

**SUPPORT TO PERSONS WITH  
MENTAL RETARDATION THROUGH CBR -  
AWARENESS AND METHODS**

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# SUPPORT TO PERSONS WITH MENTAL RETARDATION THROUGH CBR: AWARENESS AND METHODS

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Our contribution is to share some of our experiences from the last 25 years of working, in Sweden, with services to persons with mental retardation, and also from following the developments within these services in different parts of Europe and even parts of Asia. These have been 25 years of very dramatic, exciting and also positive change for the lives of persons with intellectual handicap. It has therefore professionally been an exciting period in which to work with these issues. It has been a time of change, a change characterized by the shift from an institutionally based provision of service to a community based approach as to how the needs of these persons should be met.

Kent Ericsson, as a research psychologist at the University of Uppsala, has been involved with the implementation and follow-up of the this shift in services. He has led several projects concerning the closure of institutions and the development of alternative services. His historical analysis of this process of change has contributed to our understanding of the mechanisms in society which influence which type of life a person with handicap will be able to live. Patricia Ericsson, as psychologist and senior administrator has worked in the services responsible for the provision of support and service to persons with handicap. She has experienced the consequences, for the individual, of both institutionally based and community based services and has been influential in the development of community based alternatives for all groups of persons with handicap.

## **THE NORMALISATION PROCESS**

### *Persons with handicap in the welfare society*

The change from an institutional system, where care was provided in residential homes, to community services provided through housing, in employment and through life in the community, has its roots in the welfare society which has been under development since the 1940:s. Its creation gave rise to new means of providing support and service to these persons. A more modern system of social services had to be developed if the idea of the welfare society was to be realized. This, parallel to the institutional service system, gave society two ways of channeling its support to persons with handicap.

As a result of the debate on the nature of the support of society which took place at the beginning of the 1940:s, a special Committee was given the task of finding the forms of support necessary in order to provide welfare and a good life to persons with handicap.

On many points the committee was critical of the care being provided for the partially ablebodied in residential institutions. It was thought that responsibility was only being taken for those already cared for in the institution while no concern was given to preventive health work, something which was considered necessary by the committee. They were also critical to the coercive system represented by the institutions and the patriarchal view which characterized attitudes to persons with handicap

On the basis of their criticism of institutional care, and a vision of new opportunities for service in a welfare society, the idea of the committee was that

the partially ablebodied should also have a right to avail of the services being established within the framework of the welfare society.

*The normalisation principle of 1946*

The view of the committee on these persons right to avail of the services of a welfare society was expressed as

... a given principle, 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.

In order to realize this it was considered important that the support of society be built in such a way that it be available for all. One also reckoned that this would have positive consequences for the persons concerned:

Psychologically 'normalisation' of living conditions, education, employment support etc. for partially ablebodied persons, is surely a great advantage

That the welfare society should also take responsibility for persons with handicap was, according to the committee, an expression for

... a civic basic demand: it is in entire accordance with the essence of our democratic concept, that equal human values and their equal rights be placed in the foreground

In these quotations a socio-political idea was expressed which was termed the normalisation principle .

'The normalisation principle', as prescribed by the committee, proposes, amongst other things, that special institutions for the partially ablebodied, for education, training, etc. should be the exception, not the rule.

This implied that a stand was taken for the normalization of the conditions of life for persons with handicap, a policy which should be pursued as an alternative to living a life separated from the lives of those without handicap. The means of achieving this was through the development of modern social services, within the framework of the welfare society, which were accessible to all persons.

The committee's motive for the normalisation principle, the right to avail of the services of a welfare society, was based on the idea of these persons' democratic rights. It was considered a basic civic right to avail of the same support offered to all the citizens of a welfare society. This motive should be seen in the context of the socio-political ideas formulated in the mid-forties, at the end of the second world war, in a period of democratic and economic optimism. The committee did not refer to any special group among the partially ablebodied but included all persons with handicap, even the "feeble-minded", the expression used for persons with intellectual handicap.

