

# The European Newsletter

## of (ex-)Users and Survivors of Psychiatry

No. 10 (August 2002)

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

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## EDITORIAL

ENUSP is not very well resourced and faces communication difficulties. Hosting ENUSP board and

other meetings with a membership across Europe is becoming more and more expensive. Producing a regular newsletter is also proving costly. The Internet helps to solve some of these problems. When there is no money, the ENUSP board will hold virtual online meetings. The ENUSP newsletter can be e-mailed or downloaded at minimum cost.

ENUSP acknowledges that many people do not have access to the Internet. Some people are anti-technology; some cannot afford to buy a computer. Others cannot find reasonably priced or freely available training to use a computer. Some psychiatric service users are too medicated to engage online; others are locked in a psychiatric ward and have no freedoms.

ENUSP hopes to reach out to as many people as possible. With this in mind, please feel free to distribute this newsletter to anyone who might be interested. It can be downloaded or photocopied for distribution.

Previous ENUSP newsletters can be found on our website:

[www.enusp.org/documents/newsletter.htm](http://www.enusp.org/documents/newsletter.htm)

Many thanks for your ongoing support.

**Peter Lehmann**

Newsletter-editor and Secretary of ENUSP)

## A Warm Welcome to Our New ENUSP Members !

- [Forum Association for Mutual Support in Mental Distress](#). Forum is an association for mutual support in mental distress is a non-governmental organisation formed in 2001 in Bosnia and Herzegovina. It acts as an umbrella organisation for the following seven active associations for mutual support in mental distress from Bosnia and Herzegovina. Adress: Forum Association for Mutual Support in Mental Distress, Bolnicka 25, Sarajevo. Tel./Fax +387 (0)33 219546, +387 (0)36 577090, eMail: [behar@cob.net.ba](mailto:behar@cob.net.ba), [rea@bih.net.ba](mailto:rea@bih.net.ba)
- Netzwerk Brandenburg e.V.: Working group in the Bundesland Brandenburg – survivors of crises (and psychiatric survivors) speak out for themselves and with each other – a place to contact other survivors and get information – salutogenic approach, empowerment methods. Address: Netzwerk Brandenburg e.V., Libellenweg 4, D-14772 Brandenburg, Tel. +49-(0)3381-795920, Fax +49-(0)3381-795921, eMail: [Netzwerk-Brandenburg@web.de](mailto:Netzwerk-Brandenburg@web.de)
- [Für alle Fälle e.V.](#), Mansteinstr. 7, D-10783 Berlin. Fax: +49 – (0)1212 – 533659640, eMail: [faelle@web.de](mailto:faelle@web.de)
- Verein "OASE – Power to the People, Verein für alle von Psychiatrie-Betroffenen", c/o Ulrike Burgstaller, Hohenzellerstr. 42/22, A-4910 Ried im Innkreis. Tel.: +43-7752-87696, eMail: [burgstallerulrike@gmx.de](mailto:burgstallerulrike@gmx.de)
- Individual member: Bülent Bildirici, Klauerstr. 7, D-60433 Frankfurt/Main (Germany). Tel. +49-(0)69-33088859, eMail: [jesusmoses2002@yahoo.de](mailto:jesusmoses2002@yahoo.de)
- Sakartvelos iuzerta da ex-iuzerta kavshiri (Union of Users and Ex-Users of Georgia). Non-governmental and registered national organization, founded on August 31, 2001. Aim: helping (ex-)users. To achieve this aim we were given all the rights including commercial activities, that means we are eligible for all the rights for all activities like education, training, recreation, and commercial (e.g. sheltered workshop). We, (ex-)users only, are member of the Georgian Association for Mental Health and co-operating with Hamlet Trust to strengthen our organisation. Co-chairs: Zakaria Geladze (eMail: [zazageladze@yahoo.com](mailto:zazageladze@yahoo.com)), Zaal Kakhniashvili. Address: 149, Nutsubidze St., Tbilisi 380086. Tel.: +995 32 397844 or +995 32 309097, Fax: +995 32 309097, eMail: [mental@gamh.org.ge](mailto:mental@gamh.org.ge)

## Letter to the ENUSP Member-Organisations

Dear friends,

this letter has three main topics:

- giving you information about ENUSP and reminding you at your membership
- asking for information about your organization
- asking for support: publicity and a money-contribution (no membership fee)

### **1. Information about ENUSP and reminding you at your membership**

At the beginning of 2002 the desk of ENUSP changed from Utrecht to Berlin. At this opportunity the board took the chance to reflect upon the organization of ENUSP. We are lacking information about our members, and probably our members are lacking information about ENUSP, too. In the past the contact between the board, the desk and the member-organizations was far from being optimal. To enhance this situation, since months we offer a lot of information: for example the minutes of the board-meetings, plans and topics of the coming meetings, our mailing list [enusp@topica.com](mailto:enusp@topica.com), a newsletter to download etc. We do what we can. If you have any wishes, please let us know.

