

**THE ORIGIN AND CONSEQUENCES
OF THE NORMALIZATION PRINCIPLE**

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A HISTORICAL BACKGROUND

In the middle of the 19th century in Sweden, work began on developing services for the group of people we to-day call mentally retarded. The services which were 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 mentally retarded 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 mentally retarded persons had on society. It was also during these decades that the view of the mentally retarded as a group changed. It had become apparent that the hopeful view, that mentally retarded persons could return to society, was difficult to realize. Earlier optimistic views of the mentally retarded person's right and ability to participate in society changed to a more pessimistic view. The attitudes of society towards this handicap-group 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 those living there had very miserable conditions, marked by poverty (Söder, M. 1978).

THE WELFARE STATE AND THE HANDICAPPED

Towards the end of the thirties and the beginning of the forties 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, it was to be obtained through modern social services that provided support to families through programs for housing, schools and employment. In this debate one also took a standpoint on how support should be provided for handicapped persons.

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 commenced its work by formulating a social political principle which would become the basis for their future proposals. This policy was to be called the "normalization principle" (SOU 1946:24).

The committee was basically critical to society and its means of support to the handicapped. They criticised the type of social work carried out in the pre-industrial society. The philanthropic spirit and the public protectionistic attitude of social work was in their eyes not an adequate basis for modern social work. It was also the view of the committee that this type of help represented an undesirable patriarchal attitude.

They also opposed support being provided through private organizations being responsible for particular groups, for example the blind, the disabled or the deaf. Even if the needs of these groups were being met the disadvantage of this help was that it lacked a social responsibility for the entire population.

It was also considered unsatisfactory that help like medical care, vocational training and employment exchange, even housing, was supplied from within the framework of institutional care. The committee considered that this prevented contact and cooperation with the ordinary social services.

The work of institutions was intended mainly for those already admitted there, so those not admitted did not have access to the same support. According to the committee this also implied that necessary preventional measures in society were not being developed.

THE NORMALIZATION PRINCIPLE AS SEEN BY THE COMMITTEE

As an alternative to institutionally based services the committee emphasized that handicapped persons should avail of the social services which were provided for the non-handicapped persons. Services for the handicapped must therefore be developed in accordance with the new social approach, characteristic for emerging social work methods. In a society with a social responsibility for its citizens, all individuals in need of support should have the same opportunity to have their needs met.

The view of the committee was that the organisation responsible for social service to the general public, should also be responsible for services to the handicapped. Special solutions should only be recommended if general solutions had been tried and found unacceptable. The handicapped persons need of services should be met in the same manner as the needs of non handicapped citizens.

For the committee this was a question of democracy. They considered it to be a basic civil right that the handicapped citizens of a society should have the same rights as the non-handicapped to avail of social services in society.

But the committee also had psychological motives for its principle. If the services one is in need of are provided where the person lives, he can remain living in his home-community. This was presumed to be a positive experience, as compared being moved to an institution to receive support there.

NIRJE'S FORMULATION OF THE NORMALIZATION PRINCIPLE

Nirje has most clearly formulated the significance of the normalization principle and its consequences for mentally retarded persons. During the sixties he worked for the parent association and was there one of the forerunners for the development of services which would enable this handicap-group to experience a life among non-handicapped citizens. Such demands are natural in an organization like this as it is parents and siblings who have positive experiences of the mentally retarded benefiting from and enjoying normal life. The parent association pressed this question of services in the community

so far that they started research and developmental work, in order to realize their ideas. Nirje's formulation of the normalization principle developed out of this debate (Nirje, B. 1969, 1982).

In his presentation of the normalization principle in 1969 he summarizes its significance in the following way:

"... making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society"

He thus points out that the life, which the mentally retarded have a right to live, should be similar to that of other members of society. He also points out that respect must be shown for the individual's handicap and the limitations it can give rise to. In his formulation he also indicates the responsibility of society for making this life available to the mentally retarded.

