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Critical Measures for a Political and Social Integration of (ex-) Users and Survivors of Psychiatry

Psychiatric survivors comprise a population group, which suffers the most from discriminations. Their status is characterized by the deprivation of fundamental rights, as well as by discriminations in the fields of work, housing and especially in the psychosocial support. Their rehabilitation and prevention of their further social exclusion presuppose the existence of political will for the confrontation of the causes and symptoms of exclusion as well as for the development of targeted measures against discriminations. In everyday life and especially in their interactions with authority, they need personal support towards recovery and empowerment, as well as help for return to work after long-term crises. With the assistance of special measures, such as these developed by the E.U. Harassment Project, discriminations against psychiatric survivors can be confronted in terms of both the public opinion and the psychosocial support fields. Examples are presented which illustrate how professionals, politicians, relatives, as well as survivors themselves take action up to now towards integration and elimination of discrimination.

1) Problems of Power and Discrimination

It is well known, that the situation of (ex-)users and survivors of psychiatry is not optimal and should be improved. One example of the effort of improvement and the lack of support—to say it in kind words—became evident with the conference *›Balancing Mental Health Promotion and Mental Health Care. Joint World Health Organisation / European Commission Meeting‹*, Brussels, 22-24 April 1999. Beside approximate 70 psychiatrists, politicians and other representatives of lobby groups, also one representative of ENUSP in its function as the European voice of (ex-)users and survivors of psychiatry—the author of this paper—was invited to give a short lecture and explanation of the position and wishes of the (ex-)users and survivors of psychiatry. Between other topics, he demanded the active inclusion of (ex-) users and survivors of psychiatry into psychiatry-policy, the promotion of self-help-approaches and non-stigmatising (non-psychiatric) alternatives and above all the freedom of choice as an aspect of strengthening human rights. But when the draft of the final consensus paper was presented and, no single topic was included. When he argued, that a consensus paper without consent is no consensus paper, he was put down from a member of the European Commission. There was icy silence by the representatives of the parents' organisations, the organisations of the professionals and the NGO working in the psychosocial field, the government representatives; not one single person from the variety of famous psychiatrists supported the above mentioned position of ENUSP. Only after the support by the European-Commission representative (DG/V/F), Mr. Alexandre Berlin, the ENUSP proposals were added to the consensus-paper. And afterwards nothing was heard any more from this document, even it was obviously adopted by the following conference of the health ministers of the countries, which belong to the European Union. (ex-)users and survivors of psychiatry seem to stand rather alone in their fight for the freedom of choice and self-help resources. Find more information about the consensus paper on www.enusp.org/consensus.

In 1995, when the author was a member of the board of the German Association of Users and Survivors of Psychiatry (BPE), this organisation was asked by the journal *Sozialpsychiatrische Informationen* (Social Psychiatric Information) whether it would be willing to participate in a survey on the subject of improving the quality of psychiatric treatment. It agreed to take part but changed the questions, as the board

members could not agree on whether any type of psychiatric treatment could be considered "quality." The following are some of the questions it put to 665 members of the association—(ex-)users and survivors of psychiatry who were more or less critical of psychiatry:

Did the psychiatrists address the problems which led to your admission? Was your dignity respected at all times? Were you fully and comprehensibly informed of the risks and so-called side effects of treatment measures? Were you informed about alternative treatments? What was lacking to the detriment of qualitatively good psychiatric care?

Over 100 members of the association (BPE) responded to the survey. The result: only 10 percent of those who answered said that psychiatry had helped them find a solution to the problems that had led to their psychiatrisation. Ninety percent said that their dignity had been violated. In response to the question of whether they had been informed about the risks and "side effects" of treatment measures, not one single person replied with "yes" (Peeck, *et al.*, 1995).

