How can we join forces across Europe?
The battle to ban forced electroshock in Ireland
Survivor of psychiatry confronts EU suicide conference
Why the UN disability rights convention matters
Reviews, profiles, art and a call for YOUR input
Out of our minds…

Dear readers,

I am very pleased – and more than a little relieved - to be sending you this first edition of Advocacy Update, our revived newsletter for mental health service users and survivors of psychiatry across Europe. The publication before you is the result of many months’ work by a small number of us scattered across countries. It has been driven, appropriately enough, by three mad hopes:

- To draw attention to the situations of users and survivors of mental health systems across Europe and to promote these communities' courageous work
- To ensure you know about the campaigns and activities of the ENUSP board of volunteers (and to invite you to join in), and
- To build a strong forum for the exchange of ideas, resources, art and support as we fight for our rights, dignity and alternatives

This last point is especially important for so many of us now enduring the aftermath of psychiatric treatment in isolation. Psychiatrists, academics and pharmaceutical companies all take for granted the holding of regular forums where they can pool experiences and make international connections. But such spaces are very rare and must constantly be fought for by users and survivors of psychiatry. When we do meet, it is seldom on our own terms or in private; instead, we are common objects of others’ projects, used often to ensure they meet funding criteria. It is little wonder that the voices of those who take on ‘forbidden’ topics, or come from less prominent countries are lost in all this. I was reminded of these remarkably resilient speakers – still working to make themselves heard – in a recent message from the Romanian survivor activist Gabriela Tănăsan of Orizonturi Foundation:
“We are very few in Romania fighting for rights, dignity, involvement and so on. All I try to do is to reach more who believe in our involvement and to make it real in my country. It’s hard… but I won’t give up…”

“IMAGINE 2” - Paula Salar, Romania

It is only early days, but this Advocacy Update tries to amplify and connect some of these different and less familiar voices – in the hope of producing new and liberating interpretations, tools for survival and resistance, art, and who knows what else? this edition, we start exploring what some of our conversations could sound and look like – with community news, including the latest developments from Ireland, where parliament is considering banning forced electroshock thanks to the heroic efforts of local activists. Our human rights watch, which we are particularly proud of, aims to build a user and survivor-led register of abuses and discrimination against people with psychiatric diagnoses across Europe – We hope you will use this space to raise the alert about problems in your area. Elsewhere in the Update, we offer a range of provocative, entertaining and consoling resources, including interviews, book reviews, poetry and art.

This is an enthusiastic, but tentative beginning. At the moment, we rely solely on the energy and commitment of our small team of contributors and advisors. We are limited by the fact that we have absolutely no budget, but we also know that there is a richness of talent, experience and passion in the community that could do astonishing things if collected. In this spirit, we invite you to join our team and share your thoughts on emotional crisis and unusual beliefs, the dominant biomedical model, discrimination, self-help, resilience, activism…. or any topic you would like to see covered. Simply contact us at: enusp@newsletter.org with any kind of contributions, including writing, photos and images, support with design and distribution, and feedback on this first edition. Let me close with the words of U.S. survivor and activist Sherry Mead:

“We must not let ourselves be reduced to arbitrary constructions…we must not let someone else tell our stories and have control over who we become”

Come share your voices and visions!

Debra Shulkes
Editor
Nineteen years ago, users and survivors of psychiatry united to campaign for self-determination across Europe. Faced with limited resources, many are now asking: how to maintain the fight?

The image shows a group of protesters against psychiatric force; one carries a sign that translates “It’s OK to be different.” It looks like it might be from a rally held almost anywhere in Europe last week, but the archive says otherwise: “Members of ENUSP at a demonstration in the city of Oslo, August 1999”.

The history of the European Network of (ex-) Users and Survivors of Psychiatry (ENUSP) history stretches back to 1990 when Dutch activists took the initiative to connect associations of (former) psychiatric patients from various European countries. Nineteen years later, the network’s volunteers continue to fight for our basic human rights and self-determination. At the same time, we advocate for
alternative user and survivor-controlled responses to mental and emotional distress, madness, human suffering and unconventional behaviour.

The continued drive of European activists – in the face of a serious lack of funds – is one of the recurring themes of this Advocacy Update. It was also the topic of a recent discussion with Gábor Gombos, survivor of psychiatry and Senior Advocacy Officer at the Mental Disability Advocacy Center in Budapest. Gábor, a longstanding ENUSP board member named the stakes for service users and survivors clearly:

“That the European Network continues its work so intently - even without funding- shows the extraordinary level of the dedication and the need.”

Advocacy Update takes this opportunity to congratulate Gábor on his recent receipt of the Knight’s Cross of the Order of Merit of the Republic of Hungary in recognition for his work in advancing the human rights of persons with disabilities. Look out for our interview in the next issue

Gábor Gombos
Human rights advocate

If you would like to learn more about ENUSP’s history and activities, please visit our website enusp.org
ENUSP dedicates this first edition of *Advocacy Update* to psychiatric survivor, sculptor and longstanding activist Dorothea S. Buck-Zerchin, who was born in 1917 and continues to live and campaign in Germany. Buck-Zerchin endured three stays in psychiatric hospitals in the period from 1936 to 1959 when she was subjected to coercion, including sterilization, cold wet sheet packs and injections. She was not given a single chance to talk about the origin or meaning of her psychotic episodes.

An activist in the self-help movement for more than 40 years, Buck-Zerchin testifies continually to the historical crimes of psychiatry and their effects on the current mental health system dominated by the biomedical model. She pleads for a paradigm shift toward a psychosocial system based on the wealth of patients’ experiences and the development of alternatives, such as the therapeutic principles of "Soteria" and Yrjö Alanen’s "Need-adapted Treatment." In 1992, she co-founded the [German Bundesverband Psychiatrie-Erfahrene](http://www.bpe-online.de/english/dorotheabuck.htm) (BPE) of which she is the Honorary Chair. On February 19, 2008, she was awarded the the greatest decoration of the Federal Republic of Germany for service to the community.

