TOWARDS A BETTER LIFE FOR PERSONS WITH DISABILITY: DEVELOPMENT OF COMMUNITY BASED SERVICES AND DISSOLUTION OF INSTITUTIONS

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INCLUSION OF PERSONS INTO COMMUNITY LIFE

A global disability reform is going on. The old ways of handling persons with intellectual disability are being criticized. New ways of organising services are therefore being sought. This development may be intense in some countries, less so in others. The goal of this reform is the inclusion of persons into community life. The ambition is to give support to persons so that they can live the life of others, together with others. For this to be a reality there is a need for services which contribute to inclusion. Community based services, those localized to the places in a community where persons want to live, are being developed to meet this challenge. Residential institutions which are a hinder to inclusion will therefore need to be dissolved.

Why has inclusion become the goal of disability services? The background can be found in the new ideals which were formed in the 1940:s. Democracy, the welfare society and human rights are expressions which illustrate the ambitions to develop nations after a destructive war. The UN declaration of human rights of 1948 is just an example of this. Within this framework it was natural that persons with disability were seen as citizens who belonged to society. They were persons with rights like other citizens. From this perspective it was natural to see that the normal life became a goal to strive for.

The new idea of inclusion contrasts sharply with the idea behind the residential institution. This idea was formed during the middle of the 1900th century, when industrialisation was the force which changed society. This process made persons with a

1

disability visible in public for the first time. They were identified and placed in the new institutions seen as the normal and ideal ones in these societies.

Two traditions of support can therefore be seen today. The community tradition with roots in the society of today sees persons as citizens and aims for their inclusion in community life. The institutional tradition, which sees persons as deviant people, offers care in secluded places. The content of the ongoing global reform can be said to be a shift from an institutional to a community tradition.

POLICIES OF DISABILITY

The socio-political idea of the 1940:s, seeing persons with a disability as citizens, has gradually been developed over more than 50 years. The well-known normalisation principle became a way of expressing this new policy during the 1960:s. To enable persons to live the normal life, new tasks were brought into disability services.

The international year of the disabled in 1981 became an important step to sum up the disability work of UN, which then had taken place for more than a decade. Full participation of persons into community life was the expression of the time. When the disability work of UN continued, the Standard Rules of 1993 again summed up the policy. This time equality became the basis for guiding services in the right direction. Persons were seen to have the right to equal participation in society. The participation of other citizens became the participation of citizens with a disability. Equalisation of opportunities meant that the opportunities for others also should be open to those with a disability. The value-basis which gave logic to this policy was expressed as persons with a disability having equal rights and obligations, as others. This policy of equality is also the one supported by EU.

There has also been a gradual implementation of these policies into the disability laws of several countries. In this way parliamentarians, who represent the population, clarify the view of the nation on persons with disability. Naturally, a variation is found between nations in this respect. Development of disability policy and services go hand in hand with the general development of a society.

But disability policy is not a matter for the few. It must be assimilated into the local services offering the actual support to persons. In the end therefore all those who are involved in the disability issue need to contribute to the formation of local policies.

People should dare to have dreams and visions for better lives and for services which realises these visions! Many times I have seen projects which have received new economic resources, but who have not had any idea as to how these should be spent! Not being able to distance oneself from a destructive past, one has not been able to take a step towards new types of services. This was once expressed by a father of a man with a disability: "they are modernising their mistakes!". Dreams and visions of a better life and

better services in line with accepted policies, is helping development in the right direction.

COMMUNITY BASED SERVICES

When describing a model for community based services it is necessary to clarify for whom these are intended. It is widely believed that persons with a mild disability should receive their support in the community, while those with a more severe disability should be placed in institutions. When there is an ambition to dissolve and to close residential institutions, this notion is no longer valid. As all persons are seen as citizens, all have the right to a life in community together with other citizens.

As mentioned the task is to organise services so that persons will be able to live the normal life. The meaning of a normal life is the life lived by others in the community to which they belong. There are therefore two major aspects of community based services. One is to offer an everyday life which is as normal as possible. This means to have a home, to have something to do during daytime and to participate in the life of local community. The other major task is to contribute to personal development, through public welfare services.

A home

Everyone needs a home, but how does one achieve this for a person with a disability? When looking at existing homes of persons today I find that all sorts of housing can be used. This means that apartments, semi-detached houses, villas and country-houses, small and large, can be used. But not every house can be used by everyone. In the same way as we ourselves choose our house to suit our needs and tastes, this also goes for persons with a disability. An issue in connection with the choice of house is the number of persons who will live together. Will a person live on his own? Or will he live in a group-home, a house where a group of persons live together?

