

About the impossibility of a single (ex-)user and survivor of psychiatry position

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Objective: To present the European Network of (ex-)users and survivors of psychiatry and discuss issues of concern among (ex-)users and survivors.

Method: Material from papers and documents published by and discussed among (ex-)users and survivors of psychiatry is used to outline topics of interest.

Results: The European Network of (ex-)Users and Survivors of Psychiatry (ENUSP) was founded in 1991 as an association of national/regional organizations of (ex-)users and survivors of psychiatry. The network organizes biennial conferences, all delegates are (ex-)users and survivors of psychiatry. ENUSP aims include the fight against discrimination of people with experience of the psychiatric system, support for (ex-)user/survivor organizations, influence on policy-making, legislation and human rights debates, demedicalizing psychiatry, and opposition to unidimensional approaches to mental and emotional distress.

Conclusion: (Ex-)users and survivors should be involved in monitoring psychiatric services, education and examination of mental health professionals. User/survivor-controlled services constitute an important innovative service.

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Introduction

Since 1970 criticism of psychiatry in its various forms has led to a broad spectrum of antipsychiatric and other critical discourses, practices and movements promoting the abolition of psychiatry, alternatives or psychiatric reform. This criticism emerged within institutions (e.g. Laing, Cooper, Basaglia) or outside of them as independent movements of (ex-)users and survivors of psychiatry. Critical attitudes towards psychiatry date back longer than 1970: in 1846 the 'Vereinigung der Irrenfreunde' was founded on the initiative of John Perceval (1). However, more systematic unions of (ex-)users and survivors of psychiatry have been founded in the early 1970s as part of the new social movements in various European countries as well as in the USA (2).

This paper will discuss the difficulties of claiming the user/survivor position and describe

the history of the European Network of (ex-)Users and Survivors of Psychiatry (ENUSP), its aims and the most important political positions. Some other user/survivor institutions will also serve as examples. For reasons of simplicity (ex-)users and survivors of psychiatry will be referred to as users/survivors in the text.

Naming

Naming has always been a key issue in the user/survivor movement because those concerned wanted to distinguish themselves from the attribution of being a patient or mark their distance towards the concept of mental illness, of which the majority of users/survivors are very critical. Names used or created as self-description in opposition against the terms used by psychiatry are consumers, (service) users, survivors of psychiatry, psychiatric survivors, clients,

victims of psychiatry, ex-users, ex-patients, ex-inmates, lunatics. The most common terms in German *Psychiatrie-Betroffene* (people afflicted by/confronted with psychiatry) and *Psychiatrie-Erfahrene* (people who have experienced psychiatry) do not really translate into English. Sometimes these two terms are considered as synonymous. The term *Psychiatrie-Betroffene*, however, accentuates the violence of entry into psychiatry in contrast to the term *Psychiatrie-Erfahrene*, used by the German national association of (ex-)users and survivors of psychiatry, Bundesverband Psychiatrie-Erfahrener (BPE), which has a more positive or neutral connotation.

After a long and difficult discussion, ENUSP and WNUSP (World Network of Users and Survivors of Psychiatry) decided to employ the term (ex-)users and survivors of psychiatry in order to provide a possibility of identification to the different groups and positions represented in these international NGOs. Those who identify as survivors of psychiatry distinguish themselves mainly by an antipsychiatric attitude and thus a radical criticism of the psychiatric system. Those who identify as users of psychiatry or mental health services are more orientated towards psychiatric reform and have also sometimes experienced psychiatric services as helpful. These different terms which users/survivors choose to identify themselves already reflect some of the differences in positions represented in the user/survivor movement.

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

In order to provide an overview about the most important European NGO of (ex-)users and survivors, the history and most important aims of ENUSP will be described. ENUSP was founded in Zandvoort, the Netherlands, in October 1991. Forty-two representatives from 16 European countries met at a conference to found ENUSP.

ENUSP is an attempt to give (ex-)Users/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. The Network attempts to influence institutions which produce or bring about policy on a European level, concentrating on legislation and Human Rights issues, demedicalization of psychiatry and supporting alternative(s) to psychiatry (3, 4).

