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Reference Number: VS/2003/0260, Addendum No 1 to VS/2002/0267

STEPS – Structures towards emancipation, participation and solidarity

Final report for the second year 2003/2004

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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1. Background

According to the UN-Standard rules on Equal Opportunities for people with disabilities and the EU-Charter of Civil Rights and the European Union Disability Strategy, 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. However, people with learning disabilities remain one of the most marginalised groups 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. The diversity of the people with learning disabilities must be taken into account by the services.

People with learning disabilities 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 and individualised services, self-advocacy groups, service providing organisations, authorities and professional training institutes in Europe are struggling to improve self-determination and the participation of people with learning disabilities. Professionals, service-providing organisations and users have gained experience in de-centralisation and restructuring, and continue to work towards valuing people as full citizens in the community.

In the setting of money-saving policy and neo-liberal orientation in most European countries a roll back of discrimination and exclusion of people with learning disabilities is yet to be seen.

2. Goal and Objectives

The European action research programme STEPS focused on structures, tools and methods to combat discrimination against people with learning disabilities, and to develop person-centred and community-based services. It collected European experiences and examples of

good practice with the aim of encouraging full participation and free access to materials, cultural and social resources, such as housing, leisure, work and good health care.

Combating discrimination against people with learning disabilities requires a paradigm shift, putting human rights at the forefront of practice. Organisational and financial structures of services, and legal regulations need to be changed into a person-centred approach based on the individual's rights, wishes and needs. Advocacy and self-advocacy have to be fostered to increase emancipation and participation in daily life.

STEPS aimed to find better options for good quality services that promote choice and participation and to give expert recommendations to politicians and practitioners. In addition to European-level discussion, the five local partnerships carried out local projects according to their current needs and interests, which had great impact on the results of the project.

Objectives

Comparative Framework

Comparing social services and structures throughout Europe is a challenge, particularly in relation to potential transferability of experience between the different countries and the national and local systems. Furthermore, STEPS indicated the usage of a wide variety of terms and definitions across the five national and local contexts. 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 were developed:

- **Local project / partnership profiles** to enable a clear understanding of respective arrangements and relationships characterising each local partnership in STEPS.
- **Descriptive questions** covering local arrangements within the national context to provide a descriptive focus on a series of key organisational, policy and legal dimensions.
- **A glossary of terms and service typologies** to develop a shared vocabulary and language to aid mutual understanding and information exchange.

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

- *Evaluation and publication of good practice:* Good practice within the various local partnerships and those to be developed in Phase II was shared and evaluated within the international network.

- *Local service-developments*: According to their interests and needs, each local partnership aimed to design a project, working in co-operation with users and user-groups and professionals.
- *Standards for non-discriminative services* were developed in 2004 as quality measurements and planning instruments.
- In 2004, STEPS summarised its experiences and ideas through *expert recommendations*, and developed proposals for regulations in social services which support participation, emancipation and solidarity.

3. Project Evaluation

At the last STEPS Conference in London the STEPS members were asked to complete a comprehensive questionnaire to evaluate the STEPS anti-discrimination project. The questionnaire focused on the co-operation of the 18 organisations in STEPS, communication, organisation and the question of whether the project reached its objectives. It also asked about the participation of people with learning disabilities and staff members. Another aspect was a possible continuation of co-operation. The questionnaire also included 'closed' questions as well as 'open' questions. 22 persons from the five involved local partnerships completed the questionnaire.

The summary of the evaluation, written by Klaus Buddeberg, is attached to this report. In this report some results are mentioned in italic letters in the boxes.

4. Methodology and Strategy

International network of experts

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

Most of the STEPS-partners rated the profile of the international STEPS network as 'good' or 'very good'. They highlighted the inclusion of different service systems from the different countries and also the cooperation of different interest groups. Despite the high number of partners (18) a feeling of belonging developed in the group due to a high level of agreement between the involved organisations.

All partners felt that they had gained an increase of knowledge concerning social service systems, methods and tools to achieve non-discriminative services. All benefited from different perspectives and experienced similarities as well as differences between the countries. They improved competence in networking and intercultural communication.

Cross-national exchange

In Phase II of STEPS four international conferences took place, each in one of the partner-cities where the partners discussed strategies towards non-discriminative service structures and had the opportunity to visit the partner institutions and to learn about their daily life. To share responsibility the conference programmes were prepared by the project management in co-operation with the hosting local partnership.

