

## **Activity report for**

### **Steps – Structures toward emancipation, participation and solidarity**

(Former title: “Neustrukturierung der Hilfen für Menschen mit geistiger Behinderung auf kommunaler und regionaler Ebene”)

**Reference Number:** VS/2001/0411

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## **1. Summary**

In Phase I “Steps” aimed to build a competent network of partners who have influence on structures, methods and instruments to increase participation and reduce discrimination of people with learning disabilities on a municipal level. Therefore in each partnership-city the responsible stakeholders in the social welfare administration, the main provider-institutions and a scientific link were installed as local partnerships, each will be advised by self advocacy-groups.

Thus “Steps” has established a stable network of 17 providers, administrations and universities in five countries. The network has achieved an agreement of trans-national cooperation based on the joint “starting points”, “perspectives” and “main objectives” of steps (see enclosure 4 of the trans-national cooperation agreement). Referring to these agreed papers, each local partnership developed a working plan and objectives on strategies, instruments and methods to reduce discrimination. These will be part of their contribution in phase II.

Thus a reliable and competent partnership to combat discrimination on the municipal level was established in each city with those partners who are really able to change the ways of access and participation for people with learning disabilities.

The International network and the local partnerships, both worked out clear objectives and working plans for phase II. They gained insights in the experiences and practices of the five involved European municipalities. Bilateral staff-exchanges and visits of people with learning disabilities – both exceeding “Steps”-programme in phase II – were established, several bilateral exchanges of best practices of providers and administrations took place.

## 2. Background of “Steps”

According to the UN-Standard rules on equalization of opportunities for people with disabilities and the EU-Charter of Civil Rights, people with learning disabilities should have the full right to participate in normal daily life. This has still not come into effect. People with learning disabilities are the most marginalized group in European Societies, they are not recognised as full citizens with the same corresponding rights, needs and wishes. They are discriminated in their access to material, cultural and social goods and resources of society and they are excluded from work.

People with learning disabilities who very dependant on social- and health-services are often colonized by a curative or medical approach. The services continue discrimination by providing systems of exclusion (institutional housing, sheltered workshops, etc.) and often withhold and deny rights. But there are hidden minorities of people with learning disabilities, that have no access to the social- and health-services at all and do not get appropriate support to help them claim for their rights (e.g. members of ethnic minorities in a cultural diverse society).

In this situation institutions, administrations and professional training institutes are struggling to improve quality of care and advocacy. Professionals have gained a lot of experience in de-centralising and restructuring services and are striving for a clear development towards valuing people as full citizens in the community. Approaches of Empowerment, self-advocacy or Community Care are being discussed and developed all over Europe.

A paradigm shift is necessary to combat discrimination of people with learning disabilities effectively. This means to putting their individual rights, wishes and needs into practice. Institutional systems, financial structures of services and legal regulations need to change to a person-centred approach. Methods, instruments and structures of advocacy have to be implemented to support people with learning disabilities, promoting their needs and wishes and increasing emancipation and participation in daily life. People with learning disabilities should decide about their life and be advocated in order to gain their individual rights and the access to the goods and resources of society.

In this context, the social services in Europe are facing two risks: the increasingly open market of service providers, which offers “low-budget-services”, and the risk of budget-cuts. The political context is marked by an ambivalence between the will to improve services in response to the individual rights, and the will to reduce costs in services. “Steps” has to keep the political and economic situation on the local, national and European level in mind.

### **3. Activities of the first Phase**

“Steps” – as an action research programme – focuses on structures, instruments and methods to combat discrimination. It collects European experiences and best practices to aim at full participation and free access to material, cultural and social resources (e.g. housing, leisure, work). The International network will develop extensive proposals to create and improve structures, instruments and methods within a joint understanding of the necessary shift of paradigm.

“Steps” established local partnerships with the social welfare administrations, providers and scientific links in the following five municipalities: London (Borough of Kensington/Chelsea) - Great Britain; Barcelona – Spain; Lidingö (near Stockholm) – Sweden; Rotterdam – Netherlands; Hamburg – Germany. The International Network is advised by a group of users and self advocacy-groups as well as by a group of professionals in the services.

All together “Steps” unites 17 institutions, organised in five autonomous municipal partnerships. All these institutions have a lot of influence on services and the daily living conditions of people with learning disabilities.

“Steps” conducted the following activities in phase I:

#### **International Network Building** (see point 2 – 5 of the Documentation)

All together seven bilateral meetings with possible partners and the project management took place (each two with Lidingö, Rotterdam and Barcelona, one with London). Members of the Hamburg partnership participated at each meeting. The project management presented the ideas and approaches of “Steps”, information about the systems of care were exchanged. Common and specific interests and questions, possible contributions and gains were worked out. Questions of cooperation and responsibilities were discussed, the coordinators of the local partnerships were decided on.

