

ENUSP Bulletin

No. 1 - October 2011

Dear friends,

It's been too long since we posted you an update from ENUSP. Our volunteers have been doing their best under hard conditions.

In this **ENUSP Bulletin**, the first of a monthly series, we want to share some highlights of our activities over the last year. In the pages that follow, you'll find reports of **our efforts to bring mental health service users and psychiatric survivors together across different parts of Europe.** Read about ENUSP's meeting for representatives from user/survivor organisations in 17 countries (see page 4). There's also news of **our work with the national user/survivor movement in Portugal** (see page 8). This is support we want to offer user/survivor groups in other countries.

Beyond this, you'll find news about ENUSP's latest lobbying for our full human rights in forums that decide about us (see pages 9-11). In our meetings with the European Commission, the EU Fundamental Rights Agency and national governments, we have tried to push forward the radical content of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), which our user/survivor colleagues from the international movement fought so hard to achieve. The CRPD bans all incarceration, forced treatment, and guardianship of people who are psychiatrically labelled. ENUSP needs to do more so users and survivors across Europe know their rights! For more on the CRPD and some top human rights stories in our community this year, see pages 12-14.

Lastly we report in this **Bulletin** on **our efforts to solve ENUSP's funding crisis**. Our Network has truly struggled to stay alive and connected in recent times. For the last seven years, we have worked without any funding outside fees from some members, who themselves have few resources. We're very grateful for your patience and support over this rough time. We're also glad to announce that we have succeeded in getting funding from Open Society Foundations Mental Health Initiative. For all the details of this grant, please see page 7.

We want to use this grant to build the European Network from the grassroots up over the next 6 months. To do this, we are calling on YOU to get directly involved. Please help us to create the kind of organisation of users and survivors across Europe that you'd like to see! We need your experience, your creative spirit, and your determination to create a stronger voice for all of us who have used or survived mental health systems. This includes the many users and survivors still not being reached by our movement.

To find out about the plans for the months ahead, take a look at the **Special Building ENUSP Together Attachment** to this **Bulletin**: it contains lots of new opportunities for working with ENUSP. These include a job opening for a paid web designer. Please share this information with your colleagues and friends!

We want to hear your opinions and questions about this **ENUSP Bulletin**. We hope to feature the latest announcements from your organisation or community in our next edition.

You can reach us at: enusp.info@gmail.com, or by contacting your regional representatives at the addresses via www.enusp.org. Very soon we will be setting up a telephone contact point, which could help some people who lack good internet access.

In solidarity!



Image courtesy of Gregory Oke, original source unknown

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NEWS FROM THE ENUSP BOARD'S FIRST YEAR

BUILDING THE EUROPEAN NETWORK



Gabriela Tanasan, ENUSP Chair

"ACTION NOW! HUMAN RIGHTS and RESOURCES for USERS and SURVIVORS Of PSYCHIATRY ACROSS EUROPE"

ENUSP's new Board members and other volunteers have faced a big test in taking up their roles without many resources. They have relied mostly on email to work as a team across vast distances.

In late May, the Board seized the chance to bring some representatives of user/survivor groups face to face in Brussels after the non-user/survivor organisation Mental Health Europe (MHE) offered funding. MHE (www.mhe-sme.org/about-mental-health-europe.html) receives support from the European Commission.

Called "ACTION NOW! HUMAN RIGHTS AND RESOURCES", this two-day meeting brought together delegates from user/survivor groups in **Bulgaria**, **Romania**, **Greece**, **Italy**, **Spain**, **the Czech Republic**, **Germany**, **the Netherlands**, **Belgium**, **Ireland**, **the UK**, **Latvia**, **Lithuania**, **Denmark**, **Finland** and **Sweden**. ENUSP also found a way to invite 2 participants from **Bosnia** and **Georgia** with funding from Open Society Foundations. (The Georgian representative sadly had to withdraw.)



ACTION NOW! featured a joint conference and debate among ENUSP and MHE delegates and representatives from the European Commission and United Nations on the progress of de-institutionalisation in the EU.

Among the highlights, **Erik Olsen** (Denmark) of ENUSP gave a powerful keynote address detailing the harm to human rights and dignity caused by any kind of psychiatric imprisonment.

Across Europe, he said, people with psychiatric labels are still kept in captivity. In big institutions and new smaller institutions in the community, they are targets of medical experimentation, degrading treatment and torture. More is being done, he said, to care for public property than to protect these human beings



Other ENUSP delegates called on EC and UN officials to halt the forced treatment in the community that is fast replacing institutions in parts of Europe.

The session closed with words from Hungarian psychiatric survivor **Gabor Gombos**, now also a member of the UN Committee that enforces the Convention on the Rights of Persons with Disabilities (CRPD). Some governments, he said, had signed and even ratified this Convention fairly quickly. Still they were not pursuing their obligations very seriously. The Committee would be making them face up to this fact, he said.

Psychiatric survivor and CRPD Committee Member from Hungary Gabor Gombos

"BUILDING ENUSP: STATUS, PRIORITIES, ACTION PLAN"





User/survivor delegates met privately the next day for a working seminar "Building the European Network: Status, Priorities, Action Plan". Led by Chair **Gabriela Tanasan** (Romania), the discussion set emergency goals for ENUSP that balanced practical needs (like accessing money) with our most vital work. Participants divided into 5 groups:

- Planning key actions for ENUSP + finding funding over the next 12 months
- Working on the CRPD: Lobbying and raising awareness
- The European MadPride Human Rights and Culture Festival
- ENUSP's newsletter Advocacy Update, and
- Peers in Progress, a peer support training proposal from ENUSP's Berthold Koesel (Germany).

To carry on this important work, participants also signed up for new **ENUSP Taskforces**, small teams of users and survivors focusing on these and other topics. To learn more about the work of the ENUSP Taskforces, including how you can join, **please see the attached Special Building ENUSP Together Attachment.**

The day ended in an informal dinner to celebrate ENUSP's 20th anniversary. **Maths Jesperson** (Sweden), one of ENUSP's co-founders, shared stories from the early days of building bridges among European users and survivors.

