

STEPS – Structures towards emancipation, participation and solidarity:

A European project to combat discrimination against people with learning disabilities

Abstract

People with learning disabilities are one of the most marginalized groups in European society, rarely recognised as full citizens with equal rights. The European action research programme “STEPS” focuses on structures, instruments and methods to combat the discrimination of people with learning disabilities and aims at full participation and free access to material, cultural and social resources. Partnerships between providers, social welfare administrations, universities, groups of people with learning disabilities in five European countries define the project. From England, the Tizard Centre, Parkside NHS Trust, and Kensington and Chelsea Social Services are partner members in the network with the overall project financed by the EU community action programme to combat discrimination.

Introduction

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 marginalized 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 have restricted access to material, cultural and social resources and they are often not presumed to have the ability to express themselves in work or leisure or in planning their own care and support.

People with learning disabilities who depend on social and health care services are often subject to medical models of care and treatment. Services tended to be segregated and providing a collection of functions from shelter to minimising risk, therefore tending to reinforce discrimination and exclusion.

In tackling de-institutionalisation and developing community care, services organisations, administrations and professional training institutes in Europe are struggling to improve the quality of care and advocacy. Professionals and service users have gained experience in de-centralisation and restructuring and continuing to work towards valuing people as full citizens in the community. Structures and law have changed and are still changing and philosophies such as empowerment and self-advocacy have developed. In Britain for example the government outlined their policy to “provide new opportunities for children and adults with learning disabilities and their families to live full and independent lives as part of their local communities” in the White paper “Valuing people” (Department of Health, 2001).

However, social services in Europe are facing two risks: the increasingly open market of service providers, risking low-budget and cost-led services, and the wider risk of budget cuts. The political context is marked by an ambivalence between the will to improve services in response to the emphasis on individual rights, and pressures to reduce the costs of services. The political and economic situation on the local, national and European level has therefore to be kept in mind.

The European action research programme “Steps” has focused on structures, instruments and methods to combat discrimination of 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. “Steps” was initiated by Dorothee Bittscheidt, president of the HWP – Hamburg University for Economics and Politics, and Michael Langhanky, Professor at the University of Applied Sciences for Social Work, Hamburg – who are the project leaders of “Steps”.

The EU “programme to combat discrimination financed the project for a first half year (October 2001 – March 2002)”. In this starting phase the “Steps”-partners established a reliable and competent European Network with local partnerships in five member states. In total, 17 providers, administrations and universities are members of “Steps”, consulted by a group of people with learning disabilities and a group of professional staff.

For a second phase of the project, September 2002 – August 2004, the cross-national co-operation, objectives and activities were agreed at the “First International Network-Conference of Steps” in January 2002 in Hamburg. The application for the second phase

was submitted to the European Commission, Employment and Social Affairs DG, with a funding decision for phase 2 expected in June.

This paper provides an overview of the idea, partners, objectives and activities of “Steps” project to date.

The idea of Steps

Combating the discrimination of people with learning disabilities requires a paradigm shift. Placing individual rights, wishes and needs at the forefront of practice. Institutional systems, organisations and financial structures of services, and legal regulations need to change to 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.

This requires participation and autonomy to be put before control, and the right to take risks in life as important as protection. People with learning disabilities should be able to decide on important aspects of their lives and services, including housing support, work and leisure, either through individual empowerment or participation or with advocacy support. A priority should consequently be given to individual life planning, person centred planning and advocacy. To guarantee free access to the goods and resources of society, systems approaches as “care in the community” and “community care”, need to be put into practice. Ways of assistance, in partnership with service organisations and providers, with regional, local and individual systems and resources, should be developed.

“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. By cross-national exchange, European experiences and best practice is being collected and the development of improved organisational structures, instruments and methods will be advanced. The International network will focus on three basic sociological dimensions of services: structures, finances and legal regulations, answering the following questions:

- What organisational settings and structures have to be established to combat discrimination and to improve inclusion of people with learning disabilities?
- What legal regulations are suitable to support advocacy services?
- What financial structures in social services have to be installed?

In addition to the European-level discussion, the five local partnerships will carry out local projects according to their interest and current needs. The development, improvement or

implementation of a method, structure or instrument on the local level will complete the discussion of examples and experiences. Local partnerships are seen as a precondition to changing the structures and implementing new methods and approaches.