Later studies conducted wholly or in part by independent survivors, such as the European study *Harassment and Discrimination Faced by People with Psycho-Social Disability in Health Services* produced similar results. This transnational study was conducted at the behest of the European Commission. In it, the associations of (ex-)users and survivors of psychiatry and their families from the U.K., Austria, Germany, the Netherlands, Spain and France in conjunction with a Belgian research institute put the questions to families and (ex-)users and survivors of psychiatry. The result was the same: All over Europe, people with mental health problems (or people who are called mentally ill or mentally disabled) face harassment and are systematically discriminated against in the medical and psychiatric sector, that means, they are treated less favourably than people with medical diagnoses. Main findings on harassment and discrimination in health and mental health services:

Physical problems are not taken seriously, but attributed to psychological problems. Psychiatric drugs are prescribed without informed consent. Complaints are dismissed as part of pathology. The right to read your own treatment record is rejected. Patients are threatened with discharge, separation, forced treatment or enhancement of the psychiatric drugs' dose, if they do not accept the offered treatment.

Read more about the different forms of discrimination in the health care and in the psychosocial field on the internet at www.enusp.org/newsletter/2003-6.pdf, pp. 19-22.

2) Recommendations to Combat Harassment and Discrimination Faced by People with Psycho-social Disability in Health Services

As a result of the European study, the „Recommendations to combat Harassment and discrimination faced by people with psycho-social disability in health services“ were published and presented in Brussels to the public, to the European Commission, and of course the participating organisations should make them public in their countries, and the Antidiscrimination Unit of the European Commission should finance the Antidiscrimination poster, which was one main result of the programme... But it would be true to say: should be a main result, because after the presentation of the Antidiscrimination poster, never anybody heard anything about it any more. Discrimination is everywhere.

The recommendations to combat harassment and discrimination faced by people with psychosocial disability in health services covered several levels:

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.
- 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.

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 pro-active 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.

Find more information about the recommendations on the internet at www.enusp.org/harassment.

3) The Dresden Example of a Model Measure to Combat Harassment and Discrimination

A good example of the user and survivor involvement was the agreement of the unified users and survivors of psychiatry with the Organizing Committee of the congress on "Coercive Treatment in Psychiatry: A Comprehensive Review", run by the World Psychiatric Association (WPA). Dresden, Germany, June 2007. The agreement from April 21, 2006 included:

- In the congress announcement users and survivors of psychiatry were welcomed.

- Ten scholarships for (ex-)users and survivors of psychiatry who offer active participation.
- Two (from 10) key-note-speeches.
- Reduced registration-fee for users/survivors who do not offer an own contribution.
- Participating in press conference.
- User/survivor-run congress book-stand.
- Meeting room for users/survivors only for recovery and retreat.
- Joining the Organisation and Scientific Committee.

Find all important congress documents on the internet at www.enusp.org/dresden.htm.

4) More Critical Measures for an Integration of (ex-)Users and Survivors of Psychiatry

Like all other suppressed groups in the society, only if (ex-)users and survivors of psychiatry start to organize and build a powerful organisation, they can hope that there is a chance that their demands are heard. Discrimination and exclusion show the importance of strong user/survivor organisations, the support of self-help, international exchange by financial and organisational support, cooperation between user/survivor-organisations and supporting organisations to have solidarity in practice, the integration of an independent user/survivor input in universities, magazines, the openness of professionals for publications of independent users/survivors and their organisations respectively mixed organisations with a meaningful input of independent users/survivors of psychiatry.

If you take a closer look at history and even at current developments, you can find a series of successful approaches that reject discrimination and exclusion of alternative approaches to psychic problems that many users and survivors of psychiatry want and which refer to the social nature of psychic problems. Withholding information on alternatives is another form of discrimination that denies users and survivors of their right to access to the services they most want. A number of functioning alternatives you can find in the book *Alternatives Beyond Psychiatry*: ranging from the Soteria approach, the Windhorse project and the Berlin Runaway House, to non- or anti-psychiatric projects in Alaska and Sicily, and Jaakko Seikkula's "Open Dialogue" in Finland. All of these approaches lead to a substantial reduction in coercive measures and drug prescriptions. Also family organisations can play a supporting role. Karyn Baker from the Family Outreach and Response Program (FOR) in Toronto reports how families affected by psychiatry are being trained to support their relatives in the recovery process, instead of, as usual, pushing them to take psychotropic drugs, resulting in their becoming "career mental patients." And there are a lot of strategies realizing alternatives and humane treatment, like the personal ombudsmen service in Skåne, Sweden, the Alaskan association PsychRights in getting millions in public funds reallocated to the development of non-psychiatric alternatives, advance directives, MindFreedom International, which is accredited as an NGO at the United Nations and advocates for human rights as a basis for a non-violent revolution in mental health, user-controlled research as an underpinning for alternative approaches, the training of former psychiatric patients for user/survivor involvement work in mental health and social care, the International Network Toward Alternatives and Recovery (INTAR—www.intar.org), founded in 2003, which is dedicated to advancing the knowledge and availability of alternative approaches for individuals experiencing severe mental distress (Stastny & Lehmann, 2007).

