



ENUSP Bulletin

No. 3 - February 2012

ENUSP Strategy Consultation

Welcome to the ENUSP February Bulletin, a special consultation edition devoted to developing the ENUSP strategy for the next three years!

One important goal of the Rebuilding ENUSP project is the development of a strategy to guide ENUSP's development and activity over the next three years from May 2012, when the Rebuilding ENUSP project ends. We want as many ENUSP members as possible to be involved in the strategy development process. Many members have already provided information for the discussions at the two-day strategy planning meeting in Budapest. There are many questions remaining from those discussions, and this bulletin describes what those questions are. Please send us your answers!

The Board, the two project workers Elizabeth Winder and Debra Shulkes and Jasna Russo acting as a volunteer facilitator met in Budapest for the two-day meeting in January. Jan Verhaegh, the Board Member for the North West region, was unable to attend for health reasons. The deputy from his region, Sean Crudden, attended instead. The Mental Disability Advocacy Center (MDAC) in Budapest supported ENUSP by allowing us to use their offices and equipment. An independent consultant, Noémi Kíry Ambrus, helped us to develop the programme and materials for the meeting, and facilitated on one morning without attending the detailed discussions.

Although the meeting had to be limited to the Board, the project workers, and the facilitator, information had been gathered from taskforce members. Jan Verhaegh, the absent Board member, tried out the exercises before the meeting and his responses were included in the discussions. The Board deputies and the strategy taskforce also had the opportunity to contribute in this way. **This means that ENUSP members from Czech Republic, Denmark, England, Georgia, Germany, Greece, Republic of Ireland, Italy, The Netherlands, Poland, Romania, Spain, and Sweden have contributed to the content of this consultation document.**

Below we summarise our discussions and the key questions we need to decide. We welcome your comments! This bulletin comes to you as a pdf, but with a shorter summary in a Word document which you can use for your replies. Please send them to enusp.info@gmail.com with 'Strategy consultation' and your name/organisation in the subject line. The consultation is open until 30th March. After that the Board will consider the replies we have received, and do the final work on the strategy. The strategy will be agreed during April and posted on our new website which is being developed right now.

We look forward to hearing from you!
Elizabeth Winder

Message from Gabriela Tanasan, Chair of ENUSP

This is a time of change for ENUSP. As we plan our strategy for the next three years, we are no longer an organisation that reacts to what is happening around it. We become an organisation that looks forwards and plans our path through the opportunities and threats ahead.

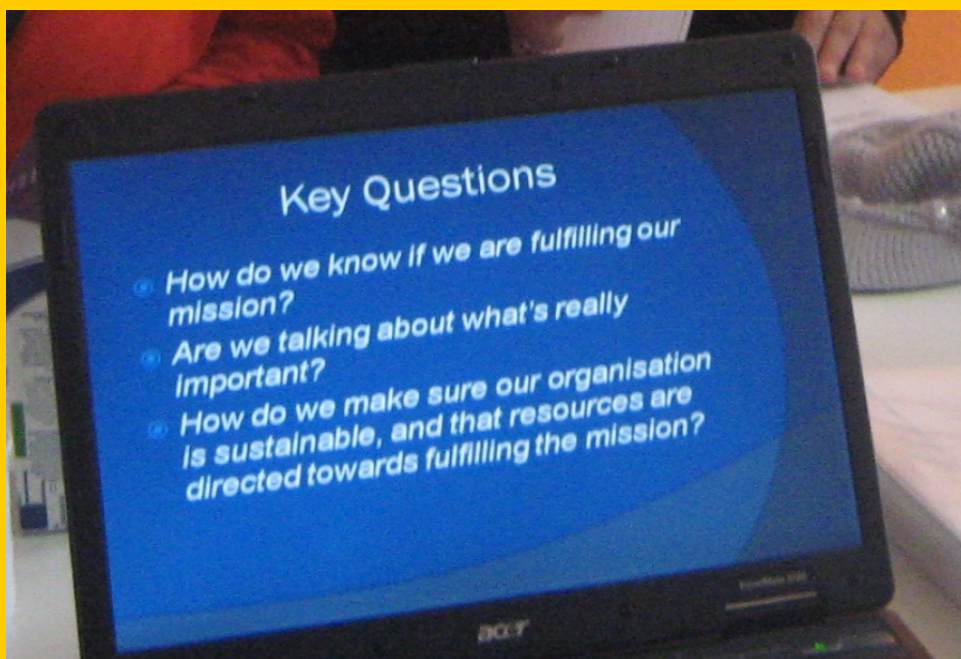
We know a lot of work is needed for ENUSP to work better, and have better communication with its members. This work has already started with the 'Rebuilding ENUSP' project, which ends in May. A lot of work still remains. We need future funding to carry on with the work.