But the house, a physical building, is not a service. It is staff who make the house into a service. They provide the support needed by persons. The staff-group needs to vary in size to meet the needs of persons. Do they have extensive needs for support, the staff-group will be larger. If persons have limited needs for support, the staff-group is smaller. The training of staff may also vary. If some persons have medical needs, a medical nurse can be part of the staff-group. If persons are deaf and therefore use sign-language, staff need to be able to communicate with sign-language.

However, a house with staff is not a home. A home is characterized by privacy. It is the place where the person has his personal belongings, those which are chosen by him. He also needs to be able to close the door behind himself. This is the place where he lives the life he wants to live, without the interference of others. To be able to contribute to a home, the service needs to know what sort of life he wants to live. Therefore the person, together with his representative, need to inform staff of his idea of a good life in his home.

Daily activities

People usually spend daytime at work, outside their home. With the normal pattern of life to strive for, this should also be achieved for persons with a disability. This becomes natural for those persons who can get employment, open or sheltered. For others, who cannot get employment, but need support, day services outside the home need to be organised.

The aim of a day-service is of course to contribute to the overall objective for community based services. A good life, while being included together with others, then becomes a goal. It is through daily activities during the five days of the week that this is to be realized. This opens up the question of which activities are preferable. This cannot be answered by pointing to specific activities. Instead one must recognise that activities must be purposeful for the person. They must contribute to a good life for him, as this is the aim of day-services. An activity suitable for a person with a severe disability is not necessarily purposeful for him with a mild disability. The choice of activities for a person is therefore a personal matter. His involvement in the choice of his activities is a necessity for this.

Traditionally one builds centres where daily activities take place. With the ambition to contribute to inclusion of persons, another way of choosing a physical setting is possible. A group of persons can be given a small place in the ordinary community, for example by hiring an unused shop, by hiring a space in an industry or by taking care of a local park. When looking to existing places the variation of environments used by day-services is very wide. Instead of a centre, day-services will take place in a set of environments in a local community.

In community based services there is one staff-group in the home. There is another who has responsibility for support during daytime. This is specialised in the development and running of daily activities. It was mentioned that the staff-group in the home should be related to the needs of persons. This also goes for the staff-group in day-services.

Community participation

A part of everyday life takes place outside the home and outside daily activities. To live one´s life, functions in community need to be availed of. Commercial services need to be used to do one´s shopping for necessities like food, hygiene and clothing. Leisure also takes place outside the home and this means participation in events like sports and culture. The social network is made up of family and friends and these need to be visited.

Day-services also contribute to community participation. Material, for example wood and textiles, need to be purchased. Products may be sold and this attracts the public to visit the shops run by persons with a disability. There are examples of persons who inform in local community about the disability issue. This creates contacts with pupils in schools, representatives for local administration and the public.

The home and the day-services therefore become a platform for participation of persons in local community.

Personal development

Personal well-being demands that persons use local welfare services like social and health centres. Visits to the dentist and the chemist are also functions which forms part of normal life.

As this concerns persons with a disability, they may be in need of some form of education, therapy or treatment which leads to personal development. One cannot maintain that there is one form of therapy suitable for all persons with intellectual disability. With the many reasons for this disability, there are a variety of therapies needed to meet the variation of needs. In the end the choice of therapy will be personal.

Amongst these persons many may have additional disabilities. This may be in the form of problems like autism, mobility, speech, hearing or vision. Apart from the disability, these persons, like anyone else, may also have all the other usual forms of ill-health and sickness. This naturally requires that they turn to those who can give adequate treatment. With the overall ambition to participate this means that the welfare services of community, used by the public, are the ones which these persons also turn to.

DISSOLUTION AND CLOSURE OF INSTITUTIONS

We must recognize that there is an institutional problem. It can be described in a number of ways. With the new policy aiming at contributing to a normal life and to inclusion of persons into the community, one must recognise that there is no place for institutionally based services. Another aspect of this problem is that institutions offer a lower standard of living compared to community based services. Institutions are therefore declined when persons and their families are given the possibility to choose. There are also institutions today which offer an unacceptable life and thereby create disability, so called imposed retardation. Therefore ongoing dissolution and closure of residential institutions has taken place since the 1970:s in several countries. In Sweden all residential institutions have been closed and since year 2000 they are abolished as a service.