Co-operation at local level

Each local partnership had agreed to develop, improve or implement a method, structure or tool within a local project. This method gave the partnership increased responsibility. They were the first steps towards the implementation of new structures at local level.

Advisory groups

In Hamburg, an advisory group of service users was formed, who worked as a "Training group" in the action research. In the group, both women and men, younger and older people as well as those who work on the ordinary labour market, in sheltered workshop or day care were represented. Some of them live in group homes, others in their own apartments.

The participants expressed ideas, demands and concerns concerning participation and self-determination, which were delivered as feedback into the local partnerships and trans-national discussions. Their comments and demands had a great impact on the International STEPS network and the Hamburg partnership.

A second advisory group of staff members in Hamburg monitored the STEPS project. Via the project management, the professionals were in permanent contact with the STEPS network and helped to keep in touch with daily practice. The results of the discussion were mirrored back into the international STEPS network.

Collecting knowledge

Through cross-national exchange in local projects, European experiences and good practice were collected and the development of improved organisational structures, instruments and methods have advanced (see Barcelona Conference). The comparison of the national service system in the frame of the comparative framework, which was published in 2004, the process of accumulating knowledge was improved.

Formulation of “Final Recommendations”

In 2004 STEPS summarised possible improvements of structures, legal and financial regulations in its “Final Recommendations”. The network aimed to find proposals for social services, which support participation, emancipation and solidarity. This forced the partnerships and the international network to work purposefully.

Clear project structure and high responsibility

The partners of STEPS had agreed on a clear project structure with a strong project management and local co-ordination responsibility. Important principles for the STEPS network were:

- Identifiable project management with clear responsibilities and central management (e.g. responsibility for finances, employment of staff, international conferences, evaluation meetings with the Training groups, documentation and reports and trans-national communication).
- Autonomous local partnerships with clear objectives, committed and reliable co-operation and acknowledged co-ordinators (in charge of local budgets, working schedules and communication at local level and within the international network).

82 percent of the STEPS-partners felt to have been sufficiently involved in the planning and decision-making process of STEPS, e.g. concerning working programmes, conference programmes and project results. Some partners pointed out that a large international project should be co-ordinated centrally to a large degree by the project management. Furthermore, the communication of the project management was commented upon positively.

The communication of the local partnerships between the international conferences was assessed as being difficult (whereas it was very good during the conferences).

More than 90 percent of the partners were satisfied with the consideration and integration of the local partnership interests. The local partnerships felt themselves well represented in the topics and issues of the project.

5. Activities, Achievements and Outcomes

• COMPARATIVE FRAMEWORK

The Comparative Framework is one of the most important results of STEPS. It was published as “Cambridge, P. and Ernst, A. (2004) A framework for comparing local and national service systems and arrangements for people with learning disabilities in Europe: the Experience of the STEPS Anti-discrimination project: Tizard Centre, University of Kent, Canterbury.”

To provide a descriptive focus on a series of key organisational, policy and legal dimensions each local partnership was asked to write a partnership profile and to answer descriptive questions on service policy and organisations. The resulting descriptions and themes addressed were directly relevant to the STEPS anti-discrimination focus as well as providing an interpretative baseline for comparing arrangements and experiences across the five STEPS partnerships. The following dimensions were taken into account:

- Devolution of responsibility
- Care markets
- Inter-agency working
- Service planning and development
- Access and eligibility
- Service models, mainstreaming and integration

- National Policies
- Advocacy and involvement
- Regulation and inspection
- Cost management arrangements
- Staff development and training

As a cross-national study with focus on anti-discrimination and learning disability, the document also provides some broader examples for comparison methodology and process in social policy.

A third element of the Comparative Framework is the glossary of terms and service typologies. It aimed to help with the development of a shared vocabulary and language in the field of social services for people with learning disabilities and to provide a reference tool to increase mutual understanding and promote information exchange and dialogue between the five partners. National terms and national definitions of the five countries/languages were integrated in one glossary.

It should be recognised that comparative work of this nature is part of an ongoing process of development. No single project can hope to achieve comparisons at all levels or across all domains or factors. Such comparisons should consequently be viewed as part of a wider European and international endeavour.

The partners agreed that intercultural communication was the biggest challenge in STEPS. The international network needed a shared terminology in the field of social services and well-documented and understandable information about the different service systems. Accordingly the Comparative Framework and the glossary were judged as the most important results of the project.

