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A Snapshot of Users and Survivors of Psychiatry on the International Stage[1]

This article reviews recent developments for those users and survivors of psychiatry and their supporters who respect the right of self-determination.

The last congress of the European Network of (ex-) Users and Survivors of Psychiatry (ENUSP) and the World Network of Users and Survivors of Psychiatry (WNUSP) in Vejle in Denmark was held in 2004. There is a lot of information pertaining to this congress on the internet at the website www.enusp.org/congresses/vejle/index. Since then, many interesting things have occurred for those users and survivors of psychiatry and their supporters who respect the right of self-determination. This view is not realized sufficiently or made use of by the national self-help groups nor by reform psychiatry. This overview should help the situation. It does not claim to cover all activities; some topics can be addressed only very briefly. There are four groups which should be mentioned in the European arena regarding users and survivors of psychiatry. A fifth group solely claims to represent them.

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

In 1991, representatives of independent groups founded ENUSP (www.enusp.org), a federation of member organizations. Central duties of the

1. This paper reflects the personal view of the author, not the view of the whole ENUSP board. Some board members feel it has a negative tone when ENUSP board needs to be positive about the good things that have happened in the last few years. Some do not believe GAMIAN is a threat, and Mental Health Europe should include everyone. Some think the paper written this way could be damaging the credibility of the ENUSP board. Some find it very long and focussing more on what the others do than what the ENUSP board is doing and see the paper as inappropriate for representing ENUSP members. On the other hand, some think it is important to put ENUSP in the wider context of the movement in general and that it is important to retain our own integrity and independence even while working with others.

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network are to influence decisions made in psychiatry on a European level, and to procure an improvement of the rights, the treatment and living situation of the users and survivors of psychiatry. The network encourages international exchange of information among users and survivors of psychiatry. It is concerned with social issues, the right for accommodation, work and income. Further concerns are human rights independent of psychiatric diagnoses, the right for drug free help, the upholding of psychiatric advance directives, the quality of psychiatric treatment (as well as the mode of action and effect of psychiatric drugs and shock administration) and alternatives beyond psychiatry. The network has advisory functions towards the European Commission and the World Health Organisation, and is member of different international organisations, for example the European Disability Forum, which is active against all forms of discrimination under the motto 'Nothing about us without us.' Due to the fact that there is room for reform-psychiatry as well as anti-psychiatric oriented organization in the network, it is a model for tolerance and democracy. Presently (December 2008), ENUSP has 47 national, 12 regional, 21 local and 5 individual members in 39 European countries.

ENUSP without Big Pharma Money

ENUSP rejects money from big pharmaceutical companies on principle and it supports the position paper by the European Public Health Alliance from 2001 about the independence of patient organizations. This says that organizations that accept funds from the pharmaceutical industry should, at a minimum, determine an upper limit to the proportion of industry sponsorship and their total income. They should also determine the role of the sponsoring body in relation to sponsored projects and to the organization as a whole in their statutes (see www.enusp.org/documents/epha-participation).

Consensus with ENUSP?

ENUSP, as an independent federation, which is exclusively orientated torward the interests of users and survivors of psychiatry, is criticized by friends of biological psychiatry for supporting extreme positions. As an example: in April 1999, I took part in the conference 'Balancing Mental Health Promotion and Mental Health Care' in Brussels, an event organized by the WHO and the European Commission (the Executor of the decisions passed by the European Council of Ministers and the European Parliament). Along with an estimated 70 government officials, people active in psychiatry and other representatives from organizations of interested parties in the psychosocial sector, I was invited as a representative of the European Network of (ex-) Users and Survivors of Psychiatry and was asked to present a paper on the position of the ENUSP. I asked for the support of self-help and non-medical approaches, the active involvement of users and survivors of psychiatry in political decisions on psychiatry (in view of strengthening human rights) and for emphasis to be placed on the freedom of choice of treatment. The first reaction was that I was

immediately reprimanded as being a radical supporter of anti-psychiatry. Not one single psychiatrist nor one representative of the relatives' associations (sponsored by the pharmaceutical industry) supported the ENUSP position. It was only after intervention of the Chair of the conference and representative of the European Commission, Alexandre Berlin, who apparently did not find the proposals so strange, that they were included in the consensus paper (www.enusp.org/consensus).

