



# ENUSP Bulletin

September 2015

## Special points of interest:

- 7<sup>th</sup> ENUSP Congress
- ENUSP speaks out
- ENUSP around Europe
- Membership

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## Welcome from our Chair

Dear friends,

Welcome to the 7th ENUSP Bulletin!

After a period of relative silence, caused by lack of human resources and funding, ENUSP is starting to renew core activities.

One of the most important activities is communication with our members and friends. In this Bulletin you will find an outline of the news and events ENUSP members have been involved in so far this year. Among the main events was the 7th ENUSP Congress in Hillerød and elections of a new Board and a new Chair.

As the new Chair of ENUSP, I would like to thank those members - both organizations and individuals - who have renewed their membership for

2015, as well as several new organizations who have applied for membership for the first time. Special thanks to the members who answered our call for information and contributed to our Shadow Report for the UN CRPD Committee. I wish all of us a productive, successful and enjoyable Autumn season and thank you for your interest in ENUSP.

Please stay in touch with us and when possible contribute to our Bulletins, providing information about (ex-)user/survivor activities in your countries and comments about what you would like to hear.

Your opinion and contribution are very important for us!

Olga Kalina,  
ENUSP Chair

*“ENUSP needs people. It is important to have individual members, because organizations may not be representative and individuals can be helped to form organizations.”*

Mette Ellingsdalen  
We Shall  
Overcome  
Norway

*“Hopefully, by assuring human and financial resources, we can keep up the work we have started, as re-building ENUSP is a concept that involves building up ENUSP to become a more professional organization that is an active player in the human rights arena.”*

Gabriela Tanasan  
Former ENUSP  
Chair

## 7<sup>th</sup> ENUSP Congress



The 7th ENUSP Congress was held in Hilleröd, Denmark from 11 to 14 December 2014 thanks to the support of our member, the **Danish (Ex-)Users and Survivors of Psychiatry** organization, **LAP**, and a number of national sponsors. 58 participants from 19 European countries were able to meet, network and agree on the road ahead for ENUSP. A pre-assembly session: “Looking at the past to reshape our future” was held on the first afternoon for members to meet and exchange ideas and opinions on ENUSP issues. In the evening, a visit and dinner at the Orion residential and cultural facility was organized by LAP, our host, with the attendance of the former **Danish Prime Minister Poul Nyrup Rasmussen**.

The Extraordinary and Ordinary General Assemblies of ENUSP took place on Friday and Sunday. During the first day of the Ordinary Assembly, delegates approved the report of the last General Assembly in Thessaloniki in 2010.

**Gabriela Tanasan**, former Chair, presented annual reports for 2011-2012. She briefly explained what had been done by ENUSP over the past years, including the 2012-2015 ENUSP Strategic plan and the annual empowerment seminars:

2011: “Nothing about us, without us” in Brussels;

2012: “From Strategy to Reality” in Zagreb;

2013: “Strategy for empowerment – Key areas of action” in Bucharest, which were made possible thanks to support from Mental Health Europe.

**Piotr Iwaneyko**, Interim Chair, then reported on activities in 2013 and 2014, including events and collaboration with the World Health Organization (WHO) and European Disability Forum (EDF).

Finally, **Eric Olsen**, former Chair, offered more details on ENUSP participation with EDF and the history of consultation with other organizations.

ENUSP's volunteer bookkeeper, **Claus-Bech Nielsen**, presented the financial reports for 2011-2014.

After this formal part of the meeting, delegates carried on discussions in smaller groups with Regional meetings.

On Sunday, a new Board was elected, with most nominees being elected unanimously.

**Olga Kalina**, from Georgia, was elected new Chair of ENUSP,

**Guadalupe Morales**, from Spain, was elected Deputy Chair,

**Sandra Marković**, from Bosnia and Herzegovina, and **Amalia Jurj**, from Romania, were elected Secretaries, and

**Katrine Wiedersoe**, from Denmark, was elected Treasurer.



Dinner with friends at Orion, residential and cultural facility



Gabriela Tanasan, former ENUSP Chair and Iris Hölling, meeting facilitator, help with Board elections

During the Extraordinary Assembly, delegates debated the proposed amendments and adopted a new revised version of the Statutes based on the experience of ENUSP over the last 10 years.

On December 13th, thanks to the support of LAP, an **Open Day Conference** was held with additional international and Danish guests. Plenary presentations were organized on topics such as survivor-controlled research, building new national structures, organising, qualifying and empowering p2p workers and peer-run initiatives on both sides of the Atlantic, as well as human rights issues and the CRPD. In the afternoon, interactive parallel sessions took place on a number of inspiring practices for the future and were highly appreciated. Time was devoted at the end of the day for participants to discuss the issues they felt were the most important, followed by a traditional and delicious Danish dinner and even more discussion.

