

## REPORT ON SEMINAR

### “Strategy for empowerment - Key areas of action”

Based on support from Mental Health Europe (MHE)  
under the European Commission Progress Programme  
with assistance of Orizonturi Foundation

**Bucharest, 8-10 December 2013**

The seminar brought together 19 representatives of users/survivors groups from 12 EU countries: Croatia, Denmark, Finland, France, Ireland, Germany, Netherlands, Poland, Romania, Spain, Sweden, and UK.

#### **SUNDAY - 8 December 2013**

#### **Welcome, Presentation of the program and brief information about the goals of the seminar Facilitators Piotr Iwaneiko and Gabriela Tanasan**

Piotr Iwaneiko opened the seminar and welcomed all participants. Everyone expressed thanks to Gabriela Tanasan for doing such a wonderful job to organize the seminar, especially with such short notice. Piotr explained the difficulties ENUSP had faced with the resignations of officers and Board members over the past year. He went on to explain that certain deputies had stepped up to fill vacant positions, including himself as Vice Chair to assume the position of Chair and that other replacements had been co-opted by the Board. Following questions from the participants, a list of current Board members and their deputies was provided. A discussion on whether it would be good to have a second deputy did not receive the approval of the majority.

Piotr and Gabriela went on to explain the objectives of the seminar:

- Review strategy;
- Decide on key areas of action and how to implement the strategy;
- Maintain continuous and effective work.

To achieve this, Piotr mentioned that fundraising and that communications, particularly via our web site, were priorities, but that what we want to do must match the resources we have.



## MHE and ENUSP - Common session

Facilitators Piotr Iwaneyko and Kristijan Grdjan



Kristijan Grdjan, Board member of MHE and the Program Coordinator for the Shine users' organization in Croatia, particularly interested in human rights and the UNCRPD gave a presentation on MHE's current work in the fields of DI, campaigning against the DMS 5 with its overly biological approach, the MHE Mapping Exclusion report, and the employment of youth with mental health problems.

After the presentation, participants expressed their thanks to MHE for this indispensable support to hold the seminar and their hope that the financial situation of the organization would rapidly improve.



In addition to Piotr's suggestion to put forward a joint candidate with MHE as a board member of other European organizations, Jolijn Santegoeds would be willing to study opportunities to work together with MHE on Family Group Conferencing. DI was suggested as a subject by many that could also be interested in connection with a joint project with MHE. Piotr confirmed that ENUSP was interested in a stable partnership with MHE in certain areas.

## MONDAY - 9 December 2013

### ENUSP strategy: review of the strategy

Facilitator - Jolijn Santegoeds



The Strategic Plan 2012-2015 approved in Zagreb was presented and commented on. Participants initially came to an agreement that the strategy was overly ambitious and it was necessary to focus on core issues. Several also commented on the fact that the reason the strategy had not been implemented since the last meeting was not only due to a lack of leadership, but also to the lack of any appointment and enough commitment by Board members to lead the strategy and a lack of any employees to help.

After this general review, and before a decision-making process on key strategy areas, Jayasree Kalathil gave a presentation "**Learning from countries with strong users' movements: National Survivor User Network UK**".

Jayasree said that the NSUN Board of Trustees, elected by the GA, was in charge of hiring employees and that members were consulted regularly for their opinion. She added that the current "no health without mental health" British strategy was in place, but that there were problems with implementation by the Public Health & Justice Committee that may no longer be in charge of this and the question was who would take their place? She also deplored the fact that the Department of Education no longer was using "well-being" and "community cohesion" as school inspection requirements, as well as minimum nutrition standards. She noted there was less funding of mental health services, less welfare available with more homeless persons and poverty and that more coercion was being used. The work done by Tom Burns from Australia (Oxford) has led to more community treatment orders. This is in spite of the full report recently overviewed in the Lancet she said showing that community treatment orders are a disaster. Jayasree reported there is a potential amendment of the Mental Health Act. On the other hand, new training has been started in psychiatric hospitals, such as "respect training" and the movement to "end the face down" policy in crisis situations.

This discussion led to the following comments:

- The project of "Recovery Colleges" known to be useful in Scotland is also planned to be started in Finland. In Sweden and Finland, there are already "Nordic summer camps" organized by users.
- Stephanie suggested that areas of joint work and comparison that could be of interest would be CTOs, patient advocates, and psychiatric inspection boards, secured (forensic/criminal) psychiatric facilities, supported decision-making versus guardianship.



