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Reference Number: VS/2002/0267

**Interim report for
STEPS – Structures toward emancipation, participation and solidarity**

Priority area addressed: The removal of discriminatory barriers to access goods and services, including housing, transport, culture, leisure and sport

Grounds of discrimination addressed: disability; (racial or ethnic origin)

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Transnational Partners:

London: Social Service Department of the Royal Borough of Kensington/Chelsea; Kensington & Chelsea Primary Care Trust, London; Tizard Centre, University on Kent, Canterbury.

Barcelona: Deputation of Barcelona, Social Services Department; Provider-Group "Aspronis"; Office for Non-discrimination, City of Barcelona; Foundation of Catalan Guardianship "Aspanias"; University of Barcelona, Institute of Educational Sciences.

Lidingö/Uppsala: City of Lidingö, Social Services for Elderly and Disabled; Social Disability Services; University of Uppsala.

Rotterdam: Foundation PameijerKeerkring; Hogeschool INHOLLAND Rotterdam, Unit of Social Work.

Hamburg: Ministry of Social Welfare and Family, Department of Rehabilitation; Protestant Foundation "Alsterdorf"; Foundation "Das Rauhe Haus"; HWP – Hamburg University of Economy and Politics; University of Applied Sciences for Social Work.



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Content of the STEPS interim report

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1. Background

According to the UN-Standard rules on equal opportunities for people with disabilities and the EU-Charter of Civil Rights, people with learning disabilities have to be recognised as equal members and citizens of society. They should be recognised as men and women, children, adults and seniors, members of specific cultures and different ethnic groups. Yet people with learning disabilities remain one of the most marginalised group in European society, experiencing multiple discrimination. As well as discrimination due to their learning disabilities, they are also discriminated against on grounds of gender, sexuality, ethnicity and age, and they are often not recognised as members of families or social networks. They are often still dependent on residential services and/or specialised services and have restricted access to material, cultural and social resources. They are very seldom presumed to have the ability to express themselves in work or leisure or in planning their own care and support.

In tackling de-institutionalisation and developing community care, service providing organisations, administrations and professional training institutes in Europe are struggling to improve the quality of care and advocacy. Professionals, service providers and users have gained experience in de-centralisation and restructuring and continue to work towards valuing people as full citizens in the community. They have experiences in diversity in the community and possible consequences of community care.

2. Goal and Objectives

The European action research programme STEPS has focused on structures, instruments and methods to combat discrimination against people with learning disabilities and to develop advocacy services. It is collecting European experiences and examples of best practice with the aim to encourage full participation and free access to materials, cultural and social resources, such as housing, leisure and work. The international network aims at structures towards emancipation, participation and solidarity.



Combating discrimination against people with learning disabilities requires a paradigm shift, putting individual rights, wishes and needs at the forefront of practice. Institutional systems, organisations and financial structures of services, and legal regulations need to be changed into a person-centred approach. Methods of advocacy have to be implemented to support people with learning disabilities to promote their needs and wishes and to increase emancipation and participation in daily life.

STEPS aims to find better solutions for advocacy services which are responsive to individual needs and to give expert recommendations to politicians with the collective understanding necessary to help effect the required paradigm shift. The international network focuses on three basic sociological dimensions of services: structures, finances and legal regulations.

In addition to European-level discussion, the five local partnerships carry out local projects according to their current needs and interests. Local development, improvement or implementation of a method, structure or instrument on the local level complete the discussion of examples and experiences. Local partnerships are seen as a precondition to changing the structures and implementing new methods and approaches.

Objectives

Comparative Framework

To facilitate meaningful comparisons and discussions in STEPS and to address some of the difficulties experienced in comparing terms and different systems the following devices are developed:

- ?? A “glossary” providing a linguistic basis.
- ?? “Key questions on service policy and organisation”.
- ?? Local project / partnership profiles.

