

Reaction to the EU / Green paper: Improving the mental health of the population: towards a strategy on mental health for the European Union.

Red paper

On improving mental health care Declaration of Patient Organizations on mental health care

Red paper contents:

- 1 Introduction
- 2 Mental health – central for citizens, society and policies
- 3 The situation – mental health a growing challenge for the EU
- 4 Developing responses: policy initiatives on mental health
 - 4.1 Patient movements and activities in the field of mental health
 - 4.2 Mental health in member states
- 5 The need for an EU-strategy on mental Health
- 6 Seeking solutions – options for action
 - 6.1 Improving mental health care
 - 6.1.1 Group-activity scheme's should be replaced by individual programmes
 - 6.1.2 Forceful measures should be eliminated
 - 6.1.3 Psycho Pharmaceutical Industry should not be privatized
 - 6.2 Promoting the social inclusion of mentally ill or disabled people and protecting their fundamental rights and dignity
 - 6.3 Improving information and knowledge on mental health in the EU

Author/Redaction:

Jolijn Santegoeds, Actiegroep Tekeer tegen de isoleer! –the Netherlands

1 Introduction

This document is a reaction from several patient organisations to the European Commission Green Paper: Improving the mental health of the population: Towards a strategy on mental health for the European Union.

This answering document is called: **Red paper: On improving mental health care Declaration of patient organizations on mental health care**

On behalf of the patients, the patient movements intend to give our point of view on improving mental health care.

This document was initiated by the following organizations:

- **Actiegroep Tekeer tegen de isoleer!**
- **Stichting Time-Out**
- **Clienten Centrum Limburg**
- **European Network Users and Survivors of Psychiatry (ENUSP)**

In this document, the use of the words 'illness', 'patient' and 'health' was inevitable for a correct correspondence towards the EU. The authors intend to keep away from the use of these words if possible, because often the responses are emotional and rooted in fear.

A happy and fulfilled life begins, when fear is not our master. Survival, love and companionship, control, freedom and fun, are valuable parts of our lives, and imbalances may cause trouble relating with ourselves and others.

Happiness is about growing emotionally. To grow we need to change, and mistakes are part of change when we learn from it.

At paragraph 6.3 contact information is included

2 Mental health – central for citizens, society and policies

There is no health without mental health.

Mental health is highly related to the social background of a person. Unequal social, sexual, economic power relations are very strong factors in causing psychological and psychiatric problems. For example violence, power abuse, child abuse, sexual abuse, traumatising events, loss of job, loss of friends, drug abuse etc. are all social circumstances which can lead to an outburst of psychic problems. Coping with these problems is a very personal process.

Across different cultures and different ages a variety of ways of dealing with grief, loss, insecurity, anger etc. has been developed.

- Cultural variety in coping with problems should not be eliminated by globalizing mental health care.
- Social and cultural backgrounds should be included as a main theme of mental health care.
- A single medical approach to mental health illnesses can not be sufficient to practice good mental health care.
- Specialized mental health care to refugees and migrants from other cultures is necessary.

3 The situation – mental health a growing challenge for EU

Mental Health is attached to several cultural problems in Europe. People who suffer from mental health illnesses are often excluded from social society.

3.1 Poorer countries

In poor countries there still is a high level of taboo and stigma.
The poorer countries are generally divided into 2 groups:

3.1.1 Emergency Group: Which includes the poorest countries, which have great economic problems and a lot of **deaths** among the population. (for example in Central and Eastern Europe)

Psychiatric patients from countries of the Emergency Group are mainly dying inside institutions, because then the 'food' can go to the working class. This is a severe economic problem. Severe neglect, severe abuse, lack of medication, malnutrition are real problems to be solved.

3.1.2 Under Average Group: are the countries which main features are: high unemployment, low social security and no existence of patient networks. (for example in Greece)

Patient networks often can not, or hardly, exist in poor countries, because of the threat of unemployment, social exclusion and dependency. People do not speak about their weaknesses, so there is a high level of **taboo**. This has got a lot to do with lack of social security.

3.2 Richer countries

In richer countries the mental health related problems are more cultural, and less economic. The main theme is the definition of mental health, which is polluted by what we intend to call the neoliberal explanation of "wealth", which makes the population unwilling to accept imperfective features of their surroundings.

This view, combined with the capitalistic marketing motives, which makes concerns willing to conquer and broaden every inch of the market, leads to a society where more and more diseases are literally established. In this way, psycho oriented industry is creating a **market** for itself, and the interests of the market distorts to do what is best for us, the people, the patients.

(* see also *psycho pharmaceutical industry should not be privatised par 6.1.3*)

Still, we see a coherence in the mental health care approach across all these countries within the European Union.

- People who suffer from mental health illnesses are often excluded from social society.
- In a lot of countries a huge variety of unwanted or misunderstood behaviour is still addressed to mental health illnesses, like epilepsy, promiscuousness, homosexuality, alternative political theories, etc.
- In all European countries it seems that mental health care also still highly supports on "what you don't see, does not exist"
- Psychiatry and mental health care is realizing way too little recovery of the mental health of their patients.
- A lot of so-called treatments are in fact acts of torture and violating human rights.