#### A GRADUAL PROCESS OF CHANGE

When services for persons with intellectual handicap were created during the last century, residential institutions of various kinds were established. This pattern of institutional support remained intact until the middle of the 1950:s. The first steps away from these institutions were taken during the 1940:ps and have gradually continued since then.

This process of change can be seen at various levels. At an **individual level**, for the person with intellectual handicap, development has meant a switch from an institutional life to an increased participation in the life of the community where the person lives, together with persons without handicap. This community participation has also effected others. For relatives this has meant that the son or daughter no longer has to be visited at a residential institution, but in a house in the local community. Neighbours, and those providing services locally, come in contact with these persons to an increasing extent, maybe for the first time.

At an **organisational level** changes have occurred in the types of service provided. A development of services has taken place which contributes to the community participation of these persons. An example is education, now being provided in the community school which is attended mainly by children without handicap. New forms of services have also been developed for adults enabling them to be in places and environments where other adults spend their time. Group homes have made it possible to provide housing in ordinary housing areas, and daily activities are now organized so that activities for these persons can take place in the same place as for persons without handicap.

At the same time, the forms of care and support which were a hindrance for the community participation of these persons, have been closed down. Some examples are special hospitals, childrens' homes and boarding schools. Even some forms of community service, which do not contribute adequately to community participation, have gone through a process of change, for example day activity centers

A change on a **cultural level**, regarded as part of the normalization process, concerns the way society perceives persons with intellectual handicap, and how their support is to be provided. The institutional tradition, with two types of establishments, the school institution and the asylum, reflected two ways of regarding these persons and consequently two types of social roles attributed to them. Those with a mild handicap who were considered "educable" were provided with schooling and were seen as "pupils". Those with a more severe handicap, who were referred to asylums and residential homes, the "uneducable", were seen as "patients" in need of care.

**A competence perspective** sums up the relation between these persons and the task of education and care, the emphasis being put on the need to increase the competence of these persons either through education or care. The function of these institutions thus being the provision of these very special activities.

**A citizen perspective**, on the other hand, is related to the normalisation process and to forms of community services. Its origins are to be found in the motives for this socio-political change, it being considered a civic right to avail of the services provided by the welfare society. It is this role of "citizen" which epitomizes the perception of persons with intellectual handicap. As a full-worthy citizen he has the right to participate in community life and his and his family's desire for such a life becomes the starting point for the type of support offered.

## **TOWARDS A CITIZEN PERSPECTIVE**

### *Social roles*

In a study of the closure of a large residential institution, a man who had moved to a new home told us, when interviewed about his new life, that he was very happy and satisfied. He had got a new home and new daily activities in the community which he once had left to be cared for at the institution. But when commenting on his new letterbox he said: "I got a new letterbox, but there is no name on it!" In Sweden, when you live in a house of your own you have a letterbox by the roadside, which has your name on it. It is natural for the postman and visitors, but also for those passing by, to know who lives in the house. For this man it was also a sign of being visible and having an identity in the community. He had come back to where he once belonged and he wanted to be recognized!

In the present change of societal support to persons with intellectual handicap, a system of institutions is being replaced by community services. Large residential institutions are being replaced by housing and premises for daily activities, in places in the community where others live or work. A physical-structural change is taking place. But the man's comment draws attention to the fact that this change has to do with more than mere physical restructuring of services. How can this aspect of the process of change, the fact that he had not become visible in his community, still lacking an identity in relation to the world around him, be expressed?

In this comment the person with handicap becomes the focal point, how he is perceived by others and how he perceives himself. In a more general sense it also raises the question of the perspective from which persons with intellectual handicap are viewed, their role in society and the nature of the relationship between them and the world around them. One way of expressing this can be found in the analysis made by Wolfensberger concerning how social roles are associated with the organisation of support of society. He found a relationship between the nature of these organisations and the social roles assigned to these persons.