ENUSP thanks MHE-SME and Open Society Foundations for supporting this meeting. We are also very grateful to UilenSpiegel Flemish user/survivor organisation in Brussels for its vital organising and financial help and its warm hospitality, and to Jan Wallcraft, Elizabeth Winder, Berthold Koesel, Maths Jesperson , Nadia Mahjoub and Jasna Russo, who all led work sessions or did translation or graphic design.

Rafaël Daem, Gabriela Tanasan, Katerina Skourtopoulou and Debra Shulkes planned the ACTION NOW! Seminar and ran work sessions.





STRENGTHENING THE ENUSP REGIONS

Users/survivors from two ENUSP regions the South-West and Northern Europe built up their connections in their own meetings this year. In late July, Belgian, Spanish and Italian user/survivor representatives gathered in Traona, Italy to plan the region's work, including the European MadPride Culture and Human Rights Festival in 2011 and beyond. A full report on this meeting is available from **Rafaël Daem** (Belgium): enuspdesk@hotmail.com

The month of August saw the annual gathering of users and survivors from the Northern region. They reunited for the Amalie Days festival hosted by Norway's We Shall Overcome, the oldest user/survivor group in Europe. ENUSP Northern representative **Erik Olsen** (Denmark) offers these reflections:

"Amalie Skram was a Danish/Norwegian author, a feminist [who] wrote a devastating critique of psychiatry as early as the end of the 19th century...During this year's Amalie Days, we had many panel debates and discussions. Late into those nights, we talked through a regional strategy to oppose the conservative forces, including some 'user' organisations, that now support forced institutionalisation and forced treatment... We need to upgrade our knowledge of all corners of the UN CRPD and how we should argue in very sensitive areas like suicide. We also decided to make a formal user/survivor organisation for the Nordic region and are discussing its name." For more information, please contact: erikpsyk@gmail.com

ENUSP GAINS FUNDS TO GROW OUR NETWORK

ENUSP has succeeded in getting a six-month grant from Open Society Foundation (OSF) Mental Heath Initiative.

The grant's purpose is to allow ENUSP to strengthen our connections with users/survivors and their organisations across the European continent.

The ENUSP Board decided to apply for this funding from OSF after an individual ENUSP member negotiated a potential grant. This was a crucial opening since ENUSP lacks the start-up money needed to qualify for European Commission funding. ENUSP rejects all pharmaceutical and medical industry support on principle.

OSF Mental Health Initiative (http://www.soros.org/initiatives/health/focus/mhi/about) is a philanthropic fund that supports initiatives to end the institutionalisation of people with mental health problems. OSF funds the development of our own representative organisations and community-based alternatives. It is especially active in central and eastern Europe and the former Soviet Union.

Work on ENUSP's application began in earnest after the ACTION NOW! Seminar. It was very demanding for a few months.

The grant to ENUSP, worth just under 30,000 euros, will support the day-to-day running of the Network, including redesigning the website, communicating closely with members, and building a member database. In recent years, these tasks have fallen on the heads of volunteers or been neglected, with heavy costs for ENUSP and many individuals. **ENUSP will retain total control over all aspects of our work.**



To learn more about ENUSP's planned project, and most importantly, to share your feedback and get involved, please see the attached **Special Building ENUSP Together Attachment.**

Gabriela Tanasan, Elizabeth Winder and Debra Shulkes all worked on the grant application with support from Erik Olsen and Katerina Skourtopoulou. Jasna Russo negotiated the possibility of a grant for ENUSP.

SUPPORTING NATIONAL USER/SURVIVOR MOVEMENTS



Focus on PORTUGAL!



ENUSP worked with Portuguese user/survivor organisation Centro de Empowerment to set the agenda of the country's first ever national conference of users and survivors with families and government. The Portuguese government funded and co-ordinated the event, which took place on October 10 and 11 in Lisbon.

The conference brought user/survivor participants from all over Portugal to the capital by bus for two days. International user/survivor speakers and critical psychiatrists were also flown in. They addressed topics chosen by local activists like **Maria João Neves**, one of two psychiatric survivors on the 6-person organising committee.

Those topics included the UN CRPD and human rights; how to set up and protect user/survivor-controlled projects; and the goal of 'recovery', a popular term in the new Portuguese mental heath plan, with very different meanings for users/survivors, professionals and government.

Maths Jesperson was one of the visiting user/survivor experts nominated by ENUSP. He shared lessons from the survivor-led Personal Ombudsman (PO-Skåne) service, which he pioneered in Sweden. This successful service offers (ex-) psychiatric patients support with their decision-making that respects the will and preferences of the person, as the UN CRPD requires. It proves that psychiatric force and guardianship are unnecessary as well as unsafe and unlawful. (See page 10 for more details). Janet Wallcraft (UK) reflected on experiences of UK users and survivors with the concept of recovery and paid work in mainstream services. Erik Olsen drew on insights from Denmark about how to create robust user/survivor-controlled organisations.

All three speakers met with an enthusiastic reception from local users and survivors and their supporters. One moderator declared the presentations "visionary" and "earthquaking". Government workers from the National Coordination Body for Mental Health also took notice. "They have opportunities to ask for money to start something like PO-Skåne in Portugal," Maths said, "so I hope they will do something."

Strikingly Portugal is one of the poorest countries in the EU. The government's decision to fund this conference shows what other states can and should do if they are serious about CRPD implementation. Local users/survivors must determine the agenda of these meetings. Our experience in Portugal demonstrates that ENUSP could offer vital support.

Consider joining the ENUSP Strategy-building Taskforce to discuss and plan how ENUSP could better support national and local user/survivor activism over the next three years. See the attachment **Building ENUSP Together** for more details.

ADVISING ON EU HUMAN RIGHTS STUDY



Representatives of user/ survivor groups from ten EU countries will head to Vienna in early November to discuss the findings of a research study about them that was funded by the EU Fundamental Rights Agency (FRA).

The study investigates the human rights situation of users and survivors of psychiatry in all 27 states of the European Union. It looks at the lives of people with intellectual disabilities separately. This is the first time that the FRA, the EU body responsible for rights protection, has researched the human rights status of either group. The results should expose where our governments ignore and breach the CRPD.

The users and survivors travelling to Vienna are from Bulgaria, France, Germany, Greece, Hungary, Latvia, Romania, Sweden, England and Scotland. These are the countries where interviews took place with users and survivors about their experiences inside institutions and in the community, their right to legal capacity and access to justice.