### **Partnership Building in Hamburg** (see point 6 of the Documentation)

Although competitors, two huge provider foundations, totalling 2000 service users in all, and the responsible administration have begun a new form of cooperation and partnership in “Steps”, in order to fight discrimination on a municipal level. In Phase I, this unique alliance was cemented through three meetings of the partnership, four visits to the partner-municipalities and the “1<sup>st</sup> Conference of the Hamburg Network”. A joint working plan was produced which aims for expert recommendations for Hamburg on restructuring the social services. The minister of social welfare and family opened the First International Network-Conference of “Steps” at the end of phase I. This shows how the Hamburg partnership gained influence and interest in the fight against discrimination in the city.

### **Meeting with people with learning disabilities** (see point 7 of the Documentation)

In separate meetings with

- ?? the users advisory-board of “Evangelische Stiftung Alsterdorf”
- ?? the users advisory-board of Foundation “Das Rauhe Haus”
- ?? self-advocacy group “Autonomous Living, Hamburg”
- ?? self-advocacy group “People first - the strong angels, Hamburg”.

a T-group<sup>1</sup> of people with learning disabilities was established which will evaluate the results of “Steps” during the whole process. Men and women, younger and old people, people working in sheltered workshop and people in day care are represented. Some of them are living in residential homes, others in shared homes or their own apartment. All participants are very interested in the ideas and objectives of the project. Eight meetings during the second phase have been agreed on. The results of the meetings will be integrated into the international Discussion of “Steps”.

In addition, each local partnership planned and prepared cooperation with people with learning disabilities just on the local level.

### **Meeting with staff members** (see point 8 of the Documentation)

To establish a T-group with professionals in the services, “Steps” organised the Day-Workshop “Development of Community based Services”. Besides the Foundation “Das Rauhe Haus”, the charity union “Diakonisches Werk” invited to the Workshop as well, in order to reach staff-members of other providers. Members of the training courses “subject orientation and assistance” at the University of Applied Sciences were invited too.

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<sup>1</sup> T-Group = Training-group in action research programmes

The one-day workshop was aimed at collecting ideas, visions, fears and claims of professionals working in the services. With the 50 participants challenges and ideas for community based services were discussed. The project management talked about “Steps” and invited participants to take part in an ongoing T-group. 25 people joined the group and will contribute their views and experiences to “Steps”.

### **First International Network-Conference in Hamburg** (see point 9 of the Documentation)

After bilateral meetings and discussions, the “First International Network-Conference” took place in January 2002 in Hamburg. All 17 institutions of the five municipal partnerships participated at the five days-Conference. With contributions and speeches from every partnership, the shared values, objectives and perspectives of “Steps” were discussed, institutions were visited and intensive discussions between the partners about their practice took place.

At the Conference the following agreements were concluded:

- Most of the 17 institutions signed the Trans-national cooperation agreement at the Conference (Some had to sign according to their institutional regulations at home).
- The papers “Starting points of Steps”, “Perspective for Steps” and “Main Objectives for steps” were worked out and agreed on as attachment 4 of the Trans-national cooperation agreement.
- The paper “Responsibilities and tasks in Steps” was agreed as attachment 3 of the cooperation agreement.
- A first design of the working schedule and the budget plan as attachment 2 of the cooperation agreement.
- The projects of the five municipal partnerships to be contributed to Phase II (see the working plans in the application form part III).

The joint commitment and involvement of the partners, the readiness for discussion and the atmosphere at the Conference was commented on by all partners as a very good basis for the International network.

### **Establishment of the local partnerships** (see application form part III)

Beginning with the aim of “Steps” to have reliable and responsible partnerships in all of the five cities, institutions and their professionals met, and with the help of the coordinators as key persons, five local partnerships were established. Links were strengthened through bilateral visits, discussions and involvement. At the International Conference, each

partnership agreed to contribute a special project to “Steps”. Ways to communicate locally were worked out. Main objectives for the local partnerships were agreed on. A working plan and a budget plan were agreed on. The Trans-national cooperation agreement was signed as a partnership.

The local projects are:

*Barcelona:* Analysis and practical recommendations ‘Civil rights of people with learning disabilities in the daily life’

*Lidingö:* Development and Implementation of “Seasonal meetings” as a future planning instrument

*London:* development of user centred services for people with learning disabilities

*Rotterdam:* ‘access to work’ - methodological evaluation and description of experiences in Rotterdam

*Hamburg:* Development of community based services and structures for Hamburg, design of experts recommendations for the local level

### **Establishing communication structures**

- Name, logo and corporate design of “Steps” were developed, implemented and published. The former title of the project was changed to “Steps – structures towards emancipation, participation and solidarity” and flyers were edited.
- Internal communication: To facilitate the exchanges of information, the project management created the “Steps newsletter” and the Steps-homepage ([www.rauheshaus.de/steps](http://www.rauheshaus.de/steps)). In addition countless emails were sent out to coordinate the network, the International Cooperation and the second application.
- External communication (see point 10 of the Documentation): “Steps” was presented in four publications of Hamburg institutions and will be presented in May in the “Tizard Learning Disability Review” (published in Brighton). The Project Management presented the project in two meetings of institutions and providers in Hamburg and announced the International Network Conference to the Press in Hamburg.
- All important documents were translated into Spanish.

