DETERMINING OUR OWN FUTURE:

"THE WAY FORWARD FOR ALL EUROPEAN USERS AND SURVIVORS OF PSYCHIATRY"

A Report of the 6th Congress of
The European Network of (ex-)Users and Survivors of Psychiatry (ENUSP)
Held together with
The Pan-Hellenic Committee of (ex-)Users and Survivors of Psychiatry

SEPTEMBER 28th - OCTOBER 1st, 2010

THESSALONIKI, GREECE

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SURVIVORS OF PSYCHIATRY

THESSALONIKI GREECE, SEPTEMBER 28- SEPTEMBER 30, 2010

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DETERMINING OUR OWN FUTURE:

"The way forward for all European users and survivors of psychiatry"

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Two versions of this Report were produced:

- One without blank pages for ease of reading
- One publishing version, with blank pages, should you wish to print this report in the normal way

Both versions are available on ENUSP's website at:
www.enusp.org >>> Documents and Reports >>> ENUSP Congress, Assembly & Seminar Reports.

CONTENTS

Page

Acknowledgments and disclaimers **iv**

Methodology **vi**

INTRODUCTION **1**

- Background to the Congress (Empowerment Seminar and General Assembly) **5**
- Programme **20**

DAY ONE - OPENING CEREMONY

Presentations: **23**

- Mary Nettle, outgoing Chair European Network of (ex)Users and Survivors of Psychiatry (ENUSP) **24**
- Iris Hölling, World Network of Users and Survivors of Psychiatry (WNUSP) **26**

DAY TWO - EMPOWERMENT SEMINAR (PART I)

Key note lectures: **41**

- Stefan Trömel, International Disability Alliance **42**
- Giorgios Giannoulopoulos, Pan-Hellenic Network of Users and Survivors of Psychiatry **62**

Working groups and workshops: Description **83**

DAY THREE – EMPOWERMENT SEMINAR (PART II) AND GENERAL ASSEMBLY

- Feedback from working groups and workshops **97**
- Introduction to the General Assembly **113**
- Minutes of the General Assembly **117**
- New voices from the South-East region **138**
- Gabriela Tănăsan, newly elected Chair of ENUSP **142**
- Closing Ceremony **143**

CONCLUDING REMARKS **150**

CONCERT **161**

ANNEXES **168**

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- Credit Illustrations: Illustrations in the Report come from two participants to the Congress: Nadezda Romanchuk and Jano. You will find short biographies and information together with the illustrations;
- Credits photographic material: The photographs contained in this Report are by two psychiatric survivors: Anne-Laure Donskoy and Maths Jesperson from ENUSP.

ENUSP would also like to acknowledge all the users and survivors of psychiatry in Europe who wished to join us for our 6th Congress, but were unable to be there. In particular, we note the efforts of Miroslav Misic, President of the user organisation Valenca in South Serbia, to attend our event, including by his personal fundraising. Unfortunately he was prevented from reaching us.

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[1] Bairaktaris, K. (2010). Proceedings of the European Congress against Discrimination and Stigma, and for User-oriented Reforms and the Right to Alternatives, September 28 - October 1: Parallel Events, Conclusions, Findings and Reflections, pp25-33. Thessaloniki: Aristotle University.

[2] Crudden, S. (2010). Break-through: A New Paradigm. http://www.indymedia.ie/article/97819

[3] Verhaegh, J. (2010). Griekse gastvrijheid [Greek hospitality]. Deviant, 67, 26-27 Available in Dutch only. (Annex 6)

[4] "MenteLibera" is run by ENUSP Deputy Board member Erveda Sansi. For her records of the Congress, please see, e.g. http://senzapsichiatria.blogspot.com/2010/10/stop-to-psychiatric-violence.html.

– The Empowerment Seminar was made possible thanks to Mental Health Europe:

“It was supported through the European Community Programme for Employment and Social Solidarity (2007-2013). This programme was established to financially support the implementation of the objectives of the European Union in the employment and social affairs area, as set out in the Social Agenda, and thereby contribute to the achievement of the Lisbon Strategy goals in these fields.
The seven-year Programme targets all stakeholders who can help shape the development of appropriate and effective employment and social legislation and policies, across the EU-27, EFTA and EU candidate and pre-candidate countries.

To that effect, PROGRESS purports at:

- Providing analysis and policy advice on employment, social solidarity and gender equality policy areas;
- Monitoring and reporting on the implementation of EU legislation and policies in employment, social solidarity and gender equality policy areas;
- Promoting policy transfer, learning and support among Member States on EU objectives and priorities; and
- Relaying the views of the stakeholders and society at large.

For more information see: http://ec.europa.eu/employment_social/progress/index_en.html
The information contained in this publication does not necessarily reflect the position or opinion of the European Commission.”

We take this opportunity to acknowledge the plight of the thousands of European recipients of psychiatry who could not come to Thessaloniki because they are being incarcerated in institutions, or deprived in other ways of the right to determine their own lives.

Our solidarity is with all of you. All of you were greatly missed.

METHODOLOGY

- The report writers have tried to use first person accounts as much as was feasible within the constraints of the report. Some of these constraints pertain to translation issues during the Congress and to the availability of information. This means that we have only been able to reproduce the texts for which we were able to obtain a translation into English.
- The title "Empowerment Seminar" came from the funder of this part of the programme. In this Report, we have used the term "Congress" to describe the two parts of the Thessaloniki event as this was the one most often used during its planning and materials prepared by the various organisers (probably also translating from local languages).

NOTATION

- Underlined word or words: to indicate emphasis.
- . . . (3 dots) indicate omitted text

ABBREVIATIONS USED IN THE REPORT

CRPD	Convention on the Rights of Persons with Disabilities, adopted by the UN in 2006 and which came into force in May 2008. It was adopted by the EU in late 2010 and came into force in January 2011. Also referred to in many texts as the UN or United Nations CRPD and sometimes, in this Report, as the Convention.
DSM	Diagnostic and Statistical Manual of Mental Disorders published by the American Psychiatric Association
ENUSP	European Network of (ex)Users and Survivors of Psychiatry
EU	European Union
IDA	International Disability Alliance
NGO	Non Governmental Organisation. Used to describe "not-for-profit" organisations and associations
OPCAT	Optional Protocol to the Convention Against Torture: the OPCAT gives to the right to the Subcommittee on Prevention of Torture and other Cruel, Inhuman or Degrading Treatment or Punishment (SPT) [which is one of the United Nations mechanisms] to send UN inspectors to visit countries and examine the treatment of people being held there
OSF	Open Society Foundations
UN	United Nations
WNUSP	World Network of (ex)Users and Survivors of Psychiatry

Here is the Greek version of the programme as it was offered in the participants' packs and beautifully produced by the team at Aristotle University... The full detailed version of the programme in English can be found in the following chapter, "Introduction".

ΕΥΡΩΠΑΪΚΟ ΣΥΝΕΔΡΙΟ ΚΑΤΑ ΤΩΝ ΔΙΑΚΡΙΣΕΩΝ ΚΑΙ ΤΟΥ ΣΤΙΓΜΑΤΙΣΜΟΥ
ΓΙΑ ΜΙΑ ΨΥΧΙΑΤΡΙΚΗ ΜΕΤΑΡΡΥΘΜΙΣΗ ΠΡΟΣΑΝΑΤΟΛΙΣΜΕΝΗ ΣΤΟΝ ΧΡΗΣΤΗ
ΚΑΙ ΓΙΑ ΤΟ ΔΙΚΑΙΩΜΑ ΓΙΑ ΕΝΑΛΛΑΚΤΙΚΕΣ ΛΥΣΕΙΣ

EUROPEAN CONGRESS AGAINST DISCRIMINATION AND STIGMA
FOR USER-ORIENTED REFORMS IN PSYCHIATRY AND THE RIGHT TO ALTERNATIVES

ΣΥΝΑΥΛΙΑ/CONCERT
ΠΛΑΤΕΙΑ ΑΡΙΣΤΟΤΕΛΟΥΣ
ΠΕΜΠΤΗ 30 ΣΕΠΤΕΜΒΡΙΟΥ 2010
ώρα 20.00

ΣΥΜΜΕΤΕΧΟΥΝ

ΘΑΝΑΣΗΣ ΚΑΙ
ΚΩΝΣΤΑΝΤΙΝΟΣ ΓΚΑΪΦΥΛΙΑΣ

ΓΙΩΡΓΟΣ ΚΑΖΑΝΤΖΗΣ

Βαλάντης Καπουρελάκος & Δημήτρης Κεχαγιάς

Science Fiction Rock by Manos & Friends

INTRODUCTION and PROGRAMME

Between September 28 and September 30, 2010, members of the European Network of (ex-)Users and Survivors of Psychiatry (ENUSP) finally had the chance to meet for our Sixth Congress in Thessaloniki, Greece.

It was our first Congress in more than six years.

ENUSP is the <u>only</u> independent organisation run by and for users and survivors of psychiatry at a European level.

INTRODUCTION

This Report tells the story of a crucial and long-awaited meeting: the Sixth ENUSP Congress, which brought together representatives of national, regional and local user/survivor organisations as well as individuals from twenty-three countries across the continent.

It was an event held in solidarity and partnership with the Greek part of our movement – through the Pan-Hellenic Committee of (ex-) Users and Survivors of Psychiatry[1]. It found its place in the Old Philosophy Building and surrounds of Aristotle University, Thessaloniki, with organising and (Greek-English) translation support from the university's School of Psychology.

This Thessaloniki space gave us a sign of what could be said and done if there was a strong umbrella network to connect and unify the national and other organisations of service users and survivors of psychiatry across Europe. As the pages of this Report bear out, this was a space for the direct reporting of our situations and concerns as people who have been on the receiving end of our countries' psychiatric systems, and for the mapping out of common demands. It was a forum for networking among user and survivor colleagues across borders, and for the pooling of rare resources about our rights and alternatives. It was a space where our differences were made visible, and yet, one where, in the final day, we would come to decide on a strategy for a stronger European[2] voice.

It was also unfortunately a space that was short-lived, and one whose creation had been at every point uncertain.

As people involved in developing the Sixth Congress, we are aware that its organisation had been a struggle for the ENUSP Board; ENUSP's Statutes had required the Board to convene this meeting by 2007 at the very latest[3]. The reasons for the delay were signs of a deeper problem: the extreme lack of resources that continues to block the efforts of the European Network. It is not an exaggeration to say that the future of ENUSP is still in doubt.

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1 http://survivorspsygreece.wordpress.com

[2] Here "European" is meant in its geographical, not merely political or administrative sense

[3] ENUSP Statutes, Article 13

This Introduction describes some of the major obstacles to the Thessaloniki Congress before outlining the steps and considerations that contributed to its achievement . It is written from the vantage point of the two authors, who were closely involved in the planning and proceedings as well as in the reporting of the Congress. An 'inside story' of the Thessaloniki event, it is also an attempt to highlight some of the fundamental goals and current predicaments of the European Network.

But before we can go much further, we need to consider just what was at stake in this meeting of users and survivors of psychiatry from across Europe called "Determining Our Own Future".

1. IMPORTANCE OF THE SIXTH ENUSP CONGRESS

Founded in 1991, the European Network is an umbrella organisation made up of national, regional and local user/survivor groups in thirty-nine countries across the continent[4]. Its members are also individual users and survivors of psychiatry who do not belong to a user/survivor organisation in their own country.

The need for an active, independent union of people who have been on the receiving end of psychiatric systems across Europe comes in response to our profound lack of power in our own countries. It comes at a time when people with psychiatric labels are routinely subjected to psychiatric force, institutionalisation, and guardianship under national and European laws, and we are not meaningfully involved in official policy and knowledge-making about us.

ENUSP seeks to advance the rights and interests and, in particular, to support the self-determination of users and survivors through two kinds of work:

- Maintaining a Europe-wide <u>support and resource network</u> , and

  Ensuring <u>direct representation</u> of our common demands, interests and concerns in forums that decide for and about us.

This mission rests on a special face-to-face meeting for ENUSP members from all of Europe (called a "Congress" in this Report), which must happen every two or three years[5]. The Congress has two parts:

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[4] http://www.enusp.org/index.htm

[5] ENUSP Statutes, Article 13

- A European conference for users and survivors of psychiatry (called the ”Empowerment Seminar” in this Report) and
- A General Assembly to elect ENUSP’s Chair and Board members from all six regions of Europe[6], whose task is to run the Network between General Assemblies. This General Assembly also determines ENUSP’s work programme for the future.

By running a European conference, ENUSP can provide users and survivors across the continent with a way:

- To connect and exchange information, experiences, opinions, support and solidarity
- To gain access to tools and strategies for self-advocacy, and user/survivor-controlled alternatives to conventional psychiatry
- To find support for the development of independent organisations of (ex-)users and survivors of psychiatry in all countries in Europe

By regularly holding a General Assembly, ENUSP ensures that it remains a democratic and fully user/survivor-controlled organisation. This means that it represents users and survivors at the grass roots. ENUSP General Assemblies have historically been instrumental in the democratic working out of positions, declarations and action plans for the future of the Network.

The delay in holding the Sixth Congress was a particular problem since the representative function of the Board was no longer working. The term of all the current representatives had already ended. Board members from some regions were no longer active, and one region (the South-East) had no representative at all[7]. Nevertheless, the meeting could not be held because the ENUSP Board found itself in a crisis.

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[6] For a description of ENUSP’s six regions, please go to Annex 1 at the end of this Report.

[7] No representatives from this region could be found at the Fifth Congress.

2. OBSTACLES TO THE SIXTH CONGRESS: A CRISIS IN THE EUROPEAN NETWORK

To explain what prevented the Sixth Congress – and why many people feared it would not happen – we need to describe the reality of the European Network for the last six years.

There are no resources to run the only independent NGO connecting users and survivors of psychiatry across Europe. Since 2005, the European Network has operated without any government funding. Its sole income is membership fees, which were introduced by a decision of the last General Assembly in Vejle, Denmark in 2004. These fees barely cover low-level administration costs.

This situation has devastated the European Network on every level. Most crucially, it has meant:

- <u>The shutting down of options for effective advocacy</u>: ENUSP cannot, for instance, be part of major policy-making events on our issues unless all participation costs of our user/survivor representative are paid for by others
- <u>The wiping out of organising capacity</u>: ENUSP can no longer keep up a central office, the European Desk, once described as "a centre of communication and information"[8] for European users and survivors. The Network has also lost its central co-ordinator (the Secretary) whose job was vital day-to-day management: maintaining close connections with members and databases; arranging seminars and Congresses; planning funding applications, etc. Despite the efforts of some Board members and other survivor volunteers to help out, most of this work has inevitably been put aside.

These were the conditions confronting the ENUSP Board in mid-2009 when it approached the crucial task of holding the Sixth Congress. This task was a very large one. It required organising and financing a meeting for ENUSP members, users and survivors of psychiatry from all of Europe.

To make the Sixth Congress happen, it was essential to draw on all available support from within the Board – from those Board members who were still active, and from a few other survivor volunteers (called Support Board Members). The Board also needed to make urgent appeals to other organisations

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[8] http://www.enusp.org/index.htm

for one-time funding.

But first there was the offer of a place for the Sixth Congress.

3. A PLACE FOR THE CONGRESS IN GREECE

3.1 Aristotle University. Thessaloniki (Organising Partner)

It was Kostas Bairaktaris, a clinical psychology professor at Aristotle University in Thessaloniki, Greece, who made the proposal to hold the Sixth Congress on the university campus. He put the idea to North-East Board member Peter Lehmann. The offer, he explained, was strictly "limited to organisational-technical support"[9]. This would mean that user/survivor co-organisers should be in control of the content of the Congress. In a speech at the Thessaloniki event, he would later explain the philosophy behind his idea;

> Our suggestion to organise and host the European conference of people with psychiatric experience . . . came as part of our incessant effort to bring forward the Voice of the Excluded and to restore their political and social rights which have been stripped away from them[10].

The psychology department has a policy of support for the emerging and independent Greek user/survivor movement, including in fostering its connection with ENUSP. This work with Greek users and survivors is closely linked with the university's own research and training programme for health workers and other professionals[11].

More than a year before the Congress, the ENUSP Board members had the chance to meet with a representative from the university Psychology Department and Iannis Karterakis from the Greek user/survivor network Pan-Hellenic Committee of (ex-)Users and Survivors of Psychiatry.[12] This

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[9] Bairaktaris, K. (2010). Proceedings of the European Congress against Discrimination and Stigma, and for User-oriented Reforms and the Right to Alternatives, September 28 - October 1,p15. Thessaloniki: Aristotle University

[10] ibid Bairaktaris, K. (2010)

[11] http://selfhelp.web.auth.gr/homeeng.htm The University told us that its work with the local user/survivor movement includes translation, IT assistance, and organising support.

[12] This meeting was sponsored by the University of Central Lancashire in Preston (UK) in return for work that ENUSP contributed to another conference co-hosted with that university http://www.uclan.ac.uk/iscri/conference_programme.php

meeting fixed many parameters for the eventual Congress. The university explained that as well as organising and technical support, its offer included a conference venue; (Greek-English) translation by its students and cultural events such as a concert at the close of the Congress.

This meeting also produced a programme that tried to juggle the various needs of the different project partners. The Pan-Hellenic Committee asked for space for work on the situation of users and survivors of psychiatry in Greece; Aristotle University urged the need for mixed spaces open to the public to promote discussion of issues among "professional people". ENUSP needed to fulfil some requirements under its Statutes. In the end, the overall shape of the programme would comprise:

- Two keynote presentations open to the public (one to be organised and controlled by ENUSP, and the other by the Pan-Hellenic Committee);
- closed working group sessions for user/survivor participants only;
- A time block for the ENUSP General Assembly.

Later on, ENUSP would learn that Aristotle University had been granted additional funding from the Greek Health Ministry , enabling it to cover the travel and accommodation costs of three "Balkan participants", meaning users/survivors from Romania, Bulgaria, Albania, Kosovo, Serbia, Turkey, Kosovo, Montenegro, Croatia, Bosnia-Herzegovina, Slovenia, or FYROM (Former Yugoslavian Republic Of Macedonia) [13]. The university said that it would fund and co-ordinate the participation of these people as well as user/survivor delegates from across Greece.

3.2 The Pan-Hellenic Committee of (ex-)Users and Survivors of Psychiatry (Programme partner)

The Pan-Hellenic Committee of (ex-)Users and Survivors of Psychiatry was ENUSP's partner in the Sixth Congress responsible for independently developing parts of the programme. Its keynote session would be a space to bring the distinct issues and positions of the Greek movement to the attention of other European users and survivors.

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[13] In a slightly comic development that would prove typical of the imperfect communication style between ENUSP and the university, Professor Bairaktaris gave the Congress a title for the purpose of this funding application that was based on a working name subsequently rejected by ENUSP. As a result, the Congress had two different names.

The Pan-Hellenic Committee is a national organisation of users/survivors of psychiatry and a member of ENUSP. It had thirty members in April 2009. ENUSP's links with the Committee, and indeed with users and survivors of psychiatry generally in Greece and the rest of the South-East region, had been weak, a situation worsened by the lack of direct representatives for the region on the ENUSP Board. The Congress, thus, coincided with the introduction to ENUSP of many Greek users and survivors, a fact that would become clearer during the event itself.

Communication between ENUSP and the Committee was direct only at the beginning. In late September 2009, a spokesman for the Committee wrote to ENUSP to confirm that the Committee wanted to go ahead with the Thessaloniki meeting to be co-hosted with ENUSP and Aristotle University.

The Committee also put forward its position that Congress funding should not come from disability organisations. This statement provoked some discussion, making it clear that there were diverging positions among our two groups (and inside ENUSP) on the topic of disability. We agreed not to press this very complicated issue while arranging the Congress. However, it would be a dominant and controversial topic in the proceedings.

Soon after, the correspondence between ENUSP and the Pan-Hellenic Committee stopped. The two user/survivor groups co-ordinated through Aristotle University; there were language and perhaps other barriers. For its part, ENUSP's focus had shifted very quickly to the overwhelming financing and organising concerns around the Congress.

4. FUNDING PARTICIPATION: A WAY FORWARD FOR ALL EUROPEAN DELEGATES?

How would ENUSP find money for its members' participation? It was clear that only a tiny fraction of European service users and survivors of psychiatry could afford to come to Thessaloniki on their own. There was a real concern to ensure the event's accessibility to all ENUSP members and not just to the better-resourced ones. This was essential both so all could benefit from the event and so our elections could be democratic and our debates and decisions representative. The Board was aware of the very real restrictions on our members in many countries where user/survivor organisations are scattered networks of individuals who lack the means to maintain a central office or even ensure regular email access.

Most pressingly, ENUSP wanted to find ways to address the fact that our network comprises and belongs to users/survivors from far more of Europe than the European Union. The Board was aware that under European Commission (EC) regulations, EC funds would not extend to participants from non EU member states. This exclusion of our non EU members was particularly troubling because we knew that many of these groups were the ones whose issues and positions were most often under-reported in the European Network. The Congress, we were aware, was a real opportunity to connect with and support users and survivors from these regions , including in their work on building up independent organisations. Because of the short time period available, the search for funding proceeded through a series of urgent requests by individual Board members to potential sponsors:

- ENUSP approached Mental Health Europe (MHE), a European Commission-funded NGO working on mental health promotion, policy-making and reform. ENUSP had co-operated with MHE on a previous “Empowerment Seminar” project on capacity-building in March, 2009[14]. In late October 2009, the ENUSP Board received news that MHE had included a second “Empowerment Seminar” project in its budget application to the European Commission based on the good model of this earlier project. Confirmation came in late January, 2010 that MHE had granted places for the travel and subsistence costs of twenty-five people with some remaining funds for accommodation. These places were available to participants based in EU states only. Under a further EC-imposed restriction, delegates could not use the money to cover travelling in their own country even if, for example, getting to the airport or railway station from their home was costly to them.

- ENUSP was granted support from the Open Society Foundations (OSF) a private operating and grantmaking foundation, aimed to shape public policy to promote democratic governance, human rights, and economic, legal, and social reform. This grant covered two delegates from non-EU countries in Eastern Europe.

- In the brief time available, ENUSP made a request to the Laces Trust, an independent charitable fund in the UK that supports access to education. The application was supported by an academic who had co-operated with ENUSP members in a joint conference earlier in the

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[14] For further details of this seminar, please see the comprehensive report produced by Jasna Russo http://www.enusp.org/congresses/empow-seminar2009.pdf

year[15]. In late July 2010, the trust granted money to cover the places of four user/survivor applicants to ENUSP's General Assembly.

5. INTENSIVE PLANNING: ENUSP'S ORGANISING EFFORTS

5.1. ENUSP Congress Co-ordinator and Organising Group

Organising the Congress would take intensive intervention with Aristotle University, sponsors, ENUSP's members and other applicants, and later individual user/survivor delegates from across Europe. To manage the vast task, the Board appointed Gabriela Tănăsan from Romania, who had become an adopted deputy Board member for the Central Region in mid-2009. Working from her home, she corresponded on every technical issue around the Congress, maintained databases and handled budgets.

She was supported by a small unofficial ENUSP organising group made up of Board participants. The group communicated round-the-clock by email. One of its first tasks was developing ENUSP's side of a thematic programme . This was an opportunity for the organising group to outline some of the main concepts and ambitions for the programme. But first there needed to be a title.

5.2 Developing the Programme

a) A Title for the Congress: Determining Our Own Future

> Now more than ever, it is about fighting for our rights, for 'the way ahead' and all the other metaphors we can think of, so that they stop being metaphors and become realities.
> For me, in 'fight' there is also the notion of hope. They feed into each other.
> (Thessaloniki planning group participant)

Several ideas had come forward as the name for the Congress, including Professor Baraiktaris's own suggestion "Born to be Wild". Turning over some of the issues facing users and survivors of psychiatry

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[15] . http://www.uclan.ac.uk/iscri/conference_programme.php

in Europe and our own hopes for the event, the group settled on one key phrase: *determining our own future*. It was a theme that, as one person explained, was grounded in the current reality of personal and political disempowerment at a time when people with psychiatric labels are commonly deprived of the most basic decision-making rights over our own lives, and we are not real partners in the places where policies and knowledge are made about us. At the same time, it was a phrase that might convey hope and the forging of a path of collective resistance at the Congress, 'the way forward for all European users and survivors'.

> Determining our own future. It has a double sense: first of all, of coming together to decide the future of ENUSP. This is truly a critical issue at a time when ENUSP, the NGO uniting users and survivors across Europe, has no public funding or resources. And secondly, it names self-determination for every individual as the ultimate aim of our movement.
> (Thessaloniki planning group participant)

Finally, the theme of 'determining our own future' would bring together some of the main goals of the organising group for the Thessaloniki programme: work on the UN Convention on the Rights of Persons with Disabilities, a special working group called Rebuilding ENUSP , and preparation for ENUSP's General Assembly.

b) Working with the UN Convention on the Rights of Persons with Disabilities

> The reason I said 'A Fight for our future' is that I have the impression that if the delegates do not come together and begin to work to look for funding . . . there will be no ENUSP. Similarly, the new UN convention on our human rights will not change things by itself- we have to fight to make this happen. The conference could be a chance to learn how to wage this fight.
> (Thessaloniki planning group participant)

In the years since the Vejle Congress, one of the key changes had been the adoption by the UN of the Convention on the Rights of Disabilities, which representatives of the global user and survivor movement had contributed to significantly. ENUSP's organising group embraced the Thessaloniki meeting as a chance to build the knowledge base about this human rights treaty for users and survivors from across Europe. We wanted to address the fact that users and survivors are still overwhelmingly deprived of access to information about our civil and human rights and legal options. We especially hoped to draw attention to the Convention's potential to advance the causes and principles closest to many in our movement; abolition of all laws allowing psychiatric force, guardianship and institutionalisation; and our right to independent living in the community and genuine informed consent on an equal level with others:

> Article 12 is the most innovative and far-reaching provision in the Convention, and has a major significance for users and survivors of psychiatry. Instead of being treated as non-persons to be acted on by others, assistance will be offered in times of crisis, confusion or distress, which we have the right to accept or refuse[16].

We knew from early on that ENUSP's keynote session would take the Convention as its theme. Still there was concern about who could speak on the treaty's relevance for users and survivors of psychiatry in Europe; this person would need to respond to people's practical questions and concerns about the Convention's real meaning and implementation in their country. A few group members approached European survivor activists to give this address, but no one was ready to take on the role, and nor could we cover the costs of survivors from further afield.

Finally, we turned to Stefan Trömel, the Director of International Disability Alliance (IDA), a global network of organisations of persons with disabilities set up to promote the Convention's implementation. He was asked to speak about "Chances and Challenges of Users and Survivors of Psychiatry in European countries". He agreed and was able to cover his own costs, a factor which influenced our group's decision. Some argued that the World Network of Users and Survivors of Psychiatry was itself an influential participant in IDA, and that cross-disability coalitions had been instrumental in the passage of the Convention into international law.

Nevertheless, this was a controversial choice, which did not sit well with everyone; some criticism found its way onto an international user/survivor email list. It was problematic, critics said, that Trömel did not himself identify as a user or survivor of psychiatry; how then, they asked, could he appreciate the significance or problems of the Convention on our behalf?

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[16] Implementation Manual on the Convention on the Rights of Persons with Disabilities. World Network of Users and Survivors of Psychiatry, p16 http://www.wnusp.net/

A second difficulty was that despite the acceptance of social models of disability among some users and survivors of psychiatry, especially in the academic world, many in our movement remained strongly opposed to the approach. This was sometimes due to poor treatment that they had experienced from national disability organisations. We remembered the statement of the Pan-Hellenic Committee:

> We would like to cooperate with any movement of people with disabilities so that our voice shall be heard louder, but we want to be sure that our rights will be supported and not forgotten and mistreated. Because this is exactly what is happening in Greece concerning the rights of the Greek disabled.
> (Statement of the Pan-Hellenic Committee of (ex-)Users and Survivors of Psychiatry, October 2009)

Different opinions are not always caused by a lack of information, as one Board participant reminded us. As a compromise, the group decided that ENUSP Board member Erik Olsen should respond to Trömel's address from a survivor activist perspective.

In the event, the issue of the UN Convention was also addressed during the Opening Ceremony from a more user/survivor perspective thanks to Iris Hölling, a recent past Co-chair of WNUSP.

6. FOSTERING SURVIVOR-CONTROLLED SPACES: ELEVEN WORKING GROUPS

> Psychiatrists, academics and pharmaceutical companies all take for granted the holding of their own regular forums where they can pool experiences and make international connections. But such spaces are very rare …[for] 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.
> (ENUSP Advocacy Update, January 2010)

Both ENUSP and our Greek project partners had put a call out for proposals for user/survivor-only working groups at the Congress. These two-hour long groups were meant to preserve some spaces at the event where user/survivor colleagues could work together comfortably and productively in private. "[N]o one questions professionals wishing to enjoy such spaces, but users and survivors encounter immense difficulties when they make similar requests," one group member put it. She stressed that the facilitators should retain control of their working group “from the very first stages, from the shaping of the concept right through to the organisation and facilitation of the event.” Eleven detailed working group proposals were received by ENUSP, covering rich and diverse topics such as “Researching suicide as an outcome of psychiatric treatment”(Germany/UK) to “Human rights and psychiatry” (from Greece) and “Organising European Mad Pride Events” (Belgium/UK). All were approved by ENUSP’s Board and translated into Greek or English for distribution to participants well in advance of the event.

6.1 Re-building ENUSP: A Strategic Planning Group:

One special working group came from some ENUSP Board participants. It was called “Rebuilding ENUSP”. Returning to our theme of “determining our own future”, this group had hopes of bringing together a small group of users/survivors to think through some of the major organisational and funding problems facing ENUSP. We knew that this was a rare chance to draw on a wealth of organising experience and activist expertise as well as knowledge of resilience in our community. The focus was to be positive, while extremely pragmatic and based on a strong belief, in the need for immediate steps to protect the future of the organisation. From this short four-hour session, we wanted to take away a working document that could be reviewed democratically through the regional meetings at the Congress and then debated as a potential action plan at the General Assembly.

6.2 The General Assembly

The planning group wanted to raise awareness about ENUSP’s General Assembly among delegates to the Congress .The agenda for this Assembly would include the election of a new Chair and Board, and discussion and decision-making about ENUSP’s immediate work programme. We wanted to highlight the roles and practical responsibilities of the Chair and Board, particularly for those intending to stand for these positions. We were also concerned that the voting process and other parts of the event were transparent, especially for those who had not attended an ENUSP General Assembly previously. Some of the efforts we made to achieve greater transparency about the General Assembly are described in the General Assembly part of this Report.

☞ A copy of the Invitation and the Agenda can be found in the Annexes section at the end of this Report.

7. THE ONES WHO MADE IT TO THESSALONIKI: ENUSP USER/SURVIVOR PARTICIPANTS

Who would ultimately take part in our Thessaloniki meeting? The Congress invitation letter welcomed "users and survivors of psychiatry and our allies from across all of Europe especially representatives of ENUSP member organisations and our individual members."

The reality was, however, that because of ENUSP's lack of independent resources, it was troublingly limited in its capacity to support its members' participation. The limitations showed up critically in our inability to fund those who did not meet EC funding rules or match other requirements of our sponsors.

Reaching some members alone with the invitation had been difficult because of administrative problems on either side[17]. Nevertheless, user/survivor organisations were tracked down and applications had come in for funded places by mid-June, 2010. The ENUSP Board had to decide on how to use the funding options to ensure the representation of (a) users and survivors of psychiatry from as many countries in Europe as possible, and (b) users and survivors who had worked on ENUSP projects and needed to report at the General Assembly.

It was essential to think shrewdly, and the ENUSP Board decided to use the 'Balkan' places from Aristotle University to support three delegates who did not qualify for European Commission funding (Bosnia and Herzegovina, Serbia, and FYROM): The OSF funding would cover one delegate from Georgia and one from Russia. Finally funding from Mental Health Europe would support twenty-five delegates from twelve EU countries, including ENUSP Board members.

Ultimately, forty-seven ENUSP user/survivor delegates would come to Thessaloniki from: the UK, Ireland, the Netherlands, Poland, Germany, Czech Republic , Hungary, Romania Georgia , Russia , Denmark, Bosnia and Herzegovina , Greece, Israel , Italy Norway, Estonia Latvia, Sweden, Belgium, Spain, France and Portugal.

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[17] ENUSP needs permanent administrative support to keep databases up to date among other crucial tasks

Forty-three of us were representatives of national, regional, or local user/survivor organisations or ENUSP; the others did not belong to an organisation. We were twenty-four men and twenty-three women.

There were difficulties in our support of these delegates in the lead-up to Thessaloniki. ENUSP needed to rely on Aristotle University to take care of all the practical details of the Congress, including the participation of the three Balkan delegates. Communication with our Greek partners was sporadic, and done mostly by email after our initial and only face-to-face meeting. Not being in a position to control the organisation of our own event meant that we could not ensure that specific issues, particularly the financial situation of many user/survivor delegates, were taken into consideration.

There were also real limits in the ways that ENUSP could support delegates during the Congress itself. The event's official languages were English and Greek; regrettably we were not able to offer translation in other languages.

Besides the ENUSP participants, there were forty-five Greek user/survivor participants at the event according to the University. In addition, there were 189 non-user/survivor participants who were academics, psychologists, social workers, doctors, nurses, teachers, undergraduate and postgraduate students of psychology, and undergraduate students of biology, theology, and law.

Roselyne Bourgon, then Mental Health Europe's Human Rights Officer, was a participant at the Congress.

CONGRESS PROGRAMME

	Morning		**Afternoon**		**Evening**
Tuesday September 28	**Participants' arrival**		**16:00-**		**19:00 Dinner**
			17:00-18:00	Registration and informal networking	
			18:00-19:00	**Official opening** • Welcome speeches • Official speeches • Presentation of the programme	
Wednesday September 29	**EMPOWERMENT SEMINAR**				
	8:00-8:45	**Breakfast**	**13:00-14:00**	**Lunch**	**19:00 Dinner**
			14:00-14:30	**Presentation of the working groups**	
	9:00-09:45	**Brief greetings** Professor Iannis Myopoulos, Rector of Aristotle University; ENUSP; Pan-Hellenic Committee of (ex) Users and Survivors of Psychiatry	**14:30-16:30**	**Working groups:** Parallel sessions *	
				Re-building ENUSP (part I) *Jasna Russo, Debra Shulkes,*	
				Researching suicide as an outcome of psychiatric treatment / Ερευνώντας την αυτοκτονία ως αποτέλεσμα της ψυχιατρικής θεραπείας *Peter Lehmann, Jan Wallcraft*	
				Human Rights and Psychiatry / Δικαιώματα και Ψυχιατρική *Ntia Koutsogianni*	
				Psychiatric Drugs and Repression / Ψυχοφάρμακα και Καταστολή *Panagiotis Kaselakis*	
				Self-help at the Balkan Communities / Η αυτοβοήθεια στις βαλκανικές κοινότητες *Akis Asprogerakas*	
				Voices and Hallucinations / Φωνές και Παραισθήσεις *Vaso Kalogianni*	

	9:45-11:15	Keynote lecture 1 **The UN Convention on the Rights of People with Disabilities – Chances and challenges for users and survivors of psychiatry in European countries** **Stefan Tromel**, Director of the International Disability Alliance Panel for questions and answers	**16:30-17:00**	**Break**	
			17:00-19:00	**Working groups:** Parallel sessions *	
				Re-building ENUSP (part II) *Jasna Russo, Debra Shulkes,*	
				Peer support specialism / Training programs for (ex-) users and survivors of psychiatry to become user/survivor workers Ειδίκευση στην Υποστήριξη Ομοτίμων στην Ολλανδία / Εκπαιδευτικά Προγράμματα για (πρώην)χρήστες και επιζώντες της ψυχιατρικής προκειμένου να γίνουν εργαζόμενοι χρήστες/επιζώντες *Simona Karbouniaris, Berthold Kösel*	
	11:15-11:30	*Break*		Organising European Mad Pride 2011 Events *Rafaël Daem, Anne-Laure*	
	11:30-13:00	Keynote lecture 2 It concerns all of us Giorgos Giannoulopoulos, **Panhellenic Committee of (ex-) Users and Survivors of Psychiatry** Panel for questions and answers		Mental Health Problems and How We Get Over Them / Προβλήματα ψυχικής υγείας και	
				Occupational Therapy Abolishes Art / Η εργασιοθεραπεία καταργεί την τέχνη	
				About Philosophy of Psychiatry / Για τη Φιλοσοφία της Ψυχιατρικής	
Thursday September 30	**EMPOWERMENT SEMINAR**				
	8:00-9:00	Breakfast	**13:30-14:30**	**Lunch**	**18:00** Closing ceremony **19.00** Dinner **CONCERT**
	9:00-11:00	Open public meeting and feedback from the working groups			
	11:00-11:15	Break			
	GENERAL ASSEMBLY				
	11:15-11:30	*Introduction of the regional meetings*	**14:45-17:45**	General Assembly of ENUSP *	
	11:30-13:30	**Regional meetings:** Parallel sessions *			

DAY ONE

OPENING CEREMONY

DAY ONE - Tuesday, September 28th

OPENING CEREMONY

Outside the sun was shining and the temperature wonderfully warm for those who came from colder climates... The “Alexandros Papanastasiou” Ceremony Hall in the Old Building of Artistotle University was nevertheless beckoning the participants to ENUSP’s Sixth Congress.

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Opening ceremonies are always important events as they often set the tone of what is to come. The opening ceremony for ENUSP’s Empowerment Seminar (and General Assembly) did just that. It was an opportunity for several well known figures to welcome the large number of participants but also to thank our host, the Aristotle University, for providing ENUSP with such a beautiful and historical venue in the heart of Thessaloniki.

Amongst the people opening proceedings were Panagliotis Kaselakis of the Pan-Hellenic Committee of (ex)Users and Survivors of Psychiatry and, above, Mary Nettle, the outgoing Chair of ENUSP and Iris Hölling from the World Network of (ex)Users and Survivors of Psychiatry (WNUSP).

Mary Nettle then formerly opened proceedings,

Mary Nettle

Thank you very much. I am Mary Nettle. I am the Chair person of the European Network of (ex)Users and Survivors of Psychiatry and I am very pleased to be here, collaborating with the Aristotle University in Thessaloniki and Mental Health Europe and the European Commission and any other sponsors whose names are on your programme. We have all worked together very hard in very difficult times. This recession that is in Greece is also in virtually every other European country, particularly in the country I am from, which is the UK, from England. We are having very great difficulties as well. So I fully appreciate the struggles that you have had as a university to support this event and the fact that we are here I feel is a little miracle. So thank you very much for having us. There are a few things I wish to say. There was a very well known user survivor activist and her name was Judi Chamberlain who died in January of this year. She was very important to us in the user-survivor movement. I wanted to share a few words with you from the Internet about her. The reason why I gathered this from the Internet, even though I did know Judi personally, is because you can then look it up yourself and hopefully translate it into Greek if you like.

The first one is a very short statement which I think is very important. It says:

> Advocate for people with mental illness dies" and it's from the American -she was American, from Boston- it's from the American National Public Radio "Judi Chamberlain, who died this weekend, aged 65, was a civil rights hero from the civil rights movement, you may never had heard of. She took her inspiration from the heroes of other civil rights movements to start something she liked to call Mad Pride. A movement for the rights and dignities of people with mental health illness.

There is a workshop about Mad Pride tomorrow. And then a friend of mine called Louise Pembroke wrote quite a long piece. I'll show you a little bit from Psychminded.co.uk. and she says:

> Judi Chamberlain wrote *On Our Own Terms* [Mary: "and I know it is on the reading list for the Psychology students among you, it's a fantastic book, I really rate it"]. It was help up as a rallying cry for the mental health service user movement when it was published in 1977, a long time ago . . . I first met Judi Chamberlain in 1988. Judi was inspirational to me as there were few women leaders in the British survivor movement at that time and here was world leader who was talking about user run rather than user-led services which for some of us was a dream we thought was not

possible and Judi made it real in her country, the USA. What was so striking to me about Judi, was her total lack of ego and stardom. Frankly, even if she had been I would certainly have forgiven it because she has the intellect hard work and unconditional compassion to back everything she did and at a time when there was not the financial rewards there can be now, Judi was not interested in kudos and personal status. All she was interested in was furthering the greater good of survivors, for us all to be met with love, compassion and with patient control of alternatives to psychiatry. Face to face, one to one, she was no different, she was interested to share experiences with us, would give us her full attention, was kind and generous. She always made you feel that whatever you had to say mattered. Judi was dignified. I never saw her raise her voice or rant at anyone. Yet she could calmly and effectively argue the most seasoned opponent under the table. She was also a fine academic but a good one in that she could a well read argument make accessible to anyone.

Judi chamberlin, 1944 -2010

"I used to imagine a future in which an army of former patients marched on the hospital, emptied it of patients and staff, and then burned all the buildings to the ground. In my fantasy, we joined hands and danced around this bonfire of oppression."

Confessions of a Non-Compliant Patient, Judi Chamberlin

To understand what Judi gave us overall, over 30 years of her life, you can listen to her speak at the 2007 World Psychiatric Association conference on coercive treatment in psychiatry. That was a collaboration with the European Network (ENUSP). Even if you never knew her or her work, listen to this 30 minutes talk, which is a bright shiny beacon to survivors across the world. Her last sentence, "Nothing about us without us" will live in my heart forever. Now you can see why when people think those sorts of things, which I fully endorse - I could not have written that better myself-, it's very important that people might like to make tributes to this leader of, if you like, the self-help movement.

To this end we have a book which one of our member has bought and her partner has put some information in the front about Judi in a very pretty way. I would recommend that anybody who wants to say something about Judi, could say something on one page, then someone else could say something on another page. It's a bit hard to fill the book but we could try because she was a very good person and it would be nice, even if you've never met her, you might think you know her in the light if what I've just said. So that's about Judi.

