

MENTAL HEALTH EUROPE  
SANTÉ MENTALE EUROPE



**Mental Health Europe (MHE)**  
and the  
**European Network of (ex-) Users and Survivors of Psychiatry (ENUSP)**

## **NOTHING ABOUT US WITHOUT US**

**How to make this a reality?**



Report of the Empowerment Seminar funded by the European Commission



**13<sup>th</sup> and 14<sup>th</sup> March 2009, Brussels**





The Empowerment Seminar was supported by 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/social/main.jsp?catId=327&langId=en>

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## Background of the Seminar



Preceding this seminar the two representatives of ENUSP (Mary Nettle and Erik Olsen) have had a one day meeting in Brussels (on 21<sup>st</sup> November 2008) with Mary Van Dievel, Director MHE, Josée Van Remoortel, MHE Senior Policy Adviser, and other five MHE staff and

trainee. MHE took the initiative for this meeting in order to discuss recent developments in the two organisations, as well as the idea of the empowerment seminar. The history of the communication between ENUSP and MHE has not been an easy one and this meeting meant an opportunity to clarify some issues and figure out the perspective. After Mary and Erik have reported back to the Board of ENUSP about the discussions at the meeting (27<sup>th</sup> November 2008) we agreed to provide Mental Health Europe with the following statement of intent:

“The European Network of (ex) Users and Survivors of Psychiatry (ENUSP) is pleased to cooperate with Mental Health Europe (MHE) on areas of mutual benefit. We acknowledge our need for practical support from MHE to help us build our capacity as the European NGO for mental health user and survivor organisations.

We are pleased that MHE and its network of member organisations sees this need to support users and survivors to have independent organisations. We welcome support members whilst this capacity building is taking place and the practical support we can receive from MHE to enable us to achieve this goal.”

The other outcome was the agreement about the Empowerment seminar, which was the joint project of MHE and ENUSP. MHE took the responsibility for full funding and organising the event for 25 participants. The ENUSP Board was in charge of the programme, the decision who to invite, facilitation and documentation of the seminar. The purpose of the seminar was to help ENUSP build its capacity and plan for a general assembly.

## Programme



The meeting was planned for Brussels on 13<sup>th</sup> and 14<sup>th</sup> of March 2009 and we started preparing the programme and thinking of who to invite at the Board meeting on 7<sup>th</sup> of January 2009. The preparation work was very quick, intense and took place via e mail and telephone. Using EU money means not being able to invite participants from non-EU member countries which is a serious limitation. Our priority was to invite users/survivors from as many different countries as possible and use the opportunity to think together and figure out the way forward for ENUSP. So the main question we wanted to work on in the Seminar was how to set realistic goals for ENUSP and achieve them in

next years given the fact that we operate without the European Desk and our only income are membership fees. This is the programme that we came up with:

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#### **Friday, 13<sup>th</sup> March**

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|--------------|--|
| <b>13.00</b> | Sandwich lunch, registration and informal networking   |
| <b>16.30</b> | Welcomes by Mary Nettle (Chair of ENUSP) and Mary Van Dievel (Director, Mental Health Europe)                            |
| <b>17.00</b> | Welcome by Trude Eliassen (European Commission DG Employment, Social Affairs and Equal Opportunities)                    |
| <b>17.30</b> | Break  |
| <b>17.40</b> | Getting to know each other and sharing expectations of what we can achieve from being here<br>Facilitator: Peter Lehmann |
| <b>19.30</b> | Buffet   |

#### **Saturday, 14<sup>th</sup> March**

- |              |   |
|--------------|---|
| <b>10.00</b> | <i>Mary Nettle</i><br>Past, Present and Future of ENUSP   |
| <b>10.15</b> | <i>Jan Wallcraft</i><br>ENUSP in Relation to the World Psychiatric Association; to the European Mental Health Pact and to the UN Convention on Rights of People with Disabilities |

<b>10.35</b>	<i>Jasna Russo and Erik Olsen</i> ENUSP and the European Research: Some Principles, Current Projects and Perspectives
<b>11.00</b>	Break
<b>11.15</b>	Discussion Facilitator: Anne-Laure Donsky
<b>12.00</b>	Break
<b>12.15</b>	Introduction into the working groups on future priorities of ENUSP Facilitator: Jasna Russo
<b>12.45</b>	Lunch
<b>14.00</b>	Working groups Facilitators: Mary Nettle, Erik Olsen, Jasna Russo
<b>15.30</b>	Break
<b>15.45</b>	The outcomes of group discussions: A way forward for ENUSP and its members Facilitator: Jan Wallcraft
<b>16.45</b>	Closing remarks – <i>Mary Nettle</i>
<b>17.00</b>	End of the seminar

### Participants



As already mentioned above there was no possibility to invite users/survivors from non-EU member states. The other limitation was that the working language of the Seminar was English because of no translation possibilities and this constituted the other criteria for participation. Contacting regional members turned to be quite time consuming and because of a very tight timeline the people invited were those who were the quickest to respond. At the end twenty six users/survivors from the following twenty countries took part in the Empowerment Seminar:

Austria, Belgium, Czech Republic, Denmark, Finland, France, Germany, Greece, Holland, Hungary, Ireland, Italy, Latvia, Lithuania, Poland, Portugal, Romania, Spain, Sweden and UK.

The participants were either member of national, regional or local users'/survivors organisations; two persons did not belong to any group. We were fourteen women and twelve men.

## Welcome



On the first evening everybody was welcomed by the Chair of ENUSP Mary Nettle, the Director of MHE Mary Van Dievel and Trude Eliassen from the European Commission DG Employment, Social Affairs and Equal Opportunities. Mary Van Dievel explained that this seminar is taking place within the frame of the social inclusion programme PROGRESS. Those in charge of the national focal points are mental health organisations but they are explicitly asked by MHE to consult with service users

organisations. She stressed the importance of knowing service users' point of view in the field of social inclusion. A lot of information about the work of MHE and the ways to get involved can be found on [www.mhe-sme.org](http://www.mhe-sme.org).