Additional information about the 7th ENUSP Congress can be found here:

Presentation by **Gabriela Tanasan**: [Annual narrative reports](#)

Presentation by **Tina Minkowitz**: [Understanding and Using the CRPD](#)

Presentation by **Jasna Russo**: [Survivor-controlled research](#)

Description of the Congress: [See Jolijn Santegoeds' blog](#)



Claus-Bech Nielsen reporting at the GA

*"They must start to think why they need violence and force to provide services."*

Tina Minkovitz  
Center for the  
Human Rights of  
Users and Survivors  
of Psychiatry  
N.Y., USA

*"As people who know madness and distress, [...] we are responsible for further exploring, advancing and sharing our knowledge to achieve a different, non-damaging and non-medical framework."*

Russo, J.; & Shulkes, D. (2015)

*"What we talk about when we talk about disability: Making sense of the debates in the European user/ survivor movement."*

In Spandler, H.; Anderson, J.; Sapey, B. (eds.) *Madness, Distress and the Politics of Disablement*. Bristol: Policy Press

*“The most common way people give up their power is by thinking they don’t have any.”*

Alice Walker cited by Naomi James National Survivor User Network UK

*“We would like to thank those members who participated and voted in the first regional elections to replace the Deputy Board member for the Central region. With a future remote voting procedure, we trust that all regions will react likewise to give their opinion, vote and input in order to ensure transparent and democratic decision-making within ENUSP leadership.”*

Olga Kalina  
ENUSP Chair

## Update since Hilleröd GA

### Teamwork

The new Board members elected in Hilleröd have met via teleconference every month since January. The quorum for Board meetings (one-half of the members) has been met each time, with the exception of once, and a meeting was called again shortly thereafter. This proves the commitment of the Board members in spite of our lack of resources. After getting to know each other better, members have shared responsibilities and are now truly working together as a team.

### Changes in Board membership

Our Board member for the Central Region, Amalia Jurj (Romania) resigned in January. The Deputy Board member for the Central Region, Monica Obreja (also Romania) kindly stepped up to fill this position. Monica, together with ENUSP, informed all member organizations from the Central region of this resignation explaining that according to the revised Statutes, candidacies were being sought for an election by the Region of a new Deputy Board member for the remaining term of office. Smaranda Iacoban (Romania) was subsequently elected and welcomed as our new Deputy Board member for the Central Region in June .

In August, our Board member for the Northern Region, Eva Ringwall (Finland) informed the Board that the Nordic Federation of Social and Mental Health had been dissolved. Eva’s candidacy to the Board in December 2014 was put forward by members from the Northern Region in Hilleröd and she was elected unanimously by all members although she was not present at the General Assembly. In fact, the Nordic Federation of Social and Mental Health

has never been a member of ENUSP, and as such Eva Ringwall was elected to the Board as an individual member, although this was not clear at the time.

Also in August, our Board member for the Northeast Region, Lina Ciuksiene (Lithuania) informed us that she had resigned from membership with Club 13 & Co., the ENUSP member she represents. This case is not foreseen in our Statutes and the Board subsequently decided to maintain Lina Ciuksiene in her position as Board member in the capacity of individual member. Indeed, after giving a presentation during our Open Day Session in Hilleröd, Lina was elected in person directly by the members in General Assembly who entrusted her with this responsibility to represent the Northeast Region.

### Future governance

The above changes, which have often occurred among Board members of ENUSP in the past for understandable reasons, demonstrate the need to continue to review rules on governance following the major revision of the Statutes in December 2014. The new system established for the replacement of Board members who resign was implemented for the first time with success and will ensure the continued representation of all regions. However, the draft By-laws containing more detailed provisions on governance and which were submitted to all members at the time of the General Assembly were not approved in Hilleröd due to time constraints. As instructed by the members in General Assembly, the Board will experiment with these By-laws and suggest how they can be revised and improved in order to submit them for approval to all members at the time of the next General Assembly.

# Follow-up to WHO-Europe Congress Project for an Empowerment Observatory

**ENUSP  
Speaks  
out**



From right to left:  
Piotr Iwaneyko, Former Interim Chair of ENUSP  
Jolijn Santegoeds, ENUSP Board Member and  
WNUSP Co-Chair  
Ron Coleman, Hearing Voices, UK

At the end of January 2014, several ENUSP representatives were invited to attend and speak at the 4<sup>th</sup> International Congress organised by WHO Europe and the WHO-Collaborating Centre for Research and Training in Mental Health in Lille, France which provided a forum to discuss new guidelines for recommendations on the empowerment of mental health users and carers. With over 400 people attending - mental health service users, ex-users and survivors, along with carers, professionals and elected officials from 16 European, African and North American countries, the debates were lively and interesting.

ENUSP spoke out in favour of certain recommendations and against those recommendations that still fail to live up to CRPD standards particularly as regards involuntary hospitalization and treatment.

Since then, our ENUSP representative in France, **Stephanie Wooley**, has attended two additional follow-up meetings in Lille related to the project

to design a WHO Empowerment Observatory to monitor the implementation of these recommendations in WHO countries.

You can see [ENUSP's statement at the Congress](#) [Information on WHOCC Congress and projects](#)



From left to right:  
Matthijs Muijen, WHO Europe  
Jürgen Schefflein, European Commission  
Jean-Luc Roelandt, Director of the WHOCC for Research and Training in Mental Health, Lille, France  
Philippe Leborgne, French Ministry of Health  
**facing Jolijn Santegoed's good practice of Family Group Conferencing**

*“The problem is not lack of knowledge, but the failure to implement policies that we know are good.”*

Guadalupe Morales  
ENUSP Deputy  
Chair

**What are we waiting for?**  
*“Community care is associated with continuity of care, greater users’ satisfaction ... better protection of human rights, and prevention of stigma.”*

EU Joint Action for  
Mental Health and  
Well-being

## European Day of People with Disabilities

**Guadalupe Morales**, our Deputy Chair, represented ENUSP and gave a presentation at the annual conference organized late last year for the European Day of Persons with Disabilities by the European Commission and the European Disability Forum (EDF). This year, the Conference was entitled “Building together a barrier-free Europe” with employment and accessibility the main focus.