At this point Mary checked with attendees that making an audio-visual recording of the conference for the purpose of writing a report was ok with everybody. She also reminded attendees that there was a consent form in people's pack about photographs being taken during the conference, also for the purpose of the report. She said that people taking pictures would wear a badge and pointed to Anne-Laure who showed her badge to the audience. She recognised that people with mental health issues did not always want to have their picture taken without their consent and wanted to ensure that this would be respected.

WELCOME SPEECH BY IRIS HÖLLING, REPRESENTATIVE OF THE WORLD NETWORK OF USERS AND SURVIVORS OF PSYCHIATRY

Mary Nettle now invited Iris Hölling, a recent past Co-chair of the World Network of Users of Psychiatry (WNUSP) to address the conference. ENUSP had asked Iris especially to reflect on some of the challenges facing the global movement of users and survivors of psychiatry in effectively advocating for our human rights. She was also able to report on the WNUSP General Assembly in Kampala, Uganda in 2009 where delegates had worked extensively on strategies around the UN Convention on the Rights of Persons with Disabilities (CRPD).

This was an important intervention in the eyes of many on the conference planning committee since Stefan Trömel of International Disability Alliance, the keynote speaker on the Convention, did not identify personally as a user/survivor of psychiatry. Given the pioneering work on this UN human rights treaty by many in the user/survivor community, this situation had been identified as a potential weakness in the programme. On the other hand, the discussions would highlight the importance of strategic alliance-building with human rights activists from outside our movement.

Iris began her speech by acknowledging the very valuable contributions of Judi Chamberlin as a past Chair of the World Network. She continued:

Dear all, ladies and gentlemen, fellow users and survivors of psychiatry in ENUSP,

I am very honoured to be given the opportunity to speak at this opening ceremony on behalf of the WNUSP board.

I have been involved with WNUSP since 1997 and have been one of the co-chairs from 2001 when WNUSP was formally founded until our last general assembly last year in March in 2009. Since none of the current European board members of WNUSP (i.e. Gabor Gombos who is one of the co-chairs, Jolyn Santegoeds, and John Mc Carthy and Peter Munn who are deputies) can be here, I was very happy to be given the opportunity to speak to you on behalf of WNUSP today.

WNUSP congratulates you for having achieved to organize this conference here in Thessaloniki and wishes you success in advancing our common cause of “determining our own future”.

The last ENUSP conference was held in Vejle, Denmark in 2004 jointly with WNUSP. We set out to cooperate in fighting for making our human rights a reality and networking among users and survivors in Europe and the world with common goals. As a result of that conference a second continental network, the PANUSP was founded also inspired by the existence of ENUSP.

WNUSP had our last world conference in Kampala, Uganda in March 2009, which was a big success and very moving experience to have our general assembly in Africa for the first time with a majority of delegates from the global south.

In that conference that was entitled Making our rights a reality we focussed on human rights of users and survivors of psychiatry in the age of the CRPD.

We were very happy to see that ENUSP is also referring to the CRPD and its significance for users and survivors of psychiatry. WNUSP, especially the co-chairs Tina Minkowitz and Gabor Gombos, but also many other WNUSP members played a key role in working on the text of the CRPD. Many WNUSP members were in New York at the Ad Hoc committee meetings and managed to have our rights recognised in the CRPD text. This was hard and demanding work, but it was worth it because the CRPD is a milestone.
We hope that we can continue to work together for advancing the implementation of the CRPD. Strategizing for how to do that locally and world-wide was the main focus of our last year's World Conference.

Although a lot of countries have ratified the CRPD and the optional protocol, the reality in all these countries does not at all comply with what the CRPD demands.
We still have psychiatric laws that deny full legal capacity to user and survivors because they allow guardianship, forced commitment and forced treatment. These laws need to be abolished because the CRPD guarantees our right to full legal capacity.
We are the experts of our own lives; nobody has the right to deny our full autonomy and self-determination because we have been psychiatrised.
The CRPD also forbids any kind of forced intervention, forced institutionalisation and forced treatment. As we all know reality is different.

Instead of forced intervention, CRPD guarantees the right to reasonable accommodation and to supported decision making. WNUSP has just issued a position paper on accessibility and what that may mean for users and survivors of psychiatry.
We have a right to self-defined support, a right to peer-support, to survivor-controlled spaces and support structures. We have the right to choose between different options, but these options hardly exist. There are a few places like the Berlin runaway-house and few options like the personal ombud in Sweden, crisis centers that are survivor-led, and projects like the one in Uganda that supports people with micro-credits to allow them to work again and regain their own lives in Uganda. There are a lot of self-help groups and initiatives, but most of them lack

funding or struggle hard to survive. We don't have the option to choose from different forms of support. Peer support is not sufficiently supported.

That means right now, we lack choice because there are no options. These have to be created and they have to be created by us and not for us by others who pretend to know what we may need.

We also have a right to political participation and self-representation. Nothing about us without us – that has been the slogan of our movement for a long time – but we know that participation often is not really wanted and not done on equal terms.

We don't need one alibi survivor on a board or committee whose opinion and input is dismissed; we need critical mass, participation on equal terms, with equal numbers, paid if the others do the jobs in their paid work time.

Policies that concern us should be negotiated with us not with so-called professionals who often pursue their own issues and agenda.

And we need a change of attitude, we are the experts of our lives, we know what we want and need in order to come to terms with madness, altered states, voices, crisis. We are the ones who own these experiences and who also have collective knowledge about how to deal with our own lives.

I am very happy and proud that Gabor Gombos was elected to the CRPD committee and Edah Maina from Kenya, who had already been on the committee, was re-elected. That means that we have two survivors of psychiatry on the committee who support our cause and also the cause other people with other disabilities. This is an example of electing survivors into important positions.

I think we all need to use the opportunities that CRPD offers to promote and advance our rights on a local, regional, national, European and international and world level.

WNUSP would love to continue and further the cooperation with ENUSP in the future because we need to speak for ourselves on all levels.

I wish us all a fruitful conference that helps us to strengthen ENUSP and our movement so that ENUSP can continue to work successfully for users and survivors.

I send you warm greetings and best wishes from the WNUSP board, and since there are a lot of people here who are also involved with WNUSP, I am sure that the results of this conference will be reported back to WNUSP.

Thank you for your attention and the opportunity to speak at this opening ceremony.

SUMMARY OF QUESTIONS AND DISCUSSION

There now followed a series of questions and comments from the floor. To highlight some the emerging concerns at this Determing Our Own Future conference, these interventions and answers from the two main speakers have been edited into themes below.

SURVEYING THE SITUATION ACROSS EUROPE: ARE THINGS GOING BACKWARDS?

- **Question from Greek participant**

I assume that Judi Chamberlin, whom you referred to before, is the one who wrote the book On Our Own, which refers to the 1960s when there was a drive not just to confront psychiatry and ensure people's rights, as networks like ENUSP are now trying to do, but also to abolish psychiatry. It has been 50 years since then. Do you think that we are backing away from what Judi Chamberlin described in her book, which was revolutionary, or have we moved forward? What would you say?

- **Mary Nettle**

When I had my personal experience of emotional distress . . . I was put in an institution far away. These were big buildings far away, in the country. A lot of people say those places were safe a haven and a proper asylum. In my view, they were stigmatising and discriminatory because you were out of sight, out of mind. Now you are living in the community, which is a lot better except that the community does not particularly like having you living there.

Judi Chamberlin's book was about service users running their own services. She spoke about the way user-run services had been co-opted to make them user-led – with professionals being recruited as the workers. Now there are lots of these user-led services. People say they listen to the serrvice users. But the service users don't run the places themselves; they're not trusted to have any money; they are not thought to be capable of running the services themselves.

- **Iris Hölling**

I think we are going backwards in some respects, but on the other hand, we have this UN treaty. It contains very clear statements about our rights [to protection] against forced treatment, for example, including forced treatment in psychiatry, and this is something new. But we lack implementation. We have a long, long way to go to really achieve these rights, and we will have to fight them. I don't know for how long. But we have this instrument, an instrument that has juridical value, which we can rely on and use and bother our governments with. And that is an achievement. We didn't have that years ago.

I agree with Mary right now that the models of participation we have are dangerous ones because they are not participation on equal terms; they are often tokenism. They are often co-option. That is maybe more difficult to attack because they can always say: "But you are involved. You are on the board. We do trialogue where professionals and family members and users survivors are all on equal together." But in my eyes, this approach doesn't really reflect the power structures that are there, the power imbalance. If there's one person that can lock me up in an institution, then I'm not on equal terms with that person. Unless that's changed, there can't be equal terms, and I think we have a long way to go.

– **Participant from Germany**

I wanted to add something to what Mary said about living in the community because it's not only about how the community doesn't like us. There's community forced treatment now, which is clearly a step backwards compared to institutions. You could get out of institutions in the 80s and 90s and so on. But since last year, there's been community treatment orders in UK. It's coming more and more. It's very nice that we have all these nice words -'partnerships', 'empowerment' 'participation', 'recovery'. But people don't need to be in institutions any more to be treated against their will. So coming back to your question, I think it's always going forwards and then backwards. I think it's a complex question, but I could not say that things are getting better.

– **Participant from Greece**

I would like to ask you whether you are aware that the situation here in Greece is literally medieval. Last May, at Dromokaitio Hospital there was a 60% cut in services to patients. With the crisis, there was also a 40% increase in hospital admissions. The level of psychological health services was low, but now it is even lower. At the same time, there is an increase in the kinds of fear that trigger psychiatric and psychological interventions: anxiety, hunger; thoughts about not having food to eat, that there is no money, that there is no way to survive, and so on. In addition, and I really mean this: real tortures happen here. This society is really barbaric. Personally, I would make a comparison between witch-hunts and attacks on mad people. Witch-hunts stopped when people started questioning whether witches really exist. I believe that psychiatric violence and oppression will stop when people start investigating whether psychiatric disorders really exist. Otherwise, psychiatric violence will exist as part of the ruling system. Thank you.

– **Participant from Greece**

I come from Crete. I want to inform you that people from Crete have the second highest rates of psychoses in all of Greece. I have been a psychiatric patient for 33 years. I am 55 years old, and I was hospitalised for many years in Souda . . . Thank you; and I would like to say something more: that I hope we've turned the page, from a dark past toward a brighter future.

– **Participant from Greece**

Society in Greece has a lot to realise, to learn . . . but big pressure has been made..The government has even done some things in the right direction, things to wake up society . . . The recession has affected everybody in Greece, that's true, all over the world. But there's so many things being done with people in Corfu, one small island in the South of Europe. There are many people there who were in psychiatry who are now allowed to live by themselves, use their money, own their lives and live their lives, and we've come to a better time.

– **Participant from Denmark**

What I would say about Judi Chamberlin – I have met her some times. And the ideas she already had in 1970 when she wrote her book *On Our Own*, well, you could ask :"Isn't it still the same?" In many ways, yes, it's exactly the same. What she's really saying is that we can't wait until the system changes so that it picks up our needs. Therefore, the book's name is *On Our Own*. We have to do it on our own. And that is very sad because government has been spending a lot of money on mental health with no results. And users are very poor. There really need to be finances put over for the user point of view, for running some of these things.

ON THE STATE AND FUTURE OF ENUSP

– **Question from Greek participant**

I would like to thank Aristotle University for having the ENUSP congress in Greece. It is a chance for us in Greece to meet ENUSP. I'm a psychiatric user for more than 10 years. And I've never known about ENUSP. I'm president of a small group of users of psychiatry in Corfu. I work in a social co-operative, and it's good to know that there are common experiences, that there are people who have had the same experiences we have had in Greece - all over the world, all over Europe. There's still hope because even in this, things are changing . . . Yet there is so much to be done . . . I would like to know some more about ENUSP, what is your direction? What are ENUSP's aims?

– **Mary Nettle**

We have not been very good about telling people what we do because we have only a small [amount of] money from membership fees. We are a body for the whole of Europe. We did publish something called *Advocacy Update*.

I say we have very little money, but we are invited to EU events quite a lot. I can tell you quite a lot about the Green Paper on mental health which we had quite a lot of input into. We had lots of meetings . . . They came up with a good Green Paper, but the ministers, the health ministers of Europe said they didn't want it. It was interfering in their autonomy. There is a new and different language in the EU, as I'm sure you've discovered . . . There's this word 'subsidiarity', which means that governments feel they can do anything they like about health issues. The only thing that the EU can do anything about is public health issues, and they were trying to say quite rightly that mental health is a public health issue, but the ministers did not like that. So they've came up with something called the Mental Health Pact,which again is a lot softer. There's no mention of forced treatment, compulsion, coercion, the UN Convention that Iris talked about.
But we have achieved things . . . There was a declaration in Dresden that was about forced treatment, coercion. We were involved in the Helsinki Declaration which was around all the health ministers in Europe, not just the ones in the EU. It was a bit more radical, but not much.
But every time we are asked to get involved, we have to say (as does everyone in ENUSP, and I'm sure the World Network) – "Will you pay my travel?" This is how we got here to Thessaloniki, for example, it was quite difficult because we had to ask and find money. They say "Yes, you can have travel expenses, but not within your own country. So I think – well, for example, the trip from Corfu to Thessaloniki is quite expensive. Then they say, "We'll pay you back in three months' time. " But what money do we have to pay out now?

I think ENUSP is a wonderful idea, a wonderful lot of people who get together when they can – mainly by skype, by email, by virtual telephone conferences. But in the EU and WHO Regional Office, we are thought of as moaning, always moaning. And we try to be positive, but how can we be positive when we have no resources to meet together to form our policy, particularly at EU level? To get to the Council of Europe? To all the events in Brussels?

. . . We have done research – in the Value+ partnership with the European Patients' Forum. We did a wonderful project about patient involvement that was funded by the European Union,and that came up with some really good things – about what is really meant by empowerment, participation, consultation.

. . . We have partnerships with the European Disability Forum whose board Erik Olsen is on because it's really important in light of the UN Convention that we all have a debate with ourselves about disability. I think I am disabled. I am disabled by society, I believe in the social model of disability, and there shouldn't be a problem with that.

So we have to work on all levels: we have to work on the campaigning, Mad Pride, sacking psychiatrists . . . But we also have to work with all the people who are still in the mental health system, and who are still our members just as much.

– **Participant from the Netherlands**

I want to underline what the Chair said. What this university has done for us is very great . . . So I would thank you for this great start of giving us the possibility to be here . . .The only possibility we had to meet was through universities like you that are organising such things.

– **Participant from Greece**

I would like to say since you all reported that ENUSP has great financial problems at the moment that every organisation should aim at strengthening itself so that nobody can affect it negatively.

– **Participant from Germany**

I'm going to come back to this question of what ENUSP has achieved up until now and what are our goals are: I also feel that we have difficulties in ENUSP. And in my opinion, the biggest achievement of ENUSP is that it still exists. It was founded at a time when there was no such thing as the United Nations Convention in 1991. So I think ENUSP achieved to make our issues visible; it brought together many great individuals who continue networking on committees. But in the last years since we are not funded any more, we don't have resources and we don't have structure, I mean a functioning structure. So I would not say that we achieved a lot. And on the other hand, complaining about not having resources will also not help us very much. Because I think only the organisation itself can build itself up and find power and find sources to continue existing.

I just wanted to say also that I think it's also up to us to grow up and establish ourselves because we are hardly a partner any more. Even when we are invited, we are not a partner because we always have to beg for travel costs. So ENUSP is not an equal partner in the European arena concerning human rights or whatever policies are made for us. So if we want to achieve that, we have to do something about that.

ON THE SOCIAL MODEL OF DISABILITY

- **Question from Greek participant**

This morning your speaker emphasised some ideas about psychiatry. One of you also stated that she supports the social model . . . That is the model which does not accept that the individual is the only one responsible for their disorder, but other external factors . . . affect their mental condition. You, as key members of ENUSP who are interested in ENUSP, are you taking action so that the social model can be implemented? Or have you abandoned this idea?

- **Mary Nettle**

First of all the social model cannot be imposed. It is a way of describing how people with a mental health problem or emotional distress are treated by society. You need to compare it with the medical model. The medical model is the model that says “You are ill because there is a problem with your brain. If you take all these pills, you will be better.”

I myself do take pills. I acknowledge I take pills. But I do not think that it is only the pills and the brain that are the problem. I think it was how I was treated when I went to school, when I lived with my husband, which was not a good time . . . [That] was very much more of a factor. I feel that if I had been in a better environment, I would be better. And therefore the social model, I feel, reflects far more the fact that it isn’t just pills. In the social model, you can take pills if you want to. It’s about autonomy. It’s about being yourself, and if your self want to take pills, agrees that pills are a good thing, that’s fine . . . It’s the medical model that imposes the pills, that forces you to take pills whether you want to or not.

- **Iris Hölling**

The point in the social model is that it’s society’s problem to deal with difference, to deal with different kinds of people, and how much room there is to accept madness or strange behaviour or strange states of mind. And that it’s society that has a problem with it, and that it’s not individualised in a person, not localised in a person, but it is a question of how accepting, how embracing our society is of the difference. And that it’s society that creates barriers and that discriminates. And the social model focuses on the outside and does not localise the problem in the person.

- **Participant from Denmark**

I would like to add about the social model . . . not to make it an academic discussion. The social model is something which has developed in the disability movement in the last 20 years. But how to understand the essence of this? There’s a change to looking at us as people with non-ordinary experiences, and behaviour that is not accepted by society. The norm has been to go in [using] psychiatry to force and control and try to change people to some kind of normality This has changed now. Now the social model talks about [how] everybody has diversity and the right to be who they are. Nobody should be allowed to go inside and control people and make them different to fit them into some kind of social system. So this is another way of trying to understand the social model because I understand there can be some discussion about this 'social model'.

But the main thing is that now we don't have a society which goes into the person and says: "You have to be like this" This is a question of freedom, freedom for everybody to be like they are. You can be an apple, a pear, or a cherry. The diversity is much more secure in this way . . . To give a diagnosis to a person, to say you are not like this is not dignified at all . . . It is an atrocity.

ON TAKING UP THE UN CONVENTION

- **Participant from Sweden**

I am from Sweden. You were talking about the Convention. I was very active in the birth of the Convention, in the lobbying in the United Nations building in New York. What we have really been working to change is now possible according to the Convention. And what I want to say is this instrument could change things, but it doesn't come by itself. now we have to carry on with implementation. We have really to work on it because I now more than 100 countries have ratified it. That means their parliaments have decided that this Convention is a legal instrument in their country. If a country has ratified the Convention, it's law. It's a law in the national law; it's more important than other national law. And it says explicitly in the Convention in one of the articles that the state should abolish or amend any national laws that are contradictory to the Convention. So, now over 100 countries have ratified it, but nothing has happened . . .

According to us, not according to our governments . . . but also according to professors of law from all round the world, there are really changes in this Convention. The first is this paragraph Article 12 on legal capacity that really means any form of guardianship is forbidden. So if a country has ratified the Convention, they have got to abolish every kind of guardianship. And the other thing is also that it is really clear in the Convention that any law allowing compulsory psychiatric treatment is not allowed . . . But nothing happens.

And why? I think really we have to co-operate much closer with lawyers, with the institutes of law . . . I was at a seminar on this Convention in Oslo, Norway. And Norway is one of the countries that hasn't ratified it. And one professor . . . said that most of the countries that ratified it really quickly didn't read it very carefully. If a country is like Norway where they . . . look closely at detail, they haven't ratified it, because they know they'll have to change their laws.

The man who led this seminar in Norway, he's a retired judge of the High Court in Norway. I met him a couple of times. At first, two years ago, he wasn't really believing in this Convention . . . that [it] would really mean you had to change the laws . . . But now when he reads it very carefully, he said he could see that any law on compulsory psychiatric treatment should be abolished. And he is a judge of the High Court.

So the thing is to implement it . . . That is the important word..we have to think about what it means, these articles and we have to co-operate with specialists in law. And then we really can change things in more countries! It will take some time, but I think it's important that we start work on that.

– **Participant from Greece**

I am the treasurer of a self-representation association based in Athens which provides health services. I heard about a Convention that many speakers here have been referring to. Can you please tell me where the whole text of this Convention can be so that I can read it?

– **Iris Hölling**

You can find the information about the Convention on the World Network's site (www.wnusp.net), on the European Network's site. the World Network has also done a manual on the Convention explaining also how we could use it.

If the Greeks have ratified, there should be a Greek translation, [voice from audience: "They haven't ratified it"!] OK, they haven't ratified . . . With the translations, you have to be careful because the German text is a lot worse than the original English text. And the disability movement has done a shadow translation that is correct . . . Our government thinks they don't do anything although our laws contradict the laws of the Convention. When they ratified it, they made a document that said "We don't have to change anything because it's all fine." And the survivors and the disability community were all angry because we all know that's not true, and we have to fight for that to be understood.

And this [CRPD] committee we talked about, that's a committee where we can complain, and we as a movement can also prepare our own shadow reports and tell the CRPD committee that we are not satisfied with how our government implements or doesn't implement the Convention. All governments who have ratified have to do reports on their progress after a year . . . The German national organisation of users and survivors of psychiatry has prepared its shadow report that will also be released when the report of the government comes, blaming them for not doing what they are supposed to do. And in some other countries, there are also shadow reports. And one can also ask for visits in the country in order to show how things are contradicting the Convention, if there are institutions where force is happening, where people are being locked up against their will – This all contradicts the Convention, and it can be shown to the Committee.

– **Mary Nettle**

In the UK, our government has ratified the Convention. They made a few reservations . . . which means they say, “Well, I don’t think our laws fit this.” And they said forced treatment was fine because it was in our best interests. And this is really what you have to watch. In psychiatry, we have things done to us because it is “good for us”; it is in our “best interests”, and that is [the phrase that] is used. You must remember that.

– **Participant from the Netherlands**

I am from the Netherlands. I would like to give some information about the Convention theme we were talking about. In Holland, there have been strong movements in past years to persuade the governments to ratify the Convention . . . One of these movements is called “Social Inclusion”. It’s somehow like a users’ network, but there are a lot of different levels. It’s just one way to conceive agreements on higher levels . . . I totally agree with the speaker from Sweden that we need such advocacy for our rights.

* * *

The Opening Session closed with Mary Nettle reading through the programme of events for coming days.

Her description included some reflections on ENUSP’s General Assembly scheduled for September 30. She said the assembly was badly needed because there had been many changes since the last one in 2004; some members were no longer able to be with us She announced here also she would be standing down as Chair of the European Network - 6 years after being elected in Vejle. She said it had been a lot of hard work, and she wished much luck to her successor chosen by the General Assembly.

The Alexandros Papanastasiou Ceremony Hall, Old Building, Artistole University, where most of the Proceedings of ENUSP's Sixth Congress and General Assembly took place.

DAY TWO

KEY NOTE LECTURES
WORKING GROUPS

DAY TWO - Wednesday, September 29th

------ Unexpectedly, some light rain greets the day but a friendly wandering dog waits for company on the steps of the University. --------

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First of all, there was a brief greeting from the Rector of Aristotle University, Pr Ioannis Mylopoulos, who talked about the dangers of the commercialisation of mental health.
Then Mary Nettle formally introduced the activities of the day which would consist of two parts. First keynote speeches from Stefan Trömel from the International Disability Alliance about the importance of the United Convention of the Rights of Persons with Disabilities, followed by a Questions and Answers session; then a keynote speech from the Greek perspective by Giorgos Giannoulopoulos of the Pan-Hellenic Network.
Mary Nettle then asked workshops and working group leaders to come and give a brief description of what activities were on offer for participants.

Mary Nettle welcomed participants to the second day and reminded the audience that the European Network is wider than the European Union and that ENUSP is also a member of WNUSP. She also stressed that despite this “our voice has not been heard very much because we are very suppressed by medication and if we are off the medication we are then suppressed by society’s attitudes. It’s very difficult to get a job, even in good times when there are lots of jobs, very difficult to get a job, very difficult to get insurance and to have a driving licence and all the practical things that we need to be a citizen of our countries. So we have great power as part of this movement but the thing is we need to know we have this power. Today we will hear about the UN Convention which places us firmly on the international map.
Mary thanked the Aristotle University again for hosting this event in such difficult times and in particular Professor Kostas Bairaktaris of the Department of Psychology, Aristotle University.

Mary Nettle then moved on to the main core of business for the morning and introduced Stefan Trömel from the International Disability Alliance. The theme of his talk would be the challenges thrown by the the United Convention on the Rights of Persons with Disabilities. This session was facilitated by ENUSP board member Erik Olsen.

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FIRST KEYNOTE LECTURE:

STEFAN TRÖMEL, EXECUTIVE DIRECTOR OF THE INTERNATIONAL DISABILITY ALLIANCE:

"The United Convention on the Rights of Persons with Disabilities – Challenges and Chances for Users and Survivors of Psychiatry"

Thank you everybody. First of all, my thanks to the organisers for inviting me to this important conference. As Mary said I am Stefan Trömel, Executive Director of the International Disability Alliance, which is basically the network of global and regional organisations of persons with disabilities that has as its main mission to promote the rights of persons with disabilities specifically now in the framework of the new Convention, the UN Convention on the Rights of Persons with Disabilities.

You should know that the World Network of (ex)Users and Survivors of Psychiatry is a member of the International Disability Alliance and the European Network (ENUSP) is also indirectly a member, through WNUSP but also through the European Disability Forum which is a regional member of the International Disability Alliance.

I was asked to speak today about the new UN Convention on the Rights of Persons with Disabilities and try to see how the user/survivor movement can use that new Convention to improve the situation of human rights of persons and users of psychiatry.

Let me start by explaining briefly what is a convention.

Convention is a legally binding human rights treaty to which our countries commit themselves to promote the rights of all their citizens or part of their citizens, in our case citizens with disabilities, and they do so in front of the international community. So they basically say “ I, as Greece, commit myself to protect and promote the rights of persons with disabilities and accept that the international community scrutinizes analyses how well or no so well, Greece is doing”.

Now, the Convention on the Rights of Persons with Disabilities was adopted in 2006 and entered into force in May 2008 so it is still relatively young and new treaty. It only obliges states that have signed and ratified the Convention. So if I take the example of Greece, Greece has signed the Convention, they did so a couple of years ago but it has not yet ratified the Convention. So right now the Convention has not yet entered into force in Greece but is entered in many other countries that are present here like the UK, like Germany, like Denmark, like Spain and others.
So it’s important for the European community to continue pushing for swift ratification of the Convention. To date 94 countries, that’s almost half of the countries that belong to the United Nations have ratified the Convention.
There is also a separate document to the treaty, an annexe to the Convention which is the so-called “Optional Protocol” to the Convention which requires a separate signature and ratification. The good news we have just received from a Greek point of view, I think it was yesterday, Greece has now also signed the Optional Protocol. This had been the main barrier to the ratification to the ratification of the Convention and of course the Protocol here in Greece.
I come back to what the Optional Protocol means for those countries which have also ratified it. It is important to realise that the negotiation process of this Convention which happened between 2002 and 2006 was a negotiation process which benefited from a very active involvement of organisations of persons with disabilities. Human rights treaties and each treaty in the UN are negotiated among governments. It’s mainly our ministers of foreign affairs who have the competence on behalf of our countries to negotiate an international treaty, be it an environmental treaty, an arms disarmament treaty, a human rights treaty.

Now in the specific context of this Convention, the disability movement managed to make it clear to governments that the Convention on the Rights of Persons with Disabilities could only be negotiated with the active involvement of the organisations representing the persons that would benefit at the end from that convention. So we managed to be in the room, we managed to be speaking and we did one more very important thing: we united forces. When the process started, a number of organisations, international, regional, national that were aware of this process started to go to New York and we realised that the only way which we could influence the process was through joining our forces, through making our demands in a unified way.

If governments who have very different and sometimes very negative positions on the issue would have been confronted with disability organisations from different parts of the world representing different disability constituencies and each organisations would have been saying different things, probably the outcome would have been that governments would not have listened to us and said "Look, they don't know what they want, every organisation is saying different things, let's just agree on this treaty among ourselves, anyway we are the only ones who have the competence to do so, and the power to do so".

Now, we joined forces, we realised that only this could have any impact. In that unity, the World Network of (ex)Users and Survivors of Psychiatry was a great active player and the demands and concerns, sometimes quite particular to the community of users and survivors of psychiatry were put on the table in front of the other disability groups: blind persons, persons with physical disabilities, persons with intellectual disabilities, deaf persons and so on and so forth. And what happened is that, thanks to the good work of the individuals that represented the World Network at that negotiation process, the concerns, the proposals that were made by the World Network became the proposals of the whole disability coalition that was established for the negotiation of the Convention. I think that lesson of unity and solidarity is a lesson that we need to maintain also now during the implementation of the Convention.

And at least the message we tried to deliver permanently from the International Disability Alliance is now that the process has moved to the national level to implementation level, this unity of the different disability constituency needs to be maintained because unless that happens certain issues might fall off the table, specifically those issues which are especially challenging for governments. And we should all be aware that the issues faced by persons with psycho-social disabilities which is the terminology we use in IDA are probably most at risk of being left out of the implementation process. So it's very important from my perspective that organisations of users and survivors of psychiatry strongly join forces with other disability organisations which often need to be persuaded and convinced about your issues and how they can be approached. Because there is of course a lack of knowledge in general society but also among other disability groups about how to approach your issues.

What is happening thanks to the entry into force of the Convention is that finally disability, including psycho-social disability is now part of the human rights agenda. Before, when our governments, when our human rights institutions, our ombudspersons, mainstream human rights NGOs, they rarely looked at the issues of persons with disabilities. Persons with disabilities were not on the human rights agenda. There were other issues: social policy, whatever but they were not part of the human rights agenda. Now this has changed and we are seeing an increasing presence of disability issues on the agendas of the different human rights place, be they public or private. I think that is a very important opportunity of which we need to use as much as possible. Also within the UN, disability is becoming part of the different elements of the human rights machinery. There is now a specific committee, I'll come back to that, that oversees the implantation of the Convention but also all the other extra committees that monitor other UN Human Rights Treaties, like the Convention against Torture, very important for us, like the Convention against Discrimination of Women, Convention on the Rights of the Child, Convention on Politic Rights, all bodies of experts at monitoring the implementation of those Conventions, most of which have also been ratified by your countries and which also should benefit persons with disabilities, including persons with psycho-social disabilities. These treaties are also increasingly, including in their work, the issues of persons with disabilities, hopefully in a way that is consistent with the new Convention on the Rights of Persons with Disabilities.
We have also seen mainstream human rights NGOs, and I'll come back to that, starting to put disability higher on the agenda. The International Human Rights Watch and other NGOs are starting to pay more attention. We have to make sure they pay attention in the right way but at least, now they are realising they can no longer ignore the rights of persons with disabilities in their work.

So let me highlight a number of general characteristics, features of the new Convention on the Rights of Persons with Disabilities:
When a country becomes a state party to the Convention, meaning when a country ratifies the Convention, that is a decision that needs to go through Parliament and all that, basically what the government is doing is, it is committing itself to align, to change all its legislation and make it consistent with the Convention on the Rights of Persons with Disabilities. So if you have legislation, like mental health law that is not consistent with the Convention, the state is obliged to change that legislation, to abolish legislation that is not consistent, to make amendment to legislation which is partly consistent or partly inconsistent.

The overall objective of the Convention of course is to promote and protect and ensure the rights of persons with disabilities. But who are persons with disabilities? Is there a common definition of persons with disabilities? We don't have at European level, a common definition. If you look at the different definitions used in the different countries, you come up with different definitions, you come up with different statistics. In the UK, they say it's 20% of the population; in Spain, my country, it's 9%, it's Romania, it's 2%> So this explains why there is great difference in definitions of disability in use. Now, the Convention: does it solve the problem? Does it provide a very clear definition? No. This was not possible. It's probably good because as we all know, the concept of disability has been changing over time and to have included in the Convention a fixed definition might have not be good after a number of years. So the Convention speaks about disability as an evolving concept that is changing. People with HIV-AIDS are people with disabilities, not in my country but in Australia and in other countries so, this has been changing all the time and will continue to change. That's good.

But the Convention does a very important thing. In Article 1, it clearly specifies who are the persons who are protected by the Convention and it says specifically "Persons with physical, sensory, mental and intellectual disability". Now why is this important for people with psycho-social disability? OK, we don't have a reference to psycho-social disability in the Convention. That was not possible. The term was not sufficiently well known and accepted during the negotiation process but the fact that this article distinguishes between intellectual and mental disability makes it very clear, that people with psycho-social disability, under the term "mental", would be covered by the Convention. So in all the countries, and there are many countries in the world where people with psycho-social disabilities are not considered currently within the national definitions of persons with disabilities, now these countries will need to revise their definitions in order to ensure that the Convention protects the rights of persons with psycho-social disability.

Another important element, important for many disability groups but also for your constituency, is the concept of discrimination on the basis of disability.

The Convention does not only protects persons with disabilities who are I'd say legally considered as having a disability in country from discrimination. No, it protects persons from any type of discrimination based on disability. For instance, persons who are perceived of having a disability and are being discriminated against; persons who might have a disability, mental health history in the past, who no longer have a disability now, being discriminated by employers or insurance companies for something that has happened in the past. The Convention asks states to outlaw all these types of discrimination but we need to be vigilant when the Convention is being implemented in national legislations, that these elements of discrimination are not left out.

The Convention is a comprehensive convention. It tries to tackle all areas of life. As we all know, full participation in society for people with disability, including people with psycho-social disability requires that we work at all levels. And Mary has raised a number of them this morning. It's about education, it's about employment, it's about change in attitudes in society; so the Convention tries to address all those areas and asks states to come up with laws, policies, practices, campaigns the really address all those areas.

It is a convention that clearly outlaws all forms of discrimination and we need to be proactively presenting all situations that are situations of direct or indirect discrimination faced by people with psycho-social disability, like some again like those Mary raised this morning. We need to proactively explain that people with psycho-social disability for instance have problems to get a driving licence or to get accepted in a university like it happens in some Eastern European countries. But the Convention also goes beyond discrimination. It's not purely an anti-discrimination convention, like we have in the area of women or racial discrimination. Not all the problems, not all the barriers that people with disability face can be addressed within an anti-discrimination framework; so it's very important that the Convention decided to go beyond.

Let me briefly address what this Optional Protocol adds to the Convention.

The Optional Protocol allows individuals from countries that have ratified not only the Convention but also the Optional Protocol to put forward complaints, individual communications to this international expert body, that I will explain in a short while, to denounce your won government in front of this committee for not having respected your rights. Now this is not something you can go there tomorrow. Tomorrow, you are being discriminated by your employer and you decide to go to that body: no! First, you have to go through your own legal system, and you might say this might take a number of years, yeah, that's the reality. Individual communications can only be submitted meeting a number of requirements and the first and most important is that your country that your country has ratified not only the Convention but also the Optional Protocol. Second interesting feature of this Optional Protocol, and it's important that you push not only for the ratification of the Convention but also for the ratification of the Optional Protocol, is that this committee of independent experts that has been established by the UN to monitor the implementation of the Convention and the Optional Protocol can also undertake inquiry procedures in countries where they get information about systematic and serious human rights violations. So this would have been perfectly something that you could have used in Greece, during the time you were trying to change the situation in Leros. And similar institutions continue to exist in other countries. I think this a good example of how you can use inquiry procedures to tackle certain grave and systematic and serious human rights violations.

One very important feature of the Convention, and not surprising, in view of what I said before of the active involvement of organisations of civil society, of persons with disability in the negotiation process, is that the Convention clearly refers in a number of articles to the vital role that organisations of persons with disabilities have to play in the implementation of the Convention. So our governments, are they now obliged to change their legislation to align with the Convention, but they are also obliged to consult with organisations of persons with disabilities when undertaking those changes of law, policy and practice.
Ok, so we have an instrument, international instrument. We seem to be far away in the UN, in New York, in Geneva, who knows where, in the moon... No! It’s a tool we have for our national advocacy work. If we think of it as something which is abstract, far away, we are bound to miss a very important opportunity. We are, in our national advocacy work, up to now we had to do it in the absence of any international instrument like this. Those countries which are part of the European Union could use some European instruments, non discrimination in work plays of course an important role, and a few other elements there. But now we have a comprehensive instrument covering all areas of life and which is increasingly ratified by all members of the UN. So we have an excellent tool, powerful tool at our disposal. We need to understand the processes through which we can use this tool. It’s a hammer. But if we think of it as a hammer, and we let the hammer lie on the table, it will not do its work by itself. It’s a hammer we have to pick up, know how it works and then start banging on the tables, on heads, on doors, wherever we need to bang this hammer. So we need to know how it works.

So now we have a hammer: Is it a good hammer or a bad hammer? I think it’s a good hammer. Let me try to explain why. The hammer, the Convention, has very important articles with overarching principles. The principles that need to be looked at whenever we read any specific article of the Convention. So it speaks about the right to employment, access to health, access to voting. It’s also an article that has a number of principles. I will mention two of them. The principle of individual autonomy including the respect for one's own choices. I think that is a very very important principle that has not always been respected for certain constituencies of persons with disabilities including users and survivors. And the respect for diversity. Madness, if I may say so, I've heard many of your colleagues say, it's not a problem, it's a reality. It's respect for diversity, for the different types of disability diversities, be it sign language, be it hearing voices. Disability is part of human diversity and needs to be respected in that way. I think there we have a huge challenge but it's very important that the Convention clearly specifies this overarching principle of the Convention.

The protection from discrimination I have already mentioned but let me complement it with one more element. The denial of reasonable accommodation as a form of discrimination. It is not only no longer possible for public authorities, private enterprises to discriminate directly a person by saying " we will not employ you because you have a mental health problem, or because you're blind". No, that is of course clearly outlawed. But also what's now compulsory for employers for universities, for everybody, when a person with disability requires an adjustment in certain practice in order for that person to be able to work, to have access to education and so on, that adjustment will need to be made. And we have to start specifying what those adjustments mean for each of our groups. Does it mean an interview atmosphere that is welcoming which might be easier for people who have a speech impairment, people who stammer? Perhaps people with psycho-social disability might benefit from that. So we need to start working out what reasonable adjustments mean for each of our groups in the different contexts. But these adjustments which before were voluntary, and employers might say "Yes, I'll give you some more time for an interview or some more time for this exam" like a favour, that people are doing to us, now it is an obligation. An obligation to provide these adjustments and not doing so is a specified form of discrimination and can be challenged legally. And we need to explore fully how we can use this process.

Article 12 of the Convention is a key article. If you have not enough time to read the full Convention, read at least Article 12. It's the heart of the Convention where the paradigm shift of what the Convention tries to promote is embedded.

Basically what this article says is that it's no longer possible to take away the legal capacity of a person who is deemed not to know what is good for her and to give her legal capacity to somebody else, being family member, the mother of father, being and institution or being work.

This is no longer possible in the Convention. What now needs to happen is that people retain capacity and are provided, if they want, with the support that they require to take decisions. Decisions that might be wrong or right, I mean who is the judge to say that a decision that I'm taking is the right or wrong decision? Now implementing Article 12 is a major challenge. It will not happen overnight. But we need to start telling our governments that they have to revise the guardianship laws and any other laws that continue allow states and judges to take those actions. Actions that were designed hundreds of years ago, just imagine the challenge that we have here in front of us when we speak to judges and lawyers. They say that this is not possible, so we have a huge challenge to change the mindsets of legal petitioners because they will say these traditions were designed to protect people with disability from abuse by third parties who will cheat you and take your home away. That is the reason that led to the existence of these provisions, which exist in all countries in one way or the other. The message we are delivering through the Convention, especially through the World Network of (ex) Users and Survivors of Psychiatry, these provisions that were deemed to protect people from abuse have become the most abusive provisions because those are the ones that mean that the person can no longer take any decisions and of course in many cases, the lack of capacity has led the person to be put away in an institution because it's the family member or the person who has the legal capacity [meaning responsibility?] who can then sign them away to an institution. So change will not happen tomorrow but it's a process that we need to start moving in order for our current system to actually change.

Another very important element of the Convention is that there can be no deprivation of liberty based on disability. Replace disability by psycho-social disability, replace it by mental health, replace it by a person who is a danger to him or herself or to others, all these situations are, according to our interpretation of the Convention no longer possible. So here again we have another huge challenge. Governments are saying "But how are we going to do that?, How are you going to deal with certain situations when the person is at risk of committing suicide, or the person is a risk to others?" So I say, let's work n alternative solutions and that's why the work that you are doing here in the university, and colleagues users is important. We need now to provide new solutions. The old solutions are against the Convention. So now we have an actual opportunity to say "OK, this old solution of taking the person, putting the person in an institution, the person has not done anything but you think that perhaps he will commit suicide or that he might a danger? No, no".

This is no longer possible, no deprivation of liberty based on disability. If the person has committed a crime, yes of course, the person, like any other person, that's equality will then to be put in prison. You will then need reasonable accommodation in prison and that person will be into some sort of special facility within the prison. But if the person has not committed a crime and is just a danger according to somebody, this situation can no longer be solved in the old way. We now have to help governments to find alternatives to those situations.

So all the mental health laws that exist in the world, and there are many of them, all of them either need to be abolished or at least significantly - I think abolished is much easier-, significantly changed because all those laws foresee these situations. [incomprehensible]. The Convention says that's not enough anymore. So now it's a challenge on all of us, of users it's important, to come up with new ways.

The Convention also speaks about the protection from torture. Now, many of the things that happen in the field of people with psycho-social disability, like forced restraint, like electro convulsive therapy, have been considered as a form of torture, not only by the Convention but also by the UN special rapporteur on torture. So any anti-torture mechanisms, torture prevention mechanisms that we have in our countries, we need to make them apply also those situations for persons with psycho-social disability.

And the Convention speaks about the need for our governments to establish a specific independent monitoring structures to analyse the functioning of the specialised services that exist in our countries, institutions and others.
The protection of integrity. No treatment against the will of the person. With no exception. Again, huge challenge.

The strong article about living in the community. Large institutions need to be closed for people with intellectual disabilities and for people with psycho-social disability. And new services need to be established for those that need to be established for those that need those services. Not everybody that leave these institutions will need those services but many of them will need them. There is a clear message to states "You now have to start with a serious deinstitutionalisation process in your countries".