In his presentation of the normalization principle he also gave his conception of which patterns and conditions of everyday life which were most important for the mentally retarded person to experience. He expressed this in eight points and meant that normalization of the patterns and conditions of life for the mentally retarded person implied: 1) "a normal rhythm of the day", 2) "a normal rhythm of the week", 3) "normal rhythm of the year", 4) "an opportunity to undergo normal developmental experiences of the life cycle", 5) "that the choices, wishes and desires of the mentally retarded themselves have to be respected" 6) "living in a bisexual world", 7) "normal economic standards", 8) "the standards of the physical facilities should be the same as those regularly applied in society to the same kind of facilities for ordinary citizens"

Nirje's important contribution is that the normalization principle and the social political implications it expresses, hereby became applicable in work for the mentally retarded. At the same time, in his description of the type of life desirable for the mentally retarded, he formulated goals for the work of mental retardation services.

The intensive debate, which was a consequence of Nirje's formulation of the normalization principle for the mentally retarded, can be explained in many ways. It can be accounted for partly in the extensive need to develop a type of service which would give mentally retarded persons an opportunity to experience a life in the community. New knowledge about the implications of integrated services is also needed.

But there is also a need for debate in order to create public support so that this type of service is developed and becomes a reality for this handicap-group.

The debate can also be accounted for by the fact that the normalization principle implies a life in the community and services must therefore develop new methods which facilitate and actively contribute towards realizing this type of life. This however, is not always obvious in a system of services which for over a hundred years has provided support through institutions whose original purpose had been to separate the mentally retarded person from the non-handicapped population.

THE REALIZATION OF THE NORMALIZATION PRINCIPLE

First 40 years after the normalization principle had been formulated, and 20 years after it had been introduced to the field of mental retardation, one can begin to see the consequences of this social political policy.

Even if we have begun to see consequences in terms of services for integration, it does not mean that all mentally retarded have been reached by services which facilitate their societal participation. Neither have we developed all the know-ledge needed in order to provide services in the community. A major task remains in order to achieve services with the qualities which are needed if a normal life in the community, as implied by the normalization principle, is to be realized (Ericsson, K. 1984).

The development from the forties and up to present day has taken place on different levels in society. Through legislation it has been made clear which body in society is responsible for organising services for the mentally retarded. This legislation also points out which services are to be offered to the mentally retarded person.

In the county councils, which have this responsibility in Sweden, an extensive development of services has taken place. In many of these services, be it residential, school or place for daily occupation, one has developed methods necessary to enable the individual to experience a participation in his local community.

A series of Acts of Parliament have contributed to the realization of the normalization principle. The Act of 1954 (SFS 1954:483) recognized the consequences of the social political debate of the forties. Primarily children and adults with a mild or moderate retardation, were hereby given the right to services in the community.

The most important step was the introduction of a school-system in the community, instead of one within an institution. By the introduction of day-schools it became possible for children to attend a local school and thus go on living at home. For the mildly or moderately retarded adult this Act of 1954 prescribed open care, that is to say houses and employment in the community.

The central residential institution was still prescribed for persons with a more severe mental retardation. Therefore, the 1954 Act applied the normalization principle in such a way that a normal life in society was seen as desirable and possible only for those with a mild or moderate retardation, that is to say "the educable". The ideas of the normalization principle were not thought relevant for more severely handicapped persons.

A further step towards realization of these social political principles was however taken in the 1967 Act (SFS 1967:940). Apart from prescribing services for societal participation for mildly or moderately retarded persons, this Act pointed out that education should be provided even for severely retarded children and youth, those who previously had been termed "uneducable". By prescribing the right to school for this group one had discarded the idea that someone is "uneducable". Even this school system must be provided in an integrated system of services, thus making it possible for children with a severe handicap to remain in their families or in another family set up. However, for severely retarded adults no integrated alternative to the institution was prescribed in the 1967 Act.

During the eighties two government Committees have presented proposals for new legislation. In the current proposal the consequences of the normalization principle are taken even for severely mentally retarded adults. It is stipulated that services in the community should be made available even for this group of handicapped persons. This should be made possible through the provision of housing and places for daily activities in the community. As a consequence it is proposed that all institutional services eventually be closed down (SOU 1981:26).