We will not be able to do everything at once so we must prioritise what should be done first. The questions in this consultation will help us know what is most important to our members. The information about your organization which we request on the membership form will also help our decisions. If you haven't already returned your membership form, please do so quickly!

All our decisions depend on getting suitable funding. Although we can work to your priorities, we cannot promise to carry out all your ideas.

I remember the words of Stefan the Great, Prince of Moldavia, about 500 years ago. He said Moldavia belonged not to him, nor to anyone else in Moldavia. It belonged instead to all their descendants, and the descendants of their descendants. In the same way, ENUSP belongs not to me, or to you, but to the users and survivors who will follow us, and their followers, and the followers of their followers. This is a crucial period for ENUSP, and we all have a part to play.

In solidarity,
Gabriela Tanasan

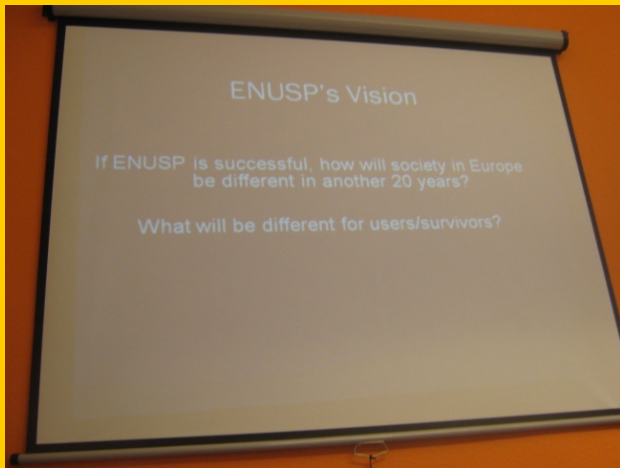


CONTENTS

1. ENUSP's Vision.....	4
2. ENUSP's Mission Statement/purpose.....	5
3. ENUSP's Values.....	7
4. Key Issues.....	8
4.1 ENUSP Organisational Development.....	9
4.2 Lobbying and representation relating to policy and human rights.....	11
4.3 Knowledge-sharing and capacity-building with members.....	13
5. Funding.....	15



1. ENUSP's Vision



First of all we thought about what society would be like in 20-30 years time, if ENUSP is successful and fulfills its purpose. What would be different for users and survivors? This distant vision, this dream, can help us take the first steps in the right direction. We summed up our ideas below:

ENUSP is working towards a Europe where

- all people are entirely free to be themselves, are valued equally, and treated with dignity*
- all people enjoy an equal right to make their own life choices*
- all people have access to a range of supports that respect their autonomy and dignity*
- human crisis is not labelled or feared, but is embraced as an opportunity for individual and community growth*
- all people have an equal chance to live a full life in the community, and they are all protected from poverty*
- the knowledge of people who have experienced crisis is respected, cultivated and given priority*
- these conditions are equally true everywhere in Europe*



Do you share this vision?

If your answer is no, what differences would you expect to see if ENUSP is successful?

We discussed that if this vision comes true, there will be no new survivors of psychiatry. Society's responses to emotional distress and crisis will no longer be something which has to be survived.

2. ENUSP's Mission Statement

A Mission Statement is a short statement about the purpose of an organisation. It is an opportunity to present ENUSP in the way we would like outsiders to see us.