There was a discussion about how user involvement can concretely take place. The Board of MHE has fifteen members, three of whom have service user background. There is one paid service user worker doing administration at the MHE office and the others are volunteering. The other topic discussed was the MHE position towards accepting the money from pharmaceutical companies. Until 1999 MHE was not accepting this source of funding. Because of the financial difficulties this decision was changed by the general assembly but no money has actually been taken from the drug companies. There is a tendency to change this decision again because of the respect for the user movement. ENUSP does not take drug companies' money and therefore has special working agreements regarding this topic with organisations like European Patients Forum which do receive pharmaceutical funding.



Trude Eliassen from the European Commission<sup>1</sup> started her welcome speech with saying that it is very close to her heart to be with us. Her presentation focused on explaining social protection and social inclusion policy of the European Union and how it is linked to inclusion of people with mental health problems. She said that social disadvantages both increase the risk of

mental health problems and also reinforce further exclusion:

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<sup>1</sup> <http://ec.europa.eu/social/>

“The problems people with mental health problems and other vulnerable groups experience can also be translated into homelessness, unemployment, low education, and subsequently, further exclusion from society.”

The instruments of EU social policy are legislation, financial instruments, social dialogue and the open method of coordination. Trude referred to people with mental health problems as a vulnerable group whose knowledge is essential to succeed in developing good practice and policy in the field of social inclusion. Her presentation was interrupted by very concrete questions from the participants which addressed our difficulties as users/survivors to get involved in decision making processes – like the fact we are not represented on boards of mental health organisations or that our contributions are not acknowledged as paid work and can only take place on the voluntary base.

“I hear what you are saying and I will take it with me but I can not give concrete answers.”

In respond to the fact that ENUSP as an organisation representing independent mental health service users’/survivors’ voice in Europe receives no funding on its own, Trude strongly recommended us to stay with Mental Health Europe.

“People with mental health issues should stay together and support each other. You should fight for more hearing inside Mental Health Europe. If the fight goes wrong, you will not succeed in getting money from EU because it’s the criteria which needs to be fulfilled in order to get the money. [...] I recommend you to stay together with those who have the same interest as you because together with them you are stronger than on your own and it’s needed. But you will find your own way.”

One participant said that this is like asking women to join the men-only committee in order to achieve their rights. Another person commented:

“There is very great contradiction between the beautiful words and documents of the European Parliament and European Commission about us and the reality of not having one chance to make those words true.”

The discussion continued in explaining the mechanisms with which our voice becomes excluded – like at the European meetings where there is only one place for ‘mental health representative’. When this place is taken by the mental health instead of the user/survivor organisation, our perspective remains excluded. Trude could not go into details of this discussion and replied that there is obviously still very much for all of us to struggle together and that we need each other in this struggle. She continued explaining the EU PROGRESS program, which is funding MHE and how this programme tries to involve different stakeholders. She ended with saying that we are very much needed to work on mental health issues and that events like this can have an important impact on improving peoples’ life.



After the welcoming speeches and discussion the seminar continued as a user/survivor only event. At the end of the first day we shortly presented ourselves an

our organisations and shared some of the expectations from the next day.

“I have five expectations of the seminar. The first one is to make contacts with all of you. I am very pleased to see you and to talk with you. The second expectation is to get to know strategies to increase users’ abilities to make their own decisions – in other words, how can users be empowered. The third is how users’ associations can be empowered. The fourth expectation is to get to know strategies to encourage cooperation among user associations and among users within the association. And the last is – which practices to avoid when users’ organisation wants to operate in the direction of empowerment of its users.”

“The things that I think are most important are rights. Rights are absolutely crucial because if we got mental health legislation it doesn’t give us rights – we can’t be empowered, we can’t be socially included. Alternatives are very important – what kind of medicine we want like acupuncture and nutrition instead of drugs. I think peer support and self-management are very important things and finally finding our own knowledge - being our own researchers, doing our own research. All the research that is done by psychiatrists is not right because it didn’t involve us. It didn’t ask the right questions or it didn’t ask them in the right way so all their knowledge is very incorrect. We need to start again and re-write all the textbooks ourselves and we can do it but we need to work very hard.”

“I am so impressed. I was never in a meeting with so many people from so many European countries and all spoke. This is really great.”

## Speeches

The next day started with three overviews, given by four presenters on different fields of the work of ENUSP.

**Mary Nettle**

### **ENUSP - Past, Present and Future A Personal Perspective by the Chair**

Eighteen years ago in 1991 ENUSP officially began followed 2 years later by the World Network (WNUSP<sup>2</sup>) which is holding a general assembly in Kampala, Uganda soon. We had our last general assembly in Vejle in Denmark in 2004 which was a joint meeting with WNUSP. We produced the Vejle Declaration which laid out ground rules for how we as users and survivors holding many different opinions from many different backgrounds can try to work together.<sup>3</sup>

In June 2007 we had the opportunity to work with the World Psychiatric Association to present at coercion in psychiatry conference. ENUSP, WNUSP and a USA led organisation called Mind Freedom International produced the Dresden Declaration which called for the end to all forced and coerced psychiatric procedures and for the developments of alternatives to psychiatry.<sup>4</sup>

We have continued to work closely with the World Network to ensure that the United Nations Convention on the rights of people with disabilities included people like us with psychosocial disabilities.

We have member organisations and individual supporters in about 39 European countries from Belarus to Ireland, from Portugal to Iceland.

We have again begun to work closely with Mental Health Europe to help them spend money provided by the European Union (EU) for all stakeholders. We have been told users and survivors are the most important group but we do not yet have the expertise to persuade them to give us the money directly.

We have links with other Europe wide networks. We are full members of the European Disability Forum<sup>5</sup> and one of our board members has been encouraged to stand for election at their general assembly in Athens soon. We are full members of the European Patients Forum and are collaborating with on an EU funded research project called *Value+* which is looking at user involvement in EU funded research projects.