Access to health, based on informed consent. How much still is access to health not based on informed consent? See the link with Article 12? With legal capacity? Now it's no longer possible that the guardian signs or accepts a specific treatment for the person that has been taken away the legal capacity. Now it's the person who should recover the legal capacity that has not to accept any health treatment, including mental health treatment, and that the will of that person needs to be respected.

There needs to be training for health professionals on the rights of persons with disabilities. A huge challenge I imagine, especially within the mental health community.

There is an article on rehabilitation in the Convention but it clearly says one important thing: rehabilitation is a voluntary thing. You cannot be forced into doing rehabilitation because somebody thinks that this rehabilitation, be it physic rehabilitation or mental health rehabilitation is good for you. You have the right to decide whether or not to undergo, to undertake that rehabilitation and none of the [welfare] benefits that you might get because of your disability can be linked to you accepting or not to undergo any rehabilitation.

Issues around families. There might be a situation where a mother or a father who has a psycho-social disability is separated from his or her child because the state thinks that the mother or father is not able to raise that child in an adequate way. But the Convention does not allow it anymore and it foresees that the family, when needed gets the adequate support when needed, to raise that child in an adequate way.

Just to finish, a few things.

I said at the beginning that ratifying the Convention means that you are obliged to change the laws, to accept that the international community reviews whether you as a country are doing it in the right way or not.

Now this is done through a committee on the rights of persons with disabilities, that is currently composed by 12 and from next year onwards [2011], by 18 individual members. They are there in their individual capacity. They are not representing governments. They are not government officials. They are individual independent experts which means in principle that they will be quite able to tell every government that they have to do things in a better way.

Now the very good news for the user-survivor community, is that form next year inwards, two of the 18 members are people with direct lived experience of being users of psychiatry. Colleague Gábor Gombos from Hungary, whom many of you know and Edah Maina from Kenya. So it's good to have people with direct experience in the committee. So if I take the example of Greece as we're here, what will Greece needs to do once it ratifies , hopefully, before the end of the year, the Convention and the Optional Protocol? Greece will then need to present a report to this committee before the end of 2012, two years later, of what Greece has done to implement the Convention. And the committee will then look at the report and will give to the Greek government recommendations. And you might think, well, knowing our governments, at least my own government in Spain, will they be very self-critical? Will they say what is missing or will they what they have done and will not identify what is missing?

And this is where we come in again as organisations of persons with disabilities. It is practice of the UN system not only to look at the reports of governments but also very importantly to look at any alternative information, especially information coming from NGOs. And very often the information provided by NGOs is much more accurate, a much better reflection of the situation on the ground than the information that the information that comes from the state. So we have the obligation of saying, to submit alternative information, so-called parallel reports to the committee. But we should know that we have very good chances that our information will be taken into account by the committee when making the recommendation to our countries.

Another important element of our Convention is not only that we have this international committee that meets in Geneva twice a year, looking at what Greece is doing, the Convention also asks each of our states to set up or allocate the role of monitoring the Convention. It might be the ombudsperson, it might be a national human rights commission, it might be a national umbrella organisation of persons with disabilities, different solutions have been applied in different countries. But there is now or there will be a body in our countries directly responsible to monitor in an independent way whether our government is or not making the changes that the Convention asks the government to do. So we have to find out and work with these national bodies which are much closer to our realities than the international structure. Important but we have to work on both levels, on the national level and also, on this second layer, with this international committee which can provide additional impetus to our advocacy national work if their recommendations are good recommendations.

We have now a number of challenges in front of us, and opportunities. The first challenge we have, we need to, and this is a general message to all organisations, but especially to organisations of persons with psycho-social disabilities, who do not often see themselves part of the wider disability community. We have to fully use this new instrument that we have at our disposal. We have to become familiar of its content; it's a very rich, complex document. We need to know what it means because if we do not have an advance interpretation of the Convention, we will not be able to achieve all the results at national level. And we need to be familiar with the monitoring elements, national and international, that this new Convention proceeds and to use them as part of our advocacy work. The things we have been doing until now, we will continue to do them. But now we have to do a few more things which I hope will help us to accelerate the advocacy work that we are doing. We have to look how this Optional Protocol work and how we can use it in a strategic way to provoke change in law and policy. From an international perspective, we need to be aware that even now that we are seeing that the Convention has not yet been fully endorsed, by the UN system as a whole, there are still parts of the UN system that use other documents, like the MI principles[1] with which many of you are familiar that probably were a good step in the past. But now, they have become superseded, replaced by the Convention because as you know the MI principle continue to proceed in circumstances in which the person can be deprived in his or her liberty against the will of the person. And that is no longer possible under the Convention. But still the MI principles are being referred to by the World Health Organisation.
We have to, or you have to, with the support hopefully of the wider disability community, continue to challenge the mental health practices that are inconsistent with the Convention. And unfortunately still, even the World Health Organisation, in the work that it is doing in the field of mental health, is not yet fully consistent with the Convention and that has been a permanent criticism and rightly so by the World Network of Users and Survivors of Psychiatry and by IDA, seconding the work of the World Health Organisation. That's a problem we have there, we still know that health professionals and mental health professionals look for the guidance that they get from the World Health Organisation. Ok, We have a lot of work still there to do.

As I said before, we also need to be proactive in presenting to organisations examples of practices and policies that are consistent with the Convention and that can be an advantage. We have to

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[1] United Nations, 'Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care' also known as the MI Principles.

present these alternative solutions so that governments realise that they can implement the Convention, that alternative solutions are consistent with the Convention and replace current practices which are not consistent with the Convention.

I said already but I think it's important to repeat it. It's very important in my view that organisations of persons with psycho-social disability join forces with other organisations of persons with disabilities. Here in Greece I know there is a very strong umbrella organisation of persons with disabilities which has done an excellent work for the wider disability community. But I'm not exactly sure how well that wider umbrella organisation is taking on board the issues of users and survivors of psychiatry. In my own country, we have a strong umbrella organisation that has a very important impact on the government but again, users and survivors of psychiatry are not fully part of that umbrella organisation. It's more families and professionals who are there, who are not always, as you know, having the same position on some of our issues.

So there we have a big issue, both for the other disability organisations but also for the organisations of people with psycho-social disability.

One very important element we should not underestimate, how much can mainstream human rights NGOs help us in our work. Now if you look at the work of Amnesty International, what are their issues? Torture, deprivation of liberty, prisoners of conscience. They will not be interested in general accessibility problems . . . but they might be quite interested in some of the issues that are faced by people with psycho-social disability which are very similar to other situations on which they have been working. Now right now, we see they don't fully understand the issue. They are starting to work on it but they're still not 100% there. 90%. We have to help them because they might be extremely important allies, especially for dome of the most striking human rights violations that we are facing, human rights violations in large institutions, it's already on their agenda. But we need to make sure that they approach those issues in a fully consistent way. That is still not happening but I think there is a huge potential in it.

We also have to use more often, not only this new committee that I've mentioned, on which we have these two members with lived experience but also other mechanisms within the UN. There is a Special Rapporteur on Torture who had done a very interesting work and come with very good reports in which he has clearly said, and we are using that, forced treatment, electroshock, that clearly inconsistent with the Convention. And not only that but they also very often amount to torture, or degrading treatment. He is doing work and visiting countries, and visiting prisons to see whether torture is happening in prisons or police stations. He is starting to visit services, targeting people with psycho-social disability to see whether torture or violence is happening in those practices and those services. We have a standard formula which a colleague of yours, who has presented a communication to the Special Rapporteur, of a specific individual in Norway that was faced with the usual problems that many of your colleagues are facing.

And finally, it is also very important that we, as organisations and user organisations of persons with psycho-social disability, get involved in international cooperation. More and more our governments, Spain, Netherlands, UK, Greece not so much but also to some extent, are bidding funds to developing countries. Most often disability is not even part of their agenda. Hut sometimes it is on the agenda and sometimes it is on the agenda in the wrong way. We are seeing international cooperation that is being done promoting mental health practices that are inconsistent with the Convention. Giving funding to renew or build new institutions, this is something that is happening. So we have also responsibility as organisations not only to look at what our governments are doing inside but also at what our governments are doing with our money, as tax payers, in other countries to ensure that what is happening outside is also consistent with the Convention. Mary I think I will stop here... thank you very much for your attention.

SUMMARY OF QUESTIONS AND ANSWERS SESSION

1- **How can we challenge effectively professionals and others telling us that decisions are made "in our best interest"? (Question from UK)**

> What we have in front of us is a long avenue. It's not something, the Convention as I said before, will not provoke immediate change and current practices to the best interest of people with disabilities will continue to be there for a long time. But now what we have is an instrument that clearly says that those practices are inconsistent with the Convention and that is something we did not have before and we have to use it in a clever way. The convention speaks about training of health professionals and it's not training on medication, it's training on how to approach,

to treat all persons with disabilities with full respect of their human rights, and so on and so on.

2- **Information is not always accessible. In some countries, only institutions have access to information and do not share it. When people are poor and badly organised you cannot have access to information. (Question from Spain)**

The Convention clearly speaks about the need to involve organisations of persons with disabilities in the implementation. It does not necessarily exclude others but it clearly gives a predominant position to organisations of persons with disabilities and that links with the issue of the fashion now of having a person with a psycho-social disability as a fig-leaf on your board so that you can say “well of course, but we are professionals and we have to get this nice person who completely agrees with us and of course who is getting some money from us, from pharmaceutical company to not be too critical of anything” So there is a risk there and can only be approached by being also unified and strong ourselves.
Often organisations of persons with psycho-social disability at least in Spain it’s weak organisation, it’s small groups, usually no national structure and we need to work on that. We need also to ask other disability organisations to help in the establishment of stronger disability organisations. We need to ask for that solidarity.
The economic crisis is not helping but in general there is a lot of money around disability. In the UK there is a lot of money in some disability organisations but very little of that money is going to people with psychosocial disabilities and we need also to challenge that.
The information is there. I agree it is not always shared. The information about the Convention is there in the public and it’s also our responsibility, our obligation to make it better known. Our governments will not come to us and say “Look what we have signed”.

3- **According to IDA, are the mentally ill people under guardianship considered automatically to be disabled or not? (Question from Hungary)**

For me there is no doubt that these people are covered by the Convention. It’s the heart of the Convention to challenge that situation.

4- Doubt about the viability of the Convention (question from Switzerland)

Scepticism is good, pessimism is bad. The Convention will not immediately change everything, that's clear. What is the difference between this Convention and the European Human Rights Convention and other UN treaties which have said similar things that have not been respected? The main reason is the reason why we have a convention. Because when the negotiation process started, people were saying, governments were saying, we don't need a specific convention. The Convention on Civil and Political Rights already foresees all that . . . all those conventions apply to persons with disability so what's the point of having a specific convention? And we were saying, Sorry but this convention in theory, in practice, does not apply to persons with disability. And now what this convention tries to do is to look at the barriers that people with disability face in the enjoyment of their human rights and tries to address them through this thematic convention that reminds states of the things they have already accepted but not applied to persons with disabilities. And further now we have a committee that is specifically composed of people who know about human rights and disability makes a huge difference to the judges who in charge of monitoring the European Court of Human Rights who have completely ignored issues that should have led to change but did not because those judges were still having the old paradigms in their head. Now hopefully we will have a committee of people who have the new paradigm in their heads, I cannot guarantee that every committee member has it but we will work on that, so that this committee will make advance interpretation and provoke change.
You will also need to work so that Switzerland ratifies the Convention which is not the case now.

5- What are the strategies in IDA to support the member organisations to help them towards implementation and the development of user organisations? (Question from Germany)

Not easy to present our strategy in two minutes but let me give some hints. One part of the strategy is to ensure that the rights of persons with disabilities and the Convention is fully taken on board in everything that is happening within the UN. As I said before, disability is now on the UN's human rights agenda but it's new but not often taken into account.
Also we need to ensure that all the different UN agencies increase their attention to the rights of persons with disabilities and improve their attention, and that is specifically relevant for the World Health Organisation as I mentioned before. They are still not doing things in a way that is consistent with the Convention and that is extremely confusing because if mental health professionals, especially in

developing countries where the World Health Organisation has special interests, they read the Convention and then read the documents of the World Health Organisation, they will come to the conclusion that the practices are consistent with the Convention because they cannot imagine that the World Health Organisation is doing something which is not consistent with a Convention which has also been ratified by the UN.

Apart from our international advocacy work, we are trying to be a bit more helpful national level. We think that we need to contribute. There is a huge capacity building challenge we are all facing around the Convention, understanding the Convention, understanding how it works, the content of the Convention, how we can use it... We can only make a small contribution to that, something that all the IDA members have to do, all the European Network members have to do etc. Our contribution is mainly on developing countries because there the challenge is even bigger. Definitely, the active presence of the World Network in the work of IDA ensures that whatever we are doing, your issues are permanently on our agenda. But of course, our resources are limited.

6- Translation of the Convention in different languages? (Question from Belgium)

Translated in a number of languages (www.) Need to monitor the different translations as some small translations changes can bring a very different meaning.

7- Is there a list of positive examples and steps, to show people who are sceptical about the changes the Convention talks about? (Question from Germany)

Issue of different interpretations of the text as barriers to the implementation of the convention. We think that something more detailed need to be produced, guidelines, especially in the more challenging areas of the Convention and all the issues that are relevant for you are part of the challenging areas. So we need to be able to work on providing these alternative solutions, we need to be able to give answers to the governments, not just criticising what they do wrong but also when they ask “what can you do?”, we need to have an answer to that. And sometimes, in some areas, we do not always have the answers. We need to find those positive . The Convention is very recent. Examples pre exist the Convention but in your area, they are not so many. We still need more positive examples.

8- **The impact of the economic crisis is severe, leading to social injustice (Question from the Netherlands)**

These are issues beyond disability. We need to join forces with the other organisations which are challenging these situations of social injustice, on international injustice which we all know exist and I think there, we are not yet part of that agenda. You know there has just been the Summit on the Millennium Development Goals, which is a key element for developing countries. At least now the document has been approved at that summit a few days ago in New York, with for the first time, a specific reference to persons with disabilities.
We cannot on those issues on our own. We have to reach out with other players that are working on that.

9- **The impact of enforced community care, poor treatment and the lack of implementation of the Convention despite the fact that it is been ratified by the UK (Question from the UK).**

It's clear that the ratification of the Convention is not a guarantee against such practices but at least now we have the tool at our disposal with which we can raise attention to it, not only at national level but also at international level and to be able to say that not only is it bad but it is inconsistent and against the Convention that your country has ratified. It gives additional impetus to your criticism but again, it's not a magic stick that would prevent governments from doing these bad practices.


THE UNIVERSAL DECLARATION
of Human Rights

SECOND KEYNOTE LECTURE:

GIORGOS GIANNOULOPOULOS, THE PAN-HELLENIC COMMITTEE OF [EX-]USERS AND SURVIVORS OF PSYCHIATRY

INTRODUCTION

The delegates now returned to the main hall of the Old Philosophy building for the second keynote session. In contrast to the internationalist perspective of the first keynote, this session had a distinctly local voice. It set out to create a space for the concerns of users and survivors of psychiatry from across the Congress's host country, Greece.

This local focus had been born out of three convictions:

- That it was crucial to bring the experiences, objections and knowledge of users and survivors across Greece to the attention of the wider European user/survivor community
- That communication between Greek users/survivors and ENUSP had been extremely limited in past years. The situation was compounded by the fact that the South-East region, including Greece, had no representative on the ENUSP board. The session was part of a concerted effort to open up a more direct dialogue
- That the Pan-Hellenic Committee of [ex-]Users and Survivors of Psychiatry needed to have control over the content and format of this session

In September 2009, Pan-Hellenic Committee spokesman Iannis Karterakis described the key agenda for the conference from a Greek user/survivor standpoint:

1. The Greek psychiatric system, its history and parameters
2. Groups and factors that influence the system (doctors, "big" doctors, pharmaceutical companies and "companies" in general, and others)
3. The situation we are faced with today and future prospects
4. Our rights and our demand and need to be treated as equals

(Statement to Thessaloniki planning committee, September 20, 2009)

At the same time, the Pan-Hellenic Committee named Giorgos Giannoulopoulos as the keynote speaker for this session. His speech would be entitled “It concerns all of us”.

Giorgos Giannoulopoulos was supported on stage by Iannis Karterakis representing the Self-Help Group of People with Psychiatric Experience in Chania; Konstantina Koutsogianni, a member of the Athens Self-Help group and Panagiotis Kasselakis, also from Athens, a psychiatric survivor.

True to its name, the talk covered many issues that resonated intensely with users and survivors from across Europe –among them, the overwhelmingly destructive impact of being deemed to be mentally ill on human rights, social and economic status, and life expectancy; the psychiatric system’s absorption of the politically dissident, the poor, and those who deviated too far from social norms; and the co-option of strands of the user movement by forces that do not serve our true interest. At the same time, it made clear the real need for deeper understanding and dialogue around the experiences of the Greek movement, including its position around the use of disability rights language and frameworks. The aim must not necessarily be consensus, but the formulation of strategies that would let us work more powerfully together to defend the human rights of users and survivors.

The text of the keynote is reproduced in English below based on the translation prepared by Aristotle University. It is followed by some reflections on the audience reaction and an account of ensuing joint human rights interventions in the Greek context that came from our work in Thessaloniki.

Giorgos Giannoulopoulos

IT CONCERNS ALL OF US

My name is Giorgios Giannoulopoulos. I am a founding member of the "Pan-Hellenic Committee of Users, ex-Users and Survivors of Psychiatry", and I work in the working structure "OUR COFFEEHOUSE" in the Psychiatric Hospital of Athens – DAPHNI.
The word "disabled" in Greek refers to the physical part of a human being. The expression "mental disability" is a neologism. A person characterized as mentally ill who accepts that he or she is disabled, does so for him/herself alone; under no circumstances could such a perception be considered as representing all people characterized as mentally ill. I personally despise the chairman of the disability association —I refer to physical disability, of course— who seems to suffer from a "Napoleon Complex".

The topic: "It concerns us all". And I will try to explain to you why it concerns us all, whether or not we are characterized as mad. And anyone characterized as mad or otherwise who prefers some politically correct terminology to describe that situation, I'm sorry but I am not going to hide behind my finger. Today's situation in our country as well as internationally, deranges and drives crazy more and more people, mainly sensitive people, who in this state of impasse and torment, are defined as mentally ill and shut down.

But first things first: so that you don’t think that “we’re all the same in this field”, as someone boldly said to me some time ago, disturbing me greatly.

There are two kinds of people characterized by the system as mad. First, the ones described as the “village madman” for whom the system could not care less, and the other kind whom authorities, every authority, would do anything to put away and at certain times, given the chance, would biologically eliminate as redundant, a needless weight, a disturbance, a destructive factor, and a threat to the coherence of society- a coherence that is needed to serve society’s economic interests. I remind you now of the well-known T-4 programme, and the hundreds of thousands of murders of the ill, the mentally ill and disabled people that took place during the Third Reich in Germany and under the guidance and supervision of that time’s great psychiatrists. The system took notice of the most well-known books and studies at that date written by (a psychiatrist, of course) Alfred Hoche under the title “*Allowing the Destruction of Life Unworthy of Life*”. The Nazis found that everything was in place to carry out their programmes. The goal had already been set. It was the different, the mad and the crippled who went first. They weren’t that creative. They just did in a hyper-efficient manner what had been done elsewhere in an amateur way and unofficially, always to the weak and defenseless. The drastic methods were always there. It was the opportunity that was missing. As it is today. And when an opportunity is missing, the system creates it. And as for the nation, the mob, it contributes to this pursuit, accepting the system’s values and standards as its own until each individual’s number comes up. The village madman was not stoned by capitalism, or by the ruling class, which only has general supervision over the system.

I don’t belong to the group that thinks that society and its people are good by nature. They aren’t, and they never were. So they shouldn’t complain about how they are treated by the more powerful - for they treat the less powerful in the same manner.

Control and especially ‘preemptive’ control are the reasons why in our country and everywhere else, the system maintains a mechanism for hundreds of thousands of people who directly or indirectly live, move, feed, profit from, and build careers in the so-called mental health field. Anyone who thinks that this number is exaggerated should take notice of the thousands of families and their members working directly in the so-called mental health field, as well as families working indirectly, which make up a still greater number.

It's not unusual that if you are mortally sick, you are left to die if you don't have money or insurance coverage. And the system won't care for that, but it will care for you in a 'preventative' sense or by use of force many times – and always for your own sake - if there is suspicion of a mental disorder.

This shows who the system considers should be kept under supervision. Supervision and not help, of that you can be sure. There is only one reason the system (and I want you to pay attention to this) began to take interest in and spend money on so-called mental health and so-called social re-integration. Only one. To put into the world methods far more effective than Goebbels's ensuring that those held to be mentally disturbed, and thus, dangerous to society can "recover" and therefore be controlled by means of psychotropic drugs and psychosurgery, for even the latter is being debated. And alas, if this message gets through, it will be accepted that for someone not to be characterized by the state as dangerous, they must take medication, even by force.
The system does not care for human suffering. It doesn't understand it. That falls by the wayside. This is its nature. When it strikes against someone, it doesn't do so personally. It's a mechanism whose parts have a partial perspective on the whole operation. The system only cares for its survival as an entity. It cares neither for persons, nor for groups, except in the sense that they contribute or get in the way of its "normal", as it defines this term, operation. When a person or a group of persons show/s a tendency to interfere in this normal operation in a given space and time, the system with no hesitation categorises them as ill, un-adapted, marginal, illegal and other similar names, and mechanisms to restore them to order are directly activated.

Humans can be quite fine, with the possible exception of certain atavistic behaviours, but the system's umbrella is just not going to include them at the given time as useful agents.

Historically speaking, almost every person who was characterised by the system as an enemy, was also a operating member and part of it. There is an exception for those elements that are outside the system's historical philosophy of existence, and course, those who are unforeseeable, those who cannot be categorised as productive branches and evolve in the system's own philosophy.

I will continue to discuss this second kind of mad person in whom the system shows an interest. Of this second kind, there is a sub-category: those people called, by me as well, "lunatics", who will occupy us a great deal.

I speak about people who, sadly enough, we have not only tolerated, but who have also managed to delude us in some part, either with the direct or, even worse, with the indirect help of certain businessmen who act and, as is sometimes written in the press, profit from the so-called mental health field, and with the help of parts of the psychiatric state or, as is it usually called, the psychiatric priesthood, that is interested in the smooth continuation of its existence and of the benefits that come from it. They are the ones that consider the lunatic, a term I also use, as exemplars for the rest of us.

When these lunatics ask for "social reintegration", they mean it on the terms of those people who cast them out of society as unwanted ones and who are now ready to take them back. They are willing to make any sacrifice needed.

And there's not much they won't do so that they are accepted as domestic pets.

Those who essentially betray the ones that are like them, looking out only for their own economic interests, cannot continuously demand benefits and rights. They give the impression that they are the crazy elite.

Of course, their ever-willing enablers give these to them freely, regardless of the fact that they're the first to despise them. And if I hear objections, I would ask those whom I address to tell me whether they would choose a love companion from the class of those that I characterise as lunatics.

Unfortunately, as I mentioned earlier, there are efforts made from various networks to promote these lunatics as representatives of the whole field, for they are easy to control, with flattery and economic promises of which they're truly fond. At every opportunity, you'll see them asking only for economic provisions. For other kinds of provisions they depend on the good will of those to whom they are humble servants.

This activity of using your condition to ask for all the more money is nothing but prostitution, as a young doctor once told me, and he was speaking the truth.

I call upon you all, at every relevant occasion, to ask for more information about the economic status, and the whereabouts of the incomes, of any mentally ill person who demands economic provisions from the state, for there is a chance they are being used as an alibi for the economic schemes of people whose incomes are far bigger and more stable than your own.

I used the word lunatic with a reason. I have to clarify here that those with neurological disorders or physical or brain injuries that affect their mentality are not mad. These people are physically ill and need a neurologist and not a psychiatrist. They should not be in a mental institution.

A few things about associations and various groups and companies: Authorities and their various supporters want us to be like monkeys in a zoo, like exhibits to be displayed as the colonists did centuries ago by transporting and exhibiting natives from their various colonies to their circus, and they really want (and do try) to install as leaders of associations, groups and companies, people controlled by them so that even this field can move according to the boundaries they set for us. They want and try to occupy us with various simplified activities, as if we all have the I.Q. of an idiot, or something worse, until sooner or later, we drop dead from the poisons that they convinced us to think of as the only way of controlling "our condition".

Take note that this is control and not treatment because the goal is not treatment but control. The "cured" mentally or physically ill person is one client less (By this I don't mean to say mental "illness" is "incurable". Everyone needs to find his own way even if he has to look in the strangest of places. Be sure that many have found their way. There is no standard recipe to be given. Look it up.)

And, of course, the domestic staff (of the companies) hears the voice of its lord and acts accordingly, even proactively if necessary.

In this part I need to highlight that participation in various groups mentally ill people's groups – coalitions etc- should be anonymous if so desired because anyone enlisted as a mentally disturbed person is going to be ruined, professionally and/or socially. It is not acceptable that someone seeking help, and thinking that he will find friends, in fact really finds himself lured into a wasp's nest that looks good from outside. And don't let me hear the words sometimes said about how going to a psychiatrist is as easy and inconsequential for your future as going to the dentist.

As for the encouragement spoken by these coalitions' members to anyone not signed-up whom they say needs psychiatric help, to go to a psychiatrist or a mental institution like this is some simple and standard matter or to let the medical members of those coalitions handle his condition and treat him, taking his data, I consider these to be scurrilous, if not worse. The people involved in these actions are nothing more than extensions of authority's hands.

If anyone has an objection, please explain to me why anyone who has or has been told that he has a mental health problem, needs to have his data collected and not be left anonymous. And if the answer is that the drugs he'll probably need have to be charged to someone, then you are insulting my intelligence.

We should not forget that psychiatry was created as a force to pursue the "dissident", and it remains as such. Every state or coalition has different criteria for characterizing someone as mentally ill. Of course, today's criteria are based on the ones set out by the American classifications of "mental disorders". Which means "whatever the big boss says". And the little employees of all levels have the DSM as their gospel.
When I say that psychiatry was created as a force to pursue the dissident, I don't mean what is generally believed - that it is just the continuation of the medieval Holy Inquisition.

Psychiatry was created and became a persecutory force after the Cartesian logical system was adopted. Gradually anyone who didn't think in a specified way, ad didn't comprehend reality from the officially authorized angle, was labelled as ill, crazy, abnormal, dangerous. The officials used medical terms and named their criminal mercenaries "doctors", because at that time a doctor's opinion was highly respected by everyone, especially the lower classes, for whom a doctor's opinion was a decree. Life was all too cheap in those days, and this was well-known by anyone who had a different opinion from what the authorities suggested. This draws on quite a lengthy conversation, but you can look it up for yourselves, and discover how old it is and how much destruction took place and is still being caused by humankind's adoption of this heartless way of thinking.

And now some words for these ladies and gentlemen, my colleagues who wish to be integrated into movements and associations of the physically disabled: First, they should accept for themselves that being called disabled is a permanent designation, and not one to be applied whenever it seems fit for their reasons; and second, since they want to be integrated into those associations that accept the fact that they are disabled in brain, thought, judgment, how can they demand equal rights, equal opportunities, equal treatment with the non-mentally disabled, since in order to use what they demand they need the very judgment they have cast away by being integrated into associations of the disabled, as mentally disabled? They have accepted that they don't have judgment. I don't know if you've got a bit confused here, but I'm sure that with small effort you'll understand very well what I mean. I believe that those who push individuals described as mentally ill to integrate into movements of the disabled do so to strip them of the seriousness and objectivity of what they say, for who gives notice to what someone says or claims or demands if that someone is mentally disabled? In the best of situations his words will be considered idle chatter. So it is a matter of course that someone else will speak for him. There lies the big issue. That someone else. Those other people. Today I highlight this point one more time: that to have someone speak in our place, as if we are stupid, is an insult to us all. Apart from the lunatics, of course.

We have an intense distaste for any kind of lobby, lobbyist, middle-man, pimp, psycho-guardian, or work-guardian, and we will not enter into any contact or arrangement unless it is made in the broad light of day. Words like "lobby" and their kind for us signify practices which we want nothing to do with.

It is, of course, understandable that a businessman of any nature puts his business first, even if the caviar he eats comes from other people's pain and grief. And this is supported as well by a left-wing parliament.

But why should the state or the European Union pay so that an individual bidder can profit? Every so often private entrepreneurs in this field make their public stands in a way that stirs up emotion so that it is accepted by the crowd.

I never heard though about anyone qualified putting forward a simple question: Why pay someone and pay them well to do a job that can be done equally by qualified public employees? (Unless the public employees can't do the job or didn't want to or don't care enough). I claim that if public employees who are part of cleared and funded Non-Governmental Organisations operating in the mental health field, had reacted in the same way they did when their own economic interests were being affected, there would be no chance of a private entrepreneur entering the field.

In our country there are many who are in the business of absorbing European Union budgets and doing nothing else. And I don't want to understand why the state hasn't eliminated them so far. The billions of Euros spent on mental health in Greece have unfortunately not borne fruition as such amounts of money should have done.

Returning to our topic, we contend that the state's payments to mentally ill persons should reflect the applicant's economic state because many mentally ill people now live in poverty, while some others, and particularly without exception those who've had direct or indirect relationships with the Greek state, receive many times the sums of the rest of us in the private sector, in addition to other provisions and benefits. Even if these people live in comfort, they say that what they have is not enough, and they ask the state for more.

And since every now and then a review is announced of the provisions and early pensions that insurance funds give to the privately insured, based on the thought that many of those are wrongly given, it is worth questioning why there's not the same constant review of those taking early pensions on the grounds of madness, from the state and general state departments, public businesses, local government, public organisations, etc. These pensions and benefits are, as I mentioned, much greater that those of their privately insured peers, and thus, they do greater damage to the state. And here I highlight the fact that the pension a private citizen takes has been paid for in his blood.

And why must the state, and as a result we citizens, also pay for the unmarried daughters of public employees, or some of their kids, who discover the easy, comfortable and rewarding solution of taking a life-long pension and health insurance from the state by being declared mad? Do we owe them something?

It is here that constant and ongoing reviews should take place, and it's here alone that this will not happen, and not just in this matter.

And because someone might wonder "Why is he picking on public employees?", I will explain myself. Public employees are employees of the state; the state was created to minister to the needs of the citizens, to serve citizens. So, public employees are employees of the citizens. In Greece, however, we have reached a point where public employees are a kind of overlord and their principal, the citizen, quite often does not have enough to feed himself. And as the people wisely say, those that do their job properly, get in trouble for setting a "bad" example. I believe I am NOT speaking an unfamiliar language.

A few things about psychotropic drugs and pharmaceutical companies.

No one knows whether psychotropic drugs and the side-effects they cause are a result of the manufacturers' carelessness or part of some research programme in the making. They use the mentally ill and some other categories of citizens as lab rats, for there are very often reports in the press about the side effects of drugs that are supposedly tested really well before being released on the public. Furthermore, the user's instructions that they come with contain an exceptionally wide range of side effects, from the most innocent to the most fatal, so that the producing companies are covered should the sufferers react and claim their rights.

As for the percentages they mention about side effects of the drugs in users, these unfortunately come only from the words of the researchers and the manufacturers and their associate researchers, and they cannot be controlled by anyone.
Films have been made to describe the dark methods and results of testing these drugs on the populations of the wretched third world.

Authorities, the system, deftly pass on and channel into the world the message, the opinion, and theory that so-called mental disorders are caused by genes, until this is widely accepted based on constant propaganda. And all this happens with the help of those who accept this fascist theory, “mental health specialists”, who enable the state to distinguish between those whose behavior is accepted and those whose behavior isn’t.

By these theories, it will soon be able to end the gestation of foetuses with non-acceptable gene combinations, as happens today with foetuses with physical pathologies. Those accepted will be the ones who have the psychological profile of a slave, a happy and obedient slave: people who like to work, who do not ask too many questions, who respect their supposed social and biological superiors and live and die happily with their situation. They will be accepted. All who cooperate with this plan are undoubtedly enemies of mankind. Today there are psychiatrists whose role is to “cure”, meaning to restore citizens who are acting up within the boundaries that the system sets. Tomorrow, psychiatrists will not be needed, because by pre-programmed eugenics everyone will be “reasonable” and foreseeable. Everyone will be biological robots. And then we will see the “Golden Age” of humanity. Men won’t be different from other animals.
Today the system needs us to work and consume. It spends a great deal of money on ensuring that we do not think, dream, ask questions or make claims
Tomorrow it will only want us to work. and that alone. There will be no reason to consume.
It is then that words, dreams, claims, rights will be a thing unknown whose meaning we won’t even be able to understand. It is a blessing that my generation won’t make it to live into this horror.
First, they started with the ”cure” for physical diseases.
Now they are aiming at the so-called mental diseases and disorders, always for the good of mankind. Always for the good of mankind, each new version-revision of the DSM includes around 50 brand new mental disorders.

Before ending, I have to mention some points that may seem unconnected but perhaps are not.

- First. Perhaps you've heard that 25% of the population will need psychiatric help at some point in life, and given the difficult social and economic situation, the figure might jump even higher. This means that psychiatric interventions will affect practically every household.
- Second. I've seen from a leaflet of a coalition of the "mentally ill" in Denmark that they have come really close to passing legislation that would enable the use of force if someone refuses to take their psychotropic medication. In Great Britain I am informed that force is already been used in these situations under certain conditions. In due time, this will probably start in our country as well with proper marketing and propaganda.
- Third. It's already under discussion that individuals who carry out extreme political actions are mentally disturbed.
- Fourth. We can take it for granted that police violence may produce public responses, but psychiatric violence, even where proven, is unthinkingly accepted by the general population.
- Fifth. We can also take it for granted that only the poor and defenseless are pursued by psychiatric or the state authorities because you see, it's easier for a poor person to be declared mad or criminal and to have his/her life destroyed, whereas no one dares to do the same to a rich person, and at this point I'm not talking about the lunatics for they themselves ask to be declared mad, and you can see the reasons for this in observing their actions.

If we connect all these points, we could very well conclude that in the near future psychiatric authorities will be able to intercede in every disruptive person's house, and administer force if they refuse to take psychotropic medication, especially in the case of poor people whose actions haven't yet been declared a mental disorder but will be soon enough.

And this will all happen with the acceptance of the general population who will take this to be ordinary practice, something normal, as it is already being tolerated more and more.

One thing is certain. The future will be really bad for all of us, especially for those who haven't been or won't be dehumanised.

And the utter foolishness of those who don't have privileges is to trust those who do, the ones that treat them like animals to be exploited. And exploitation has many faces. So does eugenics. And let's not forget the old saying: The poor don't die off; they're actually killed.

Thank you.

REFLECTIONS

We are not able to present a full record here of the discussion that came directly after this speech[2]. Nevertheless, we offer some tentative notes on the reflections and actions that ensued both in the most immediate discussion and the weeks after our Thessaloniki Congress. We do this partly in the hope of underscoring the impacts that public meetings of this kind – which remain all too rare- can have on user/survivor self-advocacy both locally and internationally.

FURTHER REPORTS OF THE GREEK SITUATION

In the immediate forum after the keynote, several Greek user and survivor delegates, in particular, came forward with detailed statements of abuses they had undergone within the psychiatric system. We heard one individual tell of "losing my brain at 32 to electroshock and lobotomy."Another described violent beatings behind the closed doors of a psychiatric institution, pointing out that if anything like this took place in a non-psychiatric setting, there would be public outcry.

Delegates referred to problems at the legal level, including not just Greece's failure to ratify the UN Convention on the Rights of Persons with Disabilities (CRPD), but the absolute enshrinement of psychiatric coercion in current local laws as 'medical treatment'. They echoed the opinion of Giorgos Giannoulopoulos that Greece was likely to adopt legislation promoting forced treatments in the community ("New laws will make things worse") – a development already noted across Europe and elsewhere, including in jurisdictions where the CRPD has been ratified.

Other speakers called out the problems in Greece as going beyond high-level disregard for the voices of users/survivors and other human rights defenders. These were matters, they said, of corruption and vested interests across government and the private sector. There was an ever-

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[2] The discussion took place largely in Greek. Although simultaneous translation was available during the proceedings, we have not had access to any English transcript subsequently. The statements below must be read with that background in mind.

growing private mental illness ‘treatment’ sector whose motive was overwhelmingly profit, and not the well-being of those on the receiving end. (“If they sign you up, this means payment for them, but destruction of the patient's life”). Representatives from a Thessaloniki-based user/survivor organisation - the Hellenic Observatory for Human Rights in Mental Health- now also came forward to endorse reports in the keynote of the reprehensible role of so-called Non-governmental Organisations. The Observatory had been documenting widespread and ongoing inhuman and degrading conditions inside the psychiatric clinics run by these private enterprises. Many of these enterprises, they confirmed, are being run on EU structural funds meant for de-institutionalisation.

Responses from European user/survivor community

The Greek contributions to the Congress – during this session and other discussions - were met by matching and corroborating reports and by statements of solidarity from visiting user/survivor participants. Several delegates from Ireland and Poland, in particular, would later comment on the second keynote intervention as the highlight of the conference:

> I think Giorgos said what needed to be said. I thought his was the central contribution to the conference . . . Listening to simultaneous translation . . . I gather he thought that a psychiatric diagnosis wrecks one's life; the drugs are poison; psychiatry is over-rated. Of course the Greek element was conspicuous throughout the conference; dominant and progressive

We note that Ireland and Poland are among the eleven countries in the European Union that have not ratified the CRPD at the time of this Report. It could be worth looking at whether there are any common issues and strategies for users and survivors in these and other places in Europe where legal adoption of the UN treaty is being resisted.

One ENUSP Board representative intervened during the discussion after the second keynote with a message about a coming UN human rights inspection visit by the then Special Rapporteur for Torture . Passing on news of this monitoring inspection, which had recently been e-mailed to ENUSP by Tina Minkowitz of the World Network of Users and Survivors of Psychiatry (WNUSP), she highlighted the fact that:

> Th[is] UN Special Rapporteur has said that the CRPD does not accept involuntary treatment or involuntary confinement and that forced psychiatric interventions may be torture or ill-treatment.[3]

Manfred Nowak, former UN Special Rapporteur for Torture, 2004-2010

She invited Greek user/survivor activists and others with relevant information to approach her after the keynote with

- Priority issues/concerns to raise
- Suggestions on key Government officials or institutions to meet
- Suggestions on places to visit in the country
- Information as possible on must-see places of detention (i.e. precise names, addresses)
- Any recent and concrete cases
- And other relevant information

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[3] To read the report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Manfred Nowak, please see: http://www2.ohchr.org/english/issues/disability/torture.htm

There was very little time to act, she stressed, because the monitoring visit would begin ten days after the Congress on October 10, 2010. Several Greek user/survivor activists expressed scepticism about the efficacy of complaining to international monitoring bodies given government corruption and the widespread disbelief of reports from the user/survivor community. Erik Olsen, an ENUSP Board Member from Denmark, spoke of the successful results of international monitoring visits to psychiatric institutions in his country, including media exposure. Opinions on the strategy were fairly divided.

UN SPECIAL RAPPORTEUR VISIT TO GREECE

Further Joint Actions by the Hellenic Observatory for The Rights in Mental Health and ENUSP based on the Congress

Members of the Hellenic Observatory came immediately to meet with the ENUSP representative after this session. The Hellenic Observatory[4] is a network to support ex-users and survivors of psychiatry to protect their human rights; the members described receiving reports over many years of torture and cruel and degrading 'treatment' at Ayios Georgios clinic in Panorama-Thessaloniki, Ayia Marina in Peraia-Thessaloniki, and Spinari clinic in Kozani, in particular. In April 2008, the Observatory had demanded that the Greek Ministry of Health immediately and thoroughly inspect these clinics based on the severity of the abuses; the response – some seven months later – had been superficial and inadequate[5].

ENUSP and the Greek Observatory decided on the need to petition for a meeting between the Observatory and the Special Rapporteur during his monitoring visit. In addition to the short time period, there were many barriers: we had no English translations of the Observatory's materials. The Observatory member Katerina Skourtopoulou worked over the next 24 hours on a translation, which she passed on to ENUSP before the end of the Congress. We reproduce extracts below.

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[4] www.paratiritiriopsy.org

[5] The Greek government has not ratified the international protocol against torture (OPCAT), which requires the set-up of an independent authority (separate from police and the citizen's protection ministry) to investigate complaints on inmate maltreatment and torture

In April 2008, the Hellenic Observatory for Human Rights in Mental Health took upon its agenda the legal complaints of numerous individuals, who addressed their causes, personally and under signature, on the unacceptable conditions of living and 'treatment', for three private clinics in north Greece.

The complaints referred to a number of major issues including complete lack of use of the courtyards and permission to leave the place within regular rights for whole years, illegal detention under involuntary treatment rules without court order, illegal refusal of release under voluntary treatment consent, dissemination of false information on the mental health of the people under treatment, excessive use of ECT[6] and physical restraint (tying down) often for pure punishment on the grounds of 'inappropriate' behaviour, severe restriction of visitors through the direction of the clinic in illicit way and despite the wishes of people under treatment, threats by the director of one clinic regarding the prohibition of contact to relatives in link to complaints, uncontrolled administration of drugs in high doses, systematic concealment of the truth and spread of false information to the people under treatment regarding their legal rights.

On November 2008, an autopsy by a committee formed by the Ministry of Health took place for Ayios Georgios and Ayia Marina clinics. The clinics were in pristine condition. Texts with patients´ rights were hung in clearly visible places according to the law. Other than that however, the committee report certified, in direct or indirect ways, most of the serious issues set out in the complaints. Improvements were proposed without however, any legal enforcement. One month after the autopsy took place, the conditions in the clinics were the same as before. No improvements were made whatsoever and the boards with patients´ rights disappeared from visible places. Lack of access to courtyards continues while many people are illegally detained against their will, in clinical conditions of unacceptable violence, breaching legal and human rights.

