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The Political Dimension of the Self-help Movement of People with Psychotic Experiences

Abstract: The development of the self-help movement of people with psychotic experience in Europe and the situation today will be presented in this paper. The emphasis will be given to the demands of this movement how the psychosocial culture should be changed to be able to deliver appropriate support. 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. 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 and reduce the great distance with which the professionals currently approach their patients.

The history of the European Network of (ex-)Users and Survivors of Psychiatry (ENUSP)

ENUSP is an initiative to give 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 and on a European level.

By the way: 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. Of course in the past, not many decades ago, psychiatrists killed hundreds of thousands during the nazi area, when they had the possibilities to act without any limitation. "Surviving psychiatry" today means 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.

Within our Network we do not differ people with different diagnoses like psychosis, schizophrenia, mania, depression and so on. There are people which are not convinced, that the psychiatric diagnostical system is a scientific one, for them the psychiatric system is more a believe-system.

The history of the Network goes back to 1990 when the initiative was taken in the Netherlands to form a network of associations of (former) psychiatric patients from various European countries. In the past the Network has organised five European conferences. In Vejle, Denmark, this year at a joined conference with the World Network of Users and Survivors of Psychiatry (WNUSP) there were 200 delegates from 50 countries world-wide, Greece included. You can read the report in the internet on www.peter-lehmann.de/articles/enusp/vejle-index.htm.

Aims and objectives

The European Network is against any unilateral approach to, and stigmatisation of mental and emotional distress, madness, human suffering and unconventional behaviour. The Network should support users'/survivors' autonomy and responsibility in making their own decisions, that is, sellf-determination. In order to implement this principle, priority has been given to the following areas:

- Act against any kind of discrimination in society (both inside and outside the mental health system) of people who have been subject to the psychiatric system;
- Support development of user/survivor groups throughout Europe (with a particular emphasis on those countries where there are no existing organisations);
- Create and support alternatives to the psychiatric system and collect and share information on the existing ones;
- Influence and try to change present treatment in psychiatry.

There the Network goes along with the European Commission and the World Health Organization (WHO). They stated—at least on paper—that "Developing innovative and comprehensive, explicit mental health policies in consultation with all stakeholders, including users and carers, and respecting NGO and citizen contributions" should be a key principle and central common goal and strategy to improve psychiatric care. This was decided at the Consensus Conference "Balancing mental health promotion and mental health care: a joint WHO / European Commission meeting" in Brussels in April 1999 (www.peter-lehmann.de/articles/others/consensus.htm). Other key principles, which are also important, were the development of new non-stigmatising and self-help approaches and the development of mental health legislation based on human rights, emphasising freedom of choice.

The reality is far away of any positive involvement of users and survivors of psychiatry in decision-making processes concerning topics of their fundamental interest. And speaking about mainstream psychiatric treatment: There is no involvement in any form of decision making, either in licensing psychiatric drugs or monitoring, or in individual decision making. Complete and understandable information, the basis for meaningful involvement, does not exist. Often psychiatric drugs are administered in a violent way or through bullying and threat. So-called psychiatric patients are seen only as cases in a double meaning: as treatment-objects, and as cases in the sense of boxes, filled with ill genes and disturbed transmitters, with a brain in the head functioning like a chemical laboratory, which regulates the body and mind like a mechanical apparatus, which is out of control.

Currently the main involvement of users of psychiatry is opening the mouth and swallowing administered drugs or presenting the buttocks to receive an injection.

ENUSP Policy

Empowerment is the key word that best shows the central interests of users and survivors of psychiatry. "Empowerment", a special term coming from USA, can be understood as "self-authorisation". Users and survivors of psychiatry should have or regain the authority over their own life, get access to information and money and speak with their own voice. Empowerment is the basis of prevention of mental disorders and promotion of mental health.

Many of us disagree with the conventional concept of mental illness and disagree with the need for synthetic psychoactive drugs—especially when prescribed for long-term daily use or even for life. But we do not close our eyes or deny the real problems many people experience. I belong to those who disagree with the psychiatric system incl. its diagnostic system. My point is, and I share this view with Karl Bach Jensen, chair of WNUSP, that people should not be locked up and left alone when they go crazy or out of their mind. A fundamental characteristic of necessary alternative mental health services would be to help people to cope with their problems by use of mutual learning processes, peer support, advocacy, alternative medicine, proper nutrition, natural healing, spiritual practice, etc.

Antidiscrimination activities

In the past, the Network participated in some European antidiscrimination programs and made proposals how to improve the situation of people with psychosocial disabilities, how users and survivors of psychiatry are often called. The last program, called "the action project 'Harassment and discrimination faced by people with psycho-social disability in health services'", was organised in the framework of the EC's Community Action Programme to combat discrimination 2001-2006. The overall aim was to raise awareness about the discrimination faced by people with mental health problems in health care services and to promote strategies to combat it (www.peter-lehmann.de/articles/enusp/recommendations.htm).

The recommendations were based on the opinions of the national partners and the Network, and inspired by the results of the focus groups that were held during the first year with users and survivors of psychiatry and health professionals.