Ms. Morales spoke out about discrimination at the workplace, which she herself had experienced, the lack of funding for user/survivor organizations and the necessity to implement good policies in practice to ensure employment for people with mental health problems. *“The problem is not lack of knowledge”, she said, “but the failure to implement policies that we know are good. Research indicates that being*

*unemployed has a bad impact on our mental health, however users and survivors of psychiatry are less likely to be in paid employment than any other disadvantaged group. From my point of view, we are the most discriminated among all discriminated groups in the world.”*

EDF President, **Yannis Vardakastanis**, and the Head of Unit for the rights of persons with disabilities of the European Commission, **Maria Luisa Cabral**, opened the conference.

For more information on the Conference, see

[Employment & Accessibility the focus of this year’s European Day of Persons with Disabilities](#)

[The full presentation given by Guadalupe Morales](#) (minute 38:57)

## EU Joint Action on Mental Health and Well-being

ENUSP is a Collaborating Partner of the EU Joint Action on Mental Health and Well-being (“JAMHWB” or “JA” for short) and as such, has been invited to attend a number of different level meetings. The JA was launched in 2013 with the aim of “building a framework for action in mental health policy at the European level” and as a follow-up to the

“European Pact for Mental Health and Well-being” launched in June 2008 (along with thematic conferences organized from 2009 to 2011). The JA will culminate in a Concluding Conference of the Joint Action in January 2016 with the results of the five Work Packages (“WP”) produced under the JA.

This year, **Gabriela Tanasan**, our former Chair, represented ENUSP at the Joint Action Stakeholders Meeting in Brussels in February. The purpose of the meeting was to present and discuss the draft reports for the five Work Packages produced.

Ms. Tanasan actively participated in this meeting emphasizing ENUSP's view on community-based care and deinstitutionalization, user involvement in all processes that affect our lives and compliance with CRPD requirements, among them the active and meaningful involvement of people with psychiatric diagnoses in making, implementation and monitoring laws, policies and programmes about us.

The same month, ENUSP was again represented at another meeting within in the framework of the JA by

**Guadalupe Morales**, Deputy Chair, in Madrid. This was the last meeting specifically devoted to WP5:

“Community-based approaches in Mental Health”. Ms. Morales insisted on the importance of users being at the center of all processes, including at the EU level, particularly when it came to accessing EU Funding. She mentioned the need to enforce the UN Convention on the Rights of Persons with Disabilities especially in the areas of human rights, deinstitutionalization, discrimination and lost opportunities, recommending peer-to-peer and training the trainers programmes to strengthen capacity building. As an expert on the media, stigma and discrimination, Ms. Morales offered to develop a review of positive media impact, action and campaigns and make suggestions for the future.

*“As part of the JA on Mental Health and Well-being, are you ensuring that measures are being properly taken to protect the rights of persons with disabilities that would be a violation against their rights under 14, 15 and 17 of the Convention?”*

Ms. Silvia Chang-Quan,  
CRPD Committee  
Member, Guatemala

Guadalupe Morales (third from the left)  
Madrid, February 2015  
JA Meeting devoted to WP5:  
“Community-based approaches in  
Mental Health”



In May, ENUSP was represented by **Timo Kallioaho** from Finland and **Stephanie Wooley**, Deputy Board Member, in Helsinki for the final Conference on WP8: “Mental Health in all policies”. Again, Ms. Wooley suggested that a more social, human-rights and justice-based approach needed to be integrated in the recommendations. She also noted the need to add ways to fight stigma and discrimination in the areas of labour policies and education. She added that the inadequacies of

current structures, including forced hospitalization and treatment, as well as guardianship measures throughout Europe prevented a true approach to mental health in all policies.

ENUSP may still provide comments before the Concluding Conference in January next year, which we hope our Chair, **Olga Kalina**, will attend.

For more information about the EU Joint Action and the Work Packages, please see:

[The Joint Action](#)

## EPF Annual General Meeting and Conference

*“We cannot have sustainable health systems without patient involvement in health policy, and concretely, patient involvement in an inclusive policy-making process which combines both a top-down and bottom-up approach.”*

Gabriela Tanasan,  
Former ENUSP  
Chair

**Gabriela Tanasan**, represented ENUSP at the EPF Annual General Meeting and Conference.

The EPF Annual General Meeting (AGM), which took place on 19 May 2015, was an opportunity to learn more about what EPF achieved in 2014 and to discuss and adopt the strategic priorities for the year to come. Board elections were also on the agenda of the meeting. ENUSP had nominated Gabriela Tanasan to be a member of the Board. Gabriela’s presentation to support her candidacy was very well received by the audience and she obtained almost enough votes to be elected among the many candidates to the Board. Anders Olauson, EPF President, and Nicola Bedlington, Secretary General, appreciated the presentation and encouraged Gabriela to submit her candidacy on behalf of ENUSP again next year.