Research with ENUSP from the Perspective of Users and Survivors of Psychiatry

ENUSP has recently been invited to partake in different European research projects. Most of these invitations are not offering a serious working partnership but rather show how attractive it has become to have the 'European user voice' as an addition in various research applications. The board of ENUSP refuses superficial roles and last minute partnership offers in projects, which are not really open for substantial changes in their research designs.

One exception is the project VALUE+ co-ordinated by the European Patient Forum (EPF), ENUSP being one of the co-founders of EPF. ENUSP had an active role in developing a research proposal, which turned out to be successful and has received funding for 2008-2010. In co-operation with different partners in VALUE+, the extent and the value of patient involvement in different EU public health projects and the necessity and value of the involvement of users and survivors of psychiatry in the field of mental health, are explored (www.eu-patient.eu/projects/valueplus/indexphp).

ENUSP also has a consultation role in another EU research project (ITHACA) on human rights and physical health of residents in psychiatry and social care institutions in 16 European countries. ITHACA will examine six institutions per country with the monitoring tool based on the UN convention on rights of people with disabilities. One board member of ENUSP is responsible for consultation with service users/survivors on all the ITHACA sites in the process of the tool development. The project ITHACA will end in 2010 (www.ithaca-study.eu).

Global Alliance of Mental Illness Advocacy Networks (GAMIAN-Europe)

GAMIAN-Europe is, in contrast, a completely different group. They promote themselves as

> … essentially a pan-European patient driven federation of national organisations across Europe assisting people affected by mental illness, either as a sufferer or as a carer. We operate within the WHOEuropean area and cover the whole range of mental illnesses. Some of the national organisations are disease specific, whilst others are umbrella groups covering the whole spectrum of psychiatry in their country.

Central goals of GAMIAN-Europe are

> … to improve the availability, accessibility and quality of treatment for all psychiatric disorders, … to reduce stigma, prejudice, ignorance and misinformation surrounding mental illness, … to promote a positive message that mental illness can be treated effectively by a variety of means.

GAMIAN and Big Pharma Money

GAMIAN-Europe is almost solely financed by the pharmaceutical companies. In 2007 for example, 88 % (= € 102,524) of their revenue came from the companies GlaxoSmithKline, Eli Lilly Benelux, Organon and Pfizer Europe. While it is considered a scandal when branches of production companies like Siemens finance counter trade-unions, in the psychiatric field it is considered honourable when Big Pharma finances compliant patient organisations. Established in Brussels, GAMIAN is helped by its proximity to the administration of the European Union, in order to get involved in programs. The president Dolores Gauci, a social worker from Malta, attaches great importance to her partnership with the European Federation of Pharmaceutical Industries and Associations (www.gamian.eu). How close GAMIAN is co-operating with Big Pharma you can read in its board-report on the internet (see www.gamian.eu/israel08/board_report.doc); there you can identify some ways in which the EU institutions get influenced by GAMIAN and Big Pharma.

MindFreedom International (MFI)

MFI (www.mindfreedom.org) is an independent non-profit coalition defending human rights and promoting humane alternatives for well-being. In earlier years, MFI concentrated its activities in the English-speaking world, the most well-known members being Judi Chamberlin, head of the international self-help movement, the managing director David Oaks and Loren Mosher, the father of the Soteria movement who died in 2004. Internationally, MFI wins high appreciation, its representatives having worked for years in the UN convention for the rights of people with disabilities where MFI is accredited with the advisory status of a non-government organization (NGO). In Europe MFI has members or sponsoring organizations in Ireland, Great Britain, France, Germany and Norway.

World Network of Users and Survivors of Psychiatry (WNUSP)

WNUSP is an international organization of users and survivors of psychiatry which advocates for their human rights, speaks internationally for them, promotes their movement around the globe and links their organizations and individuals throughout the world (www.wnusp.net). WNUSP, which is—like MFI—also accredited at the UN with the advisory status of a NGO, played a significant role in the development of the UN convention for the rights of people with disabilities. ENUSP is member of WNUSP. Gábor Gombos, as one of the

members of the ENUSP board, is one of the adopted WNUSP board members, Iris Hölling and Karl Bach Jensen represent Europe on the WNUSP board.