On our Website

[www.enusp.org](http://www.enusp.org)

you can find additional information. On the special page [www.enusp.org/groups.htm](http://www.enusp.org/groups.htm)

you can find your group. If not done already, our webmaster would be glad to receive your full address incl. e-mail, web-address, phone, fax, and a short characterization about your organization. Please send to [mail@peter-lehmann.de](mailto:mail@peter-lehmann.de) [www.enusp.org/groups.htm](http://www.enusp.org/groups.htm)

you can read at the beginning:

Warning! We cannot guarantee for the correctness of the addresses nor the actual political or personal positions of the persons or groups on the list. User/survivor of psychiatry groups have different positions and perspectives. Trying out contact addresses is always at your own risk. / ENUSP does not accept any money from the drug industry. National, regional and local organisations, however, take their own decisions. For reasons of transparency, we refer to a (co-)financing by pharmaceutical companies as far as we know about it by the addition "sponsored by pharmaceutical companies".

So the ENUSP board's proposal is, that organizations who are sponsored by pharmaceutical companies please be so kind and send a little note to the ENUSP desk about it until September 30, 2002. Then we can add "sponsored by pharmaceutical companies", "not sponsored by pharmaceutical companies" or "refuse to accept money from pharmaceutical companies" at your group name. The time (end of September 2002) refers to the next issue of the European Newsletter, published in August 2002, where we can announce this issue again.

For the time after October 1, 2002 we suggest: If somebody identifies a group taking money from pharmaceutical companies and did not mention it for any reason, please be so kind and tell that group, that they should give ENUSP knowledge about it. As – about – one third (?) of the ENUSP-member-organizations -perhaps less or more – take such money, there should be no reason to hide it.

By the way, the conflict is far away of being special to ENUSP. We refer to the "draft position paper on patient participation", developed by the European Public Health Alliance. The draft, that ENUSP got only for internal use, see

[www.enusp.org/documents/epha-participation.htm](http://www.enusp.org/documents/epha-participation.htm)

includes a quite reasonable "proposal to minimize the conflict if taking or refusing money from pharmaceutical industry".

Ensuring the independence of patients' organisations, EPHA writes, that the value placed upon the participation of patients' organisations flows from their ability to reflect, accurately and fairly, the views of the patients they represent. In order to do this, they need to be independent from other health stakeholders. As EPHA writes further on, one area of particular concern is the relationship between patients' organisations and the pharmaceutical industry. While the views of patients and pharmaceutical companies can overlap on different issues, they are not identical. While it is important that these commonalities are pursued when they exist, it is also important that patients' organisations maintain the capacity and independence to express views which are different from industry and which may be critical of industry. Some patients' organisations refuse to accept funding from pharmaceutical companies on the grounds that this is a conflict of interest. Many patients' organisations do accept funding from pharmaceutical companies.

Approaches to minimising conflict of interest for patients' organisations which receive pharmaceutical funding include:

- establishing limits on industry sponsorship as a proportion of total income; and
- clearly articulating the role of the sponsoring body in relation to sponsored projects and the organisation generally in policy documents.

Funding from pharmaceutical companies is not limited to direct sponsorship. In some cases, a formally constituted not-for-profit agency acts as a conduit between the pharmaceutical company and patients' organisations.

### **3. Asking for support: publicity and a money-contribution (no membership fee)**

To get more possibility of influence, it is important for ENUSP to get more visible. So we kindly ask all member-organizations, if there is the chance to propose speakers or work-shop-leaders on conferences to propose the invitation of ENUSP-represents. In case of, please contact your regional board-member, the Chair or the desk; see:

[www.enusp.org/board.htm](http://www.enusp.org/board.htm)

Another possibility is, that we can propose a competent ENUSP-activist to represent ENUSP.

And we ask all member organizations for a membership contribution. This is not a membership-fee. According to our statutes a decision about a membership-fee can only be done by the membership-meeting. The board and desk works hard to get funding for such a meeting since 1999, the date of the last meeting in Luxembourg. All applications have been rejected since. But we are going on to try to get funding. Meanwhile there is no more money for the desk's work. All expenses have to be paid by the board-members and the desk-activists privately. That means, beside the unpaid work they have to pay for expenses too. We kindly ask your organization to give a free donation to ENUSP, according to the wealth of your organization. At the next membership-meeting our treasurer Virpi Vesterinen will report on the financial situation – if we get the funding to finance a membership-meeting. More and more European and national authorities ask for co-financing any event. But how, if there is no money and we cannot even co-finance 0,1%? Our ENUSP's donations account-no: 53.45.57.082 at ABN AMRO Bank in Utrecht, Netherlands, SWIFT: ABN-NL 2A. Postal address of ABN AMRO Bank: P.O.Box 2059, Daalsesingel 71, NL-3500 GB Utrecht

Best wishes

For the ENUSP-board

Peter Lehmann

## **Cross-Border Defence of Human Rights of People in the Psychiatric System**

by David Oaks (Director, MindFreedom)

Violations of human rights in the mental health system do not recognize borders. The incredible power of the psychiatric drug industry does not recognize any borders. The mental health system is globalizing as never before. The World Bank and the World Health Organization have multibillion dollar plans to spread the mental health system to developing nations.

