The European Newsletter
of (ex-) Users and Survivors of Psychiatry

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Special issue

Action project to combat discrimination

Harassment and discrimination faced by people with psychosocial disability in health services. A European survey

The Newsletter of The European Network of (ex-) Users and Survivors of Psychiatry

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Content

Editorial

Dear friends,
In this special issue of the ENUSP newsletter we give you some information about a project of the European Commission, ENUSP is participating.

We want to encourage you to support your national organisations in the phase 2, in case the European Commission will agree to the application of the participating organisations with leadership of Mental Health Europe. And we want to encourage you to make own programmes to combat harassment and discrimination in all fields, especially in the health field and in the psychiatric sector. Previous ENUSP newsletters can be found on our website: www.enusp.org/documents/newsletter.htm
Many thanks for your ongoing support.

Peter Lehmann
Newsletter-editor and Secretary of ENUSP

P.S.
I changed my personal minutes from the third partner meeting into the minutes of MHE. Meanwhile the German organisation BPE stood in for the French FNAP Psy.

From BMJ.COM The general medical journal website

Research literature on harassment and discrimination experienced by people in health and in mental health care is scarce. However, testimonies of (ex-)patients and case reports such as presented by Kmietowicz, Z. (2002)(1) indicate a need for a better understanding of this phenomenon and of ways to prevent and tackle this. In addition, the activities of several mental health associations and professional bodies and some authoritative reports (2) acknowledge the need and encourage to develop non discrimination policies within health care.

Currently Mental Health Europe is developing a European Action Programme on harassment and discrimination faced by people with psycho-social disabilities in health care. Goal of the project is to collect evidences of discrimination, to raise awareness and to develop preventive and anticipating strategies. The project is developed in close collaboration with national partner organisations in the U.K., the Netherlands, France, Spain and Austria, who are actually organising Focus Group meetings with users and ex-users. After this a new serie of Focus Groups will involve care givers as well. Other partners in the project are the ENUSP (European Network of (ex-)Users and Survivors of Psychiatry) and the LUCAS Research Institute of the University of Leuven. In addition the project will look at the way the users movement and the mental health care are organised and will make an inventory of existing non discrimination provisions. The results will be compiled in a report ally with recommendations for good practices, and will be disseminated to everyone interested.

Karl Andriessen, Project Co-ordinator MHE

References:

1) Kmietowicz, Z. (2002). Trust criticised for locking up mental health patients. BMJ; 325: 1262 (30 November)

2) Royal College of Psychiatrists, Royal College of Physicians of London, British Medical Association (2001). Mental illness: stigmatisation and discrimination within the medical profession. CR91, February 2001. London.

Karl Andriessen, Project Co-ordinator
Mental Health Europe

Source:

http://bmj.bmjjournals.com/cgi/eletters/325/7375/1262/c

EVALUATION OF THE PROJECT - YEAR 1

Summary of the project Phase I and prospect of Phase II and III

FRAMEWORK

The action project on **'Harassment and discrimination faced by people with mental health problems in the field of health services'** is organised in the framework of the Community Action Programme to combat discrimination 2001-2006.

Action projects organised in this framework have to be developed in three phases.

- **PHASE I – preparatory phase**: the applicants selected have a budget and 6 months to develop the programme and methodology of their action project.
- **PHASE II – co-operation phase**: the selection for the phase II was made on the basis of a new application. It was foreseen that 30 projects would be selected. The budget for this phase will be 175,000 Euro/year.
- **PHASE III – dissemination phase**: the most interesting projects will be selected and they will have a 6 months period and an additional budget to disseminate the results.

Mental Health Europe (MHE) action project on **'Harassment and discrimination faced by people with mental health problems in the field of health services'** was selected for the PHASE I of the programme. In collaboration with Pro Mente Salzburg and the European Network of (ex-)Users and Survivors of Psychiatry, MHE has developed further the methodology and the planning of activities that will be undertaken within the action project. Other organisations have joined the initial partners: Mind (UK), LUCAS Institute (B), Cliëntenbond (NL), FEAFES (E), FNAP Psy (F).

The project was then presented for funding for PHASE II to the European Commission at the end of March 2002.

We describe below in general terms the aims, the methodology and expected results of the action project at the end of PHASE I.

AIMS

The project aims through a European partnership of European/national/regional organisations to collect information on discrimination against people with mental

health problems in health services (both general health care and mental health services) and on strategies to tackle this kind of discrimination.

While everybody has the right to health care, discrimination towards people with mental illness may take different forms – hostility, degrading jokes and remarks about the problem of the people, disbelief, to violence such as involuntary treatment, seclusion or even sexual assault – and take place at several levels:

- Access to services (hospital, dentist care, rehabilitation centre, emergency service, etc)
- Information
- Type of treatment
- Attitudes
- Access to health profession
- Dfference level of funding between somatic and psychiatric health care services

The main focus of the project will be on the discrimination faced by people with mental health problems. However as it has been reported that older persons, people from ethnic minorities or even women can suffer from double discrimination, this aspect will also be taken into consideration.

Mental Health Europe considers that the problem can be best overcome by:

- Advocacy and empowerment of people with mental health problems and their organisations
- Dissemination of information and raising awareness about the evidence of discrimination towards public health professionals and policy makers
- Ensuring that public health professionals receive during their training information about the needs of people with mental health problems (training the trainers)
- Introduce collaboration and dialogue between mental health services and health services in order to help mental health care providers to work constructively with health services to reduce fear and oppression

OBJECTIVES

The objectives of the project are:

- To increase the understanding of the phenomenon to break the huge taboo associated with this problem.
- To increase awareness about the phenomenon towards public health professionals, policy makers and service users.
- To propose strategies to tackle the problem to public health professionals and policy makers.

PARTNERSHIP [1]

- European Network of (ex-) Users and Survivors of Psychiatry (ENUSP)
- Pro Mente Austria – represented by Pro Mente Salzburg
- Cliëntenbond (NL) - an (ex-)users organisation
- FEAFES (E) – a family organisation
- Mind (UK) – a National mental health association
- FNAP Psy (F) – an (ex-)users organisation
- LUCAS Institute (B) – a research and training institute
- Mental Health Europe (MHE)

In the development of the action project co-operation will be sought with:

- Health professionals’ organisations at national/regional and European level (e.g. European Standing Committee of Nurses, European Standing Committee of Doctors, European Hospital Federation)
- National/Regional authorities

METHODOLOGY

In the project application there are 3 objectives to be reached:

1) To collect information and hard discrimination facts on the basis of different types of indicators of stigma and discrimination (service related indicators, self rating of users and relatives, legal provisions, establishment of interested groups).
2) To identify strategies to combat discrimination against people with mental

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[1] Description of the partners are in annex

health problems within general health care and mental health services.

3) To disseminate and raise awareness about strategies to overcome discrimination against people with mental health problems within general health care services.

Step 1 – to collect information on discrimination facts (September 2002 – January 2003)

To increase knowledge of discrimination different indicators of stigma and discrimination will be envisaged:

- self rating of (ex-)users and relatives regarding experienced and perceived discrimination
- legal non discrimination provision concerning people with mental health problems
- the resources available for mental health care
- the way the users movement is organised in each country involved in the action project (e.g. self-help groups, advocacy groups).

In order to collect this information different types of methodology will be developed.

Step 1.a: self rating of (ex-)users and relatives regarding discrimination

To collect information on discrimination facts at national level, National Partners will organise 'Focus Group' meetings, involving both certain at-risk groups and experiences from different settings.

A 'Focus Group' is a group of 8-10 key people concerned by a specific issue – in this case (ex-)users and family members. 'Focus Group meetings' are kind of brainstorming meetings organised around specific topics. There is a facilitator to ease the discussion and a secretary to take note of the content of the discussion. Meetings should not be longer than 2 hours.

It is recommended that the people invited to these Focus Group meetings are in a majority (ex-)users of mental health services.

Mental Health Europe is assuming that certain group of people are more at risk to be in contact with general health care services: people with anorexia, people with self-harm, people who have suicide behaviour, people who suffer of psycho-somatic disease, etc. These groups of people should certainly be involved in the Focus Groups as well as other groups, e.g. people with schizophrenia, people with depression, etc.

National Partners will organise four meetings to envisage the cases of discrimination in mental health care and in general health care including emergency services in general hospitals.

It is important that each issue is envisaged separately in order to avoid that one area overwhelms the other. So two Focus Groups should be organised on (inpatient) psychiatric care and on general health care respectively. Focus Groups meetings could be organised in 2 different cities in order to cover different social/cultural contexts.

In addition, the National Partners can decide to hold more private interviews if necessary to collect the evidences.

In January 2003, National Partners will report on their finding using an agreed framework of report.

Therefore MHE and LUCAS will develop guidelines to organise Focus Group meetings and to report on the content of the meetings.