Mental Health Europe (MHE)
MHE (www.mhe-sme.org) is the European umbrella organization of non-governmental psychosocial organizations, which, according to their own promotion,

> … represents associations, organizations and individuals active in the field of mental health and well-being in Europe, including (ex)users of mental health services, volunteers and professionals of many disciplines.

Users and survivors of psychiatry are not represented at decision making level within MHE. So the suspicion exists that within MHE there is a biased view on users and survivors of psychiatry who represent themselves adequately; or else the statement is simply due to the fact that organisations have to apply also as 'a representative of the users and survivors of psychiatry' in order to be able to receive EU grants. As their aims, MHE specify

> the promotion of positive mental health and well-being, the prevention of mental disorders, the improvement of care, advocacy for social inclusion and the protection of the human rights of (ex-) users of mental health services and their families and carers.

Since the foundation of ENUSP, there was a fruitful bilateral co-operation between MHE and ENUSP. In recent years, this cooperation declined. In GAMIAN, MHE meanwhile believed they have a partner:

> to work together in developing strategies for building a united global voice for mental health advocacy, promotion and services (to be read on the MHE website under 'July-August 2007—News from the MHE Secretariat').

Other partners are the European Federation of Associations of Families of People with Mental Illness (EUFAMI), the World Federation of Mental Health (WFMH) and the World Fellowship for Schizophrenia and Allied Disorders (WFSAD)—all sponsored by Astra Zeneca, Eli Lilly & Co., Janssen Pharmaceutica, Pfizer Inc. etc. It is questionable whether this 'global voice' will say anything about its dependency on the monetary infusions of the pharmaceutical companies, about the on average three decades reduced life expectancy on ground of continual use of neuroleptics, about the necessary reversal, about the burden of proof for harm through treatment, about the setting-up of a suicide register, about overdue non-psychiatric alternatives … Despite these serious misgivings and being always positive and pro co-operation with constructive partners, there is a big hope within the ENUSP board for a renewal of the partnership with MHE and

for strong and meaningful common empowerment-projects in the future. These are currently under discussion.

Activities and Events in Europe
A great deal occurring in Europe and beyond, as seen in the following account. It is helpful to take notice of the international (as well as the national) project results, to exchange ideas and to profit from this.

European Anti-Discrimination Study (Harassment Report)
An example of the efforts of ENUSP is the study 'Harassment and discrimination faced by people with psycho-social disability in health services' which was conducted from 2001 to 2005 on behalf of the European Commission. Those involved were organisations of users and survivors of psychiatry as well as organisations of psychiatric workers and relatives of psychiatric patients from numerous countries, as well as a Belgian research institution, MHE and ENUSP. The results of the study was the evidence that all over Europe, people with mental health problems (or people who are called mentally ill or disabled) are discriminated against, i.e., they are treated less favourably than people with medical diagnoses; in doctors' practices of all kinds, in hospitals, in emergency units, in psychiatric clinics etc. They experience discrimination in different forms; hostility, physical problems are not taken seriously, psychiatric drugs are not taken seriously, 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. In order to enable people with mental health problems to enjoy full citizens' rights, their organizations should be involved in decision-making at all levels. An anti-discrimination poster was developed by those involved, listing important addresses for complaints and organized self-help groups, as well as demands for politics, administrative authorities, and psychiatry (in detail on www.enusp.org/harassment):

- Promotion of the movement of users and survivors of psychiatry and their international communication
- (Free) training programmes for users and survivors of psychiatry so they can protect themselves from discrimination
- Support of initiatives of peer coaching, regional self-help centres, and meeting places
- Representation of mental health service user/survivor experiences and perspectives at all stages in the training of health care professionals, right from the start of their professional career
- Laws on equality, the right to legal protection of advance directives, the introduction of a suicide register

- Boards of appeal that receive the authority and structural guaranteed possibilities to sanction institutions and to influence decision-makers
- Effective representation of users and survivors of psychiatry or user/survivor workers in crisis and counselling centres, public relations work, research projects and congresses.