For this exercise we discussed what ENUSP does, how and why it does it, for whom, and what makes ENUSP unique. We agreed that with adequate funding ENUSP could improve what it does, and extend its activities.

Although ENUSP acts for its members, we recognize that ENUSP's work can have an impact for users and survivors who have not heard of ENUSP. Some member organisations feel they have good contacts with users who are in the psychiatric system long-term, and can represent them. Other member organisations do not have these contacts. It is accurate to say 'ENUSP represents a network of member organisations brought together by common values'.

We identified some unique features about ENUSP:

- Users and survivors are joined in one organisation to work on common issues. There is a common awareness among users, survivors, and people who support us that the current situation is not acceptable and that change is possible.
- ENUSP is the only user/survivor organisation in Europe independent of health professionals, families, and commercial interests
- ENUSP survived for six years without any funding, due to the motivation of its members

We then looked at the wording of ENUSP's aims and objectives in the Statutes, written around twenty years ago. The wording still reflects our current aims and no change in the statutes themselves is necessary. However the wording is not in plain English, and it is difficult to translate. A more user-friendly Mission Statement will be used to introduce the organization to members, potential members, and people outside. This will emphasise what ENUSP is fighting for, rather than what ENUSP is fighting against.

Users and survivors of psychiatry are two political streams. The user stream is interested in reforming psychiatry, training professionals, better treatments, the other is against having psychiatry and diagnoses.

Some alternatives to the biomedical model developed by users and survivors have become mainstream in some countries and may not therefore be recognised as alternatives. When these 'alternatives' are taken up by service providers, the original ideas behind the model may be lost. Representation, research, and providing information are not specifically mentioned in the statutes, although they do fit in with the stated aims and have become more of a focus since the statutes were written. The UN Convention of Rights for People with Disabilities (CPRD) give priority to knowledge generated by users and survivors and the people with disabilities themselves.

Our **Aims and Objectives**, in the ENUSP statutes, say:

The European Network aims to promote and improve the human rights of (ex-)users and survivors of psychiatry; to fight for (ex-) user/survivor controlled alternatives to psychiatry and against abuse and coercion. On the very first European Conference the following guiding principle has been adopted:

The European Network is against any unilateral approach to, and stigmatisation of mental and emotional distress, madness, human suffering and unconventional behaviour. The European Network should support (ex-)users'/survivors' autonomy and responsibility in making their own decisions (self-determination).

In order to implement this principle, priority has been given to the following areas:

- *Act against any kind of discrimination in society (both inside and outside the mental health care system) of people who have been subject to the psychiatric system;*
- *Support development of (ex-)user/survivor groups throughout Europe (with a particular emphasis on those countries where there are no existing organisations);*
- *Create and support new alternatives to the psychiatric system and collect and share information on the existing ones;*
- *Influence and try to change present treatment in psychiatry*

The **Mission Statement** is:

ENUSP gives a voice to 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 exchange of knowledge between users/survivor organisations.



Is this Mission Statement easy to translate?

Our full name is the European Network of (Ex-) Users and Survivors of Psychiatry. This is usually shortened to in documents to ENUSP. When speaking, people refer to ENUSP, E.N.U.S.P. (saying all the letters separately), or the European Network. We would like to promote one short spoken name only.

What is your preferred spoken short name?

What is your preferred short name for documents?

Do you think ENUSP should have a new logo?

Some members have suggested that ENUSP should have a new logo to show the new spirit in ENUSP. Some people feel the current logo is similar to the European Union logo, and could give the impression that ENUSP is only for EU countries.



If members want a new logo, what do you think the new logo should represent (images, ideas, spirit, etc.)?

3. ENUSP's Values

We agreed that ENUSP policies and activities should be based on the following values:

Independence: ENUSP decisions are influenced by users and survivors, not their families, health professionals, commercial interests, or others.

Democracy and genuine representation: Major decisions are made within ENUSP with the input of its members. Representation work for ENUSP puts forward positions agreed through consultation with its members.