We have smaller collaborations with the University of Central Lancashire, England. They have hosted several board meetings and we have contributed to their seminars. They are also hosting an International conference on Mental Health and Philosophy in 2010 in Manchester, England and we are considered partners in this conference. EU research money and other funding is a problem for us as it can require up to 40% contribution from our own funds and currently we do not have such funds. The first 10



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<sup>2</sup> <http://www.wnusp.net/>

<sup>3</sup> See [www.enusp.org](http://www.enusp.org) / Documents & Reports / [ENUSP Congress, Assembly & Seminar Reports](#)

<sup>4</sup> See <http://www.enusp.org/congresses/vejle/declaration.htm>

<sup>5</sup> <http://www.edf-feph.org/>

years of ENUSP life we were able to employ a coordinator and have some money to arrange meetings. The Dutch government provided the funds and then felt that it was another's turn. The Danish government provided money for the last general assembly in 2004 but despite us trying very hard we have not yet got the money for the General Assembly we need. We are now a virtual organisation relying on the internet to communicate mainly via our website [www.enusp.org](http://www.enusp.org)

Exciting things continue to happen for ENUSP and I have really enjoyed being its chair. Unfortunately all good things have to come to an end. I feel it is time for me to state that I cannot be chair of ENUSP for much longer. The active board members spend a lot of time working unpaid for ENUSP and we all have to earn a living as well. In this harsh economic climate this is going to be more difficult for me personally. I want us to consider what the best way forward is for ENUSP as I cannot see a face to face meeting for delegates from our members all over Europe very soon. I feel like a caretaker as by our statutes we should have had a general assembly in 2008. Should ENUSP organise an electronic voting meeting and how can we make that happen?

I know that new people will come forward to give energy to a fantastic organisation which can do so much to bring together users and survivors to share ideas and make some of these ideas real. I will always do what I can to make things happen for ENUSP as I believe in it as do many, many other users and survivors and importantly our supporters who rely on us to give evidence of what works from the people who really know - US.

In the middle of the night (5.00am) I decided to write down what was keeping me awake. I suddenly remembered that I had not included anything about working with health, I had been focused on social inclusion, recovery, wellbeing but we need to influence health.

ENUSP has done this. We were invited to Helsinki, Finland by WHO (World Health Organisation) for the Helsinki declaration signed by ministers of health for all Europe not just EU (European Union) countries. We made speeches and hosted question and Answer sessions with ministers.

We also worked with EU health department on the Green Paper on Mental Health, The Green Paper was rejected by the EU member states as they felt it told them what to do and the EU is unable to do this on health issues, only public health matters. The green paper was replaced with a voluntary Pact for Mental Health. ENUSP was not involved until being asked to comment at the last moment on the documents and they are starting to ask our opinion again. For health matters we have a reputation for moaning about money all the time, for the rest we need to collaborate with Mental Health Europe who has the money for stakeholders from the EU. In health we were not considered to be contributing any other opinions than lack of money. This is not fair and very untrue. It is only in health that we are treated this way because I believe they do not want to hear our message - nothing about us without us.

I want to be positive but as someone who is still on their recovery journey find it hard when working in health situations. For two days every month I work as an inspector in the English mental health system so I know what it is like from both sides. This is what we must do work from within and without the system, this is a very difficult balancing act. The 'Inspect' report from MDAC (Mental Disability Advocacy Centre<sup>6</sup>) Hungary explains a bit about this monitoring role.

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<sup>6</sup> <http://www.mdac.info/>

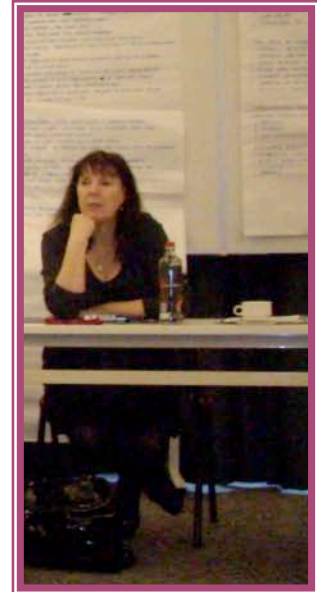
ENUSP can move from the margins to the mainstream and this can be done without losing our credibility as activists. We need to support each other - those who have recovered and those who are still at some point in their recovery journey. I am sometimes a user, an ex user and a survivor but survivor to me is the right word.

*Jan Wallcraft*

### **ENUSP in Relation to the World Psychiatric Association; to the European Mental Health Pact and to the UN Convention on Rights of People with Disabilities**

Jan worked on different tasks on behalf of ENUSP and reported about what she has done in the last year. Her presentation focused on three areas of her activities:

- Attendance the European NGO meeting on the European Pact for mental health in January in Brussels
- Work with World Psychiatric Association (WPA) – Psychiatry for the Person work stream and
- Work on the international human rights and how that fits in the work with WPA



The meeting of the NGOs in Europe working together in order to have a common policy on mental health was mostly about well being and social kinds of issues about recovery and prevention of mental illness. Mary Nettle gave us some background information on this meeting:

“This is one of the ways the pact can be implemented. The Pact itself is very specific which is why I think we weren’t invited to be a part of the discussion. Because the Green paper was very holistic, it covered every aspect of the person’s journey - recovery, well being, care and treatment. The member states rejected the Green paper on mental health because it told them what to do. And in health in particular they hate that. Health to all EU member states is their own country issue and therefore it was rejected. This was a bit of a shock to the EU people because they were building on the Helsinki Declaration, which should have been signed by all the European Ministers and therefore they felt that it is the time for the EU Green paper to be ready. They presented a Green paper, a lots of work where myself and Wilma Boevink from The Netherlands who is also on the Board of ENUSP and wasn’t able to be here today had lot of input. We haven’t heard anything because the member states have rejected it and than suddenly we were presented with a pact which had evidence paper work not from the user/survivor perspective but in specific areas, like old age, children, the very traditional health type issues. Nothing about service user involvement, empowerment, recovery, nothing. And this is why I am sure we were not been asked to be part of it. Because we would have not have liked it. [...] So this NGO meeting was trying to make us feel better.”

Besides Jan on behalf of ENUSP, John McCarthy from Mad Pride Ireland attended the European NGO meeting. He talked about how stigma can be created by forced

treatment under mental health legislation. Jan pointed out that national laws are now out of tune with Human Rights and UN view on forced treatment and that there is new attention on human rights and that we should be co-researchers.