The AGM was followed by a two-day conference entitled *“Empowered Patients are an asset to society”* on 20-21 May 2015. This Conference marked the launch of an EPF Campaign on Patient Empowerment, *“Patients prescribe E<sup>5</sup> for Sustainable Health Systems”* that will run until June 2016. “E” to the fifth power of Empowerment stands for

Education, Expertise, Equality, Experience, and Engagement .

The plenary sessions of the conference gave participants an understanding of patient empowerment and related concepts from a patient perspective.



Gabriela Tanasan, former ENUSP Chair, speaks out

The case studies of patient empowerment in practice were followed by participants’ perspectives on what is required to make it a reality. The parallel workshop sessions addressed three key aspects of empowerment identified in the [EMPATHIE Study](#): (1) Health literacy and the informed patient, (2) The new patient-professional relationship, (3) The role of self-management in chronic disease, aiming to contribute to a draft *Patient Empowerment Charter* and *Multi-Stakeholder Roadmap* (documents to be developed during the EPF Campaign).

In a [video message](#) (min 0:55), The European Commissioner of Health, Mr. Vytenis P. Andriukaitis, stated that “[...] *while we have a lot to gain in involving patients in a joint decision-making process, we need to draw a clear line between self-treatment and patient empowerment. The final treatment decision belongs to the doctor*”, People from the audience were astonished to hear this statement, some of them expressing openly the opinion that the European Commissioner has really, really gotten things wrong.

Speaking about patient/mental health service user empowerment in real life, Gabriela Tanasan said that: *“Patient empowerment also means patient involvement in every process that affects our daily lives. We cannot have sustainable health systems without patient involvement in health policy, and concretely, patient involvement in an inclusive policy-making process which combines both a top-down and bottom-up approach.”*



# ENUSP makes a difference in EU review by UN CRPD Committee

## ENUSP raises issues for EU review by CRPD

In light of the review of the European Union's implementation of the UN Convention on the Rights of Persons with Disabilities (CRPD) by the UN CRPD Committee, ENUSP has been working hard to advocate for key issues impacting the rights of persons with psychosocial disabilities within the European Union to be included in the dialogue between the UN CRPD Committee and the EU.

The EU review by the UN CRPD Committee comprised two main events this year.

First, in March 2015, the CRPD Committee compiled the "List of Issues", which is a list of questions used as a basis for dialogue between the CRPD Committee and the EU. For this purpose, ENUSP sent a submission to the Committee on our key issues of concern regarding CRPD implementation in and across the EU. ENUSP stressed that the EU must play a role to take action to put an end to substitute decision-making, institutionalization and forced treatments, and to ensure the right to legal capacity, liberty and freedom from torture and ill-treatment and further ensure access to justice for all

persons with psychosocial disabilities in the EU. Our issues, though clearly understood by the UN CRPD Committee, were initially not included in the official List of Issues submitted by the UN CRPD Committee to the EU in April due to various procedural reasons. This only made ENUSP decide to work even harder.

Subsequently, a survey to gather information from our members on these issues at the national level was launched for our "Shadow Report", and ENUSP studied the "competencies" of the EU more, to help the UN CRPD Committee understand the role and responsibilities of the EU in connection with our issues. ENUSP's Shadow Report on the EU was submitted to the UN CRPD Committee in July 2015. In this report, ENUSP again stressed the above role the EU must play for all persons with psychosocial disabilities in the EU. Our Shadow Report provided further information to the UN CRPD Committee with the aim to have our issues included in the next phase of Constructive Dialogue during the 14<sup>th</sup> session of the UN CRPD Committee in Geneva, where the EU review was on the agenda.

## CRPD Committee sessions in Geneva

ENUSP representatives were able to attend both of the CRPD Committee Sessions in Geneva from 29 March - 2 April (advocacy for the CRPD List of Issues) and from 26 - 29 August

(advocacy for the Constructive Dialogue between the CRPD Committee and the EU delegation) thanks to the financial support of the European Disability Forum (EDF).

*"ENUSP urges the EU to take action to include the rights of persons with psychosocial disabilities in the EU's human rights-agenda and remedy the widespread human rights violations in the EU."*

ENUSP Shadow Report,  
14 July 2015

*"I'm a bit concerned about the misinterpretation of the CRPD within the EU framework... with that huge amount of legislation like a pyramid or an inverted pyramid, how can you ensure that no dilution or no misinterpretation of any CRPD article takes place on the ground?"*

Mohammed Al Tarawne  
CRPD Committee Member  
Jordan

*“ENUSP is just very concerned about a scenario where the Council of Europe standards remain unchanged, imposing an ongoing barrier for our human rights in the EU.”*

Jolijn Santegoeds  
ENUSP Board  
member and  
WNUSP Co-Chair

*“We do not know when ... and how the rights of persons with disabilities will be fully recognized, protected and promoted, especially those with intellectual and psychosocial disabilities...or how long many persons with disabilities will continue to be institutionalized and deprived from their right to liberty and security by several Member States.”*

Monthian Buntan  
CRPD Committee  
Member  
Thailand



In the right corner  
Jolijn Santegoeds, ENUSP Board member and WNUSP Co-Chair

On both occasions, ENUSP representatives attended civil society briefings, “constructive dialogue” meetings, organized Side Events with WNUSP and EDF, and attended other strategic meetings in cooperation with EDF. Many thanks are due to Board member **Jolijn Santegoeds** (Stichting Mind Rights in the Netherlands and Co-chair of WNUSP), and members **Hege Orefellen**, **Liv Skree** and **Mette Ellingsdalen** (We Shall Overcome in Norway), who delivered presentations on the situation of the experiences and the rights of persons with psychosocial disabilities in Europe on behalf of ENUSP and devoted time to personally lobbying and raising awareness among UN CRPD Committee members. Their involvement did not go unremarked by both Committee members and other DPOs and NGOs, and congratulations are in order. ENUSP's hard work made a difference!