Ethical, responsible, and professional approach: ENUSP pays attention to the wellbeing of its members, staff, and volunteers, and expects high standards from its workers and volunteers. *This means members take responsibility, and share the workload rather than allowing a small number of people to become 'burnt out'. For workers and volunteers, it means putting the organisation's interest before personal interests during work activities, declaring when there is a 'conflict of interest', being on time and preparing for meetings etc. It means being realistic about what ENUSP can achieve without raising expectations that cannot be met. It means being aware of our power to influence, and using it wisely.*

Equality and respect for differences between ENUSP members: Recognising that the issues of users and survivors are different across Europe, and that ENUSP works across different economic and political systems. None of these should ever dominate. Being aware in our work that there are many inequalities between majority/minority groups and that we must try to address these inequalities.

Learning community: Sharing knowledge and skills in a process of permanent learning, an openness to receiving information, listening to others and accepting their different experiences may lead them to different views.



Do you think these are the right values?

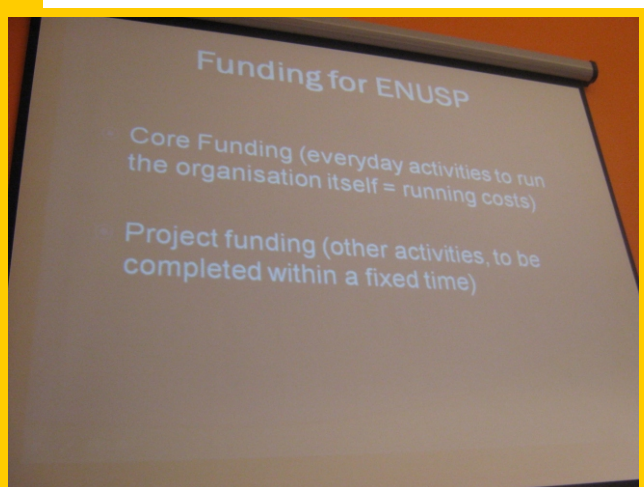
What, if anything, should be added?

What, if anything, should be left out?

4. Key issues

We identified the opportunities and threats that ENUSP may face over the coming three years. We thought about how ENUSP needs to develop in order to take advantage of these opportunities and be prepared for the threats. The issues identified fell into four categories:

- **Funding** without funding, ENUSP cannot employ workers. ENUSP's activities are limited to what can be achieved with volunteer time. In the long term, without funding ENUSP may cease to exist.
- **Administration** in the past, ENUSP has attracted volunteers who are interested in being activists, rather than administrators. This means that there is a lack of structure (policies and systems) to support ENUSP work.
- **Communication** without funding, internal communication has been mainly by email with no regular newsletters for member organisations, and little new content on the website. The 'Rebuilding ENUSP' project has allowed us to improve this situation. However, internal communication needs ongoing work. In the past, very little use has been made of press releases or media opportunities to publicise our activities and views outside ENUSP.
- **Public Image and Visibility** Public Image: ENUSP is sometimes seen by people outside as an extremist organisation, and it is in the interests of rival organisations to promote that image. This in turn could limit our opportunities to take part in forums where policies that affect users and survivors are being discussed. Within ENUSP, there appear to be accepted positions on some issues but no clear explanations on the website or elsewhere that explain what these positions are. In the past, this has led to misunderstanding by the members themselves about what ENUSP stands for, and it may discourage potential new members from joining. Visibility: ENUSP is not well known, and could promote itself more.



These issues affect three work areas:

- **ENUSP Organisational Development**
- **Lobbying and representation relating to policy and human rights**
- **Knowledge-sharing and capacity-building with members**

We then discussed how working on these issues would help us move towards our ideal society. Which issues, if ignored, would provide the greatest threat to ENUSP's purposes?

4.1 ENUSP Organisational Development

In the past, ENUSP's work has been held back because of lack of funds, lack of workers, and lack of administration systems. ENUSP needs to be supported by strong administration and organisation before it can take advantages of the opportunities in the world today.

