THE PRINCIPLE OF NORMALIZATION: HISTORY AND EXPERIENCES IN SCANDINAVIAN COUNTRIES

Kent Ericsson

Presentation, ILSMH Congress
Hamburg, 1985

Theme Disability & Support
Department of Education
Uppsala University
Sweden

THE PRINCIPLE OF NORMALIZATION:
HISTORY AND EXPERIENCES IN
SCANDINAVIAN COUNTRIES

Kent Ericsson

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 had now become restrictive 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 HANDICAPPED AND THE WELFARE SOCIETY

The normalization principle as a sociopolitical concept and its consequences, has been subject to extensive discussion during the last 40 years, a period during which modern services for handicapped people have been formed and developed. I would like to contribute to this discussion by commenting on the origins of the normalization principle and at the same time pointing to some of the experiences from implementing this idea into services for mentally retarded persons.

In search for the origins of the normalization principle I reached the year 1943. That year a Government Committee was appointed in Sweden to investigate ways of making available means of employment and self-support for handicapped persons or the "partially ablebodied" as they were then termed. The socio-political idea developed by the Committee and which was to be directive for their work, was termed "the normalization principle".

This Committee sat during a period when discussions were taking place throughout society as to the nature and development of the welfare state. These discussions became a basis for the suggestions of the Committee. The ambition to create a welfare state required that society developed social and health services which would enable those citizens, otherwise subjected to a life of need, to live a "good life".

The Committee was critical of the types of support provided by traditional institutions. At this time it was common that support to handicapped persons was provided through a system of institutional care which had developed during the 100-year period from the mid-19th century. Since the turn of the century an increasingly pessimistic view spread regarding handicapped persons' developmental potential. They were put away in institutions where there were not enough resources to provide them with a good life. At the beginning of the 1940's they were therefore being subjected to very low living standards and poor conditions of life.

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 to remain in society and there live a "normal life". This "normalization of the conditions of life" (the expression used by the Committee) 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.

The Committee also considered it to be a civil and democratic basic demand that handicapped persons were not excluded from the social planning which one sought to further and realize. This implied that

> "... the partially ablebodied should as far as possible be included in the ordinary system of social services which is under development in our land".

It is this principle which the Committee called "the normalization principle".

In this early version of the normalization principle a position is taken on the handicapped person's relationship to the welfare state. The Committee advocated the handicapped person's right to participating in and availing of, instead of being excluded from the welfare state. This viewpoint also implied a repudiation of institutional life and an institutional system of services. The normalization principle expressed thereby a socio-political position and the handicapped person's right to participation in society. It became consequentially the starting point for the development of services in society for handicapped persons which took place in the 1950's.

DEVELOPMENTS IN DENMARK DURING THE FIFTIES

During this period a debate took place in Denmark about the rights of the mentally retarded to a normal life. A result of this debate could be seen in the Act of 1959. In the introductory paragraph it is stated that the provisions of mentally retarded persons should make it possible for them to experience a life "as near to a normal life as possible".

Bank-Mikkelsen expressed the intentions for the services for the mentally retarded by saying that services should contribute towards creating "a normal existence".

> "The aim is to give the mentally retarded a normal existence, that is to say to assist with treatment of any kind and ensure living-quarters and work in the ordinary community for as many as possible."

Bank-Mikkelsen also described the ideological background to these intentions and thereby clarifies the role of the mentally retarded in society. The mentally retarded person must, he says, be seen as a fellow human being even if one with a handicap. As such he is a fullworthy citizen who must be allowed to experience the same life and rights as the non-handicapped citizen. Bank-Mikkelsen expressed this in the following way:

> "The mentally retarded individual is first of all a fellow-being, and so he must from a view-point of equality have full rights as fellow-citizen."

He also points to the alternative which is a consequence of not recognizing mentally retarded persons as fullworthy citizens:

> "If an equality view-point is not acknowledged, there is a risk of ending simply in sentimental pity, in theories of over-protection, in group discrimination or in something worse."

