

Harassment and discrimination faced by people with psycho-social disability in health services: A European survey

RECOMMENDATIONS

INTRODUCTION

The action project “Harassment and discrimination faced by people with psycho-social disability in health services” is organised in the framework of the Community Action Programme to combat discrimination 2001-2006, and is funded by the European Commission - Employment and Social Affairs. The overall aim is to raise awareness about the discrimination faced by people with mental health problems in health care services and to promote strategies to combat it.

The recommendations are based on the opinions of the national partners and the European Network of (ex-)users and survivors of psychiatry¹ and are inspired by the results of the focus groups that were held during the first year with (ex-)users and survivors of psychiatry and health professionals.

Every day, people affected by mental health problems, as well as carers and relatives, face harassment and discrimination in diverse areas of their lives. This reduces the possibility of recovery and integration in society.

Before summarising possible measures, emphasis should be put on the importance of the participation of (ex-)users and survivors of psychiatry in the formulation and implementation of these measures. The starting point for tackling harassment and discrimination that people with mental health problems or that are called mentally ill and their relatives experience, is their participation in the fight against this discrimination at various levels. The knowledge and expertise with which they can contribute is unique and of an enormous value. This is why measures that address discrimination and harassment must be elaborated by those who suffer from this situation as well as by experts and professionals. The motto “nothing about us without us” of the 2003 European Year of People with disabilities must become practice.

We suggest the development of strategies to change attitudes and the behaviour of the general public and particularly of (mental) health workers. To reduce or eliminate discrimination and harassment an explicit formulation of 'good practices' or care standards and laws on the equality of treatment should be developed and linked with the installation of boards of appeal.

Adequate funding, organisational involvement and support of policy makers are a prerequisite for the realisation of these recommendations.

¹ The term »user of psychiatry« refers to people who have mainly experienced psychiatric treatment as helpful. The term »survivor of psychiatry« in turn refers to those who have mainly experienced psychiatric treatment as being a danger to their health. These definitions are often misunderstood: to »survive psychiatry« does not mean that psychiatrists are being accused of trying to intentionally kill people. But it does mean that diagnoses such as »schizophrenia« or »psychosis« very often have a depressing and stigmatising effect, leading to resignation and chronic hospitalisation. And it means that drug-effects such as neuroleptic malignant syndrome or tardive dyskinesia or dystonic or epileptic attacks can be a danger to health and life, which have to be survived.

POLICY RECOMMENDATIONS

1. IMAGE BUILDING

- There is a need for the development of programmes to improve public perception of people with mental health problems in the general population. As future aims, programmes should also be developed for journalists and for schools to change the general behaviour and attitudes in the EU accession countries.

It is important that those programmes should be organised by groups of health professionals, (ex-)users and survivors of psychiatry and carers and be focused on the theme “harassment and discrimination - what can be done?”

- Everyone should value and support diversity.
- Everyone should listen to, and value people’s experiences.

2. PROMOTION OF THE MOVEMENT OF (EX-)USERS AND SURVIVORS OF PSYCHIATRY

The (ex-)users and survivors of psychiatry movement should be promoted. They should support and reinforce campaigning and decision-making at all the levels, in particular at the level of professionals' organisations and political organisms. Effective participation of trained (ex-)users and survivors of psychiatry is essential for the implementation and development of quality standards and research projects.

Funding and support should be invested in:

- (free) training programmes for (ex-)users and survivors of psychiatry so they can protect themselves from discrimination, become user/survivor workers employed at all levels and become trainers themselves in programmes to combat harassment and discrimination.
- the effective representation of (ex-)users and survivors of psychiatry or user/survivor workers in crisis centres, counselling centres, public relations work, research projects, congresses, networking and international exchange of organisations representing (ex-) users and survivors of psychiatry.
- the support of initiatives of peer coaching, regional self-help centres and meeting places.

3. SENSITISATION AND TRAINING OF SOCIAL AND HEALTH PROFESSIONALS

Discrimination and harassment experienced in the health field is especially important not only because social and health professionals are directly involved in the recovery of the people with a mental health problem and their carers, but also because in many cases this discrimination passes unnoticed or unchallenged.