Step 1.b – to analyse the legal non-discrimination provisions

LUCAS will describe the situation in term of non-discrimination provisions (international, European and national legislation) concerning people with mental health problems in each country involved in the project.

This work will be based on an analysis of different sources, e.g. previous studies and projects of MHE and other disability NGOs, European Commission's documents, selected national Ministries.

If necessary the findings will be completed by relevant interviews.

Step 1.c – to describe the services available for mental health care

MHE will collect information about the way mental health services are organised through contact with relevant key people from its member organisations, the HEALLO group (Health Lobbying Group), existing WHO report and contacts with the National Partners and LUCAS.

Several variables will be looked at: accessibility to out patient care, reduction of mental health beds, increased community based mental health services, but also the allocation of resources to mental health services in comparison to resources available to somatic health care.

Step 1.d – to describe the way the users movement is organised

ENUSP will describe the situation of the users movement in each country through its own network. Will be taken into account the establishment of interested NGOs, users organisations, relatives' organisations and other NGOs dealing with mental health issues.
LUCAS and MHE will develop guidelines for the collection and subsequent description.

Step 2 – to identify strategies to combat discrimination against people with mental health problems (February 2003 – May 2003)

We expect that this step will highlight the most relevant strategies to combat discrimination of people with mental health problems in health care services.

MHE believes that mental health organisations and (ex-)users/relatives organisations should work in collaboration with health professionals in this phase of the action project. It is necessary **to establish dialogue** between these groups in order to find projects that implement strategies to combat the discrimination. Developing strategies without the involvement of health professionals would not be effective enough.
LUCAS will draft guidelines to identify best practice strategies to reduce and combat discrimination. These guidelines should be agreed upon before starting the Step 2 of the PHASE II of the project.
MHE and LUCAS will draft a reporting format, which the National Partners will use to describe the projects and corresponding strategies to combat discrimination.
Bearing in mind the evaluation of the actual Action Project on Harassment and discrimination MHE suggests that before the identification of projects, the partners should adopt **a set of effectiveness criteria**, e.g. project evaluation, involvement of end-users, well-documented project, project sustainable.
At national level, National partners will be asked **to identify projects and corresponding strategies** corresponding to the guidelines adopted. To realise this NP will be asked to:

- to take contact with representative and committed health professionals
- to describe the existing strategies using an agreed reporting format (February 2003)
- to compose a Focus Group involving health professionals, mental health professionals, users and family members
- to organise 3 Focus Group meetings with them to identify strategies (from February on)
- to report the existing strategies using an agrees reporting format (May 2003)

Additional interviews can be necessary to collect the relevant information.

Step 3 – to raise awareness about discrimination faced by people with mental health problems in health care services and ways to overcome it

MHE has identified different target groups that should be reached at national and European level:

- disability organisations
- (ex-)users and relatives organisations
- health professionals
- politicians and decision makers

Step 3.a – action towards disability organisations

Too often discrimination faced by people with mental health problems is under-evaluated in the disability movement as well. Therefore it is important to use the framework of the European Year of Disabled People (2003) to disseminate information about the project and the fact that people with mental health problems are also discriminated as well as disabled people.
The disability movement is supporting the adopting of a disability specific non-discrimination directive and the results of this project could support this plea.
Mental Health Europe and its partners will raise the visibility of the project and raise awareness about its outcomes (discrimination evidences and strategies to combat discrimination). Possible strategies are:

- participating in European Year of Disabled People conferences/seminars/meetings and present the project and its various developments
- disseminating information about the project and its various development within Newsletters and web sites
- organising a European seminar for representatives from European Parliament and Commission, Mental Health NGOs, Disability NGOs, Health organisations –

HEALLO, HOPE, Standing Committee of Doctors, Standing Committee of Nurses, etc. This seminar will be organised by Mental Health Europe in collaboration with its partners.

Step 3.b – action towards (ex-)users and relatives organisations

Through the Focus Groups mental health organisations (e.g., users and family organisations) will be directly involved in the implementation of the project. This will already increase awareness with them.
Communication about the project will also be developed via MHE and its partners Newsletters and web sites.
The results of the project will also be summarised in a **booklet or poster** that should support (ex-)users and their relatives to advocate their right to non-discriminatory health care.
This booklet or poster will be made available to (ex-)users and family organisations at national level via the National Partners and at European level via Mental Health Europe and the European Network of (ex-)Users and Survivors of Psychiatry.
National Partners will organise **national seminars** for approximately 50 participants where the results of the project will be presented. National users and relatives organisations will be invited to attend as well as national health professionals' organisations, national disability organisations and national decision-makers.
Furthermore these organisation will be invited to participate in the **European seminar** (see above).

Step 3.c – action towards health professionals

Health professionals will be involved in the implementation of the project through Focus Groups and Mental Health Europe expects that this already will raise the visibility of the project and its results.
In addition, MHE and its partners would like to **develop a training programme** for the health professionals that could be implemented in the PHASE III of the action project if the project is selected for further dissemination by the European Commission or through a new application to a LEONARDO programme.
Health organisations will also be invited to participate in the National seminars and the European seminar (see above).

Step 3.d – action towards politicians and decision makers

What Mental Health Europe and its partners have learned from the project in terms of discrimination and strategies will be summarised in **Recommendations** that will be disseminated at national level via the National Partners (specific contacts and national seminars) and at European level via Mental Health Europe and the European Network of (ex-)Users and Survivors of Psychiatry (specific contacts and European seminar).
Decision-makers and politicians will also be invited to participate in the National seminars and the European seminar (see above).

EVALUATION

Evaluation will be at two levels:

- at the level of the co-operation between the partners of the project and
- at the level of the strategies to combat discrimination.

Evaluation of the co-operation
LUCAS Institute will work at the evaluation of the transnational co-operation. As LUCAS is a partner of the project, it will be an internal evaluation. The evaluation of the transnational aspect of the European action project on 'Harassment and discrimination faced by people with psychosocial disability in health services: a European survey' will include the following tasks:

1. Monitoring of the work done at European level (attainment of the objectives, accomplished tasks, implemented measures, etc.) as set in the project proposal.
2. Assessment of each partners experiences concerning the co-operation for the project (quality of communication, material produced, methodology, possible follow up impacts, etc.)

The assessment of each partner experiences concerning the co-operation will be performed through a questionnaire drafted by LUCAS for the purpose of the project.
The monitoring of the work done at European level will be done through the participation in the European meetings and the assessment of the reports and work produced.

Evaluation of the strategies
In the methodology of work we have mentioned that the partners will adopt a set of quality criteria

to select strategies and practices to combat discrimination in health services.
Mental Health Europe, LUCAS and ENUSP will draft a proposal for a set of quality criteria that will be discussed and adopted at the second European co-ordination meeting foreseen beginning February 2003.
LUCAS will also draft a matrix to identify strategies for different target groups.
Based on the list of criteria and the matrix the national partners will identify, describe and select examples of good practices and strategies to combat discrimination, in collaboration with reference groups composed of health professionals, (ex-)users and survivors and family members.
In May 2003, at the third European co-ordination meeting, the partners will have an opportunity to report on the strategies selected, described and identified as the most interesting ones. This will be a group discussion and decision.
This phase of the evaluation is also intern to the group.

Annex – description of the partners

- Mental Health Europe – is the leading organisation. Mental Health Europe is a European non governmental organisation committed to: the promotion of positive mental health, the prevention of mental distress, the improvement of care, advocacy, the protection of human rights of (ex-)users of mental health services, patients of psychiatric hospitals, their families, and carers. Mental Health Europe's values are based on co-operation and collaboration, dignity and respect, equal opportunities, freedom of choice and democracy.
  Created in 1985 as the Regional Council of the World Federation for Mental Health it had in 2001 about 70 Member Organisations and 50 Individual Members all over Europe and all EU Member States. The Secretariat of MHE is based in Brussels. Mental Health Europe publishes a monthly Newsletter in English and French and has a web site: http://www.mhe-sme.org
- European Network of (ex-) Users and Survivors of Psychiatry (ENUSP) – is a European organisation gathering (ex-)users and survivors of mental health services all over Europe. The European Network of (ex-)Users and Survivors of Psychiatry is an initiative to give (ex-)users and survivors of psychiatric services a means to communicate, to exchange opinions, views and experiences in order to support each other in the personal, political and social struggle against expulsion, injustice and stigma in our respective countries. Involvement of both user and survivor organisations from all over Europe (including the countries of Central and Eastern Europe and the New Independent States) is a unique added value of the Network. His history goes back to 1990 but it is a legally recognised organisation since 1998. The Network gives priority to the following areas: (a) Act against any kind of discrimination in society (both inside and outside the mental health care system) of people who have been subject to the psychiatric system; (b) Support development of (ex-)user/survivor groups throughout Europe (with a particular emphasis on those countries where there are no existing organisations); (c) Create and support new alternatives to the psychiatric system and collect and share information on the existing ones; and (d) Influence and try to change present treatment in psychiatry.
  At present the Network has more than 40 member organisations from more than 20 European countries. Through the membership of the member organisations the Network represents several ten thousands of (ex-) users/survivors from all over Europe.
  The Network has a web site: http://www.enusp.org
- Pro Mente Salzburg (A) – is a mental health organisation providing services to people with psychosocial disability (e.g. work rehabilitation, housing rehabilitation, crisis centre, workshops). Pro Mente Salzburg is the regional organisation of the national organisation Pro Mente Austria which is present all over Austria (15 regional associations). Pro Mente Austria was founded in 1976. They have a web site: http://promentesalzburg.at.
- Cliëntenbond (NL) (Client Union) – is a (ex-)users and survivors organisation with about 2000 members all over the Netherlands (15 regional departments). In the Clients Union people with similar experiences in mental health care meet. The Union works for the interest of (ex-) mental health care clients and tries to improve their situation. Throughout the country there are departments and workgroups. In most districts a major activity is mutual support. On an "inloopavond" or "drop-in-evening" you can join for a chat and a cup of coffee. The workgroups focus on a particular aspect of psychiatry or have a