Recently, she has voiced the need to address the European Parliament about the crimes of psychiatry during the Nazi regime including the lack of compensation and reparations for victims and their families. It is a call echoed in France and elsewhere in Europe, including by those fighting 60 years on for the recognition of the memory of thousands of psychiatric patients, "the lost people of history", detained and deported to the Nazi concentration camps.

We urge you to read Buck-Zerchin’s work, including many lectures in Germany and abroad and contributions to specialist journals and anthologies, which can be found here [http://www.bpe-online.de/english/dorotheabuck.htm](http://www.bpe-online.de/english/dorotheabuck.htm)
History was made in the Irish Senate on Wednesday December 2, 2009 when two Green party senators Dan Boyle and Déirdre de Búrca introduced an amendment to the state Mental Health Act 2001 to stop the use of forced electroconvulsive therapy (ECT).

This amendment is the result of many years of campaigning by MindFreedom Ireland, Mad Pride Ireland and other service user and survivor activists. It has drawn national attention to the long-lasting health damage and human rights abuses associated with ECT. A headline carried by the Irish Times, the country’s leading daily, stated “Psychiatric patients still given ECT without consent”. “Patients involuntarily detained in psychiatric hospitals last year received hundreds of treatments of electric shock therapy against their will,” the same article noted.

In a press statement, John McCarthy of Mad Pride Ireland said, “To have ECT imposed on a person by force and by law is in any rational person’s mind a breach of fundamental human rights. A caring profession that relies on force as a last resort with which to treat its patients is by its very nature a failed entity.”

Mary Maddock of MindFreedom Island spoke in an interview with the Irish Times of the trauma of receiving electroshock two weeks after the birth of her daughter: “I remember the
cylinders for the electric shock; I remember them taking your pillow, so they had better access to your head, taking the anaesthetic and counting backwards until you were knocked out."

"It was a very scary thing to be part of, not knowing what was happening and then waking up with the most awful pain in your head like you wouldn’t believe. And not remembering things which had happened recently. It was like a big chunk of your life being taken away."

Her statements were met by many of letters of support published in the Irish Times. Mary, who is also an ENUSP board member, told the same newspaper:

“We believe ECT is a human rights abuse. It wouldn’t be accepted in any other field of medicine, but because they [patients] are vulnerable, the psychiatric profession gets away with it…In a democratic society people have the right to choose. Why are people with psycho/social problems treated differently?

To follow the latest developments in Ireland, please see the MindFreedom Ireland website. A decision is expected from the Irish Senate on the ECT bill in March, 2010.

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**ENUSP Chair: Users and survivors must lead EU human rights research**

*Users and survivors of psychiatry must be meaningfully involved in EU human rights research – This was the message that ENUSP Chair Mary Nettle expressed to officials at a meeting of the Fundamental Rights Agency (FRA), the EU body responsible for human rights issues, in late November in Vienna.*

Overall the meeting was quite positive, Mary said, emphasising the FRA had committed to completing a research project using testimony of people with psychosocial disabilities who have experienced human rights abuses. The two-year project, valued at EUR 500,000, will take place in up to 10 EU member states. ‘We were told it should collect the voices of experience of people with mental health problems and people with intellectual disabilities about human rights abuses they may have felt in a wide range of institutions and other places," she said.

It is believed that the FRA will choose the project researchers through a tender process, however there will be no opportunity for peer review of the proposals. The tender should be published soon.

ENUSP’s admission to this FRA meeting was an important achievement. To date, we have not been invited to consultation meetings in this important process on the basis that we are not professional researchers. “We advocated for the essential participation of user/survivor researchers in any inquiry into our human rights," Mary Nettle said. “We must be acknowledged and consulted. Furthermore, this expertise should be paid for, as would be the case for any other consultancy.”
Human rights advocates expressed their relief when survivor of psychiatry and internationally praised researcher David Webb was given the chance to address a WHO/EU scientific conference on suicide and the economic crisis in Stockholm on October 14-15. The conference, organised in part by the Swedish Parliament, was the final lead-up event to an EU conference “The Prevention of Depression and Suicide” held in Budapest in December. Both events belong to a five conference series under the European Pact for Mental Health and Wellbeing. Launched in June 2008 in Brussels, this is the document in which member states commit at least in words to the meaningful role of service users and survivors in the set-up, implementing and evaluation of mental health policy:

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

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

Anne-Laure later presented a compelling paper at the Budapest conference on the unique and critical knowledge that user-led research and user researchers provide on suicide and self-harm. The full text of her presentation is available on ENUSP’s website.

Part of ENUSP’s formal statement to the Budapest event read:

“While we commend…improvements in the EC’s public mental health documentation, ENUSP remains aware that the new rhetoric is not matched by concrete and enforceable commitments to empower service users and survivors. Similarly, we question whether the “service user-friendly” language reflects any attitudinal shift away from the biomedical psychiatry model,
which is still marketed as an essential and benign suicide prevention strategy – despite an astounding lack of evidence of its efficacy and safety.”

For more information on David Webb’s work, including his recent lecture at the Stockholm conference on suicide and the economic crisis in Stockholm included, see this bibliography. In the next edition of Advocacy Update, we will feature more critical reflections from user/survivor participants at these EU conferences.

A voice for users and survivors on EU disability forum

For the first time, a psychiatric survivor from ENUSP has joined the board of the European Disability Forum (EDF). Danish activist Erik Olsen, who has 20 years’ experience in our movement, was elected this May with overwhelming support from other EDF members.