When they at one time were regarded as “L’enfant de Bon Dieu” it was the church who took responsibility for these persons. When they were thought of as inhuman they were looked after in large institutions, often under inhuman conditions. The medical tradition of care coincided with the period when these persons were seen as sick persons, whereas when they were regarded as developing persons the educational and therapeutic professions were given greater influence over the formation of the support provided by society.

These represent a number of roles which have been ascribed to these persons, expressing different views and thereby different perspectives, from which one can perceive them and their needs. From one perspective one focuses on certain aspects, while others are not given the same attention. The aspects which are not focused on are not, however, denied. In this way perspectives differ from each other regarding what is given attention, and what is considered of interest and importance. With regard to institutional and community services, these roles and perspectives can be seen to express differences concerning the background of ideas. This comparison concerns itself with the shift of perspective associated with the ongoing change from institutional to community support.

#### *The competence perspective*

When Swedish institutional services were originally established the boarding school was given a central role, as it was there that education was provided for those who were regarded as “educable”. Those who were seen as “uneducable”, were referred to the asylums. Two social roles, the pupil and the patient, were thereby attributed to persons with intellectual handicap and they have become a fundamental characteristic of these services. This was expressed as late as in the 1950:s when it was declared that the two main tasks for the services was the provision of education and care.

There are of course major differences between these two roles, but there are also similarities as they both express the view that persons with intellectual handicap are lacking in competence. Those regarded as pupils lack knowledge, and are therefore in need of education, whereas those termed patients have disabilities, and are therefore in need of care. This lack of competence becomes a common characteristic for residential institutions, and comes into focus in this perspective. The idea behind the work being carried out at institutions, was to achieve an increase in competence for these persons. This was brought about through the main tasks of education and care. The traditional institution acquired the character of a miniature society where everything could be found that contributed to the well-being of the person. At the same time the ordinary community outside the institution was relieved of its responsibility for these persons. As they did not have the knowledge to meet the special needs of these persons, they were not seen as resources for the support of these persons.

At the institution it was regarded as natural that a resident would at some time be able to leave the institution for a life outside. It was therefore natural that those with a mild form of handicap were the first to leave the institution, while those with a more severe handicap had to stay. In the competence perspective there is therefore an aspiration towards community participation, but its realization is dependent on the person, who by way of increased competence must qualify for participation with others, and to live the normal life .

Today when community services are being developed and institutional services dissolved, a physical restructuring of services is taking place. It is not natural though that the competence perspective, emanated during the institutional tradition, is left behind. Often it is being brought over to community services.

#### *A citizen perspective*

When looking for the origins of community services and the perspective associated with this tradition, one finds that they derive from the idea of the welfare society as it developed during the 1940:s. It was during this period that the socio-political objectives for the support of society to persons with handicap changed. In Sweden this was expressed in 1946, in what was called the normalisation principle.

The original idea of this social policy was based on three components. With regard to the person with handicap, the intention was to create opportunities for more normal conditions of life than was possible within the institution. As a means of achieving this persons with handicap were given the right to the use of the social services, which were then under development as part of the emerging welfare society. These were the two components which were given most attention and which were, to a certain extent, to be realized.

However, there was a third component in this socio-political idea, which was considered to be the underlying motive for reform. It was, namely, considered a basic civil right for persons with handicap to avail of the services provided by the welfare society. By thus viewing these persons as full-worthy citizens one also took a stand on the question of the role of persons with handicap in society. But to begin with this was something which applied only to those with a mild handicap. The developments which have followed during a 50 year period, have however, when it concerns persons with intellectual handicap, come to apply to all.

The basic idea of the role of the citizen is the democratic right to a life outside the traditional institution, and to participation in community life. Thereby, the similarities between persons with handicap, and the population in general, concerning human values and rights, are recognized. This perspective focuses on persons with intellectual handicap as full-worthy citizens, with a right to the normal life and to experiencing the welfare, which others have the possibility to experience.