A group of university disability law centres and human rights NGO s is behind the study. ENUSP has played a significant role. Our representative **Jasna Russo** (Germany) worked intensively on the research design, and she was later invited to join the research team as an independent survivor researcher. She was the only member of that team with personal knowledge of the topic. The project design stressed the need to do research **with** rather than **on** the study participants.

Mary Nettle (U.K.) and later Debra Shulkes (Czech Republic/Australia) also represented ENUSP on the project advisory board.

It is extremely rare for ENUSP to achieve this level of involvement in EU research about us. Normally we are offered a tokenistic role in the project long after all big decisions are made, or we are just dismissed as unqualified and ignored. The study planned for greater participation of ENUSP members. However **Mary Nettle** believes this was hard to achieve while ENUSP lacks an updated database of user/survivor contacts across Europe. "We need to think about how to involve ENUSP members better in any future projects", she said.

We will be reporting on the experiences of the user/survivor representatives at the Vienna meeting. We will also share the findings of this project with you as they become available. We would like to send the feedback of the broader ENUSP membership to the researchers of the FRA.

There are important questions at stake about the impact of this human rights study on the FRA's work. Some members are also asking whether it's time for ENUSP to pursue our own independent research on the human rights of users and survivors across all of Europe.

For more information about the FRA research study, please see www.fra.europa.eu/fraWebsite/research/projects/proj_disability_en.htm, or contact Debra Shulkes at enusp.info@gmail.com

Consider joining the ENUSP Research Taskforce to discuss your research questions and project ideas. See the attachment **Building ENUSP Together** for more details.

TAKING THE UN CONVENTION FORWARD



ENUSP Deputy Board member Maths Jesperson

ENUSP's Maths Jesperson has been leading the way in lobbying for the ratification and implementation of the CRPD across Europe and beyond. On site during the historic negotiations of the Convention at the United Nations building in New York, Maths is widely known for his groundbreaking work on the Personal Ombudsman (PO) model in Sweden. This effective user/survivor-run service offers healing support to (former) psychiatric patients in their decision-making. It, thus, shows that substitute decision-making methods are unnecessary as well as damaging and unlawful under the CRPD. Below he reflects on some of his recent lobbying work across Europe.

"The implementation of the CRPD in various countries is very hard work. The resistance of governments is really very high to changing anything at all. They are against all initiatives and proposals coming from outside (from the UN, from international NGOs), which they see as interventions in their internal affairs.

This implementation work is much harder than the drafting work we did at the UN because the state delegates to the UN were very open and interested in us. I was very surprised at how easy it was to lobby, and how easy also to discuss controversial issues about psychiatry with these state delegates...The US state delegation even sat down with us for one hour (and had many other talks with us), and agreed with all we said and promised to try to influence others in the same direction. They even criticized their president George Bush in front of us, although they were his official representatives!

But now when lobbying for the ratification and implementation of CRPD we meet much more negative and hostile reactions from the national governments.

I have been active in this lobbying on behalf of ENUSP in many European countries, including my own country Sweden, this year. In January I talked about the Personal Ombudsman model in connection with the Article 12 of the CRPD at a conference in Budapest, Hungary. In March I did the same at two conferences in Riga, followed by taking part for some hours in a meeting at the Latvian Ministry of Justice with the lawyers who are writing a new civil law for Latvia, where we tried to influence them to write this new civil law in accordance with the CRPD. They were reluctant and a bit hostile in the beginning, but after an hour they opened up, and we had a good discussion, where we gave them many concrete examples of what they could write in the new civil law to protect and guarantee human rights for persons with psychosocial and learning disabilities.

In April, I presented the Personal Ombudsman-model at a workshop at a big Fundamental Rights Agency conference in Vienna on human rights within the EU. I was also very active in the general discussion there... I talked about the importance of Article 12 on legal capacity, and asked if this was included as one of the European Commission's eight priority areas for CRPD implementation within the EU. Johan ten Geuzendam from the European Commission, DG Justice said that the EU can only work with those parts of the CRPD which fall within EU "competence", and that legal capacity belongs to the individual member states. But he strongly agreed with me about the importance of Article 12, and he promised that they will try to influence the member states when discussing the CRPD.

In May, I represented ENUSP at a working seminar in Dublin, where we developed implementing guidelines for Article 19 of the CRPD about breaking down all institutions, including new institutions in the community like group homes. The seminar, containing about 20 experts from all around the world, was organised jointly by Mental Disability Advocacy Center and Open Society Foundations.

This autumn I have already spoken about the PO-model and the CRPD at conferences in Berlin, Alzey, Lisbon and Prague.

Best-

Maths Jesperson, Sweden

For more information about the PO model, please see http://www.po-skane.org/ombudsman-for-psychiatric-patients-30.php





Interested in learning more about the UN CRPD and its meaning for you and your organisation?

You can find the full text of the human rights treaty here: http://www.un.org/disabilities/default.asp?navid=14&pid=150

We highly recommend:

-the CRPD Implementation Manual prepared by the World Network of Users and Survivors of Psychiatry: http://wnusp.rafus.dk/documents/WNUSP_CRPD_Manual.pdf

-all the resources on the CRPD and other human rights tools provided by the Center for Human Rights of Users and Survivors of Psychiatry (CHRUSP): http://www.chrusp.org/home/resources

Consider joining the ENUSP CRPD Taskforce to discuss your questions and ideas for actions around the CRPD. See the attachment **Building ENUSP Together** for more details.

THE LATEST HUMAN RIGHTS NEWS



Poster image Zack Lee / Flickr CC

ENUSP share some top human rights developments over the last 12 months

UN CRPD Committee tells Spain: End psychiatric force and guardianship

The UN CRPD Committee, which enforces the CRPD, has just reviewed the Spanish government's report on its implementation of the treaty. Spain ratified the CRPD in 2007.

The Committee's conclusions about Spain make for essential reading. They send a clear message to other governments about what they must do to implement the Convention.

The Committee warned Spain that it **must end the guardianship, incarceration (forced hospitalisation) and forced treatment of people** with psychosocial disabilities. The Committee also cautioned against the abuses of people with "perceived disabilities". This term could help users and survivors who don't identify as people with psychosocial disabilities.