The issue remains open and a new legal processing is on the way. We ask for further consideration of the case under legislation concerning human rights issues and the rights of people with mental health problems signed: The Hellenic Observatory for Rights in the Field of Mental Health .[7]
(paratiritiriopsy@yahoo.com)

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[6] ECT: Electroshock Therapy

[7] The full text of the Greek original can be found here: http://paratiritiriopsy-psy-d-p.blogspot.com/2009/07/blog-post_9406.html

ENUSP and representatives of the Hellenic Observatory next worked to demand a meeting with the Special Rapporteur and site inspections. We lacked experience in this area and relied on email support and insight from Tina Minkowitz and especially Hege Orefellen, an ENUSP and WNUSP member from Norway who had submitted cases of psychiatric force and torture to the Rapporteur; these had led him to complain the Norwegian government. Tina had warned us,

> Don't be concerned that they do not include psychiatric settings in the "priority issues/concerns" to raise [i.e. police, military, prison guards, etc.] We should treat it as if it's included there. Please make a note of this fact in any information you send out.

Further support came from International Disability Alliance. We had approached Stefan Trömel after his Thessaloniki keynote about whether any last-minute complaints could still be viable; he encouraged us strongly to petition, and IDA's Ellen Walker helped us to liaise with the Special Rapporteurs' team. On this basis, the Greek Observatory submitted its complaint.
It also received an invitation to send a representative to meet with the Special Rapporteur as part of his civil society meeting in Athens on October 10, 2010.

This meeting took place, with the participation of the Hellenic Observatory representative[8]. While it did not have the result that we desired – the Special Rapporteur did not inspect the named clinics or pursue similar complaints- we feel that there were considerable gains from our efforts. We have set out the process of our campaign as one idea of how our user/survivor networks could co-operate to ensure local human rights abuses are made known of UN/EC human rights monitors. Our organisations have incomparable direct knowledge of gross and fatal human rights violations against our members. At the moment, however, many are not pursuing their claims because of a lack of resources, training, and the faith in the interest of human rights monitors will respond to our issues.

We close with a critical commentary by Katerina Skourtopoulou on the Special Rapporteur's visit and other issues in the monitoring of human rights violations in Greek psychiatric setting. She says:

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[8] We expect to provide a fuller account of this session with the Special Rapporteur (as well as more details of the Greek Observatory's ongoing work against human rights violations in Greece's privatised psychiatric clinics) in coming editions of *Advocacy Update*, ENUSP's human rights and cultural publication. For a general description of the Special Rapporteur's recommendations, please see: "UN special rapporteur urges revision of Dublin II", Athens News Portal, October 21, 2010, http://www.athensnews.gr/portal/9/32274

On behalf of the Hellenic Observatory, I want to say we are glad that mental health structures were included in the Special Rapporteur's visit to Greece. There were indisputable benefits to his visit. But the Special Rapporteur's work was really focused on institutions and structures related to criminal offence and to migrants. From his report, I think we have to emphasise the overall comment that the conditions within the inspected places 'raise substantial concerns' in terms of health care. While observations mainly referred to the lack of material infrastructure, medical supplies and personnel, this comment opens up the ground for further investigation as well as further work to improve any problematic areas for all institutions of mental health care in Greece. The "positive impression" Special Rapporteur received from the visit to the two psychiatric units, in particular with regard to the fact that involuntary patients are not kept in isolation chambers, is indeed a hopeful sign for transformations that were very much needed and for setting an example of psychiatric treatment respecting basic human rights. Unfortunately, this observation is only linked to penal psychiatric institutions. Without doubting the good intentions of Special Rapporteur, and of those individuals who are devoted to protect the rights and truly help psychiatric 'patients', the finding certainly conflicts with publicised information on the repulsive conditions of 'treatment' and living for at least some of mental health care institutions in Greece. This information is largely based on individual 'patient' complaints.

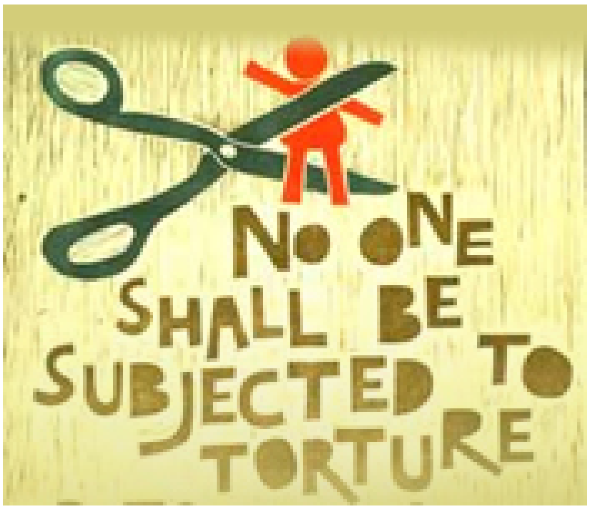
Given the current situation, it is of key importance, in my opinion, that psychiatry is being put in the context of torture and the UN Optional Protocol to the Convention against Torture (OPCAT), which Greece has not ratified yet. OPCAT reaffirms 'that torture and other cruel, inhuman or degrading treatment or punishment are prohibited and constitute serious violations of human rights'. Regrettably, in many cases, being subjected to psychiatric 'treatment' against one's will, and even voluntarily, turns out to be a truly degrading experience. If what it takes in order to achieve more efficient inspection in the future is further measures including first and foremost the ratification of OPCAT in Greece, this must be one of the major targets of (ex)users/survivors movement and any other critics of mainstream psychiatric practice that violates human rights.

Having said that, I would like to stress an issue that I deem as crucial for building a framework upon human rights protection. There are obvious problems with monitoring mechanisms when these are solely based on short-term inspections of places where people are deprived by law of any contact with society, from any observation by the community; contexts completely closed to contact with the public; places whose operators refuse any open dialogue with social critics. What is not obvious to me, and I hope to many people who stand against psychiatric violence in both its physical and mental versions, is disregarding a realistic control over human rights, by legal bodies devoted to society's well-being within medical care services.

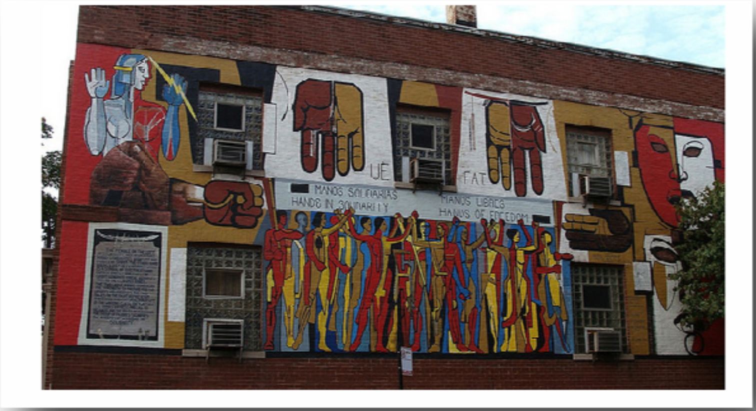
Human Rights watch inspections, from time to time, in those closed spaces where people are being deprived of their very basic rights according to the constitutions of democratic societies, including their freedom over their own body, freedom of speech, and other basic citizens' rights such as the right to call for and participate in juridical processes, is a weak contribution to the guarding of these very essential rights. If such visits, by an objective body, become regular, acquiring a preventive character, including the examination of 'treatment' on an individual basis, this would be a more dynamic means to stop human rights breaches. In my opinion, such changes could only be mobilised successfully at national level.

In connection to creating such a protective framework, an even more powerful solution to the problem could come from 24-hour inspection by video monitoring. Such equipment is very easy to install and costs very little in comparison to the huge amounts of money spent every year in medical funding supposedly for our mental health. The video data speak for itself about the health conditions and more than that, the 'endangering' behaviour of the people labelled 'mentally ill' and kept inside institutions, very often against their own will, upon the pretext of being a 'danger' to self and others. In my opinion, legislation to make this close inspection video monitoring mandatory, is the only solution for the protection of 'patient's' rights inside institutions. No matter how efficiently the team of Special Rapporteur tried to work upon such sensitive issues, no matter how valuable their work is as an objective body of observation, if the relevant social groups and policy-makers responsible for those institutions at national level, continue to reproduce the same strategies of fear, loss of dignity, pain, and eventually the deprivation of life at least in its emotional and mental forms, if they continue to reproduce a system of 'therapy in the dark', behind closed doors, where the deprivation of freedom is the key factor for 'therapy' to 'go well', nothing is going to change.

Thessaloniki, January 2011



Hands in Solidarity, Hands of Freedom.
Mural on the side of the United Electrical Workers trade union building on West Monroe Street at Ashland Avenue in Chicago, Illinois. ©Atelier Tee



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PRESENTATION OF THE WORKING GROUPS

At the end of the morning, there followed a presentation from each of the working group and workshop leaders about the activities on offer in each of the groups. Below are the details for each.

WORKING GROUPS ABSTRACTS AND SHORT BIOGRAPHIES OF FACILITATORS:

1a. Peer support specialism: Training programs for (ex-) users and survivors of psychiatry to become user-survivor workers

Abstract: For several decades, few pioneers in the Netherlands are involved in the changes towards more recovery oriented programs in Mental Health Care. Moreover client-involvement in treatment- and care facilities are promoted, accepted and in some cases even appreciated. The number of (paid) peer specialists in such contexts, was estimated at around 250 in 2008 in our small country. We might be on a way to approach a long-time desired emancipation of users of mental health services by involving peer support specialists.

On behalf of the organisation of peer workers, we started a research-project in 2006, in order to obtain a state of the art on the current position of peer support specialists in mental health services. The aim of the project was to obtain a clear view on the work that peer support specialists do – and the roles that they fulfil, thereby empowering them in their activities. Since the project was divided in two parts, there was a second focus on the available training and education for those who are eager to progress and professionalize.

After two years of research, discussion and debate in the related field, it is time to respond. There is an increasing urge to develop study-facilities for those who want to feed health care with client-expertise. University of applied sciences Utrecht and its social studies, aim to stimulate the development of a special itinerary in their education.

In this workshop we will present our findings from our research (2006-2008), some recent findings in the field (2009) and our plans for education (2011 and further). Aim: We hope to exchange thoughts and developments with represents of several European contexts and connect best practices and spirits.

Facilitator: **Simona Karbouniaris**. Simona (b. 1980) studied Social Work from 1998 to 2005 and started to work as a researcher at the Research Centre for Social Innovation after graduating in 2005. She focuses on client-participation, innovative community work and rehabilitation. In spring 2008 she and her colleague presented first insights on ‘User Participation - towards active peer support specialism in the mental health sector', at the School of Social Work of University of Kalmar. Simona is a peer specialist and client-activist herself and set up a Peer Support Project in a mental health specialized centre for people coping with eating disorders in 2009.

1b. Training programs for (ex-) users and survivors of psychiatry to become user-survivor workers

Abstract: The process of mental crisis opens chances of spiritual development. The interaction of the prime person involved in the crisis and its social environment contain the key to a successful transforming process. In a very special way, users and survivors of psychiatry have the entrance to the clearing and healing field by their own personal experiences of crisis. The EX-IN project uses scientific empirical studies that show users and survivors are in dignified in their specific way to accompany therapeutic successful, persons in crisis. The Ex-IN project members (England, Netherlands, Norway, Sweden, Slovenia, Germany) worked out national curricula to give an further educational program how to qualify the experienced person to work as an equal partner in the therapeutic process. But, for example, the German curriculum lacks of critiques of psychiatry. The phenomenon of re-traumatising users and survivors in the future working field is not questioned. The violent structure of psychosis treatment by pharmacological and physical assault is no topic. Salaries of future EX-IN co-therapists are not discussed and defined. In Germany, the information flow inside the EU process of EX-IN is organized hierarchical around the association **F.O.K.U.S** Bremen, and there is no authorized user/survivor partner involved. The associations of users and survivors of psychiatry are not equal partners in the organized internet communication platform. The idea of EX-IN primarily gives users and survivors of psychiatry a very good chance to improve the psychosocial system. My personal hope is that ENUSP will add their wishes to the curriculum and will be equal partners next to national and regional associations of users and survivors of psychiatry of the concretely education process and the actual co-therapeutic work. Also the recommendations of the action project "Harassment and discrimination faced by people with psycho-social disability in health services", organised in the framework of the Community Action Programme to combat discrimination 2001-2006, recommend (a) training programmes for (ex-) users and survivors of psychiatry so they can protect themselves from discrimination, become user/survivor workers employed at all levels and become trainers themselves in programmes to combat harassment and discrimination, (b) the effective representation of (ex-) users and survivors of psychiatry or user/survivor workers in crisis centres, counselling centres,

public relations work, research projects, congresses, networking and international exchange of organisations representing (ex-) users and survivors of psychiatry, and (c) the support of initiatives of peer coaching, regional self-help centres and meeting places (see www.enusp.org/documents/harassment/recommendations.htm). Aim: It should be discussed on a European level, how this involvement can be started resp. improved.

Facilitator: **Berthold Kösel**, born 1961 in Germany, artist, married second time, 20 year old son, high school diploma 1981, university studies agriculture, political science, mechanic engineering ,dentist, architecture, civil service Max-Planck-Institute of Psychiatry Munich, since 1982 experience with altered states of consciousness, estimated 3 years experience with assault-orientated German psychiatry, apprenticeship in cabinetmakers craftsmanship, free staff member in architecture office Lothar Keiner, free architect Bavaria free staff member in office W. Kopp, free architect Bavaria, free trained retail salesman in my shop Olympic Fruits Bavaria, between 2001-2005 two years refugee on flight (France, England, Netherlands, Greece, Turkey and Bulgaria) because of fear of psychiatric violence against my life. Since 2005 back in Germany. Work on my artist career in projects of urban architecture models, furniture, energy-soul-pictures in different systems (oil, water, acryl), work on the project "architecture and violence", workshop since 2009. Using psychiatric drugs, member of the organisation of (ex-) users and survivors of psychiatry in the Bundesland Bavaria, founding member of the psychosis self-help group "Initiative Lebensmut" (Initiative Courage To Face Life) in Pfaffenhofen near Munich. Μιλάει λίγο την ελληνική γλώσσα καθώς έζησε το 2004 για 9 μήνες ως πρόσφυγας στην Αθήνα, τη Θεσσαλονίκη και σε νησιά του Αιγαίου.

2. Researching suicide as an outcome of psychiatric treatment

Abstract: There is anecdotal and expert evidence that suicide can be an outcome of psychiatric treatment including psychotropic drugs (especially neuroleptics), electroshock and restraint, as well as from the psychological impact of diagnosis, discrimination and stigmatisation. However this evidence can be hard to collect and verify as it runs counter to the belief systems which underpin psychiatry. Moreover, there is evidence that many randomised controlled trials, especially those run or funded by the pharmaceutical industry fail to report suicides of people undergoing treatment, and there has been no support for research on possible iatrogenic causes of suicide. Aim: This workshop will explore the available evidence for the proposition that psychiatric treatment can be the cause of suicide and discuss ways in which service user/survivor led research could begin to investigate this issue and focus more attention on it.

Facilitators:

Jan Wallcraft, living in England. PhD in 2002. Manager of the Service User Research Group for England (SURGE) and freelance mental health consultant and researcher. From 1987 to 1992, co-ordinator of Mind's user network, Mindlink. In 1992, co-founder of the U.K. Advocacy Network. From 1987 to 1990, member of Survivors Speak Out's national committee. 1997 to 1999, lead researcher on the user-led Strategies for Living project at the Mental Health Foundation. Author of Healing Minds (1998); co-author of On Our Own Terms: Users and Survivors of Mental Health Services Working Together for Support and Change (2003); Being There In A Crisis (1997); contributions in Social Perspectives in Mental Health (2005); Mental Health at the Crossroads (2005); Alternatives beyond psychiatry (2007).

Peter Lehmann. Living in Berlin, Germany. Author and editor since 1986, then foundation of Peter Lehmann Publishing and Mail-order Bookstore. Board-member of ENUSP). Since 2004, member of the International Network Towards Alternatives and Recovery (INTAR – www.intar.org). Publications in English language include, Coming off Psychiatric Drugs: Successful withdrawal from neuroleptics, antidepressants, lithium, carbamazepine and tranquilizers, edited in 2004; Alternatives Beyond Psychiatry, edited in 2007 together with Peter Stastny. More see www.peter-lehmann.de/inter

3. Voices and Hallucinations

Abstract: In Athens, 6 of us meet every 15 days and participate in a group about voices and hallucinations. We shall talk about our experience within this group and we shall discuss how we can manage our voices and our hallucinations. Furthermore, we would like to hear similar experiences by the participants in the workshop. We believe that the voices and the hallucinations are much more than just a matter of medication administration; it is rather a management and a contact/communication issue. We would also like to refer to the stigma that is attached to people with voices and hallucinations experience.

Facilitator: **Vaso Kalogianni** is a resident of Athens and a teacher in retirement.

4. Mental health problems and how we get over them

Abstract: This is about an open dialogue where we, survivors of psychiatry, will discuss our experiences and the problems we have to deal with; also, there will be a discussion on alternative experiences of getting over or dealing with our difficulties as well as suggestions of alternative therapeutical methods.

Facilitator: **Panayotis Kasselakis** is a private sector employee and a resident of Athens.

5. Occupational Therapy Invalidates Art

Abstract: Art requires inspiration. Inspiration does not present itself within pressing conditions and "moulds". Occupational therapy takes away your natural talent, degrading you. At many occasions, your talent is also taken away from you due to the influence of medication. We alone, through who we really are, we can produce Art. Making art a part of hospitalisation does not produce art. Occupational therapy is a different story from art and they should not be mixed. Art is therapeutical only when you are free to act and function.

Facilitator: **Vaso Kalogianni** is a teacher in retirement and Aspa Tzioti used to work as a ceramics painter. Both dwell in Athens.

6. Self-help in the Balkan Communities

Facilitator*: Akis Asprogerakas:* I was born in 1957 and grew up in Athens. I graduated from the Polytechnic School of Milan, Architects Department. I work in YPOMEDI, in Natural Catastrophes. I am an elected member of the syndicate of public sector engineers (EMDYDAS). I was a radio-pirate since the beginning of the 70s and I participated in the events in Polytechnic School of Athens in 1973 ("Polytechneio"), relaying in my radio station the broadcasts of the November rioters. Being always intensely involved in political matters, after the change-over and within the Free Radio Broadcasting Movement, I put into action the "RADIO-MOLE" (Radio-Tyflopontikas) - one of the first radio stations of "Legalization". The MOLE team is on the air until 1985 - in spite of the direction finders, with alternative - ecological broadcastings - when the antenna is spotted and its members arrested. Again on the air in 1987-89, with correspondingly active broadcasts, in Athens. Since then, I have been assisting alternative broadcasting attempts throughout Greece.

I am active in the movement for transformation in mental health and I participate in the Self-Help Group of Athens. This is an extrovert type group, with intervening in select social issues being its core therapeutic characteristic. We focus on the defence of the rights of hunted down victims of the all the more persistently present social and psychiatric atrociousness. We are lucky to be a mixed group, consisting of voluntaries, suffering individuals and Mental Health professionals. We all participate in the group according to our own personal involvement and sensitivity and not correspondingly to our given roles. I develop actions standing against psychiatric atrocity and the mainstream biomedical model's commercialisation tactics. For the embracing and the de-stigmatisation of the suffering individuals by the community. To tear down the walls and the institutions of exclusion and violent confinement.

7. Rights and Psychiatry

Abstract: From the construction of mental illness to the shrinking of the healthy human model and from the violence of confinement to the freedom of psycho-consumer.

Facilitator: **Dia Koutsogianni** is an Athens resident and a member of the Athens Self-Help Group.

8. Medication and Suppression

Abstract: There are psychoactive medicines that act in a suppressive way, according to my experience. I would like us to reach, through an open dialogue, a conclusion about suppressive medication (e.g. Risperdal).

Facilitator: **Panayotis Kasselakis** works as private sector employee and is a resident of Athens

9. About Philosophy of Psychiatry

Abstract: This year we (from ENUSP board) are involved in the organisation and the program of the International Network Philosophy and Psychiatry. Already a longer time we are involved in the development of philosophy and psychiatry by our contacts with the professors at the University of Preston (England). Aim: In this workshop I want to explain what is philosophy of psychiatry, what it is doing and why they are interested in us. I want to discuss what we can do with philosophy of psychiatry and why it is good that we are interested in it. I want also to promote user/survivors of psychiatry to start studying it. It is not necessary to be afraid of philosophy. Studies in philosophy and psychiatry can be very pleasant, helpful and even sexy.

Facilitator: Jan Verhaegh (Deputy Board Member of ENUSP), The Netherlands. I am studying a postgraduate master-course in philosophy and psychiatry at the Institute for Psychiatry, Philosophy and Diversity (University of Preston) and did already the half of the course with success.

10. Re-building ENUSP – A strategic planning group (This workshop was run in two parts)

Abstract: Since 2005, ENUSP has operated without any public financial support. Membership fees, which were introduced by a decision of the last General Assembly in 2004, are just about enough to cover the administrative costs of running an international NGO. The fact that ENUSP must rely solely on the voluntary work of a small number of active Board members and Board supporters (introduced in 2009) in the time that they are able to commit creates an almost impossible situation, seriously jeopardizing the future of our organisation. Under these constraints, we cannot fulfill our main goals to provide a Europe-wide platform to mental health service users/psychiatric survivors, and to ensure our independent representation and the effective expression of our demands, interests and concerns in forums where decisions and policy are made with immediate effect on our lives. The aim of this working group is to launch a systematic effort to improve this situation, using our knowledge, ideas and energy to start figuring a way out of the present vicious circle. The facilitators will provide a brief explanation of the current situation and the context in which ENUSP operates. We will present some of the possibilities available for European funding and the main obstacles which ENUSP faces in accessing those funds. We will bring concrete questions to help us structure the discussion in order to think together and start planning a way forward. The outcomes of the working group in the form of priority tasks for the new Board will feed into the General Assembly and inform the regional meetings; they are intended as the first steps towards creating an action plan for the next two years. For this purpose, we will need a total of four hours of committed work and therefore kindly ask those deciding to join this group to remain in both sessions. We appreciate everybody's interest and are looking forward to this important opportunity for a constructive and outcome-oriented discussion.

Facilitators:

Jasna Russo has been an individual ENUSP member since its foundation in 1991. She has experienced psychiatric treatment in Serbia, where she comes from. For the last 18 years she has lived in Berlin, Germany. Jasna served on the Board of ENUSP from 1994 to 1997 (at that time representing the Eastern European region). At the last General Assembly in 2004, she was appointed to undertake the tasks of the ENUSP Secretary. As there was no further funding available for that post, she was co-opted to the Board in 2005. Jasna works as an independent researcher on both collaborative and survivor-controlled projects. She has an MA in psychology and has additionally learned knowledge management. Her articles have been published in different anthologies in Germany and UK.

Debra Shulkes joined ENUSP as an individual member in 2008. She is a survivor of psychiatry from Australia and is now based long-term in the Czech Republic where she works as a freelance writer and editor. In early 2009, she became a support board member of ENUSP, responsible for key writing and administrative tasks as well as gathering information on funding possibilities. She is particularly interested in improving communication and knowledge and skills exchange among ENUSP's diverse membership and allies. She is the founding Editor of Advocacy Update, the human rights and cultural publication of ENUSP that launched in January 2010.

Gabriela Tanasan is a survivor of psychiatry and an activist for user involvement in Romania. She is the Executive Director of Horizons Foundation (member of ENUSP). In March 2009, she was co-opted by the Board of ENUSP as the individual responsible for the Central European Region. Gabriela's particular interest is in organisational development. Working on behalf of ENUSP, she was the main person responsible for organizing this conference.

11. Organising European Mad Pride Events

Abstract: Overall the workshop will have two parts: the first, mostly led by Rafael DAEM, talking about the history of Mad Pride and what UilenSpiegel organised in 2007 very successfully and a second part, more hands on, more practical, mostly led by Anne-Laure on MadPride Europe 2011: deciding the central themes, organising the event in the different countries across Europe, flyer competition, as well as the issues about the coordination (practicalities, work schedule, communication between organising members etc.) and implementation of MadPride Europe 2011.

The Mad Pride : Who we are ! and what it is! A unique parade inspired by Mad Pride's of Mind Freedom http://www.mindfreedom.org/campaign/madpride.

The Mad Pride . . .	Is a movement by and for people mentally different and more vulnerable; who struggle for more input and decision.
The Mad Pride . . .	Is accessible for people and groups which deal with mental healthcare, individuals with psychiatric issues, individuals with existential concerns, people with particular psychic experiences and all who share the cause and concerns of former collection of individuals.
The Mad Pride . . .	Has a pronounced diversified character and is not prohibited to a cultural, religious or political democratic point of view.
The Mad Pride . . .	Fights discrimination, prejudice, and harmful consequences for people experiencing a spiritual & mental imbalance.
The Mad Pride . . .	Promotes economical, political, social and cultural integration of users and survivors of mental healthcare system into the larger community.
The Mad Pride . . .	Celebrates creativity, power and resilience of the human mind.
The Mad Pride . . .	Offers a forum to users and survivors of mental healthcare and triggers the public opinion to a wider interest.
The Mad Pride . . .	Has concerns to fight the stigmatisations of individuals whom live like *outcasts* and are different than the social norm.
The Mad Pride . . .	Encourages self-consciousness, awareness and moral support of these afore-mentioned individuals.

Facilitators :

Rafaël Daem became through life experience member of UilenSpiegel (MH Representative Association of Patients – Belgium, Flemish Community; www.uilenspiegel.net) in 1997 and became soon its President (voluntary basis). UilenSpiegel had and still has five goals starting from contact between (ex-)users till policy participation on federal level. Together with the Board he consolidated the Association in 2001 through the approval of the Federal Government of financing a part of the activities on yearly basis (the agreement with the Authorities is to increase the Participation and Integration of Patients on Federal level) during the first wave of MH-reforms in Belgium. In 2006, with UilenSpiegel celebrating its 10th Anniversary in 2007, he initiated the Anniversary Project (the Mad Pride being one of the events) and took part to its accomplishment. For the first time he was professionally enrolled for a small year within UilenSpiegel. He also therefore had trusted at that time the presidency to someone else. In 2009, on a ½ FTE basis within UilenSpiegel, he accepted to take upon the job of coordinating the (ex-)users' participation in the project of the federal second wave MHE reforms (2007 – 2010); in the role of MHE-patient-expert. As a result of the work accomplishments, UilenSpiegel is to take part in the third wave from 2011 on till 2014 included together with potential five other partners (non scientific and scientific). Note of the actual President : a strength of Rafaël is to be able to translate what is really living within MH (from the patients' view) into project ideas and association goals.

Anne-Laure Donskoy (UK), is a service user and a freelance user researcher and consultant in mental health. Although French she has been living in the UK for over 20 years. She has been supporting Advocacy Update as design editor and hope to contribute texts in the future as well. As a support member to the board she has chosen to use her bilingualism and support users and survivors in Belgium and in France in particular, where she is (humbly) helping to shape a genuine user movement and where she has recently published a number of papers on the issue. She is also supporting users and survivors in Portugal. She has also been active in ensuring that the user/survivor voice is somehow genuinely present in the European Commission's Thematic Conference Series (as part of the Mental Health Pact) and has herself presented at many conferences on user research and self-wounding. She has an interest in ethics, human rights, user research and philosophy.

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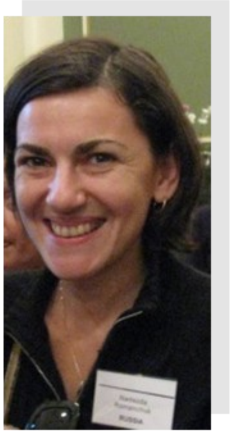
“PEOPLE” - NADEZDA ROMANCHUK



NADEZDA ROMANCHUK

Nadezda is a 33 year old Russian artist and survivor. She says,

"I never studied art. Now I am training in an art studio, with a very good person. He is an artist himself. I started to draw about 7 years ago. I am told that I have developed my own style and I'm very flattered to hear that. It is possible to communicate with any people.

All people can have problems. I very often remember this trip and didn't think it would be so good . It was my first time abroad, and everything was a very pleasant surprise. I love all that is fine - music, the nature, people and life. And in this life there are fine moments. And it is filled by love."

Nadezda also writes poetry and she wanted these few verses to go with her artwork:

Мы верим в людей

мы верим что солнечный свет никогда не погаснет
мир полон добрых идей
нам невозможно думать о несчастье...

и ещё)
мы можем довольствоваться радостью в сердце
мы верим что мир безоблачно красен
я знаю жить невозможно этим
следующий день будет добр и ясен...

We trust in people

We trust that the sunlight will never die
The world abounds with kind people
We're unable to conceive of misfortune
And also)
We can be content with joyous hearts
We trust in the world cloudless beauty
I know one cannot survive on this
The next day is going to be kind and bright...

Translation: Agita Luse

DAY THREE

FEEDBACK WORKING GROUPS

DAY THREE

PART I

FEEDBACK FROM THE WORKING GROUPS

Each working group leader was asked to give feedback from their group. When English feedback reports were sent in after the Congress, they have been included in full (Working groups and workshops 2, 8 and 11). All the other feedback reports were notes taken during the feedback session. Some are only brief due to translation issues.

Feedback from Working Group 1a

Peer support specialism (brief notes from the feedback session)

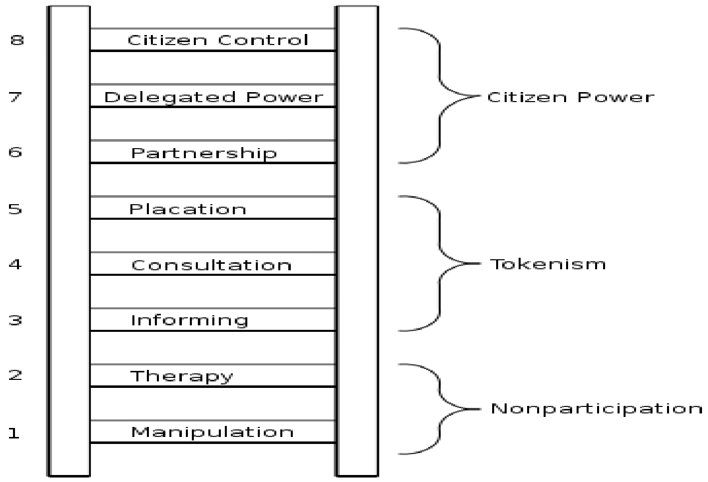
The workshop talked about different examples from different countries and the issues linked to being in or out of the system.

Feedback from Working Group 1b

Peer support specialism and training programs (sent in by Berthold Kösel & Simona Karbouniaris)

The motive of our working group was to identify the importance of support by peers. Peer (support) specialists are users in recovery. They have reflected and discovered collectiveness in their stories and the stories of other survivors. They use their experiential knowledge to improve Mental Health Services and environmental sources and become active actors in treatment, training, education or research.

At first we overlook at the increasing involvement of users, from a historic perspective. In 1970 we were striving for the acknowledgment of rights, followed by policy campaign activities and the anti-psychiatry movement. From the ‘80 on, rehabilitation has made some progress in the classic facilities. After 1990 the actual participation of users gains respect. The last years we have seen an increasing focus on recovery oriented services and empowerment approaches. A way to express the different levels of user involvement is seen in this model (by R. Arnstein).



After a short introduction we gave an first insight of our findings in West Europe (Germany and The Netherlands). In creative ways, users and survivors of psychiatry have found entrance to the clearing and healing field by sharing their own personal experiences with illness, recovery, care facilities, reactions in community.

In Germany the EX-in project searches for scientific empirical studies that show users and survivors accompany therapeutic processes successfully. The Ex-IN project members (England, Netherlands, Norway, Sweden, Slovenia, Germany) worked out national curricula to qualify experienced persons to work as equal partners besides professionals. But there is a need for further improvement and recognition.

In the Netherlands there is an increasing urge to involve (ex)users in therapeutic settings where they are working (more and more in paid jobs) as peer support specialists, next to therapists. However this also reveals the need to develop proper education, where ex-users are able to combine their reflections with theoretical and practical findings.

This movement is needed to empower the position of current working peer specialists and the Research Center for Social Innovation in Utrecht decided to work together with the Dutch foundation of peer specialists. This last mentioned consumer initiative started in 2005 and has the purpose to define and increase the quality of the profession and working conditions of peer specialists.

Client-involvement in treatment- and care facilities are promoted, accepted and in some cases even appreciated despite first resistance.

In this workshop we integrated findings from fieldwork, research, and exchanged thoughts and developments with represents of several European contexts and connect best practices and spirits. One of the present participants of the working group shared his mental health user experience, pioneering in Romania. He earned his money working in a psychiatric hospital and was part of the system there, he was one of the teammembers and well accepted.

The question rises whether it is desirable to be part of the mental health system. There is a huge urge to reform or at least rebuild the current psychiatric systems in many European countries. Being part of that, may mean, that you're accepting and practicing the things that should be changed. It may also mean that you see chances to make these changes. But as a solely individual that is often quite hard, as we have experiences in The Netherlands in several facilities. It's often needed to be either out of the system, but in contact with clients ór part of the system but at least with more than one peer support colleague.

By the end of our workinggroup-session Berthold suggests to start a network of peers, throughout the different European countries that are represented today. Any interested candidates may contact him directly (bertrapzon@yahoo.de). Other questions concerning this workinggroup may be addressed to Simona (simona.karbouniaris@hu.nl)

Feedback from Working Group 2

Researching suicide as an outcome of psychiatric treatment (sent in) (by a participant of the working-group and the facilitators)

The reasons that can lead a person to commit suicide were presented, analyzed and discussed: Among them were economic reasons, difficult social conditions, disappointment and serious diseases such as AIDS or cancer.

There was extended reference to the consequences that neuroleptics ("antipsychotic drugs") have, to their pharmacological main effects which include mainly more or less subtle symptoms that we find in Parkinson disease ("Parkinsonism"), and in a degree to which they do not only affect the muscles but the mind as well ("Parkinsonpsyche"). This mental alteration includes depression and ideas and tendencies to commit suicide; so we have a new reason why a person can be led to commit suicide.

In the discussion, the participants gave their own personal accounts. Some agreed that treatment can cause suicide or suicidal thoughts, even if it is intended to prevent it. Several had had personal experience of being involved in research. They asked questions about the research that is taking place on neuroleptics and their relationship with suicide and on the negative response on the part of the pharmaceutical companies who refuse to use these statistical researches when creating new drugs. There was also discussion on the reception this type of research gets in Europe and on user participation; finally, there was comparison with Greece where there are not yet such organized researches by neither mental health professionals nor consumers of neuroleptics.

Questions included whether there is any research comparing suicidal feelings and depression resulting from medication to suicidal feelings arising in normal life circumstances (i.e. with no medication), and if there is research on cultural differences in dealing with suicidal feelings and thoughts.

Solutions and Conclusions:

- It was a common conclusion and request by almost all participants in the workshop that this research should become widely known so that individuals receiving medication can be informed about such type of side-effects
- Users and survivors of psychiatry should be given training and education to be better able to talk on the lecture circuit to students of medicine and law
- Users and survivors of psychiatry should be part of the syllabus in Universities, especially in Law and Medicine, in order to educate and sensitize new scientists on these issues and to enable a joint research project with meaningful participation of users and survivors of psychiatry
- That in all cases, such side-effects must be written on the instructions-for-use-leaflet of each medication.
- The funding provided for such research must be used by the people involved and not to cover personal profits
- Information was given about possible funding from the E.U. and that we would be interested in ENUSP taking the initiative to conduct such research in collaboration with Greek people also here in Greece.

Feedback from Working Group 4

Mental Health Problems and How We Get Over Them (brief notes from the feedback session)

Mental health issues: how to get over them without medication but with the help of occupation. Working, having a job can be very helpful. Drama therapy too, as well as writing for finding out who we are and for expressing our feelings.

Feedback from Working Group 5

Occupational Therapy Abolishes Art (Notes sent in by translator)

The report of Ms Vaso Kalogianni and Ms Aspasia Tzioti was read. The report was on how famous artists like Vizyinos, Halepas, Katerina Gogou and Nikolas Asimo had succeeded in becoming recognised despite their psychotic experience and how they had continued their work even inside the clinics where they were hospitalised. Also, the existing conditions related to occupational therapy were discussed.

The discussion with the rest of the participants included the following:

There was a report on how occupational therapy is applied inside clinics and how many individuals feel that they are being helped; they are creative and express their emotions. Many times they also reflect their psychological experience through their work. However, there are occasions where work therapy functions negatively, such as when it is must be done during specific timeframes given to people with psychotic experience in a clinic, without them feeling inspired or in the mood to express themselves in an artistic way. Many times they are not given the option of doing things which they want to do, simply because it is not within the scheduled timeframe.

There was discussion of how people had done art work before the use of drugs/medication (art work could have also been their way to make a living, or simply a hobby) and how after long-term use, it was a struggle to be creative again. This could be because they had lost their creativity, concentration power, and persistence in creating an artistic work from the beginning until its completion.

It was also reported that in the KOI.S.P.E.* Centres, the creation of some art works is being paid for. This is important ethically, and also as motivation.

Conclusions:

The main point of this discussion during the workshop was that art work should be a true expression of its creator since people with psychiatric problems are also people with a human identity. We all agreed that it is only when intuition and expression are free that they can produce art. As a post-script on the workshop: the following day, it was said that it was right that this topic had been raised and that there should be special classes and modules (specialty) in universities and faculties for people who want be involved as occupational therapists.

*KOI.S.P.E. or in Greek ΚΟΙ.Σ.Π.Ε. stands for Κοινωνικός Συνεταιρισμός Περιορισμένης Ευθύνης which means Social Cooperative of Limited Responsibility: http://www.koispe.gr/index-en.html

Feedback from Working Group 7

Human Rights and Psychiatry (brief notes from feedback session)

The facilitator had had 20 years experience in the psychiatric system, had experience of drama and of painting as an artist.

This was her first experience running a workshop which was very important to her adn she was “very moved to see so many people”. The topic of the group was a “painful one”, looking at repression, violence and the violation of human rights. The facilitator though that through solidarity we could achieve “superhumanship” and it has been a great honour and joy to participate in the conference for her.

Feedback from Working Group 8

Psychiatric Drugs and Repression (brief notes from feedback session)

The effects of stopping drigs abruptly are rarely taken into account. It should be a personal choice to take, or not, psychotropic drugs. There is also the issues of psychiatrists who may be benefiting from pharmaceutical drug companies.

Feedback from Working Group 9

About Philosophy of Psychiatry (Notes sent in by the facilitator)

In this very interactive workshop we were together with users/survivors of psychiatry, with professional workers and some students of the university of Tessalonike. These students were besides doing the translation also very active in the discussion. They were explicitly asked by me to do that. I find it very interesting what these young students with a fresh perspective think and have to say..

At first i gave a short presentation about the new academical profession of philosophy of psychiatry. This profession started already at the beginning of psychiatry. In that time most psychiatrists were also philosophers. For a very long time, to begin with the Greek philosophers, psychiatry was an important chapter in philosophy. Sigmund Freud and Jacques Lacan were as much important for philosophy as for psychiatry.

Someone as Slavoj Zizek (also psychiatrist)at this moment is probably even more important for philosophy as for psychiatry.

One of the founding fathers of the philosophy of psychiatry is Karl Jaspers, who suffered whole his life from an illness which made him very vulnerable for infections, so he has to be very carefull with contacts with other people. So he could study on psychiatry and do important philosophy about it, but was not able to do treatments with living patients.

Also the influence of anti-psychiatry, the user/survivormovement and the new developments on the field of neuro-sciences made it necessary to do again philosophy about psychiatry.

We talked about the different chapters in philosophy of psychiatry(analyzing concepts in philosophy and psychiatry, theory of science, history, ethics, philosophy of the mind, social dimension of psychiatry) We talked a longer time about the question what it does mean that psychiatry does want to be a scientifical unterprise in relation to taken serious the problems, complaints and life stories of the patients. We have the feeling that psychiatrists often take their scientific apporoach more serious than they take serious the psychiatric patients. Sometimes the whole narrative of the patients disappear behind a scientific approach of diagnosis and medicines. An area in which this occurs very much is the field of religion. Psychiatric patients are religious or express their psychotical thoughts and experiences in religious terms. At the other side psychiatrists in western europe are mostly educated in scientifical and modern secular thinking and are not religious at all. If not stronger ; sometimes they are allergic for religious thinking or seeing it as psychotical thinking. Sometimes patients suffer from the fact that religious feelings are taboo and that they cannot talk about these feelings. To take all the feelings and experiences of psychiatric patients seriously and have some ability to cope professional with religious feelings of patients (as with their sexual feeling) does not mean that you support fundamentalism or something like that.

The World Psychiatry Association has published a very interesting handbook on psychiatry and religion. My problem with the handbook is that it is very positive about religion and that is only one side of the story. In history of philosophy we have a long history of great problems with religion and in general in western philosophy the death of God is already a long time accepted. Nowadays philosophers say that is was too much accepted in a dogmatic way and that we have to look to religion in another way.

Not only in the history of philosophy we had great problems with religion, also psychiatric patients were religious traumatized. Not only as in par example of sexual in the roman catholic church but also in other religions. And feminists say that in all religions there is a very strong dominance of males and patriarchal ways of thinking.

Speaking about all those things, we had a very active and certainly through the narratives of some users/survivors emotional impressive workshop. We could have spoken with each others for at least a week but after two hours we were obliged to stop.

Feedback from Working Group 10

This working group was divided into two sessions in order to have enough time to focus on the four very specific priorities (From documents sent by the facilitators)

A. Defining **PRIORITY AREAS** for the work of ENUSP
B. Division of **ROLES and RESPONSIBILITIES** within ENUSP (towards Bylaws), in particular the issues of difficulties and confusion between the different roles: Board members (including deputies and co-opted board members, and lately support members to the Board); The Secretary (the position used to include both book-keeping and legal representation); and also the Newsletter (Advocacy Update) and the website.