Against this background it is natural to emphasize that intellectual handicap is a normal societal phenomena and that persons who are bearers of this handicap belong to society in a natural way. This handicap exists as a consequence of man's initial conception, of his existence as a foetus, of being born and of a period of development during the early years. This course of events is a time filled with risks and some times it is disturbed. The great majority are not affected, but there are some who are, and whose normal intellectual development becomes retarded. The size of this group may vary between cultures, societies, epochs and geographical areas but the group, however, does always exist.

A person is born into a family and comes therefore to belong to this family. In this way a person acquires his heritage and is bound to a wider circle of relatives. These have their roots in the community where the family grew up and the person with intellectual handicap will, as all others in the family, belong to this community.

With the understanding of the person as a full-worthy citizen, irrespective of whether he has a mild or a very severe handicap, follows the right to influence over his life. This can naturally be exercised by the person himself, but if the person cannot express his requests, there are members of the family who can provide this support. There are also others who can be chosen as either a formal or an informal spokesperson.

As the purpose of support from society is to contribute to the person being given access to a good life, it is important that knowledge is acquired about the

nature of the life desired by the person. The question of what sort of life the person wishes to live is therefore the key to the understanding of his request for support. It should also be the starting-point for the choice of support to be offered by the service organisation.

The person's participation in the community is, from this perspective, a civil right and an obvious task for the services. The extent to which this participation is realized will depend on the services received by the person. Are they adequate to give support for a life in the ordinary community ?

But what about the competence of the person? This is of course important even in this perspective. As for all others each has a reason for wishing to increase his competence through care, treatment or by improving his capacity by other means, and this, naturally, applies even for persons with handicap. But when this does occur provisions should be in relation to, and with respect for, the requests of the person and the community in which he lives.

### **A TWO-DIMENSIONAL CHANGE**

Viewing the change from institutional to community services denotes something more than merely moving from a residential institution which later is closed down. This is of course, in itself, a very important step which has to be taken. But the institution stood for more than just a number of buildings on institutional grounds. Within its walls an outlook had developed with regard to the persons with intellectual handicap, their potential and the views held with regard to how their problems best should be dealt with. I have described this aspect of the institutional problem as being a question of perspectives, and have summed up the ideas which arose within the institution as a competence perspective.

If one introduces the issue of perspective into the change taking place it will also be included in the task of renouncing the outlook which had been created, and had prevailed, within the institution. What one needs to relinquish is not just the institution in a physical sense but even the institutional tradition. It is easy to point out that one wishes to overthrow a perspective. But it is also necessary to develop and acquire a new viewpoint, that which has here been called the citizen perspective.

### **A COMMUNITY BASED APPROACH**

#### *The question at issue*

The issue to be addressed is the question of why a community based approach to services is to-day, in the mid 1990:s, considered to be the way forward for the development of services to persons with handicap, and not just those with mental retardation. The idea of providing the support, which handicapped persons unquestionably need, in the community setting rather than in specialized segregated ones is internationally being seen as the accepted way. Sweden has had long experience of providing support to persons with handicap on the basis of a community based approach and has therefore had the opportunity to gain knowledge and experience which can be of value in an international perspective.

On an international, or global level, one very good reason for accepting this approach is the awareness and recognition that at least 50 million persons in the world to-day are persons with mental retardation! Add to that all other forms of handicap, children and adults, and the figure comes nearer to 500 million. It is thus a recognized fact that institutions cannot be built or provided for this number of persons! Therefore on purely practical, and financial grounds, it is seen that support, service and care for these persons has to be provided through the ordinary channels of each society and community. These channels, "the normal life" of every society will of course vary, but can in their various ways develop forms of support applicable for its citizens. There are and will be cultural differences but the approach, of providing support in and through the ordinary society is the same. Our emphasis is on the use of the term approach, the content of which can vary. One is therefore not only referring to CBR - Community Based Rehabilita-

tion, as this tends to be associated with a more specific model, or technique relating to certain specialities, the initiators of CBR being primarily involved in work with and for persons with physical handicap.