During the Constructive Dialogue in August, several questions on our issues were raised by the UN CRPD Committee with the EU delegation, including in the Opening and Closing statements of the Chairing Rapporteurs of the CRPD Committee. UN CRPD Committee Member Ms. Silvia Quan-Chang asked what the EU

is doing to ensure that people who have psychosocial disabilities are not forced into institutionalization or subjected and forced into medical treatment without their consent, and what measures were being taken to protect persons to ensure that third parties do not take decisions on their behalf, including forced sterilization and forced abortion. ENUSP is very grateful for the attention paid to our concerns by the UN CRPD Committee.

In the reply of the EU, the Head of the EU delegation, Mr. Michel Servoz, stated that various EU institutions are taking action on these issues, such as the EU Agency of Fundamental Rights (FRA) which is undertaking research to raise awareness, and the European Commission's new conditions attached to the allocation of EU Funds to ensure a transition from institutional to community-based support. These EU actions are somehow limited due to "shared competencies" with EU Member States, but it shows the willingness of the EU to use their powers to advance human rights.

The Concluding Observations by the UN CRPD Committee issued in September 2015 represent the final stage of this periodic review process

on the implementation of the UN CRPD by the European Union. The Concluding Observations contain the UN CRPD Committee's recommendations to the EU providing guidance on better protection and

promotion of the human rights of persons with disabilities in and by the EU. In the Concluding Observations of the UN CRPD Committee on the EU our issues were again directly addressed as seen below.

## CRPD Committees Concluding Observations on EU implementation

### Equal recognition before the law (art. 12)

“36. The Committee notes with deep concern that across the European Union a large number of persons with disabilities have their full legal capacity restricted.

**37. The Committee recommends that the European Union take appropriate measures to ensure that all persons with disabilities deprived of their legal capacity can exercise all the rights enshrined in European Union treaties and in European Union legislation such as on access to justice, to goods and services, including banking and employment, and to healthcare, as well as voting and consumer rights, in line with the Convention, as elaborated in the Committee’s general comment No. 1 (2014) on equal recognition before the law. It further recommends that the European Union step up efforts to foster research, data collection and exchange of good practices on supported decision-making in consultation with representative organisations of persons with disabilities.”**

### Access to Justice (art. 13)

“38. The Committee is concerned about the discrimination persons with disabilities face in accessing justice due to lack of procedural accommodation in European Union Member States.

**39. The Committee recommends that the European Union take appropriate action to combat discrimination persons with disabilities face in accessing justice by providing full procedural accommodation within its Member States, and the provision of funding for training of justice personnel on the Convention.”**

### Liberty and Security of the person (art. 14)

“40. The Committee is concerned about the involuntary detention of persons with disabilities in psychiatric hospitals or other institutions on the basis of actual or perceived impairment.

**41. The Committee recommends that the European Union take all possible measures to ensure the liberty and security of all persons with all types of disabilities in line with the Convention and the Committee’s Guidelines on article 14 (2015).”**

### Protecting the integrity of the person (art. 17)

“46. The Committee is concerned that persons with disabilities are exposed to involuntary treatment in European Union Member States, including forced sterilisation and abortion.

**47. The Committee recommends that the European Union take possible measures to ensure the individual right to free and informed consent to**

*“It is quite important for us that the EU Funds should not be used to support institutionalization. This is something that we are against. It is very clearly something we do not want Member States to do and what we allow is only to use EU funds to support independent living.”*

Michel Servoz  
European  
Commission’s DG  
for Employment,  
Social Affairs and  
Inclusion

*“We found that several countries have utilized funds to renovate or even to build institutions for persons with disabilities contradicting the goal of inclusion with such use of the funds. Have you had any cases that you, after finding such practice, managed to withdraw, correct, or even ask for return of the funds?”*

Monthian Buntan  
Co-rapporteur  
CRPD Committee  
Thailand

*“What steps does the EU take to ensure that its support... does not... allow the use of net beds, restraints and other non-consensual practices against persons with intellectual and psychosocial disabilities in psychiatric hospitals and in institutions?”*

Theresia Degener  
Vice Chair  
CRPD Committee  
Germany

*“The right to legal capacity, the right to liberty and the right to be free from torture and other cruel, inhuman or degrading treatment - for all EU citizens, including those with psychosocial disabilities on an equal basis with others - can be solidified by framing these as non-discrimination issues under EU policy and legislation.”*

Jolijn Santegoeds  
ENUSP Side event  
speech  
CRPD Committee  
14<sup>th</sup> session, Geneva  
August 2015

### **treatment is upheld and supporting decision-making mechanisms are provided in EU Member States.”**

ENUSP is very happy to announce this milestone result of our advocacy, and applauds the UN CRPD Committee for including our key concerns in the Constructive Dialogue and the Concluding Observations. The recommendations by the UN CRPD Committee to the EU are empowering for all ENUSP members in their advocacy work throughout the European countries and beyond. ENUSP celebrates this experience of having our voices heard by the UN CRPD Committee, and celebrates the fact that ENUSP was able to make a difference in the EU review by providing these two extensive submissions and by being present to influence history in action. ENUSP is looking forward to the further realization of our human rights in Europe, and hopes that the recommendations of the UN CRPD Committee will be put into effect by the EU institutions as soon as possible.

