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EU-Project STEPS: Structures Towards Emancipation, Participation and Solidarity
STEPS/Lidingö: The Swedish national project

PARTICIPATION OF THE PERSON IN THE FORMING OF HIS EVERYDAY LIFE:
ON SEASONAL CONVERSATIONS IN HOUSING AND DAILY ACTIVITIES

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Year 1 with STEPS/Lidingö: a progress report

STEPS is a European project where the five towns of Barcelona, Hamburg, Lidingö, London, and Rotterdam work together to respond to the discrimination experienced by persons with an intellectual disability. STEPS/Lidingö is the Swedish national project taking place in the town of Lidingö. It was established in the spring of 2002. In September 2002 work started with a period of preparation focussing on the method to be used to facilitate the person's participation in the forming of his everyday life. In 2003 the method has been applied when delivering services to the group concerned. This progress report covers the first year of the project.

The project coordinator is Kent Ericsson from the Department of Education, Uppsala University. Kerstin Lundberg is head of services to persons with an intellectual disability in Lidingö. Adriana Buzea is head of economy in the organization responsible for these services in Lidingö. Patricia Ericsson is consultant to the project.

Background and objective

Services to persons with an intellectual disability have been restructured in Sweden. Community based services have been developed while those which are institutionally based have been dissolved. A change of responsibility has meant that the regional organization, counties organizing special services, have handed over its responsibility to local welfare services of municipalities, those used by the public. This has created a new platform for the delivery of community based services.

What goes on in Sweden is a shift between two traditions of support. A community tradition is being developed at the same time as an institutional tradition is being dissolved. The logic found in the community tradition stems from a socio-political idea from 1946, which has gradually been implemented through the four Acts of Parliament from 1954 to 1993. The key to this idea is to see the person with a disability as a citizen with a right to be part of ordinary community and to live the life which is lived by the general public. To meet the person's request for a good life, personal forms of support have to be established and local resources have to be utilized.

With this citizen perspective, striving for the normal life becomes a natural objective. One need to find housing, schooling and work in the community where the person belongs, together with commercial services, recreation and culture and services for health and social well-being. If the person needs support to avail of this life, this should be offered. If this life is not available, the person with a disability can be seen as discriminated against.

The right for a citizen to have control over his life is the key to the realization of the life requested by him. It is also the guarantee that services get a local character. Thereby the realization of the community tradition, and the guarantee that discrimination does not take place, is related to the person's possibility to influence his everyday life.

The objective of this project is to increase involvement of the person himself, and his representative, in the process leading up to his everyday life and the support needed to make this a reality. When the person's request for the life he wants to lead has been met, a basis has been found to identify possible discriminating factors, that is those which hinder this life to become a reality.

A method to contribute to everyday life

As mentioned, the right to live the life of the community to which the person belongs, is a logical consequence of the citizen perspective. As it is the person who has the answer to what life he wants to live, he needs to have a possibility to communicate his views. For the organization delivering his support this knowledge becomes important as their main task is to contribute to a good life for him. There is therefore a need to create occasions when the representative of the service organization meets with the person and his representative to discuss what sort of life the person wants to live. One of those occasions is the seasonal conversation.

This method creates a forum for the person and his representative, together with staff from the service organization, to sit down to plan the activities which will take place during the coming season. In the spring for example, the summer is planned and in the summer, the autumn planning takes place. The planning during such an occasion is summed up in an agreement and signed by both parties. The activities in this agreement becomes the tasks to be realized during the coming season. At the same occasion as planning takes place, a follow-up is being carried out of what was realized of the activities agreed upon during the previous seasonal conversation.

In community based services housing and daily activities are the two forms of services to deliver the support needed day and night by the person. As these are two different services but with the same task, the good life of the person, they need to compliment each other. The method to coordinate the contributions of these two services is to start off from the person who, together with his representative, participates in the planning which is to go on in housing and in daily activities. Seasonal conversations is the method chosen in this project to achieve this participation and coordination.

A process with achievements and obstacles

This method, seasonal conversations, has been developed together with and used by services in previous projects. Therefore it is well known by the consultant to this project as being potent. It is usually well received by persons with a disability, their representatives and staff. The method has only been used in the forming of the everyday life in housing. This project widens the scope and uses the method in housing as well as in daily activities of a person.

The task of the project is to introduce this method for a group of six persons receiving their services in Lidingö. After a period of preparation it is to be implemented in the running of services. The ambition is to establish this way of work as a natural part of delivering support in housing and in daily activities. It is expected that this, after the two years of the project, has become a way of contributing to a personal everyday life, a life which is seen as desirable by the person himself.

During the process leading up to the realization of this objective, achievements will naturally be made. Obstacles will also be identified. The analysis of the process when using this method will

be an important part of to the understanding of the consequences of the ambition to contribute to a good life for persons with a disability. It is in this process analysis that the issue of discrimination will be discussed.

Apart from a better life for persons, the objective is to create a strategy for persons, their representatives and staff, in which this method is a part. This, based on the experiences of the project, will be something to turn to for those involved in using the method of seasonal conversations in this project, in Lidingö and elsewhere.

The activities of the project

With this ambition the following structure has been given to the two year period of the project. As a first step the method is introduced to persons, their representatives and staff (September - December 2002). It is then applied during a period of a year (2003). Thereafter (January 2004 - May 2004) experiences are evaluated and summed up in the project report (June 2004 - August 2004).

The introductory phase has been carried out. This meant that the consultant has had a series of conferences when meeting with persons, families and representatives and also with staff. On these occasions the project and method was introduced.

There is a reference group which is following the progress of the project. In this persons from the town of Lidingö who in various ways are involved in and concerned about the project meet to be informed. One of the members is the representative from the formal association representing persons in Lidingö. This reference group met during the introductory phase. It will meet again when progress has taken place.

Persons with a disability need to have their information presented and discussed in a way easy to understand. They have therefore formed a group who meets to receive information about the project and its activities in a way suitable to them.

The coordination group meets at irregular intervals, when there is a need to discuss relevant issues. This group consists of Kent Ericsson, Kerstin Lundberg, Adriana Buzea and Patricia Ericsson.

The international STEPS conferences are important occasions when the European partners meet to compare notes and to exchange experiences. In November 2002 this conference took place in Rotterdam.

During Spring 2003 the international conference met in Lidingö. The planning group from Hamburg visited Lidingö in February and the conference took place in May. The conference was supported by the town of Lidingö in a most generous way.

The European conference gave reason for two activities. Ahead of the STEPS conference a day was organized to show the meaning of community based services in the town of Lidingö. Conference participants were organized into small groups and in this way made visits to various services in housing and daily activities. This was followed by a discussion of the experiences gained during the day. The other activity in connection with the conference was the report which was prepared to present to the visitors the town of Lidingö, its disability services and the project.

Even if this is outside the formal project, activities have been inspired by the project. Therefore there has been an exchange of staff between Lidingö and Hamburg. There has also been an exchange of persons with a disability between Lidingö and Hamburg.

Plans for year 2

At the moment there is no reason to identify any deviance from the original plan. This means that experiences still are being gained from ongoing work. The reference-group is to meet in October to be informed about and to discuss the ongoing work. During Spring 2004 the international conference will meet in London. This is also the period when evaluation work will start to draw relevant conclusions from the experiences gained from the project. This is also the time when the project is to be reported.

References

A web-site (www.skinfaxe.se) has been set up to present the work of the ongoing project. There it is possible to find the documents produced in the project.

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