EDF fights to promote equal opportunities for disabled people and to protect their human rights, ensuring no decisions concerning disabled people are made without them. It is an entirely independent organisation. In the past, others have often spoken for users and survivors of psychiatry inside the disability rights movement.

At the forefront of EDF’s agenda is the implementation of the United Nations (UN) Convention on the Rights of Persons with Disabilities and its Optional Protocol (see our introduction to this important treaty in this Update). Other prominent issues include capacity building and proper representation in EU policy and legislation.

If you would like more information or have a proposal for matters to raise with EDF, please contact Erik Olsen at erikpsyk@gmail.com
In a great milestone for our network, (ex-) users and survivors from 25 EU countries met for two days in Brussels in March this year for an empowerment seminar. The seminar “Nothing About Us Without Us: How to Make This a Reality?” was only made possible by a one-time European Commission grant from Mental Health Europe that unfortunately did not extend to non-EU participants. As well as sharing experiences as user/survivor activists, participants were briefed on the new European Mental Health Pact and UN Convention on the Rights of People with Disabilities and changes in user/survivor-led research.

The burning issue of the meeting, however, was the lack of funding for ENUSP that is now threatening the survival of our network. What will happen, speakers asked, if users and survivors of psychiatry lose a united and independent voice at a European level? One of the immediate priorities, they said, was to strengthen communications and cooperation among ENUSP and national and local user/survivor groups throughout Europe. We must find ways to meet and organise that ensure the representation of all of our members.
This is a challenge that clearly requires all our attention. In particular, we are looking for your opinions and visions about what ENUSP’s priorities should be in coming years. How can we grow stronger? And how might you or your organisation contribute?

For full details of the seminar, including presentations notes and photos, see Jasna Russo’s excellent report

**ENUSP and Mental Health Europe: Where to now?**

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

ENUSP was extremely grateful for the support of its Brussels seminar, and our representatives have since met to discuss the possibility of renewing cooperation on certain projects. In late 2008, ENUSP’s board issued the following statement of intent to MHE:

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

Commenting more recently, board member Erik Olsen cited the dire economic state of ENUSP, “We cannot say ‘no’ to help from the public sector...We are simply too weak both in an economic sense and at an organisational level as users and survivors across Europe.” “We are taking the opportunity to do what we can,” added Mary Nettle.

**A short film about ENUSP**

Advocacy Update is pleased to link to this short film from the University of Birmingham featuring ENUSP representatives Mary Nettle and Elisabeth Winder. The discussion covers important topics including ENUSP’s role and relations with other European advocacy organisations like the European Patients’ Forum and Mental Health Europe. You can also hear a short description of ENUSP’s work on the VALUE+ project, which seeks to bring about the meaningful involvement of patients in healthcare throughout the EU. [WATCH ENUSP FILM](#)
Each issue, we plan to profile the work of one of the members of our European network. Our hope is to present the varied voices and faces of activism ranging from national, regional and local user/survivor organisations to individual campaigners. This time, we speak to Gabriela Tănăsan, Executive Director of Orizonturi Foundation in Romania. If you would like to be interviewed for one of our future editions, please contact newsletter@enusp.org

WHO: Orizonturi Foundation (www.orizonturi.org), Gabriela Tănăsan, Executive Director

WHERE: Campulung Moldovenesc, Romania

SNAPSHOT: Romanian users and survivors of psychiatry have waited a long time to be heard. It’s been a struggle for many reasons, says Gabriela Tanasan, a survivor who helped in 1995 to create Orizonturi Foundation, which supports and advocates for mental health service users. As well as a lack of funding, there is a still ingrained view, she says, that only mental health professionals have useful input on policy.

“There are very few places in Romania where people understand the need to involve all stakeholders – especially users and their supporters – in solving problems,” says Gabriela. “Only a few are working or fighting to develop social and community approaches.” The reform movement, she says, is just now taking “its first small and shy steps.”
One important move forward came through the strong user/survivor involvement in an international conference on community and social approaches to mental health, which took place last year in Gura Humorului in northern Romania. Orizonturi was one of the partners in this event whose attendees included service users and carers from Romania and Hungary, as well as local and international members of government and welfare services and professionals. Gabriela gave a paper on the role of service users in mental health reform. The large regional policy forum which she moderated was called “Community Alternatives: Rethinking mental health policy TOGETHER”
We are very pleased to announce a General Assembly and members’ conference in Thessaloniki, Greece on September 28-30, 2010

The assembly will be held in co-operation with members of the Greek user/survivor movement and the assistance of the psychology department of Aristotle University, Thessaloniki. Reporting from a recent meeting of Greek users/survivors in Athens, spokesman Iannis Karterakis said the 2010 agenda should look at “the Greek psychiatric system, its history and parameters”, assessing powerful lobby groups from the medical and pharmaceutical industries and key current and future issues. The overall message should be “our rights and our demand and need to be treated as equals,” he said. For more information on human rights abuses in the Greek psychiatric system, please see our report in the Human Rights Watch section of this Advocacy Update.

Organising this event will involve considerable work over coming months, and we would be very grateful for your assistance, no matter how small.

We will have space for 2 delegates from every country and will also be electing a new ENUSP board. We anticipate that very little funding will be available. We will ask each country to do all they can to cover the travel and accommodation costs of their delegates.

At this stage, we would especially appreciate your suggestions for a keynote speaker, topics for working groups and the agenda for the General Assembly. Please send your suggestions and offers to join the organising committee to: info@enusp.org. We will be in touch in coming months with more information. Please see the latest developments at our website www.enusp.org/events
Why a user-survivor led human rights monitor?

