

Final Report on the Local Project

“The development of community-orientated service structures in Hamburg”

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1. Preliminary Remarks

This report builds on the interim report from the first year of the project, dated 8th November 2003 and sketches out the changes that have taken place in the project development since September 2003. It describes important results of STEPS from the perspective of the Hamburg context and relates them to the more detailed papers attached.

The final section of the report introduces the project, which came into being through the cooperation between the Protestant Alsterdorf Foundation and the Rauhe Haus Foundation and is currently undergoing further development.

2. Activities During the Second Year of the Project

- Initialisation of the project, “The development of regional resources to enable people with learning difficulties to participate in community life in the Hamburg districts of Horn and Billstedt.
- Support of the user conference “Independent Living in Europe” in April 2004 in Hamburg
- Participation in the international STEPS conferences in November 2003 in Barcelona and in May 2004 in London.
- Planning and implementation of the closing, evaluation meeting of the Hamburg STEPS Partnership on 19th August 2004.

3. The development of the Hamburg “Trialogue” Communication and Cooperation

At the outset of the project, the large, influential service-providers, the Protestant Alsterdorf Foundation and the Rauhe Haus Foundation were in agreement with both the project management and the relevant Hamburg authorities that, through the Hamburg project, they would be able to make a significant impact on the development of the support system for people with learning difficulties. Fundamentally, the issue was to overcome the limits of the paradigm residential versus decentralised versus community care and to make the individual each with his/her very personal and different care and assistance needs the focal point of any planning. The aim was to actually give people with learning difficulties the right to decide about their own assistance and support needs and to ensure that they actually receive these. The aim was the development of a “master plan” for Hamburg, which would sketch out

the necessary legal, organisational and financial requirements. For this reason it was and is very important to bring important service-providers together with the relevant authorities in one project.

As a consequence of the political changes in Hamburg since Autumn 2001, first the interests of the relevant local authorities changed before they withdrew completely from the cooperative work during the final year of the project. At the outset of the project, the project management worked on the issue of community care in Hamburg in the context of an international comparison through which they wanted to support the services for people with learning difficulties. The authorities, however, were more interested in testing the possibility of the implementation and money-saving potential of non-residential, community care programmes. This approach is not appropriate for overcoming the fundamental paradigm residential versus community care.

In agreement with the service-providers, at the end of the project the STEPS project management sent a letter to the relevant senator, Ms. Schnieber-Jastram, where this view was explained. The letter states, "A further development of the current Hamburg service structure towards stronger, more individualised assistance and care outside residential care institutions is long overdue. In particular, as can be seen from the situation in England and Sweden, a consistent concentration of services on the individual's support needs, makes a significant improvement to the quality of life of people with learning difficulties and enables them to participate more fully in community life."

Individualisation in this sense, however, means that the degree of support is linked to individual needs and participation in community life cannot be denied when support needs exceed a few hours a week.

Individualisation requires integration into society. This means for example, that wherever it is possible, be it with or without assistance, the "normal" community services should be used. The general service-providers are not "not responsible" because the needs of people with disabilities are at stake.

This is valid for all spheres: living, working, education and further education, health and leisure.

When these needs are not met, as is currently the situation in Hamburg, the stronger move towards non-residential care allows/finances those with lower needs to live in the community, whereas others are referred to institutions. (see Attachment 1.)

The withdrawal of the authorities responsible for disability support services changed the project and its problems and concentrated its attention on other issues.

Both of the involved service-providers, found the STEPS project enriching for their practical work and for the first time were involved in an intensive exchange and what is more, they have arranged and begun concrete cooperation programmes (see sections 5. and 6. of this report).

The advisory function of the group of people with learning difficulties, moreover, had an extraordinarily positive effect. The members of the Hamburg Partnership supported the communication of the users with other European members in the project and the international user-conference "Independent Living in Europe" (compare the final report of the advisory group of people with learning difficulties.)

During the final project meeting, the representatives from both foundations agreed to support the international exchange between users, with their staff, assistance and extra financial support. In addition, representatives of both foundations agreed, that the document containing the demands of the advisory group of people with learning difficulties would form the benchmark for their own practice. They want to examine which demands can be quickly and unproblematically implemented in their organisations and which ones may require longer preparation (compare document 2 enclosed, the arrangements made during the final meeting of the Hamburg Partnership).