- **INTERNATIONAL STEPS CONFERENCES**

In the second year of Phase II two international STEPS conferences took place.

26th – 30th November 2003: Fourth International STEPS Conference in Barcelona, “Legal and Financial Regulations”

At the fourth conference, the international STEPS network took into account the ordinary and daily lives of people with learning disabilities in order to determine possible reasons for discrimination. The partners discussed good practice towards achieving participation, self-determination, as well as legal and financial equality.

The conference documentation is published and enclosed in this report (printed and CD-version). We would like to stress the following:

- 17 partner institutions were represented at the conference, the Hamburg Ministry of Social Welfare and Family was unable to attend.
- In preparation for the conference, each local partnership elaborated two case studies according to guidelines developed by the Barcelona partnership. The studies give an idea about the daily lives of people with learning disabilities and services in practice. Some studies describe good practice aiming to improve self-determination and participation.
- Each national working group commented on case studies from another country (e.g. Barcelona commented the Hamburg case studies, Lidingö commented the Rotterdam case studies etc.). The comments introduced the plenum discussion about good practice.
- The national partnerships gave an overview of the experience and results of the local partnerships during the first year of the project.
- We gained a comprehensive idea of the services in Barcelona by visiting services for people with complex needs, day centres and sheltered workshop and group homes for example.

As a result of the conference, the Barcelona partners felt strengthened to fight against discrimination and to improve participation opportunities as the conference was held in high regard by the organisations and authorities in Barcelona. The conference was opened by representatives of the City and the Deputation of Barcelona and the University of Barcelona. The Deputation of Barcelona invited the participants to an official conference dinner.

12th – 16th May 2004: Fifth International Conference in London, “STEPS – Final Recommendations. Human Rights and the Development of Person- Centred Services.”

As it was the last meeting of the international STEPS network, the London Conference focussed on the results of the project. The results were collected and discussed in different ways:

- Users, professionals and researches, who were involved in the local project in London, gave an impressive presentation about their positive experience with person-centred planning. STEPS recommends person-centred planning as one of the most important tools to strengthen the self-determination of people with learning disabilities.
- The local partnerships presented their national conclusions, derived from the experience of the local partnership and transferable to the European level. They were asked to report on methods and tools to realise non-discriminative and person-centred services for people with learning disabilities. Accordingly, the national partnerships had the possibility of establishing and stressing their own priorities.
- To summarise the different topics and issues in STEPS, the international network discussed and agreed on joint final recommendations, which were published in the document **“Improving the lives of people with learning disabilities. STEPS recommendations – structures, tools and methods to develop person-centred and community-based services”**. The paper does not include a complete theoretical model, but provides experience and references for good practice and encourages improvements and change of services.
- The results from the user advisory group and the professional advisory group were presented.
- Paul Cambridge and Anne Ernst presented results from the Comparative Framework.

17 partner institutions were represented at the conference, again the Hamburg Ministry of Social Welfare and Family was unable to attend. The conference took place at Kensington and Chelsea Town Hall and met significant political interest. The Mayor of Kensington & Chelsea and Mr. Michael Portillo M.P., welcomed the conference participants at a mayoral reception.

Conference documentation was published in September 2004 and is enclosed in the report (both printed and CD-version).

Nearly all members of the project took part in all international STEPS conferences. In their view the conferences were “well” or “very well” organised. The results of the conferences were important – of particular importance were the Lidingö Conference (May 2003) and the London Conference (May 2004).

• THE LOCAL PROJECTS

Each local partnership was engaged in a local project. They were the basis for the commitment and involvement of the partners: Focussed on their knowledge and interests, the projects linked STEPS with their everyday work. The results of the local projects are suited to practical work and enhance the involvement at local level. In the international network, the local projects provided experience and examples of good practice for non-discriminative services.

In the local projects, user involvement was most effectively implemented. People with learning disabilities were involved for example in developing person-centred planning methods and in carrying out research. They had a direct impact on strategies and devices at practical local level.

The local partnerships aimed to or actually implemented an improved method, tool or structure, which enhanced non-discriminative services in their community. Each partnership summarised its objectives, strategy and activities and outcomes in a local report. These are enclosed in the final report.