The background to the developments in Denmark is the changed view of the problem of mental retardation and the mentally retarded persons potential for realizing a normal life which took place during the fifties in Scandinavia and in many other countries. An optimism regarding the potential development of mentally retarded persons is to a greater extent recognized.

It is also during the fifties that the parents' movement becomes organized in Denmark and other countries and can thus with greater force express and communicate their own positive experiences of resources and possibilities for development and the rights of their sons and daughters.

NIRJE AND THE NORMALIZATION PRINCIPLE

During the 1960's the normalization principle became a concept which, up to the present day, has greatly influenced and characterized the work within the organization responsible for services to the mentally retarded in Sweden.

This forceful role of the concept was gained during the period of development which took place during the preparations for the 1967 Act of services to the mentally retarded.

Nirje, as a representative for the Swedish parents association, participated very actively in these preparations. His experiences and positions gained during this dynamic period were summarized in a formulation of the normalization principle.

There he expressed a point of view regarding the sort of life which should be possible for mentally retarded persons to live. In his own words this meant

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

Nirje also clarified the consequences of what "a normal life" should imply for the mentally retarded person and specified this in the following eight points: 1) a normal rhythm of the day, 2) a normal rhythm of the week, 3) a normal rhythm of the year, 4) an opportunity to experience the normal developmental phases of the life cycle, 5) that ones own choices, whishes and demands be respected, 6) that one lives in a bisexual world, 7) that one has a normal economic standard and 8) that the standards of physical facilities available to the mentally retarded are the same as those apply for non-handicapped citizens.

Two very important differences are to be found between Nirje's version of the normalization principle and that which was formulated by the 1943 Committee. Whereas the Committee spoke of the normalization of general conditions of life, Nirje through his eight points, specified what normalization really should imply in daily life.

The other difference is the implication or supposition in Nirje's version that the normalization principle should apply for all mentally retarded persons. The Committee only discussed "the partially ablebodied" group as that was their task. They did not concern themselves with the fate of the "incapacitated" as the more severely handicapped persons were termed.

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 community.

ACTS OF PARLIAMENT

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 is 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.

A COMMENT

When summarizing these positions on 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 mentally retarded 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, in these presentations one can find that a choice of the normalization principle also implies a standpoint on the question of the role in society for the handicapped persons.

The mentally retarded person, irrespective of his degree of handicap, is seen as a fullworthy citizen and as such have 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.

A social perspective is therefore necessary if services are to be developed which contribute towards mentally retarded persons being able to participate in society and to live under normal conditions of life.

FROM INSTITUTIONAL TO COMMUNITY SERVICES: SOME EXPERIENCES

A new goal

Extensive work in Scandinavia to replace institutional with community services, has given rise to many experiences. I wish to point to a few which I consider to have been particularly important in this transition.

The most important experience is the necessity to clarify and describe what is really meant by "normal life". It is therefore necessary to describe the life in the community of the non-handicapped citizen as it is this way of life the handicapped person also should have a chance to experience. It is first then that goals for the services to retarded persons are formulated. This will facilitate the development of the type of services which will contribute towards making "a normal life" a reality.

There are of course many ways of describing a normal life. One example is the eight points which Nirje used to describe the meaning of the normalization principle. Personally I have found a development of Nirje's expression "patterns and conditions of everyday life" to be a sensitive and constructive means of describing the type of life desirable not just for mentally retarded but for all people.

The right to a house and a home in the community is thereby basic. Mentally retarded children and youth should be able to grow up in a family, their own or another. Adults should have a dwelling of their own, or together with a small group of people, and with the services which are needed.

As well as a dwelling there must also be a place for daily activity. For children and youth this is a school with an education which meets the needs of the mentally retarded person. For adults it is primarily desirable with paid employment. If this is not realistic or available, a place in the community should be provided where the person has a meaningful daily activity, for example at or in the vicinity of a day activity centre. These daily activities should take place where non-handicapped persons go to school or work.