- The mental health service user/survivor experience and perspective should be represented at all stages in the training of health care professionals, right from the start of their professional career. This will help professionals to become more familiar with the user/survivor perspective, that is in definition different from their own.
- The basic training of health care professionals should pay more attention to the acquisition of patient-centred communication skills to discover their needs, wishes, demands and concerns and to come to an agreement regarding the content and process of care. Institutes should pursue a policy which presupposes, supports and stimulates a patient-centred attitude. Legislation should ensure that the working environment

respective the financial conditions and that employers make it possible for the health professionals to engage in such activities.

- Training programmes should focus on improving knowledge, broadening skills and changing attitudes.
- Professionals should learn and be allowed to:
 - take responsibility to challenge and expose discrimination and harassment faced by people who experience mental distress.
 - support diversity
 - value the perspectives of (ex-)users and survivors of psychiatry
 - see the whole person rather than the diagnostic label
 - reduce the great distance with which the professionals currently approach their patients.
- Prevention is as important as training. Selection procedures of health care professionals should include a verification of the attitudes towards target groups that are at risk for discrimination (like ex-users and survivors of psychiatry and other minority groups ...). It is a good policy to include (ex-)users and survivors of psychiatry in the recruitment.

4. QUALITY STANDARDS OF CARE

Beyond the relationship between the caregiver and the (ex-)user or survivor of psychiatry, there is the higher level in the organisation of care that is crucial in combating discrimination and harassment.

- Referral systems should be designed in a way that does not allow discrimination and harassment. For instance, a diagnosis should not be communicated to others without permission of the client. Electronic care records should be protected in a way that professionals can only see the information they really need. Informing the client is crucial. Only clients who know their records can give meaningful permission.
- Records of people with psychiatric diagnoses should not be treated in a different way than records from people with medical diagnoses. Dealing with records without permission shall be possible only in the presence of mortal danger to self or others, when the ability to express a natural will is temporarily reduced.
- Accident and emergency admission protocols should enable patients to receive the appropriate physical care they need. These protocols must be handled flexibly.

5. LEGISLATION ON DISCRIMINATION AND BOARDS OF APPEAL

- Laws on equality of treatment should be adopted and funds provided so that these laws can be put into practice.
- One major objective is to adopt laws that guarantee the respect of human rights in a proactive way. These laws should focus on the protection of human dignity, the right not to be violated, the right to self-determination, the right to privacy and the right to respect. For example through legal protection of advance directives, or through the introduction of a suicide register.

There should be boards of appeal that receive the authority and structural guaranteed possibilities to sanction institutions and to influence decision-makers.

They should be:

- organised nationally, regionally and locally;
- legally covered;
- easily accessible (anonymous upon request) and
- functioning independently from medical and psychiatric institutions (to protect confidentiality and to guarantee the support of victims of discrimination as it is demanded by the anti-discrimination framework of the European Union.

It would be desirable that the controlling is by (ex)-users and survivors of psychiatry. The possibility to ask for professional advice when needed should be there, the financial resources for such advice too.

6. INVOLVEMENT OF POLICY MAKERS

The health rates of the citizens of a country are a criterion of well-being and mental health is a key point in this respect.

- It is important that policy makers become aware of the tremendous lack of resources in the health field in general and particularly in mental health. This lack of resources is both structural and in human personnel and results in worsening treatment and care that hinders recovery and can lead to patients becoming chronically ill. This leads to social exclusion, preventing the patients from having equal opportunities in life, increased risk of marginalisation, disability, physical illness and mental disorders, high rates of early retirement pensions and major public expenditure in the long term. The allocation of more resources to the Mental Health, and in particular to preventative care and early intervention, area is essential.
- The elaboration of appropriate and realistic Mental Health Plans that are in accordance with the reality of the country, and more important yet, with the reality of the disability, have to be supported at all levels.
- To create the right of full involvement of (ex-)users and survivors of psychiatry and carers organisations as they are indispensable elements. This is so that people with MH problems and their relatives enjoy the status they deserve as citizens with full rights.

CONCLUSIONS

There is a need for a concerted effort on the part of the general public and professionals of mental health care and of health care to change attitudes towards people with mental health problems. Greater efforts must be made not only to increase awareness of the discrimination and harassment routinely faced by people with mental health problems and their families, but also towards the allocation of resources that ensure an improvement in the quality of the treatment. Financial resources, structural and organisational changes, which enforce the movement of (ex-)users and survivors of psychiatry, the explicit formulation of quality standards of care, the adaptations of laws and the involvement of politicians should help to make this possible.