

Restructuring the municipal and local structures of social services for people with learning disabilities

Newsletter No. 1

29th October 2001

The Hamburg Project – The first visit

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After corresponding with some e-mails, the process of setting up a European project started for us with a visit to Hamburg. We met representatives from two provider organizations and the Hamburg authorities who have responsibility for the delivery of support to persons with an intellectual disability. We also met the university representatives who are at the forefront of this initiative. After having become more informed about the planned project we are most convinced that this is an important project, one which must be realized!

Here is a large urban area in Europe which wants to restructure its services in the direction of setting up community based forms of support. The motive (at least one of them) has been expressed as an undertaking which is a response to the idea of human rights. From this perspective a person's membership of a society becomes logical, as is the right of a person to be part of one's family and of a local community.

This perspective puts this project in a global frame of reference with roots in the UN Human Rights of 1948 and the present UN global strategy of "equalization of opportunities" (1993). Thereby an attempt is made to implement a UN strategy. Even if these motives are important and potent in themselves, one must not forget however, that this is done in order to offer better lives to persons with an intellectual disability!

What is the background to our positive reaction to this suggested project? We have been part, quite actively, of a similar restructuring of services in Sweden. Our major work took place in the Stockholm area where institutionally based services have been closed and community based services established as alternatives. In Sweden, as of year 2000, the residential institution is no longer recognized as a service. This has meant that we have extensive experiences from this transition of services, in Stockholm and elsewhere.

Our motive is not in any way to promote Sweden (EU-projects should not be seen as European championships!) but to bring forward knowledge collected during this unique process of change. As a consequence of our work we have considerable knowledge about some of the phenomena which characterize the change on an organizational level. However, the most important knowledge is that this change does, if carried out in a correct way, lead to better lives as regards personal welfare and development. Being met with the respect worthy of a citizen and receiving personal support among other members of a community, has implications which are immense (most of our material is in Swedish but some is in English: <http://www.skinfaxe.se/ibs/ilcp07.htm>).

I think that one of our main comments on this suggested project is that one must not see this merely as a matter of organizational restructuring. The change of forms of support is instead a means to contribute to better lives for people with an intellectual disability! Thereby they become part of the process of change and the end criteria of a successful transition of support lies with them.

But is this project of relevance to Sweden if this restructuring has taken place? If one defines the task as one of closing institutions and the setting up of community based forms of support, the job is completed when this has taken place. But if one sees the task as one of contributing to a better life of persons, then the real task begins when persons have left the residential institution and when the new way of life is to be formed. The Swedish reform can be seen as one which has tackled the first, but not the second, task. The present community based forms of support have brought several institutional patterns into community! What is needed now is to develop these services further. The frame of reference, based on the idea of human rights, is the one needed also for the Swedish contribution to the project.

For us who have passed through this process of change, we see that a most important and positive shift of support has taken place. However, I am afraid that this is too often seen as an isolated phenomena. The institutional tradition is very strong in Europe. Unfortunately, knowledge of the fantastic achievements of personal welfare are not enough for the adherents of this tradition to keep an open and unbiased view of this transition. If, however, the persons with a disability and their families are given the role in this transition which they deserve, it might increase the possibilities for a project like this to lead to better lives.

Tame the lion

Anne Ernst, Hamburg

“Everybody is highly motivated but also anxious”, summarized Kent Ericsson his impressions after the meeting with the representatives of the foundations Alsterdorf and Rauhes Haus and the administration. “We should limit the objectives of the project. Otherwise we will get the feeling of riding a lion”.

In my opinion this is an appropriate summary of our first meeting in Hamburg: We exchanged lots of experiences, ideas and problems. In Sweden the homes for handicapped were closed down by an enactment in the end of the Seventies. The structure of the social services, now organised on the municipal level from different providers for different needs, changed completely. In the moment the Swedish are looking for an effective personal assistant and advocatoric system to guarantee the full participation of the disabled people.

In Hamburg the service provider as well as the administration have advanced innovative projects, for example under the label “community care”. But the out-patient assistance is as well at the beginning as the self-determination and the participation of the people in society. After the election in Hamburg end of September we just don’t know the direction the new government will go referring the social services for disabled people.

To sum up: The discussions encouraged all of us and showed us simultaneously once again how ambitious the objectives of the project are.

After the first meeting I would like to draw the following first conclusions for the project:

- In the next months we have to limit and to clear up the objectives for every municipal dialogue: Which interests do the institutions have in the project? What could be their contribution? And what could be their gain?
- All over the point of view have to be the people with learning disabilities, their participation and self-determination – instead of the perspective of the administration and the institutions.
- I am wondering myself whether it would be practical and possible to involve advocacy groups for the handicapped people like “People first” to strengthen their voice in the project.
- Another point is whether we should take in consideration the question how the people could make aware of the interests of the people with an intellectual disability.

The second newsletter will be send out at the end of the week. Michael Langhanky informs about the first “Conference of the Community Action Programme to combat discrimination” in Brussels.