

To:
European Commission
Directorate-general for Health and Consumer Protection
Unit C/2 "Health Information"
Jürgen Scheftlein
L-2920 Luxembourg

Concerning: Green paper on mental health

July 19, 2005

Dear Mr. Scheftlein,

Thank you for inviting ENUSP to respond to the EU Green Paper on Mental Health. Unfortunately we are not sure whether we can send an ENUSP delegate to the informal consultation meeting with civil society organisations on the Green Paper on Mental Health. As I already mailed to you the meeting is planned during my holidays. Moreover it is not easy to find someone else from ENUSP to attend, since I am one of the very few who has an employer who covers my travelling expenses in advance. Most of us user representatives have little or no money as private persons and cannot pay in advance for trip and stay.

Nevertheless, we thought it good to respond to the Green Paper by mail.

First of all, we are happy to see that the EU is aware of the importance of a policy on mental health. We are also positive about the fact that mental health is viewed from a public health point of view. Within the user movement there is a sort of common sense (experiential knowledge) that a solely medical approach to human distress is too narrow and could even be harmful. A medical view on human distress excludes poverty, violation of human rights, (child) abuse, stigma and discrimination as factors for which there is evidence that they are very strong causal factors for mental illness.

We would like to emphasize that a public health approach should not be limited to the 'general public', but should of course include people with a psychiatric diagnosis, whether living outside or inside psychiatric institutions. We feel that the European Commission is obliged to use a broad definition of 'public health', thus extending its political influence to European civilians inside mental institutions. They perhaps are most of all in need of better social and societal circumstances to improve their (mental) health.

We miss, in the Green Paper, an explicit and strong statement about users of psychiatric services, or people with psychiatric disabilities if you like, as actors in developing and executing mental health policy. In the Paper it is mentioned a few times that patient and civil society organisations should be involved in policy making, but we think this is 'nice words, no deeds' language. Especially since the Green Paper says that, when referring to the role of mental health care professionals in prevention, 'health professionals themselves can also benefit from observing patients in their daily life environment' (par. 5.3, b, p. 15). We strongly object to this use of stigmatizing language which obviously makes us objects, not partners and actors. When it comes to the role of mental health care professionals in prevention and their commitment to the importance of prevention: ask us about our daily lives

with mental illness, ask us about our daily life environment, use our knowledge in this area and ask us to set up training facilities for professionals given by experiential experts. Don't suggest observation of psychiatric objects, but emphasize communication with partners who have the experience of living with psychiatric disabilities.

When it comes to communication with experiential experts, we have a few very concrete project proposals for the EU to adopt (and facilitate) in which building knowledge, disseminating knowledge, anti-stigma strategies and living with a psychiatric disability (mental health and public health) come together.

- i) ENUSP has a website which serves about 36 European countries and their user organizations. ENUSP is a strong E-network. We would like to offer to EU the dissemination of information important to users and their organisations through our network and with the help of our powerful and impressive user movement leaders. We would like to negotiate the costs of this offer with you.
- ii) The ENUSP board has decided to let Trimbos-institute in the Netherlands facilitate the secretariat of ENUSP. Trimbos-institute will try to raise some basic funding for the European desk. But next to that, Trimbos-institute is Lead Collaborating Centre in the field of Information and Dissemination when the implementation plan of WHO Europe is concerned. ENUSP/Trimbos-institute could become a very strong alliance when it comes to gathering experience based knowledge and disseminating this knowledge into the European user movement and into MHC practice through training courses by experiential experts. We would like to explore with EU how to involve EU in this alliance.
- iii) It is our experience that most of the time policy language concerning user involvement remains abstract, because nobody seems to know how to work systematically towards user involvement. Therefore we would like to propose a European project, facilitated by EU and perhaps the Dutch government¹, and supported by WHO-Europe. In this project in four different European regions best practices of user involvement are monitored, described and analyzed on success factors and risk factors. Knowledge is developed and disseminated about effective models of user involvement and empowerment and about pitfalls and success factors. You can find the proposal attached.
- iv) And finally in the autumn of 2005, ENUSP and Trimbos-institute jointly will publish a book on how to work towards recovery for persons with psychiatric disabilities and how to work towards fruitful recovery projects for professionals within mental health care. There will be printed only a small number of books in the English language. It is more challenging to explore other, more 'modern' ways of knowledge dissemination, for instance through Internet or CD-ROM, using a translation programme, which makes the knowledge available in any required language. ENUSP/Trimbos-institute would very much like to explore with EU the possibilities in this area. Of course, the book itself would have to be available in English for EU to learn about its contents. This will be the case in October.

At the end of the Green Paper draft a few questions are formulated. Here are the ENUSP answers:

¹ In October 2005 The Netherlands organisation for Health Research and Development decides whether they will be (facilitating) partner in a European project on user involvement.

1) What are the main challenges the EU faces in the field of mental health?

Challenges are to do with the domination of the medical model approach to mental distress which leads to treatment orientated legislation and therefore further stigmatization and discrimination. This green paper with its public health approach demonstrates the need for a holistic approach to people with mental health problems

2) How can the EU help member states in improving the mental health of the population?

The EU should take the lead by demonstrating that the medical model approach as outlined above can disable some of its citizens and prevent them from being supported to establish a mentally healthy life.

3) How can the EU promote the creation of partnerships across sectors for mental health?

There is often confusion by the public between mental illhealth, intellectual disabilities and other physical impairments. It needs to be clear that mental illhealth can affect any citizen at any stage of life. Stakeholders should include the European Disability Forum, which includes family organizations in its membership and ENUSP, the European Network of Users (ex) Users and Survivors of Psychiatry on an EU wide level. The national disability councils should be encouraged to support user/survivor organisations to flourish and develop by ensuring adequate funding is in place in each member state. It is also important that employers and education providers are included as part of the partnership at state level which then meet at least annually at an EU level with EU wide organisations. All stakeholders in these partnerships should include users/survivors in their delegations to any national or European meeting as this should be common practice at local level as well.

4) How can the EU contribute through its own activities and policies to promoting mental health in the population?

Ensure that marginalized groups are enabled to be stakeholders in the process by ensuring funding mechanisms cease to exclude them from participation.

In conclusion you could say that the Green Paper at least on our side triggers new ideas and new proposals on user involvement, on building experience based knowledge and on disseminating this special kind of knowledge at European level. We would therefore be delighted to take our place on the Platform on Mental Health and look forward to ensuring that our members in all EU states and beyond can benefit from the positive approach to mental health demonstrated in this draft Green Paper.

We very much hope our proposals have triggered your interest and that you are prepared to explore them with us. We hope to hear from you.

Yours sincerely,

On behalf of ENUSP-board,

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