For all partners the local partnerships were the backbone of STEPS. Furthermore, the established and/or improved co-operation of organisations at local level was one of the most important practical effects of the project. The improvement of services during the course of the project was commented on positively by local partners: nine of the twenty-two partners judged the co-operation at local level as good or very good, nine as sufficient. Three persons were not satisfied with the co-operation at local level.

More than 80 percent said that they had gained from STEPS at the local level. Most partners want to continue the co-operation in the local partnership.

London / Canterbury: The Development of person-centred planning (PCP) in services for people with learning disabilities in Kensington and Chelsea.

The objective of the local project was the implementation of effective systems and arrangements for person-centred planning (PCP) for people with learning disabilities in the local area, which local agencies and professionals are committed to, in which service users play a determining role and in which process and final outcomes are achieved in relation to user participation, self-determination, user satisfaction and quality of life. This local development initiative is effectively part of the wider national implementation of PCP as part of the new national Learning Disability Strategy: Valuing People (Department of Health, 2001). In STEPS, PCP is also valued as one of the most effective methods for improving user-participation and self-determination.

The development and implementation of the PCP process is documented in different comprehensive papers and documents to disseminate experience and good practice.

The London partnership examined in particular the effects of culture, ethnicity, spirituality and sexuality (diversity) on access to services and service responses, including PCP. They also highlighted that health issues need to be promoted to support an independent and fulfilling lifestyle.

Extensive networking, joint commissioning and strong partnership building with local authorities and agencies, researchers, users and user groups were a crucial part of the project and are the best precondition to ensure the continuation of local activities.

Lidingö/Uppsala: Participation of the person in the forming of his/her everyday life: on seasonal conversations in housing and daily activities

The impact of the experience of the Swedish disability reform towards community-based services had a high impact on the international STEPS partners.

The term “Seasonal meetings” describes regular meetings which are held every four month with the user, his/her representative and a staff member. With the seasonal conversations the local partners focussed on methods, which give people with disabilities the opportunity to influence their own everyday life. Six people with learning disabilities took part in the project. Each person was interviewed four times during the first year of the project about housing and their daily activities. In the second year all of the participants were comprehensively interviewed to evaluate the project. The results are very positive, above all concerning the establishment of personal relations, knowledge about the wishes and needs of the person,

improvement of and influence on everyday life. The Swedish partners presented the seasonal conversations as a useful basis for a person-centred quality review of services. The report is enclosed in the final STEPS report.

Rotterdam: Work as a tool for integration and emancipation.

The local project in Rotterdam was carried out by the service-providing organisation PameijerKeerkring and the social firm OMIJ. Supervised by senior staff, students from the INHOLLAND University were involved in the local project in an exemplary manner as equal partners in the project.

The partnership is working on the integration of people with learning disabilities into the workforce of a social firm or the regular labour market. Their main activity in the second year was the development of the Handbook BART (INHOLLAND University, Stichting OMIJ, Maaskring group (2004): Handbook Bart: support, work, regulations and applications). The handbook offers employees and supervisors in the ordinary labour market, who are not trained in this field, a tool for working with people with learning disabilities. Social, intellectual and physical issues are addressed. The students were responsible for writing part of the Handbook Bart and participate in its update.

Through the local project, the Rotterdam partnership showed their strong and convincing commitment to a co-operation between the profit-making and the non-profit sector, for a comprehensive inclusion of people with learning disabilities in ordinary life and work. As this point of view was a the source of continuous challenges for the international partners, the Dutch partnership encouraged lively debate and offered methods and tools which could be used to improve the integration of people with learning disabilities.

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

The local partnership in Barcelona researched both quantitatively and qualitatively aspects of the civil rights of people with learning disabilities in daily life. Their research is based on questionnaires, interviews, and life histories, which seek a deeper knowledge of how civil rights are perceived, understood, taken into account or respected. The partnership focused in particular on the views and perceptions of people with learning disabilities, their families and people working with them. A report on the results of the research was published and is attached to this report.

In the second year of the project the partners concentrated on the elaboration of a leaflet in simple language addressed to different people and organisations involved in working with people with learning disabilities. It contains key ideas concerning the civil rights of people with learning disabilities with the aim of increasing awareness in society. The leaflet should be widely distributed.

In the international network, the Barcelona partnership emphasised the importance of seeing the daily life experience of people with learning disabilities from their perspective as well as the importance of making their voices heard. Their point of view was a useful addition to the discussion of systems and structures.