This organisational development work began at Thessaloniki, and is being carried on further through the “Rebuilding ENUSP” project. The work plan for the Rebuilding ENUSP project is based on developing better two-way communication with member organisations, so that ENUSP is truly representative of its members.

The membership and mailing lists are being revised so that when the project ends in May 2012, the emailing list for members and the contact details for member organisations will be up to date. The new website will also be online. Further work must be continued by volunteers if available, until there is funding for workers to be employed.

Board members are finding out about potential new members in their regions. There have been 5 new member applications since the project began. Several members have been in contact in response to the bulletin, or through the taskforces. They include people from countries and regions that have been long unrepresented. There is a new energy in ENUSP!

If funding can be found, ENUSP aims to achieve:

- **Staffing:** Develop employment policies and procedures, and a structure to support volunteers. Workers will be appointed when funds allow, starting with a Director by January 2013, followed by a webmaster, Fundraiser, and lastly PR/Communication Officer by 2015. The Director will be responsible to the Board, and manage the other workers when they come into post. The Director and other workers will work with all the ENUSP regions.



Do you think ENUSP should employ any other types of workers?

- **Office:** Establish an office in central Europe, so it is easier to reach from all countries, by 2015. Budapest, Prague, or Vienna have been suggested as possible central locations for the ENUSP office. Cost will be a factor in the decision, and there are significant differences in different cities and countries for renting office space, average wages, hotel costs for visitors, etc.



Where do you think the ENUSP office should be?

What are the reasons for your choice?

- **Meetings:** by 2015, hold a yearly regional meeting of member organisations in each geographical region. Other meetings including members from a number of regions could be based on topics of common interest, including joint funding applications for shared projects. The General Assembly will be held in 2013.

Would you attend a meeting of member organisations in your region?



What support might your organisation need to send a delegate to a regional or topic-based meeting?

What topics would be most useful in your region?

English is the working language at ENUSP General Assemblies and seminars, and for ENUSP communications. What working language(s) might be possible for your ENUSP region?

- **Bulletin and Newsletter:** Produce a regular monthly bulletins for circulation to members by 2014, and 3 issues per year of Advocacy Update for wider circulation by 2015.

What topics would you like to see covered in the ENUSP Bulletin and Newsletters?



Would you like to receive a print copy as well as an electronic copy of ENUSP's publications?

Do you have any other requests about ENUSP's publications?

- **Membership**



Do you know of any organisations in your area who might be interested in ENUSP membership (give details)?

Do you know of any organisations in your area who are not eligible to become ENUSP members, but who could be added to the mailing list to receive Advocacy Update? (give details)?

4.2 Lobbying and representation relating to policy and human rights*

At a 2011 ENUSP seminar, Debra Shulkes presented a written report on the forums/organisations with whom ENUSP was working, covering the type of work they do. In Budapest, she gave an update, based on recent contact with some of these forums/organisations, input from the ENUSP representation taskforce, and feedback from some former and recent representatives. The written report and the Budapest presentation will be sent to you if you email your request to enusp.info@gmail.com.

Right now ENUSP is receiving more and more offers to cooperate with other entities for example, by participating in their events or advising on their policies and projects. One key reason for this is the impact of the UN CRPD. The CRPD demands the close and active involvement of user/survivor groups in the making and implementing any law, policy or programme about us (NOTHING ABOUT US WITHOUT US).

Opportunities to work directly with law and policy-makers and others can be extremely beneficial for ENUSP. For example, they can give us access to important lobbying forums, contacts, and resources. Nevertheless, there is a real risk that some of our involvement can be a drain on ENUSP's limited resources. In the worst case scenario, our presence can even legitimise projects that go against our interests.