Every 2 years, delegates from the ENUSP members in more than 40 European countries meet at a conference where the policies for the coming period are set out. All delegates are (ex-)users and survivors of psychiatry. At ENUSP's second conference in Elsinore, Denmark, in May 1994 70 people from 25 countries participated. The third conference was held in Reading, UK, in January 1997 where 110 people from 40 countries participated. At the fourth conference in Luxembourg in January 1999 ENUSP was formalized as a 'Vereinigung' under Dutch law. The next conference is intended to take place in April 2002.

National or regional organizations of (ex-)users and survivors of psychiatry constitute the membership of ENUSP. In countries where no national/regional associations exist, local groups or individual users/survivors can become members. At the general assembly that takes place during the biennial conferences a board is elected that consists of a chair and co-chair and representatives of the five regions into which ENUSP is divided.

The following quote from ENUSP's Statutes illustrates its basic aims (5):

- 1) The aim of the Federation is to define, promote and improve the rights of (ex-)Users/Survivors of Psychiatry, to create and support alternative programs to the conventional psychiatric system, and to prevent psychiatric abuses throughout Europe.
- 2) The Federation shall achieve these aims by, among other activities:
 - (a) Contesting any kind of discrimination toward persons who are, or have been, subject to the psychiatric system.
 - (b) Supporting the development of (ex-)User/Survivor organizations in all European countries.
 - (c) On a European level, influence policy-making institutions, with the emphasis on legislation and Human Rights issues.
 - (d) Demedicalizing psychiatry.
 - (e) Offer (ex-)Users/Survivors a means to communicate with one another so they may exchange opinions, perspectives and experiences and so they can support each other in their personal, political, and social struggle against psychiatric injustices and stigma.
 - (f) Supporting (ex-)users/survivors' autonomy in making their own decisions.
- 3) The federation is opposed to any unilateral approach to, and stigmatization of, mental and emotional distress, madness, human suffering and unconventional behaviour.

Most users/survivors who meet within ENUSP find the exchange and the culture of respect

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despite the spectrum of political, cultural, religious, personal differences very fruitful. Besides being this forum for exchange ENUSP endeavours to play a role on the international arena where the politics of psychiatry are discussed and determined. Thus, ENUSP tries to have a say in the preparation of international conferences in order to get the experts' views on the agenda, i.e. the users/survivors representing themselves. ENUSP representatives often find it difficult to achieve this goal and see the risk of serving an alibi function. An ideal of partnership is users/survivors' equal representation, and equal influence in decision-making remains a challenge when psychiatric professionals and users/survivors are working together.

In order to influence European policies on psychiatry, ENUSP is commenting and debating declarations, position papers, policy guidelines of the EU, UN, WHO and other important bodies. In April 1997, for example, ENUSP was asked by WHO to comment on the planned Declaration on Quality Assurance in Mental Health Care. ENUSP made, among others, the following suggestions to promote the human rights of (ex-)users and survivors of psychiatry:

- (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 1 h.
- 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 (6).

Another example of ENUSP trying to influence European policy on human rights are the extensive comments and criticism ENUSP and its various member organizations made concerning the 'White Paper on the protection of the human rights and dignity of people suffering from mental disorder, especially those placed as involuntary patients in a psychiatric establishment' that was drawn up by a Working Party of the Steering Committee on Bioethics (CDBI) of the Council of Europe. When this paper had been published for consultation, the various member organizations discussed it thoroughly and formulated statements that they brought to the attention of their respective governments. ENUSP also adopted a statement including all the individual statements in order to criticise the paper, highlighting its dangers of forced treatment in the community and its effects that infringe the human rights of users/survivors considerably (for the full text see www.enusp.org). To ENUSP, this White Paper favours the stigmatization of users/survivors and overrules resolutions such as the 'Conclusions of "Balancing Mental Health Promotion and Mental Health Care Joint World Health Organisation/European Commission Meeting"'. To ENUSP the key points of this consensus document are the development of 'innovative and comprehensive mental health policies in consultation with all stakeholders, including users and carers', 'the development of new non-stigmatizing and self-help approaches' and the 'development of mental health legislation based on human rights, emphasizing freedom of choice, and the importance of appropriate confidentiality' (7).