supporting function. The Cliëntenbond has a web site: http://www.clientenbond.nl and publishes a magazine Bulletin called "Onderste Boven" which is published 4 times per year.

- FEAFES (E) – a national organisation gathering relatives of people with psychosocial disability. It represents 100 associations of families or 25.000 families all over Spain. FEAFES has already been associated to a project to fight stigmatisation of schizophrenia co-ordinated by the World Psychiatric Association entitled ‘Open the door’. They publish a magazine four times a year: “Encuentro”.
- Mind (UK) – a national mental health association. It exists since 1946. Mind has also a (ex-)users and survivors network called Mindlink. Both will be involved in the project. Mind is active in England and Wales. Their areas of interest are: mental health promotion, human rights, women’s issues, education/training, ethnic minorities, refugees, etc. Mind works for a better life for everyone with experience of mental distress. They have a web site: http://www.mind.org.uk and publish a magazine “OpenMind” every two months.
- FNAP PSY (F) – is the National Federation of Associations of (ex-)Users of mental health services. It was already established more than 3 years ago and it has now been recognised by the Ministry of Health in the framework of the French law of 4 March on the modernisation of health systems. The Federation has several members all over France: 31 member organisations. FNAP Psy is involved in several project at national level: (a) the revision of the law on disability with the UNAFAM; (b) a proposal for a framework law on the networks on psychiatry in France with the Ministry of Health; (c) FNAP Psy works on several projects with the Observatory of Psychiatry of the Hospital Maison Blanche, e.g. a leaflet aimed at users when they enter the hospital; (d) a project in Hospital Saint Anne in Paris to identify and combat discrimination and stigmatisation of users of psychiatric services – to start in September 2002. In 2000 FNAP Psy was involved in the preparation of the Charter of Users in Mental Health which was signed jointly by representatives of health professionals and the Minister of Health – Dominique Gillot - on 8 December 2000. FNAP Psy publishes a regular Liaison Bulletin and is going to set up a new web site.
- LUCAS Institute – is a health promotion research institute based at the University of Leuven in Belgium. LUCAS is an interfaculty centre concerning research, education and provision of services in the field of health care and welfare. Lucas' research is mainly applied, practically oriented and policy supporting research. It deals with various target groups: mentally ill people, (demented) elderly people, disabled people, young people, etc. Furthermore, LUCAS treats a diversity of research topics such as professional and informal care, quality of care, discrepancies between needed and provided care, relations between caregivers and care-receivers, expressed emotion, community support systems, stepped care programs, case management, violence, mobbing, discrimination, etc. Despite the diversity there is a specialisation in a few lines of research. The care for severe and enduring mentally ill people is one of these research lines. Recent projects are about: the transition to community support systems in mental health care in Flanders, tailor made care of people with schizophrenia, the development of a stepped care programme for the treatment of depression by general practitioners and psychiatrists, the role of the patients association "Uilenspiegel".

ENUSP Evaluation of the cooperation

At the beginning of the project – year 1, what where your expectations concerning the cooperation between the partners?
Expectation: No problems with communication.

What were your experiences in reality? If you encountered problems, how did you solve them?
Problems with communication and an hierarchic communication structure. Solved by discussion and decision to communicate directly with all partners.

1. Evaluation of the output

2.1 Step 1a: Focus groups on discrimination and harassment

At the beginning of the project – year 1, what where your expectations concerning the focus groups on discrimination and harassment?
Did not participate in focus groups

Indirect expectation: Chance for (ex-)users and survivors of psychiatry to report open, not under influence, and critically.
What were your experiences in reality? If you encountered problems, how did you solve them?
Did not participate in focus groups

2.2 Step 1b: Non-discrimination legislation

At the beginning of the project – year 1, what where your expectations concerning the collection and analysis of non-discrimination legislation?
Getting a short and comparable survey, how the legal situation for (ex-)users and survivors of psychiatry is by (paper-)law and in reality
What were your experiences in reality? If you encountered problems, how did you solve them?
Received a survey, how the legal situation for (ex-)users and survivors of psychiatry is by (paper-)law. It is common knowledge all over the world, that there is a difference between law and justice.

2.3 Step 1c: Resources of mental health care

At the beginning of the project – year 1, what where your expectations concerning the inventory of resources of mental health care?
No expectations
What were your experiences in reality? If you encountered problems, how did you solve them?
No expectations - no disappointment.

2.4 Step 1d: Organisation of the user movement

At the beginning of the project – year 1, what where your expectations concerning the inventory on the organisation of the user movement?
Receiving material from the partners for the inventory
What were your experiences in reality? If you encountered problems, how did you solve them?
Mostly good support by the partners, especially NL, UK, ES, A.

2.5 Step 2a: Inventories of strategies

At the beginning of the project – year 1, what where your expectations concerning the inventories of strategies?
No expectations
What were your experiences in reality? If you encountered problems, how did you solve them?
Missed interest in prevention of *iatrogenic* suicide by some partners. Partly solved by discussion.

2.6 Step 2b: Focus groups on strategies

At the beginning of the project – year 1, what where your expectations concerning the focus groups on strategies?
No expectations
What were your experiences in reality? If you encountered problems, how did you solve them?
Did not participate in focus groups

2.7 Step 3: Planning

At the beginning of the project – year 1, what where your expectations concerning the planning?
Equal opportunities
What were your experiences in reality? If you encountered problems, how did you solve them?
Experiences o.k.

3. general evaluation

General comments and/or suggestions
A project about harassment and discrimination faced by people with psychosocial disability in health services should integrate the study of possible hidden harassment and discrimination caused by participating partners that represent organizations and people working in health services from the beginning – in a pre-structured form that allows to handle this topic in the same functional way like all other topics.
The integration of organisations (like LUCAS), not being influenced by psychiatric ideology/science, should be widened in all projects about the mental health field.
The topic of iatrogenic damages, especially iatrogenic suicide, is too important to be handled as minor topic; it should be worth of a project by its own, lead by an organization of (ex-)users and survivors of psychiatry.

UK Report on Strategies to combat harrasment and discrimination

> *"The discrimination is the umbrella, and all these aspects the spokes underneath it"*

Introduction

This is a report of a focus group meeting that took place on Thursday 17th April 2003 at National Mind's Offices in Stratford, London, England. It was held for mental health service users/survivors, relatives of, and a variety of mental health professionals. This was for the European Union project on 'Harassment and Discrimination faced by people with Psychosocial Disability in Health Services' – a European Survey. This report forms the UK contribution of part 2 of this project on strategies to combat discrimination and harassment.

Methodology

1. Recruitment

Recruitment to the focus group was a little more difficult for the second stage of the project than we had experienced for the first stage. This was in part due to co-ordinating the various diaries of working professionals to find mutually convenient dates but made more difficult due to national train strikes. In fact, the date selected for the focus group was hit by a rail strike which prevented three people from attending.

2. Focus Group Participants

There were 6 representatives present (two men and four women) who came from various English regions, and represented a spread of interests. There was one long-term carer, and two users/survivors of mental health services. Both these users/survivors had careers in health - one had worked as a nurse in public health care and the other in nursing in mental health. These people offered as unique perspective due to their 'dual identities'. A key feature for the latter participant is that they have been a formal inpatient at a psychiatric unit for the past two years and had first hand experience of discrimination and harassment during this time. This person had to receive special permission to leave the hospital to take part in the focus group.

Other participants included the Chair of Mind, a senior social worker currently working in a high secure hospital and a member of the Diverse Minds National Advisory Panel who had thirty years experience as a general and mental health nurse. These two participants are of black and minority ethnic heritage. The final participant had worked for many years in the mental health arena, and now works as a specialist for a national mental health promotion organisation.

