop personal, lasting relationships with each other and with the staff. Because their communicatory skills, as well as their ability to predict different reactions, are limited, the group must be kept small.

Number of possible relationships rises dramatically with an increased size of the group. For example, a group of four people may, besides the fact that each one can relate to one of the other members, two can relate to one of the two remaining persons or three relate to the fourth. Altogether, this amounts to 25 alternatives. In a group of five there are 90 such alternatives theoretically. Research and experience show that the best size is a group consisting of approximately four persons.

A residence for a small group will blend in with the rest of the neighbourhood and the size of the staff will be kept down. In a small group conflicts, as well as routines, will be few and the participation in society will increase. Each individual will be given the support he or she needs

”Persons with disabilities are members of society and have the right to remain within their local communities. They should receive the support they need within the ordinary structures of education, health, employment and social services.”

The Standard Rules on Equalization of Opportunities for Persons with Disabilities. UN 1994.

From Institutions to Inclusive Homes

Some terms

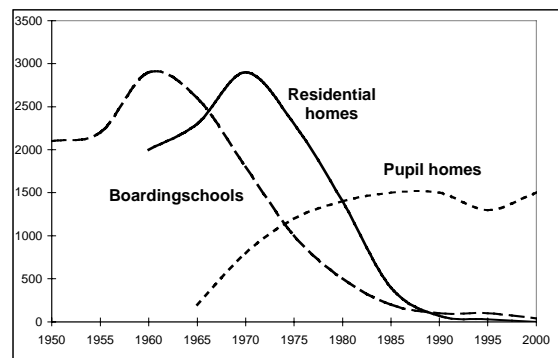
Living inclusive means that one lives either with one's family, by oneself or in a small group of people in an ordinary house that is located in a residential area. When children and youth live together their residence is called a pupil home and when the residents are adults their home is called a group home.

The term institution refers to one or more houses that are separated from their surroundings, in which many people live together, divided into different units. Institutions for persons with intellectual disabilities are called boarding schools, residential homes or hospitals.

The situation for children and youth

As the figure shows, Sweden used to have two types of institutions for children with intellectual disabilities: boarding schools and residential homes for children and youth.

The boarding schools were replaced with special classes at ordinary schools. This way many children could live at home with their families, while others, who still lived far away from their schools, were obliged to live at pupil homes located in the same area as their schools. They were offered transportation home on Friday afternoon and were returned to the pupil home on Monday morning.



The residential homes for children and youth could be closed gradually, as parents were given personal and financial support, the right to free day-care and pre-school as support from local groups of experts, so-called habilitation teams. In addition, families were given the right to short-term relief from the care of the child (usually a few days at a time or a week per month) or to have temporary caretakers in the home (usually a few hours every week).

In cases when parents were unable to care for their child in the home the right to residence in a group home for four children, placed in the ordinary community open all the time, including weekends, was introduced.

For profoundly disabled children over the age of seven an additional right was stipulated that gave them the right to special education in training schools and transportation to and from the school.

The highest number of intellectual disabled children and youth Sweden has had in institutional care is five thousand people. Today, we do not have any institutions. Out of 19 000 children and youth who is given special education, 1 400 live in pupil homes and a couple of hundred in foster homes. Out of 1 500 intellectually disabled children who are below school age, only 40 do not live with their families.

There are, in addition, some smaller anthroposophic homes and three special schools for children and youth with

intellectual disabilities. These schools accommodate those who, besides their

intellectual disabilities, are deaf or blind or who have profound speech handicaps, including autism.

As a result, we have today a whole new generation of disabled children and youth who are more emotionally mature and aware, as well as a new generation of parents, who are familiar with their children's needs and the obligations of society.

Did this process from institutions for children and youth to pupil homes take place without any conflicts? On the whole, yes! Most of the protests came, understandably enough, from the staff. During the initial phase, parents of children in residential homes were sometimes sceptic as well, but they changed their minds when they saw the advantages with pupil homes.

The county councils, who owned most of the institutions and who were responsible for the pupil homes and the special education, accepted the new system. In the long run it was cheaper for them and it was better for the children and their parents.

The situation for adults

The number of available care units at residential homes and special hospitals in Sweden increased during the 1960s and 70s, so that all adults with intellectual disabilities who wished for care could be accommodated. See figure. By the end of this period, there were around 125 institutions, one third of which were private.

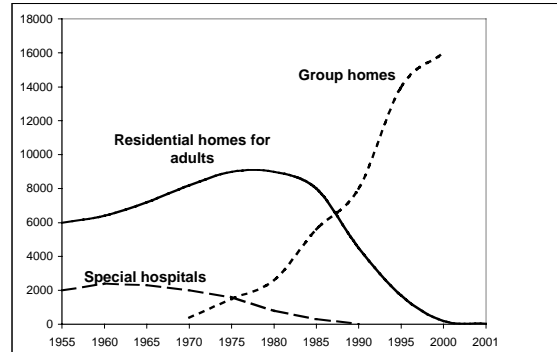
The special hospitals were closed as the need for them diminished and the residents were transferred to residential homes. The residential homes were gradually replaced by group homes.

The number of group homes increased during the 1970s. At this time a large number of activity centres were opened.

Approximately one half of the number of people who moved into the group homes came from their parents' homes and the other half came from residential homes.

Later on, those who had profound disabilities could move to group homes as well. In 1985 the parliament proclaimed that all remaining residential homes should be closed by way of not admitting any new residents. This was a drastic, but well-founded, decision!

That same year the parliament decided that group homes should be included in the state-issued loans that were given to ordinary homes. This was given on the condition that each person was given his or her own apartment that was no less than 40 square meters, as a part of the group home.



This decision was very important. At last, people with disabilities were given the chance to live like ordinary citizens! And this also included those who had very profound handicaps.

