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ENUSP Bulletin

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Special issue

ENUSP STRATEGY 2012 - 2015

INTRODUCTION

We are proud to introduce this ENUSP Strategy 2012-2015.

This document marks a turning point for our organisation. It comes twenty-one years after the creation of our European Network of (Ex-)Users and Survivors of Psychiatry. And it builds on a rich history of meetings and work by users and survivors of psychiatry from across Europe. It also takes up the work of successive past ENUSP Boards and their supporters who managed to keep the Network alive. We are aware these efforts often happened in tough circumstances. And we are very grateful to all those who did this work often at real personal cost.

It is thanks to these individuals that ENUSP exists today as something of precious value – the only united, independent voice of users and survivors across Europe.

The current Board is committed to protecting the future of ENUSP. In doing this, it tries to draw on the hard lessons of our history. Still vivid in our minds are the last few years in which ENUSP struggled to make do without any funding. During this time, we felt the incredible power of users and survivors coming together. We saw the extraordinary value and encouragement that ENUSP brings through the very fact of its existence. But at the same time we repeatedly asked: “What direction is ENUSP headed in?” And we did not know the answer. During these years, we struggled to carry out basic and crucial tasks, such as communicating news to ENUSP members and holding our General Assembly. Often we tried but couldn't manage to represent users and survivors in the forums where decisions are made about our lives. Often we witnessed as others took our place there.

We struggled repeatedly when we could not react properly to human rights abuses against our people. We were frustrated that we could not begin to take up the human rights that members of our movement fought for under the United Nations Convention on the Rights of Persons with Disabilities.

This was the thinking that led the Board to apply for funding for the Rebuilding ENUSP project. And it is thanks to the understanding of our situation of Open Society Foundations, their trust and their funding that we have been able after a long break to devote time and space to working out our own agenda.

With this strategy document, we repeat our question “What direction is ENUSP headed in?” But this time we give a concrete answer. This time we are committed to choosing our own destination. To this end, our project workers have drawn on the views and suggestions of ENUSP members, as well as input from the Board. We have begun to learn what ENUSP

members want to happen. In this document, we set out the structures we need to establish so we can keep working on our concerns together.

We want especially to thank two project workers: Elizabeth Winder, who prepared the two days board meeting and member consultation, and Jasna Russo, who pulled the outcomes of that process together and drafted the ENUSP strategy. We want to thank all the people in ENUSP who contributed to this document.

This strategic plan describes the direction we want to go in. At its end are detailed tables of tasks and their timelines; they are a map of how to get there. We are really proud to have this document among the outcomes of the first six months of the Re-Building ENUSP Project. What happens next will depend on the work and willingness of everyone in ENUSP to help reach our shared goals.

It is time for us to take action. Our future is at stake.

We warmly welcome your feedback and ideas. We look forward to our continued work together.

On behalf of the ENUSP Board

Debra Shulkes

ENUSP STRATEGIC PLAN 2012 - 2015

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BACKGROUND INFORMATION

WHAT IS ENUSP?

The **E**uropean **N**etwork of (Ex) **U**sers and **S**urvivors of **P**sychiatry (ENUSP) is the only independent grassroots organisation on a European level which unites people who are or have been recipients of psychiatric services. Founded in 1991, ENUSP aims

“to give (ex-)users and survivors of psychiatric services a means to communicate, to exchange opinions, views and experiences in order to support each other in the personal, political and social struggle against expulsion, injustice and stigma in our respective countries.”¹

The organisation is run solely by mental health service users/survivors of psychiatry and works independently of service providers, professional bodies, family members’ organisations and pharmaceutical companies. In 1998, the Network received legal recognition as a federation of European associations of (ex-) users and survivors of psychiatry. Today ENUSP comprises national, regional and local organisations from 39 European countries². We are a member of European Disability Forum and European Patients’ Forum and part of the World Network of Users and Survivors of Psychiatry (WNUSP).

