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Perspectives of (ex-)users and survivors of psychiatry

In the process of promoting mental health in Europe, people who have experienced psychiatric diagnosis and treatment as helpful in their specific situation must be heard, but so must those who have experienced them as a danger for their health and life. The use of psychiatric drugs and electroshocks in particular enhance — unintentionally — marginalisation processes, even if they are administered within the framework of medical treatment and care. This marginalisation means an increase in the number of disability pensions. The paper makes a plea for the possibility of meaningful participation — in the situation of virtual exclusion — for (ex)users and survivors in the promotion of mental health and in the prevention and treatment of mental illness. The inclusion of their experiences, interests and innovative approaches is necessary, but cannot be realised without funding and the right to self-determination, to respect and to appropriate help.

Actual forms of marginalisation processes within the framework of health promotion

A wide range of perspectives have been highlighted by the European Network of (ex)Users and Survivors of Psychiatry. The term "user" refers to people who have mainly experienced psychiatric diagnosis and treatment as helpful in their specific situation. The term "survivor" in turn refers to those who have mainly experienced psychiatric diagnosis and treatment as posing a danger to their health and life. These definitions are often misunderstood: to "survive psychiatry" does not mean that psychiatrists are being accused of trying to intentionally maltreat or kill people; but it does mean that diagnoses such as "schizophrenia" and "psychosis". which very often have a depressing and stigmatising effect, leading to resignation and chronic hospitalisation, must be prevented and that drug-effects such as neuroleptic malignant syndrome, tardive dyskinesia, febrile hyperthermia, pneumonia, asphyxia and other dystonic or epileptic attacks, which can pose a danger to health and sometimes even cause death, have to be survived. The unifying element in the European Network is dissatisfaction with the psychiatric system. This again does not deny problems that have to do with psychosocial stress or with mental ill-health and mental disorders; nor does it deny that some of the treated persons are fully satisfied with the treatment.

The report "Promotion of mental health on the European agenda" states that "many actual forms of professional action even if they happen in the framework of health promotion might even — unintentionally — enhance marginalisation processes".[1] According to thousands of reports, psychiatric treatment, especially electroshock and psychiatric drugs such as neuroleptics and antidepressants. can cause a deterioriation of mental health. Neuroleptic drugs can lead to apathy, a state of absolute emotional deadness, depression, suicidal states, confusion, delirium and intellectual

disturbances. Antidepressants can lead to apathy, depression, suicidal states, loss of creativity and lack of concentration. Lithium can lead to apathy, depression, suicidal states, loss of creativity and lack of concentration. Antiepileptics (administered as psychotropic drugs, e.g. carbamazepin) can lead to apathy, paradoxical agitation (a reaction contrary to the prescribed subduing effect), lack of creativity and epileptic attacks. Psychostimulants (administered to children in order to subdue them) can lead to apathy, depression, paradoxical agitation and memory problems. Tranquillisers can lead to lethargy, suicidal states, paradoxical agitation, sensory problems and memory gaps.[2]

Even if many individuals feel that they cannot continue to exist in their present life-conditions without taking psychiatric drugs, the treatment may still cause a deterioration of their mental health by, among other things, lowering their emotional resilience, impairing the conditions for psychosocial development and life skills, reducing their capacity to deal with the social world and to recruit the support that could be provided by other people, and diminishing their capacity to participate in the common effort to improve the environment and other conditions of life. Drug-caused receptor changes cause other mental-health-problems, making the life of many patients even worse and preventing them from having equal opportunities in life. The treatment may, thus, result in increased risk of marginalisation, disability and — death. Indeed, as a result of suicide and other causes of death, .the mortality of psychiatric patients is markedly higher than that of the population in general.

Without underestimating the responsibilities and potentials of health and social care institutions and of working life, we urgently need to enhance the resources for R&D in the field of mental health promotion. "Participation of the users" and "innovative approaches" should be the key words. New models of support in emotional crises, without the risk of causing a deterioration of mental health or increased marginalisation as a result of professional action, are needed. People with severe mental health problems need new forms of supported employment and of rehabilitation. These approaches should be based on the needs and interests of clients and users to a greater degree than they are at present.. Information, prevention and activities focusing on the major threats to health should also have high priority.

Time to rethink

There is a basic need to put discussion of alternatives to current psychiatric institutions on the European Agenda. We need a public and open discussion about innovative approaches to the development of better concepts, about methods of evaluation and sets of indicators relating to mental health and its promotion, and about the development of better methods for enhancing the visibility of the best national and European models of promotive work.