The Committee's report is available here (in English): http://www2.ohchr.org/SPdocs/CRPD/6thsession/CRPD-C-ESP-CO-1%2520.doc

UN Special Rapporteur for Torture demands a ban on solitary confinement

The UN Special Rapporteur for torture Juan E. Méndez issued a strong statement on October 18 calling for a complete ban on the solitary confinement of people with mental heath problems.



"There is no justification to hold people with mental problems in solitary confinement for it only exacerbates their problems instead of protecting them," said Mr. Méndez, who is himself a torture survivor. He made no exceptions for psychiatric institutions or medical settings.

Mr. Juan Mendez, Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment Source: OHCHR Photo

To watch the press conference, please follow this link:

Http://www.unmultimedia.org/tv/webcast/2011/10/press-conference-with-mr-malcolm-evans-mr-claudio-grossman-and-mr-juan-mendez.html

Anyone in any country can also make an urgent appeal or letter of allegation to the UN Special Rapporteur on Torture. http://www.ohchr.org/EN/Issues/Torture/SRTorture/Pages/Appeals.aspx

Three European countries ratified the CRPD in 2011

Cyprus, Luxembourg and Romania all ratified the CRPD in 2011. All three states must now bring their national and local laws into line with the CRPD requirements. The European Union itself ratified the Convention in December 2010.

In addition, the UK, Ukraine, Sweden, Spain, Slovenia, Slovakia, Portugal, Luxembourg, Lithuania, Latvia, Italy, Hungary, Germany, France, Cyprus, Croatia, Bosnia and Herzegovina, Belgium, Azerbaijan, Austria have all ratified the CRPD's Optional Protocol. WNUSP representative **Tina**Minkowitz writes, 'This means that if anyone has an individual complaint of violations that the courts of the country have not satisfactorily resolved (e.g. you are locked up in psychiatry and the courts deny your request for release), you can make a complaint to the CRPD committee."

The contact information for the committee is at: http://www.ohchr.org/EN/HRBodies/CRPD/Pages/Contact.aspx

UK psychiatric patient loses historic public appeal

The first psychiatric patient in the UK to have an appeal against his detention heard in public lost his case on October 26.

The UK Guardian newspaper reports that Albert Haines, 52, has been held against his will at Broadmoor hospital and another forensic psychiatric unit for more than 25 years. He made legal history this February when he won the right to an open hearing under section 6 of the European Convention of Human Rights.

These hearings always happen behind closed doors. It is argued that this protects patient confidentiality. An estimated 100,000 mental health tribunals have been held in England and Wales in the past seven years.

Haines claimed he wanted an open hearing to expose failings in the mental health system. He does not agree with the psychiatric label or neuroleptic drugs imposed on him, and says he has received no acceptable counselling to deal with childhood abuse.

However the tribunal rejected his appeal after a clinician claimed that the patient remained a risk to the public and to himself.

Haines's lawyer protested that her client had never physically harmed anyone. She said his hostility towards hospital staff could possibly be explained by the fact "he is in a place he desperately doesn't want to be and he's angry at being there".

Court of Human Rights compensates psych detention victim

The European Court of Human Rights awarded an Estonian woman Ms. S. 5000 euros in compensation after she was incarcerated in a psychiatric hospital without a prompt hearing. The court heard that this was a violation of Article 5(1)(e) of the European Convention on Human Rights. Under Estonian law, a person can still be forcibly admitted to a hospital on an emergency basis if a hearing follows soon afterwards. In Ms. S.'s case, there was a 15-day delay between her psychiatric detention and her hearing.

Please see this report for more information: http://mdac.info/node/806 (judgment in the case of S. v. Estonia)

High Commissioner seeks info about psychiatric violence

The Office of the High Commissioner for Human Rights in Geneva is calling for submissions on the topic of violence against women and girls and disability. The Office will use these statements in its upcoming report to the Human Rights Council.

Influenced by the work of the WNUSP international representative **Tina Minkowitz**, the Office has specifically asked for information about harm to women and girls due to forced psychiatric interventions, including institutionalisation, solitary confinement and restraint, drugging and electroshock treatment. Tina has prepared a powerful submission documenting the way that forced psychiatry perpetuates often legalised violence against women and girls around the world. For a copy of that statement, please contact tminkowitz@earthlink.net.

Your contributions should reach the Office of the United Nations High Commissioner for Human Rights by November 18, 2011. Send them to the United Nations Office at Geneva, registry@ohchr.org with a copy to Veronica Birga (vbirga@ohchr.org).

NEWS FROM ENUSP REPRESENTATIVES

ENUSP representatives reflect on their work this year



Gabriela Tanasan (Romania), ENUSP Chair

Dear ENUSP friends,

It's now been almost a year since the new Board was elected in Thessaloniki. I want to tell you a bit about my activities in that time. I have been working a lot on finding independent funding for ENUSP. This was the task that the General Assembly gave me in Thessaloniki, and in fact the first point on the work plan we received from the members there. I had promised to try my best though I knew it would be difficult.

There were not so many viable options. All the documentation like mission statements, past project descriptions and financial reports had to be written. There was also no money to fund the people working on that application.

It was a big relief and source of hope for me when our funding application to Open Society Foundations succeeded.

I felt this hope again after talking with users and survivors from 3 or 4 organisations in Finland in late September. The people there, like our members everywhere, have a lot of expectations of ENUSP; they want to be more informed about our work and to get more involved, to support us, and so on. I did networking, presenting ENUSP's real situation and speaking about our new project. I came away with even more hope. So much depends on our capacity to connect with local users and survivors so they can participate and get something back from ENUSP. I am now writing a report on my participation at this conference in Lahti, Finland and visits to Lahti, Joensuu, and Helsinki.

14/27

Users and survivors from Romania also met in the middle of October for the first Mental Health National Forum organised by Aripi Association in Bucharest. This was a great opportunity for Romanian users/survivors to meet and talk about the state of the mental health system and our NGOs, and to put the Romanian user/survivor movement in a European context. I spoke about ENUSP's history and its past projects, as well its current activities and plans for the immediate future. Romanian users and survivors need to have a louder and louder voice in everything affecting their lives: human rights, legislation, policy, services. Many say that by getting involved in a European organisation like ENUSP, we can achieve much more than by fighting on our own.