Development of structures, instruments and methods towards emancipation, participation and solidarity

?? *Evaluation and publication of best practice:* Best practice with the various local partnerships and those to be developed in phase II are shared and evaluated within the Network.

?? *Local service-developments:* According to their interests and needs, each local partnership designed a project, working in co-operation with users and user-groups (For the concrete projects please see point 4.)

?? *Indicators for non-discriminative services* will be developed as quality measurements and planning instruments

?? In 2004 STEPS will summarise the experiences and ideas through *expert recommendations*, and will develop proposals for regulations in social services which support participation, emancipation and solidarity.

3. Methodology and Strategy

International Network of experts and persons responsible

The international network of STEPS is composed of five local partnerships in London, Barcelona, Lidingö (near Stockholm), Rotterdam and Hamburg. Each local partnership includes key persons and experts in the field of social services for people with learning disabilities: representatives of the local authorities/administrations, service providing organisations, scientific links. The partners are capable and have the influence to implement changes. International co-operation encouraged them to reflect their own standards, structures and instruments, as well as those of the others.

With the international network and the local partnerships STEPS intends to contribute to a growing trust of responsible municipal managers to find better solutions for user-oriented services in a municipal partnership.

Current cross-national exchange

In phase II of STEPS four international conferences take place, each in one of the partner-cities. The partners have the opportunity to visit the partner institutions and to learn about their daily practice. To share responsibility the Conference-programmes are prepared by the project management in co-operation with the local partnerships.

Between the Conferences intensive communication is continued by interactive use of Information and Communication Technology.



Co-operation on the local level

Each local partnership has agreed to develop, improve or implement a method, structure or instrument. These practices complete the discussion of examples and experiences. They are also first steps to implement new structures on the local level.

Integration of people with learning disabilities

To prevent that people with learning disabilities are given an alibi function in the international network we decided to build an evaluation group of service users in Hamburg - a permanent group of 15 people with learning disabilities work as a “T-group” or “Training-group” in the action-research. The group is informed about the outcome of discussions, monitors the process and formulates claims, concerns and issues. This advice are delivered as a regular feed back into the local partnerships and trans-national discussions. Further each local partnership co-operate with service-users.

Evaluation Meetings with professionals of social services

A second T-group of staff members monitors the STEPS-project. 15 professionals consult the STEPS network permanently and help to keep in touch with daily practice.

Collecting knowledge

By cross-national exchange and in local projects, European experiences and best practice are collected and the development of improved organisational structures, instruments and methods are advanced. The collection of knowledge is replenished by the comparative framework.

Formulation of “experts recommendations”

At the end of Phase II STEPS will summarise possible improvements of structures, legal and financial regulations in its “expert recommendations”. They will put forward proposals for social services which support participation, emancipation and solidarity. This forces the partnership to work purposeful.

Strong project-structure and high responsibility

The partners of STEPS have agreed on a strong project-structure and a high responsibility of the project-management and the local co-ordination. Principles for the STEPS-Network:



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- ?? identifiable project-management with clear responsibilities and central leadership (e.g. responsible for finances, employment of staff, international conferences, evaluation-meetings with the T-groups, documentation and reports, trans-national communication)
- ?? autonomous local partnerships with clear objectives, committed and reliable co-operation and acknowledged co-ordinators (in charge of local budgets, the working-schedules and communications on the local level and within the international network).

4. Activities, achievements and outcomes

?? CONFERENCES AND MEETINGS

In the first year of phase II two International STEPS-Conferences took place. (Please notice that the first International Conference took place in phase I in Hamburg.)

14th – 17th of November 2002: Second International Conference in Rotterdam, “Equal opportunities for people with learning disabilities”

At the 2nd Conference experiences and obstacles on the way to non-discriminative services were collected. Main issues were:

- What leads to discrimination? – practical experiences and knowledge about exclusion and discrimination/obstacles and traps on the way towards participation and solidarity
- Collection of experiences concerning best practices and innovations to combat discrimination.