Jan and John were bringing in user/survivors point of view on each of the subjects mentioned at this meeting. The points that Jan brought up for ENUSP included:

- Regarding early intervention:
  - that discussion on early intervention should involve more young people
  - that early intervention must not mean early drugging
  
- Regarding depression and suicide:
  - that national policies trying to prevent suicide sometimes just mean taking more liberties away from users/survivors
  - statutory suicide prevention can lead to abuses, fixing statistics (for example showing that suicide rate has gone down when it hasn't) or over drugging
  - Drugs prescribed are sometimes used for suicide
  - Suicide watch – interact with people not silent observation! Sometimes suicidal people are just watched without interaction and that is not good.
  - We need more narrative kind of research about what people need
  - Involve service users/survivors in suicide prevention more
  - Suicide prevention should be about helping people want to live and not just stop them from killing themselves
  - We need more listening to people's stories, help them get needs met and live satisfying lives
  
- Regarding employment and workplace:
  - Clinical trials do not always get right answers and should not be the only form of evidence
  - We don't necessarily want to go back to the work place which is very competitive and where we can't survive
  - Pressure to get any kind of job is not helpful, so policy should not just be making people get a job
  - Clubhouse model is not necessarily the answer to everything
  - Other forms of activity – e.g. voluntary work and creativity, can be as good or better to some people than getting a job so there should be other things available, like education not just work

In general Jan said on our behalf that we support work of PACT and appreciate being invited, that we want to help increase involvement of people with lived experience but that there are practical issues around being involved - like that most of us don't have paid jobs so there is a money implication if we are going to be involved. The good thing is that ENUSP represents independent service users and survivors, who are not beholden to pharmaceutical funding or family organisations. We have a long history of consulting and involving service users so we can help NGOs find ways of consulting, involving and supporting user organisations. The last message Jan gave to the European NGO meeting is that service user peer support and self-

management must be recognised, supported and valued as a service in itself and a contribution to well being and prevention of illness/relapse.

Jan has also been involved with one Work stream of the World Psychiatric Association (WPA) started by President Juan Mezzich – Psychiatry for the Person. One of the radical aims of this stream is to try to revise international diagnostic systems (ICD) and find more person centred definitions or classifications. Jan is the only survivor involved in the work of this stream; she reminds them that she is ‘the person’ that they are talking about. She is getting only her expenses paid but no payment for the work. Every four years the WPA has a big event and the last one was held in Prag in 2008. Because the ENUSP representative Gabor Gombos could not come, Jan spoke on behalf of ENUSP at this WPA's 4 yearly Congress on the topic of human rights and the UN's recent declarations and reports on rights of people with disabilities. Jan focused in particular on the report of UN Special Rapporteur on torture and inhuman, degrading treatments because he quotes the Convention and links it with torture. Here is the content of the rest of the slides from Jan's presentation:

### **UN Special Rapporteur report to UN: Key Points**

- Persons with disabilities are frequently subjected to neglect, severe forms of restraint and seclusion, as well as physical, mental and sexual violence.
- He is concerned that such practices, perpetrated in public institutions, as well as in the private sphere, remain invisible and are not recognized as torture or other cruel, inhuman or degrading treatment or punishment.
- Special Rapporteur examines the use of solitary confinement. The practice has a clearly documented negative impact on mental health. Solitary confinement should be used only in exceptional circumstances or when absolutely necessary for criminal investigation purposes. In all cases, solitary confinement should be used for the shortest period of time.
- Persons with disabilities are often segregated from society in institutions, including prisons, social care centres, orphanages and mental health institutions. They are deprived of their liberty for long periods of time including what may amount to a lifelong experience, either against their will or without their free and informed consent.
- Inside these institutions, persons with disabilities are frequently subjected to unspeakable indignities, neglect, severe forms of restraint and seclusion, as well as physical, mental and sexual violence. Lack of reasonable accommodation in detention facilities may increase the risk of exposure to neglect, violence, abuse, torture and ill-treatment.
- Persons with disabilities are exposed to medical experimentation and intrusive and irreversible medical treatments without their consent (e.g. sterilization, abortion and interventions aiming to correct or alleviate a disability, such as electroshock treatment and mind-altering drugs including neuroleptics).
- The Special Rapporteur is concerned that in many cases such practices, when perpetrated against persons with disabilities, remain invisible or are being justified, and are not recognized as torture or other cruel, inhuman or degrading treatment or punishment.
- The recent entry into force of the Convention on the Rights of Persons with Disabilities and its Optional Protocol provides a timely opportunity to review the anti-torture framework in relation to persons with disabilities.

## **UN Convention on Rights of People with Disabilities**

- According to article 15 of the that Convention, persons with disabilities have the right not to be subjected to torture or to cruel, inhuman, or degrading treatment or punishment and, in particular, to scientific or medical experimentation.
- Article 15, paragraph 2, contains the obligation for States parties to take all effective legislative, administrative, judicial or other measures to protect persons with disabilities from torture or ill-treatment on an equal basis with others
- Article 12 recognizes their equal right to enjoy legal capacity in all areas of life, such as deciding where to live and whether to accept medical treatment. In addition, article 25 recognizes that medical care of persons with disabilities must be based on their free and informed consent.
- The Special Rapporteur notes that the acceptance of involuntary treatment and involuntary confinement runs counter to the provisions of the Convention on the Rights of Persons with Disabilities.

## **Special Rapporteur on Reasonable Accommodation**

- The Special Rapporteur notes that under article 14, paragraph 2, states have the obligation to ensure that persons deprived of their liberty are entitled to “provision of reasonable accommodation”.
- The denial or lack of reasonable accommodations for persons with disabilities may create detention and living conditions that amount to ill-treatment and torture.

## **Special Rapporteur on Restraint and Confinement**

- It is important to note that “prolonged use of restraint can lead to muscle atrophy, life-threatening deformities and even organ failure”, and exacerbates psychological damage. The Special Rapporteur notes that there can be no therapeutic justification for the prolonged use of restraints, which may amount to torture or ill-treatment.
- The Special Rapporteur notes that prolonged solitary confinement and seclusion of persons may constitute torture or ill-treatment.

## **Special Rapporteur on Medical Abuse and Violations**

- It is in the medical context that persons with disabilities often experience serious abuse and violations of their right to physical and mental integrity, notably in relation to experimentation or treatments directed to correct and alleviate particular impairments.

