

**TWO PERSPECTIVES ON THE LIFE OF THE
PERSON WITH INTELLECTUAL HANDICAP**

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**This paper was presented at the AFMR Conference
(Asian Federation for the Mentally Retarded) in Bangkok, 1989**

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THE NORMALIZATION PRINCIPLE: A NEED FOR CLARIFICATION

In the task of providing support to persons with intellectual handicap the idea of the "normalization principle" has had substantial importance during the seventies and eighties. Following its presentation in the international debate it has had extensive and deep reaching consequences. During these two decades it has greatly influenced the socio-political debate on what sort of life these persons should live in society and what type of service is needed in order to realize that life.

At the same time many attempts have been made to work for "the normal life" so that which persons with intellectual handicap ask for can be realized. There are many examples of how difficult it is to change a service organisation based on institutional principles so that it can develop and provide services which contribute to the participation of the individual in community life.

Because of the extensive debate on the "normalization principle" the concept, initially difficult to comprehend, has become even more complicated. The many interpretations have created a diffusive picture. To find the real implication one must go to the original sources.

A SOCIO-POLITICAL CHANGE

The idea behind this transition from institutional to community services can first be found in the debate on the nature of the welfare society and the role of the handicapped. It began at the end of the thirties and was concerned with the question of how a society should be formed which could guarantee its citizens good living standards and welfare. As a means to achieving this an expansion and modernization of social services was recommended.

At the same time the question was raised as to how social services in a welfare society should be developed for persons with handicap. Should the institutions, based on a 19th century philanthropic tradition, continue to be responsible for the support of society to handicapped persons, or should they be given the right to avail of the provisions of the welfare society?

The latter choice, to let a modern social service bear responsibility for persons with handicap was termed the "normalization principle" by the public committee which in 1945 suggested which measures should be taken to ensure a better life for persons with handicap.

However, a distinction was made between persons with a handicap who were "partially ablebodied" and those who were "incapable of work". It was only the former group, persons with a mild handicap, who were recognized as having a right to avail of the resources of the welfare society, whereas the others were referred to continued institutional care.

In this changed official position the implications of a new socio-political view were expressed. The reason for setting up the committee, and the task given to it, was to find ways of providing a better life for these persons. The position of the committee claimed, first and foremost, that instead of institutional life these persons should be given the opportunity to experience "the normal life", i.e. the life lead by persons without handicap.

Another official view was that the resources and amenities of the welfare society should be used to provide support and service to these persons. The type of assistance developed for persons without handicap should also be available for those with a handicap. To accomplish this these persons needed to be given the right to claim similar resources. The organizations responsible for implementing the welfare society, must as a consequence, carry out the changes necessary if the services were to meet the demands made by persons with handicap.

There is also a third point in the official view which concerns this socio-political change. How persons with handicap are regarded is also expressed in the motivation of the committee. It is a question of human rights for persons with handicap to be able to avail of the welfare service, and that these rights are basic to the democratic ideal (Ericsson, K. 1987).

THE SOCIAL ROLES OF PERSONS WITH INTELLECTUAL HANDICAP

Two of these viewpoints usually occur in the debate on the implications of the "normalization principle". The third aspect, which motivates this dramatic change in relations between society and persons with handicap, takes a stand on a very critical issue, namely the question of what social role is conferred on these persons.

It was Wolfensberger (1969) who gave particular attention to the relation between the social role conferred on persons with handicap and the way in which society chooses to organize and provide measures for them.

He points for example to the time when these persons were regarded as "Holy Innocents" and it was the task of the church to provide for them. When this handicap-group were considered to consist of "subhuman organisms" measures could be accepted which did not recognize the human needs of these persons. The large institutions, with an environment and routine which was impervious to the needs of those residing there illustrate his point well.

When the person with handicap was perceived as a "sick person" it was natural that provision was made for them within the medical services, in hospital buildings and with medically trained staff.

In an organisation which puts emphasis on the persons ability and desire for personal development the position given the teacher, the trainer and the therapist will be greatly enhanced.

SOME SOCIAL ROLES FOUND IN SWEDISH SERVICES

No proper analysis, comparable to that presented by Wolfensberger, has been made over the social roles conferred on persons with intellectual handicap in Sweden. There is however some manifestation of the use of social roles which makes it possible to characterize some such roles. It is not uncommon that one has more or less inexplicitly accepted a certain role. It has sometimes even been relatively well characterized.

Qvarsell for example has pointed to a motive which influenced the content of institutions established during the 19th century. As a reaction to what was considered the "negligent" family, which no longer could care for its children, it was regarded as desirable that conditions within the institution as far as possible resembled the traditional family including the just father figure. The person with handicap became the "child" that would receive its upbringing with the "family" of the institution.