#### **4. Evaluation** (see point 12 of the documentation)

The international network is in a constant process of evaluation and the results of the different meetings were brought into the ongoing process of “Steps” – (e.g. the papers, the programme of the International Conference and the application for phase II). After the International Conference, the first phase was evaluated on the basis of an evaluation questionnaire. The main results of the evaluation are:

##### **Cooperation in the trans-national network**

?? 17 partners from five countries with different systems, traditions, cultures and languages are cooperating in “Steps”. The International network is a big challenge; this became very apparent during the first phase. Strong project-management, clear communication and project structure, a high level of agreement and responsibility of the local coordinators and partnerships are required. The different interests and backgrounds have to be treated with sensitivity, and a common foundation of information and data have to be produced.

These principles are the key to the successful network building and were unanimously agreed on by the partners (see the trans-national cooperation agreement and point II.3.3. and IV. of the application form part III).

?? A ranking of municipalities and their care-standards must be avoided. In relation to different financial resources and different legal national situations, “Steps” has concentrated on the pro-active experiences and sees the diversity in the local partnerships as valuable (see as well point III.3.3. of the application form part III).

?? In phase II bilateral communication between partners in “Steps” has to be enforced. Partners with common questions and interests will further improve their relations through staff exchange, consultancy and transnational visits of people with learning disabilities. Administrations and providers have agreed to use “Steps” as a forum to connect more and they will also strengthen their bilateral relations on their own. This is seemed as a very positive effect of “Steps” in phase I. The first exchange between the Community in Lidingö and the Foundation “Das Rauhe Haus” in Hamburg will start in April.

### **Interests of the partners**

- ?? The partners in “Steps” are very committed to the objectives and the “vision” of the project. They have already experienced the international exchange in the first phase as a possibility to learn from other countries and they want to deepen the exchange of best practices.
- ?? The local partnerships see the cooperation on the local level as a basis for change and improvement of the services and structures in their municipalities. All partnerships are determined not to pass up this opportunity, as the projects on the local level show.
- ?? The autonomy of the local partnerships include the danger that they will get too involved much in specific questions, due to local circumstances and daily politics. The project management and the coordinators of the local partnerships as mediators have to take this in consideration (see point V. of the application). Ways of intergrating the experiences and results of the local projects into the international discussion are being developed.

### **Involvement of the people with learning disabilities**

- ?? According to the objectives and the “vision” of “Steps”, all partners have given the involvement of the people with learning disabilities high priority. Participation of people with learning disabilities in an international discussion is a big challenge. The danger is that the people will become an alibi. Thus the partners have decided to implement the involvement on a local level.
- ?? Each local partnership will involve people with learning disabilities in the local project. In comparison to the first application, this means an extension of participation in the project and shows a high commitment of the partners to combat discrimination.
- ?? Instead of the planned workshop with people with learning disabilities intensive discussions with four groups were held. All four groups agreed to work together as a joint evaluation T-group (see point 7. of the documentation).



## **Design of the project**

Although the Proposals for phase I were agreed on by all partners, they were written mainly from a German point of view. Thus had to be expanded to integrate the interests and approaches of the European partners and at the same time to be sharpened to keep a clear focus and not to overload the project or to stop on a general level. This was successfully managed in three ways:

- ?? Starting point for the project is the aim to combat discrimination and to improve emancipation, participation and solidarity. The partners decided to evaluate all proposed structures, instruments and methods by these criteria and the EU-Charter and the UN Standard-rules.
- ?? At the International Conference the starting points, perspective, objectives and activities were intensively discussed. The papers as the shared basis of the project and a working plan were agreed on (see the trans-national cooperation agreement).
- ?? In addition of the concept in the first application the local partnerships developed a specific questions or project reflections their interests and local situation. The International Conferences will be based on the experiences and results of these local projects.

## **Reasons for discrimination “Steps” focuses on**

In the first application, “Steps” had indicated discrimination on the grounds of disability as well as on the grounds of age. Because of the interests and knowledge of the partners the question of the double discrimination of people with learning disabilities from ethnic minorities gained weight. Thus “Steps” decided to concentrate on the discrimination on the grounds of disability and to focus on ethnic minorities and cultural diversity. We are convinced that the results of “Steps” are transferable for other discriminated groups, especially elderly people.

## **Expertise**

In the first application, the project management planned to publish expert-papers on the most important data about care for people with learning disabilities, the resources and legal regulations. Lots of information was collected and exchanged. Because of the intensive work on network building the project management had to put a systematic editing of the information. On hold the partners will work out the fundamental information at the beginning of Phase II (see the working plan).

## 5. Conclusions

As described above, “Steps” reached the following expected results in the first phase:

- Organisation of the International network and the local partnerships
- Establishment of the Evaluation- or T-groups with people with learning disabilities and with staff members
- Agreement on the objectives and activities, working- and budget-plan and the project structure

Participation of people with learning disabilities and the integration of the different interests of the partners are guaranteed. The question of how to organise a network with 17 partners is solved. A stable cooperation has been established.

In this process the course the Commissions support, information papers and meetings were very helpful: Putting the focus on partnership building showed the significance of a well planned and organised network for a project. We believe that we have already discussed questions and solved problems which otherwise would have caused problems later.