Those who were unable to attend due to the rail strike included:

- a user from Wales who had trained as a nurse in public health care
- a trainer and social services worker who authored the book "Phone at Nine to Say You're Alive" – an account of her experienced of being treated in the same hospital she had worked in alongside her clients
- another member of the Diverse Minds National Advisory Panel who was both a user and mental health worker.

We had other apologies from a Psychiatrist and a General Practitioner who were both unable to attend due to work commitments. Despite the low turn-out on the day, the contributions made by those who were able to attend were very good.

3. Moderator and Discussion

The Moderator was Madie Chapman, MindLink Development Manager at Mind. Some group members knew her better than others and Madie set the scene explaining the project and work gone before. The discussion took place over a half day - a total of four hours. The Moderators assistant was the reporter, Tina Coldham.

4. Other Useful Information

The group observed the following ground rules for the meeting

- Mobile phones switched off
- Respect each other and ourselves
- Contributing without pressure and allowing others to contribute
- Confidentiality
- Keep to time
- Respect other peoples points of view even if you don't agree and be non-judgemental
- Remember the ground rules and using 'time out'
- Being accepting, tolerant and patient
- Non-discriminatory practice (including language) and valuing diversity

Content of Discussion

Identified Strategies and Main Characteristics Incorporating General Recommendations for Developing and Implementing Strategies

The focus group members familiarised themselves with the first stage focus groups report. This report had a wide and varied content and it was felt from the start that the focus group could not cover all aspects that had been highlighted by the previous focus groups. However, this group came up with four strategies, two specific and two wide ranging in approach, which they considered to be of overarching importance.

Specialist Self Harm Team

Description: The establishment of 24 hour deliberate self harm teams in general district hospitals to cover a geographic area to assess the needs of someone who has deliberately self harmed – as opposed to people presenting after an accident. To have service user trained workers who understand deliberate self-harm in its many forms to work with users at an early stage to ensure they get appropriate treatment. This team would work with professionals to supplement their learning around self-harm/injury and tackle their attitudes for example, stigmatisation of this behaviour by them. This would ensure they do not discriminate in their treatment towards users who self-harm/injure.

Existing or new: Such a team exists in Queen Alexandria Hospital Portsmouth, South England set up two years ago.

Focus of strategy: All people who deliberately self-harm or injure, regardless of diagnosis, who present in Accident and Emergency [A&E] and other general hospital wards as well as psychiatric wards.

Target group: Any person who deliberately self harms. Any person who presents for the first time as a self harmer without a diagnosis yet whether presenting in general or mental health care hospital settings.

Implementation Process: This would have to be done as a hospital Trust-wide so would need Trust Board acceptance and then development project.

People Involved: Users, ex-users and survivors, relatives and professionals in both general health (primary and secondary) and mental health care services.

Necessary Means: Funding to create a new team of dedicated workers. Other means are specialist knowledge and skills around self-harm/injury, and user/survivor involvement in training workers.
Known or expected effects: Better mental health care, quicker access to appropriate services, support for the individual regarding self harm, improved relapse rate, mental health professionals knowledge base widened and more respect for individual who self harm/injure as a part of their emotional/mental distress. Hopefully this scheme could also save time of other professionals in the long run.

Evaluation of Strategy: To include: relapse rate; severity of self harm for persistent self harmers; cumulative data (who comes in, how often etc); quality of life outcomes whilst in services and outside (say by questionnaire); experience of users of the service (by questionnaire), effect on A&E units referral rate to psychiatric services, and on A&E staff work satisfaction regarding being able to meet peoples needs.

a) Risk Assessment tools for Users/Survivors

Description: A risk assessment tool for user/survivors to use in mental, general healthcare, and A&E settings. No risk assessment is done on the environment with reference to that individual's experiences and needs i.e. including staff attitudes. This strategy would address this. It would focus on risks or deficiencies in that environment to users. The principle being "The environment should do the patient no harm".

Existing or new: New. At present risk assessments are performed on individuals i.e. what risk they pose to themselves and others. Risk assessments should also be done on the physical attributes of the environment e.g. fire doors/extinguishers, ligature points etc.

Focus of strategy: Aimed at tackling the discrimination and harassment of all people with severe and enduring mental health problems in all in-patient settings.

Target group: Users, ex-users and survivors, relatives, professionals in Mental Health services.

Implementation Process: Policy and procedures group at hospital Trust that develops policy and protocols. Users, ex-users, relatives and staff to be involved from the beginning of the project.

People Involved: Users, ex-users and survivors, relatives, professionals in general health services, professionals in mental health services, the media (publicising the positive outcomes), and the Strategic Health Authorities and Regional Development Centres (National institute for Mental Health England) see www.nimhe.org.uk.

Necessary Means: Education and training (skills and knowledge). "*Staff are a risk to patients if they are not properly trained"*. Users, carers and staff working with designers/architects to develop positive safe environments.

Known or expected effects: Better mental health outcomes, better care, better staff, better environments for staff and users/survivors. Re-admission rates would hopefully drop, more respect for individuals, money saved through patients not suing (litigation).

Evaluation of Strategy: User satisfaction survey, staff satisfaction survey, staff sickness rates, staff turnover rates.

b) Holistic care of mental health services users

Description: Provision of holistic care to users of mental health services.

Existing or new: Existing strategy developed by central government, but implemented only sporadically by some services. Some services do well, others do not as the strategy highlights good practice but has no compulsion element.

Focus of strategy: All people with mental health problems in a variety of settings, particularly in-patient ones. For example: users/ex-users /survivors of psychiatry in mental health services and in general health services.

Target group: Users, ex-users and survivors, relatives, professionals in general health services, professionals in mental health services, non-governmental organisations, politicians, policy makers, pupils/students, teachers/trainers, media, general public.

Implementation Process: See example at Appendix A and attachment.

People Involved: Users, ex-users and survivors, relatives, professionals in general health services, professionals in mental health services, non-governmental organisations, politicians, policy makers, pupils/students, teachers/trainers, media, general public.

Necessary Means: Training and education. The focus group felt this should be compulsory so should be legislated for at a national level.

Known or expected effects*:* Improved care practices, real holistic care, equity of access, more respect for users/survivors, less misdiagnosis and more accurate diagnosis. It was stated, *"Early intervention equals healthier patients"*.

Evaluation of Strategy: Earlier detection of conditions that would have been missed.

Compulsory Interdisciplinary Training

Description: Compulsory Interdisciplinary Training would consist of training in key mental health aspects for general healthcare staff, and key aspects of general health care for mental healthcare staff. Re-registration for certain professionals would be dependent upon it, but it would form part of continuing professional development.

Existing or new: It is already in existence in so far as there is evidence of it being developed by the National Health Service and implemented by them and professional bodies such as the Royal College of General Practitioners and the United Kingdom Care Council. However, it is not compulsory, across the professional spectrum or aimed at enhancing current learning.

Focus of strategy: All people with mental health problems in a variety of inpatient and community settings. For example, users/ex-users /survivors of psychiatry in mental health services and in general health services.

Target group: Professionals in general health services, professionals in mental health services, their professional bodies, policy makers, and the Workforce Development Confederation, see http://www.doh.gov.uk/workdevcon/guidance.

Implementation Process: Work with agencies already converted to idea to convince policy makers of other agencies in the first place. Also devise appropriate training with agencies and educational establishments.

People Involved: Users, ex-users and survivors, carers, professionals in general health services, professionals in mental health services, pupils/students, teachers/trainers.
Necessary Means: Joint work with Workforce Development Confederation and universities. There should be involvement of users/survivors throughout.

Known or expected effects: Better healthcare, skilled healthcare workforce, and transferable skills amongst workers.

Evaluation of Strategy: Take up rate of training.

Conclusions and Recommendations

Conclusions

With regards to how the participants felt after the conclusion of the focus group, comments were made that included "uplifting", "people from different areas all thinking in the same direction", "Interesting that issues on the same track", "I'm still intrigued after all these years we are still discussing these issues", "There is hope", "Glad I could make a contribution", "It makes me absolutely furious".

One comment was made in conclusion of the discussion, and that was that we have "got to recognise good practice". There are pockets of good practice that have to be recognised and shared to improve services overall. This was said to acknowledge the good work done in amongst centring our discussion on strategies to tackle discrimination and harassment.

