Promotion of mental health and prevention of mental disorders by empowerment

Is there a psychiatry-policy without meaningful participation of (ex-) users/survivors of psychiatry?

Contribution by Peter Lehmann for: Promotion of Mental Health on the European Agenda: European Conference on Promotion of Mental Health and Social Inclusion. 10 – 13 October 1999, Tampere (Finland)

Abstract: Empowerment is the key word of promotion of mental health and prevention of mental disorders. Models of good practises like the user-controlled runaway-house in Berlin, like the user-run Hotel „Magnus Stenbock" in Sweden, like the integration of (ex-) users and survivors of psychiatry in different matters in Germany show the good results of user/survivor-orientated policy. Financial contributions to psychiatric institutions, organisations and congresses should be made dependent on a meaningful participation of (ex-) users and survivors of psychiatry and the acknowledgement and active protection of human rights. Financing of self-help- and non-stigmatising approaches should have highest priority in psychiatry-political decisions.

Empowerment

Empowerment is the key word that best shows the central interests of (ex-) users and survivors of psychiatry who are dissatisfied with existing psychiatry. „Empowerment", a special term coming from USA, can be understood as „self-authorisation". (Ex-) users and survivors of psychiatry should have or regain the authority over their own life, get access to information and money, speak with their own voice etc. (1).

Speaking more about terms: The term „user of psychiatry" refers to people who have mainly experienced psychiatric diagnosis and treatment as helpful in their specific situation. The term „survivor of psychiatry" in turn refers to those who have mainly experienced psychiatric diagnosis and treatment as being 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 kill people. But it does mean that diagnoses such as „schizophrenia" and „psychosis" often have a depressing and stigmatising effect, leading to resignation and chronic hospitalisation, and that drug-effects such as neuroleptic malignant syndrome, tardive dyskinesia, febrile hyperthermia, pneumonia, asphyxia and other dystonic or epileptic attacks can be a danger to health.

To speak from the European Network of (ex-) Users and Survivors of Psychiatry (ENUSP), an acknowledged Non-Governmental Organisation, means to focus on its several added values inclusive the broad representation from different organisations in East and West and in the different national states. ENUSP, an autonomous and democratic organisation, includes organisations from all European states, even those that are to join the EU in coming years.

Empowerment is the criterion which (ex-) users and survivors of psychiatry use world-wide to characterise their concepts more acceptable psychosocial institutions. But in Europe not only the term is relatively different, but also the idea and particularly practice. Mostly it concerns only another handling, thus still around a subject-object-relationship which leaves (ex-) users and

survivors of psychiatry in a status of the passivity and negates the chances of the so-called power of self-healing.

Many actual forms of professional action even if they happen in the framework of health promotion might even – unintentionally – enhance marginalisation processes, the report „Promotion of mental health on the European agenda“ is stating (2). According to thousands of reports, psychiatric treatment, especially electroshock and psychiatric drugs such as neuroleptics and antidepressants, can cause a deterioration of mental health. 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, physical illness and mental disorders.

But it is not only drugs or electroshocks that are risks for health, it is the exclusion of all possibilities of meaningful participation in decisions about one's own life, starting in the ward of a mental institution, where most so-called patients are only objects of treatment, and ending in political decisions on every level where the organisations of (ex-) users and survivors of psychiatry mostly are excluded – mostly. But there are some exceptions. There are some first steps in psychiatry-policy to integrate (ex-) users and survivors of psychiatry into decision-making processes.

Co-operation by integration of (ex-) users and survivors of psychiatry into the decision-making processes

Article 4 of the statutes of Mental Health Europe (MHE) says, that the aim of MHE shall be to promote mental health, to prevent mental illness and to protect and advance the interests of all people with mental health problems, persons and risks, and their relatives and families, as expressed by themselves. This last term „as expressed by themselves“ was integrated into the first draft of the statutes to ensure the meaningful participation of (ex-) users and survivors of psychiatry.

