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The latest in activism and community news from the European Network of (ex-)Users and Survivors of Psychiatry

EDITORIAL: Out of ours minds.... News and opinions from the European desk

Dear readers,

Welcome to the revived newsletter of our European Network of (ex-)Users and Survivors of Psychiatry.

For the last few months, we have been working hard on this publication with three main hopes. These are:

- to raise awareness of the harsh conditions and courageous work of users and survivors of psychiatry across Europe
- to inform you about the day-to-day advocacy of the ENUSP board of volunteers at a European level.
- to build a supportive forum where our members can exchange contacts, skills and information as we slowly build up alternatives and fight for our human rights.

It is crucial to us that this space reflects both our differences and our similarities as users and survivors of psychiatry living in 39 diverse countries. In this way, we hope also to open the way for new kinds of resistance and new connections and alliances.

ENUSP's mission is to document violations of the human rights and dignity of users and survivors of psychiatry. We demand an end to all forced treatment and the development of alternatives to the biomedical model. And we pursue these aims across the many parts of this newsletter, including the 'Human Rights Watch' which describes disturbing developments in Greek and Danish psychiatry. Our 'Resources' section explains some of the background to the new UN Convention for the Protection of the Rights of Persons with Disabilities. Advocates like Tina Minkowitz believe this could be a very liberating tool for those on the receiving end of mental health services; we hope to hear your thoughts and questions about this in coming issues. Elsewhere, you will find details of the latest activism of the ENUSP board, news of upcoming international events and conferences, and an interview with psychiatric survivor and medical doctor Tamasin Knight on alternative ways of responding to unusual beliefs.

We hope you will look out in our future publications for more reports of human rights abuses and corruption, including stories of personal experiences of mental health services and crises, discrimination and recovery. There will also be updates on the activities of big pharma and its thinktanks; a special feature on electroshock in Europe; more reports about legal developments, user-survivor led research, and the relations between mental health organisations and the user/survivor movement. Plus, of course, we feature insights into philosophy, music, self-help and healing. Please feel free to send us your letters at desk@ enusp.org. We especially would like to hear your feedback on this newsletter and suggestions for what you would like to see – or not see- in the future.

All in all, this publication is- as another support member of the ENUSP board recently joked - a very mad endeavour. On top of the madness of the huge barriers we face, there is the madness of the fact that we have no budget behind us. At the moment, we rely solely on the energy and commitment of our contributors and our distribution team. In this spirit, we would encourage you warmly to join our team and write, edit, design, take photos, draw, work on distribution, or contribute in any other way to our future ENUSP publications.

Come share your voices and visions.

In solidarity and support,

Debra Shulkes

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

FRONT LINES: ENUSP in the news

The latest in ENUSP's Human Rights Activism for (ex-) users and Survivors of Psychiatry

ENUSP TO ATTEND EU HUMAN RIGHTS MEETING

ENUSP chair Mary Nettle and board member Gábor Gombos have managed to secure places at a key upcoming meeting of the Fundamental Rights Agency (FRA), the EU body responsible for human rights issues.

Mary Nettle

The meeting, which will take place in Vienna in late November, should discuss "ways to improve human rights compliance in the area of

mental health", according to the latest official announcement.

The Agency hopes to "work with key actors in the field to facilitate their efforts."

ENUSP's inclusion is an important achievement because the FRA is currently planning a 2-year project on mental health and human rights. To date, ENUSP has not been invited to consultation meetings on the basis that we are not professional researchers. "We will be advocating for the essential participation of user/survivor researchers in any inquiry into our human rights," Mary Nettle said. "We must be acknowledged and consulted. Furthermore, this expertise should be paid for, as would be the case for any other consultancy."



FIRST EMPOWERMENT SEMINAR FOR EU MEMBERS

In a great milestone for our network, (ex-) users and survivors from 25 EU countries met for two days in Brussels in March this year for an empowerment seminar. The seminar "Nothing about Us without Us: How to Make This a Reality?" was only made possible by a one-time European Commission grant from Mental Health Europe that unfortunately did not extend to non-EU participants. As well as sharing experiences as user/survivor activists, participants were briefed on the new European Mental Health Pact and UN Convention on the Rights of People with Disabilities and changes in user/survivor-led research.

The burning issue of the meeting, however, was the lack of funding for ENUSP, that is now threatening the survival of our network. What will happen, speakers asked, if users and survivors of psychiatry lose a united and independent voice at a European level? One of the immediate priorities, they said, was to strengthen communications and cooperation among ENUSP and national and local user/survivor groups throughout Europe. We must find ways to meet and organise that ensure the representation of all of our members.

This is the challenge that we want to address in this newsletter. In particular, we are looking for your opinions and visions about what ENUSP's priorities should be in coming years. How can we grow stronger? And how might you or your organisation contribute? Please send any thoughts or comments to: desk@enusp.org

For full details of the seminar, including presentations notes and photos, see Jasna Russo's excellent report: (www.enusp.org/congresses/empow-seminar2009).