The added value of the European Network lies in the fact that it brings together the two major political streams of our movement, expressed in the notions ‘users’ and ‘survivors’. The first group (‘users’) focuses more on reforming and improving psychiatric services while the second (‘survivors’) fundamentally questions the psychiatric system as a whole, including the very premise of ‘mental illness’³. The current name of the Network, adopted in 1994, expresses recognition of our different standpoints towards mental health and psychiatric systems as well as respect for our diverse experiences, self-definitions and political aspirations. In contrast with North American organisations that have split off into ‘consumers’ and ‘survivors’, ENUSP members made a conscious decision to focus on common goals and work together in one organisation as we all believe that the current situation is unacceptable and that change is possible.

WHY DEVELOP A STRATEGIC PLAN?

The development of this strategic plan marks a turning point for ENUSP. The change our organisation is going through does not relate to our goals and values described above. With this strategy, we aim to take a more active role in the European political landscape and to become a *real* rather than just a proclaimed and occasionally present stakeholder. This strategic plan emerges as a joint effort to make the change that is necessary so that we can achieve our goals and shape our future. It emerges in direct response to the critical point that ENUSP reached in the period between 2005 and 2010 when it lost its only paid worker– the ENUSP Secretary. For the first 10 years of its existence, ENUSP was financially supported by the Dutch Government and had a desk with a paid worker through the Dutch national user organisation. In 2001, the Secretariat of ENUSP moved to Berlin, and from 2005 ENUSP stopped receiving funding for Secretariat work. The organisation somehow continued to exist thanks to the voluntary work of Board members and their supporters. However, having lost the basic administration which is vital for any organisation, ENUSP could no longer offer much to its members. The Network’s only income became membership fees that were introduced at its

¹ From the self-description on the ENUSP website: www.enusp.org

² We have individual members in some of these countries.

³ This is a broad explanation of the way the terms ‘user’ and ‘survivor’ are understood by ENUSP. We recognise that individuals in our movement have a range of reformist and radical views, and that the decision to identify as a ‘user’ or a ‘survivor’ rests with each person.

General Assembly in 2004. Parallel to this development, the representation of mental health service users began to be increasingly demanded by policy-makers, partly owing to the adoption of the United Nations Convention of Rights of People with Disabilities (UN CRPD). But having hardly any resources of its own, ENUSP's presence at different events or in relevant consultation processes became reliant on occasional invitations and the inviters' capacity to meet minimal costs. Looking back at this period, it is clear that in this situation ENUSP developed an 'occasion - driven' rather than a strategic attitude. The decision to create a strategic plan comes as a result of recognising that attitude and understanding its roots and its impact. Our collective work on this strategy expresses a commitment to achieving a fundamental change in our organisational culture. We are determined to combat the barriers to our active participation in the European political landscape.

HOW DID WE DEVELOP THE ENUSP STRATEGY?

This strategy was developed as part of the six-month project "Re-building ENUSP: Strengthening the Network of Users and Survivors of Psychiatry across Europe" funded by the Open Society Mental Health Foundations. In addition, several face-to-face meetings before this project along with intensive analysis of ENUSP's situation and the setting of priorities enabled the creation of this strategic plan. These valuable meetings wouldn't have been possible without financial support from the PROGRESS Programme of the European Commission (received through Mental Health Europe). The following chart gives a chronological summary of the steps taken to develop the ENUSP strategic plan:

A two-day **Empowerment Seminar in Brussels in March 2009** was the first face-to-face meeting for a number of ENUSP members following the ENUSP General Assembly in 2004. The key topic of the Seminar was "Nothing about us without us. How to make this a reality?". Twenty-six delegates from 20 countries worked on the following three questions:

1. What should ENUSP's priorities be for the next years?
2. What is the best way to work on these priorities?
3. What will you/your organisation be able contribute?

A full report of this seminar is available at www.enusp.org.



The **6th Congress of ENUSP** was held in **Thessaloniki, Greece from Sept 28 – Oct 1, 2010**. Entitled "Determining our own future: the way forward for all European users and survivors of psychiatry", this was a gathering of 47 delegates from 23 European countries. 17 delegates from 11 countries took part in the working group "Re-building ENUSP: A Strategic Planning Group". They analysed the current situation of ENUSP, set organisational and management priorities and identified key working areas for ENUSP for the next two years. The outcomes of this working group were adopted by the ENUSP General Assembly as a working plan for ENUSP. The full Congress report and the working plan are available at www.enusp.org.