Söder (1978) has shown how one during the period between the wars regarded these persons as a "threat to society". It was thus logical that society took the necessary measures to protect itself from these groups. In this situation it was a natural measure to introduce sterilization practices. In this one finds similarities to what Wolfensberger termed the "subhuman" element. One thereby denies these persons their natural needs and rights. It is also during the thirties that the medically orientated model of services is developed, largely through the establishment of the special hospitals. The view of the person with intellectual handicap as being a patient is a role established during this period.

In the 1954 Act (SFS 1954:483) one can find two roles. A distinction is made between the role of "pupil" and "inmate". The former is associated with those with a mild handicap, those known as "educable" and the latter those with a severe handicap, previously regarded as "uneducable".

One who clearly indicated the importance of clarifying which role is conferred on the person with intellectual handicap is Walujo (1985) whose SIVUS-method characterizes the person with intellectual handicap as "an individual under development". This role has many similarities with Wolfensberger's concept of the individual with intellectual handicap as being "a developing person".

Regarding the person with handicap as a "citizen" was a role which had a critical impact on content of the public enquiry concerning the person with handicap in the welfare society, which was presented in a report from the "Committee for the partially ablebodied". It was there clearly stated that it was a matter of "democratic rights", which even applied to persons with handicap, that formed the basis for the suggestion that even they should have access to "the normal life" and to the social services of the welfare society (Ericsson, K. 1987).

For Ericsson and Ericsson (1987) this "role of citizen" became a central issue in an analysis of the function of housing and a home for persons with intellectual handicap.

It is difficult to characterize these roles in any other way than by a description of certain "types". Some finer details can be lost and other characteristics may be too coarsely described. But these various roles, often unconscious, can affect or lie behind many of the views held but seldom openly expressed. They are therefore often rather diffuse when described. It is seldom that their significance and consequences are clearly formulated.

Amongst other difficulties is the fact that even this aspect of the field, the question of social roles, is also undergoing development. This makes it even more difficult to find distinctive illustrations.

A further difficulty in describing these various roles is the long existing difference which has been made between those who were regarded as "educable" and those considered "uneducable". With a more differentiated

analysis one would probably find that different roles have been conferred on these two groups.

The fact that persons from this handicap group have been conferred different roles shows that their situation and problems can be seen in different ways. Consequently one can say that there are several perspectives from which one can describe persons with intellectual handicap and their situation.

INTELLECTUAL HANDICAP FROM DIFFERENT PERSPECTIVES

Mercer (1965) made use of the concept of perspective as a means of bringing about a changed view on intellectual handicap. She confronted two perspectives when she described the clinical and the social. While the former is based on a view that the person with intellectual handicap is primarily characterized by his deviancy, the other emphasises intellectual handicap as a natural aspect of society. The latter view is the more relativistic one and that which she advocates.

Kebbon (1979) found that the question of perspective was an important explanatory factor with regard to the differing views held by professional groups on various critical issues in the field. Bio-medical, psychological and social approaches lead to varying perspectives from which the problem of intellectual handicap can be described and tackled. The simple explanation is of course that these different disciplines choose different approaches in viewing the problem. The choice of perspective has therefore consequences:

"Each perspective has its focus and its corresponding blind spots. More specifically it has a selective, a formative and a neglective effect, which to a certain extent determine what is seen, how it is seen and what is not seen. Furthermore it predisposes for different modes of action, i.e. in the planning of care and services".

Ericsson and Ericsson (1987) also found that differences in what was regarded as a good housing and a home for persons with intellectual handicap could be related to the perspective chosen. When Mercer's concept is used and the person is viewed from a clinical perspective and regarded as being in a constant state of development, the integrated residence is seen as a training unit which provides good conditions for treatment and development. A residence whose purpose is to achieve personal development leads to demands on the person to move on to a new form of housing in pace with increased personal competence.

From a social perspective the person with intellectual handicap is instead regarded as being a citizen with a right to housing.

A consequential approach is acceptance of the task of finding or creating life environments which provide a residence with access to neighbourhood and community. The residence is equipped as a home where one can live without the anxiety of possibly being forced to move.

THE "PERSPECTIVE OF COMPETENCE"

One can describe two perspectives which have current significance in the present Swedish service system. The first is here termed "the perspective of competence" as it emanates from the roles of "pupil" and "inmate", roles closely associated with the institutional organisation of services.