User/survivor-controlled services

Besides advocating for the human rights of users/survivors and striving for psychiatric reform

or substantial changes in the psychiatric system, the promotion of self-help and user/survivor-controlled services has always been a central issue on the movement's agenda. The Runaway-House in Berlin is a current example of an alternative institution that is survivor-controlled by the right to veto of the survivor members of the Association for the Protection against Psychiatric Violence that runs the Runaway-House (8). It is an antipsychiatric crisis centre for homeless survivors of psychiatry where the residents can live for a limited amount of time. They receive support in dealing with their psychosocial difficulties as needed around the clock; this includes living through crisis without psychiatric drugs (support in withdrawal processes is part of the offer of the house) and psychiatric diagnoses, developing new perspectives for a life outside the (social) psychiatric net. Half the staff members are survivors of psychiatry themselves. The residents organize their everyday life themselves and are considered responsible for their own lives. The house has been functioning successfully for more than 5 years now and about 300 people have lived in the Runaway-House (9). In Helsingborg, Sweden, the Hotel Magnus Stenbock which is run by the user/survivor organization RSMH gives users/survivors a possibility to live in their own apartments and to choose whether or not they want to talk to the workers or the other residents. It is financed by the Swedish government and run entirely by users.

In Germany as well as in many other countries there are self-help groups of users/survivors all over the country which are an important cornerstone of empowerment. Moreover, the national user/survivor organization BPE is attempting to start two counselling centres for users/survivors where users/survivors find non-psychiatric advice by other users/survivors, including a resource centre, the promotion of self-help groups, etc. For 1 year the BPE could employ one person to provide counselling to people on psychiatric drugs and ways of withdrawal. Voice of Soul, a user/survivor organization in Hungary, also provides computer training and language classes for its members and operates a rabbit farm in order to give its members a means to earn money.

These examples, as well as the others existing in other countries, show that users/survivors create their own alternatives to the current psychiatric system. Users/survivors are not only experts by experience, i.e. by having been treated in psychiatric services and/or having experienced madness, extraordinary states of mind or perceptions,

etc., but also by their reflection upon those experiences and by all their other qualifications in life. A considerable number of users/survivors have worked in self-help groups or as peer supporters or as providers of user/survivor-run or -controlled services. To this extent they also have 'professional' qualifications in addition to their qualifications as people who have been subject to psychiatry, who have reflected upon this experience and found ways to come to terms with it.

A considerable obstacle to realizing more of these user/survivor controlled alternatives is the constant lack of funding. It demands extreme efforts and often a very long time until users/survivors are given adequate funding opportunities. Funding has always been a key issue in the user/survivor movement. The social situation of a lot of users/survivors is precarious and except for few organizations in countries such as Sweden the user/survivor groups are in constant lack of adequate financial resources in order to run the activities they are planning. ENUSP also always had financial difficulties. Initial funding for the European Desk, which is situated in the Netherlands and locates the secretariat of ENUSP, has come from the Dutch government and for 2 years there has been a grant from the European Commission. Since 1999 there has not been adequate funding, which weakens the opportunities ENUSP has to promote its aims. Participation in international conferences is also often limited due to lack of funding. Ensuring meaningful participation also means financing policies to enable user/survivor participation and needs a reflection on influence in all the decisions and considerable involvement in an early stage.

Conclusion

This paper reflects the diversity of positions of users/survivors and thus illustrates why there cannot be the one user/survivor position, although there is much common ground among users/survivors. In order to ensure meaningful participation of users/survivors it is not sufficient to invite individual users/survivors randomly in order to present their views or the positions of their organizations. Meaningful participation can only be achieved by having equal numbers of all stakeholders and equal rights as well as equal resources, decision-making power and influence at all stages of a project, an initiative, a conference, etc. The basis is also considering the users/survivors as experts on the basis of their competencies regarding the issues.

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