Over the years, many of our members have confirmed the need for a user/survivor-run human rights monitor across Europe. This monitor would document specific incidents of inhumane and degrading treatment – abuses that are currently often state-sanctioned and invisible, escaping the interest of official complaints bodies and the media. With the possibility of protection under international treaties such as the UN Convention for the Protection of the Rights of People with Disabilities, these records could be very significant.

We believe that Advocacy Update could play a key part in this monitoring process. We encourage you to send us reports of potential human rights violations – whether at a regional, national or individual level. Reports should be sent to newsletter@enusp.org. In this edition, we highlight alarming developments in Greece and Denmark.

Abuses by Greek ‘non-profit’ institutions

Reports have reached ENUSP of the gross violation of psychiatric patients’ rights in hostels run by non-government organizations across Greece. The alert was raised midway through last year by psychiatric survivor organisations and workers at the institutions, backed by parliamentarians and academics. They allege that the non-profits – which receive funds under an EU reform programme - are using violent, cruel and degrading practices against hundreds of residents.

Critics of the Greek Ministry of Health and Social Solidarity say the government has privatised mental health care, delivering the occupants of prison-like state institutions into even worse hands. The ‘improved’ facilities, run by NGOs like EPSAMY, EPSYKA and THEPSYPA, house between 15 and 20 people whose freedom is denied based on systems of continuous control and punishment. Photos appearing in the Greek press show inmates semi-naked and strapped to their beds at an EPSAMY hostel in Athens.

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

Human rights advocates are calling on the European authorities and the Greek government to intervene urgently on behalf of hostel residents. They are also demanding an independent European inquiry into the violent and degrading practices already documented as well as the alleged mismanagement of EU funds. Users and survivors of mental health services must have a crucial role in these investigations, they say.

Advocacy Update was provided with the following contact addresses for our letters of protest and concern:

Greek Minister of Health and Social Solidarity
- Mrs Marilisa Xenogiannakopoulou
  E-mail: minister@mohaw.gr
  Headquarters: 17, Aristotelous Street, GR-101 87 Athens, Greece

Greek National Commission for Human Rights
  Email info@nchr.gr

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

Denmark supports more force

Denmark’s government has plans to introduce padded cells and more physical restraints in psychiatric institutions, according to the most recent government statements.

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

Meanwhile critics from the European Council compare the use of ankle and wrist locks with the methods used to secure and torture prisoners by the U.S. military at Guantanamo Bay. They are among those alarmed by recent suggestions from Danish Minister for Health Jacob Axel Nielsen that hospital wards use padded cells as an “alternative” to restraining patients.

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

Erik Olsen of the Danish user organisation LAP noted that its activists were speaking out against these and other forms of torture and degradation. “Several years ago, we succeeded in stopping forced outpatient treatment by convincing one of the political parties to vote against a key bill,” he said.

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

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

What the UN Disability Rights Treaty means for you

Heard about the recent UN Convention on the Rights of People with Disabilities, but still not sure what it’s all about? Want to find out more about its relevance for your country and your organisation?

The Convention prohibits discriminatory, unequal and abusive treatment of disabled people in all contexts, including medical settings. It includes users and survivors of psychiatry, who were also among its key negotiators. It has been ratified in many countries in Europe and also - in a long-awaited decision that came late last year - by the European Community. It could therefore be a critical tool for users and survivors of psychiatry fighting for human rights protection across Europe. And there have already been cases of successful advocacy and the shaming of governments since the treaty became effective.

Unfortunately, however, many service users and survivors cannot access this important information about the Convention. As a result, they may assume that it has no practical significance for people with psychiatric labels. This assumption must be challenged, says Tina Minkowitz, the Co-chair of WNUSP (World Network of User and Survivors of Psychiatry) and a lawyer and survivor of psychiatry, who worked extensively on the UN treaty. Minkowitz has highlighted the potential of the Convention in the areas that are “traditionally most pressing for users and survivors - our self-determination and freedom, especially freedom from forced treatment and detention in psychiatry.” Without any exceptions, the UN Convention expressly guarantees us rights including:

- Freedom from torture, or cruel, inhuman or degrading treatment or punishment
- Respect for our physical and mental integrity
- Freedom to make our own decisions
- Freedom from discrimination
- The right to live independently and participate fully in society
- The right to education and employment
Underlying all this is the rejection of national mental health laws imposing coercive measures – including institutionalisation and guardianship - “in our best interests”. A recent report from UN Special Rapporteur on Torture, Manfred Nowak, goes even further, suggesting that psychiatric practices done routinely against a person’s will (like forced drugging and electroshock) might be torture or ill-treatment, Tina Minkowitz said

“I think it would be useful to let ENUSP members know about the potential of the [Convention] to be used in ending forced treatment and coercion,” she added. The key point is that this “will not happen automatically without our advocacy and committed participation.”

As a first step, we need to raise awareness about the contents of the Convention among users and survivors of psychiatry and our allies. That way we can push for its ratification and implementation by states parties, without any reservations, understandings or declarations. Our right to be active in this enforcement process is guaranteed by the Convention itself.

Commenting in an Australian report, she pressed home the need for an overhaul of state policy to comply with international human rights standards:

“States must find other ways of responding to people experiencing emotional crisis, in order to comply with the Convention... and other obligations under international law. Numerous non-coercive and non-medical model alternatives exist now, and they must be researched, further developed and fully funded, as the current coercive system is de-funded.”

Where can you find out more about the Convention?

- This official UN site contains the full text and principles of the Convention for the Protection of Rights of People with Disabilities and its Optional Protocol. It also contains updates on ratifications, implementation and monitoring. Check your country’s status on the site.
- Excellent resources on the Convention can also be found on the WNUSP site, including an Implementation Manual for users and survivors of psychiatry, The site links to important UN commentaries, such as the report of UN Rapporteur on Torture Manfred Nowak
- This link to the UN Special Rapporteur on Torture includes the questionnaire for urgent appeals
- Very useful resources, including links to other international human rights instruments and examples of good practices, can be found at the new US-based Center for the Human Rights of Users and Survivors of Psychiatry (CHRUSP)

In coming months, ENUSP will provide more detailed reports on the status and applications of the UN Convention. Please let us know if there are any specific questions or practical concerns that you would like us to address by sending a message to newsletter@enusp.org.