Hamburg: The development of community-based services in Hamburg

It was the objective of the Hamburg partners to develop community-based service structures in Hamburg to foster the reform of services at local level. Due to political changes in Hamburg, the Ministry for Social Welfare and Family withdrew from the project which could not be realised at a local level. Unfortunately the partners have recognised once again a stronger tendency towards the exclusion and discrimination of people with learning disabilities. For example, there is concern that the exclusion of people with high needs from community-based services will be systematically established. At the same time, the local government plans to end the integration of children with learning difficulties into mainstream school classes in favour of “special” school centres. In this context, STEPS was partly able to stimulate discussion about the restructuring and decentralisation of services and to offer proposals for a community-based service structure.

In 2003, the two main service providing organisations (das Rauhe Haus and the Alsterdorf Foundations) have intensified their co-operation and have started the project, “The development of community resources for the participation of people with learning disabilities in society”, in which both employees and users from both service-providing organisations are involved. Focused on one district of Hamburg, the project partners have examined firstly the support and assistance people with learning disabilities need to participate in society. Secondly, they document resources and services and try to win support and volunteers in the community. The first phase of the project will continue until January 2005. A progress report will be presented in October 2004.

- **MEETINGS OF THE USERS ADVISORY GROUP**

During the second year of STEPS, the users advisory group met in Hamburg four times. A report on their activities, achievements and outcomes is enclosed within this report.

The Advisory Group of People with Learning Disabilities has made many useful suggestions which have had a significant impact on the discussions in STEPS. The users' claims are reference points for all proposals and discussion. The group members were more than capable of speaking for themselves and addressed their own priorities. They highlighted, for example, exclusion in the field of education and further education and demanded integration in the first labour market.

The user advisory group agreed on a list of demands which covers the following items:

- Self-determination
- Money
- Education and work
- Housing
- Support

The list was presented at the International London Conference in May 2004, and the final meeting of the Hamburg partnership in August 2004. At the final Hamburg meeting, the Hamburg senate's co-ordinator for the equality of people with disabilities promised to publish the list of demands as a leaflet in simple language. The Hamburg provider organisations in STEPS promised to support further co-operation of the advisory group.

The users' advisory group is very committed to the project, which contributes to the empowerment and participation of people with learning disabilities in decision making. Its members acquire intercultural skills and experience in international co-operation.

From the beginning of the project, user participation was seen as a very important issue in STEPS. Seven of the twenty-two people questioned rated the level of participation of people with learning disabilities as "very good", nine as "adequate". Four partners were not satisfied with the level of user participation.

The participation was improved in the course of the project, which was mostly as a result of the International User Conference and the involvement of users at the Conferences in Barcelona and London.

Some partners criticised the fact that users did not take part regularly in all international conferences, even though this was a constant challenge.

The co-operation with service users in the local partnerships and the impact, which the advisory group had on the project was commented upon positively. All partners agree that user co-operation should continue.

- **THE INTERNATIONAL USER CONFERENCE “INDEPENDENT LIVING IN EUROPE”**

As a continuation of the Year of People with Disability, the Users Advisory Group organised the International User Conference, “Independent Living in Europe” in April 2004 in Hamburg. The conference was not part of the STEPS project, but a STEPS co-operation project, financed by different partners from STEPS and the foundation, “Aktion Mensch”. The user conference had greatest impact on the discussions in STEPS and also on the commitment of the project partners as the conference was judged as a very successful way of integrating people with learning disabilities in international projects and of empowering in general.

More than 50 participants – users and assistants - from Rotterdam, Lidingö, Barcelona and Hamburg took part. The objectives of the conference were to learn about daily lives (housing, work, leisure) and services for people with learning disabilities in the other countries. The participants wanted to get in contact with each other and to meet new friends.

After the first conference most of the users hoped to continue the international exchange. A second conference to be held in another country with the same participants is planned for next year. Interesting issues are in their opinion work and employment, de-institutionalisation in England and Sweden and advocacy/self-advocacy.

As a result of the conference a ‘photo album’ and a report in five languages were published. Both are attached to this report.

- **MEETINGS OF THE PROFESSIONALS ADVISORY GROUP**

The Professionals Advisory Group held four meetings and took part at the final meeting of the Hamburg partnership. It was their aim to reflect on main topics in the field of self-determination and participation of people with learning disabilities. A group representative took part in the International London Conference to present the results of the group, which are published in the policy paper concerning person-centred and community-based services, "Inhaltliche Ergebnisse der STEPS-Mitarbeitergruppe". The document and a report on the activities, achievements and outcomes are enclosed in this report.

