

**FROM INSTITUTIONAL TO COMMUNITY SERVICES:
TOWARDS A NORMAL WAY OF LIFE FOR THE
PERSON WITH INTELLECTUAL HANDICAP**

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THE NORMALIZATION PRINCIPLE

During the forties a socio-political change took place in Sweden as regards services to handicapped citizens. The idea of letting the handicapped person live "the normal life" of non-handicapped was introduced. This idea was termed "the normalization principle". Earlier, the only way to give support to this group was through a system of institutional services, which separated the handicapped person from the ordinary community. With these new goals aiming at full participation in society of handicapped persons, a new type of support, community services, had to be developed.

When summarizing the normalization principle there are primarily three questions which deserve a special comment. The choice of the normalization principle implies first and foremost a standpoint on one of the basic issues concerning the nature of services for intellectually handicapped persons, namely the question: Where in society and under which conditions should handicapped people live? To-day two answers can be given. One expresses the view that this group should live within the traditional institutional setting, at a distance from the ordinary community. The alternative is that the handicapped person should live where the non-handicapped live and there lead "the normal life", participating in the community. The normalization principle implies a choice of the latter alternative.

Secondly, a choice of the normalization principle also implies a standpoint on the question of the role in society for the handicapped. The person, irrespective of his degree of handicap, is seen as a fullworthy citizen and as such has a right to live in the community under "normal patterns and conditions of everyday life".

Thirdly, by accepting the normalization principle one also accepts the view that the nature of the service provided contributes to whether attainment of "normal life" can become a reality or not. If intellectually handicapped persons are to be able to participate in society and to live under normal conditions of life, services must be developed to contribute to the realization of this life.

This socio-political position was formulated as part of a broader discussion in the country during the end of the thirties and the beginning of the forties. Then a debate took place on the creation and nature of the welfare state. The purpose of the welfare state was to guarantee citizens a good standard of life. If necessary this "good life" was to be obtained through modern social services that provided support to families through programs for housing, schools and employment.

In 1946 a government committee presented a proposal on how to improve the access of adult handicapped persons to employment and working life. The

purpose was to enable them to increase their opportunities to provide for themselves and thereby live a better life. The committee formulated the socio-political principle which would become the basis for their proposals. This was to be called the "normalization principle".

The suggestions of the committee on how to bring about a better life for the persons then termed "partially ablebodied", implied measures to facilitate their receiving employment and thereby an income, thus making it possible to provide for themselves. At the same time the committee suggested that these handicapped persons should have the right to avail of the services for the non-handicapped population which already existed in society and which were developing in pace with the establishment of the welfare state.

Their intention was that by availing of the services offered to the non-handicapped citizen it would be possible for handicapped citizens to remain in society and there live a "normal life". This was motivated by saying it meant a positive development for both the handicapped individual and for society at large. For the handicapped individual there was the psychological implication of being able to live a normal life among the non-handicapped and for society it meant that even the handicapped could make a productive contribution to working life (Ericsson, K., 1985a, 1985c).

TWO SERVICE MODELS

Today there exists an organization of institutional service. However, since the forties community services have also been developed. These have developed to such an extent that community services now can be found for all groups of mentally retarded persons. Two service models can now be presented to provide the support needed by intellectually handicapped persons.

A difference between these models concerns their physical-structural characteristics. The community service model is characterized by support to a person being provided mainly through housing and place of occupation, be it a school, a day activity centre or a place for work. These two units should be geographically separated, in different areas of the community, with two staff-groups having different responsibilities and roles.

The community model is also characterized by its proximity to the community and to non-handicapped citizens. The home of the mentally retarded is located to a residential area where non-handicapped people live and the day activity centre is located to an area where non-handicapped people work during the day. When the mentally retarded person needs services, not provided in the home or day activity centre, they should avail of the services provided for the general public in the area. Within the community model work is carried on in small groups of mentally retarded persons. Staff have a high degree of responsibility, and authority to decide over their tasks.

The institutional model has a completely different character. Typical is a large institution, often a modified medical establishment, where many people live in large groups. These are located to one large institutional area where the residential unit and place of activity are located in the same grounds. Neither is it presumed necessary in the institutional model that everyone should have access to a daily occupation, separate from their living unit. Instead it is often the case that the ward is considered to be the main place of care, therefore a daily occupation is not given priority. Any other type of service which the person may need is also provided within the framework of the institution.

As the area of the institution is of necessity large, it is most usual that it is located to a place apart from the ordinary residential community or places of work in the district. This implies often physical distance to the ordinary community. The institutional model is also characterized by a centralized administration. Little authority or responsibility is given to the staff of its different units (Ericsson, K., 1985b).

DEVELOPMENT OF COMMUNITY SERVICES

A difference was earlier made between "educable mentally retarded" and "non-educable mentally retarded" persons. Schooling was for example given to the "educable" group, but not to the others. This was the case already during the end of the 19th century. This thinking still influenced the 1954 Act of parliament of services for this handicap-group.