One example, how this form of co-operation works, was the acceptation of a resolution of WNUSP in Santiago, Chile, September 1999, by the general assembly of the World Federation for Mental Health. As spreading laws and courts' decisions on forced outpatient treatment with psychiatric drugs give (ex-) users and survivors of psychiatry deepest concern and produce desperation and depression in many cases. To destroy the human right of self-determination and to rob somebody of his or her own safe living-room create paranoia and other mental disorders. WNUSP's resolution „Because of concern about the spread of forced psychiatric procedures into the community, resolved that WFMH supports the position of WNUSP in opposition to involuntary outpatient commitment“ accepted by WFMH gives hope to prevent the danger of further spreading of forced outpatient treatment and its consequences, new and enhanced mental disorders. When the resolution was accepted, there now is the possibility to co-operate on international and national levels to prevent the human rights violation of outspreading forced treatment.

The meaning of the inclusion of (ex-) users and survivors of psychiatry became clear also with the conference ›Balancing Mental Health Promotion and Mental Health Care. Joint World Health Organisation / European Commission Meeting‹, Brussels, 22 – 24 April 1999. Also one representative of ENUSP was invited beside approximate 70 psychiatric workers and other people who were not (ex-) users and survivors of psychiatry either. So it was not coincidence that almost exclusively lectures of psychiatrists were to be heard who hardly can be called critical to psychiatry. The necessity of the inclusion of (ex-) users and survivors of psychiatry was expressed by the reaction to the given suggestions given itself by regarding common goals and strategies to advance mental health promotion and care:

„Developing innovative and comprehensive, explicit mental health policies in consultation with all stakeholders, including users and carers, and respecting NGO and citizen contributions

Development of primary care and specialised mental health services focusing on quality of care and the development of new non-stigmatising and self-help approaches

Development of mental health legislation based on human rights, emphasising freedom of choice, and the importance of appropriate confidentiality.“ (3)

Only after strong criticism (nobody from the famous and ›progressive‹ psychiatrists had openly dared it to affirm the position of ENUSP) and under friendly support by the European-Union-representatives (DG/V/F), Alexandre Berlin and Horst Kloppenburg, the active inclusion of (ex-) users and survivors of psychiatry to psychiatry-policy, the promotion of self-help-approaches and non-stigmatising (non-psychiatric) alternatives and above all the freedom of choice as aspect strengthening human rights were added to the consensus-paper.

Co-operation against human rights' violations

Characteristically it are almost exclusively (ex-) users and survivors of psychiatry which complain about violations of human rights. How important co-operation is regarding the improvement of the human-rights-situation, got clear by the statement of Theresja Krummenacher who deplored the general practice on the hearing of the council of Europe on March 3, 1999, also with the mandate of ENUSP: If non-voluntarily admitted patients do not wish to take the offered psychiatric drugs, the psychiatrists think that they do not have the possibility of making rational decisions what only could be an expression of the impossibility of the person to comprehend the seriousness of his or her situation and the need for treatment. This causes human rights' violations all the time. It is always a crazy-making „Catch 22“-situation if you are asked to accept psychiatric drugs, but when asked only the yes-answer is accepted as sign of rational decision and the no-answer, given under the same circumstances, arbitrarily is interpreted as a sign of illness.

One typical example of a psychiatric human rights' violation that is seen only by (ex-) users and survivors of psychiatry is the case of Erik X., a man without a clear nationality, born in 1946 whose mother was a Norwegian Torunn Anderssen-Rysst, who married in 1948 in Edinburgh a Scotsman Pawel Kazimierz Michalski. In 1968 the young man Erik went from Scotland to Oslo to study and to look for his biological father, where he came in contact with the Oslo Health Department Helseråd and a doctor who knew the psychiatrist Hans Torp, Erik was advised to go to the Oslo psychiatric hospital „Gaustad“. Erik thought it was a place where he could live and search for help. But he was imprisoned, and since 1968 Erik is forcibly imprisoned in Gaustad, where

he has shared a cell with Arnold Juklerød. Erik's „symptom" is his belief, that the documents about his parents he once saw are faked. For the last eleven years he has been in a maximum security ward, heavily drugged and never allowed to take a walk alone. There is no juridical commitment, so the information says, only a decision of a Gaustad psychiatrist that Erik has to be imprisoned. And – not surprisingly – of course nobody has any knowledge about something which is usually called a treatment-plan. Erik now has considerable medical problems because of the psychotropic drugs he has been forced to take for 31 years and the heavy tardive dyskinesia and the related mental problems they produced. His living conditions are intolerable. After a hard fight to improve his conditions by Norwegian self-help- and antipsychiatric activists in September 21, 1999, Erik was visited by representatives from the Committee for Prevention of Torture and Inhuman Treatment or Punishment, section of the Council of Europe in November 1999 (the report from that committee was not finished). Norwegian psychiatrists never cared for that scandal.