Therefore, the social change movement to change the mental health system needs to cross borders too. Thank you for this opportunity to build bridges between the work we are doing, and members and allies of ENUSP. I am lucky to call a number of you friends already. I have long-admired ENUSP's skillful ability to do multi-national organizing, respecting so many language's and cultures, and I know there is much to learn from ENUSP. .

I am a psychiatric survivor who experienced involuntary psychiatric drugging and psychiatric institutions in the 1970's. This is my 26<sup>th</sup> year as a human rights activist in mental health. I direct Support Coalition International (SCI), which unites 100 grassroots groups in 12 countries, with several thousand individual members. We campaign for human rights and empowering alternatives for people in the mental health system. SCI is increasingly using the name "MindFreedom" for our public campaigns, to make our human rights focus more clear.

Founded in 1990, SCI/MindFreedom is an organization "of" psychiatric survivors that is also open to the public. A survey shows the overwhelming majority of MindFreedom members, board and staff are individuals identify themselves as having personally experienced human rights violations in the mental health system. However MindFreedom is also open to any member of the public who supports its goals of freedom and self-determination in the mental health system.

As a "psychiatric survivor human rights organization," MindFreedom is apparently unique as the first and only such Non-Governmental Organization (NGO) accredited by the United Nations with Consultative Roster Status. We hope

there will be many more. MindFreedom emphasizes outreach to other grassroots organizations representing disenfranchised constituencies, such as poor, prisoners, people of color, women, people with disabilities, etc. Let me list a few of our recent activities, and introduce a few of our Sponsor Groups.

### **Resisting Forced Electroshock**

MindFreedom fights involuntary psychiatric procedures that are given against the expressed wishes of the subject. Perhaps the most controversial of these involuntary procedures is when an individual receives electroshock against their expressed wishes. Electroshock – also known as electroconvulsive therapy or ECT – involves administering a charge of electricity to the head. While some individuals feel they benefit, hazards can include permanent brain damage, memory loss and death. Because the procedure is so intrusive and potentially irreversible, every mental health consumer and psychiatric survivor organization is united against its involuntary administration.

MindFreedom has documented that involuntary electroshock continues internationally. Using MindFreedom's activist methods – such as MindFreedom's web site

[www.MindFreedom.org](http://www.MindFreedom.org)

e-mail alerts, and our publication MindFreedom Journal – we have reached and mobilized tens of thousands of people internationally about the continued existence of involuntary electroshock.

MindFreedom has focused on finding actual examples of people who are receiving involuntary electroshock, and then encouraging public responses (similar to Amnesty International). These experiences illustrate that nearly all of the public, once they are informed of this severe human rights violation, oppose involuntary electroshock. Most of the public is on our side on these kinds of issues.

### **Activities in the UN**

Another unifying activity has been our outreach to the United Nations. The president of the MindFreedom board is Celia Brown, an African American psychiatric survivor activist who lives in New York City. This past summer, Celia used our UN credentials to bring nine psychiatric survivors into the UN to participate in a major meeting to create a special UN agreement (called a "Convention") on human rights and people with disabilities. Celia spoke in the UN and said, "The existing international instruments often reflect a paternalistic medical-model perspective rather than a rights-based perspective, which is an obstacle to rights protection for persons with psychiatric disabilities. The circumstances of persons with disabilities and the discrimination they face are socially-created phenomena and have little to do with the impairments of persons with disabilities. People diagnosed as having psychiatric disabilities should not be considered as having lost the global capacity for decision-making and should be supported as autonomous agents of their own recovery."

Celia is very enthusiastic about reaching human rights allies in the United Nations. She said,

"I think it is important to participate in the development of the UN International Convention because it effects our human rights. We also raise awareness of human rights with delegates of different countries. The convention could provide legal accountability for governments and NGO's to report and monitor the international convention. Planning and developing this convention also helps unite our movement with the disability movement, internationally."

UN activities on this Convention are predicted to continue for several years.

### **Mad Pride 2002 Celebrated in Six Nations**

An international public education campaign that MindFreedom is helping to lead uses the idea of "Mad Pride" (similar to "Gay Pride") to celebrate psychiatric survivors in a positive cultural way. Mad Pride events began in England. Learning from the gay rights movement, UK psychiatric survivor activists held celebrations with lots of music from great bands to celebrate being different in a positive way.... And that's something everyone can be proud of. For three years, Support Coalition International has helped bring the Mad Pride movement to other countries. In July 2002, a variety of Mad Pride events were held in Canada, USA, France, and UK.

Toronto already had a history of similar events. 2003 will mark the 10 year anniversary of their award-winning "psychiatric survivor pride" events. Graeme Bacque of the MindFreedom Sponsor Group People Against Coercive Treatment (PACT) reports that Toronto 2002 events included a speak out and march. They even offered an "historical walking tour of the notorious psychoprison Queen Street." There was native drumming, a commemoration of many brother-and-sister survivors who did not survive psychiatry, and free food.