Participation in or utilization of what the local community has to offer is also an important aspect of normal patterns and conditions of everyday life. Shops, recreational facilities, social and health services are just a few examples of what can be useful in the area where the person lives.

But it is not adequate to merely describe the person's life in a physical manner. There are also the qualitative aspects of the normal life which the mentally retarded person has a right to. Economic and material standards must be so good that it will be possible for the individual to personally purchase what he needs to form his home. It is also important that his personal economy does not constitute a hinder for experiencing and utilizing all that the community has to offer.

The person must also be able to influence his daily life. In the home, at school, at work or at a day activity centre as well as in the community, it must be possible to express individual needs and wishes. Thereby he will influence the type of service provided and the daily life to be experienced.

In social relationships with relatives, staff and the public there must be a respect for personal integrity. The handicapped person must be met with the same respect as is normally shown to the non-handicapped citizen.

I would therefore like to formulate this first experience in the following way: with the normalization principle there is a new goal for services - normal patterns and conditions of everyday life.

Community services

If the mentally retarded person is to experience a life with these normal patterns and conditions, it is necessary that the services provided for his support are located to places in the community where the non-handicapped citizen is found. This requires developmental work in order to describe the type of services needed and the way in which they are to function. It is also necessary to build new, and to change existing services, if the traditional institutions are to be replaced by services which provide both dwellings and places for daily activity in the community and thereby make participation possible for the mentally retarded 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 community must be provided with both special 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 have responsibility 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 mentally retarded, 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.

The second experience I would like to point to is that services are needed which promote the mentally retarded person's participation in society.

Personal, not anonymous, planning

This brief comment on some of the types of services needed to promote societal participation is naturally very general. When the need for service becomes a reality for a specific family or individual it is necessary that it be provided in a form which meets the needs of just that person or group. Such individually formed services are a pre-requisite if all mentally retarded persons, with a mild or a severe handicap, are to have a chance of living under "normal patterns and conditions of everyday life". With anonymous planning the risks are great that the needs cannot be met.

In order to attain a system of personal planning it is necessary that services are provided for individuals or for small groups. It is first then that individual needs can be recognized, described and met. Small groups of mentally retarded persons are also a pre-requisite if participation in society is to increase. It is first then that the general public can become aware of individual qualities and it becomes easier to find a "niche", that is to say an environment which is so secure that the person with confidence can live, receive his education or attend a daily activity there.

A third experience I would like to point to is the necessity to form services according to the needs of the person, or the small group, who is to use them.

A complex process

Institutional services in Scandinavia have developed out of a tradition whose origins are found in the middle of the 19th century. Institutions with this background have however been built as late as during the 1970's.

Since the 1950's new services for societal participation have gradually begun to be established. In Sweden a new Act of Parliament passed in June 1985, states that all mentally retarded persons have a right to a life in the ordinary community amongst non-handicapped citizens. Services for societal participation must therefore be provided and institutions closed down.

This ongoing work for change from institutional services to those which further participation in society, has shown that this is a complex process. The mentally retarded persons themselves are naturally effected. But there are also two other groups who are effected by the changes, families and staff. When services change in character families are also subjected to change. They also "move", that is to say they must now visit their son or daughter at a new place and under different circumstances. Parents must therefore be well informed about the integrated alternative type of services, not to feel uncertainty about the future.

For staff groups the process implies a change of place and type of work, with all the formal regulations which this involves. But it is not just the physical aspects that change in this process toward increased societal participation. Even the methods used in each unit must be renewed or developed. To achieve participation in the local community for the mentally retarded person, new social methods are required.

In order to make this process of change possible it is necessary that society also takes its responsibility and takes part in the change. One must accept and even contribute towards furthering the situation in society of this handicap group. Resources must for example be made available for this transformation to take place. Relevant knowledge, attitudes and values are also necessary if increased participation in society for mentally retarded persons is to be facilitated. A fourth experience is that the process towards participation in society, is complex.