In this Act the first consequences of the socio-political change expressed by the "normalization principle" were seen. The Act stated that the teaching of "educable mentally retarded" persons should be organized in the form of "external schools", that is a school in the community, outside the traditional school-institution. At the same time the adult intellectually handicapped persons, who previously had been to school, were to receive "open-care" as an alternative to institutional care. In addition, this 1954 Act guaranteed that "non-educable mentally retarded" persons, children as well as adults, were provided with institutional service.

The statement of this Act did not of course result in immediate changes. But during the period up to the next Act of services of 1967, a development of the first community services for children and adults took place.

The 1967 Act still prescribed that community services should only be offered to persons with a mild mental retardation. Adults with a severe mental retardation should receive institutional services.

The new group to receive community services according to this 1967 Act are children with a severe intellectual handicap, who earlier were termed "non-educable". Through this Act they received the right to schooling. This was to be organized in the community, outside the school-institutions. They also received the right to services in their home in order to be able to stay on living with their parents. During the seventies community services are therefore developed to a large extent. The persons who receive these are children and adults with a mild or a moderate handicap and children with a severe handicap.

The increased experience and knowledge on how to form and run community services gained during this decade, led to the position of the 1985 Act of services namely the right to a normal life, through community services even for adults with a severe intellectual handicap (SOU, 1981:26).

COMMUNITY SERVICES

If the mentally retarded person is to experience a life with normal patterns and conditions of everyday life, it is necessary that the services provided for his support are located to places in the community where the non-handicapped citizen is found. There services must be established which provide both dwelling and places for daily activities in the community and thereby make participation possible for the intellectually handicapped person.

If a child is to grow up in a family, his own or another, the family must receive support. This can be practical help in order to simplify daily life or it can be financial support in order to reduce the economic burden of having a handicapped child. Relieving services, for example a short-stay home, can provide a family with the necessary relaxation from constantly having to care for a handicapped child. Such support helps a family to go on living a relatively normal life. Support can also be of a psychological nature for example help in coping with or treating feelings and emotions, reactions and relations within the family which are a consequence of having a handicapped family member.

Handicapped children should be able to receive their special education, whose goal is to promote personal growth and to develop practical abilities, in the same schools as non-handicapped children. The developmental stimulation provided by pre-school programmes is especially important for the mentally retarded child.

To enable the mentally retarded adult to live within the non-handicapped community, the normal housing of the this community must be provided with adjustments, services and personal support. These must be related to the individual needs of those who live there. For moderately and severely retarded persons it has been shown that the group-home is a suitable type of dwelling. 4-5 persons live together in a house similar to those in the ordinary residential area where it is located. The dwelling can be either a detached villa, a terrace house or an apartment depending on the locality. The interior may however be adapted to the needs of those living there. Even the staff-ratio, both day and night, must be related to the needs of the residents.

For adults who do not have paid employment an alternative daily activity is necessary. The day activity centre are responsible for providing this. In small groups with staff, activities found meaningful for the individual can be provided in various places in the community.

In addition to these types of provisions the handicapped person often is in need of habilitative measures, that is to say individually related means of developing the person's potential. Social, educational, psychological or medical experts may be required for these measures. These individual habilitating programmes can be provided through the special services for the intellectually handicapped, or as part of the ordinary provisions in society for non-handicapped citizens.

The various types of support and service mentioned so far are however not sufficient on their own. The handicapped person must also be able to avail of the ordinary services provided in the society for the non-handicapped. Social welfare, health centres and dentists are just examples.

INSTITUTIONAL SERVICE

It is during the middle of the 19th century in Sweden. That work began on developing services for the group of people we today call intellectually handicapped. Services created during the years up to the turn of the century were concentrated to large institutions. There was an optimistic thought behind these. As an alternative to the environments in the community where the intellectually handicapped person had not succeeded, one sought environments where demands were adjusted to the capabilities of the mentally retarded person. The intention being that measures be taken there to develop and prepare the retarded person for a return to the ordinary society.

The institutional structure, established during these years, remained during the first four decades of the 20th century. But during this period a fear developed for the negative effects intellectually handicapped persons had on society. It was also during these decades that the view of this group changed. It had become apparent that the hopeful view, that these persons could return to society, was difficult to realize.

Earlier optimistic views of the person's right and ability to participate in society changed to a more pessimistic view. The attitudes of society were now dominated by restrictivity and efforts to separate the group from the ordinary society. The function of institutions changed therefore during this period. Their function was instead to protect society from these handicapped persons. This development took place in a society characterized by economic conflict and limited resources. This influenced institutions in such a way, that persons had to live there under miserable conditions, marked by poverty.

A programme for the modernization of institutional services was carried out during the fifties, the sixties and the seventies. Old institutions were rebuilt and new ones were established.

The development of community services had led to consequences for institutional services during this period. When only a limited support could be offered from community services, it was only persons with a mild handicap who could move from the life of the institution to the more normal life in the community. Now, when community services have been developed to the extent that also persons with a severe handicap can receive a qualified support, even they can leave the traditional institution. Through community services they have got a chance to live a more normal way of life.