Respect of human rights, freedom of choice and availability of non-medical alternatives are the cornerstones of the political and social integration of (ex-)users and survivors of psychiatry.

5. Employment Needs of People with Mental Health Problems

In 1997, Mary Nettle, since 2004 Chair of the European Network of (ex-)Users and Survivors of Psychiatry (ENUSP—www.enusp.org), published her paper “Employment Needs of People with Mental Health Problems” (Nettle, 1997) which now was worked over. She wrote that the current rate of unemployment for people with psychiatric problems is 70-80%. Not because people do not want to work, but because current work structures are not flexible enough to accommodate the up and down nature of peoples' emotional lives:

Prejudice (stigma) and ignorance means employers reject people with a history of so-called mental illness. This causes people to lie about their psychiatric history and therefore have no support if they need time off work often leading to them being dismissed from their job.

Particularly in Northern Europe the Social Security system provides a minimum income for people unable to work, but the rigid, inflexible way in which the rules are enforced can lead to what in the UK is called the Benefit Trap. This means that if you are able to get a job you have to give up all your benefit, which may be worth more than the job pays, and, if you find the job is too stressful and have to give it up, you spend a lot of time waiting, often with no money at all, to be able to get the level of benefit you had before.

In the UK we have a Disability Discrimination Act, which specifically includes people with a history of mental health problems. The equivalent act in the USA includes people with so-called psychiatric disabilities. The criteria used to define disability varies according to individual experience. The way this experience is described varies from country to country. There is a debate within the movement of (ex-) users and survivors of psychiatry as to whether we should consider ourselves to be disabled. Within ENUSP, the definition of “service user” is left to the individual. This can be the same for a definition of disability. My view is that you are disabled if society treats you differently and there is no doubt this happens to us because of our mental illness label.

ENUSP established four principles in 1995.

1. People experiencing emotional distress should enjoy equal opportunity and treatment in respect of access to, retention and advancement in paid employment, which corresponds with their own informed choice and takes account of existing skills. In this principle, the rights of men and women experiencing emotional distress should be respected.
2. Equality of opportunity for persons experiencing emotional distress shall extend to all levels of work organisation and management. This calls for respect for confidentiality of personal information.
3. Every workplace should conform to standards established by the social partners ensuring a healthy and empowering work place.
4. Special positive measures, such as wage subsidies and supported employment schemes, shall not be regarded as stigmatising or discriminatory against other workers.

ENUSP is aiming to get these principles adopted in all countries and would welcome ideas.

6. The Transnational Co-operation Agreement as an Example for the Promotion of Paid Work for (ex-)Users and Survivors of Psychiatry now

The “Transnational Co-operation Agreement” for the study “Harassment and discrimination faced by people with psycho-social disability in health services. A European survey” within the framework of “Support to European Action Project to Prevent and Combat Discrimination—Community Action Programme Against Discrimination 2001-2006” showed one possibility to promote social integration via paid work for of (ex-)users and survivors of psychiatry. The agreement was accepted in 2002 by the participating organisations Cliëntenbond, European Network of (ex-)Users and Survivors of Psychiatry, FEAFES, FNAP PSY, LUCAS, MIND, and pro mente Salzburg and said in Article 6 on participation of (ex-) users and survivors of psychiatry:

Whenever possible and if the conditions are met, Partners shall ensure that services (translation, catering, etc.) provided by (ex-) users and survivors of mental health services are favoured at the same condition of any other staff member.

Why not such agreements in all your organisations now as a very first step against discrimination and exclusion?

Sources

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