On behalf of ENUSP, the ENUSP Board would like to express many thanks to those members who responded to the ENUSP questionnaire on the situation in EU countries, and we hope to complete and update the information on all European countries for future use. Feel free to upload any information on the situation of persons with psychosocial disabilities in your country to:  
[enusp.info@gmail.com](mailto:enusp.info@gmail.com)

See full text of the [Concluding Observations of the UN CRPD Committee on the EU](#).

Further information on the CRPD Committee’s 14<sup>th</sup> session, including the full list of documents related to the review of the EU can be found at [General Documentation](#).

[Official report](#) of the session by the UN OHCHR.

See the full video of the [Constructive Dialogue between the UN CRPD Committee and the EU delegation](#) on the webcast.

Follow on Twitter [#crpd14](#)

To share the experiences of ENUSP representative Jolijn Santegoeds at the sessions in Geneva, see Jolijn’s blog, [UN CRPD Committee 13<sup>th</sup> session](#) and [EU Review at 14<sup>th</sup> CRPD Session in Geneva](#).

And for those who are interested in seeing more, you can watch the webcasts of:  
[Side-event 13<sup>th</sup> CRPD Session organized with WNUSP](#)  
[Side-event 14<sup>th</sup> CRPD Session organized by WNUSP](#)  
[Side event on violence against women and girls with disabilities](#)



Live Skree, We Shall Overcome, Norway, gives a moving speech at the 14<sup>th</sup> CRPD session



## Call for your opinion on ENUSP representation

For over 25 years, ENUSP representatives have spoken out against the discriminatory practices and violations of human rights that psychiatry has caused.

This is far from an easy task when approached by official bodies for “our opinion” which will more or less be taken into consideration. The above events are examples, along with the contributions earlier this year which ENUSP provided in writing to the European Patients’ Forum (EPF) regarding its draft position paper on “Adherence and Concordance” or to the European Association of Service Providers of Persons with Disabilities (EASPD) via an interview and subsequent conference. EASPD had approached ENUSP for advice on the representation of persons with disabilities in its own structure, projects, processes and themes as part of their “Reaching out Strategy” 2014-2017. Although we are motivated to

find common ground when dealing with other European organizations, these contacts have demonstrated our differences and our specific demands compared to other “patient” or “disability” groups, and particularly the ongoing lack of respect for a patient’s “free and informed choice of treatment” in the psychiatric arena.

ENUSP has developed a template on representation and reporting and hopes to have the capacity to issue our own position papers in the future in spite of our lack of resources, rather than reacting to outside initiatives and solicitations.

We would be very happy to hear from members interested in suggesting issues ENUSP should speak out on officially, who would like to provide us with their opinions or who would like to represent ENUSP particularly at events organized in your country. Please contact us at [enusp.info@gmail.com](mailto:enusp.info@gmail.com).



Speech  
Nadya Romanchuk



Thoughts  
Nadya Romanchuk

Speak out  
with  
ENUSP!

*“[...] art can become one of the ways of advocacy. We have to show our potential, our strong sides and do it in many ways, because we all are different. Art can be one of the ways to show our personality, our soul and it doesn’t require words for understanding.”*

Nadya Romanchuk

## ENUSP around Europe

## News from our members

### France

Mad Pride has been organized for decades around the world to celebrate the human rights and spectacular culture of people considered very different by our society. Several ENUSP members have organized Mad Pride events in their countries. Finally, for the first time in France, [Mad Pride](#) was organized by our member **Advocacy-France** last year in June and was an amazing success, thanks in part to the French penchant for street demonstrations. An organization was

formed early this year composed of 7 national user and carer organizations to gear up for the 2<sup>nd</sup> edition with a march from the Saint Vincent de Paul former hospital to the Bastille. For the first time in 2015, Mad Pride also took place in Marseilles.

Financing was also obtained this year from the *Fondation de France*, the regional health authorities and the Paris town hall.

Come join us!

« FOUS ET ALORS ?  
...et alors, la folie concerne tout le monde ! Le qualificatif fou fait partie du langage commun en incluant une part de normalité. Notre slogan affirme notre revendication du droit à la différence ! »

Source: <http://www.lamadpride.fr/madpride2015>



First Mad Pride, Paris, 2014



Mad Pride, Paris, 2015

## Georgia

Guardianship legislation in Georgia is changing.