## **Special Rapporteur on Psychosurgery**

- The practice of lobotomy and psychosurgery can serve as examples. The more intrusive and irreversible the treatment, the greater the obligation on States to ensure that health professionals provide care to persons with disabilities only on the basis of their free and informed consent.

## **Special Rapporteur on ECT**

- The Special Rapporteur notes that unmodified ECT may inflict severe pain and suffering and often leads to medical consequences, including bone, ligament and spinal fractures, cognitive deficits and possible loss of memory. It cannot be considered as an acceptable medical practice, and may constitute torture or ill-treatment.
- In its modified form, it is of vital importance that ECT be administered only with the free and informed consent of the person concerned, including on the basis of

information on the secondary effects and related risks such as heart complications, confusion, loss of memory and even death.

### **Special Rapporteur on Forced Drugging**

- The Special Rapporteur notes that forced and non-consensual administration of psychiatric drugs, and in particular of neuroleptics, for the treatment of a mental condition needs to be closely scrutinized. Depending on the circumstances of the case, the suffering inflicted and the effects upon the individual's health may constitute a form of torture or ill-treatment.

### **Special Rapporteur on Deprivation of Liberty**

- Many States, with or without a legal basis, allow for the detention of persons with mental disabilities in institutions without their free and informed consent, on the basis of the existence of a diagnosed mental disability often together with additional criteria such as being a "danger to oneself and others" or in "need of treatment". The Special Rapporteur recalls that article 14 of CRPD prohibits unlawful or arbitrary deprivation of liberty and the existence of a disability as a justification for deprivation of liberty
- In certain cases, arbitrary or unlawful deprivation of liberty based on the existence of a disability might also inflict severe pain or suffering on the individual, thus falling under the scope of the Convention against Torture. When assessing the pain inflicted by deprivation of liberty, the length of institutionalization, the conditions of detention and the treatment inflicted must be taken into account.
- Prior to the entrance into force of the Convention, the existence of a mental disability represented a lawful ground for deprivation of liberty and detention under international human rights law. The Convention radically departs from this approach by forbidding deprivation of liberty based on the existence of any disability, including mental or intellectual, as discriminatory. Article 14, paragraph 1 (b), of the Convention unambiguously states that "the existence of a disability shall in no case justify a deprivation of liberty".

### **Signatories to the UN Convention**

As of the date of the submission of this report, 46 States are parties to the Convention on the Rights of Persons with Disabilities.

The Convention on the Rights of Persons with Disabilities is the first human rights treaty that contemplates the possibility of regional integration organizations, in addition to States, becoming parties to the Convention, and article 44 regulates such attribution.

The European Community is a signatory to the Convention.

### **Special Rapporteur on Changes needed to laws**

- Legislation authorizing the institutionalization of persons with disabilities on the grounds of their disability without their free and informed consent must be abolished.
- This must include the repeal of provisions authorizing institutionalization of persons with disabilities for their care and treatment without their free and informed consent, as well as provisions authorizing the preventive detention of persons with disabilities on grounds such as the likelihood of them posing a danger to themselves or others, in all cases in which such grounds of care, treatment and public security are linked in legislation to an apparent or diagnosed mental illness.

Jan's speech was followed by a brief discussion about the UN Convention of people with disabilities and shared view that it gives us equal rights on paper but that the way to make them reality will be a long one. There was an acknowledgment of the important contribution of survivors like Gabor Gombos and Tina Minkowitz to the creation of the Convention.

*Jasna Russo and Erik Olsen*

### **ENUSP and the European Research: Some Principles, Current Projects and Perspectives**

Jasna gave a summary of the up to date involvement of ENUSP in European research:



“There is a growing interest in collaboration with users and survivors of psychiatry in research and recognition that our direct knowledge of services, of mental health crises and its treatment, our experiences of discrimination and of recovery can become very useful for the production of new knowledge. User involvement in research is not only the trend in UK and Scandinavian countries but also in the European Union's public health and research programmes. Many calls for project proposals address the question of how will those directly affected by the topic be consulted or how will they benefit from the project outcomes. Being the only international European NGO which unites users and survivors of psychiatry is what turns ENUSP into an attractive and powerful partner in competition for the European research funding in number of fields like - general health, mental health, human rights, employment and anti-discrimination policies or psychiatry.

Through the lance of my personal experience of being a Board member in the past I can say that fifteen years ago (when I was on the Board from 1994 until 1997) I can't remember us ever being consulted or invited to join a research project. This situation has definitely changed and in the last years the Board of ENUSP has dealt with different collaboration proposals in the context of European research.

Although until now we never created any official policy of our involvement in research as an organisation, we have considered each of these proposals as they came very carefully and I have observed two main issues that played central role in our decisions. Those were:

1. the proposed research topic and the methodology and
2. the suggested way in which ENUSP should become involved

Most of our decisions have been negative because it rarely happened that both these criteria were met to our satisfaction. It happened that even when we have found the topic relevant for service users/survivors we didn't feel that our involvement was taken seriously – because of for example being invited to join at the very last moment, sometimes just two weeks before the deadline for the application, after the whole project design was already developed. We were expected to discuss long application documents at the short notice when they were already ready for submission and basically to accept them as they were because there was no more room for any changes or suggestions that we would eventually make. From these

kinds of invitations, it was obvious that our name is what was needed on the application but not our substantial input, so refusing such partnerships wasn't really a hard decision to make. On the other hand it also has happened that we as an organisation have been taken very seriously and invited at the very early stage to discuss the project and our role in it, but that we still decided not to collaborate because of our strong disagreement with the study design - for example when the proposed methodology was only quantitative and included large-scale collections of genetic material.

On the top of these two fundamental issues – which are again on one side - the research topic and the methodology and on the other the understanding of our involvement and our role - even when both these important criteria are fully met, there is still the third problem. Let's say that that one is of the technical nature because it is less fundamental than the other two but still it can hinder our involvement - the European Union always gives 60% and in some cases up to 80% of the project costs which means that the rest of funding should be provided by the partners involved. For the organisation like ENUSP to rise even the 20% of total costs is a big problem and this of course weakens our partner-position.