Achievements and outcomes:

The documentation of the conference is published in a printed version and on CD). We would like to stress the following items:

- All 18 partner institutions were represented at the conference.
- The Conference was prepared by a discussion on E-mail/Internet, started in October 2004. Eight discussion papers from the different countries involved were published and discussed in advance of the conference.
- In spite of national/local differences the countries involved named the same main factors of discrimination as starting point of the discussion.



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- Accordingly essential need for action is seen unanimously in the following fields:
 - advocacy/self-advocacy according to human rights, necessary skills, structures and forms of implementation
 - integration in decision making process
 - Individual future planning methods
 - human rights/anti-discrimination policy
 - attitude of professionals and society
 - community living/living in the community
 - mainstreaming services
 - work/employment
 - For each item good practices are available as a useful basis for discussion and development of non-discriminative services.

15th – 17th of May 2003: Third International Conference in Lidingö, “Organisational Structures in learning disability services”

The Conference focussed on organisational structures which hinder or support non-discrimination in service provision and independent living of people with learning disabilities.

Main issues were:

- Macro-level in Service Structures: Mainstreaming, synergism or specialisation?
- Organisational architecture in services - foundations, cluster-trusts, holdings or whatever?
- Community Support, Community Living, living Community
- How to meet the needs of the people with learning disabilities?

Achievements and outcomes:

The documentation of the Conference will be published in Summer 2003. The following results we would like to highlight:

- 16 partner institutions were represented at the Conference, 2 were unable to come to their own regret.
- The Conference was in the public interest. The Swedish disability ombudsman for people with learning disabilities held the opening speech. The mayor of Lidingö and other politicians took part at the formal opening.



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- Concerning the structures of services for people with learning disabilities the different national backgrounds have become clearer. In fact, the differences between Germany, the Netherlands and Spain where big provider organisations dominate the services and England and Sweden where the services are provided within and by the community played an important part in the discussion. The question how different systems could guarantee quality in user-orientation, participation and integration was discussed controversially. At the same time unsolved problems - above all missing user-involvement in decision making and exclusion from the community - are the same in the different service systems.
 - Crucial aspects of service provision were worked out. Transversal and flexible service structures were detected as most useful to support user-oriented and non-discriminative services.
 - The participants agreed on strong advocacy as a key point in the service structures. Powerful human rights advocacy should be independent and legally safeguarded.
 - A vice versa high commitment made the exchange of opinion and expert-knowledge fruitful for the development of new structures. Joint recommendations will be published as a basis for the discussion at the 4th and 5th International Conference.

In the Context of international co-operation STEPS was invited at the **Trans-national Conference “Interactive use of ICT in projects promoting social inclusion” in Rome, 22nd – 25th of May 2003**. Klaus Buddeberg, responsible for the web site, presented STEPS at the Conference.

?? EVALUATION MEETINGS OF PEOPLE WITH LEARNING DISABILITIES

The following meetings took place in Hamburg:

- 15th of October 2002: presentation of STEPS; What does self-determination mean?; brain-storming concerning work, independent earnings; living and housing
- 27th of November 2002: How do the members of the evaluation-group live and what do they work? What are their claims, concerns and issues?
- 4th of February 2003: deepening of the question: What are their recommendations concerning services, their flexibility, complexity and person-centred awareness?
- 23rd of April 2003: Advocacy from the user’s point of view.



Achievements and outcomes:

Summaries of the meetings are available on the web site (www.eu-project-steps.de/hamburg/).