Lastly I've taken on much of the daily organisation and administration work for ENUSP. This included ENUSP's legal registration, bank account, and web domain transfer as well as daily correspondence and organising Board meetings and the ACTION NOW! seminar. A special thank you to the Board members and to our supporters Clemens Huitink, Claus-Bech Nielsen, and Rodica Anton for all their help with this.

And a big thank you to all of you, ENUSP members and supporters.

Gabriela Tanasan, gtanasan_enusp@yahoo.com



Rafaël Daem (Belgium), ENUSP Board member for the South-West region and Deputy Chair until October 2011

Hello ENUSP folks,

I would like to share a brief report about my work as a Board member since I was elected in Thessaloniki:

First: I am responsible for the preparation of the **European MAD PRIDE project 2011** in Belgium, and I provide support to the ENUSP members working on this project in other countries (Spain and Italy). The main message of Mad Pride is empowerment. Our theme is: "I am proud of who I am!"



On Saturday 8th October, 2011, the non-profit organisation UilenSpiegel, which represents the interests of (ex-) users of mental health services in Flanders and Brussels, together with its French counterpart Psytoyens and ENUSP, held a second European MadPride in Brussels from 2 p.m. until 6 p.m. The last Belgian MadPride took place in 2007.

Mad Pride:

- is an international movement of people who are emotionally different, vulnerable but strong
- is a peaceful public demonstration of (ex-) users of the mental health system who are fighting for their rights, with the support of those in solidarity with them (social workers, family, friends, colleagues, human rights NGOs...)

•aims to raise community awareness about the rights and experience of (ex-) users of mental health services, to promote diversity and to oppose all forms of prejudice

This year's MadPride in Belgium took off at 2 p.m. on October 8, 2011 with a march from Brussels North station to Mont des Arts. It was followed by a mini-conference at Bozar, the former Palace of Fine Arts from 4 p.m. to 6 p.m. Our topic was the rights of people with mental health problems and the meaning of good support, with a focus on de-institutionalisation.

I spoke at the mini-conference as the coordinator of UilenSpiegel, my local organisation and also as ENUSP Deputy Chair. My message to regional and EU policy makers was that the independent ENUSP network needs and deserve support to develop its mission (in fighting discrimination and promoting human rights and peer support for users and survivors). UilenSpiegel is an important member of the ENUSP network, exemplary to those in other countries and regions. More reports about the success of this year's MadPride will be coming soon.

Second: In the first half of 2011, I provided support for the preparation of the ACTION NOW! seminar in May, hosting a meeting for the ENUSP organising group in April. I was also responsible for running the workshop "European Mad Pride" at this seminar. I was able to find a volunteer willing to help with preparing an invitation to the celebration of the 20th anniversary of ENUSP.

Third: I took the initiative to arrange a successful meeting of the ENUSP South-West region in Milan (Italy) from July 30 - August 1. The purpose of the meeting was to strengthen our region of ENUSP, to talk about the MadPride project, and also about the United Nations Convention on the Rights of Persons with Disabilities.

All these actions were planned according to the work programme adopted in Thessaloniki last year.

As a participant in virtual Board meetings, I brought a more critical voice as a counterweight to my caring side. I argued for a solid network, with distinctive regions, and a lot of responsibility allotted to users and survivors (and their organisations) in the network.

To finish with a personal remark: I do not really like flying, and right now I have a lot of work to do in UilenSpiegel in Flanders as a (paid) expert by experience. This means that travelling (as an ENUSP representative) in Europe is not a priority for me, but only something I will do when it is essential. In contrast, I really like hosting people from ENUSP in Brussels... Brussels is a strategic and important place in the EU.

Last but not least, I want to thank all of the people in the ENUSP network (grassroots members and the Board of which I'm part) for their important support, and my Flemish user movement UilenSpiegel that also gave financial and logistical support during a difficult period for ENUSP this year.

Let's keep in touch,

Kind regards,

Rafaël Daem



Jan Verhaegh (Netherlands), Board Member for the North-West Region

Hello everyone - Here's my news:

In June I took part in a conference of the International Society of Social and Psychological Treatment of Psychosis in Dubrovnik, Croatia. About 700 people were there to promote psychological and special social treatments of so-called schizophrenia. They included psychiatrists, psychologists, social workers, and policymakers in the field of mental health and psychiatry and user/survivors.

I was very active in the general discussions and led the push to start our own user group within this network, Later that month, I was at a meeting of the European Network For Mental Health Service Evaluation (ENMESH).. I ran a discussion group together with organiser Professor Thomas Bekker, bringing professionals and user/survivors together to talk about social justice and psychiatry.

From September 1 - 5, I was in Gothenberg, Sweden at the annual conference of the International Network of Philosophy and Psychiatry (INPP). I led a working group together with Professor Nancy Potter and Professor Tim Thornton, inviting users/survivors and professionals to talk about their communication at a collective level. I'm in contact with the INPP congress organisers about their next conference in New Zealand in June 2012. I want to organise a dialogue between users/survivors from New Zealand, indigenous people, me and professionals.

Everywhere that I go, I try to promote the Mad Pride Idea and the process of truth and reconciliation after the trauma of psychiatry.

I am also a new board member of Autism Europe where I am working to build links on our common issues. And I am one of 25 "young researchers" chosen to take part in a European Summer School in Heidelberg later this month. I will be exposing these emerging 'standard' researchers to the perspectives and knowledge of the user/survivor movement. This year I completed my own Master of Philosophy of Psychiatry at University of Central Lancashire in the U.K.

That is what I have done and hope to do in this year.

Jan, jhaverhaegh@gmail.com



Erveda Sansi, deputy Board Member for the South-West Region

To the ENUSP community,

(See:

Here's a little introduction to my work for ENUSP up to the present day. In 2009, I participated for the first time in an ENUSP seminar "Nothing about us without us". I translated the report of that seminar as well as Jan Wallcraft's speech there into Italian

http://www.enusp.org,http://howtomakethisareality.blogspot.com/2011/10/diritti-umani-e-salute-mentale.html).

Later in 2010, I attended the 6th ENUSP Congress "Determining our own future: The way forward for all European users and survivors of psychiatry" in Thessaloniki, where I was elected as a deputy Board member for the South-West Region.