As you might know European research and public health projects always take place in at least three different countries but this number goes up to 20 sometimes. There is always one institution or organisation which acts as the Coordinator and there are two kinds of project partners – associated and collaborative ones. Associated partners have stronger connection to the project – they perform work, have a share in responsibility and share of the grant.

Until now ENUSP has become the associated partner only in one European Project in the field of public health. The name of this Project is VALUE + and it is co-ordinated by the European Patients Forum where ENUSP is one of the founding members<sup>7</sup>.

VALUE + started in February last year and will last for 2 years (until 2010). This project will explore the involvement of patients' organisations in the projects funded by the EU in last ten years in order to identify both good practices and obstacles to patient involvement (in general health projects, not only in the mental health ones). The main presumption, which is also expressed in the name VALUE + is that meaningful patients' involvement leads to better project outcomes and makes these more able to effectively contribute towards improving the quality of health care. Elisabeth Winder who wasn't able to come here works on VALUE+ on behalf of ENUSP and we hope to benefit from this partnership through being able to work on the issue of mental health service users' involvement within the larger context of patients' involvement in general.

ENUSP will also have a small role in the ITHACA project<sup>8</sup>. The full name of this project is Institutional Treatment, Human Rights and Care Assessment. It is taking place in sixteen European countries and focuses on assessing human rights and general health care in different kinds of psychiatric residential settings. A number of individual user/survivor researchers was or is still working on this project (including Anna from Hungary and myself) and ENUSP will have the consultancy role at the very end when it comes to project recommendations.

Before I pass on to Erik – I would like to say two more things that occurred to me during the work on this short summary. One is the question for the discussion: Do

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<sup>7</sup> <http://www.eu-patient.eu/>

<sup>8</sup> <http://www.ithaca-study.eu/>

you think that it would be a good idea to create a paper outlining some of the ENUSP's principles of involvement in research and publish it on the website? Another one is – as you can see until now we didn't take the initiative as an organisation to do the research. We only have responded to different partnership proposals. There were many good reasons for this – like simply not having resources for this kind of work. But it might be time to change and start looking for partners that would suit us and that would be able to stand behind us. What I have forgotten to mention is ENUSP involvement in an International Network for Partnership in Research initiated by the Centre for Excellence in Interdisciplinary Mental Health at the University of Birmingham<sup>9</sup>. This small Network might be a place for us to start looking for partners that we would like to work with.”

Erik presented his idea of the research about the capacity of users/survivors organisations across Europe. He started with telling us about his involvement with European Disability Forum (EDF) and the differences he sees between the discussion on human rights in mental health and the legislations regarding disabled people and their rights.

“If the situation of our rights is to be changed, user organisations must become stronger so the issue of capacity building becomes even more important.”

Erik also attended Summer School at the University of Leeds as the part of the EDF project ERADE where he worked on disability research. Here are his slides with some quotations from his presentation.



**Research – Why?**

- ▣ Because we normally are “parasited”
- ▣ We, ourselves have to ask the questions, make the research design and analyze the results
- ▣ The research that is done today reflects the needs of professionals, medical industry and so on... and will benefit them

“Disabled persons should be those deciding on what kind of research is needed because we know the problems. When someone else conducts the research, it is always about their interest. Research is just knowledge and knowledge is language of power, which is to control your area. I am sorry to say that, but it is like that. And if we can do the research, than we can show what discrimination is

in reality. [...]

There is lots of money in research and many times when psychiatrists or anybody else tries to get research funded, they need to have user

**What kind of capacity do we have compared with mental health organizations?**

- ▣ Are we discriminated against?
- ▣ Do we get the same amount of funding as mixed or professional organizations?
- ▣ Why is it that in some countries the national disability organizations only allow not-disabled to represent us?

<sup>9</sup> [www.ceimh.bham.ac.uk](http://www.ceimh.bham.ac.uk)

voice. They take us in, use us and spit us out. We don't have any influence, so in my opinion the only way is to initiate our own research."

"We as users' organisations are disabled ourselves and even in my country Denmark we are not able to be members of national disability forum because mental health organisations sit there. In some countries mixed organisations sit there and avoid any user involvement. [...] Lot of people speak on our behalf."

"I would like to ask every user organisation on Europe how much money do they get and compare this to mental health organisations consisting of professionals and others."

### First priority: Documentation of the Situation

Mental Health Organization	Yearly Budget in \$
Mencap	329 000 000 \$
European Disability Forum	1 400 000 \$
Mental Disability Advocacy Center	673 000 \$
EUFAMI	424 000 \$
ENUSP	8 000 \$

Source HSCNEWS International Aug-Sept- 2008

### User-led research

Real and sustainable change first comes when the target group is strong enough to play a significant role in all areas.

### Pilot Questionnaire

#### Organizational questions

- What is the name of your organization?
- Which type of organization? (Checkboxes)
- What year was the organization started?
- Is it a National Organization?
- Do you have local /regional branches?
- Do you have membership?
- How many members do you have?
- Who can be members? (Checkboxes)
- What type of democracy do you have?
- Do you have a board
- If yes, have many and how many are Users?
- At the general Assembly – is it only users that can vote?

#### Economy

- What is the total budget per year?
- Where does the money come from?
- How much is the expenditure budget?
- How much of the total budget comes from project funding?

"I will just show what kind of questions I want to ask. This is a pilot questionnaire, it is not perfect."

- Are you full members of the National Umbrella organisation for Disabled?
- If not – why?
- How many works as volunteers?
- How many are employed with wages?
- Size of the organisations localities?

#### Political questions

- What do you think are the 3 most important political issues you work with?

“This kind of research could be a joint project between European Disability Forum, University of Leeds and ENUSP. Because we are not researchers as such and we need all the practical knowledge but we have to be in control of the research design and questions.”

### Last Words

- ▣ “Own spaces” - Professionals may not think about it but they have free space where they are not together with us – conferences, qualitative development, education and so on – we would like the same.
- ▣ Absolute transparency – who gets money from pharmaceutical industry – on their website – how much.... As a minimum.
- ▣ We do not want to build up the medical industry's capacity to keep users in patients' roles....