ENUSP GENERAL ASSEMBLY IN THESSALONIKI

We are very pleased to announce our plans for a General Assembly and members' conference in Thessaloniki, Greece in September, 2010

The assembly will be held in co-operation with members of the Greek user/ survivor movement and the assistance of the psychology department of Aristotle

University, Thessaloniki. Reporting from a recent meeting of Greek users/survivors in Athens, spokesman Iannis Karterakis said the 2010 agenda should look at " the Greek psychiatric system, its history and parameters", assessing powerful lobby groups from the medical and pharmaceutical industries and key current and future issues. The overall message should be "our rights and our demand and need to be treated as equals," he said. For more information on human rights abuses in the Greek psychiatric system, please see the report in the Human Rights Watch section.

Organising this event will involve considerable work over coming months, and we would be very grateful for your assistance, no matter how small. At this stage, we would especially appreciate your suggestions for a keynote speaker, topics for working groups and the agenda for the General Assembly. Please send your suggestions and offers to join the organising committee to: info@ enusp.org. We will be in touch in coming months with more information.



enusp.org. we will be in touch in coming months with more information.

ENUSP AND MENTAL HEALTH EUROPE: WHERE TO NOW?

ENUSP's Empowerment Conference in Brussels this year occurred thanks to the co-operation and extensive logistical support of Mental Health Europe (MHE). Mental Health Europe is an EU-funded agency dedicated to mental health promotion, policy-making and reform. It is also the EU-liaison office for mental health funding. It has declared its opposition on principle to accepting any funds from the pharmaceutical industry. For more information about MHE's work and policies, please see: www.mhe-sme.org/en.html

ENUSP was extremely grateful for the support of its Brussels seminar, and our representatives have since met to discuss the possibility of renewing cooperation on certain projects. Late last year ENUSP's board issued the following statement of intent to MHE:

"The European Network of (ex) Users and Survivors of Psychiatry (ENUSP) is pleased to cooperate with Mental Health Europe (MHE) on areas of mutual benefit. ..We are pleased that MHE and its network of member organisations see this need to support users and survivors to have independent organisations. We welcome support members whilst this capacity building is taking place and the practical support we can receive from MHE to enable us to achieve this goal."

Commenting more recently, board member Erik Olsen cited the dire economic state of ENUSP: "We cannot say no to help from EU sources... We are simply too weak both in an economic sense and at an organisational level as users and survivors across Europe."

"We are taking the opportunity to do what we can, " added Mary Nettle.

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

PSYCH SURVIVORS FIND A VOICE ON EU DISABILITY FORUM

For the first time, a psychiatric survivor from ENUSP will sit on the board of the European Disability Forum (EDF). Danish activist Erik Olsen, who has 20 years' experience in our movement, was elected this May with overwhelming support from other EDF members. EDF fights to promote equal opportunities for disabled people and to protect their human rights, ensuring no decisions concerning disabled people are made without them. It is an entirely independent organisation. In the past, others have often spoken for users and survivors of psychiatry inside the disability rights movement.



At the forefront of EDF's agenda is the implementation of the UN Convention on the Rights of Persons with Disabilities and its Optional Protocol (see information and resources below). Other prominent issues include capacity building and proper representation in EU policy and legislation.

If you would like more information or have a proposal for matters to raise with EDF, please contact: Erik Olsen at <u>erikpsyk@gmail.com</u>

SHORT FILM ABOUT ENUSP'S WORK

We are happy to link to this short video from the University of Birmingham featuring ENUSP representatives Mary Nettle and Elisabeth Winder.

The film covers important topics including ENUSP's role, resources and relations with other European advocacy organisations like the European Patients Forum and Mental Health Europe.

You can also hear a short description of ENUSP's role in the VALUE+ project, which seeks to make the meaningful involvement of patients in healthcare throughout the EU a reality.

http://www.ceimh.bham.ac.uk/tv/MaryandElisabeth.shtml

Look out for more reports on VALUE+ in upcoming ENUSP publications. In the meantime you can also learn more about the project here:

http://www.eu-patient.eu/projects/valueplus/project/purpose-outcomes.php



PSYCH SURVIVOR ADDRESSES EU SUICIDE CONFERENCE



David Webb

Based on campaigning by ENUSP, psychiatric survivor and human rights campaigner David Webb was invited to speak at a WHO/EU scientific conference on suicide and the economic crisis in Stockholm on October 14-15. The conference, organised in part by the Swedish Parliament, is the final lead-up event to an EU conference "The Prevention of Depression and Suicide" in Budapest this December. All these events fall under the European Pact for Mental Health and Wellbeing which expresses "the importance and relevance of mental health and well-being for the European Union, its Member States and stakeholders".

Webb, a former WNUSP board member from Australia, has published extensively on "suicidology", the science which has grown up around the study of suicide. We understand that his doctoral dissertation is the only extended review of this discipline by someone who has attempted suicide. It reveals the striking exclusion of the user and survivor perspective from the whole suicide debate – and the absolute need to hear our voices on these topics.