The knowledge accumulated during years of innovative work must be gathered and disseminated. Information has to be exchanged on the development of institutions and places that meet the needs of (ex-)users and survivors and of those who still are users of psychiatry. This by no means underestimates the legitimate and necessary work of those trying to improve the conditions inside the custodial psychiatric system in the interest of psychiatrised persons.

Questions put to the European agenda for the promotion of mental health by (ex)users and survivors are:

- What do (ex-)users and survivors of psychiatry want and need for themselves?
- Are there innovative institutions and organisations with a small or no risk of marginalisation?
- Do the institutions meet the needs of those (ex-)users and survivors of psychiatry who feel that psychiatric treatment caused a deterioration of their mental health?
- How far can innovative institutionalisation go?
- What kind of experiences are available for the invention and construction of innovative alternatives?

Cornerstones of mental health promotion

Funding and rights, self-determination, respect and appropriate help are the key themes of the organisations of (ex-)users and survivors of psychiatry, with members from about 30 European countries represented in the European Network. Resources are needed for the development of secure user-run or user-controlled alternatives to the psychiatric system. If (ex)users and survivors of psychiatry are not able to work regularly, they need money and support systems to enable them to live, and, if possible, working dignity corresponding to their individual capacities. Rights, i.e. diagnosis-independent human and social rights, are necessary to protect the body from unwanted medical manipulations, because physical health can be threatened and damaged by psychiatric methods. In addition, rights are necessary to free people from psychiatric and other arbitrary acts and from patronising attitudes.

Funding and rights, self-determination and respect, control of one's own life situation and appropriate help (that is, help in a situation in which there exists a subjectively experienced need in emotional crises of a social nature), are not new demands. They may be enshrined as general principles in recent publications focusing on the promotion of mental health, but they are not put forward explicitly as the voices, needs and rights of (ex-)users and survivors of psychiatry. As no references to the publications in the form of dissertations, documentations, memoranda, press-releases, books, magazines, or articles of their organisations, are made, we might be entitled to ask whether real, emphatic support for the organisations of (ex-)users and survivors of psychiatry does in fact exist within the framework of mental health promotion. I have the sad impression that (ex-)users and survivors of psychiatry, not all but still too many, are treated in the same way as they are in psychiatric institutions and statements, without real human dignity or value.

Funding and appropriate help

Funding is necessary to create effective social and emotional support controlled by (ex)users and survivors of psychiatry themselves and by people they trust. Therefore the European Network favours run-away houses, crisis spaces and communication centres combined with self-help offers, without registration and without compulsive methods; supportive institutions to which people do not have to be removed by police-force, but where they can go with trust instead of fear, even when they are emotionally extremely stressed, at their wit's end or confused.

One example of an appropriate and user-controlled institution is the Berlin run-away house. It is intended for people who have decided that they want to live without psychiatric diagnoses and without psychoactive drugs. In the run-away house they can regain their strength, talk about their

experiences and make plans for the future without psychiatric views of illness blocking access to their feelings and their personal and social difficulties. The house is manned around the clock by a team of social-workers, survivors of psychiatry and psychologists. Half of the staff members are themselves survivors of psychiatry. Our experience of more than two years of work in the run-away house has shown that, in principle, psychic crises can be managed without psychoactive drugs and without means of coercion.

Alternatives are needed within the psychiatric system as well. At our last conference, in 1997, it was stated that the development of alternatives within the psychiatric system calls for collaboration with professionals and, therefore, unfortunately, often an unacceptable level of compromise. Projects tend to be unambitious and inappropriate for users' needs. It is very difficult for professionals, and also frequently for users themselves, to understand that traditional methods and approaches might be both ineffective and damaging. It is essential for (ex-)users and survivors of psychiatry to own their own experiences and, if alternative strategies are effective in helping them, the helpers must recognise and respect that all individuals have their own reality and needs.

Rights and self-determination

The basic legal problem in psychiatry is forced treatment. I have too little space here to go into all the other psychiatric violations of inmates' rights. Of course we know that physicians have the duty to forcefully treat a person that cannot express his or her natural will rationally and is in deadly danger — but whoever died from a syndrome characterised by a lack of haloperidol? If people who do not work inside a psychiatric institution do not know about the dangers and risks caused by the administration of psychiatric drugs and electroshocks, they may not understand that fundamental violation of the inviolable dignity which should be guaranteed by human rights' declarations and national constitutions.