Jayasree Kalathil speaking about NSUN

## ENUSP strategy: agreement on key areas of action

Facilitator Jasna Russo



After the general discussion, below are the key areas of action participants felt were the most important, including comments:

**1. Fundraising.** It is particularly important to find funding for on-going affairs, to hold a General Assembly and to hire an employee. Denmark may be in a position to host a General Assembly. The possibility of funding by OSI and EDF partnership needs to be reviewed. When projects are funded, this can be a good way to hire employees and also involve new members.

**2. Structure and functioning of Board, General Assembly and Membership.** A new look at the structure of the Board and General Assembly, including how persons should be elected, is needed. Should the general membership be called on to help? It was also suggested that a "mentor" could be called on for help with better structuring the organization. A Coordinating Committee / Emergency Coordinating Group in close contact with the Board would also be a good idea.

**3. Communications.** To increase membership and improve relations with members, communications are vital, particularly the web site. A shorter newsletter, presence on Facebook and links with blogs are necessary. A membership campaign could be done. The application itself should be made easier to fill out.

Three working groups were then organized and worked separately at the next session.

## Report back from working groups, input from other groups

### 1. Communications Working Group

**Participants:** Rene Van Der Male (Netherlands), Lupe Morales (Spain), Timo Kallioaho (Finland), Jayasree Kalathil (UK), Katrine Wiedersoe (Denmark)

The first priority is to establish an up-to-date list of current members, which Lupe agreed to ensure. Existing lists will be sent to her. Then ENUSP should go on to recruit new members via the publication of a newsletter. The newsletter must be shorter and simpler to publish. Debra had already collected articles for the future issue of *Advocacy Update* and Gabriela will search for them in archive. This newsletter would have to be translated and disseminated to as many different countries with user/survivor groups as possible.



The Regional Representatives need to be reappointed at the General Assembly and need to be in greater contact with the Board.

Specific persons need to be recruited as volunteers to be in charge of projects, such as the newsletter, networking, regional contacts and Facebook. Once these people are recruited, Skype forums can be used to communicate. The Board needs to design a plan to integrate volunteers.

There is no current webmaster which is urgent. Jolijn would be willing to help with making immediate updates to the Web Site.

#### **Needed:**

- Money to pay new website, maintenance
- Receiving computers
- VITAL determine where are our members and how we can help each other.

## **2. Working Group on General Assembly, Structuring the organization, Board functioning, membership**

**Participants:** Jerzy Bajkowski (Poland), Piotr Iwaneyko (Board member, Poland), Maths Jespersen (Board member, Sweden), Karl Bach Jensen (Denmark), Monica Obreja (Romania)

### **General Assembly**

There is great hope that Denmark (LAP organization) could host a General Assembly within one year or in early 2015, together with a European congress. This will depend on when an answer could be given by the LAP organization (January Board Meeting and April General Assembly). The GA should allow participants to spend four days and three nights.



**Day 1** could be devoted to reports on past activities to bring everyone up to date.

**Day 2** could be devoted to a thematic conference that could interest Denmark, including an exchange of experiences (suggestions: peer-to-peer networks, reducing coercion, problems with forensic psychiatry, training of persons with mental health problems).

**Day 3** could be devoted to regional-oriented meetings, joint strategies and synergies.

A joint organizing committee with ENUSP and the Danish LAP organization would be necessary for the GA and the Congress. Fortunately, LAP has already organized two such events and has experience with this.

Approximately 50 people from European countries and local participants could be expected to attend. Travel for participants from certain countries could potentially be financed via private funding in Denmark, but these expenses must be taken into consideration and hopefully financed.

If Denmark is not possible, an alternative venue could be Poland.

### **Structuring and decision-making**

Projects and position papers are crucial. The idea of having a second deputy did not appear necessary to the majority of participants. However, a greater commitment from Board members and Deputies is vital.

ENUSP was registered in the Netherlands and the Statutes are complicated because Dutch law applies. The "contact address" is in Denmark. Danish law on non-profit organizations is much less complicated and it could be studied whether it would be worthwhile to transfer the NGO registration there.