This contribution is based on experiences from the last 25 years of working, in Sweden, with services to persons with mental retardation, where a change has taken place in the direction of a community based service system, that is to say a service based on the idea of an integrated rather than an institutional way of providing support. Reference is made to the integration of a service, which in itself is specialized, but integrated into for example, the ordinary system of schooling, the general social and medical services and physically into the local community in which the person lives. In western Europe and North America this has meant a change characterized by the switch from an institutionally based provision of service to a community based approach whereas in other parts of the world one has had the task of developing an integrated system of support from the beginning. It is experience from this latter context that one usually associates with the concept of CBR.

But the interesting aspect is that in spite of cultural, social and even economic differences this process of change and development, or just development, has many similarities. The basis for our experience is primarily from Sweden but the course of events which have taken place there are not unique. The same stages and processes of development can be seen in many countries, ranging from Western Europe to developing countries in Africa and even richer countries of Asia, for example Japan.

#### *Early Swedish experience*

The pattern was very clear in Sweden and followed the general process of development in society. In the middle of the last century a new awareness developed as to the existence and the specific needs of persons with intellectual handicap, mental retardation. Prior to this one found this group together with all other dependent groups in society, the sick, the physically handicapped, the mentally ill, or just the poor. They were either neglected, many becoming beggars, others dependent on charity in places like the "Poor Houses" common in many countries of western Europe. A new awareness of the mid 1800:s led to the establishment of specialist services for this group, the initiative to begin with often being taken by voluntary organisations based on private charitable funding. The special awareness at this time was heightened by the introduction of compulsory schooling - when all children are to go to school then, and often first then, does one discover those with intellectual handicap, those with learning disabilities.

The private initiative in Sweden was soon followed by a new social awareness and the intervention of the public authorities, private services being subsidized by the state, though still run by charities. The nature of the services was based on the idea of family life, the extended family where persons of all ages, staff and clients alike, lived and worked together, often in large houses in rural areas. The image of the large house, spacious grounds, in an idyllic setting, became the ideal.

To start with this was also the model for the public services which were under development, these being seen as the responsibility of the newly established county authorities. But the content and the objectives for these services gradually changed. One sees how the philanthropic tradition, based often on Christian principles of optimism and caring for ones fellowmen loses its impact and the institutions became places where persons were merely retained, or even punished, the goal being to care for as many as possible, as cheaply as possible. These persons come to be described as parasites and a burden for society, and as the institutional solution was still considered the only way of providing support, the demand for institutions grew and the burden increased.

As a reflection of the economic and social state of the Swedish society, the numbers of persons in need of support was also increasing. Increasing industriali-

zation and urbanization at the beginning of this century put greater demands on a previously rural population, more people were found incapable of coping with these new demands, amongst whom were those with intellectual handicap. And the demand for facilities increased thereafter. It also had been recognized that persons with mental retardation were most often in need of support during long periods, or for a life-time. This led eventually to a decision in the late 1920:s to convert unused military barracks into institutions, the special hospitals which came to be run on much the same lines as the institutions, which in recent years, have so shocked the world. Places whose sole purpose has been to hide away the unwanted members of society.

#### *The emergence of a welfare society*

These experiences, from the decline in institutional standards and the unanswered needs of those who were never admitted, together with the experiences from the concentration and refugee camps of the war years in Europe, were issues which came to be debated during the process of developing the idea of a welfare society. In Sweden the concept of the normalisation principle was conceived, suggesting, amongst other things, that the normal services under development as part of the welfare society (schooling, health care, social services etc) should be made available also to persons with handicap, as an alternative to providing mere placement in institutions.