Erik concluded with pointing out again how important capacity building for users' organisations is: “If we just run around and say - I am proud to be on that or that committee than user organisations will fall apart. I think we need to have some visions and my vision is that we have a user-run University for the health of the soul or something like that.”

## Discussion

The presentations were followed by one hour discussion which started with some more questions around Jan's involvement with WPA and critics of psychiatric diagnoses.

“Professionals do not take time just to get to know the person and than to initiate dynamic search together with the person into what is it all about. [...] They just jump into diagnosis, than they stick to it and often they are wrong.”

There was a short exchange of alternatives to diagnosis like the open dialogue method or the idea that we should train professionals and ourselves how to “unlearn the diagnosis because a person disappears behind it”.

One participant observed that that all presentations had one thing in common, which was “that our language is not in *their* language” and the question remains “how do we put *our* words into *their* biological discussion?”

The biggest part of the discussion went on about research and whether doing research is a way forward for us.

“In UK research is where we are good people. We are mad people but in research we are OK. It is the government who says we have to be involved.”



Two books that are coming out in April in UK have been shortly presented by their editors who were at the seminar. Those are “This is Survivor Research”<sup>10</sup> and “Handbook of Service User Involvement in Mental Health Research”<sup>11</sup>.

The question about how to start in countries where there is neither survivor research nor user involvement resulted in a

vivid exchange of experiences and ideas.

Some thought that it is good to start research without funding, do small surveys and look for the contact with the Universities. The others have made the experience that University people are not really interested to cooperate with us unless they have to. On some places user research started because there were users working at the University already and it was clear that they would never have got the funding as mental health service users only. One idea was that our member organisations could get involved with the European research projects which often require a role for users/survivors. This could be one way to initiate user/survivor involvement in countries where this is not the case. There was also a concrete share of experiences and examples where to ask for research funding in different countries. Our web site could be used more for exchange of information and for presenting existing user/survivor –led projects.

But at some point in this discussion a fundamental issue was raised about whether all we do will now turn into research and if getting involved in research is the only way left to achieve – ‘nothing about us without us’. It was strongly suggested that research might be a field of interest for a group of us but not for everybody. At this point we continued talking more precisely about what we exactly mean with research and how it can become connected to the other topics on our agenda, for example the implementation process of the new UN Convention for rights of people with disabilities. Coercive treatment has been an issue for ENUSP for a long time. Some of us feel that we should collect the evidence about the disproportion between the reality of our human rights and the content of the Convention, that collecting such evidence is about doing research and that research is one possible and legitimate way of taking our work on the issue of coercion forward. The others thought that we should discuss much more in detail the terminology that we use in regard of user/survivor-led research, peer support etc.

“I am trying to put the term user out of the name of our organisation. I don’t know what we use? It is their term - that we are using their services.”

<sup>10</sup> <http://www.pccs-books.co.uk/product.php?xProd=467>

<sup>11</sup> <http://eu.wiley.com/WileyCDA/WileyTitle/productCd-0470997958.html>

We were reminded of the ENUSP Seminar in Kolding, Denmark (1994) where we discussed extensively our own definition of ourselves and in particular whether we are disabled or not.<sup>12</sup>

“We had very cross words with each other and we can spend all our energy and time describing ourselves. We also have a very long title for our organisation trying to include everybody.”

Everybody agreed that we should not continue such discussion but still should be become more precise when discussing research, because there are “different philosophies behind our thinking”. We continued focusing on the question what could ENUSP concretely do and the ideas mentioned included the task of disseminating information and communicating more with each other. One suggestion was starting a newsletter. At the end it was pointed out that in order to be able to perform any kind of work, we have to become strong as an organisation and that needs to be our first priority.

## Working Groups



In order to make the most of the seminar and provide everybody with enough space to make their contributions, we split into the three small groups. Each of the groups had a facilitator and one and the half hour time to work on the same three questions:

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

Here are the outcomes from the working groups presented in the plenary followed by the discussion.

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<sup>12</sup> See the report ‘Our Own Understanding of Ourselves’, [www.enusp.org](http://www.enusp.org)

## Group 1



This group started will collecting all the ideas about what should be ENUSP priorities for next years:

- promote more information campaigns (more interaction) to strengthen the partnership between the users organizations
  - find out the information (research and legislation) about current situations in member countries and to do something about the problems (stigmatisation/discrimination) working with different media
- 
- raise awareness
  - encourage users/survivors to rise up their voice
  - Art and culture: collaboration/participation.
  - Collaboration with wider scale of organization in order to get better known in member countries including those outside the EU
  - find a stable financing for ENUSP
  - UN conventions implementations.
  - user perspective to family issues (e.g. parenthood); social inclusion.
  - Manifestations
  - dignity to organization by creating democratic, transparent and interactive structure (electronic voting,...)

Following this initial discussion the group divided into three small groups and the three main priorities for ENUSP derived:

1. to build firm foundations for ENUSP which also includes having firm foundations in user groups locally and nationally.
2. social inclusion and
3. research and legislation

The next question discussed was how this is to be done.

We need to raise awareness about the work that ENUSP does within our member organisations and also with politicians and the media. We should minimise practical difficulties like different languages, different points of where people are in their recovery journey etc. Minimising does not mean simply not talking about these difficulties; it means acknowledging them but not letting them dominate our thinking as an organisation.

We want to be an independent, self-sufficient organisation and also have partners, but in all our partnerships we need to make clear that we are independent and self-sufficient.

And finally – what we will contribute?

Paying membership fees might be one way. If people have trouble doing this, they can do voluntary work instead.

On the 4<sup>th</sup> of June this year are the EU parliament elections. We could encourage people who are standing for elections to know about mental health, to know about ENUSP. This is one time that they are very keen to know because they want to be voted. All of us have a vote as citizens and we should use it.

One person can help doing research proposals for us – trying to find partners and do joint proposals.

It would be nice to have this meeting again in six months maybe in order to keep continuity with this group and find out what things have happened. Smaller scale user meetings inside the region were another idea.

## Group 2



First priority seems to be to strengthen the board so that anything else can happen at all. That would lead to improving the communication with user groups and strengthening the user movement.