Several complicated provisions regarding the election procedure for the Board and the question of "Individual membership" provided for in the Statutes should also be reviewed. There are more and more "psycho-radicals" with only a web presence in Sweden for example. The nomination process for Board Members should be organized in advance, rather than accepting spontaneous nominations during the General Assembly. A working group should be set up to review the Statutes, simplify and update them.

Membership application: The application form was deemed too complicated. Asking previous members to fill out such a detailed form may be insulting or put off potential new members. A shorter application form, including a direct description of the organization that can be published immediately on the web site would be easier and more relevant. However, it should not be a race to get as many members as possible. Concerns were expressed about family and professional organizations attempting to join as members. Therefore, it would be good to create a membership/accreditation committee. Should one of the criteria be the refusal to accept any financing from the pharmaceutical industry? In any event, new members must agree to all policy documents.

The draft by-laws provided previously by Debra Shulkes should be reviewed, approved by the Board and submitted to the next GA.

### **3. Fundraising Working Group**

**Participants:** Sean Crudden (Board member, Ireland), Amalia Jurj (Romania), Oana Girlescu (Romania), Gabriela Tanasan (Romania), Stephanie Wooley (Board member, France)

Sean Crudden introduced the session by reminding everyone that "money is the root of all evil" and that is why it is so important to be careful in this area!

#### **Current Finances**

Piotr informed participants that he had taken the necessary measures to control ENUSP's bank accounts and gave additional information on the financial position. Claus-Bech Nielsen, ENUSP's accountant for many years, will be asked to provide a financial statement for 2013 and it is important to prevent any risk of audit in spite of the very low financial position. Fortunately, Claus-Bech is willing to assist ENUSP on a volunteer basis until financing of his fees is possible.

#### **Urgent areas to be financed:**

Administration, secretariat, virtual office (Wordpress)

#### **Projects that could be financed:**

- Communicating experiences;
- Publications for sale, including e-books;
- Renew Web Site possible to provide advisory services to people, allow people to share experiences
- General Assembly, with a conference having as potential themes: CTOs, social-oriented alternatives, how to change public opinion, promotion of best practices (Personal Ombudsman, Family Group Conferencing, Runaway Shelters).



### Potential financiers:

- Open Society Institute Mental Health Initiative
- Private donors: Maths Jespersen suggested this target and has met some members of the Essel family from Austria which has a foundation. There is also a German-Swedish The Right Livelihood Foundation which gives an Award (Alternative Nobel Prize) started by a famous stamp collector philanthropist, Jakob von Uexkull, that he suggested could be approached. Other private donations could be solicited, particularly in Russia, but personal connections are needed.
- "Crowd-funding": Rene Van Der Male is a member of the Okapi Foundation in Denmark, which is a collective group of donors. They have a meeting scheduled very soon to distribute the last of their funding. Rene will see if it is still possible to submit a request.
- Grundtvig Fund: Jasna Russo suggested seeing if this fund is available in 2014 for projects in communications, exchanges and adult learning. 20,000 Euro grants are available outright, without matching funds required. The deadline for this fund is usually once a year, in February.

### Other ideas for sources of funding:

- U.N. in the fields of development, ending discrimination
- WHO
- EU Programmes, Social Fund
- Euro-Millionaire and national lotteries
- Kellogg's and Coca Cola Foundations
- On-line donations via our web site and other web sites
- Working with smaller NGOs (ask members for suggestions): X-Y, Light for the World, Mama Cash, One man can make a difference

### Action Plan:

1. Review leads found previously, survey of members to create a data base of more potential financiers
2. Draft documents necessary to support applications (accounts, annual report)
3. Draft project descriptions

Gabriela Tanasan would be willing to be the leader of the fundraising committee. Stephanie Wooley and Jolijn Santegoeds agreed to be members of this Committee.

**Concerns expressed:** Western versus Eastern strategies



**TUESDAY 10 December 2013**

**Hands-on action: who does what? Declaration of commitment to kea areas of action -  
Action plan for 2014-2015**

**Facilitator: Stephanie Wooley**



**Why?**

Problems in the past with a lack of appointment/commitment to strategy and a lack of employees to help.

It is necessary to call on members for help and to get involved.