The last comment has to go to the user/worker who had attended the meeting from hospital. They said, "***Its been good to talk about some of the ideals, but I'm going back to live there by 8 o'clock tonight". "That's the reality". "We've discussed this for years, but I'm going back there with no change".***

Recommendations

The following recommendations are extrapolated from the above.

a) Users, ex-users and survivors of mental and public health care

- **To know that you are not alone when it comes to harassment and discrimination and take strength from that fact,**
- **To be actively involved in training on aspects of being a user/survivor of mental health problems/services to professionals at whatever level.**
- **To demand the right to proper care whether physical or mental health care for themselves.**

b) Relatives

- **To help users/survivors access help for their physical health needs,**
- **To be respectful of the user/survivor viewpoint and encourage user/survivors to get involved in professionals training.**

c) Health care Professionals

- **To be aware that discrimination and harassment takes place amongst it's ranks in many forms, in particular with regards to physical health care for mental health users/survivors,**
- **To actively challenge that discrimination,**
- **To be open to new ways of working in particular with regard to attitudes around self-harm/injury,**
- **To be aware that risks exist as a result of the systems and environments in place to 'care' for individuals.**
- **To be aware that good communication between the different parts of the healthcare system is paramount, but that confidentiality is an integral issue here.**

d) User/Survivor and carer Movements

- **User and carer movements to keep going and keep involving itself in training of health care professionals at every level.**
- **User and carer movement to keep involving itself in the planning, design, implementation and review of mental health services, including pushing for more innovative approaches as suggested above,**

- **User and carer movement to keep highlighting the need for appropriate physical care for mental health users/survivors,**
- **That more people speak out to heighten awareness of the discrimination aspects of what's said above.**

e) Local, National and European politicians

- **To listen to the experiences of people with mental health problems whatever their diagnosis is, or how severe and enduring it is. In particular those who self-harm/injure, have suffered physical health problems concurrently with their mental health problems, and those who have found psychiatric settings detrimental to their physical and mental well being.**
- **To insist that their health care workers operate in a non-discriminatory way,**
- **They concern themselves with the provision of up to date appropriate training for all health care staff.**

Third Partners Co-ordination Meeting – 23-24 May 2003 – Brussels

Minutes

Attendees: Leo de Graaf (MHE), Chair / Madie Chapman (MIND) / Yolanda Cardona (FEAFES) / Margret Korn (Pro Mente Salzburg) / Chantal Van Audenhove (apologised on 24 May) (LUCAS) / Katleen De Rick (LUCAS) / Peter Lehmann (ENUSP) / Roxana Radulescu (attended on 24 May) (MHE) / Karl Andriessen (MHE), Project Co-ordinator, Minutes of the meeting

Apologised: Claude Finkelstein (FNAP Psy) / Annie Gruyer (FNAP Psy) / Geeta Bhagola (Cliëntenbond) / Tina Coldham (MIND) / Josée Van Remoortel (MHE)

Content:
1. Welcome by the Chair
2. Agenda of the meeting
3. Minutes of last meeting
4. Results of Step 1a: focus groups
5. Results of Step 1b: non-discrimination legislation
6. Results of Step 1c: available mental health care
7. Results of Step 1d: organisation of the user movement
8. General agreement on the reports
9. Results of Step 2a: strategies to prevent and to combat discrimination
10. Results of Step 2b: focus groups with users, survivors and health workers
11. Proposal for the evaluation of the first year
12. Discussion on translations of documents of the Project
13. Planning of Step 3
14. Work plan and timing of Step 3
15. Approval of the co-financing
16. Promotion/publicity for the Project
17. Considerations for the application for Step 3
18. Conclusions and further planning

1. Welcome by the Chair

Leo De Graaf opened the meeting and thanked the participants for their attendance.
It was mentioned that two National Partners were not present. The representative of the Cliëntenbond was recovering from a surgery, and the representatives of FNAP Psy had to deal with other business. The participants expressed their disappointment, especially because FNAP Psy had not attended the previous meeting either. It was underlined that all partners had to engage themselves properly to reach the aims of the project.

2. Agenda of the meeting

Peter Lehmann (ENUSP) mentioned, that both topics he had sent in time to MHE where not on the agenda. The first point concerned e-mails that he had sent to MHE and were nor replied neither distributed to the partners. The second point concerned problems to fulfill the transnational agreement, which should ensure that services provided by (ex-)users and survivors of psychiatry should be favored. Peter Lehmann agreed to discuss these topics later during the meeting.
The agenda was approved.

3. Minutes of last meeting

The minutes of the last Co-ordination meeting (7-8 February 2003) were looked at. Peter Lehmann asked to include one item on page 6, in point 10: 'Guidelines to collect good practices and strategies to combat discrimination': 'Peter Lehmann made the proposal to add a special category 'people having attempted suicide as an effect of psychiatric treatment' (to come over this taboo). He promised to distribute a scientific paper to come over the negligence of this topic, which is of great interest for many (ex-)users and survivors of psychiatry'.
Indeed, the proposal to add a category was made during the last Co-ordination meeting, but it had not been approved by the meeting.
Taken this remark into account, the minutes of the meeting of 7-8 February were approved.

4. Results of Step 1a: Focus Groups

Focus Groups were held by the five national partners. The reports were sent to MHE, but the report of FNAP Psy was rather poor.
Katleen De Rick (LUCAS) presented the draft summary report 'Discrimination against people with mental health problems in general health care and in mental health services. Report of the Focus Groups, Step 1a of the Project'. This draft was prepared based on the reports of the National Partners and was forwarded to the participants prior to the meeting.
Several questions and remarks were formulated.

- Is there information on misuse of medication (informed consent) and on difficulties of users to get access to their medical files ? It appeared that these topics were not mentioned in the Focus Groups. It was agreed that this observation could be mentioned in the conclusions of the report.
- Peter Lehmann will e-mail his (other) questions to Karl Andriessen (MHE) who will forward them to LUCAS.
- Information on the participants of the focus groups can be included in the introduction
- Yolanda Cardona (FEAFES) mentioned that not only (ex-)users but also relatives had to deal with a lack of treatment.
- She also pointed out that we must be careful with the language. For example, on the last page, it must not be suggested that relatives are discriminating their family member with mental health problems.
- Madie Chapman asked to modify the sentence in the middle of page 7, where it is said that users can exclude themselves from society, to change this into '(ex-)users are excluded by society and can also exclude themselves'.
- The expression 'mentally ill' appears a few times in the text. This should be changed, for example to: people with mental health problems.
- Another point on page 8: 'adequate staffing'. The exact meaning of this was not specified in the Focus Groups.

Katleen de Rick and Chantal Van Audenhoven (LUCAS) will prepare the final edition of the report.

5. Results of Step 1b: non-discrimination legislations

Until now, only little information is available. We had received the report from FEAFES (Spain), Cliëntenbond (Netherlands), and Mind (UK), and a message from Pro Mente Salzburg (Austria) saying that nothing specific was available.
Leo De Graaf (MHE) mentioned a recent European report and he referred to the ministerial conference of Malaga. He will forward these documents.
Katleen de Rick (LUCAS) will prepare the final edition of the report.

6. Results of Step 1c: available mental health care

Karl Andriessen (MHE) had written a draft paper that was circulated to all partners prior to the meeting.
Madie Chapman (MIND) made some corrections on the information that was included for the UK. This will be included in the report.
Karl Andriessen will finalise the report.

7. Results of Step 1d: organisation of the user movement

The draft report by Peter Lehmann is very extensive. Some amendments to make:

- In the Austrian section, there is a comment that refers to a link between user groups and social organisations. This sentence will be deleted.
- Madie Chapman had e-mailed a new report of the Sainsbury Centre for Mental Health, on the mental health user movement in England. The link to this report will be included.
- In the UK section, there are some mistakes. Madie Chapman will e-mail these to Peter Lehmann.

Peter Lehmann will finalise the report.

8. General agreement on the reports

The final editions of the reports of Step 1 and 2 will be sent to MHE in due time. The reports must be approved during the next Co-ordination meeting. However, if the European Commission does not allow us to continue with the Project during the Year 2, then the reports will be agreed upon by e-mail contacts.

9. Results of Step 2a: strategies to prevent and to combat discrimination

The National Partners of Austria, UK and Spain presented their findings, based on the forms that were provided by LUCAS. We received a short report from the Netherlands. The French partner had announced to provide the report before the meeting but the report was not received.

Austria:
- Intensified education of physicians
- Anti-stigma campaign, public education
- Medical association continued education
- Case manager for person with mental impairment
- Reading room, with literature recommended by users
- Meeting of users for users

The first four strategies are new, the last two are in function.

UK: the strategies were not listed separately, but included in the report of the Focus Groups with users and health workers.
- Specialist self-harm team (24h) staffed by users, in general hospital
- Risk assessment tool for users/survivors
- Holistic care of mental health service users
- Compulsory interdisciplinary training

The first one is an existing (pilot) strategy, the second one is new. The third and fourth were developed but not as such implemented.
One member of the group in which these strategies were discussed, was a user and health worker, which was important in that meeting.