An **Empowerment seminar**: "Building the European Network: Status, priorities, action plan" took place in **May 2011 in Brussels** for 25 delegates from 16 EU countries and one non-EU country. Aspirations for ENUSP's work and the current limits were discussed. The clear finding of the working group "Planning key actions for next 12 months" was the urgency of securing funding. Related tasks were distributed and the next steps agreed. The ENUSP Strategy taskforce consisting of 13 members from 12 different countries was established.



The project “**Re-building ENUSP: Strengthening the Network of Users and Survivors of Psychiatry across Europe**” received a 6-month grant from the Open Society Foundations beginning from **November 1, 2011**. Since that date, two project workers have been employed; one is in charge of drafting a three-year strategic plan with input from the Strategy taskforce. The Board held a two-day meeting in January 2012 to develop a consultation document related to the strategy. This extensive document, including a number of related questions, was sent to ENUSP member organisations for consultation. The project worker summarised the replies received in the internal report ‘ENUSP Strategy: Consultation Outcomes’. Taking these outcomes into account, she drafted the strategic plan. After another round of consultation with the Board and the Strategy taskforce, the strategic plan was finalised.

ENUSP takes this opportunity to thank all our members who contributed their thoughts, ideas, visions, and time to the creation of this strategy – either by taking part in the above-mentioned meetings or by sending in emails and/or replying to the consultation document. However, developing this strategic plan would not have been possible without financial resources. ENUSP very much appreciates both the grant from the Open Society Foundations and the funding of our Empowerment seminars from European Commission PROGRESS Programme monies received through Mental Health Europe. This financial aid given without any further interference with the content of our work enabled us to create our own long-term agenda.

ENUSP’S MISSION

ENUSP is an independent and genuine voice of mental health service users and survivors of psychiatry all over Europe. We advocate for the full human rights and self-determination of users and survivors in forums that decide about our lives. ENUSP supports the self-representation of users/survivors, the development of user/survivor organisations, and the production and exchange of user/survivor knowledge.

ENUSP’S LONG-TERM VISION

ENUSP is working towards a Europe where

- all people are free to be themselves, are valued equally and treated with dignity
- all people have the power to make their own life choices and to speak for themselves
- all people have access to a range of supports which respect their autonomy and dignity
- all people are protected from poverty and have an equal chance to live their lives to their full potential
- human crisis is seen in its social context; it is not medically labelled or feared, but is embraced as an opportunity for individual and community growth
- the knowledge of people who have experienced extreme crisis is valued, cultivated and informs systems of support
- the above conditions are equally true everywhere in Europe.

ENUSP'S ORGANISATIONAL VALUES AND APPROACH

Due to ENUSP's recent circumstances described in the section '*Why develop a strategic plan?*' above, we were often not in a position to fully practise the way we wish to work. Acknowledging that gap between our organisational aspirations and the reality, we are determined to ground our work and policies consistently in the following values and principles:

Independence

The decisions in ENUSP are autonomously made by users and survivors, based on their own beliefs and interests and not those of their families, health professionals, commercial groups, or others.

Transparency and genuine representation

Major decisions are made following close consultation with, and input from, ENUSP members. When in a representation role, ENUSP puts forward positions agreed through consultation with its members.

Responsibility

ENUSP members take responsibility for the organisation as a whole and share the workload rather than allowing a small number of workers and volunteers to become burnt out. Board members, workers and volunteers put the organisation's interest before their personal interests and declare when there is a conflict of interest. We are realistic about what ENUSP can achieve and do not raise expectations that cannot be met.

Ethical and professional approach

ENUSP expects high standards from its workers and pays attention to the wellbeing of its Board members, staff and volunteers. When anybody feels that they will not be able to work, they promptly communicate this so that their tasks can be re-distributed and ENUSP work can continue.

Respect for differences

ENUSP works across different economic and political systems and recognises that the issues of users and survivors are diverse across Europe. None of the geographical regions should ever dominate. The political positions of the two main streams (users and survivors) are equally respected and taken into account. ENUSP is also aware of inequalities among all kinds of minority and majority groups and stands against any discrimination based on ethnicity, culture, religion, gender, disability or sexual orientation.