We are particularly interested in opening up inquiries and debate about the significance of human rights law and the social disability model for different service users and survivors.

Advocacy Update thanks Tina Minkowitz for her generous help with this report.
“POWER” - Kaety Moore, UK
Beyond Belief: An interview with Dr. Tamasin Knight on alternative responses to unusual beliefs

Medical doctor Tamasin Knight was hospitalised for delusions, and went on to write the practical guidebook Beyond Belief: Alternative Ways of Working with Delusions, Obsessions and Unusual Experiences. The book queries and rejects the usefulness of traditional psychopathological labels and treatments. It argues instead for accepting the individual’s own reality and assisting them to cope and live with their beliefs. ENUSP spoke with Tamasin, who is currently based in Ecuador.

Your book is about finding new ways to work with people with unusual belief systems. What made you want to write it?
The initial motivation that made me want to do the research described in Beyond Belief came from my own experience of unusual belief systems and of receiving psychiatric treatment for this. I discovered that psychiatric treatment tended to focus on removing ‘abnormality’ and trying to make people ‘normal’ rather than focusing on what the person themselves wanted help with or considered important. I believed people should have a choice, and so I felt compelled to look for alternative ways of working.

I read about the work of Marius Romme and the Hearing Voices Movement. I found their approach of accepting the voice-hearers’ own explanation for their voices, and working within the voice-hearers’ own reality, to be inspirational. As a result, I decided to expand their approach to the experience of unusual beliefs and different ways of seeing reality.

Did you have a specific audience in mind?
I had three main audience groups in mind: i. People having problems surrounding unusual belief systems (who may or may not be users/survivors). ii. Families and friends of people with these kinds of experiences. iii. Mental health professionals (and students) interested in different ways of working. Having said that, the book is for anyone interested in unusual beliefs and different ways of understanding the world.

You write:
“Lots of people have beliefs that others may consider to be strange, unusual or not based in fact, and there are many people in society who are living successful independent lives who have beliefs that meet the criteria for delusions.”

Why do you think only some of these people become psychiatric patients?
The key factor here is whether the person is able to cope with their experiences. If a person becomes very distressed, preoccupied or overwhelmed by their experiences they are likely to become a psychiatric patient. In contrast, if they are able to cope with their experiences it is likely they will stay out of the psychiatric system. The support that the person has in their life is important in determining their ability to cope with unusual or distressing beliefs.

How could things be done differently? For example, how might you work with someone who was worried that strangers could read her thoughts?

I would first listen to that person, and really try and understand her reality and belief system. Is it everyone that can read her thoughts or just some people? Are there any situations when people can’t? What is it that worries her most about the situation? And crucially, what help does she want? Does she want to find ways to prevent others from reading her thoughts, or would she prefer it if her self-esteem was such that she was no longer bothered by others reading her thoughts?

Listening to a person in such a way can be helpful in itself in providing moral support, and can be the first step in helping the person finding more specific ways of coping.

So following on from this, I’d work with the person to find strategies to help them feel more in control and less distressed by their experiences. Different strategies will work for different people. Some people who feel others can read their thoughts find ‘psychic self-defense’ strategies – such as visualising a shield of light surrounding themselves – helpful at keeping out unwanted telepathic thoughts. Others find that wearing a certain hat is beneficial for them. And others find that improving how they feel about themselves enables them to be less bothered about whether other people are reading their mind.

You suggest many great coping strategies, such as meeting regularly with others who have similar experiences. Why do people find these meetings helpful? What can you do if you don’t have access to such a group – say because you live in an isolated place?

Thank you! Meeting with others who have similar experiences can provide a safe place for people to talk about their beliefs and experiences without fear that they will be ridiculed or pathologised because of their beliefs. Being part of such a group can enable people to receive emotional support and practical strategies to help them cope with their beliefs, and get on with their life.

If there are no groups near where a person lives I’d suggest they look on the Internet to see if there are any online support groups for people with the kind of experience they are having. I am aware of online support groups for people with many different types of unusual beliefs.
How have other doctors and professionals treated your work? I imagine they say that accepting a person’s unusual reality means ‘colluding’, and it will make them worse. What is your response?

I think that increasingly mental health professionals are recognising that mainstream psychiatric treatment doesn’t have all the answers and so are becoming interested in alternatives. So overall I’ve been pleased with the response I’ve received.

But yes, there are those who say this approach is ‘colluding’. To them I would say we shouldn’t be colluding with the idea that there is only one way to interpret reality, one set of beliefs which are acceptable, and another that are ‘delusional’. Instead we should be accepting diversity and promoting the right of people to be different. I think the survivor movement has a key role here in promoting this message.

It is important to say that accepting a person’s belief system doesn’t mean you have to personally share it, or even pretend to share it. Rather it is about respecting another person’s reality (in a similar way that one would respect another’s religious beliefs without having to share them) and helping that person to cope with their experiences.

While some may worry that accepting people’s beliefs is going to ‘make them worse’, this is something that is not seen in practice. For example, suppose someone is frightened because they believe ghosts are going to attack them. Telling them that they are deluded and that there are no ghosts isn’t going to help them. It is just going to make them feel more frightened and alone. In contrast, accepting that person’s reality as being real for them, listening to that person, trying to understand how they are feeling, and working with them to find ways of coping with the experience (for example, looking at books about defending oneself against ghosts) would likely help them greatly.

