

Lecture within the session “Civil Right: the White paper”, together with Jean Claus and Paul Schnabel, to the “European Conference on Mental Health 2001: Visibly Improved, Improved Visibility” organized by Mental Health Europe – the European Section of the World Federation for Mental Health, Conference Centre ‘De Doelen’, Rotterdam, March 7-9, 2001

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## **White Paper on the protection of the human rights and dignity of people suffering from mental disorder, especially those placed as involuntary patients**

The White Paper is composed by the Working Party about psychiatry and human rights, a subordinated institution of the Steering Committee on Bioethics of the Council of Europe.

The opposite of the intention in the title is the case: As soon as the White Paper passes, it enforces an extensive right of treatment of the psychiatrists inside as well as outside psychiatry. Even after leaving a psychiatric institution after an acute stay and in freedom, (ex-)users and survivors of psychiatry might be forced to receive prophylactic applications of psychiatric drugs for the rest of their lives.

Just looking to the evil and not yet resolved wholesale killings of so-called mentally ill with the cooperation of the psychiatrists during the atrocious time of German fascism, we should realise it is about time that ultimate consequences were drawn. Patients may never again be at the mercy of psychiatrists devoid of all rights. Not only in Germany, but in a lot of other states, the White Paper is heavily criticized. People with psychiatric diagnoses must not be discriminated legally against people with medical diagnoses.

### **How did the White Paper come about?**

On January 3, 2000 the working group of the Steering Committee on Bioethics published the “‘White Paper’ on Protecting the Human Rights and Human Dignity in the Field of Psychiatry – more especially those within Psychiatric Institutions.” This White Paper serves as a basis for discussion to lay down guidelines, which should be incorporated into new Legislation from the European Council.

Background: On April 12, 1994 the Parliamentary Assembly of the European Council adopted the Recommendation 1235 (1994) concerning Psychiatry and Human Rights, wherein the Ministerial Committee calls for the adoption of new recommendations. Thereupon the Ministerial Committee formed the new Working Group on Psychiatry and Human Rights (CDBI-PH) to operate under the authority of the Steering Committee on Bioethics (CDBI).

The concrete persons, the names of the people of the Working Group of the Steering Committee who wrote the paper are not known. Perhaps they are secret. I am critical against the White paper, this is not a secret. In September 2000 I distributed an international press release and published the main statements in the White Paper.

### **What does the White Paper say?**

Not a court should decide about forced commitment, but a “relevant independent authority”:

“It was thus noted that, in some countries, the relevant authority may be a doctor authorised to take such a decision within a psychiatric establishment, for example, who should be independent in relation to the doctor who proposed the placement measure, in others, it may be a social worker or hospital manager, who may work alongside the doctor examining the patient for the purposes of involuntary placement.”

Only the psychiatrist should decide whether to treat by force or not:

“It was underlined that the psychiatrist in charge of the care of the patient should be responsible for assessing whether the patient still meets the criteria for involuntary placement or treatment.”

In emergency cases (you know, in psychiatry everything is emergency) any so-called “medically necessary intervention may be carried out immediately”:

“When because of an emergency situation the appropriate consent cannot be obtained, the Working Party, on the basis of the relevant provisions of the Convention on Human Rights and Biomedicine, considered that any medically necessary intervention may be carried out immediately.”

There should be the possibility for force outpatient treatment:

“The Working Party also felt that courts and court-like bodies should be able to sentence a person to placement (in a medically appropriate place), and/or treatment...”

The White Paper describes the diagnoses, whose owners should be subject of treatments:

“It hence was of the opinion that mental disorders could not be classified with absolute precision and that the term ‘mental disorder’ could cover mental illness, mental handicap and personality disorders (as regards mental handicap, it was noted that some countries used the concept of ‘learning disability’). (...) However, it was suggested that involuntary placement or treatment should only be appropriate with regard to certain types of mental disorder, e.g. some people suffering from psychoses or severe neuroses, certain types of personality disorder and in significant mental handicap. Persons with a mental handicap sometimes exhibit behaviour which is seriously aggressive and/or irresponsible. Such behaviour may or may not be associated with mental illness. In a situation where mental handicap is associated with mental illness, management of the situation occasionally requires the use of the legislation on involuntary placement and treatment. The term ‘significant mental handicap’ has been used as a description of this disorder.”