C. **FUNDING** issues: In particular: ENUSP - FUNDING APPLICATIONS

MAIN TASKS

1. Searching for information on available funds and their selection criteria
2. Making summaries/reporting to the board

3. Deciding where to apply for funding
4. Working on the application
5. Preparing all the required documents which are likely to include:
    a. Action plan/Strategy
    b. Financial reports of last years
    c. Legal documents of ENUSP (such as registration and statute)
    d. Etc.
6. Searching for sources of co-funding
7. Applying for co-funding

After successful application – grant/funds management will become an additional task

D. **SUMMARY: RECOMMENDATIONS** to the next Board / Paper for the regional meetings

OUTCOMES & RECOMMENDATIONS OF RE-BUILDING

Priorities for ENUSP over the next two years

ENUSP should have an action (strategic) plan covering the next 2 years.
Regional meetings should suggest priority areas for the work of ENUSP (please see the separate document on this topic **BELOW**). The priority areas strongly suggested in the Re-building group included:

ORGANISATIONAL PRIORITIES

- Finding and securing stable operational financing in order to re-establish an ENUSP desk/office; this is the essential first step to allow the NGO to truly achieve its mandate for users and survivors of psychiatry across Europe.

- Ensuring ENUSP has a reliable and functioning structure, which is also democratic, transparent and interactive

WORK PRIORITIES

- Continuing **Advocacy Update** as a means of providing a Europe-wide platform to mental health service users/psychiatric survivors and improving distribution of the publication

- Ensuring ENUSP representation at major decision and policy-making forums (this includes actively gaining information about relevant meetings, their topics etc in order to organise our voice there)

GOOD MANAGEMENT PRIORITIES

- Creating more detailed rules and procedures for the good management of ENUSP, e.g. a description of the tasks of Board members. The General Assembly should appoint a taskforce to draft a procedure document with the goal of explaining rules and regulations that are not covered by the Statutes

Note: Most funders require evidence of an organization's good quality management among their funding criteria.

"Rebuilding ENUSP": A busy and lively workshop...

RE-BUILDING ENUSP (thereafter known as "ENUSP WORK PROGRAMME" when it was adopted by the GA the following day)

ORGANISATIONAL SUGGESTIONS	WORKING AREAS
1. Finding stable financing for ENUSP so that it can become an independent and self-sufficient organisation capable of retaining these attributes also when engaging in partnerships	**1.** Ensuring ENUSP representation in major decision and policy-making forums (this includes actively gaining information of relevant meetings, their topics etc in order to organise our voice there)
2. Ensuring ENUSP has a reliable and functioning structure, which is also democratic, transparent and interactive	**2.** Continuing **Advocacy Update** as a mean of providing a Europe-wide platform to mental health service users/psychiatric survivors
3. Ensuring transparency of the work of the ENUSP Board (e.g. establishing regular reports on its activities etc)	**3.** Expanding knowledge base of situations in different countries (e.g. by initiating small networks of people from different countries who are interested in specific topics like forced treatment, recovery or the implementation of the CRPD)
4. Strengthening connections among ENUSP members (e.g. establishing contact people for each organisation)	**4.** Establishing a solid basis for ENUSP's involvement in research and other projects (e.g. by creating a set of principles for ENUSP's involvement in collaborative projects)
5. Re-establishing the European Desk/Office	**5.** Generating educational/self-advocacy resources (e.g. by producing resource booklets for distribution across the network about, e.g. forced treatment, the history and role of the survivor movement, the UN CRPD)
6. Establishing regional associations/networks	**6.** Supporting the creation of functional member organisations through sharing knowledge
7. Capacity building (training for the Board, organisational counselling)	**7.** Lobbying together with WNUSP
8. Establishing principles for communication (internal and external)	**8.** Working on CPRD implementation and producing shadow reports
9. Attracting selected outside expertise (e.g. legal and bookkeeping support from non-users/survivors)	**9.** Training professionals
10. Re-organising the ENUSP regions (so that every country in a region at least shares a border some of the others)	**10.** Creating art
11. The Board should visit regions in person to consult with members.	**11.** Euro Mad Pride
12. Respecting legal obligations of the board (such as having a regular general assembly)	

OTHER URGENT SUGGESTIONS REGARDING STRUCTURE:

- The Secretary should not be a Board member
- Book-keeping should not be done by Board members
- It is the task of the Board (Treasurer) to actively supervise book-keeping
- Legal representation of ENUSP should be done by at least 2 persons

THE PRIORITY OF FUNDING

The Board should attempt to access an operational grant from EC funds. It should be able to provide a record of its attempts in this direction.

The Board should appoint an ENUSP member to work on an application for this grant. The work of this person should be paid for, and the Board should support this person to best of its abilities.

OTHER FEEDBACK FOR THIS IMPORTANT WORKING GROUP:

“It was the most numerous group with participants coming from various countries (11 countries). Very active participants and it was difficult it was to give time to everybody for having a say). Participants seemed really interested in re-building ENUSP; this means that re-building ENUSP is a real need. There were other priorities voiced by participants besides those listed by the facilitators. It is very important that the final document was approved by the GA as a working document for the future.”

Feedback from Workshop 11

Organising European Mad Pride Events (sent in by the facilitators)

This was not a working group but a workshop on how to organise European MadPride for 2011, coinciding with World Mental Health Day events.

The workshop did not start very well. We found the room allocated: it was a shoe box! Just about big enough for about 4 people to stand in... This was apparently due to the fact that our workshop had been missed out in the programme in the packs. Still the Mad Pride spirit prevailed and we set up the workshop, with the help of many volunteers just as undeterred as us, on the main landing of the floor, thus attracting passing people as well.

The workshop started with a presentation of a film of the Mad Pride 2007 which was organised in 2007 by UilenSpiegel which showed participants what a Mad Pride meant in reality and what could be achieved with imagination and coordination. This help clarify the Mad Pride concept. Mad Prides are joyous and peaceful demonstrations in streets, local happenings, theatre productions, stalls, speeches and rallies, writings, poetry readings. Their aim is to highlight our struggles, such as discrimination, stigmatisation, forced treatment, deprivation of liberty, disempowerment in a non aggressive but powerful, creative and imaginative way.

The facilitators went on to explain their vision for a Mad Pride on a European scale and the importance of the theme “Mind Freedom”, the freedom and the pride to be who we are, in our “madness” and with our differences.

The focus then moved on to the practicalities of organising such an event or series of events, what they could look like, issues of communication, advertising the events etc.

The facilitators mentioned there would be a poster competition and the winning artwork (painting, drawing, photograph etc.) would attract a prize of 1,000 euros which would reward the user organisation. The winning artwork would also be used on all the publicity material for the European Mad Pride.

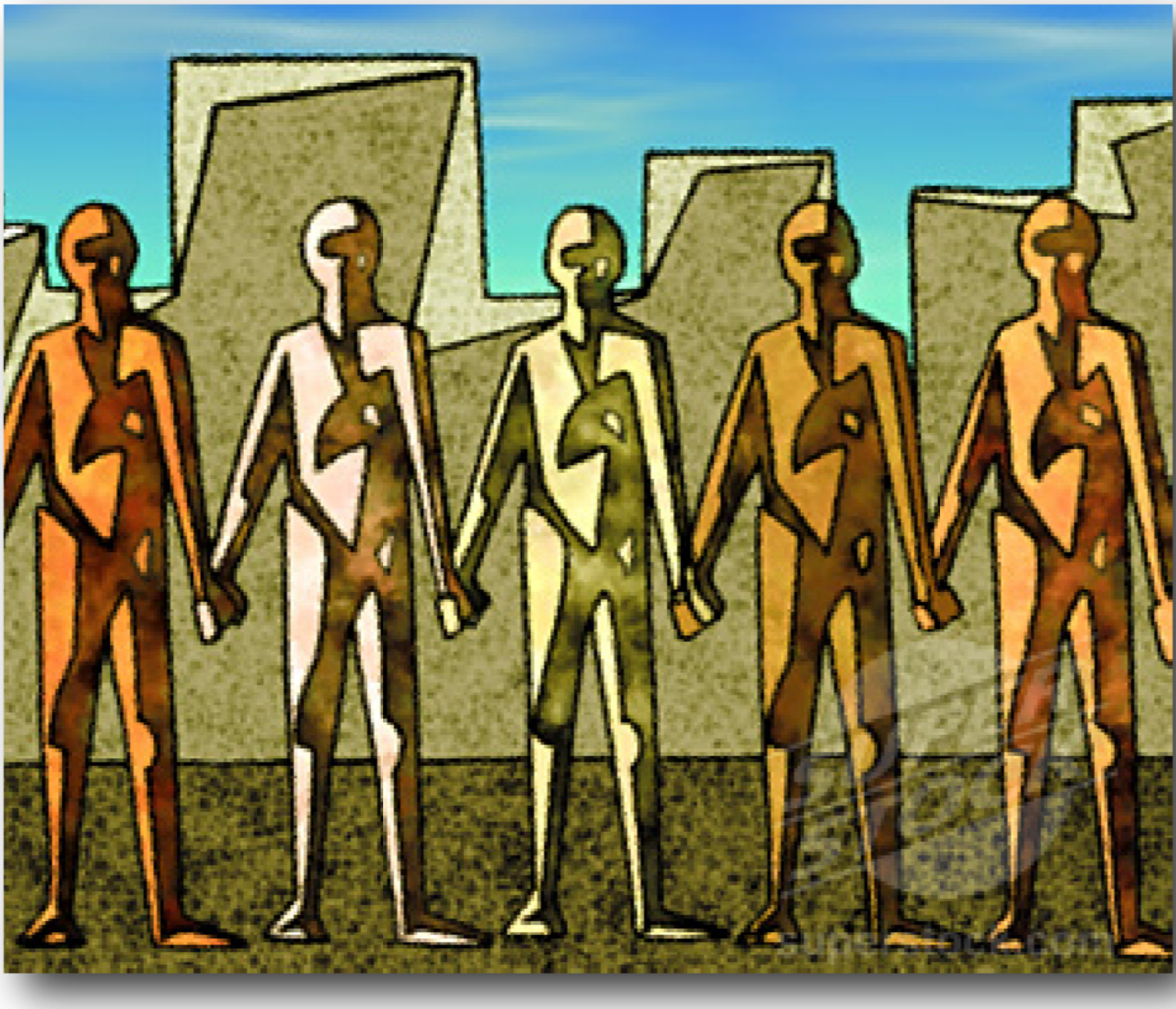
In order to facilitate information and communication a facebook page had already been created and can be found at: http://www.facebook.com/?ref=home#!/pages/European-MadPride-2011/146810525344211. A specific website would also probably be created at a later stage.

The overall impression from attendees was positive and very supportive of the project.

The project can be contacted at: rafael@uilenspiegel.net and aldonskoy@talktalk.net

Why don't you come to our European Mad Pride workshop celebrating "madness"!

Presenting the film from Mad Pride 2007



Hands in solidarity...

DAY THREE

GENERAL ASSEMBLY

DAY THREE

PART II

REPORT ON THE GENERAL ASSEMBLY OF THE EUROPEAN NETWORK OF (EX-)USERS AND SURVIVORS OF PSYCHIATRY

☞ Understanding the General Assembly

The European Network is a federation of national and local associations of (ex-)users and survivors and of mixed organisations with a significant (ex-)user/survivor membership. From those countries where there are no such associations, exceptionally individual (ex-) user/survivor members are also accepted. The main decision making body of the Network is the General Meeting consisting of (at the most three) delegates, only (ex-)users/survivors, of each participating country.

General Meetings take place alongside the European conferences which should be held by the Network every second or third year.. Between two subsequent Meetings an elected board runs the Network. The board consists of a Chair (elected by the General Meeting) and of six regional board members, each representing one of the six regions in Europe (elected by the delegates of the respective region).

This structure intends to make the Network a grassroots, democratic and fully (ex-)user/survivor controlled organisation.

* * *

Below we provide an abridged narrative account of the ENUSP General Assembly(GA), which took place on the afternoon of September 30, 2010, the final day of our Congress in Thessaloniki . Complete minutes of this GA, including all interventions by participants and procedural parts, can be found on ENUSP's website: www.enusp.org

During the first half of the GA, the departing Board members and other central contributors to ENUSP were called on to describe their activities over the last six years. Their activity reports, and the text of the work programmes and declarations approved, can be found in the special GA documentary Annex that comes with this Report.

1. THE BACKGROUND

One of the most important parts of ENUSP's 6th Congress– and a driving force behind the event- was the chance to hold a General Assembly (GA) for all members of the Network. The last membership GA had been held some six years earlier on July 20, 2004 in Vejle, Denmark. This meant another membership assembly was due by 2007 according to ENUSP's Statutes (Article 13). Among the crucial tasks of the GA were the election of a new Board and Chair, and the discussion and choice of our Work Programme for the future.

By 2010, the urgency of this General Assembly had become extremely clear. ENUSP was facing severe management and functioning problems such as:

- The resignation or inactivity of Board members and deputies elected in Vejle for different regions, including the Board's Treasurer .
- The lack of any 'Secretary of the European Desk', i.e. a part-time worker whose task had been to co-ordinate and administer the European Network and its Board. This situation was due to the absence of funds in ENUSP to pay for this work.

In response to this difficult situation, the Board had trialled some emergency solutions, including the adoption of (unelected) Board members and deputies to replace missing representatives from the regions. Three user/survivor volunteers called "Support Members" were also enlisted to give intensive support to the Board.

When news came of the chance to hold the General Assembly in Thessaloniki, Board participants expressed strong hope that the membership would now intervene directly and democratically to work out a sustainable solution – including the election of committed new Board members representing <u>all</u> the regions, armed with a clear mandate for ENUSP's future.

This General Assembly also gave Board participants a chance to explain to the membership all that it had done in the six years to keep the Network alive.

2. LEAD-UP EVENTS

a. The Invitation and topic list

The Board needed to send all ENUSP members an official invitation to the General Assembly at least four months in advance based on Article 15 of the ENUSP Statutes. On May 25, 2010, the Congress Invitation was dispatched, signed by Board Member Peter Lehmann:

> And we invite all ENUSP members to the Ordinary General Assembly of ENUSP, which will be held on September 30, 2010, 14:15. Place: Aristotle University of Thessaloniki, Ceremony Hall 'Alexandros Papanastasiou', Faculty of Philosophy (Old building, 1st floor), Ethnikis Aminis Street, 541 24 Thessaloniki, Greece.

This invitation, included a "Topic list of the Ordinary General Assembly of ENUSP"[1].

1. Welcome words
2. Election of the assembly's membership chair
3. Counting the number of delegates with voting rights
4. Decisions about the correctness of the membership assembly
5. Adoption of the topic list
6. Election f the minute writer and his/her supporter
7. Report of the board, including treasurer
8. Election of the new board, including chair, deputy chair and treasurer
9. Membership fee
10. Decision about the new secretary and place of the Desk
11. Working programme for the future
12. Other topics

☞ The complete document can be found in the **Annexes** section at the end of this Report.

b. Work on ensuring transparency and inclusion

The Congress Invitation tried to explain the significance of the General Assembly for ENUSP's future. It especially urged ENUSP members to keep the Board elections in mind when choosing their delegates – the potential voters and members of ENUSP's Board. There was an appeal to member organisations: to ensure the fair representation of delegates at the General Assembly,

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[1] This document can be found in Annex 3 at the end of the Report

considering gender balance and the diversity of opinions about how to reform or abolish psychiatry and create alternatives:

> When choosing delegates, please take into consideration that the General Assembly will elect a new Board including its Chair. ENUSP needs conscientious, energetic and responsible board members who are able to represent us at a European level at conferences, lobbying and advocacy events.

In the weeks before the 6th congress, an initiative came especially from committee members who had never attended an ENUSP General Assembly to make the proceedings as transparent and inclusive as possible. This led to the drafting of a special “Background Briefing on the Election Process“ document that was distributed in the Info Packs, and that tried to explain in simple English what would happen during both the General Assembly and the regional meetings held earlier the same day . This comprehensive document can be found in the Annexes section of the Report.

c. Run-up (cumulative) events on Sept 30, 2010

The planning committee had envisaged that the day of the General Assembly would include a cumulative programme - so that each event should feed logically into the next and culminate in the General Assembly.

The day began with the follow-up reports of the eleven Working Groups held the previous day as part of ENUSP’s Empowerment Seminar. Among these was the report on the Rebuilding ENUSP group, whose round table had debated practical strategies to protect the future of the organisation. Its findings included 12 organisational suggestions and 11 target working areas. A print-out of these was now distributed for discussion at the six regional meetings of ENUSP directly preceding the GA.

The next event was the regional meeting announcement to all ENUSP delegates. The delegates were told about the tasks and composition of the regional meetings to be held concurrently over a two-hour block. At each meeting, the region‘s member organisations should come together to elect their two representatives for the next ENUSP Board: the regional Board member and her/his deputy. After this, they should compile any concerns from the region for discussion at the General Assembly, giving particular thought to their needs for ENUSP’s Work Programme.

Finally, the delegates were reminded of the practical tasks of Board members and deputies, i.e. as co-ordinators and as representatives. They were strongly encouraged to select people with enough time and resources to commit to ENUSP.

The results of the regional meetings would be reported and manifested at the General Assembly.

3. THE GENERAL ASSEMBLY

a. Welcome words

The General Assembly began with a welcome from Mary NETTLE (UK), the current ENUSP Chair. She said she had been the ENUSP Chair since her election in Vejle, Denmark in 2004; the six years, she said, had highlights and lowlights. She introduced the others on the stage as the people - Board Members and 'support members'- who had been most active on the Board.

b. Approval of General Assembly Facilitator

The General Assembly next approved Iris HÖLLING (from the Association for the Protection from Psychiatric Violence, Germany) as General Assembly Facilitator ('Facilitator')

c. Approval that enough members were present and finalising of topic list

The Facilitator asked for a head count of people with voting rights; twenty-seven [27] voting members were counted. She then confirmed that all correct procedures had been followed according to the Statutes; there were enough voting members present to go forward. The topic list distributed four months earlier was now approved, with two extra topics (reports from regional meetings; adoption of a special statement on Truth and Reconciliation in Psychiatry) formally added. Others could be submitted later if time allowed.

4. REPORTS FROM THE BOARD

The Facilitator next turned to the reports from the ENUSP Board, including the (acting) Treasurer. For this purpose, the people providing activity reports were

- The Chair and some of the Board Members and Deputy Board Members who had been elected at the VEJLE GA;

- Several Adopted Board Members or Deputies and Support Members who had joined the Board later on, and
- ENUSP representatives for specific tasks and projects

Most of these activity reports had been distributed to Congress attendees in English and Greek language versions before the GA. Some others had been provided (in English language only) at the start of the GA. The Annex section of this Report contains the full first-person reports of most of these speakers; in addition, we reproduce a portion of Mary NETTLE's report as retiring Chair below .We have tried to transcribe the statements of those who did not submit written reports, as well as additional comments made during the presentations. The reports are listed below in the order that they were delivered.

☞ THE FULL TEXTS TO THE FOLLOWING REPORTS CAN BE FOUND IN THE ANNEX SECTION AT THE END OF THE REPORT

a. Report of Mary NETTLE as Chair

Mary began by announcing her decision not to stand for re-election as Chair after holding the position for 6 years.

> I am not standing for the board but I will always be a supporter. This is because I believe passionately in the things that ENUSP represents particularly because user/survivors are united by a common experience of often being labelled mentally ill and treated with medication which brings more problems and with no understanding of individual emotional distress.
>
> I feel we have achieved a lot in the last six years[;] the main one is that ENUSP still exists with no funding except from membership fees. It has been a struggle but with support from many people spending a lot of unpaid time which has been detrimental to their finances and even sometimes their health here we are in Greece 6 years after I was elected in Denmark.

She added that this decision brought on mixed feelings: there was relief from her ongoing heavy work burden as a volunteer; but she also felt regret since being Chair had given her important opportunities and brought her into contact with many good people. She then read from her Chair's report, which can be found in the Annexes section.

b. Report of Adopted Board Member Jasna RUSSO

Jasna summarised from her activity Report. She noted in closing that as her last input to the Board, she had conceptualised the four-hour working group ‘Rebuilding ENUSP‘ together with Gabriela TĂNĂSAN and Debra SHULKES.

c. Report of the Board Member for the Northern region - Erik OLSEN

Erik read from his activity report.

d. Report of the Deputy Board Member for the North-West region – Jan VERHAEGH

Jan summarised from his activity report. He ended by emphasising his personal endorsement of the “Truth and Reconciliation Statement (TRIP)” about the harmful practices – now and historically- of psychiatry. He said this statement should draw long overdue attention to the crimes of psychiatrists against so-called handicapped people during the Holocaust. He also expressed his friendship and solidarity with Muslim people who are the targets of racism, and he urged everyone to share this solidarity.

e. Report of Support Board Member Debra SHULKES

Debra summarised from her activity Report.

f. Report of Deputy Board Member for the North East region – Piotr IWANEYKO

Piotr said that he had been part of the Board since 2004. Unfortunately, his activities for the Board in recent years had been somewhat restricted as he had been physically disabled.
He described his work inside Poland and some international co-operative efforts, including conferences where he had tried to publicise the work of ENUSP. He said he had participated through his Polish organisation in a EC-funded programme that ran workshops in Poland for participants from across Eastern Europe; their topic was the mainstreaming of education and employment for users and ex-users. Although ENUSP was not a partner in this project, he had tried to draw attention to ENUSP’s ideas in doing this work.
He noted finally that he participated in the General Assembly of WNUSP in Kampala, Uganda.

g. Report of Adopted Deputy Board Member for the Central Region - Gabriela TĂNĂSAN

Gabriela had been the main organiser of the conference, including the GA, and the Facilitator therefore used this opportunity to thank her for her hard work.

Gabriela explained that she came from a small town in the north of Romania, where she was the head of Orizonturi, a user and ex-user organisation that had been a member of ENUSP for many years.

She said she had joined ENUSP's Board in March 2009 after attending an ENUSP empowerment seminar in Brussels as the Romanian representative. Since then, she had done her best to be an active Board Member. She had been ENUSP's representative in the negotiation and arrangement of the current conference with the other organizers; this work had started in March 2010. She thanked her colleagues on the Board who helped with these tasks, and expressed her hope that the event had been a good one for participants.

h. Report of ENUSP's representative in dealings with the World Psychiatric Association (WPA) – Jan WALLCRAFT

Jan summarised from her activity report. She invited any delegates to approach her personally if they had any questions about her work for ENUSP with the WPA. She closed by saying that she hoped that this work would have some impact on the activities of national psychiatric associations, but this remained to be seen.

i. Report of Support Board Member Anne-Laure DONSKOY

Anne-Laure summarised from her activity report.

j. Report of Board Member for the North-Eastern region- Peter LEHMANN

Peter summarised from his activity report. He closed by saying that he had visited Greece five times to give lectures on user/survivor topics in universities and hospitals. These activities, he stated, had paved the way eventually for the present Congress in Thessaloniki.

k. Report of ENUSP's representative in European Patients' Forum (EPF) (Value+ Project) – Elizabeth WINDER

Elizabeth summarised from her report. This report covered the history and achievements of ENUSP in EPF's important Value+ project. She concluded by saying it was vital that ENUSP continue to be in contact with grassroots patients so that their voices could come through to the makers of health policy and law. She stressed that this was the most important task facing the new Board. She wished them all good luck, adding that she and many others would be prepared to give support in that work.

l. Report of ENUSP Treasurer - Peter LEHMANN (in place of the elected Treasurer, who was not present)

Peter told the GA that he was not the elected ENUSP Treasurer and therefore no formal statement could be expected of him. He would, however, provide an oral account of the financial affairs of the organisation which he had taken care of for the last five years. For each year until 2009, he said there was a report accessible on the internet, containing all figures. He said that the relevant books had been inspected and found to be correct at a Board meeting held on September 26, 2010.

He said that ENUSP's bank account had a current balance of about 200 euros. The organisation had debts of about 1000 euros related to the pre-financing of the Value+ project. He said a payment of about 5000 euros was expected from the European Commission, which should be used to settle these debts.

At this point, an unidentified questioner from the floor asked Peter to identify the project attached to the 5000 euros.

Peter said that it was the Value+ Project that Elizabeth Winder had spoken about. He said ENUSP would face further invoices this year for its membership fees to other European bodies as well as more bills for work by individuals. These debts would come to about 700 euro.

He noted that since it was the middle of the financial year, he had not prepared a balance sheet for ENUSP; otherwise he would need to do this task twice, i.e. for the GA and for ENUSP's annual tax filing.

Peter concluded his account for the Treasurer by saying that ENUSP had about 100 British pounds in its Paypal account.

5. SUMMARY OF QUESTIONS ABOUT THE BOARD AND TREASURER'S REPORTS

The Facilitator next thanked the Board and the Chair for their work. She said it was the General Assembly's task to approve the reports, and she invited the attendees to ask any questions of the speakers.

The discussion focused on the problems caused by the departure of the elected Treasurer. Some concerns were raised by delegates about the confusion of the roles of Treasurer and bookkeeper on the Board. An explanation was offered that there was no clear European law on this issue, and that ENUSP had lacked funds to pay for an external bookkeeper. It was strongly advised that in future these roles be kept separate, which could mean ensuring adequate funds to pay for external bookkeeping. The Facilitator noted that this echoed the findings of the Re-Building ENUSP group.

She said that according to the Statutes, the GA now had to approve or disapprove the given reports. Following this, the GA would elect a new Board and then choose one of the new Board Members as the ENUSP Treasurer. This new Board would have to decide separately on the identity of the bookkeeper.

The General Assembly now voted on the approval of the Board Reports: The results were :

- **In favour: 21**
- **Against: 0**
- **Abstaining: 6**

The Board and Treasurer's Reports were therefore ADOPTED by the GA.

Based on this approval, the Facilitator thanked the Board for its work.

6. ELECTION OF THE NEW BOARD, INCLUDING CHAIR, DEPUTY CHAIR AND TREASURER

The next item on the agenda was the election of the new Board, beginning with Board Members and Deputy Board Members from each of the regions.

a. Nomination of Regional Board Members

The Facilitator asked whether the six regions had each managed to elect a Board Member and Deputy Board Member. She called on a spokesperson for each region to report on their election results. These results were as follows:

Preliminary results: election of Board Members and Deputies

i. **Central Region**: Czech Republic, Hungary, Liechtenstein, Moldova, Romania, Slovakia

The meeting included representatives from the Czech Republic (2), Romania (5), and Hungary (1; non-voting). They had elected:

Board Member: Gabriela TĂNĂSAN (Romania)

Deputy Board Member: Stefan BANDOL (Romania)

ii. **North West Region:** Ireland, The Netherlands, United Kingdom (England, Northern Ireland, Scotland, Wales)

Board Member: Jan VERHAEGH (the Netherlands)

Deputy Board Member: Sabita GURNEY-BRANFORD (UK)

iii. **South West Region:** Andorra, Belgium, France, Italy, Luxembourg, Portugal, San Marino, Spain, Switzerland

The meeting included representatives from Belgium (1), Italy (2), and Portugal (1). They had elected:

Board Member: Rafaël DAEM (Belgium)

Deputy Board Member: Erveda SANSI (Italy).

[At this point, Rafaël also announced his intention to stand for the position of Chair]

iv. **Northern Region:** Denmark, Finland, Faroe Islands, Greenland, Iceland, Norway, Sweden

The meeting included representatives from Sweden (1), Denmark (2) and Norway (3), respectively. They had elected:

Board Member: Erik OLSEN (Denmark)

Deputy Board Member: Maths JESPERSON (Sweden)

v. **North East Region:** Austria, Estonia, Germany, Latvia, Lithuania, Poland, Russia

The meeting included representatives from Germany (2), Latvia (2), Poland (3), and Russia (1).

They had elected:

Board Member: Piotr IWANEYKO (Poland)

Deputy Board Member: Berthold KÖSEL (Germany)

vi. **South East Region:** Albania, Armenia, Azerbaijan, Belarus, Bosnia & Herzegovinia, Bulgaria, Croatia, Cyprus, Georgia, Greece, Israel, Former Yugoslav Republic of Macedonia (FYROM), Malta, Montenegro, Serbia, Slovenia, Turkey, Ukraine

The meeting included representatives from Bosnia & Herzegovina (1) , Israel (1), Georgia (1) and Greece (3) They had elected:

Board Member: Katerina SKOURTOPOULOU (Greece)

Deputy Board Member: Asmati AUGUSTIN (Georgia)

The Facilitator asked the nominated Board Members to take their seats on the stage.

[After consulting with the attendees on procedure, the Facilitator announced that the General Assembly would proceed to elect a new Chair before voting on the new Board. This was particularly necessary because of the intention of Rafaël DAEM, the South West region nominee for the Board, to stand for Chair; his election to that role would result in the need to choose a new regional Board Member].

b. Election of the new Chair of ENUSP

The Facilitator asked whether there were any further nominations for the Chair.

- *Stefan BANDOL proposed Gabriela TĂNĂSAN based on the extensive work that she had done in the preparation of the conference.*

The Facilitator asked Gabriela whether she would accept the nomination to be Chair, and Gabriela replied that she did accept it. The Facilitator asked whether there were any more nominations for the position of Chair, and there were none.

She now invited the two candidates – Rafaël DAEM and Gabriela TĂNĂSAN - to state why they were standing for the position.

- Gabriela responded that it was going to be a challenge. She believed that some attendees at the conference had seen her commitment in action. This would be an opportunity to continue the grassroots work that she had been doing in Romania, only now across a broader European context.

- Rafaël thanked the last Board of ENUSP for its work. He said that, if elected, he planned to respect the traditions it had established. By way of personal background, he explained that he was a service user living in Brussels and a postman by profession. He was also an expert by experience and the co-ordinator of the user organisation Uilenspiegel.

  He said he had been very impressed by the proceedings at the conference, and very motivated to continue this work in the role of Chair. If elected, he would have the logistical support of his organisation to complete administrative work. He added that the outcomes the working groups of the conference, in particular Rebuilding ENUSP, would be a source of inspiration.

The Facilitator now said the GA could proceed to the election of the Chair. She asked if the attendees wished to have an open ballot. She also asked if there were any outstanding questions or comments.

- Jasna RUSSO reminded the General Assembly of the need to observe a gender balance in the composition of the Board. She noted that this requirement was not being met based on the Board Members who had been nominated by the regions. She said that she could not propose a solution to this issue.

The Facilitator confirmed that the lack of gender balance on the Board was a problem, albeit one alleviated by the appointment of some female Deputy Board Members.

- Erik OLSEN said that he thought the proposed Board was relatively balanced between the genders, and it should be acceptable.

- Peter LEHMANN said there were different ways of looking at the issue of balanced representation. Applying this to the selection of the Chair, he said that the last Chair had been a woman whereas the next one might be a man; and the last Chair had come from western Europe, but the next one might come from eastern Europe. He said the election of the Chair should not be used to repair gender imbalances on the Board as the responsibilities of the Chair were too important.

The Facilitator noted that at least a good gender balance had been achieved in the selection of the two candidates for Chair. She asked if there were further questions.

- Mary NETTLE commented that she had experienced difficulties in her time as Chair as she lacked the support of her national organisation. Noting Rafaël's comment already that his organisation would give him this help, she asked Gabriela if she had similar support.

- Gabriela responded that her organisation had supported her while she co-ordinated the Thessaloniki event. She reiterated that her organisation would now certainly support her in the role of ENUSP Chair.

- Peter LEHMANN asked Gabriela whether she would have the financial flexibility and support from her organisation that could be required for her urgent representation of ENUSP – for example, in a situation where expenses were only reimbursed subsequently. He observed that in the past this had been an issue for some Chairs and Board Members.

- Gabriela replied that she did not know if this issue was so relevant at this point. It was difficult, she said, to comment on meeting the hypothetical costs of representation without knowing the places and details involved. She reiterated that she had the support of her organisation, but she could not pledge the availability of large sums of money for her travel.

- Erik OLSEN added that the lack of money in Gabriela's region should be weighed up against the fact that it might be important for that region to have more power on the Board.

- Peter LEHMANN noted that Rafaël was based in Brussels and asked if this meant he had any connections to EU institutions.

- Rafaël responded that his organisation Uilenspiegel had some important contacts. In addition, they had engaged a consultant some three months earlier to seek out EC funding and connections for one project. This meant that there was already someone working on these issues inside his organisation, but whether or not ENUSP joined these efforts would be a decision for the new Board.

The Facilitator took more questions for the candidates from the floor:

- Vahid DULOVIC (TK "Fenix" Tuzla, BiH) asked the two candidates to each write down their 'vision for re-building ENUSP'.

- Debra SHULKES noted that it was important that the Chair acknowledge and be sensitive to the differences between users and survivors of psychiatry as the two main streams of ENUSP members. She asked Rafael how he planned to meet this criterion.

Responding to Vahid's question:

- Gabriela said that she believed the development of an Action Plan by the Board was vital for re-building ENUSP.

- Rafaël said that he would be faithful to the recommendations of the working group Re-building ENUSP, which had been circulated in a document prior to the regional meetings. He singled out five of the points from that document:
  Finding stable financing for ENUSP; strengthening cooperation among ENUSP member organisations; reestablishing the European Desk; continuing *Advocacy Update*; and carrying out the Mad Pride project.
  He added that he would give himself two years in which to undertake these goals; he said that at the end of this period both he and the Board should be externally evaluated.

For time reasons, the Facilitator limited the comments and questions from the floor about the Chair to just three more:

- *The next question came from an unidentified Greek-speaking delegate. She asked both candidates to comment on the term 'disabled' - and in particular, whether they thought it should apply to people with 'psychiatric experience'.*

Gabriela spoke next to the issue of the general use of the word 'disabled' to describe users and survivors of psychiatry. She said that she could not accept this term because it negated the fact that people were able to fulfill their goals. Drawing on her life experience, she said that she had been able to accomplish some of the things that Stefan had mentioned; it had been hard, she said, and the situation had been very different twenty years ago. But users and survivors were very able to do wonderful things.

Reflecting on the same question, Rafaël said that he could accept the term 'disabled', and that he wanted to acknowledge that there were people not present at the General Assembly because they were not able to be there. This fact should not be hidden. Someone's social context or personal context could make them disabled. He said he had no judgment about people's choice to use the word 'disabled' to describe themselves, but that it was vital to pay attention to which word they used.

As a final remark, Rafaël said that irrespective of the result of the election, he would be happy to work alongside Gabriela. Gabriela added that her position was the same.

The Facilitator now asked for volunteers to count the votes from the secret ballot. It was agreed that two persons without voting rights - Elizabeth WINDER (UK) and Nenad Peric (translator of Vahid DULOVIC, BiH)–– would count the ballots for the election of Chair.

A secret ballot was held to determine who would be the next Chair. After comparing their separate tallies, the counters reported the following results:

Total votes cast: 27
Votes for Rafaël: 7
Votes for Gabriela: 19
Abstaining: 1

Gabriela TĂNĂSAN was therefore ELECTED as the new CHAIR of ENUSP.

The Facilitator asked Gabriela if she accepted her election, and Gabriela agreed that she did accept it. She thanked everyone for their support, including those who had not voted for her. She told those people that they could come to her with suggestions about what she could do better. She thanked those who had voted for her, saying she was very touched. She said she would stay true to the goals she had pledged to the General Assembly over the next two years.

c. Election of the new Board of ENUSP

- The Facilitator turned to the election of the Board. She noted that since Gabriela had become Chair, she could no longer be the Board Member for the Central region. Stefan BANDOL, who had been chosen as the Deputy Board Member, should therefore take over as this Board Member. The Facilitator announced the final nominations for the new full Board Members of ENUSP:

Central region: Stefan Bandol (Romania)
North West region: Jan Verhaegh (the Netherlands)
South West Region: Rafaël Daem (Belgium)
Northern Region: Erik Olsen (Denmark)
North East Region: Piotr Iwaneyko (Poland)
South East Region: Katerina Skourtopoulou (Greece)

An open ballot was then held on the election of the new Board. The results were as follows:

Total votes cast: 21
Votes in favour: 20

Votes against: 0
Abstaining: 1

The nominated Board Members were therefore ELECTED.[2] The Board accepted its election.

d. Election of Deputy Board Members

The Facilitator came to the election of the Deputy Board Members. Given the lack of a candidate now for this position in the Central Region, she called on persons from the region, asking if they had devised a back-up plan for this situation. The region had foreseen that Debra SHULKES should take the Deputy's position as a fall-back.

The Facilitator called for a vote on the election of the following nominated Deputy Board Members:

Central region: Debra Shulkes (Czech Republic/Australia)
North West region: Sabita Gurney-Branford (UK)
South West region: Erveda Sansi (Italy)
Northern region: Maths Jesperson (Sweden)
North East region: Berthold Kösel (Germany)
South East region: Asmati Augustin (Georgia)

An open ballot was again held, with the following results:

Total votes cast: 22
Votes in favour : 22
Votes against: 0
Abstaining: 0

The nominated Deputy Board Members were therefore ELECTED

The Deputy Board accepted its election.

e. Election of Deputy Chair of ENUSP

The next item on the agenda was the election of the Deputy Chair; according to the Statutes, this position had to be filled by one of the Board Members. The Facilitator asked Rafaël DAEM if he would be willing to stand for this position.

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[2] The fall-off in the number of votes (i.e. from 27 to 21) was explained by virtue of the fact that some voters had probably left the General Assembly after the election of the Chair. These numbers continued to vary slightly for the rest of the GA, presumably because voters were coming and going.

The Facilitator asked if there were any other nominations, including self-nominations, for the position of Deputy Chair from within the Board. There were none. The Facilitator asked the GA to vote on the instatement of Rafaël DAEM as Deputy Chair. The results of the open ballot were as follows:

Total votes cast: 23
Votes in favour: 22
Votes against: 0
Abstaining: 1

Rafaël DAEM was therefore ELECTED as DEPUTY CHAIR of ENUSP.

f. Election of Treasurer of the Board

The GA now came to the matter of the election of the Treasurer from among the elected Board Members, excluding the Chair and Deputy Chair. The Facilitator asked if there were any nominations.
Stefan BANDOL was nominated. There were no other nominations.

The Facilitator asked the GA to vote on the instatement of Stefan Bandol as Treasurer. The results of the open ballot were as follows:

Total votes cast: 21
Votes in favour: 20
Votes against: 0
Abstaining: 1

Stefan BANDOL was therefore ELECTED as the TREASURER of the Board.

7. ENUSP MEMBERSHIP FEE

The next topic on the advertised programme was the ENUSP membership fee. The Facilitator asked if anyone wished to speak to this topic.

Erik OLSEN Reported that the members in the Northern region had been complaining that they were being unfairly penalized by the current membership fee payment rules (as agreed upon by the VEJLE GA). These members' organisations were often very big, having up to 25,000 members, and thus, their fees could be extremely high based on the current per capita rate [i.e. 0.10 euro per member] . Erik said the annual fee due from these organisations could be up to 5,000 euros, and they were not prepared to pay this amount.

He therefore proposed that an absolute ceiling of around 200 or 300 euros be set on the annual ENUSP membership fee due from each individual organisation.

It was eventually agreed that it would be good form for the GA now to decide to set a limit of 300 euros as the maximum membership fee. The VEJLE GA had introduced the membership fees, and so it made sense for these issues to be dealt with at GA level.

The Facilitator therefore asked the GA to approve the following proposal:
'the membership fees set at the VEJLE GA will remain the same, however the annual fee per organisation cannot exceed 300 euros per year' . The results of the open ballot were as follows:

Total votes cast: 24
Votes in favour: 21
Votes against: 1
Abstaining: 2

The proposal was, thus, ADOPTED.

8. DECISION ABOUT NEW ENUSP SECRETARY AND PLACE OF THE DESK

Turning to this item on the agenda, the Facilitator noted that there was not currently funding for a Secretary (central co-ordinator) of ENUSP.

The Facilitator here also highlighted the fact there was no present funding for the rental of an office for the European Desk. Any decision that was made now on these points would have to take into account these considerations.

The Facilitator asked if there were any submissions about these matters. Rafaël DAEM put forward an offer from Uilenspiegel of a work station for ENUSP in Brussels. He noted that this could entail a desk for one person as part of a larger office, including a computer and telephone facilities. Further conditions would have to be agreed upon later.

The Facilitator confirmed this offer of a place for the Desk, and she asked if there was anyone wishing to nominate themselves for the position of Secretary, even knowing that it would be unpaid. She asked Rafaël if he already had someone available to do the work of Secretary

> *One delegate asked whether for now Rafaël might simply offer ENUSP an official address for the Desk. This address should, she said, be connected to the paid position of Secretary. She stressed that one of the findings of the Rebuilding ENUSP group had been that the Secretary/co-ordinator position should not be voluntary because it involved too much work. Instead, the Board should look for funding to support the person in this position.*

It was emphasised that the order of these decisions was important: the funding must come before the appointment of a Secretary. She suggested that for now, the General Assembly only accept Rafaël's offer for a new site for ENUSP's Desk (i.e. for its relocation from Berlin to Brussels). If funding became available, the Board should look to appoint a paid Secretary.

The Facilitator asked the GA to approve the proposal that:

'The General Assembly approves the change of ENUSP's official address to that of Uilenspiegel in Brussels. The GA will not decide on the appointment of the Secretary, but leave that matter to the Board since there is currently no funding for the position.'

The results of the open ballot were as follows:
Total votes cast: 24
Votes in favour: 21
Votes Against: 2
Abstaining: 1

The decision to move ENUSP's Desk to Brussels was, thus, ADOPTED.

9. WORK PROGRAMME FOR ENUSP'S FUTURE

The next advertised matter was the Work Programme for the new Board. The Facilitator noted her earlier promise that the regions would have the opportunity to report on their findings and recommendations for this programme. She now asked the elected Board Members or other regional representatives to perform this task.

> *Speaking for the Central region, Stefan BANDOL reported* that the Central region had concluded there was a need to continue Advocacy Update. It was also crucial to elaborate

> by-laws ensuring that ENUSP and its Board had a clear structure, and that the tasks and responsibilities of Board Members and others in the organisation were properly separated and described.
>
> *Speaking for the North East region, AGITA LUSE* summarised that region's suggestions. She said that the region had recommended creating a special email group/mailing list for the North-East member organisations, i.e. a North-East regional network.