Strengthening the board could be achieved by:

- sharing the workload,
  - supporting the web work,
  - filling vacancies on the board,
  - ensuring that board members are active,
  - encouraging the organisations to pay their membership fees by explaining them what they are used for and
- making reciprocal links via website between ENUSP and user organisations.

The completion of the board with representatives of underrepresented regions was discussed and participants were invited to stand for adoption.

ENUSP activities could be improved through building capacity around training, research and self management. The individual members could offer training to other ENUSP members on particular skills. There is already a capacity among us and we could build on that. We are currently not sharing our expertise and knowledge and we need to improve the communication.

One idea was to use the website for announcements of individuals offering training – so that they can travel to other countries and help with certain kinds of things like how to build the organisation, how to use the recovery tool etc. The competences of these people could be approved by the board.

If there should be funding available board members could be invited to local or regional meetings to present about ENUSP and spread the information on our work. Another idea was to make a kind of human rights watch so that every time there is a problem in one country we become pro-active rather than only responding. But that would need links to human rights organisations.

There was an extensive discussion in this group about the web page because it seems to be very important for communication. Web site could be used to explain how users/survivors can work on the European level, it can become a platform for more information and reports but that would need a small crew of people to look after the website. All members and friends of ENUSP could put a link to their website in order to make ENUSP visible.

One topic was the next general assembly which is planned to take place next year in Greece and the question about what are the minimal expectations of such meeting and what has to be provided in regard of accommodation and travel.

### Group 3



The main priority is to strengthen ENUSP because it is a valuable organisation with lots of potential. There was long discussion in this group whether ENUSP should try to ally with Mental Health Europe rather than stay on its own because of the danger of becoming completely isolated. What ENUSP definitely needs is funding in order to get the office, the secretary and the possibility

to communicate and develop. It was recognised that funding usually comes with projects and that doing for example research does not mean that you have given up your agenda or your values. There must not be a contradiction between the goals of the organisation and applying for projects. One more priority mentioned was strengthening communication either through events or exchanging the information via website.

One way of achieving all this is through dialogue and partnership with Mental Health Europe. This should not contradict our independent existence because we could ask just for the logistical help as it was for this seminar. There was the idea of identifying MHE members on the local level, getting in contact with them and with politicians and spreading the message of ENUSP e.g. who do we represent and what we are working on. There was a focus on research as one possible way and a brain storming on what kind of research we should initiate. We could start investigating mental health legislations and the ways in which they oppose what the UN convention on rights of people with disabilities promotes. This kind of research could also strengthen individual users, local organisations and ENUSP. Other specific topics could be the investigation of forced treatment or user/survivor knowledge of recovery. The possible concrete contributions of the participants of this group included: providing legal advice on violations of human rights locally; being a liaison person for ENUSP; writing research proposals and applications; contacting member organisations and clarifying things regarding membership fee, plans for general assembly etc.; intensifying local contact with MHE and EU Parliament in Brussels; just staying an ENUSP member and working on own capacity-building; creating an information booklet with glossary on questions like – what is ENUSP?; what is survivor movement?; what is forced treatment etc.; communicating history and statute of ENUSP to members.

## Closing Discussion



There were lot of similarities in the outcomes of the working groups – like building foundations, strengthening the board and ENUSP as the organisation.

“There is also a point that we can’t do anything without any money. We can try and pretend that we are very good and very wealthy organisation but we need to be true at least with ourselves.”

“We need resources in order to be able to consult more with our members instead of just saying – this is what we have done.”

“I think of the old phrase from the United States – ‘it is not what the United States can do for you, it’s what you can do for the United States’. And I would say - it is not what board can do for you, it’s what you can do for the board. [...] My idea is that each of you goes back to your organisations and say who will take the responsibility to be the contact person to the board.”

The priorities that we agreed upon were:

- strengthening the board and communication with the member groups
- getting in the membership fees and
- producing one page text for the website with explanation about what the membership fees are used for.

Some people offered support to the board and it was suggested that they contact the board saying what kind of work exactly can they offer and would than be contacted back.

Further suggestions included:

- a short, comprehensive up-to-date information on ENUSP which could than be translated into other languages
- volunteers could translate more of the ENUSP website contents into other languages;

- the Board could write a paper on their activities;
- there could be a newsletter of ENUSP again,
- to initiate small networks of people from different countries who are interested in specific topics like research or recovery.



In the last ten minutes the discussion about our future relationship to MHE after this seminar has started. One difficulty addressed was that MHE can fund only member states of the EU and that ENUSP members are more than EU. Other difficulties related to our past involvement with MHE and

also some of their organisational rules. There were opposing opinions expressed on this and we concluded to leave this topic for the board meeting.

At the very end the issue of membership fees was raised again and also dissatisfaction expressed.

“The amount of membership fee to pay depends on how many members the organisation has. We are rather big and want to know what is there for us in the membership fee. [...] If the minutes would be distributed, than we would know hat the board is doing, otherwise it is a problem for us.”

“We had a long conversation about the value for money regarding the membership fee in our group. We know that this is an issue and we are not trying to get away from this issue. That is why we are having a meeting like this and inviting people because we know - we are not doing very well. We have acknowledged that to anybody who wishes to hear. We are trying today to be a way forward, to be constructive There is no point saying – what do we get for the membership fee. We know we need to give you something for the membership fee which is better than what you have now. The board has internet meetings because it’s all that we can afford and none of us has the time to write the notes and to type them up because we don’t have a paid worker or anything like that. We struggle so hard to do things it is getting too much. We need to work together to try and make things better.”

There was also an explanation that membership fees were introduced at the last general meeting of ENUSP in Vejle (Denmark) and that no delegates were against that. But some did not vote on this though.

“The fact that we are not funded is the discrimination of users within the European Union and if you don’t see that, you don’t see the situation.”

“After we paid the membership fee I must say that I felt more connected to ENUSP than before. And each amount is the amount. So – the concept of solidarity!”

The Seminar was closed by Mary Nettle:

“We have had, I think, a very worthwhile day and the half. It has been an effort to manage to get this together but it is so worthwhile. You have all come, you have thought about coming, you have had the ideas and it really helps those of us who are struggling for the ENUSP to continue. So I would like to say - thank you very much to you all. That was fantastic.”





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