About data protection the White Paper says:

“It was also considered that (...) relevant medical information on the patient’s health, including medical data, could be transmitted to the medical doctor or appropriate health and social care workers who may request it. (...) It was also underlined that measures such as (...) listening to patients’ phone calls should be applied in compliance with the house rules of the psychiatric establishment concerned.”

About more details, for example about forced electroshocks and renaissance of eugenic methods you will hear within the statements, which were published in the time after the press resolution.

## **Positive comments to the White Paper**

I will start with the statements, which welcomed the White Paper. The only one, I know, is the one of the German parents' organisation. Mainly they say that it would be an essential mistake to limit forced treatment to special diagnoses. Dangers might be caused – alone or together with other conditions – by a mental disease or disorder. Each mental disorder, which is mentioned in modern classification manuals, should be treated even by force. To limit the treatment to the subjective benefit of a patient would not be good, because sometimes, so they say, there would be patients who experience their successful healing not as a benefit. And

“legal procedures of the subjects against psychiatric decisions on necessary treatments should not have postponing effects. ... To listen in phone-calls should be possible by therapeutical reasons or by reasons referring the security of the institution.”

I do not know the statement of EUFAMI, the “European Federation of Associations of Families of Mentally Ill People”, but I can imagine it is quite similar.

## **Mixed Comments to the White Paper**

Now I come to organisations with no clear attitude to the White Paper. We had asked Mental Health Europe (MHE) for support against the White Paper. About forced treatment inside psychiatric institutions and within the flats of the people (“ambulant”) they wrote:

“Involuntary treatment and ambulant involuntary treatment are the crucial and most controversial points of the whole document. Opinion is controversial on both issues.”

This statement is disappointing. The World Federation for Mental Health was more supportive, when the plenary assembly of that organisation accepted the resolution of the World Network of Users and Survivors of Psychiatry (WNUSP) in September 1999 in Santiago de Chile:

“Because of our concerns about the expansion of community based forced treatment we have resolved, that the WFMH will be supporting the resistance WNUSP against community based forced psychiatric treatments.”

Even when I am guest of MHE at this conference, I may say “Shame on MHE” for this objected support of (ex-) users and survivors of psychiatry.

Another mixed statement came from the German Society for Social psychiatry. They say that forced treatment should not be objected generally, but should be combined with the offer of drug-free treatment.

## **Critical Statements on the White Paper**

The United Kingdom Advocacy Network (UKAN) published a critical statement, but with such a strange first sentence that I have to quote it: “Compulsive treatment should only take place for therapeutic reasons.” But mainly they are arguing for more rights of the people, for better possibilities for independent advocacy and especially for advanced directives: “The use of Advance Directives should be provided for within legislation.”

UKAN distributed an additional paper from the Common Agenda Project at Greater London Action on Disability (GLAD), and this leads to all the objecting statements: GLAD says:

“A law that promotes the health of the individual and also protects the public is always an unhappy marriage. It leads directly to extreme discrimination and catch-all laws which

result in custody rather than healthcare for people who self-harm (often women), for people who attempt suicide and also for voluntary patients. We also believe that ‘danger to self’ should be more clearly defined, and a distinction should be made between people who self-harm, who neglect themselves and people who try to bring about their sudden death. ... We recognise that many medical treatments involve risk of adverse effects. But risk consensually accepted by doctor and patient is very different, we would argue from compelling people to take risk. Side effects of many compulsory treatments are extreme, and often irreversible. Deaths are fairly frequent. There must be stringent safeguards against compulsory treatments where there is any risk of death or irreversible damage. This we would see as being an issue of that most fundamental of human rights – the right to life.”