Mad Pride events were also held in Vancouver, Canada by Madness 101, in Massachusetts by the Freedom Center, in

Leeds, UK, and more.

Mad Pride events come in all sizes — from hundreds of people, to just one person leafleting on a corner. Of course, Mad Pride events can be held any time during the year, though typically they are held in July — Mad Pride Month. For two decades, July 14 ("Bastille Day") has been a day for psychiatric survivors to speak out about human rights, because of pioneering work by the Mental Patients Liberation Alliance in New York State, USA.

### **Challenging World Health Organization on Mental Health Issues**

The United Nation's huge World Health Organization (WHO) has a major program to expand the current mental health system internationally. This WHO program could eventually involve billions of dollars, and hundreds of millions of people. WHO has worked closely with the psychiatric drug industry in creating its program. Perhaps this is why the manual that WHO published to implement their plan emphasizes a psychiatric drugging approach. MindFreedom filed its concerns with WHO, also pointing out that WHO's manual just gives lip service to consumer empowerment without any actual funding or enforcement mechanisms for advocacy and human rights.

### **International Strategy Conference**

For the third year in a row, MindFreedom has held a multi-national strategy conference, bringing together psychiatric survivor leaders with key allies. In the 2002 Strategy Conference, MindFreedom identified an urgent international threat to human rights in mental health, and that is Bush Administration attacks on the human rights of people in the mental health system. The most egregious of these attacks is the appointment by the Bush Administration of psychiatrist Sally Satel, MD to a key mental health advisory position. Even leaders from overseas stated that expressing concern about Sally Satel was an international concern, because of the ramifications.

Dr. Satel is a psychiatrist who is from the extremist American Enterprise Institute, which is well-funded by large corporations. In her speeches, web site and book, Dr. Satel opposes the very idea of mental health consumers and psychiatric survivors. Dr. Satel calls for immediate "overnight" termination of all government funding to such activity. Most ominously, Dr. Satel supports the massive expansion of involuntary psychiatric drugging to more than 100,000 more Americans. These huge corporations are the same ones behind international campaigns to take away our human rights.

We also identified the power of the pharmaceutical industry as one of our main concerns. Psychiatric drug corporations are among the richest corporations in the history of the world. We are pro choice. Many of our members choose to take prescribed psychiatric drugs. However, the power and influence of the psychiatric drugs is dominating the mental health field internationally. That's why we held a multinational protest last year at the World Federation for Mental Health meeting in Vancouver, Canada. We must link up with those concerned about the power of large corporations to challenge the force and fraud of the pharmaceutical industry.

### **International Alert and Advocacy System**

MindFreedom extensively uses the Internet to send out alerts to tens of thousands of people internationally about human rights violations, including the rise of involuntary psychiatric drugging, solitary confinement, restraints, lack of alternatives, and the general disempowerment of people in the mental health system. If you would like to be notified by these occasional alerts, e-mail to [office@mindfreedom.org](mailto:office@mindfreedom.org), or sign up via the web site. You can also contact us if you are interested in becoming a member, or if your local organization is interested in being a Sponsor Group in MindFreedom. We hope ENUSP will some day also be a Sponsor Group!

Below are a few examples of Sponsor Groups in MindFreedom.

#### **Association des Groupes d'Intervention en Dfense de Droits en Sante Mentale du Quebec— in Montreal, Canada**

— celebrated its 10<sup>th</sup> anniversary of advocate by and for psychiatric survivors with a gathering of 400 in the Fall of 2001. They utilize training, conferences, protest marches and art to educate the public about human rights and empowerment of people in the mental health system. The Mad Movement is alive and well in Montreal! They especially want to hear from French speakers.

#### **People Against Coercive Treatment in Toronto, Canada**

has protested the expansion of involuntary psychiatric drugging out into the community. They held "psychiatric survivor" pride events, including marches and public education events, to educate the public about the accomplishments of the psychiatric survivor community.

### **Second Opinion Society in the Northern Area of Canada– the Yukon**

– has continued to run its successful community center. Among their unique methods of community education about recovery and empowerment was to enter a team in a very popular group marathon near Whitehorse, Canada.

### **We Shall Overcome in Norway**

is one of the oldest psychiatric survivor organizations. They continue to publish their magazine on human rights in the mental health system, and to advocate for their members' human rights.

### **The International Center for the Study of Psychiatry and Psychology (ICSPP) is now Based in New York City**

They are a professional organization networking psychiatrists, psychologists and mental health workers throughout the world who wish to change the mental health system, to provide a broader range of non-medicalized services, and to promote the human rights of clients. They recently held a successful conference on this subject.

### **Center for Advocacy in Mental Health in India**

The director for the Center for Advocacy in Mental Health, Bhargavi Davar, reports that,

"ECT is a very major concern with us and there is a lot of abuse of this treatment in India. Direct ECT is still widely practiced by the state hospitals. It is also used indiscriminately for any and all kinds of 'diagnosis' and of course we have known it to be used to quell political dissent."