Over the last two years, ENUSP has worked with:

- **Law and policy-making forums at different levels:** At **European Union level** the Fundamental Rights Agency, European Commission directorates. At **United Nations level** - World Health Organization- Europe. At **national level** -the Portuguese and Latvian governments
- **Pan-European Non-Governmental Organisations (NGOs):** ENUSP is a member of European Disability Forum and European Patients' Forum
- **Other NGOs :** Mental Disability Advocacy Center, Mental Health Europe
- **Universities:** the University of Central Lancaster, the Aristotle University Thessaloniki
- **Psychiatrists' groups:** the World Psychiatric Association.

For the most part, the cooperation with these groups was not planned, but happened in response to offers they made to ENUSP. (This was largely due to our lack of funding)

* Please see the following section for details of ENUSP's work with other user/survivor organisations such as the World Network of (ex-)Users and Survivors of Psychiatry (WNUSP)

The following questions were sent to the representation taskforce:

- Which organisations/bodies is it most important for ENUSP to work with?
- Why is it important for us to work with these kinds of organisations/bodies?
- When ENUSP is asked to send a representative to take part in someone else's event/project, what are the considerations on which it should base its reply?
- What are the responsibilities of ENUSP representatives?
- What are the principles ENUSP should use to choose its representatives?
- How should ENUSP support its representatives?

Working with the answers from the Representation Taskforce, ENUSP aims to:

A. Create an ENUSP Policy on Cooperation with Non-User/Survivor Groups

This policy will cover three forms of cooperation available to ENUSP: **representation** at others' events, **involvement** in their projects, and **collaboration** on joint projects with them. It will set our guidelines for:

1. When to accept and when to reject invitations
2. Appointing ENUSP representatives
3. The task and responsibilities of representative, including the process for consultation with ENUSP members
4. Supports for ENUSP representatives, e.g. small electronic discussion groups where representatives can discuss concerns and strategise their involvement

B. Create representation support structures in ENUSP

As part of these supports, ENUSP will build a **databank of ENUSP experts**, ready to represent and advise us on particular topics.

C. Develop an ENUSP Representation Plan • This plan will set out the priorities and steps for our cooperation with others, including

1. **Pan-European NGOs.** We will explore whether we can achieve more impact by joining other umbrella groups such as European Social Forum
2. **Law and policy-making forums.** We will review our current involvement and identify other forums where we want to have a voice. Suggestions of forums where ENUSP should be active are: United Nations bodies and Council of Europe (including their anti-torture monitoring bodies), and EU parliament.



ENUSP has the option to apply for ECOSOC status. This means we would be on the list of NGOs consulted by the UN and invited to participate in the events of UN treaty bodies. Do you agree with this step?

Please see this link for more details: <http://csonet.org/index.php?menu=17>

Have you got any comments on forums where ENUSP has been active in the past?

Have you got any suggestions about law or policy-making forums where ENUSP should become active?

3. Other groups with similar values or overlapping goals. We will identify other groups that we could work with to achieve our goals and actively seek cooperation with them on common issues. Suggestions of these groups are: INTERVOICE (International Hearing Voices Network), International Network Toward Alternatives and Recovery, Soteria Network, European Network of Independent Living, Critical Psychiatry Network, some carers' groups.



Have you got any suggestions of other groups that ENUSP should work with?

How do you think representatives could consult with the grassroots?

Have you got any other comments about ENUSP's work with others?

4. Funded collaborative project When ENUSP has a clear representation policy and plan, we may choose to lead a collaborative project with one or more other organisations.

4.3 Knowledge-sharing and capacity-building with members

Knowledge-sharing refers to information about good practices, legal options, and alternatives developed and/or led by service users and survivors. ENUSP's recent activities have included speaking at conferences in Portugal and Finland to service users, survivors, health professionals, government representatives, and funders aiming to develop new services in their countries. Users and survivors report that their influence is greatly increased when a user/survivor speaker from outside their country talks about unacceptable practices within the country and good practice elsewhere. ENUSP does not have an easily available reference collection of such information, or guidance where such information can be found.

Knowledge-sharing also refers to gathering and sharing information about the situation of service users and survivors in order to strengthen representation and lobbying. Although there are several survivor researchers in ENUSP, ENUSP itself has not carried out any research of this kind.