The 1985 Act of parliament on services for this handicap group states that community services must be offered to all intellectually handicapped persons, irrespective of degree of handicap. These services must also be formed to suit most of the handicapped persons who are to use them. At the same time this Act states that all institutions are to be closed down. Alternative community services must be provided.

Work has already started on closing down large institutions in Sweden. From this we know some of the consequences of this intention of the 1985 Act. The intellectually handicapped person can experience a more normal life with a higher living-standard and a greater participation in society. But we also know that the most complicated part of this process of change concerns not the handicapped persons, but persons and organizations around him. It puts a strain on parents and relatives and on staff, but they also show satisfaction when the period of change is over. There are also organizational and economical problems to solve. Values and knowledge of the service-organization and of the community at large, needs to be developed in order to relate to and to work with the handicapped person in his new role and setting in society (Ericsson, K., 1984).

TOWARDS A NORMAL WAY OF LIFE

For the handicapped person the differences between these two models are critical. They offer two completely different types of environment, and therefore completely different conditions for personal development. By means of the varied experiences of the persons, the everyday life and the future quality of their life will vary greatly.

This "normal life", with a personal character, concerns no longer only those with a mild or a moderate handicap, as was the case with the first types of community services. These services have today become a reality even for persons with a severe or a profound handicap, who are now moving from institutional care to community services.

Because of this development it has been possible for these intellectually handicapped persons to leave the large institution for a more normal way of life in the community. For many this has meant a radical change. The everyday life of the handicapped person is characterized by a more normal pattern of life as regards the physical environments and his social relationships. This life has also led to a personal development, both emotionally and with regards to their abilities. It is a dramatic experience to see the change which has taken place for the handicapped person who has moved from the traditional institution to good community services.

The positive outcome for the intellectually handicapped person of this process towards participation in society is an incentive for this development to go on. There are of course a series of problems to be tackled as work with services delivered within the framework of the ordinary society demand new solutions, social methods and social relations characterized by equality. It is therefore not uncommon that mistakes are made, which is just an indication of the fact that a lot of research and development remains to be carried out. Most common however is that persons receiving community services experience a better life. If this was not the case the idea of these services would not have become a reality to such a large extent as is the case at the moment.

ARE THESE EXPERIENCES OF RELEVANCE?

The development of services for intellectually handicapped persons since the forties in Sweden has of course been part of a general process of development. The economy and values of society has resulted in socio-political aims which have contributed to the development, models and experiences of community services which can be seen at the moment.

Is there anything of relevance in these experiences for a country which is at an early stage in the development of services? There are of course many conditions which are specific for a country like Sweden. Buildings where these services are located, are for example built within the norms of general housing in the country. The same situation, the use of general norms, applies for example to the special schools for intellectually handicapped children. Therefore there are specific solutions which are unique for Sweden.

There are however models and socio-political ideas developed during this period, which can be used by other countries, bearing in mind, of course, specific local conditions. When it concerns housing for example, it has been shown that the ordinary housing of the local community can be used for housing for intellectually handicapped persons. Some alterations must sometimes be made according to the needs of the persons living there. The point is however that now, no special building, for example in the form of an institution, needs to be built.

The socio-political idea behind community services, expressed in the concept of the "normalization principle", can be applied in other cultures than the Swedish. One aspect in particular put forward by the 1943 committee has a general value. One of the major reasons for suggesting that handicapped persons should have the right to avail of social services for non-handicapped persons, was the opinion that this was the only and best way to guarantee

services to handicapped persons. By using the ordinary services of society the needs of the handicapped would be satisfied to the same extent as those of the non-handicapped.

The alternative, to create separate services for handicapped persons at the same time as services of the welfare state were provided for non-handicapped citizens, would never have resulted in services of quality to the handicapped.

Today many countries can be seen to be in the same situation when faced with demands to develop services for handicapped persons. Should a country create special services, with separate programmes, staff and economy, or should the services, which handicapped persons rightly need, be available through a development of generic services? The "normalization principle", applicable in this situation, argues for the right of handicapped persons to use the services of non-handicapped people.

It is also my opinion that Swedish experiences have shown that today there are two models of services, the institutional and the community model. It is therefore no longer necessary to build traditional institutions when creating services for intellectually handicapped persons. There is even less reason for this when one sees that some countries have started to close down their institutional services, because alternative services have been found which better suit the needs of handicapped persons and which have been proven to be beneficial to the persons receiving this type of support.

In some circumstances there is talk about "developing" countries and "developed" countries. Concerning services to intellectually handicapped persons, it is my opinion that these expressions are not adequate. The "developed" countries are certainly not always "developed" in the sense that they can offer adequate services for their handicapped citizens. Instead many of these countries offer mainly institutional services, often in large out-of-date institutions. There is therefore a common objective for these countries, as well as for "developing" countries, to create services in the ordinary community for its handicapped citizens.

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