Openness

ENUSP is open to sharing information, listening to others and understanding their different perspectives. We are a learning community, also willing to share our knowledge and skills.

GOALS 2012 – 2015

Through the intensive work of developing this strategy, we have identified the most important goals that ENUSP aims to achieve over the period of the next three years. In order to achieve these goals, we need a secure source of funding. Finding that source is not listed among the goals because funding is not a goal in itself but a necessary pre-condition for working towards these goals. ENUSP aims to achieve the following four general goals over the next three years:

1. Develop ENUSP's policies and procedures in order to support the future work of the organisation

ENUSP has Statutes, which are rather general. More precise policies and procedures have been developed over the course of the last 20 years, but they have not been written down. This means that often the information has to be sought from past board members. At its last General

Assembly, ENUSP decided to develop and adopt Bylaws which will describe procedures in the organisation in much more detail than the Statutes. We also want to establish rules and policies for our co-operation with other organisations, and principles for our representation, for ENUSP's involvement in research, and for the provision of advice and consultancy, etc. These steps are necessary in order to ensure the continuity of our organisational structure as well as accountability towards members and the transparency of our procedures and policies.

2. Develop strong communication among ENUSP members, within the regions, and with the ENUSP central office so as to enable active involvement of ENUSP members in ENUSP's work

Establishing a database of ENUSP members is the first step towards enabling effective communication. We plan to re-establish an ENUSP office with at least one paid worker as this is vital for communication with members and the management of the organisation. Initiating regional and thematic meetings will be subject to funding. ENUSP has started issuing a regular Bulletin as well as re-designing and improving its website. The release of ENUSP's cultural and human rights publication 'Advocacy Update' is foreseen three times a year. These newly started activities, which have already received a lot of positive feedback, are to continue in a regular and more effective way over the course of the next three years.

3. Strengthen external communication and advocacy in order to widen the impact of ENUSP's work

ENUSP is a member of European Union-wide forums such as European Disability Forum and European Patients' Forum. As important as these memberships are, ENUSP still needs to find a way to directly influence European law and policy-making bodies as well as other relevant forums where reforms and legislation that affect users and survivors are discussed, adopted and evaluated. We want to participate actively in the implementation of Article 4 (Paragraph 3) of the UN CRPD, which requires the close consultation and active involvement of our representative organisations in all decision-making processes concerning our lives⁴. Due to its minimal resources, ENUSP hasn't been very proactive and strategic in finding new partners and exploring different cooperation possibilities. We want to advocate and lobby on matters of direct concern to our members, to issue position papers and press releases, to increase the visibility of users/survivors and to establish and occupy our place among other stakeholders. The recently created task force 'Representation' has started improving this area of work. In the course of the next three years. ENUSP plans to secure its place in the European political arena.

4. Extend ENUSP's knowledge base and make it accessible to members

ENUSP comprises organisations and individuals who are skilled and experienced in the areas of law, advocacy, self-help, research, alternatives to conventional treatment, campaigning, publishing and more. The expertise of our members is rich and diverse. We want to work on collecting and developing ENUSP resources so as to facilitate information exchange and capacity building among our members. We want to structure our collective knowledge around different areas of interest in order to make that knowledge available, and to share and expand it.

⁴ Art 4.3 of the UN CRPD reads, "In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organization."

WORK AREAS

In order to work towards the above-listed goals, we have decided to give priority to the following work areas in the next three years:

- Organisational development
- Lobbying and representation relating to policy and human rights
- Knowledge-sharing and capacity-building

We will now outline what is concretely to be done in each of these work areas and when it should happen. The purpose of this plan is not to dictate the work in any bureaucratic or technical way but to help us come together and focus our energies on achieving what is most needed in the next period. Achieving these objectives will be subject to decisive factors such as securing funding and finding suitable workers and volunteers as well as the effectiveness of the Board. The three tables that follow are meant to serve as a guide and orientation; they require a flexible approach as both the objectives and the time line might need adjustments according to the concrete circumstances of ENUSP's work.