Capacity-building refers to activities and trainings which widen the range of skills within an organisation. At the moment ENUSP does not arrange any activities like this, though ENUSP people are sometimes speakers or participants at such events.

These questions were sent to the research taskforce:

- What type of research issues are important for ENUSP?
- Why are these the most important issues?
- When ENUSP receives an invitation to collaborate in a research project, what are the principles on which it should base its reply?
- Do you have any ideas about specific research topics?
- In what way would these research topics benefit ENUSP members?

There was a strong suggestion that stigma and discrimination from relatives, from mental health professionals, police, general physicians, should be a topic for cross-border research and a tool for change, using the media to raise awareness, The results relating to stigma and discrimination from relatives must be treated more sensitively but careful presentation to carer groups could improve family relations.

ENUSP aims to:

ENUSP Position statements - publicise agreed position statements in plain English on the website, with definitions of ambiguous or easily misunderstood words (this includes some words used in the statutes). Establish a consultation procedure with member organisations for the development of future position statements.

Resource bank - collect and make available on the website resources (in any language) from ENUSP member organisations, and links to other resources, on the topics of good practices in mental health, alternatives to the biomedical model and guardianship, working with the CRPD, building independent user/survivor organisations, training packages developed by users/survivors to support user/survivor models or activities.

What information would you like to find in a resource bank?



Do you currently use any website resources which would be useful for ENUSP? Please list.

Does your organisation have any training experience or resources which could be useful to other ENUSP members? Please explain.

Taskforces E- discussion groups - set up electronic forums where users/survivors across Europe can share information on different issues.

Working with member organisations - share current information about external opportunities that ENUSP is aware of trainings, fundings, events, human rights; establish a clear picture of the needs of member organisations, and the situations in their countries; identify priorities for research and capacity building, and opportunities for cross-border mentoring and co-operation.

These will form the basis for future projects/funding applications.

Working with the user/survivor organisations outside Europe - Building stronger connections with the World Network of Users and Survivors of Psychiatry (WNUSP) and Pan-African Network of People with Psychosocial Disabilities (PANUSP) could enrich the resources and contacts ENUSP offers to its members.

Capacity building for representatives establish training needs of current and future ENUSP representatives, to include those working with external organizations, and those visiting ENUSP member organisations. Develop resources/training packages to meet these needs. This should include where to find basic information on laws and rights and mental health systems in different countries.

Capacity building is possible on many topics. Which are most important to your organisation? (Number 1 to 5, 1 = most important, 5 = not at all important)



- The UN Convention on the Rights of Persons with Disabilities (CRPD) and other advocacy tools for users and survivors based on an international human rights framework
- Lobbying policymakers, eg on CRPD implementation in your country
- Alternatives to psychiatry and approaches developed and controlled by users/survivors
- Building sustainable user/survivor organisations, funding and running user/survivor-controlled projects
- Awareness-raising or training (including professionals) in user/survivor approaches?
- Campaigning or training for the public around attitudes to users/survivors
- Other, please say

What kind of support do you think ENUSP could provide with the priorities you have chosen?

5. Funding

The continuation of all this work depends on getting funding. The project workers have researched funding opportunities and presented a report. This is available on request from enusp.info@gmail.com. We will make a funding application before the end of the Rebuilding ENUSP project, based on the final strategy.

We want to focus our resources on the areas where they will have the greatest positive impact for users and survivors.



What three things could ENUSP do, which would have the greatest positive impact for users and survivors in your organisation?

How can we make the work of ENUSP more visible?

Please add any other comments about ENUSP's strategy.



'Rebuilding the Network Together'
Budapest, 20-23 January 2012
MDAC Office

*ENUSP Bulletin February 2012, copyright ENUSP
Elizabeth Winder - Editor
Nadia Mahjoub and Gabriela Tanasan - Design and formatting*

The Rebuilding ENUSP project is funded by the Open Society Institute



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

ENUSP – Registered Office

Vesterbrogade 103, 1.sal
1620 Copenhagen V, Denmark

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