The group held a protest last year against violations of human dignity at the Badhusa Mental Health shelter in Ervadi, Ramanathapuram, India where 28 people were killed by a fire. They were kept chained to their beds in thatched huts. When the fire started they could not escape. The community did not intervene and the owner has abdicated himself.

### **Netherlands Group Promoting Human Rights. Medical and Therapeutic Selfdetermination in the Netherlands (MeTZelf)**

is a new MindFreedom Sponsor Group dedicated to human rights in the field of health. The following are excerpts from the group's goals, provided by liaison Mira de Vries. The goals apply to psychiatry as well as general medicine:

- Physicians, therapists and other (para)medical practitioners are to be directly employed by the client and serve no other interests than the client's;
- Physicians and therapists are not to be involved in matters which are not strictly about healing, such as child custody, or imprisonment;
- The exercising of other human rights, such as the right to housing and education, may not be made conditional to the person subjecting him or herself to any form of medicine or therapy.

For more information on Support Coalition International, see the web site

[www.MindFreedom.org](http://www.MindFreedom.org)

Support Coalition International address is PO Box 11284; Eugene, OR 97440 USA. Phone: (541) 345-9106. Fax: (541) 345-3737. E-mail address: [office@MindFreedom.org](mailto:office@MindFreedom.org)

The new issue of MindFreedom Journal is finally going to press after long delays. It is a special issue about electroshock.

The next issue of MindFreedom (Winter 2002/03) will be at the press in November. Published by Support Coalition International, this will be a special 68-page issue of MindFreedom with the theme of stopping electroshock. For a sample copy, people can send 4 US-\$ to SCI; POB 11284; Eugene, OR 97440 USA. Easiest way to pay is via credit card on our web site. We take VISA, Master Card, Discover & American Express. Since it's a small amount, some people just send cash, though we can't guarantee security for it. We do take checks in any currency as long as the bank is big enough to have USA connections. Or join via our web site.

## Coming Congresses and Events

November, 14, 2002 (Thursday): Congress “**TRIPTIEK – Two sides of psychosis**“ by users and professionals. Place: The Oranjerie, Roermond (Netherlands). Organisers: Sandra Escher (NL) / Marius Romme (NL) and others. Participants between others: Michaela Amering (A) / Karl Bach Jensen (DK) / Thomas Bock (G) / Wilma Boevink (NL) / Ron Coleman (UK) / Peter Lehmann (G) / Pino Pini (I) / Wouter van de Graaf (NL) / Rene van der Male (NL) / Jan Verheagh (NL) / More information: Congress secretariat, Mrs. Vivianne Lambrichs-Gransier, Department of Psychiatry, Academic Hospital of Maastricht, P.O. Box 5800, 6202 AZ MAASTRICHT, Telephone : +31 (0)43 3877444, Fax +31 (0)43 3875444, E-mail: [vivianne.lambrichs@pspy.azm.nl](mailto:vivianne.lambrichs@pspy.azm.nl)

November 23, 2002, in Ried Austria) and in the German language: “**Interessensvertretung in der Psychiatrie – Peers als neuer Weg?**“ Veranstalter: Verein “OASE – Power to the People, Verein für alle von Psychiatrie-Betroffenen” in Kooperation mit dem Land OÖ, ENUSP und dem Verein Omnibus. ReferentInnen: Frau Mag. Geltner, Michael Chmela, Dr. Günther Miniberger, Peter Lehmann, Dr. Marc Rufer. Eintritt frei. Anmeldung erbeten. Ansprechperson Verein “OASE”: Ulrike Burgstaller, Hohenzellerstr. 42/22, A-4910 Ried im Innkreis, Tel.: +43-(0)7752/87696; email

[burgstallerulrike@gmx.de](mailto:burgstallerulrike@gmx.de). Bei Interesse werden Folder zugesandt. Veranstaltungsort: Krankenhaus der Barmherzigen Schwestern, Schloßberg 1, A-4910 Ried im Innkreis, Festsaal. Beginn: 10 Uhr

May 29, until May 31, 2003, Berlin: **Oecumenic Churches Day**, with a common information stand with the Federal Organisation of (ex-)Users and Survivors of Psychiatry in Germany (BPE), the organisation [Für alle Fälle e.V.](#) (“For all cases”, Berlin) and ENUSP.

The First “**Art Therapy World Congress**” will take place in Budapest, March 30 to April 3, 2003. If you are interested, ask for the “Preliminary Registration Form”, which includes more information, at the address [meeting@euroweb.hu](mailto:meeting@euroweb.hu)

**INTERNATIONAL CONFERENCE OF CRITICAL PSYCHOLOGY** – Contesting conflict, challenging consensus. 27th – 31st August 2003. In the World Heritage City of Bath, England; hosted by the Department of Psychology, University of Bath Critical psychology takes many forms, and has challenged many fields of psychology. Critical psychologists have confronted numerous boundaries within psychology, and in several fields these challenges have been extremely successful. Critical psychology has infiltrated many mainstream ideas. Is critical psychology becoming part of the mainstream? What are the dangers of this? When we achieve consensus, do we lose energy? Is it time to find new grounds for challenge, create new allegiances? This conference provides an exciting opportunity to take stock of the shifting boundaries and lines of conflict in contemporary critical psychology – to question current and emergent divides. Papers in any area of critical psychology will be considered.