WPA Congress in Dresden 2007

For the first time afterwards, there was the recommendation for an effective inclusion of users and survivors of psychiatry at the conference 'Coercive Treatment in Psychiatry: A Comprehensive Review,' organized by the World Psychiatric Association (WPA) in June 2007 in Dresden. It was agreed with the President of the WPA organizing committee, Thomas Kallert, that keynote lectures would be held by users and survivors of psychiatry. They were included in the organizing committee and the costs for the user/survivor-led symposia were carried. Users and survivors of psychiatry took part in the press conference. They paid a reduced entrance fee and organized free information stands. The 'Declaration of Dresden Against Coerced Psychiatric Treatment' (www.enusp.org/dresden/ddec.pdf), a pleading from ENUSP,WNUSP,MFI and BPE (German Federal Organization of Users and Survivors of Psychiatry) which demanded the banning of forced treatment, was distributed in the congress brochures. Apart from Judi Chamberlin, Dorothea Buck (www.bpe-online.de/english/dorotheabuck.htm), the honorary chairwoman of the BPE, gave her sensational keynote lecture 'Seventy Years of Coercion in German Psychiatric Institutions, Experienced and Witnessed.' Her lecture and message (to take the content of psychoses serious, and to listen to patients and to talk to them!) can be down-loaded from the internet (www.enusp.org/dresden.htm). The WPAChairman Juan Mezzich wrote in *World Psychiatry* in October 2007:

> After her lecture, the WPA president presented a thank you speech for Ms. Buck's articulate and moving lecture. At an immediately ensuing press and news conference, representatives of the WPA, Council of Europe, and user organizations sitting at the main table held a lively exchange of questions and comments with press representatives and the general audience. The issues experienced globally by service users, the patterns and diversity of the organizations, and prospective opportunities for continuing the Dresden dialogue and for user participation in activities of the WPA and their national member societies were broadly discussed. ... A renewed commitment to the clinician-patient relationship appears crucial as well as building an effective dialogue with patient and user groups (as well as trialogues[2] including families) respecting the diversity of their perspectives.

2. A Trialogue is a development, which has long been exclusive to the German-speaking countries. In Trialogue groups, (ex-) users and survivors of psychiatry, carers and psychiatric workers meet regularly in an open discussion forum that claims to be on neutral terrain—outside any therapeutic,

Naturally, the way from avowal to realistic dialogue is a long one, quite apart from producing a real change in psycho-social practice. To politically agree with it is one thing, but to turn it into reality and to abstain from the power and money is another thing. Apart from this, there are disrupting factors everywhere. Thus, in Dresden, there was libel and slander by a minority group of radical survivors of psychiatry, saying that those participating at the WPA congress and who spoke against forced treatment, functioned as collaborators of the torturers. The author Robert Whitaker ('Mad in America') and David Oaks, who had pleaded for human rights and alternatives in a symposium 'Banned by Bio-psychiatry: What Users and Survivors of Psychiatry Really Want', led by the author of this article, were invited by the Board of the German Federal Organization of Users and Survivors of Psychiatry (BPE) to a parallel meeting and were asked to justify their congress participation. Bizarre, but, not surprising in that setting, was the contribution of Norman Sartorius, former president of the WPA and director of the psychiatric department of the WHO, at the closing meeting of the Dresden conference. He complained about the critical positions of the participating organizations of users and survivors of psychiatry and demanded the participation of other, more compliant organizations. Dolores Gauci of GAMIAN-Europe logically participated at Sartorius' symposium, 'The long road: A patient-centred discussion on the chronic management of mental illness' at the WPA-congress on 23rd September 2008 in Prague sponsored by Big Pharma Pfizer Inc. The promoted product at that symposium was Zeldox (ziprasidone). How big is Pfizer's budget for this symposium? How much money will Mr. Sartorius and Ms. Gauci receive for their participation? To this day, the organisers refuse to answer these questions.