**Board Members who have agreed to be contact persons for our three key strategy areas (this does not prevent contact at any other time with any other Board members):**

Lupe Morales: Communication

Stephanie Wooley: Fundraising

Maths Jespersion: General Assembly

**Board commitments:**

- A history of the transition of Board members since the GA in Thessaloniki will be drawn up and sent to all participants
- Once the list of current members is updated, a communication will be sent to all members as soon as possible in the New Year with:
- Summary of the seminar
- Short version of "member profile" for web site to fill out
- Call for 2014 membership fees
- Call for financing suggestions
- A work plan to recruit volunteers and integrate them will be drafted by the Board.

**Communications Committee - Board contact Lupe Morales**

- Call for 2014 membership fee and profile;
- Immediate update of the membership;
- Immediate update of the website;
- Bulletins and Advocacy Update;
- Maintenance of the website, appointment of the webmaster;
- Management of the e-mail ENUSP Desk address;
- Future Bulletin or Advocacy Update;
- Translations of Bulletin in different languages;
- Management of ENUSP's e-mail address.

**General Assembly - Board contact Maths Jespersion**

Maths will ensure contact with the potential Danish hosts. Answer should be received either in January 2014 (GA in 2014) or April (GA in 2015). If this plan is successful, it will be necessary to create:

- Joint organization committee ENUSP-LAP;
- Organization committee for Congress (theme, speakers, etc.);
- Organization committee for GA (Board nominations in advance).



## **Fundraising - Board contact Stephanie Wooley, Committee Chair Gabriela Tanasan**

- OSI - MHI
- Grundtvig Fund
- Okapy Group
- Oother potential options
- Data base on funding opportunities

## **Next most important future working groups:**

- External relation EDF, EPF, CE FEC, WAPR, EUFAMI
- Statutes and by-laws
- Country of registration
- Position papers and representation
- SOS Emergency Task force for Mental Health issues

## **Consolidation of the network how to develop greater user involvement across European countries; user involvement in Romania**

**Facilitator: Gabriela Tanasan**

Gabriela Tanasan gave the presentation "User Involvement in Mental Health - Bridging the gap between challenge and practice", with concrete examples at Orizonturi (Horizons) Foundation showing that the user involvement is possible, even if with very big efforts.

The ARIPI (Wings) Association's activity was presented by Stefan Bandol, Chair of the organisation: eight art exhibitions, nine protest meetings against the mental health law (at the Ministries of Labour, Health, Social Protection and Hospitals), demonstration against the use of cage beds at the Czech Embassy in Bucharest, including media interventions, the organisation of two major national health forums with over 70% of those attending being users. ARIPI is running the project "Spornic European Village" as a vacation and meeting site for user organizations. One Romanian house is already almost completed. Other Member State donors are being sought. A land concession could be granted to them to build a national-style house. A total of 39 buildings are planned.

## **Evaluation and concluding remarks**

Before the conclusion, Stephanie Wooley mentioned that she had been contacted on the subject of Mad Pride by Rafael Daem (Belgium), Erveda Sansi (Italy) and Claude Deutsch (France), who along with the Spanish movement for mad pride in Oviedo were planning to organize Mad Pride events in 2014 and would like support from ENUSP. The participants felt it would be good for an ENUSP representative to attend these events or participate with a presentation if a conference or workshop were held at the same time. None of the participants present are involved in Mad Pride in their countries. For a "European" movement, it would be good to involve the Mad Pride groups in the UK and Ireland, which have been active for some time with this event. Piotr said the question with a more detailed request should be submitted to the Board.



## Conclusion

Piotr concluded that everyone would fill out their "satisfaction" survey, but that he was very satisfied himself, from A-Z, starting with the organization locally, the content, the involvement of everyone and the friendly atmosphere during the seminar.

An adequate organization will allow ENUSP to develop and continue its strategy by resetting all structures to match our resources, finding representatives and volunteers who commit themselves to provide tools, resources and policy for our three core actions.

The greater transparency and involvement are necessary, and the right persons needed to be responsible and their responsibilities better defined.

A General Assembly would require a lot of organization and knowing how to be useful to our members. Only this way can ENUSP become the valid representative of the user/survivor movement in Europe, which should be the objective of the new Board.

Piotr concluded by saying that there were big challenges ahead, particularly knowing what we want and what we can do, based on the current reality and situation of ENUSP.