Adequate services?

Previously, it was mainly mildly retarded persons who got a chance to lead a life under the normal patterns and conditions of everyday life. To-day, because of the closure of traditional institutions this is a reality also for persons with a more severe handicap.

The increased societal participation which persons have experienced has led to positive changes. It has enabled them to lead a better life in the community and there experience a personal development.

Even parents find it a positive experience to have a son or a daughter living the normal life. One has a very different feeling visiting a villa in the community instead of the large traditional institution. For staff this change in services means that their working conditions are considerably improved. They can now work with small groups for whom they have far-reaching responsibility and authority.

This implies greater freedom and better opportunities for satisfying the personal needs which they now can see within the small group. The conclusion one can draw to-day is that "normal patterns and conditions of everyday life" is possible when the person has access to services which in both range and content is related to his particular needs.

It must also be stated that much still remains to be done in developing adequate services. A 40 year period has passed since the normalization principle was formulated for the first time. 15 years ago it become a concept used within the services for the mentally retarded. It is therefore a relatively short period during which "normal patterns and conditions of everyday life" has been able to serve as a goal for services.

Abuse of the normalization principle is not uncommon. It is for example not right to talk about "participation in the community" when a mentally retarded person is placed there without the services he needs in order to be able to lead this life. Lack of adequate services is a phenomenon which exists in integrated services as well as in institutional. We must admit that we are at an early stage in the process. It is necessary that it continues, is penetrated and intensified. The fifth experience is therefore, if the normalization principle will lead to normal life in the community will depend on whether adequate services are available or not.

A citizen with rights

The most important experience I would like to formulate concerns the attitude, ours and others, towards people of this handicap-group: the mentally retarded person must be seen as a citizen with full rights to the normal life in society! If he is given another social role it will be very difficult to understand this ongoing process towards increased participation in the community.

Not until we accept the mentally retarded person as a fullworthy citizen, irrespective of his degree of handicap, does the normalization principle become logic, the work of the ongoing transition of services become natural, and the normal life become unquestionable.

REFERENCES

Bank-Mikkelsen, N-E (1964): The ideological and legal basis of the national service for the mentally retarded. From: J. Öster, H. Sletved (Eds): International Copenhagen Congress on the scientific study of mental retardation. Vol. 1. Copenhagen: Det Berlingske Bogtrykkeri.

Bank-Mikklesen, N-E (1969): A metropolitan area in Denmark - Copenhagen. From Kugel, R.B. and Wolfensberger, W. (Eds) Changing patterns in residential services for the mentally retarded. Washington: Department of Health, Education and Welfare.

Ericsson, K. (1985): The origin and consequences of the normalization principle. IASSMD Congress, New Delhi.

Kebbon, L. et al (1981): Evaluering av öppna omsorgsformer. Stockholm: Liber förlag.

NFPU (1981): What shall we do with the large institutions? NFPU-symposium. Naestved (Denmark): Imprint.

Nirje, B. (1969): The normalization principle. From Kugel, R.B. and Wolfensberger, W. (Eds) Changing patterns in residential services for the mentally retarded. Washington: Department of Health, Education and Welfare.

Söder, M. (1978): Anstalter för utvecklingsstörda. (Institutions for mentally retarded persons). Stockholm: Stiftelsen ALA.

SFS 1954:483 Lag om undervisning och vård av vissa psykiskt efterblivna. (Law on education and care for certain mentally deficient persons).

SFS 1967:940 Lag angående omsorger om vissa psykiskt utvecklingsstörda. (Law on services for certain mentally retarded persons).

SOU 1946:24 Förslag till effektiviserad kurators- och arbetsförmedlings-verksamhet för partiellt arbetsföra m.m. (A proposal for a more effective use of social workers and employment agencies for partially ablebodied persons).

SOU 1981:26 Omsorger om vissa handikappade. (Services for certain handicapped persons).