In December 2010, I collected articles, accounts and testimonies of abuses in psychiatry in Italy. I sent all this documentation (31 articles, press releases, stories, reports and video links) to a researcher for the EU Fundamental Rights Agency study "Fundamental Rights of People with Mental Health Problems and People with Intellectual Disabilities". These articles covered the topics of community living, fundamental rights in institutions, legal capacity and access to justice.

Later in December, I wrote an article describing what has been happening in the psychiatric wards of Milan's Niguarda hospital as well as in many other psychiatric wards in Italy: several people have died after being tied to their beds and by other humiliating, degrading and painful methods. Dr. Calchi Novati, who first objected to these methods and later exposed them, was subjected to heavy personal attacks at work. I translated this article into English for ENUSP. It can be found at:

Http://howtomakethisareality.blogspot.com/2011/10/serious-abuse-and-coercive-practices-in.html.

I write articles about human rights abuses inside psychiatry; they have been published in some magazines and websites. I also manage two blogs: senzapsichiatria.blogspot.com (which translates as "without psychiatry") and howtomakethisareality.blogspot.com.

In February 2011, I began to set up a group for user, survivor and supporter volunteers in Italy. After several meetings we founded the Associazione di Promozione Sociale "Il cappellaio matto" ("The Mad Hatter" non-profit association).

In April 2011, I gave a speech for ENUSP at a WHO affiliate event in Trieste about de-institutionalisation. This speech emphasised that we cannot speak about "de-institutionalisation" if we keep using restraint methods like binding people to beds, if we keep rolling out dangerous psychiatric drugs, and if forced psychiatry continues to be the law. I translated the speech into English; you can read it at http://howtomakethisareality.blogspot.com/2011/10/beyond-walls-deinstitionalisation-and.html

Vincenzo Jannuzzi of the "Il cappellaio matto" group made two designs for the European MadPride competition, promoted by the Belgian user/survivor organiation Uilenspiegel; one of these designs won first prize and was used for the official European Mad Pride 2011 posters.

In June, I attended the ENUSP/MHE Capacity Building Conference in Brussels, where MDAC invited me to take part at a public discussion on the right to vote between civil society and the Venice Commission. Unfortunately I couldn't attend because I couldn't be reimbursed for travel costs.

In June, I was invited to attend a meeting organised by Trieste's Mental Health Department (Dipartimento di Salute Mentale) under the title "Impazzire si può" ("You can go crazy"). I gave a little speech there about the existence of the world and European networks of (ex-) users and survivors of psychiatry and announced that we were organising European MadPride 2011. I invited people to help translate ENUSP and WNUSP documents into Italian (and vice versa), to make them more accessible to a larger international audience. Italy is a francophone country, and there are very few people in the user/survivor movement who understand English.

In July/August I helped to organise the ENUSP South-West Region meeting. Some users from "The cappellaio matto" attended one session, and they were very enthusiastic. Some of the participants went to Florence to interview Giorgio Antonucci, who was for many years the head physician on an asylum ward and never once restrained a person, locked a ward door, or used psychiatric drugs or psychiatric force.

The year culminated in MadPride Milan, the very first event organised by "Il cappellaio matto". For a full report on MadPride Milan, please see page 24.

Erveda, <u>esansi@libero.it</u>



Stéphane De Geest (Belgium), ENUSP representative at European Patients' Forum, ad hoc representative at events in Brussels

At a European level, my working programme for 2011 included attending the Annual General Meeting of European Patients' Forum (EPF: http://www.eu-patient.eu/) in Brussels on the 12th and 13th April as the ENUSP representative. At the meeting, I learnt that EPF wishes to diversify its funding sources. I raised a critical voice (together with others) about the issue of EPF receiving money from the pharmaceutical industry.

The EPF Board should release a text on this issue soon for the approval of its members before the final revisions to its fundraising policy. I also took part in some interesting EPF workshops, including one about how individual organisations can succeed in getting EU funding.

Through EPF I received an invitation to a European Commission information day about its new "FP7" funding programme.

I attended this event for ENUSP in Brussels in June, but could not see any openings for ENUSP to apply for funding. The EC seemed to be more concerned with promoting its own image than the programme itself. I learnt that the name 'FP7' will change.

More generally I have been taking steps to pursue outstanding payments from EPF to ENUSP (for the completed Value+ project) and to promote the European MadPride project with EPF. [Stéphane's other role is as President of UilenSpiegel Flemish user/survivor organisation, an active ENUSP member]

This year I also took part in the ENUSP-MHE seminar held in Brussels in May. The relevant points for me were having contact with other members, taking part in workshops and hearing presentations about where and how is ENUSP going, its work programme, and European MadPride. I am still waiting for news about the working groups.

Finally UilenSpiegel has been focusing on how we can be an active ENUSP member. We have achieved this to date and still hope that everything will improve within ENUSP.

Yours,

Stéphane De Geest

President, UilenSpiegel

ENUSP also expresses our thanks to:

Katerina Skourtopoulou (Greece)

for all her work as the Board Member for the South-East region in 2011. Katerina spoke on the topic of violence against women in the workplace at a European parliament conference organised by Mental Health Europe (MHE) last December;. She also did some vital outreach to users and survivors in the long under-represented South-East region, especially Greece and Bulgaria. She took on much day-to-day work for ENUSP, including recording minutes of board meetings, planning the ACTION NOW! Seminar, commenting on and assisting with the ENUSP funding application.

Anne-Laure Donskoy (UK)

for her great efforts in coordinating ENUSP's representation at European Commission conferences in 2010 and 2011. Anne-Laure also maintains ENUSP's facebook page and assisted with the set-up of an email list.

Jean-Marc Lenoble (France)

for all his technical assistance.

Lina Ciuksiene (Lithuania)

for her help with representation.

ENUSP MEMBER NEWS AND ANNOUNCEMENTS

Please send a brief description of your latest happenings and upcoming events to enusp.info@gmail.

NORWAY

Norwegian user/survivor group testifies before UN Human Rights Committee

Norwegian user/survivor organisation We Shall Overcome (WSO) has filed a shadow report with the UN Human Rights Committee describing abuses of the human rights of users and survivors in Norway. This document also highlights questions which the UN Committee should ask the Norwegian government. The text prepared together with the World Network of Users and Survivors of Psychiatry (WNUSP) and International Disability Alliance (IDA), can be found here:

http://www2.ohchr.org/english/bodies/hrc/docs/ngos/WSO_WNUSP_IDA_Norway103.doc

The Norwegian government was called before this UN Committee in Geneva in late October. Mette Ellingsdalen and Hege Orefellen of WSO testified at the country examination and at the Committee's meeting with NGOs. ENUSP looks forward to hearing their reports on the meeting.