This perception of how society should develop was not only based on the experience of the negative consequences of institutional care, or the impossibility of providing support for all through this means, but also on what was seen as a democratic right, namely that even persons with handicap had the right to live in society, be part of society and to receive the support they may need from the ordinary services of that society. In these developments one sees the origins, in western Europe, of the concept of a community based service. The process of developing such a service has, however, taken 50 years to realize in Sweden, and, as institutions still exist, the debate continues throughout Europe and North America!

#### *Why chose a community based approach?*

From this presentation of early developments one can distinguish two major factors which have contributed to the choice of a community based approach. Firstly, there is a material and practical aspect showing that institutional models cannot provide services, irrespective of standard, for all. Apart from the numerical aspect, it is a recognized fact that standards tend to deteriorate in relation to size, high institutional standards being excessively expensive. Consequently the negative effects increase and become destructive for those in need of support. The second aspect has an ideological basis, namely the maintenance of the right for persons with handicap to remain in society, receiving support within the ordinary systems of that society. In many countries this is to-day being seen as a human rights issue which is often reflected in national legislation.

Both these factors have an historical perspective, why did it develop? But to-day, 50 years on from the Swedish debate on the development of a welfare society and integrated services, and from an international perspective, we have also gained considerable experience of running community based services. These experiences serve as a third factor in answering the question of why this approach should be chosen. Namely the positive consequences of providing a community based service. And when ones looks at these consequences one can see that they also have both a practical and an ideological dimension.

#### **SOME CONSEQUENCES OF A COMMUNITY BASED SERVICE**

When looking at the consequences of a community based approach we have chosen to consider the implications for the persons themselves, for their families and their communities. Our view of the consequences is based on experiences dating from the early seventies when I worked at a large institution, a special

hospital for persons with mental retardation. At this special hospital there were many specialists, but they, we, did not and could not create a good life for these persons at this special place, in the countryside, and far from their home community. They could not be “cured”, so when they left the hospital, even if they had improved, they were still in need of support. So the question was, what is required in order to provide that support in their permanent life situation, and probably for life? In answering this question certain choices have to be made.

This situation is like being at a crossroads - one cannot choose to travel along two roads at the same time! If the community based “road” or approach is chosen, it brings with it certain consequences, one comes to certain places and one gains certain experiences, different from those gained by choosing the institutional, the special and the segregated, approach. Our experience is that the consequences of the community based approach are better for the individual person with handicap, for the family of this person, for the community around the person, and for society generally.

I would like to present these experiences in terms of the possibilities that a community based approach gives rise to, that is, opportunities for developing new perspectives on the issues of handicap and services to persons with handicap. I will first summarize these in 5 key words, or concepts, around which I shall then elaborate.

1. A community based approach gives rise to greater OPTIMISM, both with regard to how society sees persons with mental retardation and to the persons chances for individual development.
2. It can lead to a greater RESPECT for the persons themselves, for their families and for the community in which they live.
3. This approach makes it possible to find ORDINARY SOLUTIONS, to make use of ordinary conditions and people to provide the help and support required.
4. It becomes possible to formulate the objectives and goals for support and service provided as being THE NORMAL LIFE, a good life in the home/local community.
5. A community based approach to services requires, and also increases societies AWARENESS of these persons, they become visible, and society sees not just their needs but also their possibilities.

I would now like to elaborate a little more on each of these five concepts, illustrating the consequences we have seen of taking a community based approach to service and support for persons with handicap.

### 1. OPTIMISM

A community based approach to the issues of handicap and persons with handicap brings with it a very positive and optimistic view of the persons potential, chances to develop and of living a good life in his/her community. If the child/person is initially accepted and kept within and by his family and community, the likelihood of a positive development increases, this in itself having a positive effect on the persons developmental potential. Being surrounded and supported by other persons without handicap, brothers and sisters and other children, and family members of all generations, provide relationships with persons from whom he can learn and copy and gain support and instruction.