„The truth about cats you hear from the mice", a slogan of a Berlin self-help-group was. Co-operate with us „mice", if you want to strengthen human rights in psychiatry. There are some examples of co-operation attempts and approaches in this connection, here I refer to Germany. Complete psychiatry laws were developed by political parties in the federal states of Berlin and Hamburg under inclusion of (ex-) users and survivors of psychiatry – laws which in particular contained the legal security of advance directives for the protection of the right of self-determination and human dignity (4, 5). It is a pity that these laws were not accepted by the parliaments. Also at the hearing to the care-law in 1989 (ex-) users and survivors of psychiatry have been heard, although much too few. Consequence was the recommendation in the implementing regulations of the law, that advance directives should be respected – a small step into the correct direction. But we want certainty of the law also for us. Human rights are not divisible. (Ex-) users and survivors of psychiatry have to have the same rights as so-called normal patients.

Co-operation by integration of (ex-) users and survivors of psychiatry into projects on national levels

In 1995 the board of the national German organisation of (ex-) users and survivors of psychiatry was asked to participate in an investigation on quality-control and improvement of psychiatry. The desire for co-operation had been placed by the editorship of the psychiatric periodical ›Sozialpsychiatrische Informationen‹. A decision was made to participate in the inquiry but to change the questions. questions. For example the question „How can the quality of psychiatric care be improved" was modified into: „Was their an interest in psychiatry to find an answer to the question what caused your admission into psychiatry?" respectively „Did you receive complete and under-standable information about risks and so-called side-effects of treatment measures?"

About 130 people participated in the survey. Their responses gave a highly disillusioning answer to the existing psychiatry. Because only 10% of the answering persons experienced an assistance for the solution of the problems which had led to the psychiatrisation. Frequently human rights have been violated. Human attention and warmth, individual being with, fearless bond of trust were demanded and not fulfilled. For a group of (ex-) users and survivors of psychiatry the psychiatry altogether including psychiatrists is unnecessary. Force, the use of psychiatric drugs, coercive measures, electroshock, constraint belts or physicians who believe to know better about their patients than themselves are unnecessary. Alternatives are considered important,

though in order to allow freedom of choice: alternative psychotropic drugs e.g. natural and homeopathic means, self-help, runaway-houses, Soteria-like alternatives with soft rooms (6). Surely you may imagine that without inclusion of (ex-) users and survivors of psychiatry and without their modification of the questions these – also for political planning instances – vital results would not have become recognisable.

Members of the German association of (ex-) users and survivors of psychiatry call themselves „people who are experienced in psychiatry". The slogan of the organisation is a wisdom of the old China: „If you want to know something, then ask an experienced person and not a scholar."

Co-operation by national financial support of self-help

Here again an example from Germany: One result of the inquiry of the German association of (ex-) users and survivors of psychiatry 1995 was the fact that in psychiatry basically there is no information about the risks and so-called side-effects of prescribed psychiatric drugs. As a result of the co-operation at the inquiry now, since August 1999, the German association of (ex-) users and survivors of psychiatry is offering a nation-wide advice on psychotropic drugs from the view of (ex-) users and survivors of psychiatry. By telephone and in writing here (ex-) users and survivors of psychiatry and their relatives can get advice about psychiatric drugs and withdrawal-risks and possibilities. This advice from the view of (ex-) users and survivors of psychiatry is necessary too, because people who experienced psychiatric treatment – the experienced ones – have another emphasis on this topic and other interests than physicians or the drug industry. This advice became possible by the granting of a paid working place by the official employment office. The advice on psychiatric drugs for (ex-) users and survivors of psychiatry by (ex-) users and survivors of psychiatry is supported by means of the German „Bundesanstalt für Arbeit" (Federal Institution for Work). Among other things one tries to answer the following questions:

- How do neuroleptics and other psychiatric drugs work?
- Are there alternatives to neuroleptics? How do naturopathic drugs work?
- When does it make sense to take psychotropic drugs? Which books inform understandably about psychiatric drugs?
- Do neuroleptics make dependent?
- Are the new atypical neuroleptics better than the classical ones?
- Why am I to take olanzapine (Zyprexa) suddenly although I was well on my old medicine?
- Do neuroleptics cause despondency (depressions)?
- Why do I end in the psychiatric ward, although I take my maintenance dose?
- How do I find the psychotropic drug best for me and the dose best for me?
- How do I come off most favourably? Which risks are there when withdrawing?
- How do I find a physician who helps me when coming off?

Indisputably it is a requirement of reason that passive swallowers of psychiatric drugs develop to human beings who take psychiatric drugs or withdraw from them by self-determined and rational decision and who

eventually design the decided act of withdrawal in such a way that the risk of repeated psychiatrization is diminished optimally.

Co-operation by license agreement of non-stigmatising approaches and alternatives to psychiatry

To stay in Germany: The Berlin user-controlled Runaway-house, opened in 1996, is an antipsychiatric crisis-centre for people without a flat who mostly spent a long time in psychiatric institutions and now decided to live without psychiatry, without its diagnosis and without psychiatric drugs.

Experiences since 1996 show, that the stay in the runaway-house helped 20% of the residents to move into their own apartments (sometimes with an individual support worker for some hours a week). 25% moved into other institutions such as sheltered accommodation, supported living, women's places. 17% went to stay with friends or their families. 13% went into a psychiatric or psycho-somatic hospital. As for this group it is important to note that for example in 1998, four out of eight residents who went into psychiatry stayed only four days in the Runaway-house, the other four less than a month. 7% left for the street or shelters for homeless people and 5% are unknown to the team of the Runaway-house. Statistically, it is evident that the longer the stay in the Runaway-house the higher the number of those who move into their own apartment or into a considerably less intensive form of supported accommodation (7, 8).

Hotel „Magnus Stenbock“ in Helsingborg in Sweden is one the world-wide largest user-run institutions for (ex-) users and survivors of psychiatry. In this hotel of the national Swedish association RSMH (ex-) users and survivors of psychiatry can live in their own apartments, and in the community-rooms they can find peers and people to talk with and if needed. It is a unique institution for the mass of (ex-) users and survivors of psychiatry who only want this one, but get it almost nowhere: to have a room for their own and are let alone if they want it. The hotel is financed by the Swedish state which had recognised, that such a form of housing saves a lot of expenses (9, 10).

More proposals for co-operation on different levels

In 1997 ENUSP made further suggestions of co-operation, when it was asked by the World Health Organisation (WHO) for a statement to the draft „WHO Quality Assurance in Mental Health Care: Human rights of people with mental disorders“. As features of a qualitatively acceptable psychiatry among other things four conditions were called by ENUSP which for (ex-) users and survivors of psychiatry are of substantial importance and can help to cause the conditions for a quality improvement (11).

Condition 1: „At any given facility, there should be sufficient space for the number of inmates or patients admitted. There should be phone boxes for inmates or patients in every psychiatric ward. There should be easily visible coin-operated telephones at the entrance hall of each psychiatric institution. In each psychiatric ward there should be an easily visible notice stating that inmates or patients can get writing paper, envelopes and stamps if wanted. There should be notice boards in every ward on which local, regional and national organisations of (ex-) users and survivors of psychiatry can put uncensored information. For each inmate or patient there should be the offer to have a daily walk in the open air for at least one hour. On each ward there should be a kitchen where inmates or patients can prepare food and drinks around the clock. The non-smokers' right to have good air to breathe should be guaranteed. The smokers' right to smoke as long as they want should also be guaranteed. Meals served to inmates or patients should meet

recommended minimum nutritional requirements. The needs of people who want special diets should be met.“

This condition was formulated by the German association of (ex-) users and survivors of psychiatry and taken over by ENUSP. It 1994 in Germany the demands where told to the „Bundesdirektorenkonferenz“ (the leaders of psychiatric hospitals) who run a conference under the slogan „dialog with users of psychiatry“. Since then the German association of (ex-) users and survivors of psychiatry has tried to get a statement of the German psychiatrists to this demand – in vain. The demand probably rather is to be addressed to politicians, connected with the request to give only such psychiatric institutions the possibility to receive money from the health insurance companies if they fulfil the mentioned condition of quality of care.