As county councils are responsible for providing these services, development for a change of service has been going on in order to realize the intentions expressed in the various government proposals. There is of course both quantitative and qualitative differences between different counties. Throughout, there is however, a process towards the realization of the normalization principle and its intentions. Services are being developed which increase the mentally retarded person's opportunities to participate in society and thereby furthering the deinstitutionalisation process.

The type of daily life which the mentally retarded person can experience depends on how the staff-group, who provide support and service, succeed in expressing the intentions of an increased societal participation. For it to be realistic and meaningful staff must be aware of, and understand, the implications of a life in society. New methods of work are necessary if the retarded person's contact with society is to increase.

In this respect great variations can be found throughout the country. There are many fine examples of how contacts between mentally retarded persons and non-handicapped citizens has been achieved. But there are also examples of how difficult it is to change the methods used in institutions, to those which are needed for a realization of the normalization principle.

TWO SERVICE MODELS

Today there exists an extensive organization of institutional services. However, since the forties another type has also been developed, namely integrated services. These have developed to such an extent that integrated 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 mentally retarded persons.

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

The integrated 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 integrated 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.

These two service models have their origins in very different intentions and therefore they have different goals. A second dividing-line between these two models is therefore the question of the relationship between the mentally retarded person and society: where in society and under what conditions should mentally retarded persons live? The normalization principle gives an answer to this question in that it stands for the view that handicapped persons should live in the same community as non-handicapped people.

The institutional model is an expression of another view on the question of the relationship between the mentally retarded person and society. From the middle of the 19th century until the formulation of the normalization principle in the forties, a completely different view was held on this question. The policy had been to create a life apart from the community and under other conditions than those usual in normal society.

A third difference between the integrated and the institutional model of services concerns the type of environments offered to the mentally retarded person. By environment is meant the immediate physical and social environment of the retarded person. During a week a person experiences a series of different environments in his home, school, place of work or in his contact with the community. An environment can be described by its premises, their character and location. It can also be described by the type of activities carried out there and how it is equipped, also by the people he meets there, both handicapped persons and staff. The social relations in the group influences the social environment.

The environment in the integrated model is characterized by its proximity to the community and to normal life. There, mentally retarded persons can experience normal housing and the schools and places for work in the vicinity. In contact with the nearby community they can also experience the people and environments of the community.

In these environments there is an opportunity for personal relationships as the groups they live in are small. The environments made available through the integrated model offers extensive contacts with non-handicapped citizens.

The environments of the institutional model are instead characterized by lack of participation in the local community. They are also marked by the fact that most of the mentally retarded person's life is spent within the institutional

area. The physical environment is that of an institution, often hospital like. Social contacts which occur are mainly with other retarded persons or with staff. If a daily occupation is not provided then the environment which a person can experience can be limited to that of an institutional ward.

For the retarded person the differences between these two models are critical. They offer two completely different types of environments, and therefore two completely different conditions for personal development. By means of these different experiences the everyday life and the future quality of life offered varies greatly between these two types of services. One can say that two "worlds" exist for the mentally retarded person. The "world of the community" implies a life with non-handicapped persons whereas the "world of the institution" limits the normal life of the person (Ericsson, K. 1981).

The purpose of this description of the two models has been to briefly present the most important consequence of the normalization principle. When it was formulated it gave expression to a changed social political attitude towards the handicapped in general. Nirje's development of the concept, specified for the mentally retarded in particular, showed the necessity for new goals. These required a new service model, if they were to be realized.

Even if this process of change from institutional to integrated services has been complicated and not easily made, a development has taken place since the forties. In the beginning it was limited but at the end of the sixties, during the seventies and now during the early eighties, this development has taken place to an increasing extent. It is thus we are able to-day to describe in detail two models for the organization of the provision of support and services to mentally retarded persons.

Because of this development it has been possible for many mentally retarded persons to leave the large institution for integrated services in the community. For many this has meant a radical change in their life. It has also led to a personal development for these individuals and it no longer only concerns those with mild or moderate mental retardation as was the case with the first types of integrated services. These services have today become a reality even for the severely or profoundly retarded person who are now moving from institutional care to integrated services with positive consequences for their everyday life and personal development.

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