It had also reinforced two work priorities set out in the document circulated by the Re-building ENUSP group. In particular, it had focused on the need for the sharing of knowledge and experience among member organisations, with more experienced organisations to offer consultancy (e.g. to less experienced/resourced groups in the eastern part of Europe). It had also highlighted the need for a reassessment of the current regional divisions, which seemed to lack a clear guiding principle. On balance, she said, however, that the majority of the regional members accepted the current regional distribution.

The GA Facilitator, who had attended this meeting as a representative of her German organisation, reported that the region also endorsed the first two organisational priorities of the Re-building ENUSP group – i.e. finding stable financing for the organisation, and ensuring that ENUSP has a reliable and functioning structure, which is also democratic, transparent and interactive.

The Facilitator asked if there was any more input from the regional meetings.

> *Speaking for the Northern region, ERIK OLSEN* reported that its meeting had confirmed the importance of all of the goals put forward by the Re-building ENUSP group. The next step, he said, was to see how much could be accomplished practically in the next 1-year period. As another idea from the region, Erik outlined its experience in forming a regional committee to work on international issues. He said this could be a successful way to proceed – across ENUSP- given that some national and regional organisations felt quite isolated.

In view of the limited time remaining, the Facilitator now made the proposal that "the General Assembly vote to adopt the findings of the group Re-Building ENUSP as the new Work Programme."

She noted again that the group's recommendations – divided into 12 organisational priorities and 11 work areas – had been circulated earlier that day to the attendees for discussion at the regional meetings. Several of the regions had already endorsed these priorities in their submissions to the GA. The full text of this document, which was in front of many voting members, can be found in the **Feedback from working groups** section on **page 115** of this Report; it is entitled **"Recommendations of Rebuilding ENUSP Working Group".**

By adopting this document as the Work Programme of ENUSP, she said, the new Board would be committing to making it the basis of their Action Plan [i.e. for the next two years]. Furthermore, they should use it as a focus in their meeting the next day with the outgoing Board.
Erik OLSEN said that he totally endorsed this proposal and that the General Assembly should determine the desired content of the Board's Action Plan. This plan would be essential for securing funding in this future.

The Facilitator therefore made the proposal that:
"The document produced by the Re-building ENUSP group should become ENUSP's new Work Programme, and the new Board should form an Action Plan based on this Programme"

Jasna RUSSO added from the floor that there was an additional (related) document containing recommendations that had come out the Rebuilding ENUSP group. The Facilitator agreed that this document could also be part of the Work Programme to be confirmed by the GA .

An open ballot was now held on the proposed Work Programme of ENUSP, with the following results:

Total votes cast: 22

Votes in favour: 21
Votes against: 0
Abstaining: 1

The findings of the Re-Building ENUSP Group were, thus, ADOPTED as:

- **The Work Programme for ENUSP's new Board**
- **The basis of the new Board's Action Plan**

10. OTHER TOPICS

Coming now finally to other topics on the agenda, the Facilitator referred first to the **Truth and Reconciliation in Psychiatry (TRIP) Statement'**, a document which had been circulated to the attendees by Janet Wallcraft. For a summary of the content of this statement, please see the statement by Jan VERHAEGH under 4 (d) above. The full text can be found in Annex.

There was some discussion about whether the GA or the Board should vote on ENUSP's endorsement of this policy statement. Finally it was held that the GA should decide since it had been distributed to delegated during the conference. The Facilitator put forward the proposal that

"The ENUSP GA approves the Truth and Reconciliation in Psychiatry statement circulated by Janet Wallcraft."

The results of the open ballot were as follows:

Total votes cast: 23

Votes in favour: 18
Against: 1
Abstaining: 4

The TRIP statement was, thus, APPROVED.

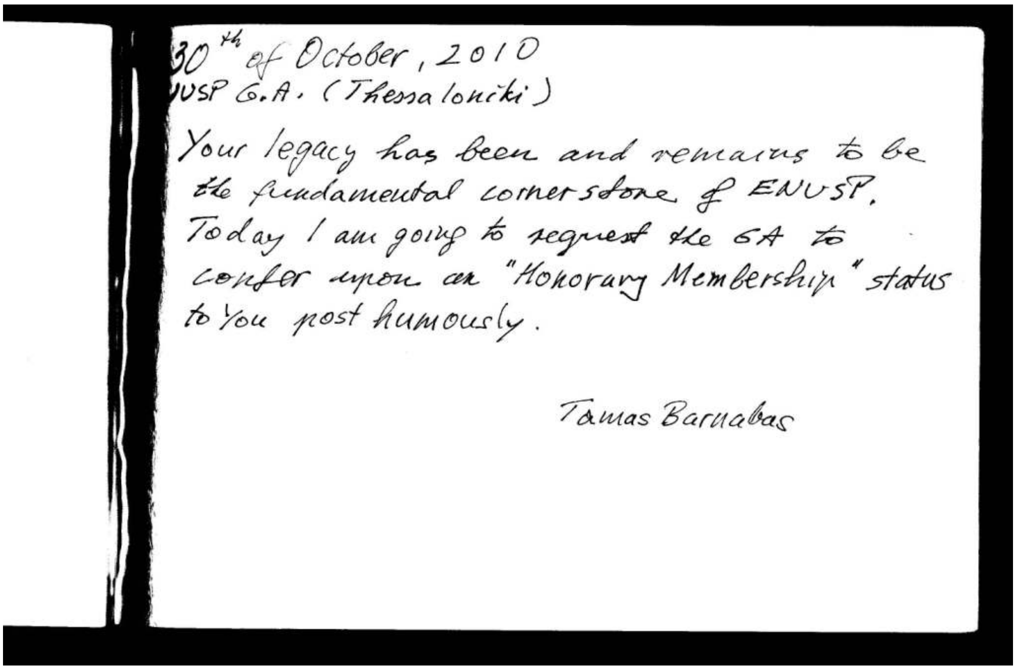
The Facilitator noted that one of the other topics proposed for discussion had been the establishment of a taskforce to prepare by-laws, i.e. more detailed rules about the governing structure of ENUSP. She suggested that this task should now be covered under the above-described Work Programme.

TRIBUTE to JUDI CHAMBERLIN FROM THE SIXTH CONGRESS OF ENUSP

At the start of the Thessaloniki Congress, Mary Nettle, then Chair of ENUSP read a tribute to the US survivor activist Judi Chamberlin, who had died on January 16, 2010. While not everyone at the Congress had met Judi, her place in our movement was well-known and her work quoted and respected across Europe. ENUSP compiled a tribute book of the messages from delegates to send to Judi's partner Martin Federman; its pages filled up quickly during the Congress. Finally on September 30, 2010, at the very end of ENUSP's General Assembly, one delegate made a request for the meeting to confer honorary membership on Judi Chamberlin.

The request was met with a long round of applause and unanimous agreement. Based on the General Assembly's request, newly elected ENUSP Chair Gabriela Tănăsan issued the following honorary membership certificate to Judi Chamberlin.

There was no time remaining for any further business. The Facilitator therefore closed the General Assembly and thanked the participants greatly for their patience.



30th of October, 2010
USP G.A. (Thessaloniki)

Your legacy has been and remains to be the fundamental cornerstone of ENUSP. Today I am going to request the GA to confer upon an "Honorary Membership" status to You posthumously.

Tamas Barnabas

European Network of (ex-) Users and Survivors of Psychiatry
Hoveniersstraat 45, 1080 Brussels, Belgium desk@enusp.org www.enusp.org

On Oct 1st, 2010, the Sixth General Assembly of the European Network of (ex-) Users and Survivors of Psychiatry (ENUSP) in Thessaloniki, Greece decided unanimously on the award of **honorary membership of ENUSP** to

Judi Chamberlin

in recognition of her deeply treasured contributions to our movement.

Chair,
Gabriela Tanasan
Tanasan

Board of ENUSP:
Gabriela Tanasan, Romania (Chair); Rafaël Daem, Belgium (Deputy Chair); Erik Olsen, Denmark; Jan Verhaegh, Netherlands; Katerina Skourtopoulou, Greece, Piotr Iwaneyko, Poland; Stefan Bandol, Romania (Treasurer)

NEW VOICES FROM THE SOUTH-EAST REGION

One of the achievements of the Thessaloniki Congress was the election to ENUSP's Board of two direct voices from the South-East region – who can give vital expression to the concerns of users and survivors in countries in this region.

Katerina Skourtopolou (Greece) of the Hellenic Observatory of Rights in the Field of Mental Health, is the new South-Eastern Board Member. Her deputy isAsmati Augustin (Georgia) of "Equality" Users and Ex-Users of Georgia .

The South-East region has long been under-represented in ENUSP. It is hoped that these elections will aid ongoing communication to the wider European user/survivor movement of the distinct experiences, problems and objections across the region. ENUSP is particularly committed to supporting the development of autonomous organisations of (ex-)users and survivors of psychiatry in this region, and in all places across Europe where these organisations remain chronically under-resourced or do not yet exist.

The region comprises Albania, Armenia, Azerbaijan, Belarus, Bosnia & Herzegovina, Bulgaria, Croatia, Cyprus, Georgia, Greece, Israel, Former Yugoslav Republic of Macedonia (FYROM), Malta, Montenegro, Serbia, Slovenia, and Turkey.

Approximate map of ENUSP's South-Eastern Region whose size reflects the size of the challenge.

Below, Katerina offered some reflections on her own experience of the Congress and its significance for the Greek movement, and other key issues,

The European Congress that took place in Thessaloniki, Greece was a very strong step towards alternative approaches to mental health. In my opinion, it was a very successful conference with a large audience, of both professionals and people with psychiatric experience. The venue of the conference carries a special meaning since Greece still remains, unfortunately, one of the countries where most psychiatric institutions and mental health care are far from a real effort to cure people and help them to return to their ordinary lives, whilst breaching of human rights is a constant issue. The organizing committee, the organisations and individuals who worked for the realisation of this conference and helped in its sponsoring deserve all our gratitude, for bringing forth a forum especially for the voices of the people who have suffered in psychological terms and have been subjected to psychiatric maltreatment, as well as for those people seeking alternative ways of psychotherapy, different from mainstream psychiatry.

On a more personal level, my participation in the conference, as a survivor of psychiatric ‘treatment’, was a very strong step towards healing of wounds, towards real therapy, at least to a certain extent. Becoming part of the board of ENUSP as a representative for the South-East region, has given me an impetus to fight for changing the situation, both for Greece and for other countries, at a stronger pace than before. I want to express my gratitude to those individuals, members of (ex)users and survivors networks in Greece, who elected me into this position and who encouraged me to be myself by their own attitude of sincerity, open dialogue, kindness, and lack of fear to condemn injustice and violence. Equally, I want to thank from my heart the members of Hellenic Observatory For Rights In the Field Of Mental Health for encouraging me to get involved in their group work, sharing their experiences with me, and accepting me as a colleague. I also want to deeply thank the members of the Pan-Hellenic Committee of [ex-]Users and Survivors of Psychiatry, and in particular Giorgos Giannoulopoulos, for having literally created the user/survivor movement in Greece out of very harsh situations, for having kept things going at a gradually more and more dynamic pace, for opening up a very important discourse that was very much missing from Greek contexts. A very big ‘thank you’ also goes to Peter Lehmann, for encouraging me to get actively involved with ENUSP, as well as to all members of ENUSP board, both old and new, for their constant attitude of support and their on-going effort for dynamic intervention, despite all bad experiences. I hope that through my contribution, I will manage to stand up to the standards of all these individuals, up to their constant effort for social equality, and respect of life for all people with psychological and mental health problems.

− On the CRPD in the Greek context:

Apart from the ratification of OPCAT, a key issue that has recently arisen at European level regards the ratification of the Convention on the Rights of Persons with Disabilities (CRPD). I would like to take the opportunity to express my support for the ratification of this document, and effort for its subsequent implementation at national level. I know that a lot of people within (ex)users/survivors movement in Greece, mainly represented by the Pan-Hellenic Committee of [ex-]Users and Survivors of Psychiatry, but also perhaps by other groups and as individuals, probably disagree with this view given that the term 'disability' is used in this document as an umbrella term to include also people ordinarily categorized as 'people with mental health problems'.

Following Giorgos Giannoulopoulos, in his keynote speech, as well as other people[1], I am myself very much against calling people with psychological or mental health problems 'disabled' or with 'mental impairment' – the other expression used in the document – unless of course it is their own choice; otherwise, it is a very wrong and very dangerous categorisation. Giorgos Giannoulopoulos, has very eloquently discussed the kind of ideologies hiding behind any potential categorisations of the human mind, and I agree very much with the rejection of this term for people suffering from some kind of psychological pain, or indeed anyone else, unless it is their own choice. I believe that we should do all it takes so that global community never reaches an escalation of medically classifying people in order to turn them into some kind of 'objects' to be handled, but even further, that we, as a society, also withdraw, to the point we are presently carrying out such classifications, which to me form, in any case, the core of current psychiatric practice, regardless of recent documentation.

However, apart from the problem of general categorisations, if we put them aside, at least temporarily, by accepting their functioning as merely technical terms, I believe that the text of CRPD itself, offers us a very strong base to fight for the respect of our rights at any instance that we are obliged to accept psychiatric 'treatment', involuntarily or not, for whatever reason. For me, the abolishment of the ill use of the term 'disabled' or 'mentally impaired' and any instrumentation that might arise through such usage in order to cancel people's rights, resides in the text of CRPD itself. Regardless of how a person with mental health problems is labelled, the text of the CRPD itself forms a very strong basis against any discrimination on the basis of disability, including any labelling that causes to lose all fundamental rights for a full integration to society, and even more than that, against any involuntary 'treatment' in practice. There is very clear reference to the establishment of legislation defending freedom, equality in social, economic, and legislative terms, and the full array of very basic rights in order to have a full life, independent and fully integrated to society with no difference from other human beings (Articles 1-5, 12- 15, 18-23, 27 deserve special attention as they refer to very basic issues that have been the focus of (ex)user/survivor and anti-psychiatric critique). Given the principles this document is clearly defending, I believe that its ratification by the Greek state, and subsequent implementation, could form a very dynamic starting grounds in order to bring forth further transformations of the Greek laws regarding mental health 'treatment'. I believe that if relevant groups of users/survivors work together with the help of various specialists on legal issues, legislation could be produced that protects from any ill use of the categorising terms included in the Convention, especially the term 'mentally impaired' that has arisen a negative response to the

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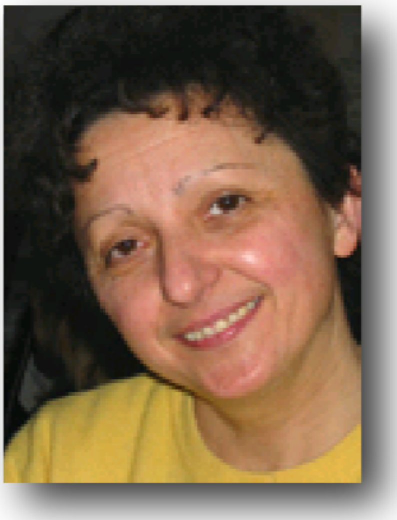
[1] Many of the positions expressed on legislative issues echo the views expressed by Mary Nettle in her opening speech. I am grateful to her for sharing them with all of us.

ratification of the Convention from the part of user/survivor movement. This legislation could be used in link to the implementation process of the Convention once this is ratified. This legislation could even more, be put forward as propositions for parliamentary voting, before ratification process goes on.

The opinion I express here, remains personal; it might be disputed by a number of people in the (ex)user/survivor movement, but it is also open to dialogue. Regardless of any differences continually expressed within mental health activism, I believe that what we need above all is to make decisive steps towards the establishment of constant dialogue, constant feedback, constant communication and taking up initiatives. Despite different views, and even different ideologies, our basic targets remain common.

Greece, unfortunately, remains a country where mental health care is still far from respecting human rights. Recently, the flow of individual complaints and allegations from people suffering psychiatric maltreatment has started to increase, thus certifying the scale of the problem. I believe that it is time for all of us involved in networks and movements demanding humane conditions for mental health treatment, demanding real therapy and return to society, to join our forces and act more decisively - if we want a better society, for ourselves and others.

March 2011



GABRIELA TĂNĂSAN

NEWLY ELECTED CHAIR OF ENUSP

Gabriela Tănăsan is a survivor of psychiatry and an activist for user involvement in Romania. She is the Executive Director of Orizonturi Horizons Foundation (member of ENUSP). In March 2009, she was co-opted by the Board of ENUSP as the individual responsible for the Central European Region. Gabriela's particular interest is in organizational development. Working on behalf of ENUSP, she was the main person responsible for organizing this conference.

Of the situation for Romanian users and users and survivors, "It's been a struggle for many reasons", says Gabriela.

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***".**

CLOSING CEREMONY - Thursday September 30, 6 pm - 7pm

Finally, to mark the end of the formal proceedings at the Thessaloniki Congress, all local and visiting participants gathered in the Alexandros Papanastasiou ceremony hall. They had come to hear the summary impressions and reflections of five speakers, representing the four groups that had developed and realized the event:

- Giorgos Giannoulopoulos, Pan-Hellenic Committee of (ex-) Users and Survivors of Psychiatry
- Mary Nettle, former Chair of ENUSP
- Gabriela Tănăsan , new Chair of ENUSP
- Sotiris Lainas, Self-help Promoting Program, Department of Psychology, Aristotle University in Thessaloniki
- Professor Kostas Bairaktaris, Department of Psychology, Aristotle University in Thessaloniki

The first to speak was **Giorgos Giannoulopoulos** of **the Pan-Hellenic Committee:**

> Dear Colleagues,
> I would say to you simply that our meeting here with ENUSP went pretty well. The truth, in fact, is that it went really, really well. I have a strong impression that it will be fixed in the memories of everyone here in the most positive way. It was the first opportunity to meet together like this in our country, Greece, and we didn't know one another. This coincided with the election of new people, new Board members, who will hopefully be able to act on the problems that concern us – and those problems are many.
>
> My point is that in spite of the efforts that we have made all these years in Greece, in Europe, and internationally, this whole mission that preoccupies us seems strangely sunk. We have heard so much talking, but the steps we are taking seem backward, or the same. I am afraid that the entire social movement of people diagnosed and stigmatized as mentally ill will end up co-opted and integrated into the system. The leadership of ENUSP has the potential to stop this from happening. I believe that we all have the good will and the awareness to make advances and change things for the better. But I say once more that I feel that nothing has really changed in all these recent years - unless we count [having] the freedom, the right to say a few words. We have new states, new areas and new regions; thus, new issues have arisen.
>
> I believe that the new Board of ENUSP will do everything that it intends to promote our issues – *everybody*'s issues. I have emphasized that the fight for our rights is a long one; it began many years ago now. And we may remain for another 50 years at this same pace.

I don't know what will happen, but the whole mission has been diverted, and it seems that the government is starting to take back our rights. In closing, I would like to wish success to the new Board. And I will stress once more that no one should use the word 'disabled' or 'disability' to categorise anyone other than himself or herself - without the permission of that person. I hope that your impressions of Greece are happy and good ones.

The next speaker was **Mary Nettle,** the **former Chair of ENUSP**:

This is the first time I've heard those words 'former Chair of ENUSP'. They go straight through my heart. It is because they are true. I did not stand for re-election, and so it is my choice to be the former Chair. But I am very delighted with the new Chairperson, and also with the fact that this university in Thessaloniki has allowed us to use its buildings, and it has supported us so well. Our General Assembly ran over by a long time, but that was because we had six years of information to get across. We should have an assembly every two years. And it would be lovely if Thessaloniki were able to host us in two years' time. I suspect at this moment, you'll say "No, never again", but we can think about it, or you can suggest a sister university in Athens.

I will now hand over to Gabriela, whom a lot of you know because she helped to organise this congress.

Gabriela Tănăsan , the **new Chair of ENUSP** now addressed the participants:

First of all, I want to say a few words as the organiser of this conference on behalf of ENUSP. I want to thank Professor Bairaktaris, Julie Stamati, and the team of students who made my work easier. And I want to thank each small team involved in registration, accommodation, transportation, everything – Our thanks go to all of you…

And now, as the new Chair, I'm still very moved. It's not a very comfortable position…I don't want to go into this now, but having worked on the group 'Re-building ENUSP', I know the difficulties. And hearing Mr. Giannopolous . . . [I can feel that] service users and survivors of psychiatry from all over Europe have many expectations of ENUSP.

The new Board will try to implement what we have heard in the last few days: suggestions and recommendations for the new Board. We plan to promote and support the movement all over Europe and make the voices of users and survivors loud.

As for me, it's an honour to have been elected as the Chair of ENUSP today at this conference hosted by Aristotle University.

Then followed her incoming statement to the Board :

I dare to say that we, as board members, came into inheritance. I don't want to blame anybody. I just want to emphasize that we have to put much time, energy, work in making

> ENUSP a strong, efficient and accountable organisation . . . The strategic action plan is the crucial tool for building a solid ENUSP. But we have to sort out some organiaational issues before to create this important leading document.
>
> We come from different countries, with different cultures, ways of understanding and perception of the things in general, with various perspectives on the problems the (ex-) users and survivors confront with and their solutions. We, as individuals, are very different natures. Nobody is perfect . . . BUT it is in our strength to leave out vaingloriousness and prejudices, to avoid or clarify misunderstandings and misinterpretations, and come together to serve people who gave us their trust.
>
> In my capacity as a Chair I want to ensure you that I will try to do my best for democratic, transparent and interactive governance.

Sotiris Lainas, representing the **Self-help Promoting Program (Department of Psychology, Aristotle University)**, proceeded to share his thoughts:

> I would like to thank all our friends, the people from Greece and other countries who came to Thessaloniki. We did whatever we could to support the organisation of this meeting, this conference – which happened six years after the last one. I hope that the next meeting will take place on time. It was a conference and a gathering of great interest. It was a conference which highlighted oppositions but also agreements, and this represents the liveness of this movement. It is a movement, which by definition, because of its goal, is constantly in conflict. In my opinion, this ongoing struggle against the large forces which keep people excluded can involve the defeat of these forces as well.
>
> I hope that in future we will aim at organising not just conferences, but simple meetings of people who have common goals such as solidarity, unity and mutual support. Thank you all very much.

The closing words went to **Professor Kostas Baraiktaris** of the **Department of Psychology at Aristotle University:**

> This event in Thessaloniki is one of many – past and future - in support of groups that are socially excluded to various degrees. We act solely as technical support to these groups, bringing forward their own leading role.
>
> We seek the abolition of the psychiatric monologue and its consequences. And we reject both scientific and so-called alternative practices whose only purpose is the building of careers for professionals on the bodies of the socially excluded. So we will go on; we will carry on. We are at your disposal on the basis of our shared goal. This shared goal is the quest for everyone’s freedom.

> Please let me end by referring to the over-populated group of our volunteers – there are around 50 of them – who have worked all this time to coordinate our event. We see their as a leading example; they are confronting mainstream and dominant scientific perceptions; they are joining in the assertion and pursuit of new ideas and solutions for our society.

The ceremony ended with the presentation by Professor Baraiktaris of flowers in thanks to a representative of the Aristotle University student volunteers, Mary Nettle, and Julie Stamati of the Department of Psychology organising committee.

* * *

JANÚ

"Contenzione"

("Restraint")

“antonucciliberamanicomi”

This piece is in recognition of Giorgio Anonucci's work, who was the first person in Italy to create a self-managed asylum psychiatric ward and freed psychiatric prisoners by giving them back their money, their documents and the keys.

RISPERDAL

These images come from the work of the artist Enzo Jannuzzi, “Janú”, who was born in 1946 in Spezzano Albanese, Italy. Since 1969, he has produced art albums, drawings, installations, wall paintings, and published in magazines and lately online journals. He also adores making three-dimensional paper models!

A critic of psychiatry, Enzo Jannuzzi attended the Thessaloniki Congress with Italian delegate Erveda Sansi, who was later elected as a Deputy Board member for the South-West region. She writes of her experience:

"Since the Congress, I have followed and prepared information about the horrible events that happened in one of the biggest Italian hospitals, Milan’s Niguarda Hospital and other cases like Francesco Mastrogiovanni’s. I gathered up materials from Italian (ex) – users and survivors of psychiatry, responding to a request for Fundamental Rights Agency (FRA) Research Project Information. I would like to form a network in Italy of (ex)–users and survivors groups that is not controlled by the psychiatric system. We are hoping to create an Italian ENUSP group and website to give the opportunity to successive users/survivors to join. I also want to help to organise European MAD PRIDE, which is a special goal of the South-West Region".

DAY THREE

CONCLUDING REMARKS
CONCERT

CONCLUDING REMARKS

REFLECTIONS ON THESSALONIKI: “A BREAKTHROUGH AND HOPE FOR THE FUTURE?”

ENUSP’s Sixth Congress, “Determining Our Own Future” was a meeting that was long awaited, and one that many people feared might never happen in the absence of resources and support. It was a meeting planned by the organising team under extremely difficult conditions. It was a meeting that ultimately brought together nearly 100 user or survivor colleagues from 23 countries in a lecture hall in Thessaloniki.

The reflections below have been compiled based on our discussions with other user/survivor participants in the weeks and months afterward. Several people generously shared their thoughts on the event with us via email; we are grateful, in particular, to a small group of (14) participants who were able to complete the evaluation form that can be found in the Annexes to this Report. We have quoted from some of their statements – and revisited the event proceedings - in the hope of capturing what this user/survivor Congress meant to different participants. We have also turned to several rich accounts that were published independently by participants, including our Congress partner, the Pan-Hellenic Committee.

This review of the Congress is far from comprehensive. It cannot capture the many and complex meanings of this event for the users and survivors who came from very different places socially, culturally and economically in Europe. Some of them were representatives of independent national or regional user and survivor organisations. Some came from countries where user/survivor groups are being led by a handful of volunteers who have no regular email access. Others were individuals from places where independent user/survivor networks are still a goal being courageously worked toward. Over time, we hope it will be possible to trace out more of the legacy of this important gathering for ENUSP and its members – though we believe there are signs of its consequences even in this Report. For now, we have chosen to reflect on what was gained and immediately learned in Thessaloniki, keeping in mind the question that appeared in the midst of one delegate’s appraisal and did not leave us.

“Was this a breakthrough really and hope for the future?”

We think of the usual definition of ‘breakthrough’ as ‘the overcoming of a significant obstacle of restriction’. We also note the very tentative optimism of this comment – and the question mark at its end. There are indeed ways, we believe, that this Thessaloniki event was a breakthrough and a point of transition, of possibility, and hope for ENUSP and its members. There was also a real sense in which it revealed the considerable difficulties and uncertainties now facing the European Network. We survey some these issues below, referring to the loose objectives of the ENUSP organisers:

1. Strengthening connection among European users and survivors
2. Working with the UN Convention on the Rights of People with Disabilities, and
3. Election of a new ENUSP Board representing all regions of Europe with a clear Work Programme for our future

First objective : Strengthening connections

This was to be, the programme said, “a conference for users and survivors of psychiatry from across Europe to exchange experiences, opinions and support in our struggles against exclusion, injustice and discrimination.” Coming so many years after the last ENUSP membership meeting, this Congress created a chance for sustained and face-to-face communication among user/survivor colleagues from across Europe that was crucial to many of us.

Participants came to the Congress with very diverse experiences of activism and different expectations. Those who had greater experience of international co-operation stressed the importance of building upon existing connections and knowledge in our movement, “getting together with old friends and colleagues, gaining some new ones, exchange of information, gaining some new information on the subject” as one person said. Others, in contrast, had only very limited past opportunity to compare and speak out about their situations as people who had been on the receiving end of psychiatric systems, or to describe their work as activists. This was a rare chance, one person commented, to come together “to openly and bravely express our opinions and support each other". Some delegates mentioned that they wanted to know more about strategies for self-organised action:

> It was my first conference. I have not much experience at patients' organisations in my country as they only start to develop now. So it would be good to receive experience from those who have done this for a longer time.
>
> I'm so glad to get to know all of you. We are only a few people [who] know what's going on in self help movement and mental health politics to get the other people aware.

From the very start, delegates used the Congress to deliver direct country information, seeking to expose under-reported crises and abuses. The atmosphere was charged , and their messages urgent:

> What's happened in the United Kingdom is that since last year there's been community treatment orders. It's coming more and more. People are being given substandard housing, substandard employment in the community . . . And they don't need to be in institutions any more to be treated against their will.
>
> I come from the Netherlands. I don't know what you read in the paper about things there, but the situation is really horrifying . . . They are abolishing all welfare support . . . And we're told we have to pay for the credit crisis.
>
> In addition, and I really mean this: real tortures happen here [in Greece]. This society is really barbaric.

The drawing together of these accounts was important, as Giorgios Giannoulopolous of the Pan-Hellenic Committee demonstrated:

> I've seen from a leaflet of a coalition of the 'mentally ill' in Denmark that they have come really close to passing legislation that would enable the use of force if someone refuses to take their psychotropic medication. In Great Britain I am informed that force is already been used in these situations under certain conditions. In due time, this will probably start in [Greece] as well with proper marketing and propaganda.

Some of the user/survivor participants – in particular, those who had gathered from across Greece-noted that they were coming into direct contact for the first time with ENUSP and its promise of

European-level networking and action. They voiced strong interest, but also used the space to convey uncertainty and expectations:

> It is a chance for us in Greece to meet ENUSP. I'm a psychiatric user for more than 10 years. And I've never known about ENUSP. I'm president of a small group of users of psychiatry in Corfu. I work in a social co-operative, and it's good to know that there are common experiences, that there are people who have had the same experiences we have had in Greece - all over the world, all over Europe. There's still hope because even in this, things are changing . . . Yet there is so much to be done . . . I would like to know some more about ENUSP, what is your direction? What are ENUSP's aims?
>
> As an overall conclusion the conference was a positive thing. Many misunderstandings and falsehoods that obviously existed (surely existed for us) were clarified . . . We hope that the new ENUSP administration will do something (anyway, ENUSP is the main European institution for us to claim our rights and dignity) for all those deaths in mental institutions . . . for all those humiliations[1].

In her Opening Ceremony address, World Network representative Iris Hölling had spoken of our "right to self-defined support*,* a right to peer-support, to survivor-controlled spaces and support structures*".* Others did not always use the same terminology, but noted why being part of an event whose agenda was determined by other users and survivors was significant. They had been able to forge connections and access very relevant resources from colleagues

> The best part of the event was to meet a lot of different people with similar ideas on equal needs . . . to be connected to real fighters for freedom and self empowerment.
>
> I got a very interesting book from [another survivor] about how to come off the psychiatric drugs but I am still receiving medicines. I have shown the book to the psychologist but he said when he reads the book to the users everybody will leave the medicine.
>
> Although I was quite new in that business, I had easy access to the people.

Many delegates remarked that they had gained especially from small closed group discussions both within the official confines of the programme (the working groups and regional meetings) and in informal meetings outside. The working groups, they said, had fostered participation:

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[1] Bairaktaris, K. (2010) Proceedings of the European Congress against Discrimination and Stigma, and for User-oriented Reforms and the Right to Alternatives, September 28 - October 1: Parallel Events, Conclusions, Findings and Reflections, p27-29. Thessaloniki: Aristotle University.

> I attended the philosophy and psychiatry group. It was good that we could communicate in this group on our personal experience and the group was not too big.
> The second workshop was about peer counseling. It was interactive. I was able to exchange e-mail contacts with them and the situations from different countries were compared.
>
> [There was a]constructive introductory presentation of the topic by the organiser, raising key issues at both individual and social level. A lot of discussion followed the presentation, both in theoretical and in practical issues, bringing forth a very creative dialogue.
>
> Working groups with people expressing views strongly, openly, and in dialogue, without fear.

One delegate suggested the work from these groups should now be recorded and taken further:

> I would like to participate to more working groups. The feedbaks of working groups were too short. The possibility of diffusing the results of such working groups through written copies would very much develop the entire work.

But there needed to be adequate space and time, another person told us, for the exploring of complex topics:

> I think that spare time was quite needful to get in touch with the other participants. I think sometime you need more time to get an impression of the people's minds and to share their vision of the world. I think the topic is quite sensitive, so sometimes it is not too easy to exchange ideas at once.
>
> The different standpoints within our movement were sometimes evident. It is also important to put together needs and goals of users, ex-users and survivors of psychiatry – that we are all one group. I do not know – maybe I am a user heretic.

Thinking about connections in survivor-controlled space inevitably raises questions about the mixed space of the large and formal public assembly hall – whose audience was largely Greek non-user/survivor professionals. This situation was likely most evident to the Greek user/survivor participants, one of whom said:"[P]rofessionals of mental health . . . were the main organisers of the conference." The warm hosting style of Aristotle University was generally praised by ENUSP delegates. But it was also clear that even the university's provision of solely organisational-technical support could be an issue when user/survivor participants were not properly consulted. The decision of the University to film the proceedings without any prior explanation or seeking of consent was problematic for some user/survivor participants.[2]

Participants appreciated the Greek-English translation of almost the entire proceedings by students of Aristotle University. But the need to use English as a common language throughout the Congress also caused problems for some delegates. It is hard for us to gauge the full impact of language barriers at the Congress. Some delegates were able to improvise solutions by way of colleagues who were fluent in several languages, and one delegate arranged for his own interpreter. Delegates had some suggestions about what could be done to address the situation, requesting more accessible language and written support materials:

> I must improve my language basically, but it would have been easier by any written support.
>
> [O]ur English should try to be not to difficult - to help us not to loose us. (Comment on the information materials prepared by ENUSP for the Congress).

Speaking at the General Assembly, new ENUSP Deputy Chair Rafaël Daem reminded us that there were “people who are not present because they are not able to be here. This fact should not be hidden.” A few other people also mentioned those who were missing:

> The region I represent is indeed weakly organised and under-reported.
>
> Teleconferencing for people unable to attend might be an option to think of.

But, for the most part, we can only note a troubling silence.

For those of us who were able to go to Thessaloniki, the co-operation appeared to raise hopes. It seemed to build a belief in the possibility of more connected actions:

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[2] We would later learn that the university – like ENUSP itself- was documenting the Congress as a record for participants. ENUSP’s own practice in these cases is to provide full advance information about any photographic, film or audio recording so as to give attendees the option of withholding consent as well as signposting on the day who would be taking pictures on behalf of ENUSP so that those who did not want to be in shot can be identified.

> I think that this event was really a good opportunity to create a common goal and for that reason a good opportunity to meet.
>
> Because of the discussion panel I got in contact with quite a few people. I could share opinion, ideas and make conversation all in once. It was also a good opportunity to create something common and new.
>
> Perhaps there are even more possibilities to build networks around Europe.

Second objective: "Now we have a tool":

Working with the UN Convention on the Rights of Persons with Disabilities

The Congress was a crucial chance for ENUSP to work with users and survivors on new tools and strategies for (self-)advocacy. The programme described a focus for the first time on using "the UN Convention on the Rights of Persons with Disabilities . . . to achieve reforms and self-determined alternatives for users and survivors of psychiatry".

As we have seen, ENUSP's planning group was very aware of the need to make the Convention known to our members as a human rights treaty that was shaped significantly by psychiatric survivors. The planners hoped to convey the relevance of the treaty to the fights that many users and survivors have long been waging with limited resources across Europe: campaigns against forced treatment, guardianship and other practices that deprive us of the right to decide on our own lives, and for our meaningful involvement in policy and law-making about us. We sensed that awareness of the Convention among our community was still fairly low.

The challenge clearly was how to work with this human rights treaty among our diverse group in Thessaloniki. We pause here therefore to reflect on the impact of the two key interventions about the Convention that happened at the Congress: the open ceremony speech by World Network representative Iris Hölling, and the keynote presentation the next day by Stefan Trömel of International Disability Association (IDA).

Each of these interventions did much of the crucial work described by Trömel in his keynote description of ‘CRPD capacity-building’ – that is, they gave help with “understanding the Convention: how it works, the content of the Convention, how we can use it.” Iris Hölling, in particular, conveyed a powerful message that the Convention belonged to us as users and survivors of psychiatry: “
I think we are going backwards in some respects, but on the other hand, we have this UN treaty. It contains very clear statements about our rights [to protection] against forced treatment in psychiatry, and this is something new.”

There were very clear signs of the effect of these speeches throughout the question and answer sessions that followed them and indeed the entire Congress, with audience questions ranging from basic orientation (where people could find the instrument and its translations) to detailed concerns about the status of the treaty in different countries, and particular practices (for example, community treatment orders)that should be banned where the CRPD has been ratified.
These sessions also saw some user and survivor activists volunteering information about their own efforts to ensure ratification and implementation nationally. Some had very close knowledge of the treaty:

> You were talking about the Convention. I was very active in the birth of the Convention, in the lobbying in the United Nations building in New York. What we have really been working to change is now possible according to the Convention. And what I want to say is, there are really changes in this Convention.

Despite this marked interest, the feedback from other user/survivor participants pointed to reservations and doubts about the Convention among European users and survivors. Among the most prominent at this Congress were those related to the treaty’s use of disability language and the involvement of representatives of disability organisations in its presentation. These objections were often grounded in particular national and cultural contexts. They could be substantial enough to block interest in the content of the international law treaty altogether:

> What is unclear to us is why the Director of the International Disability Alliance, who took part in the conference as the foreign keynote speaker , kept calling the patients “disabled”. . . Many

> mentally ill people among us do not accept the characterization of ‘disabled’ (Bairaktaris, K. 2010).[3]
>
> [W]e must work on alternative terms of speech like ‘altered states of consciousness’ . . . ‘Disability’ in German translation sounds like not good energy.

Delegates also expressed scepticism about whether formal legal change would transform the lives of users and survivors:

> The old European Convention was also giving a lot of rights . . .
>
> In the UK, our government *has* ratified the Convention. They made a few reservations. . . which means they say,”Well, I don’t think our laws fit this.” And they said forced treatment was fine.

Some participants told us that Stefan Trömel’s presentation had been helpful for experienced user/survivor activists. Still they wondered about its accessibility to those new to the treaty:

> . . . Maybe for people who were not top good informed, it was a bit too quick and too much content in short terms.
>
> Stefan . . . made a very good presentation of the CRPD –but people who have never studied the CRPD before had probably hard to remember what he said . . .
>
> I could better follow the speech on a written base.

These concerns and especially cultural issues need to be taken into account by ENUSP in thinking through future strategies for working with our members toward the implementation of the UN Convention. During the open discussions at the Congress, users and survivors named different materials on the Convention that they would like to see from ENUSP, including more accessible manuals and lists of cases where the treaty had been used successfully to defend the rights of users and survivors. ENUSP Board member Erik Olsen agreed there was a need for the Network to continue raising the awareness and building the strategies of users and survivors across Europe around the

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[3] Ibid Bairaktaris, K. (2010), p 27

Convention. But he added that for this organising to happen, there had to be real support and resources for independent user/survivor organisations.

Third Objective: **Determining our own future:**
The election of a new ENUSP Board and adoption of our future work programme

> **I** can't say too much about the election day. Of course I'm happy for [the Chair and the Board]-and because of that, I expect a lot from them-because I know they can. But also . . . somehow it seemed that ENUSP is at a crossroad now.
> (Romanian ENUSP delegate)

The Congress culminated in the holding of a general assembly for ENUSP members, including two key parts: a democratic election of a new Chair and a Board and the adoption of a Work Programme for the coming years. It is these steps which we would like to draw out as a final focus in these comments on the event called "Determining Our Own Future".

This Sixth Congress General Assembly had been long anticipated by the ENUSP Board, whose positions had extended three years beyond their term because of the Network's financial and organising problems. It was a chance for the democratic election of a new Chair and representatives from all six regions of ENUSP. This election process took place on the last day of the Congress. Six new Board members and their deputies were chosen, covering all parts of the continent.

As their new Chair, ENUSP members elected Gabriela Tanasan from Romania. Her election also marked a major shift, bringing the concerns of another frequently overlooked region to the fore of the European Network. Perhaps the most significant regional election happened in the South-East, which had lacked a representative on the Board for many years. New Board member Katerina Skourtopoulou was elected from Greece along with her deputy Asmati Augustin from Georgia. This was an important change, ensuring ongoing direct links with a region whose concerns and perspectives have long been under-reported. At the same time, it will allow greater support to user/survivor organisations which are working to establish themselves in this region.

This General Assembly reached a peak in the discussion and final approval by members from all regions of a two-year Work Programme for ENUSP. The programme had come from the bottom-up of the membership at the Congress, based on priorities drafted by the Rebuilding ENUSP group.
The largest of the working groups, it brought together delegates from eleven countries at a round table to address the crisis now stopping ENUSP from organising and advocating effectively for European users and survivors. The resulting programme contains twelve organisational and eleven work priorities, which can be found on page 113 of this Report. At its core is the need to pursue stable operational funding so that the European Network can become self-sufficient and carry out its mandate.

AFTERWORD:

WAS ALL THIS A BREAKTHROUGH?

> Listening now to Mr. Giannoulopolous, I realise the expectations that psychiatric survivors have of us
> (Gabriela Tanasan, New Chair of ENUSP)

Listening too to other participants at the Sixth ENUSP Congress and to daily news from the user and survivor world, it is clear that there is an urgent need for a strong and genuine self-representative organisation that can speak our common concerns and advance our human rights in Europe.

The newly elected Board and Work Programme represent chances for a real movement forward for the European Network. Still, despite the breakthroughs at this Congress, the way ahead remains uncertain. It is clear to us that the aims expressed at this Congress – Determining our own future; Rebuilding ENUSP – are not ones that can ever be achieved at a single event. They are processes requiring ongoing work, commitment - and resources.

The Sixth ENUSP Congress in Thessaloniki was a vital event. In three short days, it affirmed how much can be achieved when users and survivors of psychiatry are organised and connected across Europe. It showed what can happen when there is support for our individual and collective self-determination.

THE CONCERT!