Norway still has not ratified the CRPD.

IRELAND

Sign and circulate petition to free Irish survivor John Hunt

Mad Pride Ireland also calls on you urgently to sign its petition to free Irish survivor John Hunt, who is now being imprisoned and forcibly drugged in a psychiatric unit. His physical and mental health are deteriorating rapidly. Both this petition and a Mad Pride petition calling for the cessation of force in psychiatric units can be found at this link:

http://www.madprideireland.ie/

Mad Pride Ireland's John McCarthy writes: "Please spread the word for us far and wide. If we bring change in Ireland who knows where that change will spread."

Upcoming conference on the drugging of human distress

A free two-day conference "MEDICATING HUMAN DISTRESS: CONCERNS, CRITIQUES AND SOLUTIONS' will take place on 16 and 17 November 2011 in Cork, Ireland. The conference will address and consider: (a) the use of medication as the dominant response to distress in mental health care; (b) medication withdrawal concerns, strategies and solution, and (c) creative and enabling non-medicated ways of working.

For more information and to register, please send an email to h.gijbels@ucc.ie

Hearing Voices campaign: End restraint and seclusion NOW

In a recently launched campaign, **Hearing Voices in Athens** calls on all mental health professional bodies and user/survivor and family networks and movements to take an open and public stand against the use of mechanical restraints and seclusion cells in the mental health system and elsewhere. Their campaign statement reads:

"Widely known is the extended and unauthorized use, in almost every mental health unit, of mechanical restraint and seclusion... in order to deal with instances of, supposedly, "dangerous" behavior, but also, very often, to control behaviors of people with mental health problems who show no signs of "dangero[usness]", no matter how this is defined... "

"Mechanical restraint (and seclusion) is not a medical action. Even more, it's not neutral "risk management". It traumatizes, often irreversibly, the person who experiences it, while deaths of mechanically restrained people, often forgotten tied on their beds for days, are not rare deaths much more common than what is widely thought and that are almost always covered up by "corporate solidarity" and are unlawfully attributed to other causes."

You can find the rest of the statement here:

http://www.hearingvoices.gr/index.php?option=com_content&view=article&id=91&Itemid=65&lang=en

An online petition has been issued in Greek and will soon be translated into English. Please contact Marina at mlykov@gmail.com for more information.

First festival of survivors in Crete

In June, the Pan-Hellenic Committee of (ex-) Users and Survivors of Psychiatry organised a festival in Crete. Translator Maria Migiani reports: "I believe all of you who came to Thessaloniki in September 2010 [for ENUSP's conference and General Assembly] were a big inspiration and source of strength for the Greek users." More news about this festival is forthcoming from user/survivor activist and event organiser lannis Karterakis.

Berlin rose garden conference: A breakthrough for survivor-controlled alternatives

The Berlin Association for Protection Against Psychiatric Violence (Verein zum Schutz vor Psychiatrischer Gewalt) ran an extraordinary conference entitled "Searching For A Rose Guardian: 'Fostering Real Alternatives To Psychiatry' on September 2 and 3, 2011.

More than 200 user/survivor activists, researchers, and practitioners came from across Europe, the US and Australia to discuss our own perspectives on madness, distress, self-harm and suicidality. Other panels and working groups asked what conditions were needed for the development of user/survivor-controlled research and our own alternatives to psychiatry. All speakers were local or visiting user/survivor experts except for a few public officials and critical psychiatrist Peter Stasny. They included survivor researcher Professor Peter Beresford from the UK, and Dr. David Webb, the world's first suicide attempt survivor to complete a PhD about suicide.

The exhilaration in the lecture hall was palpable as user/survivor colleagues exchanged approaches developed and practiced by peers from around the world. Later when UK survivor Clare Shaw spoke of self-harm as a means of survival typically misunderstood and punished by psychiatry, many of us were left in silent tears.

Attending for ENUSP, Chair Gabriela Tanasan gave welcome and closing addresses while Deputy Board member Maths Jesperson spoke on supported decision-making in Sweden. I was privileged to be part of a panel discussion on the needs of user/survivor-controlled projects, and also moderated a group on suicidality and self-harm.

A full programme of the event, held in both German and English with simultaneous translation, can be found here: http://www.weglaufhaus.de/kongress/

For more accounts of this conference, please see this description by Professor Peter Beresford: http://www.communitycare.co.uk/blogs/social-care-the-big-picture/2011/09/european-mental-health-big-problem-and-insights-for-new-solutions.html.

Publication of the conference proceedings is expected next year. The ENUSP participants give special thanks to Jasna Russo, the conference co-ordinator.



Debra Shulkes

BELGIUM, SPAIN, ITALY

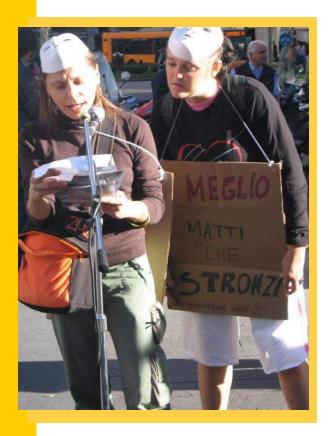
European MadPride takes off!

Early reports have come in about the success of European MadPride events in Brussels, Asturias and Milan on Oct 8 and 9. The events included marches and occupations of public space, seminars, and documentary film screenings. **Erveda Sansi** shares highlights of the events in Milan:

"I am proud of who I am": The Birth of MadPride Italy

Milan MadPride was the first event organised by our new user/survivor organisation "Il cappellaio matto" (The Mad Hatter). It was also the very first MadPride happening in Italian history.

On the afternoon of October 8, a sit-in took place in Piazza San Babila, one of Milan's most central squares. Many people came from all over Italy to participate, including activists from Verona, Reggio Emilia, Torino, Roma, Genova, Jesi, Sondrio, Catania, Giardini Naxos, Trieste and other cities. We distributed info flyers and communicated with the public. 40 participants wore white masks that we offered. A theatrical performance took place, written especially for the occasion, alongside other powerful improvisations by users/survivors.