If instead the child is rejected and “put away” on a full-time basis, at an early age, to live with other persons also with handicap, as for example in an institution, from whom is the child to learn? What does he see around him? Specialists with whom he cannot identify, or others with handicap and perhaps other deviant behaviours. Or if the child is rejected and instead “hidden away”, a child whose existence is denied by its environment, then its chances of development are greatly limited. The child does not come in contact with other children, with whom he can play and learn, and be accepted.

But if the child or person with handicap is accepted as a full-worthy member of its community, as one of its ordinary citizens, its very acceptance becomes a source of development providing the family with a more optimistic view of the persons potential. And when the persons response to positive stimulation is seen by the family, and the community, a more optimistic view can be furthered. This process can even be seen as reducing the handicap person's dependence on society, acceptance and informal support from the surroundings often leading to greater independence.

Some examples from Swedish experience are the children, who, on being admitted to the local school, in a special class, were able to get there themselves and develop social relationships which had a supportive effect, where participation in games and leisure time could be shared with non-handicapped neighbours, when children can be seen in local shops and other situations. Or the young woman who was provided with a daily activity nearer to her home and was thus able to cycle (learning to cycle having been a personal wish which had now been fulfilled) to her place of occupation instead of requiring special transport to the special institution.

In both cases one finds an examples of persons who became "visible" for the local community, communicating an optimistic view of their situation and gaining access to a natural support from within their own community.

## 2. RESPECT

Another consequence or aspect of working from a community based approach is that it builds on, and furthers, a respect for the person, for the family and for the way of life and culture of their community. Respect has to be shown for how these persons, at a personal and community level, think, feel and what they expect and require from life. The views, wishes and customs of the local community need to be recognized and respected and used in the development of the support and service required.

This in turn influences the methods of work and approaches from those responsible for developing services and support. This requires that one asks and listens to those concerned and that they are helped to express their wishes and needs, and that these are responded to with respect. This is the opposite to imposing or dictating views and measures on persons, their own views being ignored, criticized or suppressed. From a discussion based on mutual respect, ideas and initiatives can grow and flourish and solutions can be found.

There are now many examples from the European experience where persons with handicap are themselves demanding to be respected, listened to and taken seriously. A 22 year-old girl asked a group of 1.000 conference delegates, professionals and politicians in the field of mental retardation, "I want to be with you, among you, MAY I?" She was speaking on behalf of all those who felt left out, ignored, whose views and wishes were not listened to, not respected. A poster in the London Underground had a picture of a small boy with Down's Syndrome and the words "They call me Mongo, but my name is David!" He was asking to be regarded as a person in his own right, not one of a diagnostic group.

In the matter of community based services this requires that the experts or professionals also go to the person, to their homes and to their community, using a language which is understood and showing respect for the persons life-style, this being in contrast to the admittance of persons with handicap to strange environments far from their cultural base. This is especially relevant in the situation where those responsible for the service represent a different culture, as is the case with many foreign aid projects. Sensitivity to the culture and traditions of a society is a question of respect.

In the Swedish context and in the development of its service system this implied the establishment of a community based "district-team" localized and integrated in the local community. These teams, including social, psychological, educational and medical professional groups work with the person with handi-

cap, with their family and through the ordinary agencies in society, kindergartens, schools, child care clinics, work places, etc. The professional specialized groups can therefore work with and through the ordinary staff of these agencies, using them as their “field workers”!

### **3. ORDINARY SOLUTIONS**

A community based approach to the provision of support and service to persons with handicap makes it possible to look for and use ordinary, rather than special, solutions. The starting point for the child or person with handicap is to consider how one would react to or treat the non-handicapped person in a similar situation and having that as the guideline from which to start. This approach refers to all aspects of life, the provision of housing, health services, schooling, social or recreational activities. The child with handicap needs the same health care as non-handicapped, the benefits of attending a kindergarten or school like other children, though with special support or educational methods, participating in the same social activities and meeting with other people in the ordinary community life, for example, shopping, transport, sports etc.