Condition 2: „It should be acknowledged by psychiatric associations and/or by reforms of the law that advance directives (made during non-doubted states of normality) about wanted and unwanted treatments have to be respected.“

Condition 3: „(Ex-) users and survivors of psychiatry should be involved in the education (including the boards of examiners) of psychiatrists meaningfully. Organisations of (ex-) users and survivors of psychiatry should be acknowledged as organisations of individuals with a high level of expertise. There should be ombudsmen and ombudswomen who are (ex-) users and survivors of psychiatry at national levels on a well-paid level.“

It is up to the decision makers to assume offers for improved inclusion of (ex-) users and survivors of psychiatry into education, decision-making processes on each level, monitoring and to secure them by formal decisions and sufficient financing as well as and negative consequences for psychiatric institutions who do not want to co-operate at all.

Condition 4: „There should be bodies including (ex-) users and survivors of psychiatry specifically charged, at national levels, with monitoring the respect of human rights of people with mental disorders or who are said to have mental disorders. The task of these bodies should include the registration of new treatment measures and decisions of ethics' commissions in research fields.“

More offers for co-operation are welcome. ENUSP is eager to hear on which fields somebody wants to co-operate. Where are the limitations? Why is co-operation needed at all? How much money is available by cutting the conventional psychiatric field? Which parts of power will be yield in favour of the participation of (ex-) users and survivors of psychiatry respectively can be taken away from psychiatric institutions to give it to (ex-) users and survivors of psychiatry and their organisations?

Summary

Here again central interests and goals of (ex-) users and survivors of psychiatry regarding the development of mental health policies, promotion of mental health and prevention of mental disorders:

- User orientation in prevention and support
- Inclusion of (ex-) users and survivors of psychiatry and acceptance of their treasure of experience on all levels of decisions, administration, education and research
- Protection from unwanted medical manipulations (no psychiatric right to arbitrary forced treatment)
- Freedom of choice as a characteristic of quality of care

- De-institutionalisation instead of constant development of community psychiatry. Development of alternatives to psychiatry for (ex-) users and survivors who made bad experiences with psychiatry or who doubt the competence of medicine to solve psychological problems of social nature
- Financing of self-help and alternatives by splitting the available money.

Financial contributions to psychiatric institutions, organisations and congresses should be made dependent on a meaningful participation of (ex-) users and survivors of psychiatry. Meaningful participation means that (ex-) users and survivors of psychiatry are integrated in planning processes, are supported financially to participate, are integrated in all meetings and decisions and speak more then few minutes in meetings and congresses.

ENUSP is very sad to tell at this „European meeting on promotion of mental health and social inclusion“ in Tampere in October 1999, financially supported by the European Commission, that this European Commission decided in summer 1999 not further to support ENUSP. This decision makes it very complicated for ENUSP to exchange information and even to have a well-functioning desk to make co-operation optimal. ENUSP hopes for support to change the bad situation again.

„Psychiatric services belong to the users“, Eero Lahtinen from STAKES (Finland) said at the „Joint World Health Organisation / European Commission Meeting“ in Brussels in April 1999. This should become reality: (ex-) users and survivors of psychiatry should be included effectively into all topics.

At first glance this proposal may seem expensive and rich of conflicts. However, self-help and empowerment as means for promotion of mental health and prevention of mental disorders in particular – in view of sinking public funds and increasing efforts for equal opportunities – are justified not only morally, but also help to guarantee mental health and the prevention of mental disorders. ENUSP and the organisations, which are organised in ENUSP, are ready for co-operation.

Sources

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