The evaluation of the group process showed that the meetings and international contacts, which were established during the course of the project, had a positive effect on daily work. They brought new impulses and insights which improve the self-determination of people with learning disabilities in the services. Above all, they recommended the extension of the participation of staff and users in international projects.

Ten of the twenty-two members were "satisfied" or "very satisfied" with the level of participation of staff members in the project. Their crucial role as a driving force in the local partnerships and the importance of bi-lateral exchanges were emphasised.

Most partners agreed that professionals should be equal partners at international level to include their knowledge and to enable the results of STEPS to be anchored in local participative structures and services.

- **RECOMMENDATIONS OF STEPS**

As previously mentioned, the international STEPS network agreed on its final recommendations at the London Conference in May 2004. The document, "Improving the lives of people with learning disabilities. STEPS recommendations – structures, tools and methods to develop person-centred and community-based services" summarises the international discussion in the STEPS project and provides keywords and references for good practice and practical experience. It can be used as a pool of ideas and guidelines for non-discriminative services. The following topics are discussed:



- Social discriminatory practice
- National legal and policy frameworks
- Citizen and human rights perspectives
- Advocacy/self-advocacy
- Decision making/user involvement
- Needs assessment
- Person-centred planning
- Service systems/models
- Mainstreaming/specialised services
- Mixed economy/social care markets
- Service planning
- Funding/cost management arrangements
- Quality assurance
- Service providing organisations
- Organisation and leadership
- Integration in work
- Education and further education
- Workforce development

The recommendations of the international network are made complete through the recommendations of local partnerships and the advisory groups. Attached to this report are the following documents:

- Recommendations of the local partnership Lidingö/Uppsala
- Observations on PCP from the London partnership
- Observations and remarks from the Hamburg group
- Demands of the user advisory group
- Inhaltliche Ergebnisse der STEPS-Mitarbeitergruppe



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- **SEMINAR “SELF-DETERMINATION AND PARTICIPATION OF PEOPLE WITH LEARNING DISABILITIES”**

In Hamburg, Anne Ernst gave a series of lectures on “Self-determination and participation of people with learning disabilities” at the University of Applied Sciences for Social Work in Summer 2004. A seminar programme is attached to this report.

The students gained an overview of the theoretical discussion about terms and approaches to discrimination, participation and self-determination etc., international and national human rights and anti-discrimination legislation, and the local and international activities of the STEPS project. The students took part in the International User Conference “Independent Living in Hamburg” in April 2004, which was in their view a very impressive and important experience.

The seminar met with good resonance: Two students focussed on the seminar in their final oral exams. One student plans to do a period of work experience in Lidingö/Sweden. Another student hopes to find a work placement in London.

- **PARTICIPATION AT CONFERENCES**

On behalf of STEPS, members of the project management took part in various national and international conferences. For example:

8th September 2003 in Brussels: **“Session with the Phase II Promoters – Trans-national Actions to Combat Discrimination - Community Action Programme to Combat Discrimination (2001-2006)”**: Anne Ernst took part on behalf of the project management.

19th September 2003 in Dortmund: Together with the users Oliver Millies, Oliver Schmidt and Karl-Heinz Ahlbeck, Anne Ernst, took part in the **Congress “Wir wollen mehr als nur dabei sein! Menschen mit Behinderung und ihr Recht auf Teilhabe”**, organised by the Bundesvereinigung Lebenshilfe and the University of Dortmund. Anne Ernst contributed the presentation „Mitstimmen statt Mitbestimmen”.

16th – 21st January 2004 in Mumbai, India: Anne Ernst took part in the **World Social Forum**.



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16. April 2004 in Hamburg: Congress „**Mitten im Leben! Kinder und Jugendliche mit Behinderung im Gemeinwesen**“, organised by the Foundation Das Rauhe Haus. Anne Ernst held one of the introductory speeches about services for children with learning disabilities in Sweden (document “Ansatzpunkte aus der Kinder- und Jugendbetreuung in Schweden”)

5th – 6th July 2004 in Prague: Anne Ernst took part in the **Annual Conference of the Community Action Programme to Combat Discrimination: “Equal rights in an enlarged Union”**.