1. ORGANISATIONAL DEVELOPMENT

ORGANISATIONAL DEVELOPMENT		2012		2013				2014				2015	
OBJECTIVES AND MAIN TASKS		III	IV	I	II	III	IV	I	II	III	IV	I	II
1	Continuous and effective administration												
1.1	Regular updating and maintenance of member database												
1.2	Creation and maintenance of different e mail lists (for members; for the distribution of the Bulletin and Newsletter; for press releases etc.)												
1.3	Summarising requests and other incoming information for the Board												
1.4	Coordination of Board activities												
1.5	Management of e-mails and postal correspondence of ENUSP												
2	Regular update and maintenance of the website												
2.1	Allocating responsibility for the content of the website												
2.2	Training at least two people to upload documents												
2.3	Appointment of a proofreader for the website												
2.4	Appointment of a webmaster												
3	Securing operational funding												
3.1	Continuous search for operational and project funding possibilities												
3.2	Work on applications												
3.3	Issuing yearly activity reports												
3.4	Issuing yearly financial reports												
4	Monthly Bulletin												
4.1	Developing the structure of the Bulletin												
4.2	Improving the design of the Bulletin and developing a template												
4.3	Releasing monthly Bulletins												
5	Newsletter <i>Advocacy Update</i> three times a year												
5.1	Establishing the Editorial Board												

15	Establishment of ENUSP office												
15.1	Search for rental												
15.2	Equipment of the office												

2. LOBBYING AND REPRESENTATION

LOBBYING AND REPRESENTATION		2012		2013				2014				2015	
OBJECTIVES AND MAIN TASKS		III	IV	I	II	III	IV	I	II	III	IV	I	II
1	Development of policy on ENUSP's representation												
1.1	Drafting guidelines on representation in the member organisations that we are part of (EPF, EDF, WNUSP)												
1.2	Consulting members and finalising the guidelines under 1.1												
1.3	Disseminating guidelines prior to GA												
1.4	Exploring options for membership in European Social Platform and other Pan-European NGOs												
1.5	Drafting guidelines for ENUSP representatives in European NGOs												
1.6	Consulting members and finalising the guidelines under 1.5												
1.7	Disseminating guidelines prior to GA												
1.8	Applying for ECOSOC Status to boost participation at United Nations events												
1.9	Exploring possibilities for ENUSP's participation in law and policy-making bodies and forums such as UN treaty bodies, UN and European detention monitoring bodies (including SPT and CPT), OHCHR, WHO, the Council of Europe, EU Parliament, EC Directorates, FRA												
1.10	Drafting guidelines for ENUSP representatives in policy and law-making bodies												
1.11	Consulting members and finalising the guidelines under 1.10												
1.12	Disseminating guidelines under 1.10												
1.13	Drafting policy on representation at conferences and events												
1.14	Drafting guidelines for ENUSP representatives at conferences and events												
1.15	Drafting reporting templates in order to ensure effective communication between ENUSP and its representatives												
1.16	Consulting members and finalising the documents under 1.13, 1.14 and 1.15												
1.17	Disseminating the documents under 1.13, 1.14 and 1.15 prior to the GA												
2	Development of policy on ENUSP's involvement												
2.1	Drafting general policy on ENUSP's												

	consultation services													
2.2	Drafting policy on ENUSP's involvement in research projects													
2.3	Drafting guidelines for persons acting as consultants and advisors on behalf of ENUSP													
2.4	Drafting templates in order to document and evaluate ENUSP involvement													
2.5	Consulting members and finalising the documents under 2.1, 2.2, 2.3 and 2.4													
2.6	Disseminating the documents under 2.1, 2.2, 2.3 and 2.4 prior to the GA													
3	Development of ENUSP's collaboration with other organisations and/or in projects													
3.1	Evaluating ENUSP's co-operation with different forums/organisations (including FRA, EC directorates, MDAC, MHE, WHO, WPA)													
3.2	Exploring possibilities of joint events and/or projects with organisations that share our vision and values (ENIL, INTAR, CPN and others)													
3.3	Searching for calls from funders for project proposals													
3.4	Developing project ideas													
3.5	Finding partner(s) for joint project(s)													
3.6	Applying for funding for joint project(s)													
4	Ongoing advocacy work													
4.1	Researching human rights violations and other issues that require action across Europe													
4.2	Exploring relevant EU and national legislation and policy documents and UN publications that need input/comments/reaction from ENUSP													
4.3	Exploring good EU and national practices in legislation and policy, service development and research													
4.4	Issuing and disseminating press releases													
4.5	Issuing and disseminating position papers													
4.6	Initiating human rights submissions to UN treaty bodies													
4.7	Following up and evaluating all advocacy activities													