- The T-group of people with learning disabilities has made many useful suggestions which highly influence the work in STEPS. To mention only some proposals:
 - The people with learning disabilities want to participate in all levels of decision (persons, services, politics and policy).
 - They want to have the possibility to negotiate and complain about decisions.
 - Living units should have maximum five inhabitants.
 - Complexity in services and in decision making needs to be reduced.
 - The people with learning disabilities would like to co-operate with a “partial/biased” mediator to achieve their rights and wishes.
 - Education and vocational training need to be play a more important role.
 - The services need to guarantee flexible and person-centred support according to the needs and wishes of the people (instead of stiff categories according to service structures or legal regulations).
- As the users themselves the international network find it increasingly important to include people with learning disabilities. Thus for the Barcelona and the London Conference we are looking for appropriate forms to integrate the users and their voice (e.g. working with user experience and key studies, structured discussions and user-workshops etc.).
- The group has started to organise an international user-conference in connection with STEPS which will take place in spring 2004 in Hamburg.

?? EVALUATION MEETINGS WITH PROFESSIONALS OF SOCIAL SERVICES

The following meetings took place in Hamburg:

- 11th of December 2002: Presentation of STEPS, Support for people with learning disability in practice; Dichotomy between residential and non-residential care
- 26th of March 2003: Continuation residential vs. non-residential care; safety vs. uncertainty; self-determination vs. non-autonomy; flexibility vs. immovability; quality management; finances



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Achievements and outcomes:

Summaries will be available on the web site latest end of June.

- The T-group of staff members is very interested in experiences from other countries, the interest in international co-operation increases.
- The group has made a lot of useful suggestions, e.g. on advocacy and fulfilment of human rights, social regional budgets and personal budgets, which highly influence the work in STEPS. To mention only some proposals:
 - On the basis of their experiences the professionals would prefer independent counsellors and independent advocacy.
 - Quality management should be independent from the service providing organisations as well.
 - The T-group thinks about regional service structures in combination with regional budgets.
 - Sharp categories of support are seen as artificial distinction which become increasingly blurred.

?? PROJECTS OF THE LOCAL PARTNERSHIPS

The five local partnerships have developed the following local projects:

London/Canterbury: *Development of user centred services for people with learning disabilities*

Activities between September 2002 and May 2003:

- mapping the organisational location and components of Person Centred Planning (PCP) and the different ways users are involved in the process
- identifying aspects of discrimination in relation to PCP and service users and the role for advocacy
- mapping the organisational system and the relationships and structures between agencies
- organisational meetings
- evaluation of PCP with Kings College London

Further the London Partnership is engaged in the process of developing advocacy groups and quality networks, the integration of health and social care in the Borough of Kensington/Chelsea.



Barcelona: Analysis and practical recommendations *“Civil rights of people with learning disabilities in daily life”*.

The local partnership in Barcelona concentrate on evaluation of experiences in the Spanish advocacy (tutelar) system and of the municipal office of human rights in Barcelona in co-operation with service-users.

Lidingö/Uppsala: *Testing and implementing a method of personal future-planning called “seasonal meetings”*.

The user-centred method is developed and introduced in co-operation with users and staff in Lidingö. In spring the first “seasonal meetings” or “seasonal conversations” have taken place with very useful results. Discrimination in everyday life has been identified and activities have been started to counter the discrimination on the local level.

(Further information please find on the web site of the local project www.skinfaxe.se/steps)

Rotterdam: *“Access to work” - methodological evaluation and description of experiences in Rotterdam.*

- 29th of Nov. 2002; 6th of February: Meetings of the Steering Committee
- 4th of February, 18th of February; 4th of March; 25th of April; 13th of May: Meetings of the methodology-workgroup
- Three students of the INHOLLAND University are studying and observing persons with learning disabilities who work in the social firm OMIJ. An interim report is published in Dutch (enclosed in the report) and will be translated in English. The final report will be finished in autumn.

Hamburg: *Development of community based services and structures in Hamburg*

- 1st Workshop: 25th of October 2002: presentation of targets in the field of care for people with learning disability in role reversal between the local administration and the service providers
- 2nd Workshop: 17th of January 2002: presentation of the actual situation
- 3rd Workshop: 21st of February: Continuation of the discussion: Problems with Finances/finance system; Residential vs. non-residential care
- organisational/preparation meetings

The group has agreed on first statements about the development of community based services and structures.