GLAD also reminded the different Human-Rights-Declarations not to be forgotten:

“... We would ask how mindful is it of the United Nations Declaration of Human Rights, and more specifically the UN Resolutions: The protection of persons with mental illness and the improvement of mental health care’ (1991) and also ‘Standard Rules on the Equalisation of Opportunities for Persons with Disabilities’ (1993)?”

The German Organisation of (ex-) Users and Survivors of Psychiatry re-published a statement that Gerhard Schroeder, now Bundeskanzler, had given 20 years ago:

“We intercede for the right of self-determination of all people. In the psychiatric institutions of the Federal Republic of Germany and of Berlin-West the human rights were not observed – even the official ‘Psychiatry-Enquete’ of the government showed this. We are indignant, that psychiatrists do not only lock up human beings for their whole lives into psychiatric institutions, but they want to incapacitate those who could escape from their claws, too. Just looking to the evil and not yet resolved wholesale killings of so called ‘mentally ill’ with the cooperation of the psychiatrists during the atrocious time of German Fascism, we realise it is about time that finally consequences were drawn. Patients may never again be at the mercy of psychiatrists devoid of all rights.” (Translation by Peter Lehmann & R. Bartle)

Landsforeningen Af nuværende og tidligere Psykiatribrugere (LAP), the Danish organisation of (ex-) users and survivors of psychiatry, declared, that there should not be a legal discrimination:

“On the principle of informed written consent, each individual person should have full self-determination as regards his/her own treatment, including the right to non-pharmaceutical help/treatment. We find that people labelled as mentally ill or as having a mental disorder should have the same rights as have other citizens, also with regard to privacy and the administration of information sensitive to the person involved. ... In our opinion, compulsive treatment should only be applied in case of situations, which are absolutely and apparently life threatening.”

This is exactly the legal state of normal ill persons. LAP continues:

“We are totally unable to understand why the Working Party behind the White Paper is considering that in exceptional cases the possibility of permanent infringement of an individual’s capacity to procreate (point 11, 7) should exist. Compulsory sterilisation is a thing of the past and was abolished in Denmark long ago.”

The European Network of (ex-)Users and Survivors of Psychiatry (ENUSP) summarised the different national statements, and my special thanks and acknowledgement go to Gábor Gombos, Clemens Huitink and Karl Bach Jensen, who made a brilliant statement, from the content and according to the formal necessities.

“In ENUSP we question the need for a special legal instrument concerning the human rights of people labelled as mentally ill or having a mental disorder. We want the same human rights, as have all other citizens. Special legal instruments and legislation most often deal with legitimatizing why we should not have the same human rights as other human beings...

A treatment against the will shall fundamentally base on the same law principles as in the medical area: treatment with informed consent. The obligation to explain intended treatments and depict risks realistically, against which psychiatric institutions obviously constantly offend, has to be finally carried through. If the person intended to be detained is unable to make a legally recognised declaration, his/her natural will have to be respected. If he/she cannot express his/her natural will, an advance disposition will have to be respected. If this disposition is not recognised, one has to proceed on the assumption of a denial of the consent...

We take strong exception to a development within psychiatry resulting in the person's private home being used as the physical frames of compulsive treatment...

We wonder about the nonchalance with which the resolutions made at the Health Ministers' conference in November 1999 in Brussels shall be offended. With these resolutions the bills formulated at the conference 'Balancing Mental Health Promotion and Mental Health Care', a common meeting of the WHO (World Health Organization) and the European Commission in Brussels in April 1999 have been accepted. Counting here in particular: the 'development of mental health legislation based on human rights, emphasising freedom of choice' (quoted of: World Health Organization / European Commission (1999): Balancing mental health promotion and mental health care: A joint World Health Organization / European Commission meeting. Brochure MNH/NAM/99.2. Brussels: World Health Organization, p. 9)''

[The whole declaration](#) you can find on the internet.