After the decision made by Constitutional Court, which declared the current guardianship regulations unlawful, the Parliament started to work on a new legislation package. The Court obliged the Parliament to ensure that guardianship legislation is in compliance not only with the Georgian Constitution, but also with the UN CRPD. As a result, the new legislation was designed and approved by the Parliament. Instead of guardians, the courts will appoint

supporters, who in theory will not be able to make decisions instead of the person. People currently under guardianship will have to pass an assessment by a multidisciplinary team, and in each case the court will decide individually on the extent of support required by “people with psychosocial needs”. This new term replaced the term “legally incapable” in the legislation. Authors of the legislation package consulted our local member of ENUSP, **Partnership for Equal Rights** (PER) before the Hearing.

*“The Constitutional Court of Georgia obliged the Parliament to ensure that guardianship legislation is in compliance not only with the Georgian Constitution, but also with the UN CRPD.”*

Olga Kalina,  
ENUSP Chair

## Romania

In November 2014, **Orizonturi Foundation** together with **Mens Sana Association** issued a position statement in response to the Romanian UN Ambassador Maria Ciobanu who stated in one of the hearing sessions of Romania before the UN Committee on Economic, Social and Cultural Rights held in November 2014 that the Romanian national legislation is more favourable

than the CRPD, thus trying to justify the State's failure to make any efforts after the ratification of the CRPD to amend the domestic laws or to pass new ones that would be consistent with the CRPD and support its implementation.

The [position statement](#) was endorsed by ENUSP.

*“[...] the (Romanian) Ambassador's statement [...] endorses government apathy in regards to the requirement of aligning domestic legislation with the CRPD.”*

Position Statement



*Movement*  
Nadya Romanchuk



*In space*  
Nadya Romanchuk



*Tropical summer*  
Nadya Romanchuk

*Happy Birthday to  
our Russian  
member Club  
Phoenix!*

## Russia

Our Russian member, **Club "Phoenix"**, located in Saint Petersburg, celebrated its 15-year jubilee in February 2015. According to estimates there are almost 30,000 people with psychiatric diagnoses in just this one city of Russia. However, community services are not developed and these people face huge stigma and loneliness. Club "Phoenix" founded in 2000 tries to provide services and space for meetings and creative activities of people diagnosed with psychiatric conditions.



Evgeny Kolyasov deserves the gratitude of all Club members



Old Russian samovar is a usual thing on our table

Club "Phoenix" celebrating its 15-year jubilee

**“I cannot live without painting and writing verses, it’s my second life.”**

**Nadya Romanchuk**, Deputy Board Member of ENUSP for the North East Region, thinks that art can give meaning to people’s lives and serve as a powerful tool of rehabilitation.

*“People with weakened mental health almost always are more sensitive and vulnerable, and sometimes a very rich spiritual world is hidden behind this sensitiveness and vulnerability. A very different approach is necessary for these people, because it is easy to do harm and very difficult to find out what is happening inside of the soul.*

*I think that people still haven’t solved the problem of how it is possible to give people with such a rich and vulnerable soul a chance of living in society without getting wounded. And what can help such people? From my point of view, only art - in its different forms. This is especially true because other possibilities are often very limited. Art means expressing emotions, positive or negative. Art means self-realization. We know that many geniuses were suffering and what was helping them? Only the process of doing what they loved.*





Dream  
Nadya Romanchuk



Blessing  
Nadya Romanchuk

*They couldn't exist without that. When you paint, it's like renewal, you are becoming content with your life and you have this feeling of achievement, self-confidence. And this is very important."*

During her presentation at the Congress in Hillerod, Nadya said how she believes that art can become one of the ways of advocacy. *"We have to show our potential, our strong sides and do it in many ways, because we all are different. Art can be one of the ways to show our personality, our soul and it doesn't require words for understanding."*

Nadya was hospitalized for the first time when she was 16. She lives in Saint Petersburg, Russia, with her father and brother who is also a user of psychiatry. She started to paint and write verses in 2008 and received a formal education in wood painting. *"For me, it's like a second life",* says Nadya and than corrects herself. *"No, it's my whole life, period."*

*"We have to show our potential, our strong sides and do it in many ways, because we all are different."*

Nadya Romanchuk,  
Deputy Board  
Member for the  
Northeast Region

## Finland

The meeting place **OLKKARI** belongs to the relatively recent organization, ***Olkari-Kokemus-ja vertaistojat ry*** (Association of experts by experience and peer supporters) established in 2012. Some members of the **Mental Health Association for the Seinäjoki Region (SAMY)**, which is a member of ENUSP, work at OLKKARI as volunteers. One of our activists, **Timo Kallioaho**, wanted to share the history and activities of OLKKARI with us.

### OLKKARI - Meeting place of mind welfare and activity without alcohol



– You are welcome to take a break, chat and meet people that may have same experiences in life as you! Find friends, hobbies, use your own skills and influence things!



### EXPERIENCE EXPERTS

*“The most important values we have are: equality, independence, taking into account everybody's needs, humanity, peer support, flexibility.”*

Timo Kallioaho  
Olkkari

*“This project actually started out as early as 2010, when here in my home town of Seinäjoki, a special training course for users of mental health services was organized. I attended the first course during 2010-2011, and this way, got the title of “expert by experience”. The training course was very good and provided us a lot of knowledge about different kinds of psychiatric disorders, practice in how to talk to big audiences about our experience (e.g. at schools) and how we can develop society so that there will no longer be discrimination/ stigma, etc. Today, in 2015 there are about 70 trained experts by experience here in Seinäjoki.*

*After taking our training courses, we decided together to establish this association, which is also an NGO. We wanted to have a meeting point for us (mental health experts by experience - where we could gather together when we like. We received financing from the Finnish Slot Machine Association, and we have become, I believe, an independent and a grass roots actor here in my home town.*



Stephanie Wooley (France) and Timo Kallioaho (Finland)  
Helsinki, May 2015  
Final JA Conference on WP8: “Mental Health in all Policies”  
After the Helsinki JA conference, a toast to getting our message across!