UN-Convention on the Rights of Persons with Disabilities

At the end of 2006, the General Assembly of the United Nations adopted the first human rights treaty of the 21st century, the historic 'Convention on the Rights of Persons with Disabilities.' One of the most groundbreaking parts of this convention is Article 12 on legal capacity. It says that 'persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life' and that they shouldn't be prevented from 'exercising their legal capacity.' According to this statement, all forms of guardianship must be abolished and forced treatment must be eradicated from psychiatric laws. During the preparation of the convention, this paragraph was much debated at the United Nations. In the beginning, the majority wanted to exclude persons with severe psycho-social disabilities or learning disabilities from this right. These persons were seen as being too confused to be able to exercise their legal capacity. It was said that a guardian in legal matters—as 'a last resort'—could substitute

familial, or institutional context. Campaigners call it a new and exciting form of communication, an opportunity to gain new insights and knowledge, an exercise for interacting beyond role stereotypes, and a training for working together on an equal basis—accepting each other as 'experts by experience' and 'experts by training'.

for such a person. This opinion was much criticized by the disability movement, including users/survivors of psychiatry, ENUSP board-member Gábor Gombos, the participating delegation of WNUSP who continually co-operated in the development of the convention and the MFI-President (Celia Brown) who was substantially involved.

The view of the users/survivors of psychiatry flowed into the form of the UN-Convention, as legal capacity is a fundamental element of the dignity and rights of every human being. It was acknowledged that there are some persons who have difficulties expressing and communicating their wishes, but this is no argument for depriving them of basic human rights. As an alternative to substituted decision-making, the disability movement suggested supported decision-making. Instead of guardians who have proxy decision-making authority for the person, they suggested that people who are close friends or personal supporters could just help these persons express and communicate their own decisions. In January 2006, this idea was presented at a seminar in the UN-building in New York. The seminar was persuasive, because afterwards the majority of the delegates changed their opinions and embraced supported decision-making as a solution for abolishing guardianship completely.

At the seminar, some practical examples of supported decision-making were presented. One of these examples was PO-Skåne (Personal Ombudsman in Skåne, Sweden), a user-controlled service with personal agents that has grown out of the Swedish psychiatric reform of 1995. It was presented byMaths Jesperson, the former ENUSP-Newsletter editor. On 3rd May 2008, the convention, which includes people with psychiatric problems, came into effect after having been signed by enough national governments. The discussion which flared up as to whether people (possibly through psychiatric treatment) had to first become disabled so that they could call upon the convention, or if a psychiatric diagnosis is equated with being disabled and so justifies calling on the convention in case of psychiatric encroachments, shows that conventions are just one step on the path to prime human rights.

Trialogue in Europe

At the congress of the German Society for Social Psychiatry (DGSP) 2007 in Munich, the ENUSP-board-member Jan Verhaegh and the author of this article partook in the trialogue chaired by Jürgen Bombosch where possible common positions with relatives of users and survivors of psychiatry and thoseworking in psychiatry were discussed. After the ensuing discussions lasting for weeks, the executive boards of the German Society of Family Members of Psychiatric Patients, the DGSP, and ENUSP passed the paper 'Trialogue and self organisation—Munich theses and demands for a social mental health system in Europe' (see www.enusp.org/documents/trialog).

It says that social psychiatry in Europe is only possible if the rights of the users/survivors of psychiatry for physical inviolability and for their own decision making according to the Convention on the Rights of Persons with

Disabilities are protected. It also respects the interests of their families, the core groups which are handled in the psychiatric context; users/survivors of psychiatry, relatives and professionals, all negotiating with the same rights on the basis of law, and providing ideal support including adequate resources for independent self-help groups for users/survivors of psychiatry. These people should be protected from forced treatment, alternatives beyond psychiatry should be furthered, and the users/survivors of psychiatry and their relatives should be acclaimed as experts in the sense of the recovery movement, independent of pharmaceutical companies. As well as this, the power of one-sided definitions of those working in psychiatry should be transferred into a democratic culture, providing everyone with a change of perspective and an open discourse with equal rights.

