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Report on the STEPS users advisory group

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Background:

STEPS recognized the need for a strong and dedicated group of users from the involved services for people with learning disabilities to act as a continuous forum to advise the project management and to monitor and evaluate the outcome of “STEPS”. Thus a group of 13 service-users with learning disabilities met regularly during the STEPS project. The group-members were mainly users of two service-providers in Hamburg: five women and seven men from various age groups with different levels of disability and in different biographical situations. This group was highly committed to STEPS and very productive as a result of these three aspects.

Objectives:

The main objectives of the group were to discuss:

- crucial points of discrimination, conditions of housing, work and leisure and to relay their demands, concerns and problems back to the STEPS management
- the development of STEPS’ achievements and the integration of their wishes in the STEPS-process.
- quality of services and options to improve them according to users’ needs

Methodology and Strategy:

During the second phase the group co-ordinators, realised that the group-members were more than capable of speaking for themselves and we learned to adapt to their forms of discussion, time management and forms of expression. Thus we could leave strategies and methods of advocacy and worked together to



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- brainstorm about concerns and needs;
- reflect on demands towards improving services;
- discuss difficulties in bringing about improvements and their ambivalences;
- plan and organise the User Conference “Independent Living in Europe”;
- assign responsibilities during the conference and to
- evaluate STEPS

Description of the activities in the user-group in Phase II:

During Phase II of STEPS, four meetings were held. Each meeting had a theme, decided on during the previous meeting and included a STEPS report, and conclusions to be implemented in STEPS.

07.10.2003 Leisure time and holiday
09.12.2003 social network, living and housing
27.01.2004 Education and further education
19.10.2004 Meeting with the Hamburg Partnership: Evaluation of the STEPS-Project

In march 2004, the user-group met twice to prepare the International User Conference “Independent Living in Europe”. Furthermore they had an evaluation meeting for the User Conference in Mai 2004.

Achievements and Outcomes:

The users represented in the group helped the project management to keep a close eye on the everyday living conditions of people with learning disabilities and showed in different ways, that priorities in STEPS had to be adjusted:

- STEPS was initially very focused on service-provider structures and thus concentrated on housing and financing as well as community-based services. The users’ advice was not to overlook aspects of exclusion which were more important in their view, such as exclusion from education, cultural opportunities and work, which means exclusion from income and fair wages.



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- STEPS held five international conferences with experts from service-provider organisations, universities and social welfare authorities but did not plan to hold a users conference. The advisory group demanded an International User Conference: "Independent Living in Europe". The Conference took place in February 2004 in Hamburg. It was initiated and supported by STEPS but was an independent project launched by this group. Thanks to the involvement of all the group members the conference was very successful.
- STEPS often discussed methods and best practices of quality management in service provision. The users advisory group set up a list of demands and claims, which were accepted as quality standards by the German provider-organisations involved in STEPS. They are published to be disseminated and implemented in these organisations with the support of the Hamburg Co-ordinator for equality of people with disabilities.
- The users group demanded for a continuous exchange of users knowledge in Europe and forced to implement a second International User Conference of users in 2005.
- The group asked to support the structures of self-advocacy in Germany and ended in a consultation whether the group members and the members of user-boards in provider-organisations should gather in a "people first group".

This demands-list shows some of the ways in which users' claims supported and changed the focus of the International STEPS network. Their claims had a significant influence and impact at the national level (the Hamburg partnership) and also at international level. Their clear and sometimes revealing statements presented a challenge during the whole process. We wrote in the first report on Phase II that we were looking for adequate forms of ensuring the participation of users in international cooperation. We believe that STEPS has finally implemented a suitable way of enabling their participation within two modules:

- The international user meeting on independent living
- The consultation boards at national level

At the end of STEPS Phase II a third element of participation and significant influence was launched:

In August 2004, a national conference of STEPS took place in Hamburg, where the users – advisory- group, staff advisory-group, provider-organisation management, the social welfare authority and the project-management took part. This was the first time in STEPS, where the users advisory-group stood in direct contact with the management of service-provider



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organisations. This meeting was a great success: The users managed to present their claims in such a way that they were accepted by all professionals as quality standards in service provision. The management promised to implement these demands as inner-institutional benchmarks of participation and non-discrimination. (see: Demands of the STEPS advisory group of people with learning disabilities)

Products developed and available:

- Minutes of the users meetings.
- Demands of the user advisory-group.
- 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.

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