Spain:
- Walk to Camino de Santiago, with users and mental health workers
- Mental health observatory, a communication and consulting website
- Positive publicity campaign, to inform the general public
- Committee for the defence of the image of the persons with a mental illness
- Schizophrenia without rejection

All five strategies exist.

In the Netherlands only limited useful information was found. The Cliëntenbond reported that a lot of organisations that they had asked to provide information on non-discrimination strategies did not co-operate. The major reason given for this was that organisations were tired of being targeted with questionnaires on several issues.

10. Results of Step 2b: Focus Groups with (ex-) users, survivors and health workers

Each National Partner had the opportunity to present their findings. Two groups were held in Austria, Spain, and the Netherlands. One group was held in the UK. FNAP Psy, the French partner had said that we would receive their report before the meeting, but the report was not received.

- Austria
  The content of the strategies discussed was similar to the strategies mentioned in their Step 2a.

- UK
  The strategies were discussed in the Focus Groups and listed in their report.

- Spain: Some additional topics were discussed in the Group as compared with Step 2a.
  For example:
  - Compulsory mental health exams for health professionals, and visa-versa
  - Individual approach, tailor made care
  - Protocols for practice
  - To get (ex-)users and relatives in politics
  - Follow-up of Mental Health Plan

LUCAS will draft a summary report of the strategies. However, we foresee difficulties with this because the amount of information is different per country and per strategy and does not always follow~~s~~ the agreed format.
After discussion it was agreed that the strategies would be listed by target groups that were identified for this project, and secondly by country.
The National Partners were asked to send the contact addresses and references of publications (if available) of the strategies/projects to LUCAS in order to include this information in the report.

11. Proposal for the evaluation of the first year

Katleen de Rick (LUCAS) presented a draft form for the evaluation of the first year regarding the co-operation and the results. It's important that we ask ourselves if we have reached our goals and how the co-operation went between all partners. After discussion it was agreed that the draft would be amended. The form will follow the outline of the project and ask for expectations and outcome on each step of the Project.

12. Discussion on translations of documents of the Project

Peter Lehmann (ENUSP) remembered at article 6 of the transnational agreement, signed by all participants of the project at its beginning, which demands that, whenever possible, partners shall ensure the services like translation are provided by (ex-)users and survivors of psychiatry. But until now translations have not been offered, or MHE planed to make the translations. He already had brought this up in e-mails again and again sent to MHE in the last months before the meeting, however he had not received any reply. Leo de Graaf gave an explanation of the problem: the idea, that (ex-)users and survivors could do such a qualified and paid work is so new for professionals, that even mentioning this topic a few times does not raise awareness in them. This explanation was accepted. Peter Lehmann emphasised that he knows native speakers (with the same level of qualification as workers of MHE: no qualifications as professional or trained translator) who can be interested in working for the project. He referred that the people he is speaking from are qualified experts in translation by experience, or have unfinished university-exams - a quite common experience in the biography of (ex-)users and survivors of psychiatry. After discussion it was agreed that unfinished exams are common problems hindering the access of (ex-)users and survivors to the labour market and that we are free to use the transnational agreement to enhance the situation of people with psychosocial disabilities by offering them paid work and that we could try this, if the Commission agrees. MHE shall check this, and if the Commission agrees, texts for translation will be send to ENUSP, together with a descriptions of the royalties, and then ENUSP will forward the texts to competent translators. An average of three faults per page was agreed as the limit for good translations. Madie Chapman agreed to control the translations. The partners agreed that they will be available to check the translations.

13. Planning of Step 3

Karl Andriessen (MHE) presented the aim of Step 3 and the proposals of actions that already were formulated towards different target groups: 1) disability organisations, 2) (ex-)users, survivors and relatives organisations, 3) (mental) health professionals, and 4) politicians and decision makers. After a discussion on the possibility to aim at other target groups as well, it was decided not to include new target groups. Point 4 will be changed to 'politicians and "other" decision makers to give some space if it should be necessary. Further it was agreed to make a clearer distinction between (ex-)users and survivors, and relatives organisations. Below you find the most important points of the discussion. Please see pages 5 and 6 of the modified summary paper (dated 23-24 May 2003) of the Project for the overview of Step 3.

- Step 3a: Disability organisations
  - ➢ It was agreed that the Partners should refer to the European Year of People with Disabilities and should try to get involved in actions or meetings that are organised in the countries.
  - ➢ A European seminar will be organised by MHE with its partners.

- Step 3b: (Ex-)users and survivors movement
  - ➢ A booklet or poster will be made.
  - ➢ The National Partners agreed to increase the publicity for the Project in their country and towards their members and stakeholders.
  - ➢ The National Partners agreed to organise a National Seminar with approximately 50 participants. LUCAS has good experiences with this kind of meetings and is willing to share their experiences and to lend advice to the partners.

- Step 3c: Relatives organisations
  See Step 3b.

- Step 3d: (Mental) health professionals
  - ➢ Providing appropriate training to (mental) health workers was often mentioned in the Focus Groups as a strategy to prevent or combat discrimination in health services. It also seemed that health professionals

would support such a programme. Hence, the Project certainly must develop a training programme.

- Step 3e: Politicians and other decision makers. Recommendations will be formulated.

14. Workplan and timing of Step 3

- ➢ The next Co-ordination meeting will be held in Brussels on 3 and 4 October 2003.
- ➢ It was planned to involve an expert in communication to help us in this step of the Project. Peter Lehmann (ENUSP) offered to look for a contact or an expert.
- ➢ After discussion it was agreed that the communication system would change. The partners can send messages directly to each other, however with cc to MHE. MHE must be able to keep the overview of what happens in the Project.
- ➢ The provisional date to hold the national seminars was 3 December. It was agreed that the partners can choose their own date according to local circumstances.
- ➢ Information on websites: MHE will see if it is possible to include a German and Spanish translation of the presentation of the Project on their website. Then, the National Partners of Austria and Spain could put a link on their own website, instead of making their own translation.

15. Approval of the co-financing

- ➢ MHE had prepared the document with the calculations of the details of the co-financing of each partner and this document was discussed during the meeting. However, there was a small mistake in the document. So it was agreed that MHE would try to correct this and send a new document to all partners. After this, the partners will send their letter of commitment by fax to MHE on Monday 26 May, and send the original letter with the post.
- ➢ The maximum refundable number of working days of all partners was fixed.

16. Promotion/publicity for the Project

This item was already discussed during the meeting.

17. Considerations for the application for Step 3

- The application must be submitted to the Commission by MHE before the end of May. The different questions from the Commission were discussed. Below are the major points.
- A major problem is that we don’t have information from FNAP Psy, the National Partner from France. We don’t know if they will sign the letter of co-financing. Peter Lehmann (ENUSP) proposed to ask the German user organisation to take over and send as its representative Kerstin Kempker, who was included in the preparation phase of the project and is familiar with the history, idea and course of the project. After discussion it was agreed that MHE would continue to keep trying to contact FNAP Psy until Tuesday morning. If there were no news from them by 11.00h, Peter Lehmann would be asked to contact the German organisation so that they can submit a letter of co-financing to MHE.
- It was underlined that if we replace one partner in the project this does not mean that we will restart discussions that have already taken place in the past. We must proceed and develop the Project according to schedule.
- Difficulties that were faced during the last year included: difficulties in finding health professionals to participate in the Focus Groups, communications in the project, difficulties with invoice system, shortage of money, too much work, sometimes poor quality of reports.
- It was noted that some partners actively involved users in the Project, for example in the organisation of the Focus Groups.
- The Commission asks us to formulate some recommendations for them. An important recommendation is that we are not aware of their evaluation criteria.

18. Conclusions and further planning

The meeting ended with a round-table where everyone had the opportunity to say how she or he had experienced working in the project, and especially this meeting and the period prior to it. After this, the Chair thanked the participants and closed the meeting.

REPORT OF THE FOCUS GROUPS

Discrimination and harassment are important problems for people with mental health problems. What many do not know is that these problems also occur in mental and public health care. This step of the European project aimed at collecting information on discrimination and harassment in health care, experienced by people with mental health problems.

1. METHOD

To collect information on discrimination facts at national level, the national partners organised 'focus group' meetings. Focus groups are "groups of 7 to 10 people, recruited on the basis of similar demographics, psychographics or behaviour, who engage in a discussion, led by a trained moderator, of a particular topic" (Greenbaum, 2000). In this project, we aimed at involving 10 persons in each focus group. That size allowed maintaining an active, but not superficial discussion.