The majority of the partners said that their expectations in the STEPS project have been met by up to 75 or 100 percent. More than three quarters were of the opinion that the objectives of STEPS have been realised by up to 75 or 100 percent.

The most challenging problems to tackle were communication problems and the understanding of the complex service system in the other countries. Sometimes competition between countries and services can hardly be avoided.

In the view of the partners, the most important results of the project were:

- *Learning from the others, sharing experiences*
- *Establishing productive cross-national links*
- *Joint action towards emancipation, participation and solidarity*
- *Comparing the differences between the countries*
- *Transfer of good practice*
- *Strengthening national co-operation*
- *Reflection about discrimination*

The partners were asked whether they would like to continue the STEPS project. 68 percent answered ‘Yes’, 14 percent answered ‘No’.

Our priority for the future would be to focus on the creation of common European positions and proposals for non-discriminative services for people with learning disabilities or to focus on aspects of work as a tool for social inclusion or the importance of self-advocacy.



6. Products

Enclosed in the report are the following documents:

Overall view on the STEPS-website: www.eu-project-steps.de.

The website remains online next year.

Users' advisory group:

- Report on the users' advisory group.
- Demands of the users' advisory group (German/English).
- The Photo album and report from the International User Conference "Independent Living in Europe" in Hamburg, April 2004.
- The website of the User Conference: www.user-conference.de.

Professionals' advisory group:

- The report on the professionals' advisory group.
- The document "Inhaltliche Ergebnisse der STEPS-Mitarbeitergruppe".

Local partnership London/Canterbury:

- The report on the local project in London/Canterbury 2004.
- Observations on PCP from the London partnership.
- Paul Cambridge: STEPS 2 Outline Proposal. An Idea for Developing the EU Funded STEPS Project into a New Second Phase, May 2004.

Local partnership Upsala/Lidingö:

- The final report "Influencing one's everyday life: On seasonal conversations in disability services".
- The document "EU-project STEPS/Lidingö: activities and timeline."
- Website www.skinfaxe.se/steps/.

Local partnership Rotterdam:

- Final report on the local project of the Rotterdam STEPS trialogue, August 2004.
- INOLLAND University, Stichting OMIJ, Maaskring group (2004): Handbook Bart: support, work, regulations, and applications.



Local partnership Barcelona:

- Final report on the local partnership Barcelona.
- Report “Discrimination for Reasons of Disability, STEPS 2003
- Leaflet “Iguales en dignidad y en derechos” (Spanish/Catalan)

Local partnership Hamburg:

- Final report on the local partnership Hamburg.
- Observations and remarks of the Hamburg group, May 2004.
- Website www.eu-project-steps.de/hamburg.

International STEPS-network:

- “Cambridge, P. and Ernst, A. (2004) A framework for comparing local and national service systems and arrangements for people with learning disabilities in Europe: the Experience of the STEPS Anti-discrimination project: Tizard Centre, University of Kent, Canterbury.”
- The Documentation of the 4th International Conference in Barcelona in printed version and on CD.
- The Documentation of the 5th International Conference in London in printed version and on CD.
- The document, “Improving the lives of people with learning disabilities. STEPS recommendations – structures, tools and methods to develop person-centred and community-based services”, May 2004.

Project Management

- Klaus Buddeberg: Evaluation of the STEPS project, August 2004.
- Newsletter No 13, “Reports on the local projects, information about the promoters-meeting in Brussels” (published 16th September 2003) and Newsletter No. 14, “The Annual Conference “ Equal rights in an Enlarged Union in Prague (published 12. July 2004)
- An overview on the STEPS web-site (www.eu-project-steps.de).
- Leaflet “STEPS – Structures towards emancipation, participation and solidarity”
- Anne Ernst: Programme of the seminar “Self-determination and participation of people with learning disabilities”, in Hamburg, Summer 2004.

- Anne Ernst: Presentation “Ansatzpunkte aus der Kinder- und Jugendbetreuung in Schweden”, April 2004.

7. Continuation of the activities

The partners are considering continuing activities in the following ways:

Paul Cambridge from the Tizard Institute, University of Kent, has designed **a possible second phase of STEPS**, which might provide the opportunity to continue with collaboration. He is in contact about this with different partners from the STEPS network and is looking for funding.