For online submission of papers please check conference website:

[www.bath.ac.uk/psychology/critical/](http://www.bath.ac.uk/psychology/critical/)

All enquiries to be sent to:

[critpsy-enquiries@bath.ac.uk](mailto:critpsy-enquiries@bath.ac.uk)

## Report of the “Conference on Psychosocial Rehabilitation with International Participation“

Ljubljana, May 30 – 31, 2000, organized by Sent (Slovenian Association for Mental Health) and The Governmental Office for the Disabled and Chronically Sick of RS

### INTRODUCTION

Psychosocial rehabilitation (PSR) consists of a number of activities that evidently help an individual improve his quality of life. Among others, PSR enables a prognosis of psychotic and repeated mental disorders, which would, in its absence, greatly obstruct an individual’s everyday life. We can only produce valuable psychosocial rehabilitation programs, when we join our activities, which implies interdisciplinary work of various professionals and an actual inclusion of patients and their relatives into the process of recovery. PSR unites professionals, patients and their relatives equally into a work group, which then strives to achieve the highest possible level of patient’s independence. Ethical and pragmatic conditions are a basic foundation for psychosocial services to operate. PSR is based upon respect, solidarity, eagerness, strengthening of healthy parts of an individual’s life, and hope into an improvement of conditions. Due to new anti-psychotic and anti-depressive treatments, as well as rehabilitation

programs, which have helped to improve the prognosis of psychotic disturbances, we remain optimistic. By taking an equal part in the processes of help and self-help programs, we learn from our patients and their relatives, how to progress in the sphere of mutual help and strengthen our humanism. PSR allows no patronage, omniscience or supremacy, what it demands, is an examination of already known facts and an openness to new modifications. Each human being is a world of its own, and every ill person is a teacher to all of us, who try guide him through the process of moderate dialogue.

Care planning, adjusted to each individual, requires much more than just dedication and will from professional workers and courage of its beneficiaries, it also requires several prospects for its realization. The quality of our work is hindered by many obstacles in our environment. Conditions for vocational training and employment, a network of residential units with assistance, which are now temporarily being substituted by shelters, are components, still missing in our society. In addition, we lack trained professionals, familiar with successful (PSR techniques, such as teaching social and everyday skills and cognitive psychotherapeutic behavioural techniques. We also need more staff, trained to stimulate the development of self-help and self-control processes.

Today, psychiatrists are still able still prescribe free anti-psychotic treatments from atypical group, but we are (constantly being warned about their high expenses. Forms of community care service, such as work therapy and personal assistance on patient's home, remain completely unavailable at the moment. Training and employment II opportunities are minimal. Due to great work overload and rising needs, staff employed in the services that provide help, work with low budget and under constant stress. This conference was organized in order to warn the planners of new programs about the imperfections in the current system and alert them about the relativity of high costs of rehabilitation. More than 20 per cent of first category early retirements in our country are due to mental illnesses, furthermore, more than 80 per cent of these people are unemployed. Most of them are capable of working, although under some adjusted conditions. This contribution could be useful to patients as well as to our society. What we need, is more patience, less stigmatisation and appropriate services within the institutions as well as outside of them. Mental health patients show different levels of disturbances. Those have to be recognized and treated in a manner, least harmful to an individual and society.

Dr.med. Vesna Svab (SENT, Psihiatricna klinika Ljubljana)

## **NON-GOVERNMENTAL ORGANISATJONS IN THE FIELD OF MENTAL HEALTH**

The role and the importance of unprofitable, voluntary organizations which provide their services in the field of mental health, vary from country to country. Social cooperatives in Italy are establishing and controlling residence communities and providing conditions for employment of people, who used to be treated in psychiatric hospitals. Austria has a wide network of unprofitable voluntary organization, which work closely together with psychiatric institutions and provide adequate services in the community. Unprofitable voluntary organizations in other countries control campaigns for changes in legislation and advocacy service networks. They also inform and educate general public about beneficiaries' rights.

Some countries have accepted „national strategy of community care“, which enabled them to bring social and health institutions closer to the needs of beneficiaries and community. They have created conditions for a creative and continuous cooperation of public services, involuntary unprofitable sector and private sector.

Slovenia has, in the past ten years, achieved tremendous results in developing social care services and unprofitable voluntary sector in the community. However, it has not achieved as much in the field of community psychiatry and rehabilitation. The latter follows only professional demands and conditions of institutions, instead of adapting to beneficiaries' needs and life in the community.

“Market shares“ of voluntary unprofitable sector, providing social services in the community, are very important in Slovenia. Organizations provide a wide range of social care services, such as day-care centres, drop-in centres, social clubs, domestic care services, voluntary work, holiday-making and organized recreational activities. Residence groups are established and managed mostly by unprofitable voluntary organizations. Mental health organizations can influence advocacy, changes in legislation and educational programmes. Vocational training programmes for people suffering from mental disorder are being carried out in centres and workshops for disabled people.