Critics say (ex-) users and survivors of psychiatry more or less waste their time in these meetings, because they could use their energy more productively in the self-help and human rights movement. Additionally, in Trialogue groups stereotypes are perpetuated: whereas (ex-) users and survivors of psychiatry speak about their personal experiences, psychiatrists and relatives speak about *the other* and their reactions to mad experiences by excluding themselves as private persons. So the Trialogue tends to be a subtle variation of the case presentation, where one person has experienced something, and the second one—the 'expert'—knows beforehand, what the first one—still a medical object—'in fact' has experienced.

ENUSP was involved when in Rome in May 2008, the European Democratic Movement for Mental Health (EDMMH) was founded. The international federation, of which those working in psychiatry are also members, stands for the abolition of psychiatric force and the banning of electroshock:

> The Society's aims are of a scientific and social nature. Its objective is to work to reach the judicial and social equalisation of people with a psycho-social disability, and to take action against the stigmatisation and discrimination of those same people. In practice this means: dismantling asylums, opening doors, banning physical contention and pharmacological abuse, as well as forbidding invasive methods such as electroshock and psychosurgery.

The Chairman Lorenzo Toresini is a former colleague of the Italian reform psychiatrist Franco Basaglia who died in 1980. The future will tell what this federation can achieve (for statutes and contact data www.enusp.org/documents/edm). This also applies to the exercising of influence by users/survivors of psychiatry from within. Their initiative will determine what they can achieve together with, and within the federation.

Outlook

A congress entitled 'Joined world-congress against discrimination and stigma, for user-orientated reforms in psychiatry and the right to alternatives' planned

by ENUSP, MFI, the Pan-Hellenistic Committee of (ex-)Users and Survivors of Psychiatry and the International Network toward Alternatives and Recovery (INTAR—www.intar.org) at the University of Thessaloniki in September 2009 would have provided a big forum for those interested in the European psychiatric scene. It would have included people involved in many worldwide innovative projects—among many others Windhorse, Soteria, Family Outreach and Response Program (FOR) in Toronto are organized in INTAR. In 2008, FOR was essentially involved in the organization of an INTAR-Alternatives-Congress in Toronto with worldwide participation (www.enusp.org/toronto). It impressively showed how effective independent family organizations can be. But, after initial benevolent interest, the Greek governmental administration turned down the financial support and the congress has had to be cancelled.

WNUSP is planning, together with the Pan-African Network of Users and Survivors of Psychiatry (PANUSP) and Mental Health Uganda, its third World Congress in Kampala, Uganda, in March 2009 (information at www.wnusp.net). How the ENUSP board should be able to organize a membership meeting with its poor finances, is presently (December 2008) very questionable. Because only some ENUSP member-organisations pay their membership-fees, the non-payers (see www.enusp.org/nonpayers) hinder ENUSP in growing as a strong organisation, building the necessary connections and developing an overdue counterbalance against GAMIAN and the unlimited enforcement of the interests in profits in the psychosocial field. ENUSP stands for and must continue to work for human rights, humanistic treatment methods, advancement of the self-help field, alternatives beyond psychiatry, and freedom of choice.

The many problems to be coped with demand constructive cooperation. Unfortunately, among the users/ survivors of psychiatry, as everywhere, there is dogmatism as well as sectarianism, arrogance and machismo. Added to this, Scientology (via the Commission for Citizens' Rights) and the pharmaceutical industry try to influence for their own purposes possible critics of psychiatry such as self-help groups. There are also attempts by the friends of coercive psychiatry to defame opposers of psychiatry with political background as all-inclusively being Scientology friends. Team work is by no means taken for granted.

In the end, a co-operative act in the direction of humane treatment, the strengthening of human rights, self-help and alternatives is dependent on how effective it will be to take the bread from the trouble makers' mouths and, on the other side, to maintain independence from the profit orientated pharmaceutical companies, to engage in honest and sustainable discussions with each other, to work together against defamations, to support independent users and survivors of psychiatry in an organizational as well as financial manner (for the bank account for donations to ENUSP see www.enusp.org/donations) and to open the door to them for real participation.

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