The national partners had to set up focus groups with users, ex-users and survivors of psychiatry. The criteria for these participants were the following: being a user, ex-user or survivor, willing to tell about personal experiences concerning discrimination and harassment, and able to participate in a discussion group. If possible, the national partners could organise separate focus groups with relatives of users, ex-users and survivors of psychiatry. To be included in a focus group, the potential participant had to have knowledge of the discrimination or harassment experienced by the relative and had to be willing to tell about the experiences of the relative, and able to participate in a discussion group. It was not possible to organize focus groups in which users, ex-users and relatives were present at the same time. The national partners had to make sure that different social categories were represented in the focus groups, like male and female, older and younger persons, ethnic groups, members of user organisations and individuals. People who were in a hierarchical position against other participants, spouses or close friends, … could not be included in the focus groups.

Please find the table with the overview of the participants at the end of this report.

A moderator for whom a manual was developed led the focus group. Please find the manual and its appendix in the appendix of this report. Four questions had to be answered:

1) What are the experiences of harassment and discrimination?
2) What were the users' personal reactions to discrimination and harassment?
3) What are the causes of discrimination and harassment according to the participants?
4) What kind of strategies could be developed to combat discrimination and harassment?

Each partner organised 2 to 4 focus group discussions. In sum, 14 focus groups were organised (11 with users (n = 96) and 3 with relatives (n = 26)). The discussions were tape-recorded and the national partners wrote a report based on tapes and field notes.

2. EVIDENCE OF DISCRIMINATION AND HARASSMENT IN HEALTH CARE

When collecting facts on discrimination and harassment, a distinction was made between discrimination and harassment experienced in public health care and discrimination and harassment in mental health care. Both treatment by professionals and the professionals' attitudes towards users can be a source of problems.

2.1 Discrimination and harassment in general health care

Treatment

The most frequently stated fact of discrimination and harassment in general health care concerns the treatment of physical problems. Physical problems are very often attributed to the psychological problems or are looked at from that perspective. This implies that users do not get the necessary treatment.

> *One user reported going to the GP with bad headaches. The GP diagnosed it as due to stress and depression and would not believe it was a physical complaint. The user then went to a chiropractor who diagnosed and successfully treated a trapped nerve (England & Wales)*

Sometimes access to general health care is completely denied to users or repeatedly postponed (even in crisis situation) or treatment is negligent. The needs of the user are not always respected. Some professionals deal with diagnosis in a very careless way. There are general hospitals that tend to refer users immediately to psychiatric hospitals. Users also feel that psychiatric wards in general hospitals are cheerless and comfortless, in contrast with other hospital wards.

> *The persons labeled as mentally ill are refused by the general hospital and directly transferred to a psychiatric hospital. (France)*
>
> *"What do you expect me to do? You are a borderliner." This was the first time this user had heard she had a diagnosis of Borderline Personality Disorder. Due to this diagnosis,*
>
> *she felt labeled as "an attention seeker" and "manipulative" by the psychiatrists. (England & Wales)*

A big problem in general health care is that professionals do not know how to deal with self-mutilation, which leads to low-quality care. Several users testify to having experienced the following: care without anesthetics, use of unsterile bandages, painkillers being denied, being tied up instead of cared for.

> *One user visited the Accident and Emergency unit (A&E) after an incident of self-injury. They were left in A&E without any pain relief and were asked whether going to have stitches for the injury was part of the 'ritual'. (England & Wales)*

There is also evidence that some independent working professionals, like dentists or general practitioners, refuse to treat users. One user complained about a dentist who told the patient that he would be treated worse than others.

> *A general practitioner rejected a user, for he knew that she had a psychological illness. Only after repeated interventions by the user's mother, the user was treated. (Austria)*

Attitudes towards users

Many complaints of the users regard the professionals' attitudes towards users. Far too often professionals in general health care treat users with disrespect and give inappropriate or condescending comments. They do not always take the problems seriously. Sometimes the user is blamed for the problems, laughed at or not believed. It is also obvious that users are not treated well when doctors ignore the user and only talk with the one who accompanies the user.

> *The receptionist shouted out her name and telephone number in front of other patients, some of whom the user knew because the area she lives in is quite small. (England & Wales)*
>
> *A user visited the GP with a friend who acted as an advocate. The GP only addressed the advocate and became very angry when the user asked the GP to look at his physical complaint. (England & Wales)*

2.2 Discrimination and harassment in mental health care

Treatment

Discriminating or harassing facts regarding treatment are often caused by the professional's neglect of the user's needs and wishes. Sometimes professionals refuse to treat the user, even when in crisis, or the user is continuously referred to other professionals. Referrals are not always adequate. The user's request for a treatment change can be rejected, but it is also possible that treatment is changed without the user's consent. It happens that users are threatened with discharge or separation if they do not comply with the treatment proposed by the professionals. Refusing one form of treatment can cause the denial of access to all forms of treatment.

> *A user went through a psychosis (later he was diagnosed with schizophrenia). Treatment was refused, just like medication. (The Netherlands)*
>
> *A psychiatrist tried to change the treatment without informing the user. Afterwards this psychiatrist said: "As a psychiatrist you always have to deal with people who do not have enough insight in their situation." (The Netherlands)*

The quality of the treatment can be very problematic. Some users complain they have been badly treated. One user says he has been locked up in the bathroom for several hours, another user had to stay in a box because no beds were available. Someone with a borderline personality disorder in crisis was not admitted to the crisis ward.

> *A user was put in an isolation room with the door opened. After a while, he was getting very uncomfortable. A nurse closed the door by purpose so he felt even worse. (The Netherlands)*

The problems concerning medicinal treatment are diverse. First, medication can be misused. Users are for instance given medication to stay calm or are given too much medication. Sometimes medication is used instead of therapy because the professional cannot or does not want to spend time on the user. It was also reported that experimental medication is prescribed without the user's consent. Second, the experience of the user regarding medication is ignored. A change of the medication can be refused, even when it has severe side effects. Sometimes the professional's refusal to give medication is seen as inappropriate.

> *A user keeps quiet about not taking antidepressant medication in front of health professionals. She stopped as she was experiencing physical problems, but feels she can not express her worries and can not declare not being on medication as this would be seen as a symptom of her mental health problem. (England & Wales)*

> *They prescribe pills as if they were popcorns. (Spain)*

Other therapies than medicinal treatment are often not available, like psychotherapy or occupational therapy, or are not presented to the users. Users in hospital do not know how to spend their time. Older patients are not stimulated anymore.

> *Information on modern treatment concepts (psychotherapy) is only given years after the initial outbreak. (Austria)*

The treatment of physical problems can be problematic in general health care, but also in mental health care. Again physical complaints are regarded as psychosomatic or are disregarded, even in the case of self-mutilation. Dental care is neglected.

> *We know that the molecules used in psychiatry damage teeth. The pain and the loss of their teeth handicap the people concerned. (France)*

> *Consultant treated myosotis psychosomatically for over a half year. (Austria)*

Several prerequisites for quality care are not fulfilled. Insufficient qualified staff causes high work pressure and an insufficient number of beds forces the professionals to discharge users too soon, even still in crisis. The continuity of care is not guaranteed: the user does not get help from the same professional and has to tell his story over and over again, doctors do not read the user's files, waiting times are long. The treatment settings are not always nice and clean and based on a large scale.

> *Professionals find it normal that a person has to wait several hours. Appointments are not respected. The specificity of psychiatric problems (e.g. difficulty of getting up early) is not taken into consideration. (France)*

Complaints about these facts are often denied because the professionals act as if complaining is part of the pathology.

> *"If I argue back, or want an explanation, then it's my illness." (England & Wales)*

Attitudes

The same attitudes as found in general health care apply for mental health care: disbelief, disrespect, user not taken seriously or being laughed at, condescending or accusing treatment. Other negative attitudes that were reported are indifference, insulting behaviour, lack of understanding, hopelessness, discouraging remarks. Users often do not appreciate immediately being called by their first name. The professionals' body language often speaks volumes.

> *The general feeling is that they do not make any efforts to low themselves to the comprehension level of patients and relatives. They usually use an incomprehensible terminology. (Spain)*

> *"If you are not quiet now, you will have to stay longer." (Austria)*

> *"It's him again". (Austria)*

Some disorders cause special problems: self-mutilation and sexual problems are regarded with fear and disgust; their parents cannot visit people with anorexia as they are seen as the origin of the disorder.

> *A user reported to his therapist that he had had a one-night stand with someone of the opposite sex when he had been in a long term same sex relationship. The therapist said: "Oh, thank goodness, aren't you pleased to know that you're normal'. (England & Wales)*

Users in mental health care are often threatened by the professionals to be (longer) hospitalised or to be knocked out with sedatives. Physical abuse is reported as well.

A big problem is the lack of sensitivity for differences between people, e.g. cultural, racial, sexual and religious differences. His homosexual partner could not visit one user, homosexuality is regarded as a disease, transsexuals are curiosities and not respected, professionals refuse to speak the official language.

> *One user said when there was a transsexual on an acute unit; all the staff on the other ward came up to have a look. (England & Wales)*

User characteristics can cause problems as well. Users who have their own opinion are not appreciated and users who are smart are not taken seriously (as if smart people can't have psychological problems). Asking for an explanation or standing up for oneself is seen as part of the pathology.