Systems and processes are rarely gender-neutral. In “Steps”, developed, approved and recommended methods, instruments and structures will be examined in relation to their implications for gender. For example, attention will be paid to the differences in access to social, cultural and material goods between men and women with learning disabilities. Special attention will be paid to exclusion of women through double discrimination. Another issue is the individual right to sexuality, with people with learning disabilities being safe from sexual abuse and being free to express their sexuality. A third dimension is discrimination on the grounds of ethnicity. People with learning disabilities who are members of minority ethnic groups are frequently excluded by services and support systems in European societies as services have been slow to develop and provide cultural competent support. Ethnic-diversity and multi-culturalism is needed in many European communities but often missing from support services for people with learning disabilities.

The partners in “Steps”

“Steps” intends to collect experiences in Europe through local partnerships of experts involved in reforming and restructuring social services in the countries involved. The established International network in “Steps” includes five autonomous European city-partnerships in the following municipalities: *London/Canterbury* (Borough of Kensington/Chelsea) - Great Britain; *Barcelona* – Spain; *Lidingö/Uppsala* (near Stockholm) – Sweden; *Rotterdam* – Netherlands; *Hamburg* – Germany.

Each local partnership includes the key-stakeholders in the field of social services for people with learning disabilities: administration, carers and providers and scientific research links - each consulted by a group of users and self advocacy groups. The partners are in the position to reform the organisation of social services in a way that assists with emancipation and participation, combating discrimination in access to social, cultural and material resources. They can also promote independence and raise local standards, using indicators for non-discriminative assistance. All institutions are known as innovative in their field in the national contexts.

Partners in Steps are:

London: Social Service Department of the Royal Borough of Kensington/Chelsea (senior manager Hector Medora); NHS - Parkside National Health Trust (manager Zenobia Nadirshaw, Steve Carnaby); Tizard Centre, University of Kent, Canterbury (Senior Lecturer Paul Cambridge, Lecturer Steve Carnaby).

Barcelona: Deputation of Barcelona, Social Services Department (manager Assumpció Pulido); Provider-Group “Aspronis” (manager Francesc Durá); Office for Non-discrimination, City of Barcelona (manager Guadalupe Pulido); Foundation of Catalan Guardianship “Aspanias” (senior-manager Josep Tresserras); University of Barcelona, Institute of Educational Sciences (lecturer Isabel Paula).

Lidingö/Uppsala: City of Lidingö, Social Services for Elderly and Disabled (finance-manager Adriana Buzea) and Social Disability Services (manager Kerstin Lundberg); University of Uppsala (lecturer Kent Ericsson).

Rotterdam: Foundation Pameijer Keerkring (manager Peter van der Hoeven and project manager Bart Branderhorst); Ichthus-Hogeschool, Unit of Social Work (dean Susana Menéndez).

Hamburg: Ministry of Social Welfare and Family, Department of Rehabilitation (senior manager Renate Kurt-Petersen, senior officer for European social affairs Monika Offermann); Foundation “Alsterdorf” (senior manager Wolfgang Kraft, manager Theodorus Maas); Foundation “Das Rauhe Haus” (senior manager Dietrich Sattler, manager Michael Tüllmann); HWP – Hamburg University of Economy and Politics (president Dorothee Bittscheidt); University of Applied Sciences for Social Work (professor Michael Langhanky, project manager Anne Ernst).

Integration of people with learning disabilities

Changing structures is considered as a participative process according to the individual needs, wishes and aspirations of people with learning disabilities. Proposals for improved structures, methods and instruments shall be evaluated by people with learning disabilities as well as by professionals in the local partnerships. The participation of people with learning disabilities in an international project with sociological and political issues requires qualified preparation, translation and assistance. Thus, “Steps” decided to build an evaluation group of users in Hamburg, working as a “T-group” or training -group in the action-research - a group of stakeholders who are informed about the outcome of discussions, who monitor process and progress and advise on concerns and issues. In this T-group, women and men and older

people with learning disabilities, as well as those with more severe disabilities will be represented. There will be people who work in sheltered work, people who have regular work or who have no access to work, people in residential care, married people in private housing and people supported in therapeutic living units. It is a mixed group, supported by professional assistance of the self-advocacy group "Autonomous Living". In addition the local partnerships will work in co-operation with users, such as to develop user centred services or future planning methods locally.

A second T-group was established with staff-professionals from different providers in Hamburg. 25 people joined the group and will contribute their views and experiences to the cross-national discussion in "Steps".