Towards closure

One does not suddenly decide to close an institution. It is part of a longer process. To illustrate I will give a brief presentation of the Swedish experience. The first step was taken in the 1940:s. A vision was formulated for a welfare society in which persons with a disability were included. Naturally this did not become a reality at this time, but the first step had been taken. The welfare legislation during the 50 years to follow has gradually shifted disability services away from institutions to the community.

In the early 1970:s community based services became accepted and wide-spread. Social innovations led to new forms of channelling services to persons. The new services offered a better standard than had been seen earlier. In a group-home they lived in a small group of 3-5, each had his own room and they got daily activities outside their home during the working-days of the week.

This new living standard became the basis for criticism of institutions. Families and staff demanded that persons still living in institutions should have the right to the same standard. As institutions began to be dissolved persons left for a life in the community. Community based services developed to meet the needs of all. This dissolution of institutions also made them economically unacceptable, as the costs of all aspects of what was offered by the institution could no longer be covered by a diminishing group. Finally a law was passed to make it mandatory to close all institutions.

The process of transition from institution to community has not only concerned intellectual disability services. This is part of a broad process of change of a country. All disability institutions have been closed during the last 50 years, also for other groups than those with an intellectual disability. There has been a strong political opinion supporting this change, expressed by people who are concerned and by an active disability movement.

This has taken place at the same time as Sweden as a nation has changed. New ideas of social services has led to the introduction of non-coercive methods. New views on education have emerged, stressing the task of recognising the individual´s potential for personal development. New standards for housing have been introduced, this of course having consequences for housing of persons with a disability when they are seen as citizens and members of society.

Setting up new lives

It is necessary to clarify the aim of institutional closure. This takes place as there are new objectives for disability services. When these are realised better lives and personal development occurs. The task is therefore to set up new and better lives for persons, outside the institution. This goal concerns all persons, even those with a severe disability.

With an aim like this the consequence is that the key to closure lies in the alternatives. When community based services are made available, which offer the person a better life, then he can move. When there are services for all, everyone can move and the institution can be closed. The focus for this process therefore lies in the development of community based services.

Persons move to new services

As the new services are intended to offer a person a better life, homes and activities need to be personal. The first step is therefore to clarify what a better life means to persons at

the institution and what services are needed to realise these lives. This personal information is attained through an assessment of persons´ needs for new services. Experiences show that it is possible to carry out such an assessment. To give this validity, persons and their representatives need to be involved as well as their families and staff. The contributions of families and relatives is especially important as they will have an active role in the life of their family member after he has moved to his new life.

The result of this assessment becomes the basis for establishment of new services. Houses need to be built and activities need to be arranged. Welfare services in the new places in towns and villages need to be informed that new people will be needing their services in the future. A person can only move when his new services becomes available. The move from an institution to community based services should not be seen as the end of a process of dissolution. Instead it is the beginning of the setting up of new lives. A lot more remains to be done to increase the quality of these lives.

This very complex process of development takes place during a long period. Its length depends on the number of persons who are to move and how many will get the opportunity to move every year.

Evaluation

The evaluation of the process of transition from institution to community shows that it is possible to create new services and that persons can use the public welfare services of the local community. When interviewing staff about what they found to be the most important development they had seen, they referred to them having seen personal growth - "they had become persons".

When interviewing persons themselves, those who had moved to new group-homes, they expressed in several ways that they appreciated their new lives. They liked to have something of their own. When asked, they did not want to return!

Families of persons experience a stressful period during the process of transition. When it starts one is worried as one does not know how the person will respond to his new life. But when the person has moved and settled down in the new services families are very glad about the persons´s move from the old institution.

Staff who have experienced working at an institution, as well as at a group-home, see the change as important. They report that new service offers a better life for the person. It also offers better working conditions for staff as the degree of freedom is higher than before.

A FINAL COMMENT

A fundamental change is going on as regards intellectual disability. A new role has been attributed to persons as they are seen as citizens and members of society. This has led to a new perspective. From this one sees new goals, new tasks and new solutions. Better lives

for persons have been experienced when this perspective has been applied. Inclusion therefore has become an overriding policy. This has consequences for the type of service to promote. Those are desirable which contribute to the inclusion of persons, others need to be dissolved. This is the reason for the ongoing development of community based services and the dissolution of institutions.

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