As stated above, neuroleptics, antidepressants, lithium, anti-epileptics (administered as psychotropic drugs), psychostimulants (administered to children in order to subdue them) and tranquillisers can have severe, permanent and even lethal effects. David Hill and the British organisation MIND have estimated that, by 1992, 190,000 people were known to have died from the neuroleptic malignant syndrome, a so-called side-effect of neuroleptics — without taking into account the huge number of unrecorded cases.[3] Another example is the above average incidence of breast cancer among female psychiatric patients: the rate is 3.5 times that among patients in medical hospitals, and 9.5 times than in the average population.[3,4] This obviously has to do with increased production of the hormone prolactin, another so-called side-effect of psychiatric drugs. Since 1978 it has been mandatory in the USA to make information available on the fact that rats which receive neuroleptics in maintenance treatment and in comparable dosages may start to develop neoplasm in breast glands that may result in tumours. In Europe no such information is available. This emphasises the necessity of receiving informed consent when administering psychiatric drugs. It is the perspective of the European Network to implement or strengthen users', ex-users' and survivors' rights to self-determination at all levels of the psychiatric system. The following principles, cited from the 'Mental Health Observer', written by (ex-)users and survivors of psychiatry, should be applied:

- People experiencing psycho-social disabilities should enjoy equal opportunities 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 with psycho-social disabilities should be respected.
- Equality of opportunity for persons with psycho-social disabilities should extend to all levels of the work organisation and management. This implies respect for confidentiality of personal information.
- Every workplace should conform to standards established by the social partners. ensuring a healthy and empowering work-place.
- Special positive measures, such as wage subsidies and supported employment schemes, should not be regarded as stigmatising or as discriminatory against other workers.[5]

The European Network aims to get these principles adopted in all countries and would welcome ideas. The Network also wants to have equal opportunities for (ex)users and survivors of psychiatry at congresses and other events, not only in the form of invitations, but also in the form of scholarships, funded travel and accommodation. This is a special message from Finnish (ex-)users and survivors of psychiatry who do not have the money to come to conferences and therefore consider themselves largely excluded. One proposal is to double the fee for psychiatric workers, to enable (ex-)users and survivors of psychiatry to participate, because they are generally in a very bad situation socially.[6]

Towards user-oriented mental health services in Europe

In addition to supporting the development of alternatives and human and social rights and the exchange of relative information, the European Network makes proposals to introduce or improve quality assurance in the psychiatric and psychosocial field.

In April 1997 the European Network was asked by the World Health Organisation to comment on the planned Declaration on Quality Assurance in Mental Health Care. To promote human rights of people in the psychiatric system the European Network suggested, among other things, that:
- (Ex-)users and survivors of psychiatry should be invited to hearings before legislation is enacted.
- (Ex-)users and survivors of psychiatry should be invited to be ombudsmen and ombudswomen at a national level.
- There should be a body including (ex-) users and survivors of psychiatry at a national level to monitor the human rights of people who have, or who are said to have, mental disorders, and to record new treatment measures and decisions of ethics' commissions in research fields.
- (Ex-)users and survivors of psychiatry should be involved in the education and examination of health and psychiatric professionals in a paid capacity.
- Irreversible treatments such as psychiatric drugs, electro- and insulin shock for mental disorders should never be carried out on an involuntary patient or without informed consent. Psychiatrists who treat patients without informed consent should lose their medical licence.
- Clinical trials and experimental treatments should never be carried out on an involuntary patient without informed consent. Institutions carrying out any such measures should be obliged to prove that any damage arising was not caused by these measures.
- Coin-operated telephone-boxes, writing paper, envelopes and stamps, uncensored notice boards, kitchen facilities, and smoking and non-smoking areas should be available in all psychiatric wards;

- Patients should be allowed daily walks in the fresh air for at least one hour;
- For every psychiatric bed there should be one bed in an anti- or non-psychiatric run-away house or comparable institution. Every other psychiatric bed should be in a Soteria-like institution.[5]

Conclusions

A considerable number of actual forms of professional action, especially drug-treatment of psychosocial problems, even if carried out within the framework of the psychiatric system, enhance, albeit unintentionally, marginalisation processes.. The European Network of (ex-)Users and Survivors of Psychiatry sincerely wishes for serious co-operation to improve those approaches in the provision of mental health care that promote marginalisation among the citizens of European member states through processes that reduce the ability to work and thus lead to an increase in the number of disability pensions.

The European Network will — of course — co-operate with all organisations and people who seriously stand up for better conditions for (ex-)users and survivors of psychiatry — and who seriously stand up for them not only through words, but through actions, too.

The European Network wants to have a meaningful participation to ensure input and influence for (ex-)users' and survivors' interests in international organisations such as the World Health Organisation, the European Network on Mental Health Promotion, the European Network on Mental Health Policy and the World Federation for Mental Health. Modern promotion of mental health in Europe has to integrate and promote the innovative approaches of users and clients themselves.

References

The list of references is available on request from STAKES, Mental Health R&D Group,
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