4. Results from the Perspective of the Situation in Hamburg

Challenges for the Hamburg Support System

In comparison with the other European countries in the study, the situation in Hamburg is characterised by the following:

- Over 90% of all city funds for so-called integration support, from which support for people with learning difficulties is financed, end up in the financing of residential accommodation. 5,600 disabled people live in Hamburg and outside Hamburg (financed by Hamburg) in residential “complete care”. Hamburg uses funds for community care in the case of 1,200 disabled people. Here the maximum monthly costs per case are lower than the average monthly cost of residential accommodation. In addition, we know that approximately 70% of all disabled people do not live in residential care and yet receive no community care. From this structure, it is already clear, that people with high support needs have no chance of receiving care in the community, i.e. outside institutions.
- Residential care of people with disabilities is available from few service-providers. The largest of these in Hamburg is the Protestant Alsterdorf Foundation. These service-providers have significantly improved and modernised their services in the past 20 years. Most of them, in particular the Protestant Alsterdorf Foundation and the Rauhe Haus have significantly increased the number of decentralised group homes in the city of Hamburg and have closed parts of their old institution buildings. They would be able to make more progress in their development from residential care to decentralised care to community care, if the city re-financing of community care were not limited to a small number of hours per day and the corresponding level of funding. Two conclusions can be drawn from this:

In Hamburg many people with disabilities live in a “complete-care” situation, and could be cared for in their own homes if the support system were more flexible. Following the comparisons with other countries, in particular Sweden and England, this development would mean a much higher standard of living for people with disabilities.

Any such more flexible system would, at the same time mean that people with disabilities currently living outside residential care would seek limited access to support and assistance.

- If the changes in the support system are implemented according to the development course currently being tested, there would be significant risks involved for the service-providers and the authorities, or to be more precise their financial situation: the reorganisation of the service-providers towards a much more individualised development of their services would mean that the funds invested in complete residential care could no longer be used, but would not be available for other areas, while the newly developed care and support system outside residential care would receive too little financial support from the service-providers. The authorities would experience a similar risk: during the intermittent period they would be responsible for the extra costs involved in setting up the more individualised support system.
- These risks, as shown in the comparison with England and Sweden, occur in particular because the community service-structures for “ordinary” citizens do not consider people with disabilities. The overwhelming “complete-care” situation created by the service-providers has relieved the normal infrastructure of these services. As well as the legal right to equality there is often a complete separation of people with disabilities with regard to their rights as citizens in many services. Because of this development the community seems ill prepared for the task of actual integration.
- The sum of obstacles to change is greater than it seems at first glance in comparison with the support systems in the other countries in the

study. Hamburg has developed a relatively high-quality care and support system. The service-providers in disability support services are modern and forward-looking organisations. The structural obstacles, however, to turning this system upside down and making the support and needs of people with learning difficulties in their personal social and regional networks the starting point for granting support, seem to be very difficult to overcome. The examples of England and Sweden show that a very strong political will is necessary to bring together the interests of large service-providers and those who are responsible for the community with the aim of seeing and treating people with disabilities as truly equal members of the community with the right to participation. At the centre of any such process would be the step to give people with disabilities the right to decide about their support needs and be able to receive assistance independently of financial issues and service-providers. In Hamburg none of the necessary prerequisites and foundations for this focus are available. The contributions of the Swedish and English cooperation partners have shown which structures in Hamburg would need to be created to carry out such a development.

These judgements of the situation in Hamburg were created in close exchange with the European partners. They have led to recommendations for the further development of the support services for people with learning difficulties, which were discussed at the STEPS 2004 Conference in London with the European partners. They can be found in the report in Attachment 3.

5. The Impact of STEPS: Supporting Decentralisation Projects and Supporting the Community as it Rediscovered its Integration Tasks.

The STEPS project coincided with the closure of one of the larger residential parts of the Protestant Alsterdorf Foundation, the Karl Witte House. 168 residents were to be re-housed in various Hamburg districts. The management staff from the Protestant Alsterdorf Foundation who were

responsible for the organisation the re-housing and who used STEPS project and their international contacts intensively, wrote the following in an interim report: "In Sweden and in England the closure of institutions was determined by law and was demanded by the public. We had no such instructions, neither from the city authorities nor from our clients or their representatives. Quite the opposite: there were people who would have liked us to stay the way we were: a calculable household, a low point on the services scale or the last stop where we can allow people to disappear if they don't fit into the modern scale. (Birgit Schulz [ed.]: *Entschlossene Gesellschaft. Das Auszugsprojekt „Karl-Witte-Haus“*. Eine Dokumentation, [Determined Society. The Karl Witte House move project. A documentary]. Hamburg 2003, page 110). Through the contacts made during the STEPS project, important experiences for the course of this project were acquired (see Attachment 4.):

- Positive developments for the residents in such projects depend to a large degree on the willingness and the competence of the staff to guarantee clear links to the new districts from the outset.
- Through decentralisation and integration projects in the STEPS cooperation cities, the danger of transferring old exclusion structures into the new environment and the community is overcome by the appointment of new staff, who have not previously worked together with the residents.
- People who have spent long periods of time in institutions need advisory support and advocacy during such radical changes. These services were also organised by the Hamburg project.
- The advisory group of users makes it apparent not only how sophisticated and personal their interests and abilities are, but also their obstacles and insecurities with reference to life in the community. For this reason disabled people in further education were involved - also as trainers - and the contact between residents and disabled people with experience of living in the community was supported.
- In the project to close the Karl Witte House people who had previously lived in secure accommodation were also included. The experiences of

similar projects – particularly in England – were specially evaluated and transferred to the situation in Hamburg.