In particular, STEPS 2 would aim at the exchange of learning and development in the field of anti-discrimination, social inclusion and learning disability between the ‘Old’ and the ‘New’ European states. Please find attached to this report the “STEPS 2 outline proposal”.

The involved partners in the **International User Conference** are planning a second User Conference with the same group of people in one of the other cities in STEPS. The users are highly interested in a second meeting.

From the project management, Michael Langhanky and Dorothee Bittscheidt are considering publishing a **STEPS anthology** in Spring 2005. It should contain the most informative and innovative essays and presentations from the STEPS partners concerning best practice of person-centred and community-based services. Originally funds for this publication should have been applied for during a third phase of the trans-national actions.

Bi-lateral co-operation will be continued. The Rotterdam partners for example have established a very good working relationship with the STEPS partners in Hamburg. An exchange of staff and experience is being set up as a bi-lateral project.

All local partnerships will continue to **co-operation on the local level** to enhance the activities in the field of non-discrimination, but also in other fields of action.



As PCP had become a central policy objective and a mainstream policy instrument for helping developed user-centred services, the *London/Canterbury partnership* will continue implementation and improvement of PCP processes. They will continue their efforts to involve service users at the individual level in their own PCPs and to a greater degree at the general level in self-advocacy, service processes and decision-making.

The *Lidingö partnership* will present the results from the local project in Lidingö to those who have not been directly involved in the project and on national conferences. The results of the project will surely have an influence on further research projects by the Swedish partners.

The *Rotterdam partnership* will continue its co-operation to improve and implement the Handbook 'Bart'. It has recently been introduced to the social firm OMIJ. From November 2004, the staff will be trained according to the methods described in the book. Together with INHOLLAND students, the personnel department intends to update the Handbook.

As a result of their experience at the Hamburg User Conference in April 2004, the partners plan to support user advisory boards at the organisational level of services. The aim is to strengthen users' influence on services.

The local project of the *Hamburg partnership* "The development of community resources for the participation of people with learning disabilities in society" will initially be continued until January 2005. Further local projects, primarily in the fields of work and employment, are planned.

The foundations Alsterdorf and Das Rauhe Haus promise to ascertain whether the demands of the user advisory group are being realised at local level.

8. Recommendations to the Commission

At the end of Phase II of the trans-national action we would like to stress again the high impact Phase I had on STEPS. The intensive networking was a reliable basis for the intensive work and the precondition that all partners remained “on board”. The conferences in Brussels and the communication with the commission were of great importance for the success of the proposals and the project.

With regard to the structure of the STEPS project, which was established during the first phase of the project, we would like to highlight once again the following issues:

- The local partnerships in STEPS, with their different interest groups and the practically orientated local projects were the backbone of STEPS.
- We would recommend the inclusion of users and professionals as equal partners in international projects.

In the second phase of the project, the STEPS project management and all partners gained significantly from the meeting of trans-national action promoters and the Annual Conference of the Community Action Programme in Prague, July 2004. We saw the brochures about the community action programme as useful information about activities and priorities of the European Commission.

At the same time we would have appreciated more reliable communication with the EC concerning trans-national action in general and the STEPS project in detail. With regard to the contents of the project, we would have liked to receive feedback on the activities and the products of STEPS to get an idea of whether or not the expectations of the EC were met. (Some Ministries in Germany use for example standardised evaluation sheets to give the funded projects feedback.)

With reference to the evaluation of the trans-national action, which was carried out by Ernest & Young, we would have liked to have received comprehensive information about its orientation and the evaluation process. Some of the partners suddenly received a e long questionnaire via email, which was difficult to complete. Most of our partners refused to answer the questions.



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As far as we know, possible results of the evaluation were not distributed. We only found one sentence in the Green Paper “Equality and non-discrimination in an enlarged European Union” (May 2004) that “the broader impact of these projects and their relevance for the future development of anti-discrimination policies at EU and national level remains questionable in some cases” (p.24), which might be connected with the evaluation.

We have linked this to the withdrawal of a possible Phase III of the trans-national action. Even if we agree in general with the Commission’s priority to implement non-discrimination legislation, we regret that the results of the trans-national projects have not been distributed.

We would have appreciated a platform for the trans-national projects in the Community Action Programme to combat discrimination, to exchange information, to establish contact with each other and to distribute results and papers.

In order to distribute the reports and publications at the end of Phase II, a joint platform would be useful for all trans-national projects and other interested persons.

Hamburg, October 2004