The subject under discussion is a person with an intellectual handicap and thus a person with a function, developed only to the degree that attains a low level in relation to others. An attribute of an intellectual handicap is that the person does not have all the social abilities which are required in order to cope with the ordinary demands of daily life. Severely handicapped persons also often have an "additional handicap" which involves a low functioning level even in other respects for example sight, speech or motor abilities. This further emphasises the view of the person as one lacking in competence.

Seen in this perspective the focus is put on the "lack of competence" and this becomes the main issue. Finding and taking adequate measures to increase the persons "competence" becomes the dominating feature if the situation is viewed from this perspective.

The measures which are natural to take are those which influence the limited functional level of the person. These measures can of course be of various sorts. Pedagogical measures are intended to develop educational abilities associated with school, whereas social measures, for example social training programmes, can be used to develop the person's social ability. Psychological measures can be directed towards personality development or to treat possible deviant or undesirable behaviour and medical intervention can either treat organic disorders or health issues.

These choices naturally influence which places or environments in a community are chosen to be used in the provision of services, be they schools, day activity centres, therapeutic centres or premises where medical and health services are provided. The category of professional staff chosen is also dependent on which type of measures is to be provided. Obviously the choice of goals for services and the means to reach them is also subject to the perspective in which they are viewed.

Common for these various types of measures, when related to the formation of the services provided, is that they aim at having a developmental function for the person.

In the competence perspective the person with intellectual handicap is always a receiver of developmental measures. Seen as a person with "lack of competence" one is placed in a passive and subordinate position in relation to staff whose task is to have knowledge of, and responsibility for providing the developmental measures.

When does the person with intellectual handicap achieve access to a participation in society? In a service system based on this perspective it is achieved first when the individual has reached a level of ability to be able to cope with, be "mature" enough for, the demands which he/she is expected to meet. Participation in society should also be regarded as meaningful for the individual, and this occurs when the experience has developmental effects.

One can say that requirements are made on the individual if he/she is to be allowed to participate in community life: the person is expected to have certain capabilities! The "burden of evidence" is thereby put on the person with handicap who is obliged to qualify for or earn his right to participation.

THE "PERSPECTIVE OF THE CITIZEN"

The other perspective described, and here called "the perspective of citizen", is derived from the view of the person with handicap as having the role of "citizen".

The basis for this view is a recognition of the person as a fullworthy citizen in society irrespective of kind or degree of functional level. Behind this lie democratic egalitarian ideals on everyone's right to a good life and to access to the services offered by a society based on such ideals. The concept of intellectual handicap is thus regarded as a normal phenomena. It is a normal process in a society that children are conceived, born and grow up, a process which however is associated with risks, of which some may lead to lower intellectual functioning and to handicap.

The dominating feature of this perspective is that the person is given a possibility to live the normal life as lived by persons without handicap, i.e. in a family and home, but also with nursery facilities, schooling, and employment, as well as access to the services in the community which are availed of by persons without handicap. The organisation responsible for realizing these conditions must make use of the means available if the "normal life" is to be made possible.

The means available for the provision of services seen in this perspective are measures such as the adjustment of housing to the needs and wishes of the person with handicap. Similarly means are needed to chose day activities so that they are meaningful and that premises and environments, where these activities can take place, are locally accessible for the person concerned. In consequence this implies social measures directed towards the environments made use of by these persons both now and in the future.

From this perspective it is naturally also desirable that personal measures also are available i.e. measures which contribute to the development of the person in the functions where there is limited ability. The difference between "the perspective of citizen" and "the perspective of competence" is that the person with handicap has influence over when, where and how these measures should be offered.

It is just the question of the person's influence over his situation which is the critical issue in this perspective. This also influences staff roles. Staff within the services become providers of service and support but on the terms of the person concerned. In addition to the traditional skills held by staff, concerning the person's limited functioning levels, the staff also need to be knowledgeable in social matters like housing, employment policies and local social services.

Participation in the life of society, seen from this perspective, becomes a right, with a "democratic" motive, which is associated with the perception of the person as a fullworthy citizen.

A TWO-DIMENSIONAL DEVELOPMENT OF SERVICES.

This way of understanding the social political idea implied by the normalization principle bears certain consequences. Foremost is the question of a changed life situation for the person with intellectual handicap. This necessitates working for a greater participation in the life of society instead of being restricted to institutional life as previously.

This also points to consequences for the development of the services. To begin with it concerns the type of service i.e. substituting institutional services with integrated. This includes the question of the closure of institutions and the theoretical and practical development of services which can contribute to an increased participation in the life of society for persons with intellectual handicap.

The view of the normalization principle as presented here gives particular attention to the aspect that as a consequence a change in the content of the services must take place. How services are described and thus how one chooses tasks, questions to be answered and methods to be developed are all associated with the perspective chosen. Depending on the point of origin, institutional or integrated services, two perspectives can be distinguished and these are here called "the perspective of competence" and "the perspective of citizen".