Objectives of Steps

In STEPS different municipalities with different cultural backgrounds, social welfare systems and traditions in social work are working together to improve, shape and change services for people with learning disabilities to reduce discrimination and exclusion. The partners from London/Canterbury, Barcelona, Lidingö/Uppsala, Rotterdam and Hamburg want to develop ways to aid emancipation, participation and solidarity, through joining the perspectives of providers, administrators and researchers. The differences between structures, backgrounds, services and institutions provide an opportunity to share experiences, best practice and also difficulties. Each local partnership will have different priorities within the overall objective, contributing in its own unique way. For the second two-year-phase of the project the partners have agreed the following main objectives.

Comparative Analysis

Comparing social services, structures and data about learning disabilities throughout Europe is difficult. Another challenge for the trans-national dialogue is the different terms and their definitions in use describing systems, organisations and learning disability itself. The project will establish the necessary basis for further international discussion in order to be able to understand the issues properly.

- A *"glossary"* will be developed as the linguistic basis for the exchange of information between the five countries involved covering the most important terms in the field of services for people with learning disabilities.
- To combat discrimination it is crucial to know how social and economic background relates to the exclusion and discrimination of people with learning disabilities, and "Steps" will share *knowledge on the reasons for discrimination*.

- The *Collection and comparison of the most important data and information on national practice on human rights* and existing advocacy systems will help to improve inclusion and community development.

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 during Phase II will be shared and evaluated through the Network. Financial service-structures, legal regulations and institutional settings of services will be included. Attention will be paid to independent advocacy arrangements, which safeguard individuals' rights.
- *Local developments:* Depending on their interest and needs, each local partner designed a project for Phase II, working in co-operation with users and user-groups. The following projects have been agreed:

Barcelona: Analysis and practical recommendations "*Civil rights of people with learning disabilities in daily life*". With qualitative research, the civil rights of people with learning disabilities will be analysed. Practical recommendations will be made to help ensure that the civil rights of people with learning disabilities will be effectively developed.

Lidingö/Uppsala: *Testing and implementing a method of personal future-planing called "seasonal meetings"*, which intends to increase the involvement of people with learning disabilities and their representatives in the support process.

London/Canterbury: *Development of user centred services for people with learning disabilities.* The partnership will examine the introduction and evaluation of person centred planning in Kensington and Chelsea in London within the overall policy framework *Valuing People: a New Strategy for Learning Disability for the 21st Century* (Department of Health, 2001).

Rotterdam: "*Access to work*" - *methodological evaluation and description of experiences in Rotterdam.* The Foundation "PameijerKeerkring" placed 75 service users in the social firm OMIJ Rijnmond. They are employed and trained with other people distanced from the labour market, for example in shops and a laundry in the community. The experiences will be described and training methods developed.

Hamburg: *Development and edition of expert recommendations to restructure social services in Hamburg.* The partnership aims to produce concrete proposals for helping political progress for the development of "community based services and structures" and an advocacy system of person-centred support.

In addition,

- *Indicators for non-discriminative services* will be developed as quality measurements and planning instruments, and there will be *proposals at the European level* about developing personal budgets and advocacy. At the end of the project “Steps” will summarise the experiences and ideas through expert recommendations, and put forward proposals for regulations in social services which support participation, emancipation and solidarity.

The second phase of “Steps” is scheduled to start in September 2002, dependent on EU funds, and will last two years. Four International Conferences are planned in the two years of the project under the themes: “Reasons for discrimination” (Rotterdam), “Organisation development” (Lidingö), “Legal regulations” (Barcelona) and “Financial regulations” (London). The outcome will be evaluated by the T-groups of people with learning disabilities and professional staff.

The success of “Steps” will depend on good communication and information exchange and the partners in Steps will concentrate on developing transferable lessons and knowledge. For a possible third phase of the project “Steps” may explore the possibility of publishing a manual against the discrimination of people with learning disabilities.

Expected results

- A linguistic basis for the exchange of information across the five partner countries
- Shared knowledge about the reasons for the discrimination of people with learning disabilities
- Indicators and a set of crucial data about human rights, advocacy, inclusion and community development
- Evaluation and publication of best practice, experiences and the reform process
- Quality control methods that can be used throughout the EU
- Policy, methods and strategies for the participation of people with learning disabilities
- Proposals for legislative steps with regard to finance, organisation and the implementation of advocacy.