3. KNOWLEDGE-SHARING AND CAPACITY-BUILDING

KNOWLEDGE-SHARING & CAPACITY-BUILDING		2012		2013				2014				2015	
		III	IV	I	II	III	IV	I	II	III	IV	I	II
1	Establishment of database of ENUSP Experts												
1.2	Developing a questionnaire for members to learn about their expertise												
1.3	Establishing database of user/survivor experts, structured into thematic areas such as alternatives, advocacy, research, CRPD, translation etc.												
1.4	Updating and maintaining database of user/survivor experts												
1.5	Training for members												
1.6	Developing a questionnaire for members to learn about their training needs												
1.7	Identifying capacity-building priorities												
1.8	Creating thematic training packages												
1.9	Delivering training to members												
2	Creation of ENUSP resource bank												
2.1	Gathering links and sources of information on key legislation affecting users and survivors across Europe												
2.2	Collecting relevant research and other reports												
2.3	Collecting good practices and initiatives												
2.4	Collecting concepts, research and practical work developed by users/survivors												
2.5	Setting up a communication system in order to continuously extend the resource bank												
3	Creating discussion forums												
3.1	Exploring members' needs around discussion and identifying key topics												
3.2	Setting up electronic discussion forums in different languages												
4	Thematic meetings												
4.1	Exploring topics of interest for members												
4.2	Setting up a system for on-line conferences												
4.3	Preparing content of conferences												
4.4	Reporting on conferences												
5	Developing collaborative events/projects with members organisations												
5.1	Exploring the needs of member organisations for joint actions, events and projects with ENUSP												
5.2	Searching for funding possibilities												
5.3	Sending information about project funding possibilities to members												
5.4	Working on joint applications with member organisations												

IN CONCLUSION

The main objective in the next three years is to build up an effective operational structure of ENUSP and to secure its funding. We see this as a matter of urgency and as a fundamental precondition for our further engagement in issues that affect users and survivors across Europe. Building up a solid base for our independent organisation will not only enable us to take action with and on behalf of our members but also to work towards future joint projects of interest to our people. Achieving this strategic plan will hopefully allow the next one to focus more on creating such projects.

LIST OF ABBREVIATIONS

ECOSOC	<u>The United Nations Economic and Social Council</u>
ENIL	<u>European Network of Independent Living</u>
ENUSP	<u>European Network of (ex) Users and Survivors of Psychiatry</u>
EDF	<u>European Disability Forum</u>
EPF	<u>European Patients' Forum</u>
FRA	<u>Fundamental Rights Agency</u>
GA	General Assembly
CPN	<u>Critical Psychiatry Network</u>
CPT	<u>Committee for the Prevention of Torture</u>
INTAR	<u>International Network Toward Alternatives and Recovery</u>
MDAC	<u>Mental Disability Advocacy Center</u>
MHE	<u>Mental Health Europe</u>
OHCHR	<u>Office of the High Commissioner for Human Rights</u>
SPT	<u>Subcommittee on Prevention of Torture</u>
UN CRPD	<u>United Nations Convention on the Rights of Persons with Disabilities</u>
WHO	<u>World Health Organization</u>
WNUSP	<u>World Network of Users and Survivors of Psychiatry</u>
WPA	<u>World Psychiatric Association</u>

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ENUSP HAS MEMBERS IN 38 EUROPEAN COUNTRIES - AND WE NEED MORE

ENUSP – Registered Office

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ENUSP bank-connection for donations:

Danske Bank, Holmens Kanal 2-12, 1092 Copenhagen K, Denmark,

Account holder:

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

International Bank Account Number (IBAN Code): DK7630003719376320,

Bank Identifier Code (BIC / Swift Code): DABADKKK