

Lecture to the meeting " Mental Health: 'Stop Exclusion – Dare to Care'", WHO Headquarters, Geneva, Switzerland. April 6, 2001. [Press-release](#). [Deutsche Übersetzung](#)

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Stop Exclusion, Dare to Share!

Commentary of a "Mental Health Advocate" at the World Health Day 2001

Mental Health: "Stop Exclusion – Dare to care", WHO Headquarters, Geneva, Switzerland. April 6, 2001

In 1977, in a state of cumulated problems in my life (partnership, work, final examination in my studies), I went crazy. Afterwards, when there was the time to discuss this situation with my friends, they all said that they might have gone crazy, too, if they had been in the same situation.

Psychiatric workers who treated me in the madhouse were not my friends. But they were medical professionals, and so they gave me a lot of diagnoses, wrapped up my clothes, tied me down to the bed, put me in restraints and gave me a lot of neuroleptic drugs. Soon I was told to be an incurable schizophrenic, ready for the ward for chronic mentally ill. The drugs had made me fat, impotent, suffering from Parkinson disease, made me apathetic and suicidal, and I had developed a drug-caused tardive dyskinesia, in the form which is known as rabbit-syndrome. Who cared?

When I came free again, but with the prescription of depot-neuroleptics, I had the decision to live my life as a zombie or rather to kill myself immediately. Never before I had the idea to kill myself. I decided to stop taking the neuroleptics. Within 4 weeks I got healthy again – only my liver did not recover completely from the treatment.

Now I will not lament that I had not received enough care, when I was in the madhouse. The problem was, that I got too much of this kind of treatment that is called psychiatric care. Who really cares about all these people suffering from the effects of the treatment? Who cares, for example, that so many people kill themselves under the influence of the treatment with these psychotropic drugs? This should really be an issue for WHO: Suicide is one of the most frequent death-causes among people labelled as schizophrenics, all people with this diagnosis are receiving neuroleptics from the beginning. Since the beginning of the fifties, when neuroleptics have been introduced to the market, suicide rates of people treated with neuroleptics grew dramatically. A lot of epidemiological studies have proved this catastrophe.

Millions of stories could be told, day after day, year after year. Who does not like to listen to personal stories? But rather than repeating personal stories all the time, let us change the situation, let us go forward from care to share. Share your power and your money with the users and survivors of psychiatry. This would make a difference.

"Developing innovative and comprehensive, explicit mental health policies in consultation with all stakeholders, including users and carers, and respecting NGO and citizen contributions". This is one of the nine key principles, which were identified as a central common goal and strategy to improve psychiatric care at the congress "Balancing mental health promotion and mental health care: a joint World Health Organization / European Commission meeting" in Brussels in April 22-24, 1999. Other key principles, which are important not only in Europe, are the development of new non-stigmatising and self-help approaches and the development of mental health legislation based on human rights, emphasising freedom of choice. It would make me happy to see these principles confirmed and developed at every meeting of the World Health Organisation. Of course, if we have human rights like other human beings, medical professionals have to give up some power and influence; they have to share them with us, money too.

We, who disagree with the conventional concept of mental illness and disagree with the need for synthetic psychoactive drugs – especially when prescribed for long-term daily use or even for life – do not close our eyes or deny the real problems many people experience. My point is, and I share this view with Karl Bach Jensen, member of the interim committee of the World Network of Users and Survivors of Psychiatry (WNUSP), that people should not be locked up and left alone when they go crazy or out of their mind. A fundamental characteristic of necessary alternative mental health services would be to help people to cope with their problems by use of mutual learning processes, peer support, advocacy, alternative medicine, proper nutrition, natural healing, spiritual practice, etc. For example alternative pharmacy knows a lot about herbs and homeopathic medicine which can help your body and mind relax and regain its balance. There might not be that much profit in these things, but it is the future.

In this field ex-users/survivors can play an important role as staff-members and consultants, having the knowledge about what helped them. Such services linked with a positive sub-cultural identity and dignity can be provided by the public or with public financial support by the user/survivor movement itself giving people the space to meet and create their own lives.

If people are locked up to save their life or to prevent them from doing serious damage to others, nobody should have the right to force upon them any kind of treatment. As a defence towards compulsory treatment psychiatric wills or advanced directives – telling which kind of treatment a person wants or doesn't want if it comes to involuntary commitment – should be legally adopted by all states and nations.

Alternative systems and non-central services to meet the needs of people experiencing mental health problems would minimise and in the long run make the use of synthetic and toxic psychiatric drugs needless. Until the final abolition of these drugs a lot of people need help and support to withdraw from the drugs.

Reminding the World Health Organisation of the key principles of the Brussels Conference, I ask to support the resistance of the European Network of Users and Survivors of Psychiatry and WNUSP against the "White Paper on the protection of the human rights and dignity of people suffering from mental disorder, especially those placed as involuntary patients". The working group of the Steering Committee wrote this Paper on Bioethics and serves as a basis for discussion to lay down

guidelines, which should be incorporated into new Legislation from the European Council. If accepted by the European Council, it would encourage psychiatrists to administer their compulsory treatment within the madhouse and outside, in the community. It would encourage administering compulsory electroshocks, to allow commitment without a decision of judges, even to allow compulsory sterilisation. I want to encourage you to share your influence to protect our human rights, as far as they exist at all.

And I want to encourage you to care for the participation of the World Network of Users and Survivors of Psychiatry. This democratic organisation, that has been financially supported by the International Disability Foundation in 2000, will be formally founded in July 2001 in Vancouver. It is the only NGO representing users and survivors of psychiatry worldwide. By the way: When I was invited to the meeting in Geneva, I had to sign a paper that I, as an advisor to the WHO, did not receive money from the tobacco industry. Why not developing a paper to sign that people who received money from the drug industries – for example family organisations or some psychiatrists – cannot be advisors of the WHO at the same time?

When you discuss human rights again, representatives of WNUSP would be glad to be invited. In this world-organisation there is a huge treasure of experience and knowledge.

Finishing with a good example of sharing – sharing money – is the money, which the German Minister for Health gave our German organisation to develop a website for the Internet. It is just an example, not the one-fits-for-all recipe to solve all problems. In their politics of social inclusion the German government gave the money to help our organisation to participate in the developing technical life. Free internet-access in psychiatric institutions would allow the inmates to share their experiences with the world outside – their friends, parents, children, other interested people.

This may be a look into the future. At present, you, the representatives of WHO, can at least have quick contact to the independent organisations of users and survivors worldwide:

- in Europe: www.enusp.org
- in the world: <http://wnusp.net>

WNUSP is still inviting user- and survivor-organisations to become members. If you know of such organisations, especially in so-called developing countries, please refer them to WNUSP. And, most important: One of ENUSP's and WNUSP's most critical issues is funding which these international NGOs constantly lack, so any ideas for them to find funding are more than welcome.

Share your power, your influence, your money, your time on congresses and meetings like this one, more and more. Thank you very much for the hand, you stretched out towards me. I will not let it go again. And beside me are millions of users and survivors of psychiatry. See their hands, stretched out for inclusion and human rights.

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