> *A user was told that he was "OK, intelligent and eloquent" so he did not need help. They had "worse cases". (England & Wales)*

2.3 Personal reactions

Users who experience discrimination or harassment go through different emotional reactions: powerlessness, vulnerability, helplessness, anger, humiliation, feeling written of or traumatised, guilt, emptiness, being hurt, fear, disappointment, loneliness. One user reported increasing suicidal tendencies.

The personal strategies to prevent discrimination and harassment can be placed in two categories: avoidance strategies and problem solving strategies.

Some users apply strategies that allow them to avoid discrimination and harassment. Some stop appealing to professionals or only appeal to a known trustworthy professional, others stop telling the truth. Other avoidance strategies are neglecting the problem, letting it happen or looking for explanations.

Other users apply strategies in order to solve the problems: having removed irrelevant information from the files, asking advice or involving someone else, considering lodging a complaint or taking legal action, standing up for the users' rights of for oneself. One user made up a story in order to get hospitalised and another user injured him self to receive the needed attention. Another user established a self-help group.

3. DETERMINANTS OF DISCRIMINATION AND HARASSMENT

The focus group participants were asked if they could explain discriminating and harassing behaviour.

Some of the causes are related with professional characteristics, like professional arrogance, personal problems, fear of mental illness, a lack of knowledge of mental health (possibly due to inadequate training), carelessness, prejudices and insensitivity for cultural differences.

The organisation of (mental) health care is also blamed. The participants mention a bad work climate, burn out, straining, routine work, competition and the importance of economic success. If de-institutionalization does not go together with the development of good alternatives, users are put in a bad light.

Some users say that there would be less discrimination and harassment if users were able to stand up for oneself and/or if they were better organised. Users can be excluded by society and can also seclude themselves from society.

Apart from the professionals and the users, other parties can be a cause of discrimination and harassment. The government is blamed when it does not take measures, like implementing a good anti-discrimination legislation. Media are favoring negative attitudes if they only show negative images concerning mental health and mental health care, and family members advance stigmatisation if they feel ashamed.

4. RECOMMENDATIONS TO COMBAT DISCRIMINATION AND HARASSMENT

INDIVIDUAL USERS

It is recommended that users do not feel guilty or ashamed about the discrimination or harassment they experienced. It is important to accept and respect oneself. One should be aware of the fact that many users are experiencing the same problems.

If a user experiences discrimination or harassment, it is necessary to react, for instance by expressing one's opinion and feelings or by lodging a complaint. Drawing up a will can prevent discrimination and harassment.

A user should know that he does not stand alone. Sometimes family members or others can play a significant role.

USER MOVEMENTS

In order to prevent further discrimination and harassment, users should take action as a group. An important task for the user movement is raising awareness about discrimination and harassment and exerting pressure to solve the problems. The user movement can also play a role in the training of professionals, by testifying about bad experiences and by showing what it means to have a mentally ill health. Another possible action is to make family members aware of users' rights, self help groups, methods to lodge complaints, ... Last, user movements should go on promoting mental health and creating positive images. Therefore they have to stimulate users to break down the taboo.

PROFESSIONALS IN HEALTH CARE

In the training of professionals, more attention should be paid to the prevention of discrimination and harassment. First of all, professionals (especially in general health care) should know more about mental health problems and about what it feels like to have a mentally ill health. Nurses and doctors (certainly general practitioners) should learn how to deal with people with mental health problems. Second, they should be made aware of discriminating language, a human approach and cultural differences. Third, professionals in emergency services need special education. Self-mutilation would be one of the important topics. Training has to continue in the course of the professional career. An important aspect of training would be the active participation of users and the development and dissemination of good practices.

In order to enhance the quality of health care, the user's opinions and needs should be respected. Treatment should not only consist of the prescription of medication but also of different therapies. Nurses can be a link between the user and the doctor. Both in mental health care and in general health care, increasing attention for users' physical problems is needed.

On an organisational level, health services should guarantee adequate staffing and supervision and they should undertake actions to prevent burn-out. Waiting times should be reduced and the user should be able to appeal to the same professional as much as possible. Procedures to lodge complaints should be installed and used in a proper way.

LOCAL, REGIONAL, NATIONAL AND EUROPEAN POLITICIANS

On the individuals' level, politicians can undertake some actions. They can make a legally accepted means of the psychiatric will or they can support user and family movements. Laws or decrees concerning discrimination and equal rights should be useful for people with mental health problems as well.

On the level of organisation of health care, the politicians can play an important role. The politicians should guard the quality of care, amongst others by enhancing the quality of the professions and the number of professionals in services, by safeguarding the quality of care, by detecting, sanctioning and preventing bad practices and by limiting the power of the pharmaceutical industry. More means for research on this topic is necessary.

On a broader level, politicians are responsible for raising awareness and for taking all these kinds of problems into account when implementing community care.

GENERAL PUBLIC AND MEDIA

To prevent and combat discrimination and harassment, the focus group participants were of the opinion that the general public and the media have to be targeted as well.

To educate the general public, it is recommended to start in schools and colleges. Young people should be familiarized with mental health and with concepts as tolerance and non-discrimination. It is suggested to arrange sensitizing campaigns, in which for example experiences of users can be told. Special target groups are policemen and relatives of people with mental health problems.

With regard to the media, there should be more attention for a correct and non-discriminating coverage, for instance by taking the edge of the link between violence and mental illness. For that, informing the journalists could be a good idea.

Reference:

Greenbaum, T.L. (2000) *Moderating focus groups. A practical guide for group facilitation.* London: Sage Publications.

Letter from ENUSP to LUCAS

(June 6, 2003)

Dear Chantal, dear Katleen,
as promised at our last meeting, here some commentaries. Report of the Focus Groups Step 1a, Draft paper from May 7, 2003

From an European point of view it would be important to add these critics toward discriminating practice in psychiatric treatment by psychiatrists as well as GPs:

2.2.
"The quality of treatment...."

1) In general people complain about
a) treatment without informed consent: no information about risks and alternatives at the beginning of the treatment, not during the treatment and not during the step to long-time treatment, for example no information about suicidal effects of neuroleptics, no information about enhanced risk of breast cancer in women under the influence of psychotropic drugs, no information about early symptoms of tardive dyskinesia and tardive psychosis, no information about early signs of agranulocytosis, febrile hyperthermia, neuroleptic maligne symptom, and much more
b) no help to come over the problems which led to psychiatrisation

"Several prerequisite for quality of care are not fulfilled."

2) In general people miss the right to see their own treatment records. In Germany this is one of the most frequent questions: Why am I not allowed to see the records about my own treatment?

These complaints for example you can see in the research, the German national association published in 1995, see http://www.bpe-online.de/infopool/recht/pb/umfrage.htm

Attitudes

3) Very often women complaint, that they have been misused sexually in their families, got crazy about this, and they repeat misuse in form of normal violent psychiatric treatment: men are taking their clothes, they are brought naked to bed, they are fixed in the bed, men people grab at their body and get busy with the bodies of the defenceless women (as they know these situations from former misuse).

About these complaints for example you can read in Kerstin Kempker's book about the Berlin runaway-house, see www.antipsychiatrieverlag.de/verlag/titel1/flucht.htm

2.3 Personal reactions

4) People start to organize in groups and provide alternatives to the psychiatric system themselves.

3. Determinants of discrimination and harassment

5) Politicians do not give any money for self-help, even if the European Commission and the WHO demand the support of self-help, see http://www.enusp.org/documents/consensus.htm
For example the Berlin government denied to support the group "For all cases", even if the Berlin self-help steering group proposed to support this organisation, with the silly argument "no money there". (Non-psychiatric self-help-groups receive money.)

4. Recommendations

6) about adequate staffing: In a lot of countries organisations of (ex-)users and survivors of

psychiatry reclaim the right to define their own interests incl. what is adequate support and staffing. They feel it an ongoing discrimination if professionals go on to define themselves what is an adequate help and staffing.
To enhance the quality of care resp. to introduce the first step on the way to quality of care (there are people who say that psychiatric quality could be enhanced, and there are people who say that there is no quality in psychiatric care at all), ENUSP made proposals in:
ENUSP: Comment to: "Quality Assurance in Mental Health Care, Draft. Human Rights of People with Mental Disorders", WHO 1997; publication of the comment in worked over form: "Forum – The Declaration of Madrid and current psychiatric practice: users' and advocates' views", in: Current Opinion in Psychiatry (1999)

I just took the easiest available examples, from Germany. To deliver concrete examples from other countries, I can ask via our ENUSP-mailing-list. If you want me to do that, please tell.

Please do not hesitate to contact me, if you require any further information.

Kind regards
Peter Lehmann