*The most important values we have are: equality, independence, taking into account everybody's needs, humanity, peer support, flexibility.*

*I would like to emphasize the fact that EVERYBODY who is involved in our OLKKARI meeting point has his/her own background with either mental health problems or substance abuse problems. I have to say that in the beginning of the year 2012, we did receive a great deal of assistance from the psychiatric department of the Hospital District of South Ostrobothnia (which is geographically the umbrella organization in this part of Finland) to start up. But, in spite of this, we are independent.*

*The weekly activities at the OLKKARI meeting point are flexible so that persons can visit this place whenever they like during opening hours. The main idea of this user-led meeting point is for service users to plan various activities. I organized a workshop where I told others about ENUSP and our very important work in Europe. I also translated the ENUSP website into Finnish so that everyone could understand what ENUSP is doing.*

*In OLKKARI, you can meet many talented service users who sing karaoke songs, have artistic activities, including painting, cooking food and who give peer support for other persons who occasionally visit OLKKARI.*

*Here you can have a cup of coffee (for only 1€ you get as many cups as you like!) and chat with others or read the local newspaper. You also can surf on the Internet for free. At OLKKARI, we have tried to offer a low threshold place for almost everybody. I often visit and I truly appreciate everything they have done.”*

## More News

Despite being a suicide survivor and a survivor of psychiatric care in the Soviet Union, **Signe Baumane** from **Latvia** has managed to become a thriving filmmaker who recently released "[Rocks In My Pockets](#)" - an award-winning animated feature film

about her family's history of mental illness told with the help of art, humour and animation.

The film has been screened in over 70 film festivals worldwide. Latvia had selected the film as the county's entry to the Oscars.



"Rocks in my pockets"



Signe Baumane



**The Rusihak Organization in Turkey**, which is a mixed organization for the promotion of human rights in mental health care, launched a [film about human rights violations in Turkish institutions](#) ([trailer](#)).



"I think they regard us as prisoners..."  
(interview with an in-patient, English subtitles to video 2, 2:20)

**Prateeksha Sharma in India** says, "We can easily make people into bonsais: miniature versions of themselves, whose ideas, wings, vitality or dreams are cropped, diminished and turned around to suit those others around

who want them to grow in a certain way."



**Alternatives beyond psychiatry in the UK:** Global mental health actors need to take greater account of these alternatives if they are serious about defining 'global' in a way that is respectful and inclusive of other (both non-psychiatric and/or non-western) ways of being, seeing and doing.

See these [alternative support systems to the top down imposition of western biomedical realities](#) from around the world.



"There is no pathology or illness lurking in anyone, as far as I am concerned, but a deep wounding that can heal, given time, scope for expression and a safe space for communication. People, like plants, will always recover and get back on the path of their growth, once there is even one hand to hold."

Prateeksha Sharma



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**We're on the Web!**

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

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**Lay-out**

Gabriela Tanasan, Romania

## Membership

If you would like to join ENUSP, please fill out our [membership form](#) on line and return it to [enusp.info@gmail.com](mailto:enusp.info@gmail.com).

Membership is available both for organizations and for individual members. Members of ENUSP who did not update their membership for 2015, please use the same forms to renew your membership!

**We are counting on you!**

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## Donate

Dear members and friends of ENUSP, please remember that it is hard to find funding for our representatives to attend important events and raise our voice. We depend on invitations and occasional support from donors (both individuals and organizations). However, it is unlikely that our travel and accommodation costs will be covered by the organizer of an event if our presence is not highly desirable.

ENUSP needs more financial independence to be able to choose events, where we can make the most impact, and that is why we need your support. Please click on [donation](#):

**We appreciate your support!**

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## ENUSP's next steps

We are very pleased to announce the **5th ENUSP Empowerment Seminar: "Strengthening the (ex)user/survivor voice in Europe"**, supported by Mental Health Europe (MHE) and the European Commission (Rights, Equality and Citizenship Programme, Priority: RDIB-Rights of persons with disabilities).

The seminar will take place in **Brussels, Belgium, on 13-15 December 2015**.

This working seminar will be comprised of three parts. In the first part, we would like to present and discuss the positive and negative results of our efforts and achievements since our last General Assembly in Hillerod; the second part of the seminar will open up the possibility to explore and discuss in person our future cooperation with the European Disability Forum (EDF), European Patients Forum (EPF), Mental Health Europe (MHE) and the European Union. Before the final conclusion of the seminar, we would like to split the participants into task groups and define ENUSP's next steps.

We are looking forward to welcoming 24 participants who have applied and whose participation will be covered.

Additional registration remains possible for other participants who would like to attend at their own expense. For information, please contact us at [enusp.info@gmail.com](mailto:enusp.info@gmail.com).