Various service-providing organisations have since had experience of decentralisation of this kind. These have been extended, qualified and professionalised through the results of STEPS and the experiences of colleagues in England and Sweden. The growing number of decentralisation activities carried out by the Hamburg service-providers is a way of focusing on the regional social sphere with regard to the greater integration of people with disabilities, in particularly people with learning difficulties.

This intention follows the Hamburg project in the context of the STEPS project, which is dedicated to the development of regional resources for people with learning difficulties to improve their participation in society. (Compare Attachment 5.) The Protestant Foundation Das Rauhe Haus and the Protestant Alsterdorf Foundation worked together during this project. It is, as a consequence of STEPS, a joint project between these service-providers. As well as staff from both foundations, foundation residents also took part. The project was concentrated on a region in Hamburg where between 25 and 40 people with learning difficulties use the services of the foundations. Here both the support and assistance needs of users and the community are analysed: the improvement of general community services, the acquisition of support from public figures, the organisations and supporters in the region, and specific publicity for the aims of the project. In particular the aim is to achieve the regular use of public leisure, culture and educational opportunities by disabled people in this region of Hamburg. The criteria for success or operationalisation of a good project ending are described as follows: the number of social contacts and the participation in public life, a growth of choices for people with disabilities, an increase in recognition through the population about the lives of disabled people in their community, an increase in knowledge of staff about “their” community, an increase in motivation to do community work and to cooperate, generally a growth in the staff competency in community-based services. Previous action and further plans can be found in Attachment 5.

A further example of how STEPS has brought the discussion on decentralisation and community orientation forward with much hard work is the debate about the move towards non-residential care in the context of the money-saving programme which the Rauhe Haus is currently considering with the well-known German expert Prof. Dr. Dr. Klaus Dörner, who held an advisory function during the first project phase of the Hamburg Partnership. According to him, the growing number of ill and elderly people in Europe hold the key, which will direct the specialisation and division of the support system towards community-orientated support systems. People with learning difficulties were integrated into this system and were supported by professionals during this emancipation process. In the context of the money-saving discussions it is possible that this positive process can have negative consequences: if people with learning difficulties give up their “special status” their quality of life would worsen if they were not to receive the necessary support for participation or network development. Another danger is the restriction of integration to those who can be cost-effectively integrated into the community. People who require a higher level of support would, according to this scenario, remain in large residential care, where their “care” can be achieved more cheaply. The letter to Senator Birgit Schnieber-Jastram (see Attachment 1.) is to be viewed in connection with this discussion.

The extension and professionalism of decentralisation projects and debates, supplemented by activities for the development of regional resources for people with learning difficulties, do not replace the necessary paradigm shift, but are suitable for preparing service-providers and the city for the fact that people with learning difficulties can and should demand their rights and their implementation.

6. Further Activities

In general, all members of the STEPS project in Hamburg are interested in and are trying to make the discussions and results of the STEPS project in Hamburg known. For example, the Rauhe Haus Foundation is currently producing the brochure “Not if, but how! Community care at the Rauhe Haus”

where the experiences of the STEPS project are also expressed. (see The Concept, Attachment 7.)

Both Foundations, Alsterdorf and the Rauhe Haus, will continue their cooperation, in particular the joint project, “the development of regional resources to enable people with learning difficulties to participate in community life” whose first phase should be completed in January 2005. Further cooperation projects, above all in the field of work and employment for people with learning difficulties are currently being discussed.

On a bilateral level, individual contacts with partners in the other STEPS partner cities are being maintained to examine specific questions and ideas in international exchange.

Both Hamburg Foundations have agreed to consider the demands of the advisory group of people with learning difficulties and to check whether their demands are being implemented. Furthermore, they have agreed to continue to support the international exchange between users and the activities of advocacy groups.

7. Available Documents

- Attachment 1. Letter to Senator Birgit Schieber-Jastram
- Attachment 2. Agreement of the Hamburg Partnership on further activities.
- Attachment 3. STEPS 2004 London. Observations and remarks from the Hamburg group.
- Attachment 4. Birgit Schulz: Supporting experiences from the STEPS project for our staff and management duties during the closure of the Karl Witte House.
- Attachment 5. Project from the Hamburg STEPS Partnership: “The development of regional resources to enable people with learning difficulties to participate in community life.”

- Attachment 6. Tüllmann
- Attachment 7. Concept from the brochure "Not if, but how! Community care at the Rauhe Haus.
- Minutes from the final evaluation meeting of the STEPS Partnership, group of authority and institution representatives.
- Michael Langhanky: closing remarks from the final evaluation meeting of the Hamburg STEPS Partnership.
- The Hamburg Partnership Internet page.
- Article (??)