MadPride activists gathered in Piazza San Babila, Milan The sign reads: "Better to be mad than to be an asshole"

At six o'clock, a roundtable event began at Milan's "La Casa della Cultura" (The City Culture House). The conference hall was crowded. **Elena Hileg Jannuzzi** of the "Il cappellaio matto" group, our best organiser, introduced the roundtable.

Mirko Mazzali, a lawyer in the Niguarda case as well as an activist and a Milan city councillor, exposed unjust double standards around the imprisonment of people with psychiatric labels in Italy: he explained that when somebody gets sent to an ordinary prison in this country, they know when they go in and when they will be released. In contrast, people sent to forensic hospitals cannot know when they will be let out again (See this report in Italian for more information about this issue: http://www.youtube.com/watch?v=zXRY6QT8W2I).

Then Gigi Bettoli from Trieste, the president of the Friuli-Venezia-Giulia region cooperative, spoke about psychiatric patients' right to work and to have regular work contracts like all other Italian citizens. In Italy, psychiatric patients routinely work without state work contracts and without state social security contributions.

Psychiatrist Calchi-Novati from Niguarda hospital spoke about conditions in the psychiatric wards there, which are only growing worse and worse: patients are always strapped to the 13 beds of one ward. The old asylum ideology is now resurfacing. This divides the wards by the levels of restraint applied there. She also highlighted many abuses that have taken place in recent times both in the Niguarda wards and in other hospitals.

Natale Adornetto, a psychologist and psychiatric survivor, gave spoke about the humiliating and traumatising experience of being tied to a bed and forced to endure psychiatric treatments . He shared passages from his book about this ordeal.

Umberto Sceresini from "Il cappellaio matto", told his story "How a madman is made" (Come si fabbrica un matto). He was widely attacked and defamed because he dared to denounce embezzlements in the municipality where he worked.

Sandro Cappannini, a founding user/survivor activist in Italy, said that we have to struggle for our freedom against forced psychiatry, and we need to organise more events such as MadPride. His proposal was to occupy an abandoned monastery in order to accommodate people who want to escape from psychiatry and to resist forced treatment.

Two more activists, **Rocco Morra** and **Sara Rizzitano**, came all the way from Sicily by car. Rocco Morra spoke about his experiences as an activist on Sicily's Telefono Viola, a telephone hotline assisting people in crisis, including those who have endured psychiatric abuses in Italy. He detailed many abuses and tortures, sometimes fatal, perpetrated by professionals on the psychiatric wards. Sara Rizzitano pointed out that abuses are also rife in other branches of medicine.



You can find MadPride Milano photos and videos on the facebook page: "MadPride Milano" and at howtomakethisreality.blogspot.com and senzapsichiatria.blogspot.com

Soon we will be releasing more reports of this roundtable. Most participants expressed their wish to organise similar events, and we discussed our future. For the first time, user/survivors and our supporters have begun to form an Italian network!

Image courtesy of Gregory Oke, Source unknown.

USERS/SURVIVORS ELSEWHERE...

SOUTH AFRICA

Dutch survivor reports live from PANUSP conference

Jolijn Santegoeds of Mind Rights in the Netherlands was in South Africa for three conferences, including the founding meeting of the Pan-African Network of People with Psychosocial Disabilities between October 13-15. To follow Jolijn's meetings with local user/survivor organisations, her inspection visits to institutions and her daily reporting from the PANUSP conference, please visit her blog: http://www.punkertje.waarbenjij.nu/. PANUSP has launched a new website at http://www.panusp.org/

WORLD

Occupy Mental Health/Occupy Psychiatry

Join people everywhere who are occupying the world - the pro-democracy movement that started with the Arab awakening and inspires people everywhere.

Occupy Mental Health/Occupy Psychiatry means taking back our lives, minds, hearts, bodies, choices and freedoms from the psychiatric industry, pharmaceutical company lies, and government-sponsored brain damage, traumatisation, false promises of healing, segregation and scapegoating.

The discussion is happening at this public page: https://www.facebook.com/event.php?eid=228200117234391

User/survivor actions are being planned at Occupy events the world over on Oct 15 and after. Can we raise our voices in Europe? Let's make ourselves heard in this pro-democracy movement. Whose minds? Our minds. Whose choices? Our choices. Whose lives? Our lives. We are the 99%.

For more information, please visit the statement on the Occupy Movement released by the Center for the Human Rights of Users and Survivors of Psychiatry (CHRUSP): http://www.chrusp.org/blog/entry/2295923/occupy-everywhere-occupy-psychiatry

http://www.chrusp.org/home/publications

We would like to hear from anyone interested in exploring this idea. Please contact enusp.info@gmail.com (Debra Shulkes)

Truth and Reconciliation in Psychiatry

Truth and Reconciliation in Psychiatry (TRIP) is an international campaign and petition calling_for public apologies for the physical and psychological damage done by psychiatric treatment. The petition reads, "If psychiatry is to reform and work in partnership with patients and service users these wrongs need to be recognised, atoned for and recompensed." For more information, please see http://www.causes.com/causes/586257-truth-and-reconciliation-in-psychiatry/about

Commemorating Victims of Psychiatry:

Several survivors have expressed their interest in setting up a website to commemorate the lives of the people who did not survive psychiatric interventions. We are aware of only one memorial website, which is run by the Danish group Death in Psychiatric Care http://www.doedipsykiatrien.dk/ (in Danish only).

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We would like to hear from anyone interested in exploring this idea. Please contact enusp.info@gmail.com (Debra Shulkes)

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Image source: FREEE Protest is Beautiful 2007 silk flowers, dimensions variable, ©the artist courtesy: The International 3



ENUSP HAS MEMBERS IN 34 EUROPEANS COUNTRIES - AND WE NEED MORE

ENUSP – Registered Office

Vesterbrogade 103, 1.sal 1620 Copenhagen V, Denmark

ENUSP bank-connection for donations:

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ENUSP - European Network of (Ex-) Users and Survivors of Psychiatry,

International Bank Account Number (IBAN Code): DK7630003719376320,

Bank Identifier Code (BIC / Swift Code): DABADKKK