The task implied in a change of services should therefore also lead to a change of perspective. Measures and methods are thus needed in order to achieve this change of perspective.

One who gave attention to this question was Wolfensberger (1983), who termed the task "valorization". The expression is developed from the term "value", implying that the value given a person with intellectual handicap should change. The task involved is to achieve a change so that persons previously devalued be recognized as fellow human beings. Wolfensberger also points to a series of measures which can be taken in order to achieve such "valorization"

The dominating consequence of this view on services is that there needs to be a two-dimensional approach to the development of services if a change is to take place in the lives of those with intellectual handicap. Both the development of services from an institutional to an integrated form and a change of content from a "perspective of competence" to a "perspective of citizen" is needed.

This two-dimensional development can however in no way be taken for granted. One can find a situation where the form of services have been changed without a change in perspectives taking place. This can be one explanation to why the development of integrated services have not always achieved the results expected. Evaluation studies have for example shown that the realization of the integrated service model lacks many of the components which one would expect (Kebbon, L. et al, 1981). This can also be an explanation to why the closure of institutions does not always lead to the fulfilment of the goals set, when persons move from institutional to integrated services.

The situation can arise that some integrated services can work from the "perspective of competence" whereas others have an approach based on the "perspective of citizen". With such differing approaches there is a risk that differences in goals and methods can give rise to conflict. In an analysis of residential services Ericsson and Ericsson (1987) have shown that one can find two approaches to the question of housing and a home which derives from differences in perspective and role.

DISCUSSION

Services for persons with intellectual handicap are in a process of development which has been greatly stimulated by the socio-political thinking expressed in the "normalization principle".

These ideas are however in many respects diffuse and unclear and have therefore given rise to much debate and many interpretations. This can also be seen in the variation in existing practical solutions. Even theoretically many different ways have been sought to develop and formulate the idea. There is therefore still a great need for analysis.

The most generally known change brought about in the spirit of the normalization principle concerns the nature of services and primarily the organisation of institutional care, its closure and the development of new services as an alternative to the institution.

In the analysis presented here it has been pointed out that there is even a more comprehensive change of content, the origin of which is found in the different views held on the role given to the person with intellectual handicap.

This situation has been expressed in terms of "the perspective of competence" and "the perspective of citizen". The task to be carried out involves a change of values and frame of reference which results in replacing the "competence perspective" with the "perspective of citizen".

The concept "integrated services" cannot therefore be seen as an unequivocal term, but must instead be developed and given form and content. If consciousness is lacking there is always a risk that new problems and conflicts arise when new forms of service are created, while the purpose has been to provide positive alternatives in exchange for the negative experiences of the large institutions.

The life-situation for the person with intellectual handicap is crucially dependent on the choice of perspective made in developing of new services. The point where these two perspectives most deviate concerns the question of the person's influence over his own life. It is first from the "perspective of citizen" that this aspect becomes apparent and self-evident. The influence over a person's own life-situation risks being limited if clarity does not exist concerning the necessary changes in the content of the services.

REFERENCES.

Ericsson, K. 1987: Services to further the participation of mentally retarded persons in society. Uppsala J Med Sci, suppl. 44:217-220.

Ericsson, P. Ericsson, K. 1987: Community services: Housing and a home. Contribution to AFMR Congress, Singapore. Uppsala: Mental Retardation Research Project.

Kebbon, L. 1979: Perspectives on mental retardation. Contribution to IASSMD Congress, Jerusalem. Uppsala: Mental Retardation Research Project.

Kebbon, L. Granat, K. Ericsson, K. Löreljus, J. Nilsson, A-C. Sonnander, K. 1981: Evaluering av öppna omsorgsformer. Stockholm: Liber förlag.

Mercer, J. 1965: Social system perspectives and clinical perspectives: frames of reference for understanding career patterns of persons labelled as mentally retarded. Social Problems, vol. 13, 19-32.

Söder, M. 1978: Anstalter för utvecklingsstörda. Stockholm: Stiftelsen ALA.

Walujo, S. 1985: SIVUS - en gruppdynamisk metod. Socialstyrelsen redovisar 1985:2. Stockholm: Socialstyrelsen.

Wolfensberger, W. 1969: The origin and nature of our institutional models. Washington: President's committee on Mental Retardation.

Wolfensberger, W. 1983: Social role valorization: A proposed new term for the principle of normalization. *Mental Retardation*, vol. 21(6), 234-239.

SFS 1954:483 Lag om undervisning och vård av vissa psykiskt efterblivna.