Are the work conditions of these organizations just as brilliant as their influence at providing community services?

Funds for organisations are provided by the Ministry of Labour, Family and Social Welfare, Foundation for funding humanitarian organizations and government employment institutions. Apart from that, these organizations also receive funds in the form of donations from Ministry of Health and Health Insurance Institute. The continuity of work within organizations is guaranteed mostly by those who finance social services.

Slovene NGOs have been striving to achieve adequate and complex legislation in the field of mental health. They have also been trying to update the legislation of humanitarian and charity organizations, and provide financing of

programmes, such as residence communities, educational programmes and health services.

Unprofitable, voluntary organizations are rarely included in planning and forming of strategy and policy in the field of mental health. They are only included in the process either individually or on local levels.

Joint cooperation of unprofitable voluntary organizations is slowly gaining ground in Slovenia. Unfortunately, not as much interest for integration is shown, as one would expect.

Approximately 700 members and about 1000 beneficiaries are actively included in mental health organizations.

Do these circumstances require a clear vision of care development in the field of mental health care?

*(Conference-report, p. 3f. and 41)*

## **Letter to the European Patients Forum**

Dear friends,

the board of ENUSP decided on its meeting in Berlin, August 23-25, 2002, to join the European Patients Forum. Peter Lehmann, Berlin, will be the representative. He is authorized by ENUSP to sign the Declaration.

ENUSP regrets that it was excluded at the beginning of the discussion. As we heard, only two "patients' groups" from the psychosocial field had been invited to the preparation meetings. Other than GAMIAN, the other invited group was Mental Health Europe, which probably does not claim to be a Patients' Group. Our Pan-European organisation with member-organisations was not invited, in spite of the fact, that ENUSP is well-known and respected. To ensure future misunderstandings, we would be happy to learn who was responsible for our exclusion.

We regret that again we have not been invited to the July 2002 meeting, and especially we regret that we did not hear any motion from GAMIAN to include us. This is the prime reason that ENUSP cannot support Mr. Rodney Elgie from GAMIAN to be the speaker of the EPF.

We regret, that in the minutes Peter Lehmann's comment is not mentioned, namely that before speaking about any candidates, the tasks, the needed time and the skills of a speaker should be discussed. It would damage the authority of each representative if there would be the impression that he is elected for other reasons than for his skills.

As openness about the recourses of the participating organisations is one of the principles all organisation agreed, we would first like to know the sources of organisations in particularly whose is the representative candidate in the role of speaking for EPF. There are rumours that GAMIAN receives a lot of money from drug companies, which is a problem, where their independence might be undermined. Last year the European Public Health Alliance brought this problem to the consciousness of its members and other interested groups. We do not know any sum GAMIAN is receiving, so we are not able to give a more concrete comment. But as we know, that especially this issue everywhere causes argument, we would prefer if somebody would be speaker of EPF, who is not a the source of arguing. The problem, not knowing about the independence of a candidate, might be diminished if we would learn the sources of GAMIAN.

We are sure that it is better to be honest about all doubts at the beginning, so further on there remain no concealed problems which might grow and damage the reputation (and on the surface, very appealing future) of the EPF, which we want to support.

Best wishes

For the board of ENUSP

Peter Lehmann

## **Letter to Valdeko Paavel and Colleagues, Organizers of the Congress of Mental Health Europe in Tallinn (Estonia)**

Dear friends,

one year ago I was asked to join the advisory-board of the MHE-congress in Estonia in November 2002. I was pleased about the invitation, joined and made a lot of proposals, all into the direction of user/survivor-integration into the congress. When I asked months ago, which part of all my proposals were accepted, I got no answer.

I made the proposal to join the preparation-meeting in August 2002, and I got the answer, that they are searching for someone to pay the travel. Now it is September 2002, I never got any message again, I guess I am "forgotten". So I

ask you kindly to delete my name in all congress-documents. I would feel quite bad if my name would be connected with the conference when, in reality, I totally failed to give any input for the programme.

If you make the next congress, of course I would be glad to be invited again. Have a nice congress in Estonia, best wishes

Peter Lehmann

## **Treatment-Induced Suicide. Suicidality as a Potential Effect of Psychiatric Drugs. Part 2**

by Peter Lehmann

*(Worked-over) Contribution to the conference Coping with stress and depression related problems in Europe, organized by the World Health Organization, the European Commission and the Federal Ministry of Social Affairs, Public Health and the Environment (Belgium), Brussels, October 25 – 27, 2001.*

Atypical psychiatric drugs have suicidal effects, too, as the report of Austrian Ursula Froehlich in Brave New Psychiatry shows:

Since I began taking Leponex (clozapine), I do not want sex anymore, did not feel like moving and had no joy in life. A life without joy is, however, worse than death. All that remained with me is watching TV, where I have watched others living for seven years. I am still alive biologically, but my senses are long since dead, everything that I former enjoyed I am not able to do anymore. In a way, my life does not exist anymore, I feel so empty and unimportant. In the mornings, the feeling is the worst. Every day I intend to start a healthy life the following day, to throw away the drugs, to drink many vitamins and fruit juices and to start with a daily fitness routine. The psychiatric drugs cause a feeling as if it was possible for me to start with a completely different, a new life the following day. But when I wake up in the morning I feel like smashed, and I never come out of bed before 9 o'clock, my depressions are so extreme that I think of suicide every day. (quoted from Lehmann 1996, p. 70ff)

Psychiatrists did not do differ in their own experiences of these drugs. In 1954 and 1955 Hans Heimann and Nikolaus Witt (1955) of the Psychiatric Department of the University of Berne published their experiences after once taking Largactil, the prototype of chlorpromazine. They experimented with spiders and 1080 control subjects; they had three self-experiences and nine experiments with as many psychiatrists and pharmacologists. The marked inferior feeling and the feeling of powerlessness, structural element of the syndrome of Parkinson's disease caused by psychiatric drugs, after taking Largactil became very clear in the following excerpts:

I felt physically and mentally ill. Suddenly my whole situation appeared hopeless and difficult. Above all, the fact that one can be so miserable and exposed, so empty and superfluous, neither filled by wishes nor by something else, was torturing. ... (After finishing the examinations): The tasks of life grew immense in front of me: dinner, go to the other building, come back – and all of that by foot. With that this state reached its maximum of uncomfortable emotions: The experience of a passive existence with clear knowledge of the other possibilities... (p. 113)

### **Suicide-register as a form of prevention**

In February 2000 the German Organization of the (ex-) Users and Survivors of Psychiatry put forward the demand to the health minister to introduce a suicide-register with special consideration of associated psychiatric drugs, electroshocks, restraint and other forms of psychiatric compulsion (Lehmann 2001, p. 46). The missing of a registration of suicides associated with psychiatric treatment methods, covering all areas of a country, is a serious evil; such data are a fundamental prerequisite for cause-research and an important basis for prevention and early detection. An obligation to notify the authorities of suicides associated with psychiatry and psychiatric drugs could enable preventive measures and instigate reliable studies that discover the connection between suicidality and the effects of psychiatric drugs. Not only neuroleptics, as shown, but antidepressants (Healy 2001; Lehmann 1996, p. 194ff) and electroshock (Frank 1990), too, should be watched very attentively.

Reports of (ex-) users and survivors of psychiatry who have been pushed into suicide attempts after traumatizing treatment with psychiatric drugs, electro- and insulinshocks (see for example Kempker 2000), must no longer be ignored. Physicians and relatives have to be informed about the risk of drug-caused depression and suicidality. The users of psychiatry need to be informed so that they can make a carefully considered and informed decision about

taking or not-taking an offered psychiatric drug and if necessary can take less risky measures against their depression.

### **Appendix: Continuous discrimination of (ex-) users and survivors of psychiatry**

At the conference “Balancing Mental Health Promotion and Mental Health Care: A Joint World Health Organization / European Commission Meeting“ in Brussels in April 1999 the inclusion of (ex-) users and survivors of psychiatry into mental health policies was accepted in the Consensus-paper:

Common goals and strategies to advance mental health promotion and care include: (...) Developing innovative and comprehensive, explicit mental health policies in consultation with all stakeholders, including users and carers, and respecting NGO and citizen contributions. (WHO 1999, p. 9)

A representative of the European Network of (ex-) Users and Survivors of Psychiatry was invited to the conference Coping with stress and depression related problems in Europe (Brussels, October 2001), again organized by the World Health Organization and the European Commission.

Instead of ensuring his active inclusion to enable professionals and politicians to learn from the treasure trove of experiences and knowledge of (ex-) users and survivors of psychiatry, they did not feel the need to offer him an equal right's plenary presentation. Even after remembering the consensus paper, the Belgian Federal Ministry of Social Affairs, Public Health and the Environment asked him only him “to take an active role in the discussion during the workshops“ (Leen Meulenbergs).

This is an old-fashioned allocation of roles for the representatives of (ex-) users and survivors of psychiatry, who should play an active role as experts in congresses, which deeply concern them. This conduct is to be rejected as discriminating and against the spirit of equal rights.

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<http://www.enusp.org/documents/consensus.htm>

Translation by Pia Kempker

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## **Varia**

There was a program funded by the European Commission:

### **COMPULSORY ADMISSION AND INVOLUNTARY TREATMENT OF MENTALLY ILL PATIENTS – LEGISLATION AND PRACTICE IN EUROPEAN UNION MEMBER STATES**

It was done by the CENTRAL INSTITUTE OF MENTAL HEALTH, MANNHEIM (which cannot be characterized as a good address). Anyway, you can see the final report via

[http://europa.eu.int/comm/health/ph/programmes/health/proj00\\_08\\_en.html](http://europa.eu.int/comm/health/ph/programmes/health/proj00_08_en.html)