ΕΥΡΩΠΑΪΚΟ ΣΥΝΕΔΡΙΟ ΚΑΤΑ ΤΩΝ ΔΙΑΚΡΙΣΕΩΝ ΚΑΙ ΤΟΥ ΣΤΙΓΜΑΤΙΣΜΟΥ
ΓΙΑ ΜΙΑ ΨΥΧΙΑΤΡΙΚΗ ΜΕΤΑΡΡΥΘΜΙΣΗ ΠΡΟΣΑΝΑΤΟΛΙΣΜΕΝΗ ΣΤΟΝ ΧΡΗΣΤΗ
ΚΑΙ ΓΙΑ ΤΟ ΔΙΚΑΙΩΜΑ ΓΙΑ ΕΝΑΛΛΑΚΤΙΚΕΣ ΛΥΣΕΙΣ

EUROPEAN CONGRESS AGAINST DISCRIMINATION AND STIGMA
FOR USER-ORIENTED REFORMS IN PSYCHIATRY AND THE RIGHT TO ALTERNATIVES

ΣΥΝΑΥΛΙΑ/CONCERT
ΠΛΑΤΕΙΑ ΑΡΙΣΤΟΤΕΛΟΥΣ
ΠΕΜΠΤΗ 30 ΣΕΠΤΕΜΒΡΙΟΥ 2010
ώρα 20.00

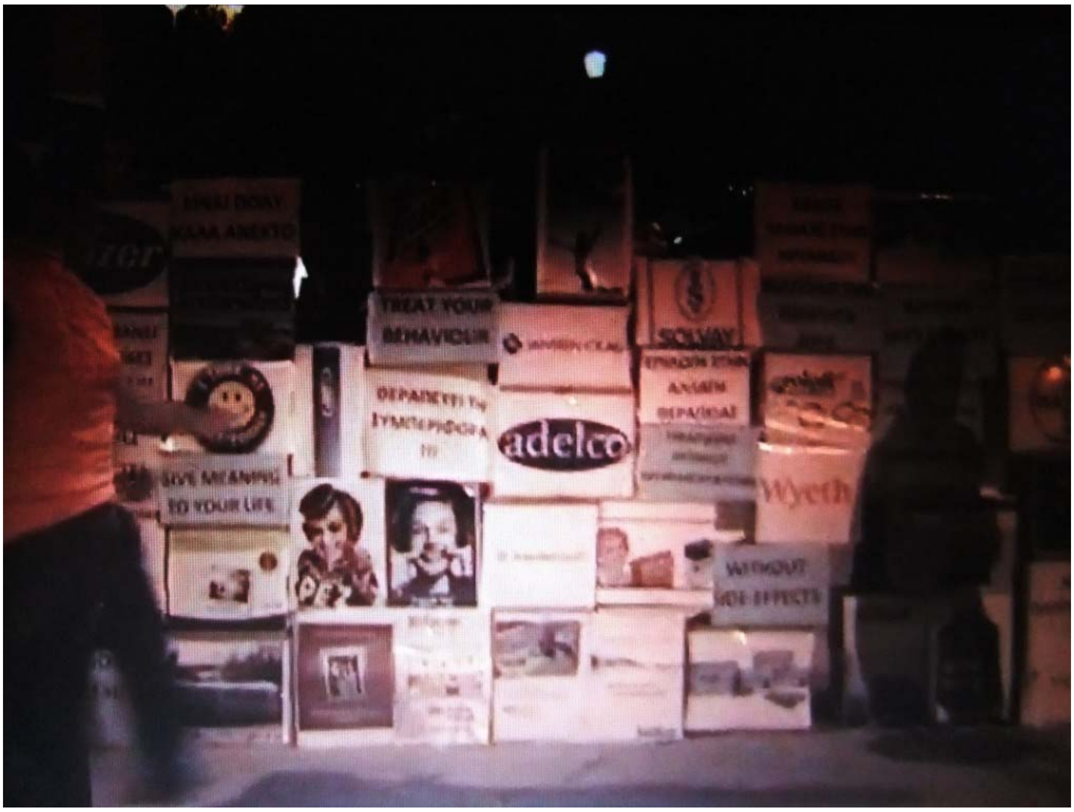
ΣΥΜΜΕΤΕΧΟΥΝ
ΘΑΝΑΣΗΣ ΚΑΙ
ΚΩΝΣΤΑΝΤΙΝΟΣ ΓΚΑΪΦΥΛΙΑΣ
ΓΙΩΡΓΟΣ ΚΑΖΑΝΤΖΗΣ
Βαλάντης Καπουρελάκος & Δημήτρης Κεχαγιάς
Science Fiction Rock by Manos & Friends

Το έργο συγχρηματοδοτείται από το Ευρωπαϊκό Κοινωνικό Ταμείο κατά 80%
και από το Υπουργείο Υγείας και Κοινωνικής Αλληλεγγύης κατά 20%

From a participant to the concert, Sean Crudden:

> “In the public square that night a banner declaring, "Stop the psychiatric violence!" was slung across the apron of the stage dominating the city square, films of violent psychiatric intervention were blazed across an outdoor screen. A heavy wall constructed of cardboard boxes displaying the logos of all the prominent global pharmaceutical companies was unveiled. At a signal users and survivors rushed the wall, demolished it, kicked it asunder; with shouts of triumph. The music and singing was of a quality to be found no-where else in this small globe except Greece. Users and survivors danced and jived in the square for over an hour. The square is bounded on three sides by impressive buildings and on the fourth side (behind the stage) by the Aegean Sea”

Manos’ “science fiction rock” act had kicked off the evening, followed by the fall of the Big Pharma Wall,



The concert proper then continued, with different acts giving their time free for the cause. This went on for quite some time late into the evening. As the pictures show, the ambiance was very joyous and many participants from the conference danced, daring the shy ones to join in the fun. Here is also a YouTube link to a short video, which was posted by a participant: http://www.youtube.com/watch?v=RbciYk_u4Wg


STOP THE PSYCHIATRIC VIOLENCE


STOP THE PSYCHIAT


Lilly
Pfizer
ΕΙΝΑΙ ΠΟΛΥ ΚΑΛΑ ΑΝΕΚΤΟ
ΠΡΟΛΑΜΒΑΝΕΙ ΜΕΛΛΟΝΤΙΚΕΣ ΥΠΟΤΡΟΠΕΣ!!!
zyprexa
ΚΑΝΕΝΑΣ ΚΙΝΔΥΝΟΣ!
GIVE MEANING TO YOUR LIFE
PROZAC

POSTCARDS FROM . . .

Wish you were here ...

Aristotle enjoying some late afternoon sunshine!

The White Tower: A famous Thessaloniki landmark. Today it houses a city museum.

Above: Neo-classical detail above the front door of a house; **Right:** Town house detail

One of the most delightful surprises of Thessaloniki, for amateurs of urban poetry in the midst of busy cities . . . This little street boasts much creative sense of fun - while canaries sing to their heart's content to passers-by!

ANNEXES

ANNEXES

Page

1. ENUSP's six regions 168
2. Invitation letter for participants to ENUSP's Sixth Congress 169
3. Invitation letter for participants to the General Assembly 172
4. Background briefing about the election process 173
5. Reports to the Board from Board members, Deputy Board members and Support members to the Board 179
6. Article by Jan Verhaegh about the Congress 191
7. Truth and Reconciliation in Psychiatry-Draft Statement 193
8. Evaluation form 196

ANNEX 1

ENUSP's SIX REGIONS:

- **Central Region:**
  Czech Republic, Hungary, Liechtenstein, Moldova, Romania, Slovakia

- **North West Region:**
  Ireland, The Netherlands, United Kingdom (England, Northern Ireland, Scotland, Wales)

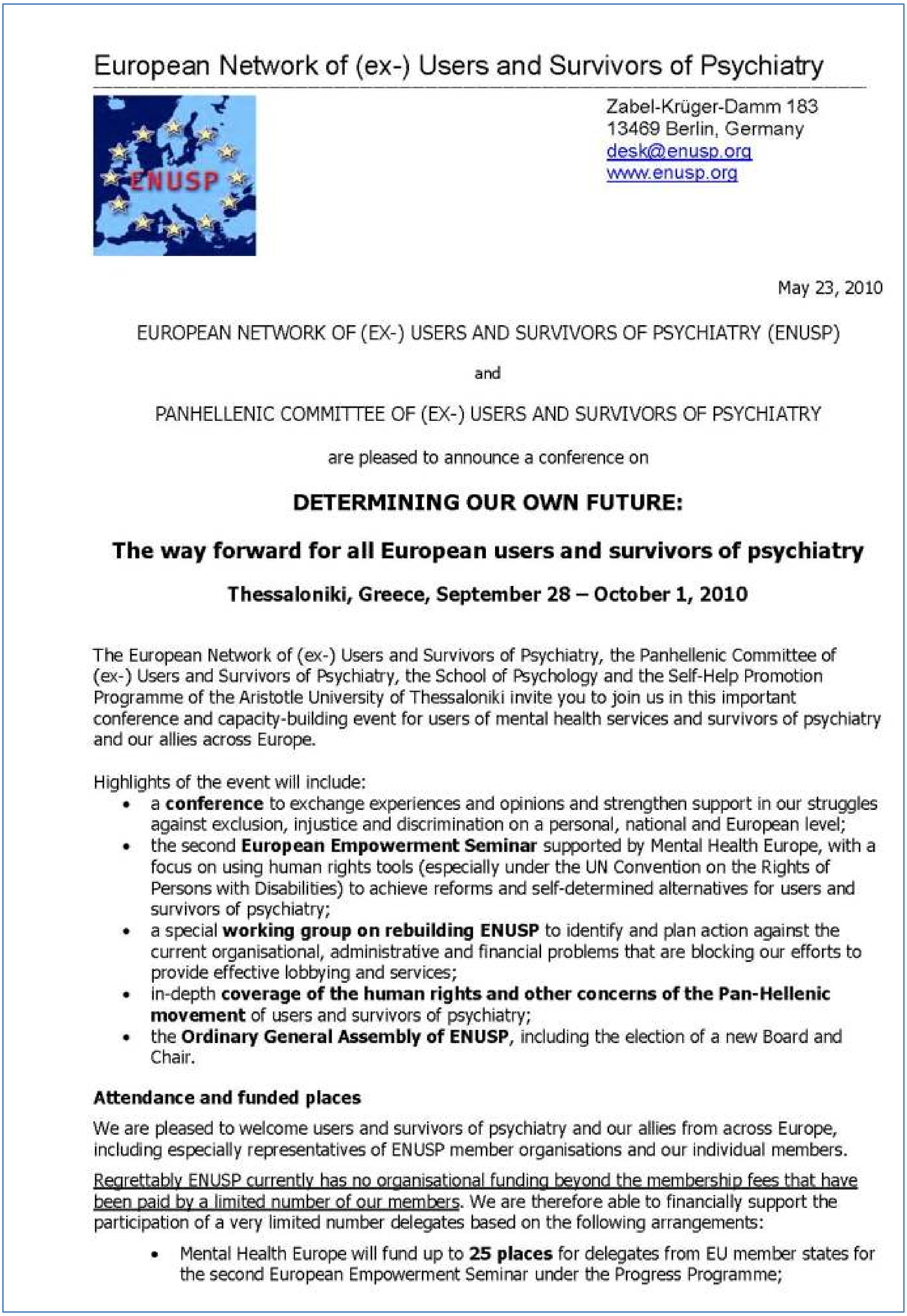
- **Northern Region:**
  Denmark, Finland, Faroe Islands, Greenland, Iceland, Norway, Sweden

- **North East Region:**
  Austria, Estonia, Germany, Latvia, Lithuania, Poland, Russia

- **South West Region:**
  Andorra, Belgium, France, Italy, Luxembourg, Portugal, San Marino, Spain, Switzerland

- **South East Region:**
  Albania, Armenia, Azerbaijan, Belarus, Bosnia & Herzegovina, Bulgaria, Croatia, Cyprus, Georgia, Greece, Israel, Former Yugoslav Republic of Macedonia (FYROM), Malta, Montenegro, Serbia, Slovenia, Turkey, Ukraine

ANNEXE 2 - INVITATION LETTER FOR PARTICIPANTS TO ENUSP'S SIXTH CONGRESS



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

ENUSP

Zabel-Krüger-Damm 183
13469 Berlin, Germany
desk@enusp.org
www.enusp.org

May 23, 2010

EUROPEAN NETWORK OF (EX-) USERS AND SURVIVORS OF PSYCHIATRY (ENUSP)

and

PANHELLENIC COMMITTEE OF (EX-) USERS AND SURVIVORS OF PSYCHIATRY

are pleased to announce a conference on

DETERMINING OUR OWN FUTURE:

The way forward for all European users and survivors of psychiatry

Thessaloniki, Greece, September 28 – October 1, 2010

The European Network of (ex-) Users and Survivors of Psychiatry, the Panhellenic Committee of (ex-) Users and Survivors of Psychiatry, the School of Psychology and the Self-Help Promotion Programme of the Aristotle University of Thessaloniki invite you to join us in this important conference and capacity-building event for users of mental health services and survivors of psychiatry and our allies across Europe.

Highlights of the event will include:

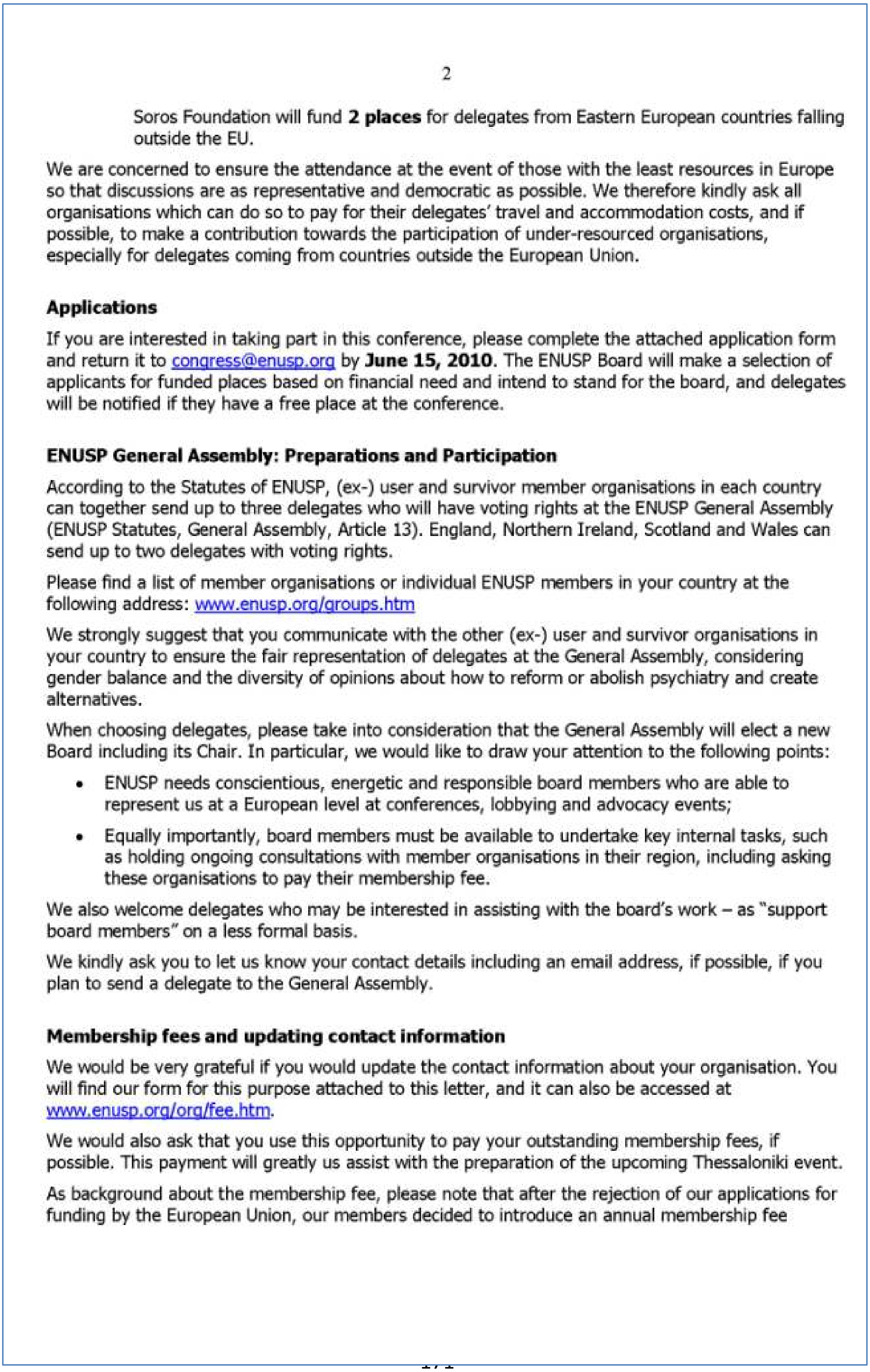
- a **conference** to exchange experiences and opinions and strengthen support in our struggles against exclusion, injustice and discrimination on a personal, national and European level;
- the second **European Empowerment Seminar** supported by Mental Health Europe, with a focus on using human rights tools (especially under the UN Convention on the Rights of Persons with Disabilities) to achieve reforms and self-determined alternatives for users and survivors of psychiatry;
- a special **working group on rebuilding ENUSP** to identify and plan action against the current organisational, administrative and financial problems that are blocking our efforts to provide effective lobbying and services;
- in-depth **coverage of the human rights and other concerns of the Pan-Hellenic movement** of users and survivors of psychiatry;
- the **Ordinary General Assembly of ENUSP**, including the election of a new Board and Chair.

Attendance and funded places

We are pleased to welcome users and survivors of psychiatry and our allies from across Europe, including especially representatives of ENUSP member organisations and our individual members.

Regrettably ENUSP currently has no organisational funding beyond the membership fees that have been paid by a limited number of our members. We are therefore able to financially support the participation of a very limited number delegates based on the following arrangements:

- Mental Health Europe will fund up to **25 places** for delegates from EU member states for the second European Empowerment Seminar under the Progress Programme;



Soros Foundation will fund **2 places** for delegates from Eastern European countries falling outside the EU.

We are concerned to ensure the attendance at the event of those with the least resources in Europe so that discussions are as representative and democratic as possible. We therefore kindly ask all organisations which can do so to pay for their delegates' travel and accommodation costs, and if possible, to make a contribution towards the participation of under-resourced organisations, especially for delegates coming from countries outside the European Union.

Applications

If you are interested in taking part in this conference, please complete the attached application form and return it to congress@enusp.org by **June 15, 2010**. The ENUSP Board will make a selection of applicants for funded places based on financial need and intend to stand for the board, and delegates will be notified if they have a free place at the conference.

ENUSP General Assembly: Preparations and Participation

According to the Statutes of ENUSP, (ex-) user and survivor member organisations in each country can together send up to three delegates who will have voting rights at the ENUSP General Assembly (ENUSP Statutes, General Assembly, Article 13). England, Northern Ireland, Scotland and Wales can send up to two delegates with voting rights.

Please find a list of member organisations or individual ENUSP members in your country at the following address: www.enusp.org/groups.htm

We strongly suggest that you communicate with the other (ex-) user and survivor organisations in your country to ensure the fair representation of delegates at the General Assembly, considering gender balance and the diversity of opinions about how to reform or abolish psychiatry and create alternatives.

When choosing delegates, please take into consideration that the General Assembly will elect a new Board including its Chair. In particular, we would like to draw your attention to the following points:

- ENUSP needs conscientious, energetic and responsible board members who are able to represent us at a European level at conferences, lobbying and advocacy events;
- Equally importantly, board members must be available to undertake key internal tasks, such as holding ongoing consultations with member organisations in their region, including asking these organisations to pay their membership fee.

We also welcome delegates who may be interested in assisting with the board's work – as "support board members" on a less formal basis.

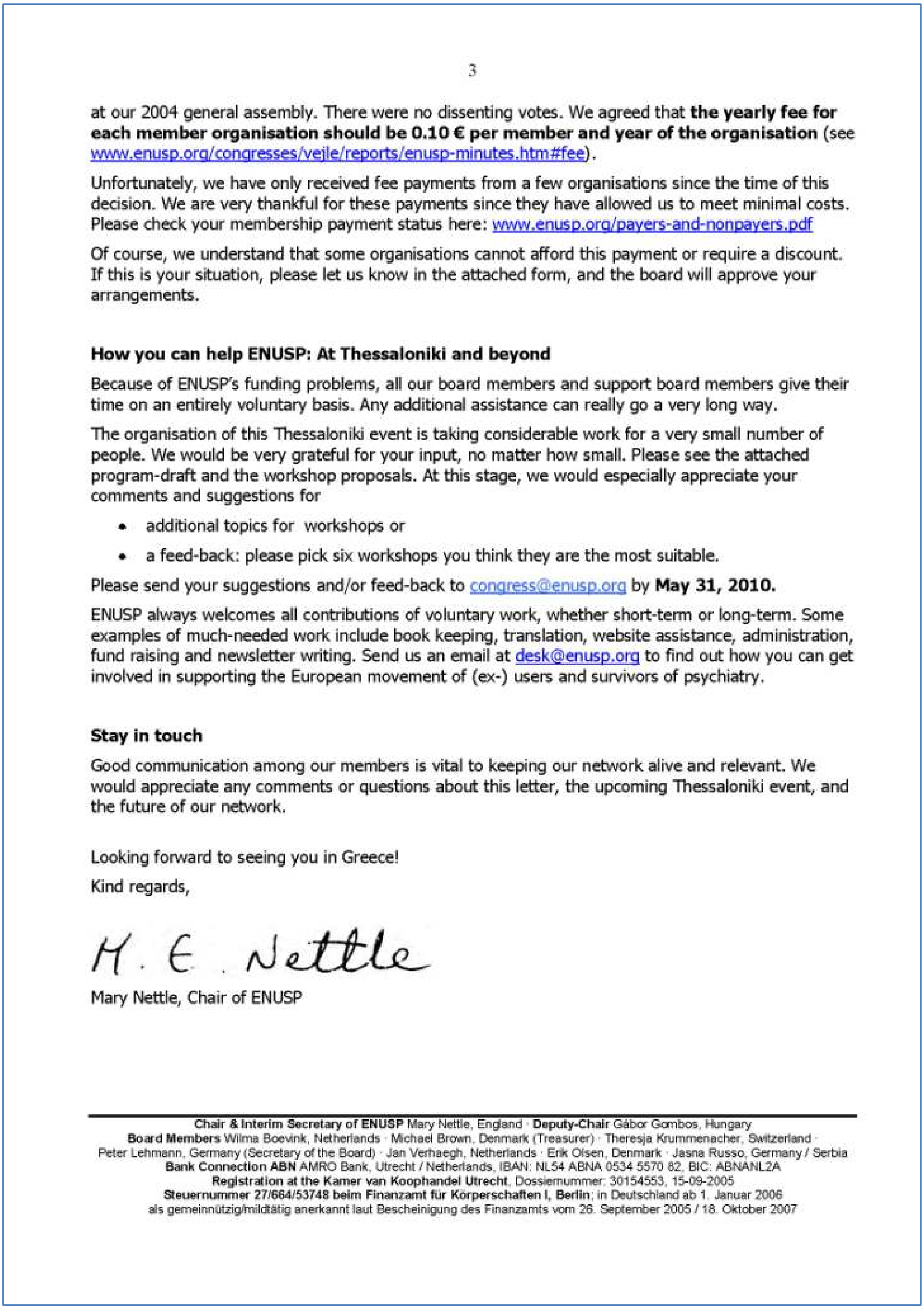
We kindly ask you to let us know your contact details including an email address, if possible, if you plan to send a delegate to the General Assembly.

Membership fees and updating contact information

We would be very grateful if you would update the contact information about your organisation. You will find our form for this purpose attached to this letter, and it can also be accessed at www.enusp.org/org/fee.htm.

We would also ask that you use this opportunity to pay your outstanding membership fees, if possible. This payment will greatly us assist with the preparation of the upcoming Thessaloniki event.

As background about the membership fee, please note that after the rejection of our applications for funding by the European Union, our members decided to introduce an annual membership fee



at our 2004 general assembly. There were no dissenting votes. We agreed that **the yearly fee for each member organisation should be 0.10 € per member and year of the organisation** (see www.enusp.org/congresses/vejle/reports/enusp-minutes.htm#fee).

Unfortunately, we have only received fee payments from a few organisations since the time of this decision. We are very thankful for these payments since they have allowed us to meet minimal costs. Please check your membership payment status here: www.enusp.org/payers-and-nonpayers.pdf

Of course, we understand that some organisations cannot afford this payment or require a discount. If this is your situation, please let us know in the attached form, and the board will approve your arrangements.

How you can help ENUSP: At Thessaloniki and beyond

Because of ENUSP's funding problems, all our board members and support board members give their time on an entirely voluntary basis. Any additional assistance can really go a very long way.

The organisation of this Thessaloniki event is taking considerable work for a very small number of people. We would be very grateful for your input, no matter how small. Please see the attached program-draft and the workshop proposals. At this stage, we would especially appreciate your comments and suggestions for

- additional topics for workshops or
- a feed-back: please pick six workshops you think they are the most suitable.

Please send your suggestions and/or feed-back to congress@enusp.org by **May 31, 2010.**

ENUSP always welcomes all contributions of voluntary work, whether short-term or long-term. Some examples of much-needed work include book keeping, translation, website assistance, administration, fund raising and newsletter writing. Send us an email at desk@enusp.org to find out how you can get involved in supporting the European movement of (ex-) users and survivors of psychiatry.

Stay in touch

Good communication among our members is vital to keeping our network alive and relevant. We would appreciate any comments or questions about this letter, the upcoming Thessaloniki event, and the future of our network.

Looking forward to seeing you in Greece!

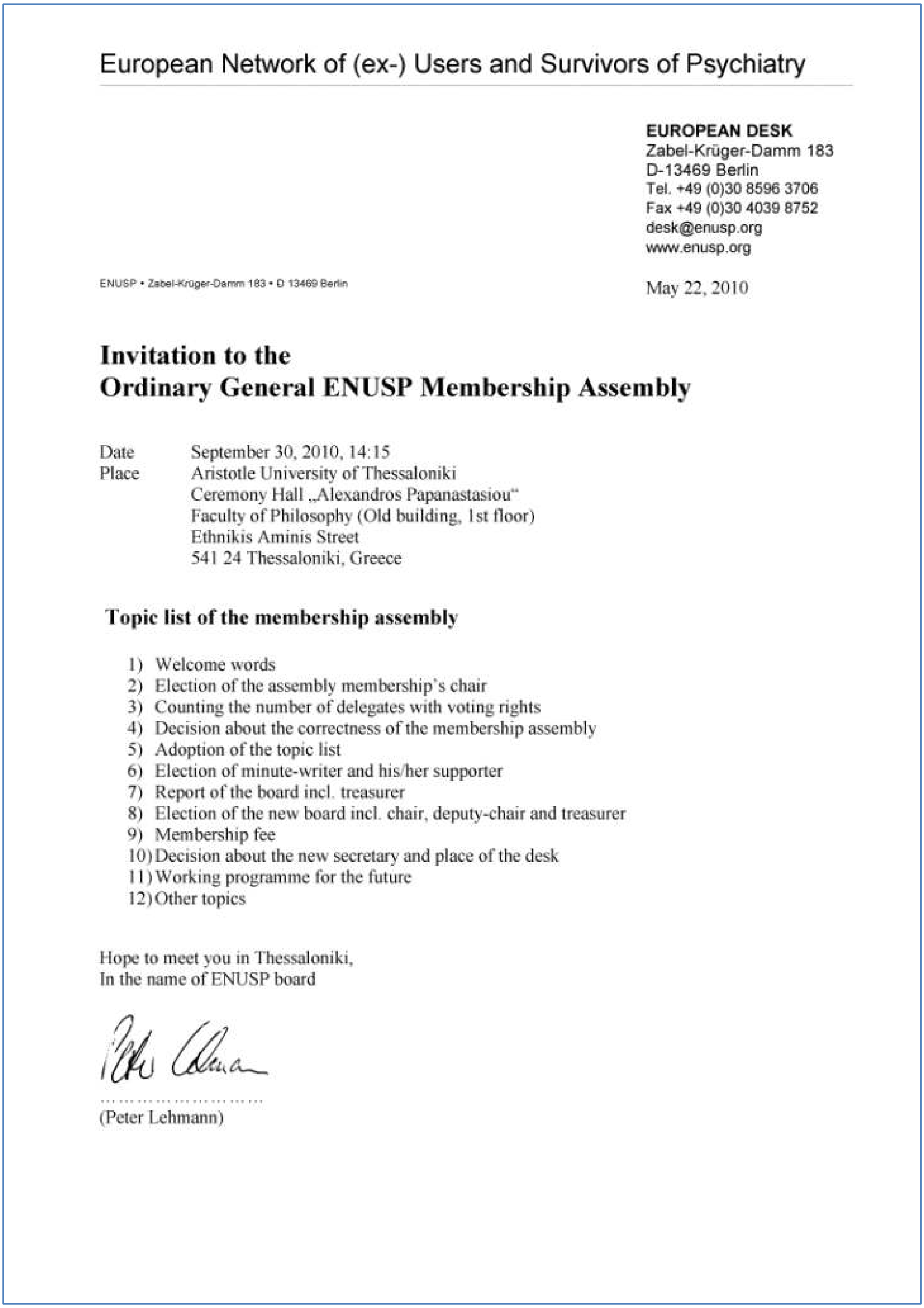
Kind regards,

M. E. Nettle

Mary Nettle, Chair of ENUSP

Chair & Interim Secretary of ENUSP Mary Nettle, England · **Deputy-Chair** Gábor Gombos, Hungary
Board Members Wilma Boevink, Netherlands · Michael Brown, Denmark (Treasurer) · Theresja Krummenacher, Switzerland · Peter Lehmann, Germany (Secretary of the Board) · Jan Verhaegh, Netherlands · Erik Olsen, Denmark · Jasna Russo, Germany / Serbia
Bank Connection ABN AMRO Bank, Utrecht / Netherlands, IBAN: NL54 ABNA 0534 5570 82, BIC: ABNANL2A
Registration at the Kamer van Koophandel Utrecht, Dossiernummer: 30154553, 15-09-2005
Steuernummer 27/664/53748 beim Finanzamt für Körperschaften I, Berlin; in Deutschland ab 1. Januar 2006 als gemeinnützig/mildtätig anerkannt laut Bescheinigung des Finanzamts vom 26. September 2005 / 18. Oktober 2007

ANNEXE 3: MEMBERS' INVITATION TO THE GENERAL ASSEMBLY



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

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ENUSP • Zabel-Krüger-Damm 183 • D 13469 Berlin

May 22, 2010

Invitation to the
Ordinary General ENUSP Membership Assembly

Date September 30, 2010, 14:15
Place Aristotle University of Thessaloniki
Ceremony Hall „Alexandros Papanastasiou“
Faculty of Philosophy (Old building, 1st floor)
Ethnikis Aminis Street
541 24 Thessaloniki, Greece

Topic list of the membership assembly

1) Welcome words
2) Election of the assembly membership's chair
3) Counting the number of delegates with voting rights
4) Decision about the correctness of the membership assembly
5) Adoption of the topic list
6) Election of minute-writer and his/her supporter
7) Report of the board incl. treasurer
8) Election of the new board incl. chair, deputy-chair and treasurer
9) Membership fee
10) Decision about the new secretary and place of the desk
11) Working programme for the future
12) Other topics

Hope to meet you in Thessaloniki,
In the name of ENUSP board

……………………………
(Peter Lehmann)

ANNEXE 4

BACKGROUND BRIEFING ABOUT THE ELECTION PROCESS

Dear Delegates,

We have been working under difficult conditions on the preparations for this month's conference in Thessaloniki. This document is intended to provide some important information about the election of ENUSP's new board due to take place during this conference. It is meant especially for delegates who will take part in the election process for the first time, but it may also serve as a timely reminder for past delegates.

As you already know, our programme will include **regional meetings for each of the six regions of ENUSP** to be followed by a **General Assembly of ENUSP**. This process will lead to the election of a new ENUSP Board, including a new Chair and Deputy Chair. Please note that all of these positions are voluntary (unpaid) under the Statutes.

ENUSP also has vacancies in the following important support positions:

- Book-keeper
- Webmaster/mistress
- Secretary to the European Desk. i.e. co-ordinator of ENUSP

These positions are not subject to elections, and the new Board will determine their details. They are meant to be paid positions, however no funding for them is currently available. If you or someone you know would like more information about these roles, we would suggest that you or they contact the new Board at desk@enusp.org

Below we provide an introduction to/reminder of the content and proceedings of ENUSP's **regional meetings** and **General Assembly**.

A. A BASIC GUIDE TO ENUSP REGIONAL MEETINGS

a. What are the six regions of ENUSP?

ENUSP's six regions are set out below. Please use this information to determine which regional meeting you should attend in Thessaloniki.

1. Central Region:

Czech Republic, Hungary, Liechtenstein, Moldova, Romania, Slovakia

2. North West Region:

Ireland, The Netherlands, United Kingdom (England, Northern Ireland, Scotland, Wales

3. South West Region:

Andorra, Belgium, France, Italy, Luxembourg, Portugal, San Marino, Spain, Switzerland

4. Northern Region:

Denmark, Finland, Faroe Islands, Greenland, Iceland, Norway, Sweden

5. North East Region:

Austria, Estonia, Germany, Latvia, Lithuania, Poland, Russia

6. South East Region:

Albania, Armenia, Azerbaijan, Belarus, Bosnia & Herzegovina, Bulgaria, Croatia, Cyprus, Georgia, Greece, Israel, Former Yugoslav Republic of Macedonia (FYROM), Malta, Montenegro, Serbia, Slovenia, Turkey, Ukraine

You can find a list of member organisations for each country and region at www.enusp.org/groups.htm

b. When will the regional meetings take place?

The regional meetings will all be held at the same time - from 11.15 am to 1.30 pm on Thursday September 30.

You can find the entire programme for the conference in your delegate pack as well as at http://www.enusp.org/congresses/thessaloniki/program.pdf

c. What will happen at the regional meetings?

Delegates from the member organisations in each region will come together to choose their two representatives for the next ENUSP Board: a Board member and her/his deputy.

This will also be a chance to formulate topics to submit for discussion to the General Assembly.

d. What are the responsibilities of the regional Board members and their deputies? What kinds of skills and qualities do these representatives need?

In addition to being (ex-) users or survivors of psychiatry and at least 18 years old, Board members must be committed, hard-working, and reliable. They must have the time, energy and practical resources to co-ordinate activities with the members in their region. This includes responding to inquiries and requests from members; sending important mail-outs; and ensuring communication between the Board and relevant member organizations. They will need to take part in regular Board meetings, which take place via teleconference approximately once per month, as well as any irregular meetings. They will need to pass on all relevant information from those meetings to their regions.

Board members are also often called on to present ENUSP's standpoints on important issues affecting users and survivors at a European and regional level. This may include representing ENUSP at conferences and in other key policy and decision-making forums

Deputy Board members are elected to ensure that someone can take the relevant Board member's place and fulfils her/his tasks if this proves to be necessary.

You can find more information about the roles of Board members and Deputy Board members in ENUSP's Statutes at: http://www.enusp.org/documents/statutes.htm
The Statutes emphasise that there should be a good gender balance reflected on the ENUSP Board.

e. Can current Board members be re-elected?

According to ENUSP's Statutes, "Board members may serve a maximum of three consecutive terms" (Article 6).

f. What happens if a regional meeting can't decide on its Board member and deputy Board member?

If a region can't decide on its representatives, then all delegates with voting rights at the General Assembly will elect that region's Board member and deputy Board member based on nominations from the region. If there are no nominations from the region, this issue will be discussed at the General Assembly. This problem happened only once previously (i.e. at the last General Assembly where no representative for the South East region was elected), and we hope that the situation will not be repeated.

B. SOME GUIDELINES FOR THE ENUSP GENERAL ASSEMBLY

a. When will the ENUSP General Assembly take place?

The General Assembly will be held from 2.45 pm to 5.45 pm on Thursday September 30 (i.e. shortly after the regional meetings).

b. What will happen during the General Assembly?

You will find a full programme for the General Assembly in your information pack. Below we provide a summary of some of the most important matters:

During the General Assembly, some current Board members will present short reports of their work since the last General Assembly. This should include a report from ENUSP's current Secretary as well its treasurer on the organisation's finances.

The nominations for a new Chair of ENUSP will then be collected. The new Chair will be elected by delegates who have voting rights at the General Assembly. Each country has a total of three [3] votes. Voting usually takes place by a show of hands. All decisions of the General Assembly are determined by an absolute majority of votes, unless the Statutes or the law indicate otherwise.

The Board members and deputies who were elected at the regional meetings will be confirmed during the General Assembly. These new Board members will nominate a Deputy Chair from among their group, and this person will be elected by the General Assembly. The Deputy Chair should take over the Chair's tasks whenever the Chair decides that this is necessary.
For more information about the composition of the Board and the proceedings of the General Assembly, please see ENUSP's Statutes: http://www.enusp.org/documents/statutes.htm

d. What are some of the powers of the General Assembly?

According to Article 13 of the Statutes:

The General Assembly:

- has full authority over ENUSP, including power over the Board;

- has the power to establish committees and task forces to execute special tasks. The board or the General Assembly should appoint a survivor or (ex-) user of psychiatry to co-ordinate each committee or task force;
- determines ENUSP's work plan and budget for each year;
- has the right to approve or disapprove the reports from the Secretary and the treasurer;
- determines the number of regions in which the represented countries are divided.

c. Who can be nominated to be Chair?

Anyone who is present at the General Assembly can nominate themselves, or be nominated by other delegates, to be elected Chair. If the person is nominated by others, she or he will need to briefly state whether they accept their nomination.
It is preferable if the Chair is not one of the elected Board members from a region. Otherwise that region will probably need to re-elect at least one of its representatives.

l. What are the responsibilities of the Chair of ENUSP?

The Chair is the public face of ENUSP and the central point of contact for the organisation. This carries a substantial responsibility in terms of commitment to the values and beliefs of ENUSP. Like the Board members, the Chair is often required to represent ENUSP's positions at key European policy-making events.

Although the next Board will need to determine the exact tasks and requirements of the Chair, we believe the following considerations are important:

- The Chair must be able to embrace the different cultural, economic and social realities which exist across the 39 countries represented in the organization;
- The Chair should acknowledge and be sensitive to the differences between 'users' and 'survivors' as the two main streams of ENUSP and make sure that both groups are represented;
- The Chair must be a good communicator, have a (proven) good command of the English language and be able to convey ENUSP's positions clearly and powerfully;
- The Chair must be capable of distinguishing between her/his personal interest and the interests of the organisation and always prioritise the latter;

- The Chair must be accessible to all the Board members and to all members and easily available when needed;
- The Chair must be proactive in ensuring correctness, fairness and respectful communication within the Board and among members; s/he must be ready to combat early signs of difficult situations;
- The Chair is responsible for the effective working of the Board. At present, as there is no money for paid workers, the Chair is also responsible for coordinating and allocating tasks. This includes preparing the agenda and action points for Board meetings.

ANNEXE 5

REPORTS TO THE BOARD FROM BOARD MEMBERS, DEPUTY BOARD MEMBERS AND SUPPORT MEMBERS TO THE BOARD

Chair of ENUSP for six years – I have survived.

I am not standing for the board but I will always be a supporter. This is because I believe passionately in the things that ENUSP represents particularly because user/survivors are united by a common experience of often being labelled mentally ill and treated with medication which brings more problems and with no understanding of individual emotional distress.

I feel we have achieved a lot in the last six years the main one is that ENUSP still exists with no funding except from membership fees. It has been a struggle but with support from many people spending a lot of unpaid time which has been detrimental to their finances and even sometimes their health here we are in Greece 6 years after I was elected in Denmark.

Highlights in no particular order.

The Helsinki Declaration – a major event with all the health ministers of Europe. ENUSP was involved as speakers.

Dresden Declaration – a World Psychiatric Association seminar on control and coercion the first time they had held such an event, a lot of ENUSP speakers and our user/survivor colleagues from MindFreedom and WNUSP and was one of Judi Chamberlin's last overseas trips.

Milan – WAPR (World Association for Psychosocial Rehabilitation) - user/survivor event, users and survivors from all over the world came together to talk about their experience.

Manchester - International Network for Philosophy and Psychiatry ENUSP were partners in this event and had many speakers.

Brussels – Cooperation with Mental Health Europe for an ENUSP seminar. Helped revive enthusiasm for what we do resulting in Advocacy Update newsletter. ENUSP is also a member of the European Disability Forum which has given us knowledge of the CRPD (Convention on Rights of People with Disabilities) and it is good to see user/survivors belonging to this broader disability community.

Luxemburg – Working with the European Commission on the mental health green paper to implement the principles in the Helsinki declaration. Not approved by the EU health ministers so now have the Mental Health Pact where ENUSP we managed to get David Webb from

Australia who writes very eloquently of his life as a survivor of suicide to be a keynote speaker at a scientific Pact event on the subject and ENUSP managed to provide speakers at some other Pact events.

Gothenburg - Value + event. ENUSP were equal partners with the European Patients Forum on this research project which has produced some very useful products about how ‘patients ‘are involved in EU research projects.

Vienna – EU Fundamental Rights Agency another research project with much involvement from ENUSP.

This has been a quick tour of places I have seen in the last six years but it doe not describe all the hard work that goes on to make sure that we are included in a fair way in all the events I have briefly described. Often it is a virtual world we operate in thank goodness for the internet. Thanks for everything ENUSP has enabled me to do.

Mary Nettle - 9 September 2010

Report by Erik Olsen, Board member for Northern region

I have been involved with ENUSP, beginning by sitting in the organizing committee for the Second Conference of Users and X/users held 1994 i Elsinore Denmark.

There I met Users/x-users from 26 European Countries- and that was a turning point for me-

I told I want people who experience psychiatric problems – to have the same rights as anybody else in our societies – and the applaud for that, told me that it was the right way .

