

Mental health: facing the challenges, building solutions

About us, but still without us

Report on the WHO Ministerial Conference on Mental Health. Helsinki, Finland, 12-15 January 2005. By Wilma Boevink (wboevink@trimbos.nl)

Among some 500 people ten to fifteen users/survivors of psychiatry were present at the Ministerial meeting on Mental Health in Europe from 11-15th June in Helsinki Finland. This meeting was the result of almost ten years of preparation by WHO, the European Union, the Council of Europe and a number of member states of WHO European Region. Its aim was to get the consent of the 52 countries in the WHO European region on European mental health policy described in the Mental Health Declaration for Europe and in the Mental Health Action plan for Europe.

- Two days before Christmas the chair of ENUSP asked whether I wanted to be a delegate in Finland in January. The organisers invited Mary Nettle and Gabor Gombos as speakers and a few places were created for ENUSP delegates. Places yes, but no money came with it for trip and stay. Just a few weeks to go, no money, no information. Luckily my organisation and it's president are more and more becoming aware of the importance of user involvement and I got facilitated and I went. -

Fifty two countries sent 32 ministers of health and an unknown number of secretaries of state and other country delegates. Also several ngo's (non governmental organisations) like ENUSP, Amnesty International or the Association of European Psychiatrists, observers, temporary advisors and the press were present. All gathered in a large conference room in Helsinki for a 4 day programme. Scheduled were plenary sessions, plenary discussion, parallel sessions and, of course, the adoption of the declaration and action plan. All the people present opened with a minute of silence for the Tsunami victims.

- When I entered the large conference room I was very impressed to see the names of all those countries on the plates: Belarus, San Marino, Georgia, Tsaa, UK, Sweden, Italy of course. 52 Countries: I didn't even know the European region did have this many countries. Because I felt so overwhelmed I started the meeting very tolerant, if not to say very naive. I thought: it is huge political effort to have all these countries, which such differences in social economic circumstances, accept one mental health declaration, of course WHO can't at this stage involve users or urge these countries (more than they did) to do so. There are more important issues at stake. So I thought. -

Challenges in the European Mental health policy are (in words): user participation, human rights, evidence base and best practices, finding/reallocating resources. Mental health is public health which means an emphasis on nonmedical solutions to human distress and preventing social exclusion. The primary aim is to improve the wellbeing of people and their functioning by focussing on strengths and resources, raising the resilience and improve protective external factors.

- I was impressd by all this attention for social and societal factors in causing mental ill health and in healing distressed persons. A lot of interesting information as well. Information at European level was a relief for me after all this miniature stuff in my own country -

Europe has several problems. We have more deaths by suicide than by traffic accidents. Problems of mental health are underestimated. At European level there are several ethical dilemmas like stigma and prejudice. One of the many slogans I heard during these days was: We all are equal, we all are different. Mental disorders are linked with poverty (unemployment, trauma/violence): there is a vicious circle. 65% of the beds are in large institutions. Europe doesn't do good at this point (world record). The mental health budget is just a fraction of the total health budget: 1,5 % in poor countries of the world. There is a treatment gap: in developed countries 35,5 to 50,3% of the needs are not met. In developing countries 76 to 85% of people with mental health care problems didn't receive treatment. There are several negative trends:

- human rights are not improving
- predominance of acute and medical care disregarding longterm/psychosocial needs
- increasing influence of pharmaceutical industry

- But I got more and more frustrated during these days. Almost all speakers emphasized the importance of engaging and empowering users. Words, not deeds. WHO asked, somewhere during the preparations, the countries to invite ngo's, particularly users, to be part of the country delegations, so I was told. There were, as far as I could tell, two countries who did: Norway and Tsjechia. But also during the conference it was obvious where we were in hierarchy: at the bottom. Speakers in the end of a plenary session (with high performance of Gabor and Mary), seated at the of the line etc. -

On the European agenda can be found issues like:

- enhancing the status of mental health care in public health
- enhance and allocate resources
- human rights

The burden of mental disorders is increasing and is second to cardiovascular disease. Europe has the highest rates of suicide, 150.000 per year. It is the second cause of death among young adults. Talking about costs doesn't mean talking about more money, but about reallocation resources. European principles in building mental health care are:

- * driven by needs/experiences of users
- * based on evidence
- * sensitive to local culture and resources

And WHO considers it her responsibility to stimulate best practices, to advocate these best practices and to monitor them.

And a final remark from a high WHO official, Mr Danzo: when projects are well designed, you always can find money.

Since I got frustrated at hearing all these words, but nothing concrete on user involvement, I also got nervous. Because I knew I had to ask for the microphone to get rid of this frustration. And asking for the microphone is something BIG at such a conference. But I succeeded in giving a statement on behalf of ENUSP:

“I am a delegate of the European Network of Users and Survivors of Psychiatry. I am one of the very few users present at this meeting. I am also a researcher in the area of user involvement and empowerment. From this combination of roles I would like to make a recommendation to the ministers of Europe and to WHO.

The past few days almost all of the speakers pointed out the importance of user involvement, -participation and empowerment. I sense risk that these words will remain abstract concepts or ideological principals. That most of us will not be able to get a clear and realistic picture of how to work systematically towards user involvement or how to facilitate user empowerment. So I would like to propose to the Ministers of Europe and to WHO:

- i) that we support the development of best practices of user involvement in four to five different European regions;
- ii) that we monitor these best practices for the coming years;
- iii) and that we develop and disseminate knowledge about effective models of user involvement and learn about pitfalls and success factors.

The European user network is offering to help you find and develop these practices. We have the experience, we are developing knowledge and we are prepared to disseminate both to help the Mental Health action plan work! Thank you.”

- I did it! The floor was mine for a few seconds! -

The Mental Health Action Plan shows the next priorities for the next decade:

- i) foster awareness of the importance of mental well-being;
- ii) collectively tackle stigma, discrimination and inequality, and empower and support people with mental health problems and their families to be actively engaged in this process;
- iii) design and implement comprehensive, integrated and efficient mental health systems that cover promotion, prevention, treatment and rehabilitation, care and recovery;
- iv) address the need for a competent workforce, effective in all these areas;
- v) recognize the experience and knowledge of service users and carers as an important basis for planning and developing services.

You can find more about the Mental Health Declaration for Europe and about the action plan on

http://www.euro.who.int/mentalhealth/conference/20030718_1

To execute the Declaration WHO has, among other, appointed four themes and for each theme a Leading Collaboration Center. The themes and appointed organisations are:

- Stigma (Scotland government)
- Promotion and Prevention (STAKES, Finland)
- Services and workforce (Italy)
- Information, research, dissemination (Trimbos-institute, The Netherlands)

I would like to end with a small anecdote. At one point during the conference in a plenary session Gabor mentioned to feel somewhat like an animal in a zoo, since there were so few users. The chair answered: like in a zoo you can't tell who are the visitors and who are the animals. In my notes I found back the annotation: this zoo will go bankrupt soon if you count the number of animals/officials to be fed and if we, the very few users present, should be the paying visitors to keep the business going.

No health without mental health. No mental health without us. Involve us, let us in. Nothing about us without us!

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