(Further information please find on the web site of the local project www.eu-project-steps.de/hamburg/)

Achievements and Outcomes:

- In the partner cities concrete improvements of services are realised or planned in the context of the local projects.
- User involvement is realised in the local projects.
- Joint aspects of the local projects are: person centred planning methods; social regional budget and personal budget; advocacy methods and structures.
- Students in the partner universities have a gain from the project: E.g. in Rotterdam a group of students participate in the project workgroup. In Hamburg a seminar “Equal but different” were given.
- The partners hope to be politically strengthened in their community. E.g. due to the successful 3rd International Conference the social services for elderly and people with learning disabilities in Lidingö were in general interest.
- The co-operation on the local level has positive outcomes for the communication between the partners, e.g. due to the discussion in the Hamburg Partnership the foundation “Das Rauhe Haus” and the ministry of social welfare and family re-started communication after a long time in respect of content.
- Some bilateral co-operations have developed in consequence of STEPS: Between the Foundation “Das Rauhe Haus” and the City of Lidingö an exchange of users (summer 2003) and staff members (summer 2002) takes place.
Professionals and users of the Protestant Foundation Alsterdorf visits the Foundation PameijerKeerkring in June to learn about innovative work projects in Rotterdam.

COMPARATIVE FRAMEWORK

In March STEPS has started to prepare the ‘comparative framework’ to collect important data, knowledge and experiences. Responsible for the comparative framework are the academic leads in the local partnerships.

- 18th – 21st of March 2003: Preparation meeting in Canterbury (Paul Cambridge, Anne Ernst)
- Development and publication of ‘Information on the comparative Framework’, template for the glossary of key terms, comparative questions and standard partnership profiles; the English example (enclosed in the report)



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- Presentation of the Comparative Framework at the 3rd International Conference in Lidingö

Achievements and outcomes:

- In our opinion the lack of language skills and knowledge about the services in the different countries are main obstacles in international co-operation. At least at the international conferences the necessity of a shared linguistic basis and shared knowledge about the services in the five countries have become obvious. For example, the important distinction between residential and “ambulant” (non-residential or community) care in Germany is mostly unknown in other countries. Neither well known is as well the idea of Guardianship in Spain.
- Already the English glossary which was presented as an example at the Conference in Lidingö has been very helpful in understanding the presentations of the English colleagues. Thus all partnerships are highly committed to the idea and have promised their co-operation. We have agreed to publish the ‘Comparative framework’ in preparation of the Conference in Barcelona, November 2003.
- To gain greater benefit STEPS has agreed to exchange material with the EU-project “Idresnet -“European Intellectual Disability Research Network”, supported from the European Union Fifth Framework for Research and Development.

?? COMMUNICATION

To co-ordinate the STEPS-network intensive and professional communication is necessary. More than half of the work of the project management is communication:

- summary, translation and passing on issues and results to the different groups
- co-ordination of activities with the local partnerships
- personal contact with the partners to stay in touch.

Achievements and outcomes

Intensive communication helps to maintain commitment and engagement of the partners who are constantly and personally involved in the process. The partners contribute ideas and advice and take on responsibility for the project.

5. Recommendations to the Commission

- We would like to stress again the high importance of phase I for the international cooperation in STEPS. Intensive partnership building has been the basis for the intensive work in STEPS and the precondition that all partners keep on it. Both Conferences in Brussels was of great importance for the success for the project.
- As mentioned in the enclosed letter we have missed some E-mails from the commission (because of unknown reasons). We would like to suggest to make available letters, mails and documents for the projects on a web site (e.g. the site circa).
- According to our experiences we would like to recommend (above all for projects with many partners) a project structure with a strong project co-ordination and a clear leadership.
- The model of local partnerships is suitable to keep the partners involved continuously and to guarantee a visible gain for the local level as well.