So inspired by this we in Denmark from the MAD Movement and SIND (MIND Denmark) decided to make a purely user run national organization. We did that in 1999 – LAP, and then I formed a Regional group in Copenhagen. We had finished organizing Users and X-Users in Denmark and where covering all regions in Denmark.

After that we worked on the Statutes of WNUSP and it was founded in Canada-

At the Vejle World meeting and General Assembly of ENUSP I was elected to the board.

The last 6 years I have worked quite much with WHO – first we got a chance to write one sentence in the declaration- in the last minutes – we decided to formulate that user organisations which ran their <u>own</u> recovery groups or selfhelp groups should be supported.

It was not much but I fingerprint of user influence….

Later I was in the Empowerment of Users and Carers project between WHO and the Commission.
The first part about the definition of Empowerment went OK but when it came to the Indicators (that will say the way empowerment should be measured) it seems to me that the outcome where vague, more to the interest of the mental health professionals and so on….
Another thing that bothers me with WHO, is that they are beginning to invite GAMIAN into the high level groups.
I have been insisting that we should have a NEWSLETTER again
I am proud that Mary and I initiated the cooperation with MHE so we could make Empowerment seminars paid by MHE through EU money from Progress- but run by us.
I have met with the other organisations in the Nordic Region three times a year – two times with NFSMH and 1 time with We ShaLL OverCome, Galebevægelsen and Aurora Norway in " The Days of Amalie"
Unfortunately the "Old big organisations " RSMH Mental Helse Norway and MTKL do not agree about our contingent and find it not understandable that users alone should run organisations of users, survivors of Psychiatry….
I suggest that we strengthen the Regional Networks… I will start with The Nordic Region.

Last but not least – I have been elected first to the board and secondly to the executive Committee of EDF European Disability Forum … and here we can come with suggestions, for a lot that will strengthen our positions- the board will have to work on something the next couple of years. /Erik

Report by Jan Verhaegh, Board member for Western Region

Six years board-member of ENUSP –
For many years I am active as a user/survivor activist. I started in 1997. I was board-member of the National Council for Disabled People for Europe in the Netherlands from 2003 and am still member of that council.
I started my board-membership in 2004 with a travel through Europe; to study on Europe and to meet other board-members from ENUSP, especially in Eastern Europe. The first day of my trip I visited Concentration-camp Buchenwald in Weimar. Then I visited Peter Lehmann, our

publisher in Berlin and bought some books about psychiatry from him. In Berlin I visited also the Jewish Historical Museum. We were in the museum of Das Haus am Wansee. At this location meetings took place where the heads of the nazis decided to kill all Jewish people in Europe.

After having seen these essentials of European history I went to Budapest to Gabor Gombos, long time board-member of ENUSP.

He told about the situation of psychiatry in Eastern Europe, about Budapest, about his work for United Nations. And with him I visited the large scale psychiatric hospital in Budapest.

The next board-member I met was Piotr in Cracow. With him I visited the most essential place of European Culture and History; Auschwitz. This experience was one of the saddest days in my life. Special when I realised that the genocide in Auschwitz started with the killing of 250.000 psychiatric patients in Germany during fascism. Never has at official level taken place a dialogue between official organisations of psychiatrists and official organisations of users/survivors. At this moment we have started a process of truth and reconciliation to do.

The last week of my voyage I visited Bosnia, and Srebenica. I learned a lot of Vahid who is leading an organisation of soldiers with post traumatic stress disorders. I have learned from psychiatrists about the fate of women in war. So I learned about war, genocide, racism, sexism democracy and bureaucratic dictatorship, large scale psychiatric hospitals, psychiatry in Eastern Europe, stigmatisation, discrimination, poverty. I wrote an article on the voyage in A Dutch magazine for mental health. I was also involved in a European Social Forum in Athens.

Such a voyage (on own costs) as in Europe I made also in Africa, where I did workshops as on the World Social Forum. My voyage to Africa completed my knowledge about the situation of psychiatry and psychiatric patients all over the world.

In 2004 I met on a congress about asylum-seekers and refugees in Stanford in United Kingdom the manager, Chris Heginbotham and some professors from the University of Central Lancashire in the department of philosophy of psychiatry. This has led to an annual meeting of the board of ENUSP and the professors of Central Lancashire in Preston.

Last year we were involved in the annual conference of the International Network Philosophy Psychiatry. All of us did keynote lectures, workshops and so on. I study now in the third year of the postgraduate master-course of philosophy of psychiatry in Preston. Next year I hope to finish my last year with a philosophical analysis of some parts of a large scale European research project on the onset, continuing and recovery of psychosis (wrongly and stigmatising called schizophrenia)

I participated in conferences and congresses as from European Disabled Forum, World Congress of Voice Hearing Intervoice, Mental Health Europe, and so on. The Congress of the World Association of Psychiatry about forced treatment in Dresden was the most impressing one, the celebration of the tenth birthday of Uilenspiegel (an organisation of user/survivors) in the European Parliament Belgium in the most pleasant one.

In the time that I was deputy board-member psychiatry discovered that I suffer from the syndrome of Asperger, a kind of autism. At this moment I am chosen also board-member of Autism Europe.
(organisation of family of and people with autism)
I should like to be chosen again as board-member and am special interested in to do things with philosophy of psychiatry, to represent older people (I am 64) and issues around autism
I have always also thought about other and general issues and was present on all meetings each month.
What I enjoyed most was the collaboration and friendship with my colleagues. The leading of Mary Nettle as chair was very friendly and nice.

Reports by Support Members to the Board (in alphabetical order)

Report by Anne-Laure Donskoy

I became a Support Member to the Board of ENUSP as a result of a Board meeting held in Brussels in March 2009. The role of a Support Member is new to ENUSP is not clearly defined as such. However, using the fact that I am fully bilingual French-English and that I have connections with France and Belgium, but also that I have an interest in Portugal and Sweden, I decided to concentrate my activities mostly within those geographical areas:

- I have been working to support the creation of a user movement in France and have recently created an Internet Forum, together with a French service user which is called “Parole d’Usagers- Nothing About Us Without Us” and can be found at http://usager.forumactif.net/index.forum. I have put links to ENUSP’s activities, the newsletter etc. on the forum.

- I have been active in Belgium since 2008, with health professionals from the French speaking community and, since the autumn of last year, I have started to support the Dutch speaking user-led organisation UilenSpiegel in organising European MadPride 2011. The project is moving one big step forward with the presentation at this Empowerment Seminar of a workshop on how to organise the event in member countries throughout Europe.
- I made a point of visiting the Centro do Empowerment last year while I was on a personal visit to Lisbon. There I met with service users and we discussed issues of communication with ENUSP, issues of cut backs in Portugal and implications for user participation.
- I made contact in Sweden in May with the Director of a Club House who would like to make contact with French user organisations with a view of setting up a network of European Club Houses. On this occasion, I saw my role purely as putting people in touch.

Other activities:

- I have been extremely active in supporting ENUSP's presence within the European Commission's Thematic Conference series as part of the EU Mental Health and Wellbeing Pact.
  I ensured the presence of David Webb from Australia for the second conference in Stockholm in November 2009 and was the only service user to present at the third conference which was held in Budapest in December 2009. I have been involved in the fourth conference, on social inclusion, which will take place in Lisbon this November and where we hope to be present. I have been lobbying for a service user presence at those events which has always been very difficult to achieve at all, and even more so in a meaningful way. However, I take the stand that it is better to be visible and argue for a meaningful involvement than to be invisible.
- I am a survivor researcher by background and am keen to focus on representing ENUSP in this area as well as continue working with the European Commission.
- I helped with the preparations of the University of Central Lancashire (UCLan), ENUSP and International Network of Philosophy and Psychiatry (INPP), which was held in Manchester in June 2010. There I also co-presented an interactive session on Philosophy

for people who are not used to philosophy and I created a 30 minutes, 3 character performance, called “Socrates’ Café” about the ideological, moral and physical abuse which patients and distressed individuals have had to endure for centuries, asking why those who knew and had the power to, including health professionals and philosophers, remained silent. (photos on the ENUSP Facebook page).
I also reprised the presentation I did at Budapest about the myths surrounding self-harm and issues with self-harm research.

- I represented ENUSP at the European Disability Forum’s Annual Day in Brussels in 2009 and will do so again this year. At those events, I always make appoint of raising the issues of mental health which are often “invisible”, or come as an afterthought at “disability” events. I also network, again with a view of making the Network more visible to others.
- The Newsletter:
  I have offered practical as well as editorial support to the Editor of the newsletter “Advocacy Update”, Debra Shulkes. In particular, I did the layout and looked after the general design. We hope to acquire more professional software which would give the newsletter a sleeker look in the future.
- I created and am looking after two Facebook pages:
  One for ENUSP and one for European MadPride 2011
- Thessaloniki:
  I gave as much practical support as I could during a busy personal time, to the organisation of this event.

Bristol, September 2010

Report by Jasna Russo

2005 – 2010

I am a survivor of psychiatry from Serbia, living in Berlin (Germany) for last 18 years. ENUSP was the first user/survivor organization that I have joined as an individual member back in 1991. At the second Conference in 1994 (Elsinore, Denmark), I was elected to the Board and have served on it as a representative of the Eastern European Region until 1997.

At the last Conference in Vejle (2004) I successfully applied for a position of the Secretary of the Board but by the time I was supposed to take it (from January 2005) this position was not funded any more. I therefore volunteered on the part of secretarial tasks until May 2005 but was not able to continue any more due to my full time job. From that time onwards I joined the Board as an adopted member. As the region I originally come from (South East Europe) did not elect a representative for the Board, I took some related tasks on me, but being aware that I am not able to represent the region and reminding on the need to integrate this part of Europe in ENUSP. I am very glad that organizations from Bosnia and Serbia have joined ENUSP since our last Conference.

Apart from taking part in Board meetings and dealing with our different understandings of what does it mean to build up the capacity of the organization or represent it, I was occasionally writing a letter or a statement on behalf of ENUSP or arranging a meeting. My main contributions in the last years included:

2007

April/May

working on the application for the EU public health project *Value+* co-ordinated by the European Patient Forum. The application was successful and ENUSP became an associated partner in this 2-years project (from 2008 – 2009). See more at www.eu-patient.eu

June

organizing a Board meeting in Berlin

2009

Jan – April

conceptualising ENUSP Empowerment Seminar in Brussels “Nothing about us without us. How to make this a reality” and producing a report of this event (1) (available at www.enusp.org)

(1) received a fee of 400 € from Mental Health Europe for writing this report. All my other activities listed here were voluntary.

2010

April

Working on the proposal for the Project: *Fundamental Rights of People with Mental Health Problems and People with Intellectual Disabilities* together with the Consortium made of Human European Consultancy (Netherlands), University of Leeds (UK), University of Galway (Ireland) and Mental Disability Advocacy Centre (Hungary). The proposal was successful and received 1,5 years funding from Fundamental Rights Agency (Vienna). ENUSP has a place on the Project Advisory Board.

In my other work which mainly focuses on research and writing, I often make my affiliation to ENUSP public, aiming to increase its visibility. The list of those works from the last six years would exceed an agreed limit of 500 words.

I hope for ENUSP to find a strategy to build up and secure its independent future and overcome the weaknesses and chaos of last years.

Report by Debra Shulkes

My name is Debra Shulkes. I am a psychiatric survivor from Australia now living in the Czech Republic. Since March 2009, I have been active in ENUSP as a support board member.

In the time, I've tried to learn as much as I can about the different concerns of survivors and users across Europe. I have seen my role as looking for and offering people ways to convey these concerns effectively for self-advocacy and advocacy - I would like everyone to know about the human rights instruments that should protect us all from psychiatric violence and degradation - irrespective of the official laws and positions of our governments.

I have tried to develop a solid understanding of the UN Convention for the Rights of Persons with Disabilities (CRPD) and its Optional Protocol. And I hope very much to support other survivors and users as we lobby together for the full ratification of these human rights treaties in our countries- as well as our right to participate meaningfully in their implementation and monitoring. I have found the CRPD Implementation Manual that was created by the WNUSP (http://wnusp.rafus.dk/documents/WNUSP_CRPD_Manual.pdf) very helpful!

My background is in writing/journalism and, to some extent, the law.

My main activities were:

- founding Advocacy Update, ENUSP's revived newsletter and researching, writing and editing its first issue. You can read a copy here: http://www.enusp.org/newsletter/2010/1.pdf

- writing internal and external materials for ENUSP, often based on detailed study of human rights instruments, like the CRPD. We have begun to issue very occasional press/position statements. It would be great to see this work continue with the development of ENUSP policy statements on critical issues based, however, on substantial research and common reflection

- fully documenting board meetings

Report by Jan Wallcraft

My experience of working with the World Psychiatric Association (WPA) representing ENUSP

I took over being the ENUSP representative with WPA from Peter Lehmann in April 2009, so have now had this role for over a year, and am a Supporting Member of the ENUSP Board.
My WPA role has been a bit complicated as I had already become involved with them as an independent consultant on a voluntary unpaid basis for the previous year or more. I was originally invited to speak at WPA events by a psychiatrist, Michaela Amering, from Vienna, who is very friendly to service user perspectives. Since I became involved with WPA in this way, I have spoken at a number of events in the Person Centred Psychiatry programme, when Juan Mezzich was President. I attach a link to an article I wrote based on a talk I gave at the WPA World Congress of Psychiatry in Czech Republic, 2008 http://www.ijic.org/index.php/ijic/article/view/501/1000. While at that event, I was contacted by Mary Nettle, chair of ENUSP and asked to say something about the new Convention on the Rights of Disabled People, on behalf of ENUSP, and I did make this presentation and sent a copy of the powerpoint to Mary who circulated it and it was used as the basis of a submission by ENUSP to the UK Joint Committee on Human Rights in October 2008.
Since then I have been involved for the past year with the WPA Task Force on working in partnership with service users and family members. This taskforce includes Michaela Amering and a prominent WPA Board Member Helen Hermann from Australia who is in charge of WPA publications. She is, like Michaela, also genuinely committed to partnership working with service users and has a good attitude. I have kept ENUSP in touch with the progress of this work. As part of this work, I carried out a review for WPA of literature on user and carer involvement, and helped to carry out a survey for them about service users and family members' views on ten key issues from the literature on involvement and partnership working. I consulted ENUSP Board members for this survey, along with a wide range of other service

user/survivor contacts I have around the world, including WNUSP board members. I attended the recent WPA Scientific Congress in Beijing (1-6th Sept) to report back on this work, and I invited ENUSP Board to let me know any other issues they wanted me to raise. One member asked me to enquire what is WPA's response to the UN Convention of the Rights of Disabled People Article 25 which says that all people have the right to freely consent to treatment – what advice is WPA going to give psychiatrists about forced treatment given this new right which appears to apply to all of us. I raised this with the WPA Ethics Committee and ENUSP are invited to put this question to the next meeting of the Ethics Committee in October.

Report by Elizabeth Winder

I have worked for several years leading a mental health advocacy service in Oxford, England, training workers and volunteers to visit psychiatric wards to make patients aware of their rights, and to support them in accessing those rights. I was motivated, as many advocates are, by my own frightening experience in a psychiatric hospital, when there was no-one independent to support me.

My advocacy organization was a member of the United Kingdom Advocacy Network, an ENUSP member organization. That's how I found out about ENUSP, and I joined the ENUSP mailing list to find out more. When the European Patients' Forum (EPF) was being set up, the Board asked for someone to represent ENUSP at EPF. Heleen van der Leest and I volunteered for this work and attended the early EPF meetings.

This was frustrating work at first. EPF Board members attended meetings to put forward the European patients' views about EU health policy, but as ENUSP representatives we got little information about what was happening and little opportunity to feed in ENUSP views. We (and other member organizations) made it very clear that this was not acceptable – after all, this was the point of being EPF members. Gradually, with some changes on the Board, EPF became more organized, got more funding, was able to employ staff, and established better communication with member organizations. As volunteers, our work was now to help to shape EPF's strategy, and to keep the ENUSP Board and elist informed about EPF's health policy work, responding to consultations so that our views contributed to the EPF's position papers. The European Patients' Forum is now a strong voice for patients within Europe, with a regular mailing (http://www.eu-patient.eu/Publications/EPF-Mailing/) describing all EPF's policy work. ENUSP has contributed to that development.

In 2007 I was a member of an EPF group working on EPF’s strategy. We came up with the idea of a European project, researching patient involvement in health-related projects funded by the EC. I suggested the title, Value+, to emphasise the message that patient involvement adds value. Jasna Russo helped to shape the project plan. The project received EC funding, and ENUSP became a partner along with several other patient organizations, and one academic research organization. In the meantime I had given up my job because of physical illness. Fortunately I was well enough to take on the Value+ project work for ENUSP.

The work involved arranging focus groups for patients who had taken part in EC funded projects, finding out the challenges and barriers, what the benefits are, and what is needed to support good practice in patient involvement. This meant working with patients with all sorts of long-term or recurrent conditions, not just psychiatric patients. It was surprising how much we all had in common, including the experience of stigma and discrimination. From this information we developed a toolkit, which contains a definition of meaningful patient involvement, a model for meaningful patient involvement in projects, indicators for meaningful patient involvement, resources and tools. This has been well received by patient organisations. I am proud that ENUSP has been able to lead this work and has shown such expertise which is valued by other types of patient. The toolkit, and other resources produced by the project, are available at: http://www.eu-patient.eu/Documents/Projects/Value+%20Toolkit.pdf

The toolkit is being translated into several other languages.

ANNEX 6 : This paper by ENUSP board member Jan Verhaegh is only available in Dutch

verslag

Griekse gastvrijheid

Eind september 2010 werd in het Griekse Thessaloniki het zesde congres van het Europese Cliëntennetwerk ENUSP gehouden. Pas benoemd bestuurslid Jan Verhaegh was erbij. Over zijn ervaringen op het congres en het reilen en zeilen van het netwerk doet hij verslag.

Het Europese netwerk van cliënten, *European Network of Users and Survivors of Psychiatry* (ENUSP), is in 1991 opgericht op een congres dat georganiseerd werd door de Nederlandse clientèle. De Nederlandse Cliëntenbond was destijds een belangrijke factor in de Europese cliëntenbeweging. Overigens ook op wereldniveau. Clemens Huitink, inmiddels jarenlang medewerker voor buitenlandse zaken bij GGZ Nederland, heeft een aantal jaren op voortreffelijke wijze de rol van secretaris van het Europese Netwerk van patiënten vervuld. De eerste jaren kon het Europees Netwerk functioneren omdat de Nederlandse regering de Cliëntenbond daar subsidie voor gaf. Sinds de medewerker van de Cliëntenbond uit het bestuur is vertrokken en de regering de subsidie van de cliëntenbond gekort heeft, is ons netwerk straatarm. De enige inkomsten bestaan uit contributies van aangesloten leden. Alles bij elkaar drieduizend euro per jaar. Helaas krijgen alleen rijke organisaties geld van de Europese commissie. Het beleid is dat je dertig procent zelf moet inbrengen. Op basis van die eigen bijdrage krijg je er 70% bij. Heb je niks, dan krijg je ook niks.

Belangrijkste punt in het beleidsplan van ENUSP: hoe komen we aan geld? Even belangrijk is wellicht: Hoe komen we aan vrienden?

Academische vrienden

Dankzij vrienden uit de universitaire wereld hebben we jarenlang kunnen functioneren. We hadden vier jaar goed contact met de afdeling Mental Health and Psychiatry van de universiteit van Central Lancashire in Preston. Die nodigde ons ieder jaar uit voor een conferentie en gaf ons gelegenheid als bestuur bij elkaar te komen en een bestuursvergadering te houden. Tijdens een van deze conferenties hebben we met een gedeelte van de Wereld Psychiatrie Vereniging twee dagen vergaderd over de mogelijkheid een diagnostiek te ontwikkelen die kijkt naar de hele persoon binnen zijn context. Bijzonder, want psychiaters hebben vaak moeite met het woord 'survivors' (overlevenden) dat deel uitmaakt van onze naam. Wij hechten er aan: enerzijds omdat deskundige hulpverlening vaak noodzakelijk is bij het overleven van een ernstige aandoening. Anderzijds omdat het in Europees verband (in Nederland soms ook) een hele kunst is om de psychiatrie te overleven.

Ons laatste congres in september 2010 was mogelijk omdat de Aristoteles Universiteit van Thessaloniki ons, Griekse cliënten en cliënten uit andere landen van Europa, uitnodigde deel te nemen aan een congres over stigmatisering en discriminatie. Het congres werd georganiseerd door verschillende afdelingen van de universiteit. Uitsluiting, stigmatisering en discriminatie zijn onderwerpen die vanuit de sociale psychologie, andragogie en sociaal werk werden bekeken. Deze afdelingen hadden een vijftigtal vrijwilligers gemobiliseerd, die meehielpen met de organisatie van het congres. Ook inhoudelijk hadden ze zich goed voorbereid. Zowel de behulpzaamheid als het empathisch vermogen van deze vrijwilligers was fantastisch. Ze kenden bijvoorbeeld de door mensen die zelf te maken hebben met het syndroom van Asperger, gevonden diagnose van Neuro-typical voor zogenaamd normale mensen. De meeste Nederlandse hulpverleners weten waarschijnlijk niet wat dat woord betekent.

Speerpunten

Het congres kende naast het programma waar professoren, medewerkers en studenten aan de universiteit aan deelnamen besloten bijeenkomsten, alleen toegankelijk voor cliënten. Een daarvan vormde de ledenvergadering van het ENUSP. Daarin werd verslag gedaan van de activiteiten sinds het laatste congres, zes jaar geleden. Er werd ook een nieuw bestuur gekozen. Gabriela Tanasan uit Roemenie is onze nieuwe voorzitter. Plaatsvervangend voorzitter, tevens voorzitter van de Belgische patiëntenorganisatie 'Uilenspiegel', is Rafael Daem. Handig is dat hij in Brussel woont; het Europese parlement is gemakkelijk te bereiken. Zelf ben ik zes jaar geleden gekozen tot vervangend bestuurslid. Nu ik dat zes jaar tot grote tevredenheid van mijn collega's in het bestuur heb gedaan, ben ik met unanieme stemmen en positieve aanbeveling van het oude bestuur gekozen tot officieel bestuurslid.

Beleid werd er ook ontwikkeld. Het ENUSP streeft ernaar om een erkende, dus van middelen voorziene, Europese cliëntenorganisatie te worden. Ze wil bij beleidsbepalende bijeenkomsten aanwezig zijn en het beleid beïnvloeden. Andere belangrijke speerpunten zijn: 'Madpride' en de 'Waarheid en verzoening commissie'.

Madpride is een vervolg op blackpride, womanpride en gaypride. Het betekent: ondanks dat (of misschien juist omdat) ik een psychische handicap heb, ben ik trots op mezelf. Of trots op mijn ouder, partner of kind met een psychische handicap. In de Verenigde Staten en Engeland zijn als verschillende 'madpride' demonstraties gehouden en in Brussel heeft 'Uilenspiegel' een paar keer met succes een demonstratie en symposium onder die naam gehouden. Rafael Daem wil dat, als plaatsvervangend voorzitter van ENUSP, in zoveel mogelijk landen gaan doen.

deviant

26 December 2010 nr. 67

Ander speerpunt is een waarheid en verzoeningsprocedure, geïnspireerd door de activiteiten in Zuid Afrika na de Apartheid. Daar werden commissies benoemd die zowel met slachtoffers als daders probeerden de waarheid van wat er tijdens de apartheid gebeurd was te achterhalen en onder ogen te zien. Met als doel: een verzoeningsproces tussen de daders en de slachtoffer van de apartheid op gang te brengen.

Niet dat wij psychiaters daarmee op één lijn zetten met daders van apartheid, en de psychiatrie als een apartheidssysteem zien. Maar wereldwijd gezien zijn er heel wat patiënten het slachtoffer geworden van verkeerde handelswijzen van de psychiatrie. Met als meest zwarte bladzijde de moord op 250.000 patiënten in de Duitse psychiatrie gedurende het fascisme. We willen daarover, samen met de belangrijkste verenigingen van psychiaters, een proces van waarheid en verzoening aangaan. Enerzijds als erkenning en omwille van een schadevergoeding voor de slachtoffers, anderzijds om nieuwe humane rampen in de psychiatrie te voorkomen of te beëindigen.

Foto Jan Verhaegh

Jan Verhaegh (rechts) met andere vertegenwoordigers van Europese cliëntenorganisaties

Eredoctoraat

Professor Kostas Bairaktaris, initiatiefnemer van het congres had zich er voor ingezet de Duitse Peter Lehmann, medeoprichter van ENUSP en auteur van een aantal belangrijke boeken, een eredoctoraat te verlenen voor zijn inspanningen op het gebied van de humanistische antipsychiatrie.

Tijdens de plechtigheid hield Bairaktaris een voordracht, volgens de traditie van de Frankfurter Schule, over de crisis in de maatschappij, de economie, de politiek en in de wetenschap. Vooral de crisis in de wetenschap werd door hem uitstekend toegelicht. Hij liet zien hoe het heersend paradigma van de biologisch reductionistische psychiatrie vaak beschadigend werkt voor cliënten en dat het vervangen moet worden door een ander model. Met nadruk stelde hij dat het de taak is van kritische wetenschappers om aandacht te besteden aan een ethiek van sociale rechtvaardigheid. Wil een wetenschapper dat doen dan komt hij er niet onder uit de heersende economische en politieke verhoudingen te analyseren en te kijken hoe je die kunt veranderen. Een congres houden met Europese cliënten en ze daarbij ondersteunen was voor hem een manier om uitgestoten, van hun stem beroofde mensen, weer in staat te stellen hun stem te laten horen en zich te organiseren. Wij zijn hem en de Aristoteles Universiteit hiervoor heel dankbaar.

In zijn dankwoord vertelde Lehmann dat hij ooit zijn studie moest onderbreken vanwege een psychische crisis, met daaropvolgend een onvrijwillige verblijf in de psychiatrie. Eenmaal ontslagen moedigde Manfred Liebel, hoogleraar sociologie, hem aan zijn studie af te ronden en bij hem te promoveren op zijn eigen ervaringen met waanzin. De vraag hoe psychofarmaca werken, en wat we op grond daarvan kunnen zeggen over de aard van waanzin, gepland als een klein hoofdstuk in dat proefschrift, leidde tot steeds nieuwe vragen. En vervolgens tot het schrijven van een boek, het oprichten van een uitgeverij, steeds meer inspanningen voor alternatieven zoals zelfhulp buiten de psychiatrie en voor mensenrechten voor cliënten van de psychiatrie. Vanwege al dat werk bleef zijn proefschrift ongeschreven. Lehmann noemt het een 'passende ironie' dat hem nu voor het werk dat zijn promotie verhinderde, een eredoctoraat is toegekend.

Wij mogen blij zijn met dit eredoctoraat. Hiermee is het werk van Peter Lehmann wetenschappelijk erkend zijn als kwalitatief goed werk. Moge zijn stem daardoor zwaarder klinken en verder reiken. In een tijd waarin we griezelverhalen horen over psychiaters die ontslagen worden als ze kritiek op pillen hebben, komt dat goed van pas.

Perspectieven

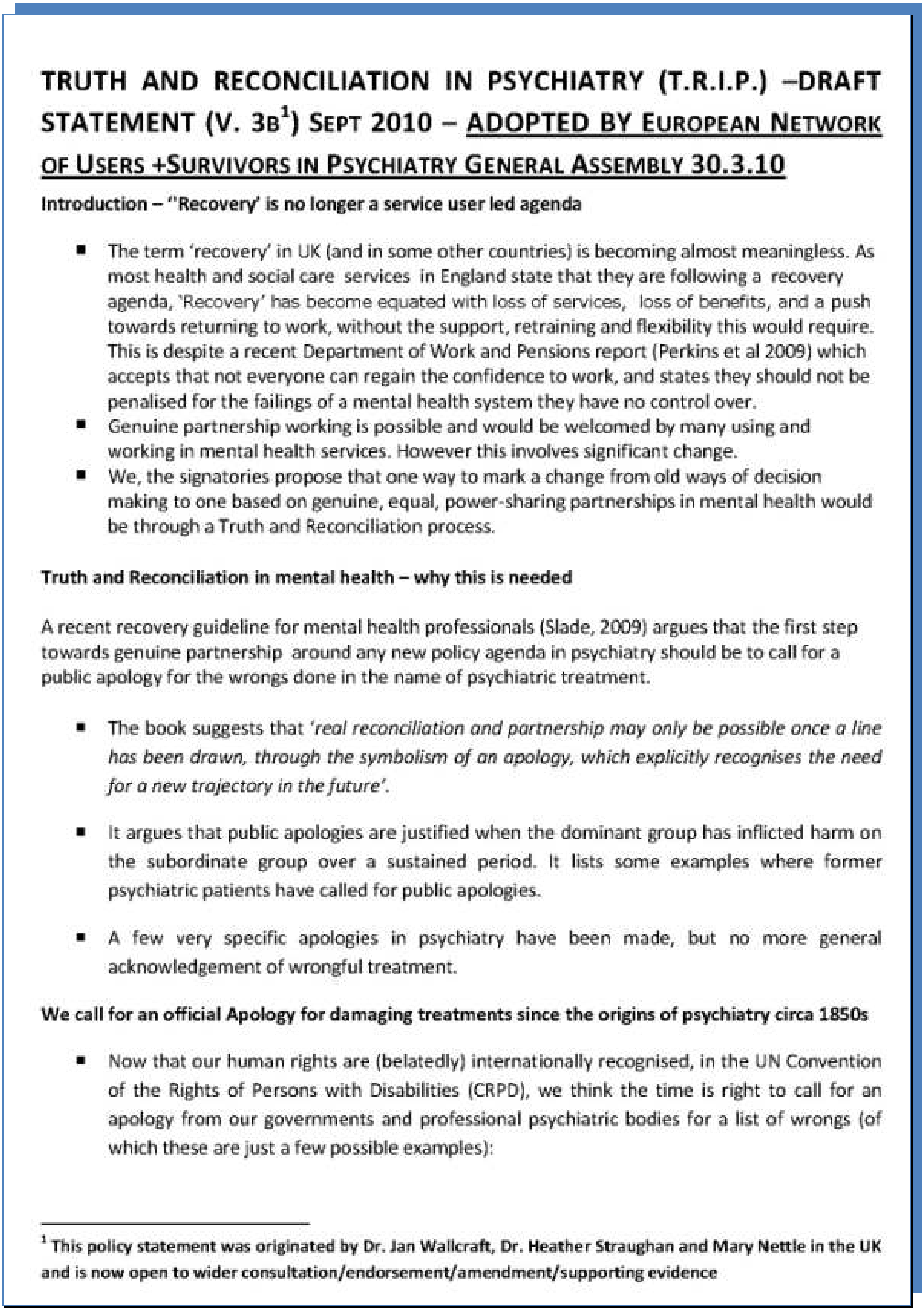
Uit ervaring weet ik dat het voor universiteiten en voor ons als ENUSP heel vruchtbaar kan zijn als we worden uitgenodigd samen een conferentie te organiseren. Zelf ben ik dankzij de contacten met de Universiteit van Central Lancashire een mastercursus Philosophy of Psychiatry gaan volgen. Het is een driejarige cursus, gebaseerd op het Oxford Textbook of Psychiatry, die vooral door psychiaters gevolgd wordt, maar ook openstaat voor cliënten. Ik begin aan het laatste jaar en kan deze cursus van harte aanbevelen.

Op dit moment vormen uitnodigingen uit de academische wereld de basis van ons bestaan. We zouden graag anders willen en zelf activiteiten organiseren. Maar het is erg moeilijk om aan middelen daarvoor te komen. Onze verwachting is dat het in de toekomst alleen maar moeilijker wordt. De rijke landen worden steeds nationalistischer. Daarbinnen is weinig ruimte voor zoiets als internationale solidariteit, toch de basis van ons werk.

Zorgelijk zijn ook de ontwikkelingen die Loic Wacquant beschrijft in zijn boek *'Straf de armen'*. De afbraak van de verzorgingsstaat maakt dat mensen hun uitkering verliezen en dat er minder zorg is voor mensen met weinig geld. Wie dan geen werk kan krijgen wordt lastig en gaat stelen. Wacquant laat statistieken zien waaruit af te lezen valt dat het aantal mensen dat in de gevangenis werkt evenredig groeit met de afname van mensen die in de zorg werken. Die kant willen we niet op. Ook met het oog op de groei van rechts extremisme, vreemdelingenhaat, stigmatisering, discriminatie en afbraak van solidariteit zien we donkere wolken aan de horizon. Hoogste tijd voor verzet. Is het een goed idee om uit solidariteit moslim te worden? Salam Aleikum.

Jan Verhaegh

ANNEXE 7



TRUTH AND RECONCILIATION IN PSYCHIATRY (T.R.I.P.) –DRAFT STATEMENT (V. 3B[1]) SEPT 2010 – ADOPTED BY EUROPEAN NETWORK OF USERS +SURVIVORS IN PSYCHIATRY GENERAL ASSEMBLY 30.3.10

Introduction – "Recovery' is no longer a service user led agenda

- The term 'recovery' in UK (and in some other countries) is becoming almost meaningless. As most health and social care services in England state that they are following a recovery agenda, 'Recovery' has become equated with loss of services, loss of benefits, and a push towards returning to work, without the support, retraining and flexibility this would require. This is despite a recent Department of Work and Pensions report (Perkins et al 2009) which accepts that not everyone can regain the confidence to work, and states they should not be penalised for the failings of a mental health system they have no control over.
- Genuine partnership working is possible and would be welcomed by many using and working in mental health services. However this involves significant change.
- We, the signatories propose that one way to mark a change from old ways of decision making to one based on genuine, equal, power-sharing partnerships in mental health would be through a Truth and Reconciliation process.

Truth and Reconciliation in mental health – why this is needed

A recent recovery guideline for mental health professionals (Slade, 2009) argues that the first step towards genuine partnership around any new policy agenda in psychiatry should be to call for a public apology for the wrongs done in the name of psychiatric treatment.

- The book suggests that *'real reconciliation and partnership may only be possible once a line has been drawn, through the symbolism of an apology, which explicitly recognises the need for a new trajectory in the future'.*
- It argues that public apologies are justified when the dominant group has inflicted harm on the subordinate group over a sustained period. It lists some examples where former psychiatric patients have called for public apologies.
- A few very specific apologies in psychiatry have been made, but no more general acknowledgement of wrongful treatment.

We call for an official Apology for damaging treatments since the origins of psychiatry circa 1850s

- Now that our human rights are (belatedly) internationally recognised, in the UN Convention of the Rights of Persons with Disabilities (CRPD), we think the time is right to call for an apology from our governments and professional psychiatric bodies for a list of wrongs (of which these are just a few possible examples):

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[1] This policy statement was originated by Dr. Jan Wallcraft, Dr. Heather Straughan and Mary Nettle in the UK and is now open to wider consultation/endorsement/amendment/supporting evidence

- Oppressive, incorrect and unproven medical theories underpinning damaging treatments dating from the 1850s onwards which have been harmful physically and psychologically (not to deny that many individuals working in psychiatry and mental health services do their best to help patients and service users. This is not about individuals but a chance for psychiatry as a whole to admit and redress the failings of its profession).

- Creation of a body of dubious 'knowledge' based on research service users/patients had no involvement in or choice about, and which has been given legitimacy to overrule people's own self-knowledge and expertise by experience.

- Creating stigmatised services which isolate people from their families and friends and wider society and make it hard to recover self-belief, health and social status.

The right to reparation

- We suggest that the apology should be negotiated internationally – through service user/survivor representatives at EC and UN level. It should be accompanied by demands for reparations including:
    - Provision of services defined by service users based on collective knowledge and expertise and service user/survivor controlled research
    - Early intervention in first break/psychosis which is non-medical and non-stigmatising and based on existing work such as Soteria and service user led crisis houses.
    - Financial help for peer support and self management
    - Education and training in individually chosen + valued skills
    - Legal status for advance directives, advance statements, living wills, fully negotiated care and treatment plans
    - Repeal of all forced treatment legislation which discriminates against people using mental health services and is out of line with CRPD

References

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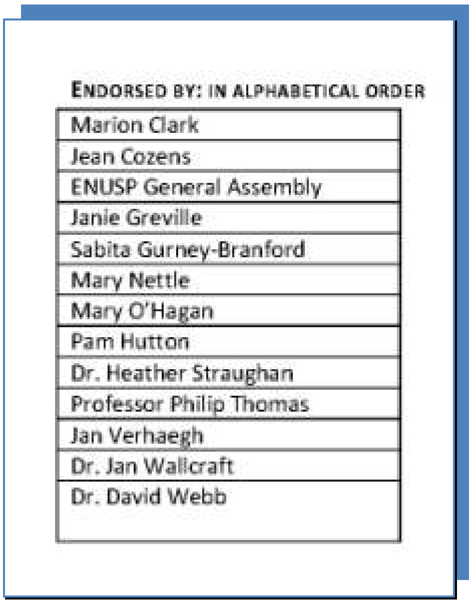
- Perkins, R., Farmer P., Litchfield, P. (2009). Realising Ambitions: Better employment support for people with a mental health condition. Department for Work and Pensions.
- Slade,M. (2009) Personal Recovery and Mental Illness, Cambridge, Cambridge University Press
- UN Convention on the Rights of Persons with Disabilities



ENDORSED BY: IN ALPHABETICAL ORDER

Marion Clark
Jean Cozens
ENUSP General Assembly
Janie Greville
Sabita Gurney-Branford
Mary Nettle
Mary O'Hagan
Pam Hutton
Dr. Heather Straughan
Professor Philip Thomas
Jan Verhaegh
Dr. Jan Wallcraft
Dr. David Webb

ANNEX 8: EVALUATION FORM

European Network of (ex-) Users and Survivors of Psychiatry (ENUSP)
and the Pan-Hellenistic Committee of (ex-) Users and Survivors of Psychiatry

Joint conference on

DETERMINING OUR OWN FUTURE: The way forward for all European users and survivors of psychiatry

Thessaloniki, Greece, September 28-30, 2010

ENUSP-CONFERENCE EVALUATION FORM

Your Opinion is Important

Thank you very much for taking the time to fill out this evaluation form.

You do not need to include your name or the name of your organisation unless you wish to do so.

We warmly welcome your honest feedback and encourage you to use the form to express your opinion and suggestions more fully. We will use your feedback to complete our reports to our external funders and to improve our future conferences.

1. I am:

a) an individual member of ENUSP	Yes ☐	No☐
b) the delegate of an ENUSP member organisation	Yes ☐	No☐

c) other ....

2. In my opinion, the conference was well organised.

a) Strongly agree	☐	Please say more if you wish
b) Agree	☐	....
c) Neither agree nor disagree	☐	....
d) Disagree	☐	....
e) Strongly disagree	☐	....
		....

3. The materials in the delegate's pack were helpful to me.

a) Strongly agree	☐	Please say more if you wish
b) Agree	☐	....
c) Neither agree nor disagree	☐	....
d) Disagree	☐	....
e) Strongly disagree	☐	....
		....

4. Please rate the main parts of the programme below

Official opening:

a) Very good ☐
b) Good ☐
c) Average ☐
d) Poor ☐
e) Very poor ☐

Please say more if you wish
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………………………………………………………………………………
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………………………………………………………………………………
………………………………………………………………………………

Keynote lecture 1 (Stefan Trömel, International Disability Alliance : “The UN Convention on the Rights of Persons with Disabilities: Chances and challenges for Users and Survivors of Psychiatry”)

a) Very good ☐
b) Good ☐
c) Average ☐
d) Poor ☐
e) Very poor ☐

Please say more if you wish
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………………………………………………………………………………

Keynote lecture 2 (Giorgos Giannoulopoulos Pan-Hellenistic Committee of (ex-) Users and Survivors of Psychiatry: “It concerns all of us”)

a) Very good ☐
b) Good ☐
c) Average ☐
d) Poor ☐
e) Very poor ☐

Please say more if you wish
………………………………………………………………………………
………………………………………………………………………………
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………………………………………………………………………………

Working groups:
Which working groups did you attend?

1. ………

a) Very good ☐
b) Good ☐
c) Average ☐
d) Poor ☐
e) Very poor ☐

Please say more if you wish
………………………………………………………………………………
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2. ………

a) Very good ☐
b) Good ☐
c) Average ☐
d) Poor ☐
e) Very poor ☐

Please say more if you wish
………………………………………………………………………………
………………………………………………………………………………
………………………………………………………………………………
………………………………………………………………………………
………………………………………………………………………………

3. Regional meetings

a) Very good ☐
b) Good ☐
c) Average ☐
d) Poor ☐
e) Very poor ☐

Please say more if you wish
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4. General Assembly

a) Very good ☐
b) Good ☐
c) Average ☐
d) Poor ☐
e) Very poor ☐

Please say more if you wish
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5. Closing ceremony

a) Very good ☐
b) Good ☐
c) Average ☐
d) Poor ☐
e) Very poor ☐

Please say more if you wish
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....
....

6. Other aspects of the conference:

a) The accommodation provided to me by the conference organisers was…

a) Very good ☐
b) Good ☐
c) Average ☐
d) Poor ☐
e) Very poor ☐
f) Not applicable ☐

Please say more if you wish
....
....
....
....
....

b) The conference facilities were ...

a) Very good ☐
b) Good ☐
c) Average ☐
d) Poor ☐
e) Very poor ☐

Please say more if you wish
....
....
....
....
....

c) The meals were.....

a) Very good ☐
b) Good ☐
c) Average ☐
d) Poor ☐
e) Very poor ☐

Please say more if you wish
....
....
....
....
....

6. I found it easy to participate in this event

a) Strongly agree	☐	Please say more if you wish, in particular if you found it difficult to participate
b) Agree	☐	....
c) Neither agree nor disagree	☐	....
d) Disagree	☐	....
e) Strongly disagree	☐	....
		....

7. What for you was the best part of the event?

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8. What changes would you recommend for the next ENUSP conference?

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9. Would you like to add anything else?

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Please contact us at desk@enusp.org if you would like more information about the results of this evaluation.

THANK YOU VERY MUCH!