What would be a good first step if someone wants to learn more ways to cope with a distressing or disabling belief?

I would suggest reading my book ‘Beyond Belief – Alternative ways of working with delusions, obsessions and unusual experiences’. This can be downloaded for free from http://www.peter-lehmann-publishing.com/index.htm
Linda Andre is an electroshock survivor who has spent the past 30 years recovering from her experiences with ECT. Her book is fascinating, essential and unique in many ways. Published more than three decades after Leonard Roy Frank’s *The History of Shock Treatment*, it is the first book in the English language written by a shock survivor to include the voices and perspectives of survivors. It considers shock (also called electroconvulsive treatment, or ECT) from multiple perspectives: medical, scientific, legal, social, moral. It is thoroughly researched, painstakingly documented, and its overall level of scholarship—in particular its reliance on primary rather than secondary sources—is superior to that of any existing book by professionals (who are users and promoters of this practice seen by many as a form of legitimised abuse).

In focusing on the collective history of the ordinary people—mostly women—who have undergone electroshock, rather than the proclamations of the men who have made careers out of administering and promoting it, the book reframes traditional notions of what history is and who gets to make it. The author doesn’t place herself outside of history as a supposedly objective observer, but tells us she writes from her firsthand experience as a maker of this history. The result is a book that is compelling in its immediacy and reads at times like a detective novel.

The reader is drawn to the conclusion reached by the author, which follows logically from the evidence of seven decades presented in her book: only a ban on shock can protect patients from serious and permanent brain damage.

This book should be required reading for judges, lawyers, relatives, patients and clinicians. Because of its readability, style, and even at times wit, it will interest general readers as well. It is particularly relevant for European readers since in 2004 the European Council accepted a recommendation that calls forced electroshock administration ethical’ (see: “Recommendation of the Committee of Ministers to member states to ensure the
protection of the human rights and dignity of people suffering from mental disorder, especially those placed as involuntary patients"). The current scandal involving the continued use of forced shock in a society which defines itself as humane shows us how up-to-date Linda Andre’s book is.

- Peter Lehmann

## Artist Profile: UK survivor-poet Carol Batton

Manchester-based poet Carol Batton is unique. A frequent and much sought-after performer at events in and around the city, Carol also distributes copies of her poems to anyone who cares to read them. She estimates that she may have given away fifty thousand sheets of poems.

Described by some as ‘the poet laureate of the survivor movement’, Carol writes with great courage and wit on topics such as the failure and absurdity of the mainstream mental health system. It is rare to find a poetic voice this sharp, funny and accessible. Her mission, she says, is “to expose psychiatry as bad; to do the poems and get through life somehow”.

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**Drug trials**

Don’t believe anyone who is not kind to animals.

**Another "The Pills" Poem**

I say it makes me miserable,
She says, "That cannot be"
I say that I am certain,
(but so is she)
She says "So say the drug firms,
And they have done research"
I say "They make the profit."
She says I am psychotic,
She says that I can’t know these things
And cannot be believed.
She says I’m being awkward, and should take more of these.

**One side effect...**

It’s only got one side effect
You really must give it a try
It’s only got one side effect
It makes you want to die
Where I'm from
I am of Mediterranean origin, but have lived in England and Ireland for all of my life. My initial career was in the sciences: developing, building and testing microprocessor devices for University College, Cork. I discovered art while living in hostels in London. There was little to do, so I enrolled in various night school classes and ended up going to the Byan Shaw School of Art on scholarship though leaving after a year. I always enjoyed art at school; at university, I spent more time sketching the lecturers than listening to what they had to say.

What drives me
My art is quite influenced by this scientific background. I remember once reading about how at school Einstein wanted to know what it would be like 'to sit on a photon of light'. My art tries to capture that imagination. There is an attempt to experiment with both paint and painting techniques. The work hopes to catch a sense of motion and flux.

‘Enhancing life rather than diminishing it’
I was in the psychiatric system for 20 years, and I was diagnosed with nearly everything, and prescribed nearly everything. Many of those I met whilst in hospital had done nothing that might be described as aggressive or criminal. The hospitalisations followed through certain persons finding that the activities and self-expression of these patients were in some way offensive. Psychiatry forms its right to 'treat' out of the fact that certain manifestations of self and behavior might be inconvenient.

I think that we should ask questions and challenge things. It is the only way to exact real change, whether this involves formulating a climate change treaty or standing up for the rights of those in the psychiatric system. I think ‘being you’ - whatever that might entail and whatever the opinions of others - is one of the most basic human rights there is (so long as you don't deliberately erode other people’s rights). No person external to you should have the right to force an identity on you that you may not want.
For me, there is no absolute standard: the normal is simply the habitual, and the habitual does not simply vary across societies and communities; it also varies across individuals, and the concepts those individuals have of themselves and the Universe of which they are part. For me, there is no definite 'right or wrong' but instead a series of circumstances that evoke different appropriateness according to their own particular context.

Art is a means of enhancing life rather than diminishing life.

Are you a writer or artist interested in displaying your work? Would you like to develop and share your expertise as an editor, designer, IT consultant, publicist or proofreader?

Advocacy Update would be delighted to hear from you at enusp@newsletter.org.

UPCOMING EVENTS, CONFERENCES, PROJECTS AND PUBLICATIONS

Real People: The Self in Mental Health and Social Care June 2010

Interested in the connections between philosophy, psychiatry and the user/survivor movement? A wide-ranging debate on these issues can be expected at a conference in Manchester, UK between June 28 and 30 this year co-organised by ENUSP and the University of Central Lancashire.

The 13th International Conference of the INPP (International Network of Philosophy and Psychiatry) will offer opportunities for dialogue between and amongst mental health professionals and mental health service users and survivors. Abstracts are invited on any subject that addresses the core theme of the conference – the self in mental health and social care.