A fundamental consequence of this approach is that the need for special buildings and facilities is no longer seen as the primary factor in providing for persons with handicap. The special factor required, beyond the ordinary solutions, can be found in additional knowledge, alternative methods or in additional support which supplements the ordinary provisions, for example, specially qualified teachers and extra teaching assistants in the kindergarten or school.

In practice this has, in Sweden, resulted in the handicapped child attending the ordinary kindergarten but having access to personal assistance in addition to the basic staff, or the establishment of a special class within the framework of the ordinary school. Adults may attend ordinary places of work but be provided with work assistants to support them in their task. Instead of the residential institution ordinary housing is used for groups of persons with handicap who live together with support from a staff group.

### **4. A NORMAL LIFE**

From this perspective it becomes clear that the goal and objective for the support provided to the person with handicap is to enable them to live as normal a life as possible, within their normal community setting. This then includes a cultural factor, the normal life varying between, and even within, cultures. In order to formulate the objectives for individual measures taken it is necessary to understand the cultural setting in which they are to be applied. The choice of individual goals need therefore to be related to the normal life styles of the persons concerned.

In Sweden learning to ride a bicycle can be seen as an example of a typical Swedish cultural factor, where most children learn to cycle, and use them in their daily life. Also participation in swimming activities and being able to live near to lakes and waterways being requirements desirable if one is to live a normal life in rural Sweden. But these goals can be quite irrelevant in another cultural setting. Eating traditions and habits are a typical example of the need for cultural sensitivity. Which, if any, utensils are to be used? Spoons, knives and forks, chopsticks or fingers? Also the question of where and how meals are taken. Too often one sees the implementation of foreign habits and traditions being introduced through imported standardized training programmes insensitive to local and individual needs.

In other words, the choice of a community based approach in the provision of support requires that cultural factors are given high priority in order to understand the nature of the “normal life” for the person concerned. In institutional forms of support these factors are not given priority, goals and objectives being limited to the life within the institution, and the opportunities provided in that setting, rather than in the normal life of the community outside.

A further consequence is that the objectives of the support provided is individualized and personal, related to the person's and their families understanding of the normal life. There is no "One Way of Life" for persons with handicap but instead many different life styles which require both psychological and practical measures if it is to be attained. Psychological, in order to understand the needs of the person, and practical, in order to implement them. The physically handicapped person may be in need of a wheelchair but he must also live in a situation where use of a wheel chair is practically possible!

## 5. AWARENESS

This brings us to the fifth and last point, namely that a community based approach builds on, and requires, a community and society which is aware of the existence of, and the needs of, persons with handicap! A society cannot provide support for its citizens if it is not aware of their existence and of their needs! But, as long as they are hidden from society, in their homes or in institutions, there is no way of increasing this awareness!

Bringing about such awareness is a process which includes, perhaps begins with, **information** as to facts - the first being that persons with handicap exist in all communities and all societies! From a knowledge of the facts, and knowledge regarding persons with handicap, an **understanding** of the needs of these persons can develop. Following an understanding, an **acceptance** of these persons, and their right to a good life in the community, can be brought about. Acceptance of these persons, as part of a community, and recognition of their needs, should create the awareness necessary to initiate the **provision of support**.

We maintain that such an awareness in a community leads to a richer society, a society which recognizes the rights and needs of all its citizens being a step towards accepting a responsibility for meeting these needs. This is the process which in Sweden started to develop in the 1940:s, and is still going on, 50 years later. The same process is taking place in all societies. From Ethiopia, one of the poorest countries in the world, to Britain, where handicapped people are still trying to get a Civil Rights Bill passed which will improve their possibilities of living in the community.