Anne-Laure Donskoy, a support board member at ENUSP, lobbied energetically for the inclusion of user and survivor-led research, stressing the importance of first-person experience. "The significance [of David's inclusion in Stockholm] is very high, " she said, "David brings a unique dimension to the subject matter, having not only survived the experience but also written about it in a thoughtful and innovative way. He brings to the fore the experiential dimension, often forgotten in the midst of meaningless economic statistics."

Donskoy has also campaigned for the admission of presentations by ENUSP speakers in Budapest on topics such as the link between psychiatric drugs, depression and suicide, and how user research can help demystify the links between self-harm and suicide. At the time of going to print, ENUSP is still waiting for a response.

For more information on David Webb's work, see: <u>http://www.peter-lehmann-publishing.com/articles/index.htm#webb</u>

Look out for a report from David on his experience in Stockolm as well as more information on user/survivor-led research in coming ENUSP publications.

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



Over the years, many of our members have stated the need for a user/ survivor-run human rights monitor across Europe. This service would document incidents of torture and inhumane and degrading treatment – abuses that are currently often state-sanctioned and invisible, escaping the interest of official complaints bodies and the media. With the possibility of protection under international treaties such as the UN Convention for the Protection of the Rights of People with Disabilities (see "RESOURCES" below), these records could be very significant. We believe that this newsletter could be the beginning of this monitoring process. We encourage you to send us reports of potential human rights violations – whether at a regional, national or individual level. Reports should be sent to desk@enusp.org. In this edition, we highlight alarming developments in Greece and Denmark

"OUR EYES ON ABUSES AND RESISTENCE"



HUMAN RIGHTS ABUSES IN GREEK INSTITUTIONS

Reports have reached ENUSP of the gross violation of psychiatric patients' rights in hostels run by non-government organisations across Greece. The alert was raised earlier this year by psychiatric survivor organisations and workers at the institutions, backed by parliamentarians and academics. They allege that the NGOs – which receive funds under an EU reform programme-are using violent, cruel and degrading practices against hundreds of residents. Critics of the Greek Ministry of Health and Social Solidarity say thegovernment has privatized mental health care, delivering the occupants of prison-like state institutions into even worse hands. The 'improved'facilities, run by NGOs like EPSAMY, EPSYKA and THEPSYPA, house between 15 and 20

people whose freedom is denied based on systems of continuous control and

punishment. Photos appearing in the Greek press show inmates semi-naked and strapped to their beds at an EPSAMY hostel in Athens.

Writing to European parliament last year, several Greek politicians described the government's mental health policy as "a huge blow to psychiatric reform in Greece, endangering the physical and mental integrity of hundreds of patients." This policy goes directly against the social rehabilitation aims of the EU Psychargos funding programme, they say. Academics from Aristotle University in Thessaloniki claim the central motive of the non-profit organisations is "profiteering...rather than the reinstatement of human rights, which were violently taken from the internees."

Human rights advocates are calling on the European authorities and the Greek government to intervene urgently on behalf of hostel residents.

They are also demanding an independent European inquiry into the violent and degrading practices already documented as well as the alleged mismanagement of EU funds. Users and survivors of mental health services must have a crucial role in these investigations, they say.

Please consider protesting to the Greek National Commission for Human Rights

President Mr. Kostis Papaioannou

Email info@nchr.gr

ENUSP thanks Julie Stamati and other members of the psychology department at Aristotle University in Thessaloniki for their help with this report.

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DANISH GOVT SUPPORTS MORE FORCE IN PSYCH WARDS

Denmark's government has plans to introduce padded cells and more physical restraints in psychiatric institutions.

For many years the European Council has severely reprimanded Denmark for the force used in the country's psychiatric clinics. Controversial practices include immobilising patients who are attached to beds with abdominal belts and ankle and wrist straps. In several cases, this degrading and painful treatment has continued for months on end, with patients restrained at meal times and when using toilets and showering. It is common for no restrictions or time limits to apply tro belt fixation. Psychiatrists have defended these techniques in the national media.

Critics from the European Commission compare the use of ankle and wrist locks with the methods used to secure and torture prisoners by the U.S. military at Guantanamo Bay.

Nevertheless, the Danish Minister for Health Jacob Axel Nielsen is now suggesting that psychiatric wards start using restraints on mobile patients, applying hand and leg-locks to prevent people from fighting back. He says this will minimise patient violence. He also suggests that the wards use padded cells as an "alternative" to restraining the patients.

Commenting on the recommendations, opposition spokesperson Mette Fredriksen noted that while the rest of Europe was taking steps to avoid violent restraint, the Danish minister's message to psychiatry was that more force is the future. A spokesperson for the Socialist People's Party said the minister's suggestion was grotesque, adding it was ridiculous to replace force with more force.

The Danish user organisation LAP (<u>http://www.lap.dk</u>/) continues to speak out against these and other forms of torture and degradation. Several years ago we succeeded in stopping forced outpatient treatment by convincing one of the political parties to vote against a key bill.

Two years later a similar law is being threatened. This time we might not be able to stop them.



Jacob Axel Nielsen

-Erik Olsen ENUSP

For more information, please contact: erikpsyk@gmail.com