Key topics will include, but are not limited to:

• Mind and meaning - self, identity and recognition in mental health care
• Definition, language and the philosophical dimensions of the service user/survivor movement
• Social justice and mental health – communities, rights and inclusion
• Involving service users and survivors meaningfully in the management and direction of research, care and support
• Service user and survivor driven innovation in mental health and social care
• Recovery and personal objectives
• Reclaiming the self after mental health interventions
• Spirituality and mental health
• Alternative realities through music, art, theatre, and literature
• Personal and community capacity, social and cultural capital
• Culturally relevant assessment and diagnosis reflecting diversity and difference
• Scientific psychiatry, classification and the individual

Further information and abstract forms are available on the conference website at www.uclan.ac.uk/inpp2010 Please e-mail any questions and completed abstract forms to inpp2010@uclan.ac.uk

Unfortunately the economic climate means there is unlikely to be any help available for travel and accommodation costs. If your abstract is accepted, you may get a free place at the conference.

ENUSP General Assembly Thessalonika Greece 28 – 30 Sept 2010 (see p15 for details)

PsychOUT: A Conference for Organizing Resistance Against Psychiatry May, 2010

PsychOUT: A conference against psychiatry will take place at the Ontario Institute for Studies in Education in Toronto on May 7 and 8, 2010

The convenors write:
“Over the last century, proponents of biological psychiatry have used the language of science to naturalize the medical model as an essential way of organizing and managing human experience. In contrast, collective resistance against the theories and interventions of psychiatry has intensified over recent years….The purpose of this global conference is to provide a forum for psychiatric survivors, mad people, activists, scholars, students, radical professionals, and artists from around the world to come together and share experiences of organizing against psychiatry.”

Find more information and details of the call for papers here: http://ocs.library.utoronto.ca/index.php/psychout/PsychOUT/schedConf/cfp
Led by our Belgian members from UilenSpiegel, talks are already under way about organising next year's European Mad Pride celebration next year. **Saturday 8 October 2011** is the scheduled date, with events to unfold over the surrounding weekend.

Originating in the late 1990s primarily in the United Kingdom and the United States (though opinions differ as to where exactly), Mad Pride is a movement that celebrates the human rights and diverse and lively culture of people on the receiving end of mental health systems. Protests including public bed pushes raise awareness about the inadequacy of current ‘treatments’ and the widespread use of force. In recent times, celebrations have taken place in Brussels, London, Ireland and across North America and Africa, featuring music, poetry readings, film screenings and street theatre.

Timed to coincide with World Mental Health Day on Monday 10 October, 2011, the European Mad Pride festivities will have Brussels at their centre. There will be a common theme for each of the participating countries to interpret in its own creative way over the weekend.

As part of the preparations, ideas are already being floated, including a poster competition, with all submitted designs to be used in some way, and the Belgian activists may also run a blog. They invite you to view this video of the 2007 Belgian Mad Pride event: [MAD PRIDE 2007, Brussels](#)

If you are interested in getting involved at a national or international level, or would like more information or to offer support, please contact [rafael@uilenspiegel.net](mailto:rafael@uilenspiegel.net)

**CALLS FOR CONTRIBUTIONS**

**Your involvement counts!**

**‘Walkabouts’: Participate in a documentary**

**ENUSP** has received the following request from Christfried Hübner, a documentary maker in Germany, who seeks contributors internationally for his new project:

“To perceive psychosis as a possible way of achieving spiritual development is an approach whereby we try to understand the nature of extreme mental states. In referring to the walkabouts made by Aborigines, the title of the film comments on their stance on people experiencing these exceptional mental conditions: ‘Firstly we allow them to have it (meaning the psychosis), and then we ensure that there is always someone around them.’

The film is about people who have been through this process - in one way or another - and have used their experiences to help others: people who have developed, continued and
spread theoretical approaches in understanding these extreme mental states and offer practical assistance. People who have found new strength by overcoming their own fears, disparities and confusions.

For this film, I'm looking for people who would like to depict their own experiences. I would like to accompany them with a film camera in their daily lives with the aim of enhancing the understanding of people who are going through a mental crisis, and hopefully to show possible avenues for development.

The aim of the project is to produce a 90-minute documentary that will be shown internationally. Any contributors will be paid under contract although the financing of the project is as yet uncertain.“

Christfried Hübner
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Tel. mobile +49-(0)177-5210300

### Scarsongs Trauma Reader: Seeking contributors

ENUSP has received a call for contributions to an international publication about trauma. A collaboration of the Icarus project, the Bay Area Radical Mental Health Collective, and Activist Trauma Support, the publication has the working title “SCARSONGS: An Anthology Articulating the Terrain of Trauma and Resilience”. The organisers write:

“Our aim is to create a beautiful, creative, readable document about trauma and resilience, drawing from a diversity of communities and backgrounds and addressing a wide range of topics and experiences. We invite submissions in a range of formats, including, but not limited to, essays, interviews, stories, poems, songs, illustrations, photographs, paintings, and collage. We invite submissions on

- The wounding and the pain - abuse, assault, rape, war, death, police brutality, oppression, physical and structural violence, ritualistic and systematic abuse, natural disasters, catastrophic and chronic illness, birth and generational trauma, and political repression. Fear, anxiety, panic, dissociation, nightmares, addiction, post traumatic stress, depression, self-mutilation, self-harm, suicide.

- The healing and resilience – community support, creativity, grieving, nature, self-care, personal ritual, expression, therapy, activism, holding abusers and oppressors accountable, connecting with allies, looking inwards and speaking out.

- The importance of trauma work to building movements of collective liberation and social justice.