## **Transatlantic Statements to the White Paper**

WNUSP supported the statement of ENUSP without any exception. DHARMA ("Diversity, Humanity, and Resourcefulness in Mental Anguish"), an organisation located in Chapel Hill, North Carolina, sent a statement to the European Council, referring to the stigmatising content of the White Paper:

“It does nothing to dismantle the myths and stereotypes that are used to justify depriving people with psychiatric labels (PPL's) of their rights. Instead, it presupposes that PPL's lack insights into themselves do not know what's good for themselves, etc. and promotes widespread discriminatory reactions to the dehumanising prejudices. ... The White Paper is a piece of fascist propaganda that hides behind expressions such as 'best interests of patients', 'dignity' and 'therapeutic' while it desensitises people to abuses against PPL's, thereby promoting continued abuses against them. ... The White Paper supports a dehumanising attitude towards PPL's. For example, without valid grounds it treats PPL's

with suspicion and links them to sex offences and other crimes, thus promoting criminal treatment of them.”

### **Comments of different agencies in one country (Germany)**

May I give you finally some statements of organisations in Germany, who are not part of the movement of (ex-) users and survivors of psychiatry.

The Umbrella Organisation of Psychosocial Services says, the paper should be worked over in totally. Forced outpatient treatment has to be objected totally:

“Since nearly three decades we try to get a psychiatry free force and assault specially in the community sector with its homes, sheltered work places for disabled persons, the sheltered living etc. We experience that in the homes of elderly and disabled persons traditionally there is a grey sector for force methods which are not legally (f.e., imprisonment in rooms without legal basis, giving or not-giving of cigarettes, restriction of social contacts etc. etc.). To legalise formal force methods in this formally hard to control region in spite of law for guardianship, home control, home law) would be fatal for all participants.”

The general German Welfare Organisation objected the White Paper totally too. The reasons are very similar to the reasons of the Danish user/survivor-organisation I reported. That means: equal rights for people with psychiatric diagnoses, treatment only with informed consent, data protection, right to see the own psychiatric records, right to choose between different treatment offers, independent advocacy, no listening in phone-calls.

The government of the Bundesland Rheinland-Pfalz says that it should be mentioned in the White Paper, that it is only a minimal standard, and laws in other countries who are more developed, specially guaranteeing the fundamental constitutional rights of the people must not be worsened by the White Paper.

I started with a family organisation, and I end with a former board member of that organisation, Ms Linde Schmitz-Moormann. In an article published in a family-magazine she said:

“The White Paper goes far behind the line of the German quality standard and is partly dehumanising. ... The patients are not allowed to have control over their bodily inviolability, but over the bedside table. This says everything.”

### **Final comment**

ENUSP made a lot of proposals to change the White Paper and offered support:

“The White Paper, as presented by the Working Party, should be withdrawn. With a view to working out a new proposal to the Committee of Ministers of the Council of Europe, a new working party should be appointed, the European Network of (ex-)Users and Survivors of Psychiatry (ENUSP) and the member organisations of this Network being richly represented. The time has come when the people whom the recommendations concern – in this case people labelled to be mentally ill or having a mental disorder – participate.”

P.S. At the Conference Mr. Jean Claus, Secretary of the working group on Psychiatry of the Council of

Europe, objected the mentioned critics by the (ex-)users/survivors-organisations, the welfare-organisations and the governmental departments at the White Paper. The names of the “experts” he was not allowed to tell. Users have been included in the development of the White Paper, he said, but their names he did not tell too. The question why not one member of ENUSP – the democratic organisation of (ex-)users and survivors of psychiatry, acknowledged as non-governmental advisory organisation by the World Health Organisation and the European Commission and representing the organisations of the East-European countries, too – was not invited to participate, he answered, that to invite too many people would have been too expensive.