Today, 60 percent of all adults with intellectual disabilities live in group homes, 20 percent live independently and 20 percent live with their parents.

The group homes are located in apartment buildings, row houses and single-family houses. An alternative type of housing consists of a number of apartments close to each other in the same apartment building, with one apartment set aside for the staff and as a place to meet for the residents. This type of meeting place is sometimes set up for people who live in the same neighbourhood, as well.

Every year, a considerable number of people with intellectual disabilities move from group homes to apartments nearby, due to developments in social skills that they have made. No one should have to be more dependent than is necessary! By moving to an apartment nearby, the person is able to keep in touch with friends and staff.

One important advantage with the group home is the fact that it can easily be put to

other uses or sold when it is no longer needed, as opposed to an institution.

Daily activities and leisure time

The daily activities in the community or neighbourhood where the group home is situated are necessary for those living in group homes, with their parents or alone. These daily activities used to be limited to special activity centres, but they have been expanded with an increasingly work-oriented establishment. As a result, intellectually disabled persons, either in small groups or individually, take part in some type of service or production. The loneliness that many feared would occur as a consequence of inclusive living

never became reality. However, it is necessary that staff encourage and support the individual in choosing activities, participation in courses, etc. Naturally, those who possess limited abilities need support in order to experience and participate in different activities. In addition, youth leaders who organise leisure activities are necessary.

As it turns out, many people with intellectual disabilities possess great skills in making new friends and acquaintances. It is striking, the way they are able to, and enjoy, rambling in the community and many of them belong to different organisations or clubs.

Can any person with intellectual disability live in a group home?

Yes! As long as the home has been designed for disabled people, a person with extensive needs for care can live there as well as in an institution. Problems may occur when residents have behavioural problems, such as screaming and shouting. This will require additional staff and has sometimes led to the placing of a group home in the countryside where neighbours will not be disturbed.

There are a number of smaller treatment homes where adults with intellectual disabilities may live for a limited time. No persons with intellectual disabilities live in mental care facilities. Also, there are no homeless persons with intellectual disabilities.

During the early stages, in the 70s, complaints from neighbours were fairly common when group homes for adults were being planned. But through openness, information and trained staff we have learned how to prevent and minimise these problems. The general public's knowledge and experience of people with intellectual disabilities have increased and now they are not perceived as disturbing or threatening.

Did the situation improve?

A large number of studies on how it is to live in a group home as an adult have been

done. These studies verify the advantages of this type of living compared to living in an institution.

50-80 percent of the relatives of people with intellectual disabilities were against the closing of the institutions. They were afraid of the prejudice their adult children would encounter, and feared they would not be able to handle traffic, that they would be lonely, that their new homes would be under-staffed etc. -But none of these things have occurred! In follow-up studies the number of satisfied relatives is around 80 percent.

Studies have shown that those living in inclusive homes were given care that was more focused on the individual, that they felt safer and needed less medication. Aggressive and self-destructive behaviour decreased drastically. Those persons who had the most severe disabilities improved the most, in relation to their disabilities.

The staff gained more influence over their work, they had less set routines and more freedom to take their own initiatives. However, they were also given less training and supervision than they had previously received at the residential homes.

A Testimony

Åke Johansson lived for 32 years in a residential home for the intellectually disabled. This is his account:

What happens to people who live like this? They become passive and to be passive entails not knowing what is going on around them and not caring about it. You take the day as it comes and you do not wonder why everything is the way it is. Everyone around you behaves the same way; they all walk around in a sort of lethargy that becomes somnambular. You do not even have to care about your own clothes. Everything is decided for you.

Eventually this environment comes to represent safety. That which is new or different causes fear. As a result, no one causes any problems; no one starts to shout, wanting to leave. The will to leave is broken down; it does not exist any more. There is no room for real life inside such walls; this is why it is not to be found there either. You do not live, you exist.

From **Åke's Book** by Kristina Lundgren. 136 pages. Riks-FUB. PO 55 615. S - 102 14 Stockholm, Sweden

Should Institutions be Renovated?

Because of the decrepit condition of many institutions for intellectually disabled people in Europe, renovations or the building of new institutions are necessary. It is when this situation occurs one should consider investing in group homes and activity centres instead. But this kind of paradigm shift takes time! In the meantime there is much that could, and should, be done inexpensively, at the institutions. For example:

- Divide dormitories with low walls or curtains.
- Divide the residents into small groups that have their own staff and that live and eat together and have their own common room.
- Try to include persons of both sexes in the groups.
- Give all residents their own wardrobes by their beds and bedside lamps.
- Give everyone their own clothes and shoes so that they can get up and go outside every day.
- Provide everyone with meaningful daily activities in locations outside those where they live.
- Use large dining halls for something else.
- Increase the rights of individuals to decide for themselves what their day should look like and how they should use their money and spare time.
- Increase the staff and give them more responsibility for planning the day and the week for the residents they are responsible for.
- Give the staff increased authority to encourage contact with parents, siblings and friends.

The End of an Era

The figure below shows the number of intellectually disabled persons living in institutions in Sweden between 1880 and 2000. The time spent in an institution could be anywhere from a few years to a whole lifetime. Altogether, 100 000 people are estimated to have lived in institutions.

Sweden and Norway are the only countries that have closed their institutions for intellectually disabled people. Denmark has closed a large number of institutions. In Holland, however, the number has gone up. England, Wales and Scotland have closed almost all their special hospitals. The situation in the other European countries is unknown as statistics for the number of institutions, their size and character, is lacking. In the 1960s institutions were being closed in the U.S.A., but this took place without any measures being taken to provide for other types of appropriate facilities and as a result it was rightfully criticised. The process came to a standstill.