Outcome of the studies was that 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.

Therefore, before summarising possible measures, emphasis should be put on the importance of the participation of users and survivors of psychiatry in the formulation and implementation of these measures. It was recommended, that the starting point for tackling harassment and discrimination 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 so-called experts and professionals. The motto "nothing about us without us" of the 2003 European Year of People with disabilities must become practice.

The project participants suggested 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 were seen a pre-requisite for the realisation of these recommendations. First topic in detail:

PROMOTION OF THE MOVEMENT OF USERS AND SURVIVORS OF PSYCHIATRY

The movement of users and survivors of psychiatry should be promoted. Effective participation of trained users and survivors is essential for the implementation and development of quality standards and research projects.

Funding and support should be invested in:

- free training programs for 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 programs to combat harassment and discrimination.
- the effective representation of users and survivors of psychiatry or user/survivor-workers in crisis centres, counselling centres, public relations work, research projects, congresses, networking and international exchange.
- the support of initiatives of peer coaching, self-help centres and meeting places.

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 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.

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.

- For example the legal protection of advance directives, or 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.

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

The current situation: I am very sad to tell you that the European Commission decided in 2004 to go on with his policy of rejection ENUSP's application to funds from antidiscrimination-programs, on the grounds that ENUSP is an organisation with few income, that means, not rich enough to get supported. The decision was done against our application within an program called "anti-discrimination programme". Now an organisation of professionals receives the money for organisatorical support—money, that was foreseen only for organisations of people with psychosocial dissabities themselves or with a meaningful involvement in decision making bodies.

Self-help, help to self-help and promotion of self-help

Self-help, help to self-help and promotion of self-help are of fundamental interest for users and survivors of psychiatry. There will never ever be any progress in healing, recovering, treatment, personal development, prevention and so on without the enhancement of our self-help resources. This is the message of the organised users and survivors of psychiatry all over the world. Self-help is the fundament of self-determined reflection of so-called symptoms of mental illnesses. This is not a contradiction to professional support, it is just the other side of the medal. How can professional support in the mental health system be effective, when activating self-help resources is not the result for the individuals' starting point to take responsibility for the own life, especially after a psychiatric crisis or coming off psychiatric drugs?

About the half of all psychiatric users decide not to take the prescribed drugs or to withdraw, like people with non-psychiatric diagnoses do also. Because in general professionals never speak about possibilities to come off psychiatric drugs, I take this chance here to speak about this important topic.

Gerda Wozart from Germany, one of the authors of the book "Coming off psychiatric drugs" (please find more information on www.peter-lehmann.de/books/withdraw.htm) encourages other so-called psychiatric patients: "We are on our own, called upon to live in a responsible way. We are not only sentenced by others, muzzled by others. We always have more forces (and self-helping forces, too) available than we might have thought in dark days."

Some authors of "Coming off psychiatric drugs" regard it as a fundamental condition to notice their own (co-)responsibility for their lives, their problem-burdened past and their responsibility for their future. Carola Bock from Germany says self-critically: "Today I know that I am partly to blame for the states of crisis because I acted wrong and was no angel at all. I often tried to solve my problems in a wrong way, too top-heavy, and I had not collected enough experience of life either." What better place for such an insight is there beside a self-help organisation?

As long as they make an open, non-invasive interchange of personal problems possible, self-help groups build the scope for mutual advice and for the spread of information about possible damages caused by psychiatric drugs and problems with coming off, as Nada Rath, born in Yugoslavia, reports: "Most important were the conversations with users and survivors of psychiatry who had comparable experiences and a similar attitude towards the world."

For Una Parker from England co-counselling means the end of the danger of psychiatric drugs and electroshocks again: "It has made a very great difference to me, and I think that the support I have had from regular co-counselling sessions not only kept me out of the psychiatric system but also helped me be much more effective in my life."

Conclusion

To support the involvement of users and survivors of psychiatry, and to support the efforts to create self-help-organisations have to go parallelly with financial measures, often the only measures which work. Self-help is the basis of personal development and recovery, and of political involvement of users and survivors of psychiatry. So financial contributions to psychiatric institutions, organisations and congresses should always be made dependent on a meaningful participation of users and survivors of psychiatry, there should always be a percentage for funding self-help and direct representation of users and survivors of psychiatry.

At first glance this proposal may seem expensive and rich of conflicts. However, only help to self-help and empowerment can be the fundament of a modern psychosocial system. On this fundament appropriate support—that means, psychosocial support targeting the real needs of people in emotional distress—can be developed. To a democratic society belongs a democratical mental health system. In such a democratical system the perspectives, wishes and treasure of experience of users and survivors of psychiatry have to be valuated; the people themselves have to be integrated in all aspects of decision making and education within the mental health system. On the middle and long term, empowering the people to enhance their self-help resources will save a lot of money of the society, and it will make your work more effective and more senseful.

The full involvement of users and survivors of psychiatry and carers organisations in the society is an indispensable element. Only on this basis people with psychiatric problems and their relatives can enjoy the status they deserve as citizens with full rights.