- Experiences of trauma support on an individual, community and political scale."
We understand trauma as self-defined and submissions can stay anonymous if desired. The deadline for submissions is March 21st, 2010. You can also send us your ideas and ask for feedback on whether they would fit.

For more info and submissions, email: scarsongs@gmail.com

Tell us about your ‘empowering practices’

What does ‘empowerment’ mean to you and your organisation? As part of a three-year project run by WHO and the European Commission, ENUSP’s Erik Olsen is looking for examples from European user/survivor groups of activities that strengthen them.

The WHO/EC project aims to deepen the empowerment of users of psychiatry and carers, as promoted under the 2005 European Mental Health Declaration and other more recent agreements. ‘Empowerment’ here describes the level of choice, influence and control that people exercise over their own lives. Organisers agree that users and survivors of psychiatry have historically been left out of decision-making about us, and we continue to face exclusion and discrimination at every level. A recent report from WHO admits that this lack of influence or control can severely damage physical and mental health.

Olsen would like to hear your views on projects that you or your organisation found rewarding. Your analysis should try to identify why a particular activity or approach was empowering for users/survivors. Participants so far have pointed to factors such as being made aware of their rights; learning skills they choose; having real decision-making power, including the freedom to make the ‘wrong’ decision; feeling a strong sense of community; and having the chance to express anger.

Your submissions will be used to set benchmarks for official bodies deciding on “what is a good empowerment project and what is not”, Olsen says. We must fight to ensure that the description ‘good empowerment project’ remains a meaningful one for users and survivors, and not just a public award for organisers with ticks in all the right boxes. Olsen would like to see more research measuring who is actually empowered by mental health projects, tracking whether benefits reach service users and survivors. For more details, please contact Erik Olsen at erikpsyk@gmail.com

MindFreedom needs your views on self-determination

The ENUSP desk recently received this request for European input from David Oaks of MindFreedom International (MFI). MFI is a US-based non-profit advocating to protect the human rights of people affected by the mental health system. More details can be found at its website: http://www.mindfreedom.org

"I know we are all very concerned that there is a major global push to promote western-style mental health care internationally, but without adequately including the empowered
voice of mental health consumers/users and psychiatric survivors, to support principles of human rights, self-determination, advocacy and alternatives.

One small but important step: MindFreedom has a proposal for a basic printed handbook (in multiple languages) to help support empowerment and self-determination of mental health consumers/users and psychiatric survivors in poor and developing countries. All of you are welcome to e-mail me any input, ideas, statements of support, interest, etc., please spread the word. We are especially encouraging input those in poor and developing countries, but all are welcome to provide suggestions.”

For more information, please contact David W. Oaks, Executive Director, Mind Freedom International; email: oaks@mindfreedom.org; office phone: (541) 345-9106; fax: (480) 287-8833

CALLS FOR FINANCIAL SUPPORT

Berlin’s Runaway House seeks your help

Berlin’s Runaway House (Weglaufhaus):
A refuge for survivors of psychiatry

Psychiatry treats personal crises and conflicts and extraordinary perceptions with often arbitrary and humiliating diagnoses,”write the organisers of the Runaway House "Weglaufhaus" project in Berlin. But what are the options for those seeking refuge from harsh life events, including encounters with mental health services? Without work, money and a place to live, escape often ends where it started: in mental hospitals, without any rights. Founded in 1996 after a 10-year struggle, the Berlin Runaway has since offered homeless women and men admission, protection and the chance to share experiences and regain energy and support.

ENUSP recently learned that the survival the Runaway House and associated projects is at risk. Current funding will run out at the end of the year. The project depends on charitable donations.
Please consider contributing to:

Bank: Berliner Sparkasse
Account no.: 115 001 8450
Owner: Verein zum Schutz vor psychiatrischer Gewalt e.V.
IBAN: DE66 1005 0000 1150 0184 50
BIC: BELADEBEXXX

The house employs qualified staff who have had their own experiences with diagnoses, psychiatric institutions and other hardships, and are available to residents around-the-clock. For more information, please contact: weglauflaus@web.de

Support India’s only mental health advocacy center

The Center for Advocacy in Mental Health, Pune is led by a survivor of psychiatry, Bhargavi Davar. Now in its 10th year of work, it is the only national-level agency in India representing the collective voices of service users and survivors. To date, operations have been supported by grants and sponsorship from development and human rights agencies. Over time, and especially due to compromising demands from donor agencies, the need has become clear for independent funds for user/survivor advocacy and alternatives. The center’s website used to be a crucial networking tool, but organisers were forced to abandon it recently owing to the lack of funds.

The center carries out important advocacy and healing work in a variety of ways, including-

1. Sanchit [meaning ‘collection’] – An oral history archive pooling the lived experiences of users and survivors of psychiatry in India, especially women.
2. A traditional healing archive in multi-media form which collects the cultural resources available in India for healing from psychosocial traumas
3. Peer support and safe spaces locally for users and survivors to rest and make their own choices.
4. Extensive library resources on promotion of alternatives and user survivor advocacy. (Book contributions or campaign materials are very welcome.)

Over the next three years, the Center aims to expand Sanchit and our user survivor advocacy to the Asia-Pacific region. There are also plans to deepen the research into cultural and alternative resources for healing from psychosocial problems.

Bharghavi writes: “We actively solicit your contributions to our work through donations. About €350-700 ($500-1000 US) will do well. It will help start up the website again as well as our story collection. This is the priority.” For further information, including details of wire transfer arrangements, please contact Bhargavi V. Davar; Director, Center for Advocacy in Mental Health Plot No. 9, Survey No. 50/4; Kapil Villa, Ground Floor; Satyanand Hospital Lane Pune 411048, India. Tel: 0091-20-26837644, 26837647; bvddavar@gmail.com
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For more information about becoming a support member, please see: join ENUSP

Donations will be gratefully received here

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