The violation of fundamental human rights of patients by mental health care must stop rather today than tomorrow.

Mental health care should make more efforts on recovery and rehabilitation.

4 Developing responses: policy initiatives on mental health

In general, inside the institutions, there is not enough ability to give sufficient care and attention to the patients. Therefore a lot of force is (ab)used on psychiatric patients, mentally disabled and elder people (with Alzheimer etc) etc.

Mental health care is strongly related to the social economic situation of the specific country and the ability to invest in the quality of mental health care.

- **Poverty must be banished.**
- **But banning poverty is not a task of mental health care.**

In Italy psychiatrists are investing lots of money and energy in solving poverty problems for their patients. So, it happens that if you are considered a mentally ill person you'll receive a "salary" and a house (and maybe a little job). But in fact, this has nothing to do with medicine, these are issues which are competence of social services.

As a fact, once in Italy, we used to have the right to ask for a council flat, or a job, or a unemployment aid, but now this is no longer really possible if you are a psychiatric patient, because in that case, it is the psychiatrist's responsibility to organize all that. I am speaking of new laws that are gradually getting through in Italy.

So, what really happens is that there is **a shift of responsibility from social service to medical social services**. Medicine should have no saying in social issues... if someone suffers from a lung disease due to poor housing conditions, the doctor is not going to find a new house. But this person can, on personal bases, gather medical documentation and ask social institutions for support.

Psychiatry wants to break this direct link between the citizen and the government, and it achieves this with his false logic that sees people as "incapables" (that is the legal term used in Italy). (*also see par 6.1.2 forceful measures should be eliminated*)

Often Psychiatry denies the person and its role of moral agent, and this is the most serious offence against human rights.

The rest is just layers of oppression over this core violation.

Since the beginning of industrialisation, the daily life has been reduced to produce, to animate to consume and to throw rubbish away for a primitive purpose: to improve money and power of the ones, who dictate the world. No normal man or women would do the entire mind tiring robot work, if there would not be a permanent menace.

Therefore the main function of coercive psychiatry is not to help people - that's a complete false pretext - but to statute sharp examples on bad functioning human beings in behalf to impress and shock the whole population (so called special and general prevention).

Coercitive treatments find their legal reasons in the medical excuse. Psychiatry has always been a state tool for covert social control, and the medical excuse is the means by which it can look over the rule-of-law by appealing to "right to cures".

There is no mental illness, only sufferance of the soul, and its not a medical issue and it should never be handled by doctors. If we allow this dialectic to perdure we are justifying a coercitive system which has its root in the Catholic Inquisition. Inquisitors also claimed to save souls, and psychiatry appears on the scene when the inquisition leaves it, and its a well documented fact that there is historical link between the inquisition and psychiatry.

It is not up to us, the patient organisations, to prove the inexistence of mental illness, it is PSYCHIATRISTS who have to prove their claim.

The **psychiatric jargon** is very complex in its nature, mainly because it disguises all it really refers to. (*see 1.Introduction*) The psychiatric jargon is a tool for the psychiatrist to maintain a powerful position.

For example: **The harm done by psychiatrists is called: iatrogenic damage.**

Words play a very important role in the mental health system, and we must be sure to call "things" with their real name.

The diagnosis itself is THE stigma. Campaigns like Zero-Stigma by EUFAMI (sponsored by drug companies) bear the ideological roots of all stigma: the idea that some people are organically ill in a way that compromises their mental abilities.

Is not that we have to prove that "mentally ill" people are not, after all, "dangerous", or the like.

- **We have to claim that there are no mentally ill people, but just people who suffer in personal ways, which are not to be subjected to a medical regime in virtue of their ideas and behaviours.**

In the Richer countries, it is nowadays mainly due to capitalistic policies to choose the cheap way: to oppress, instead of mental health care, and to make people pay for a long-term treatment which has no healing effect for the patients. A group-activity-scheme is an easy way to claim the rules, and to keep the patients restricted, with the purpose underneath to maintain order in the institutions without high costs. (** also see 6.1.1 group activity scheme should be replaced by individual established programmes*)

Underneath also lays a main cultural problem, which we intend to call the neoliberal explanation of "Own responsibility", which causes individualism across society, where people are like rivals, and not helping each other. In this neoliberal climate pointing at the borders of acceptance, dropping each other down and "own responsibility" is way more accepted than to make efforts to help the not-working, and help-needing class.

Often the very **real strengths and skills of people in this class are denied**, so that the contributions they can and do make to their community, without being employed, are not valued and encouraged.

- The attitude towards psychiatric patients in general, in all countries, should be bettered, so that patients are no longer 'secondary humans'. Improvements can be gained by protecting the human rights and equality, by encouraging inclusion of patients into the society, by giving more respect, by less stigmatization, by stimulating (public) understanding of the difficulties the patients are coping with.
- **Violence must be banished**
- From a social point of view, based on pluralism and social inclusion, cultural efforts should be made to establish more tolerance and a better understanding of 'humanity', 'wealth' and 'own responsibility' in society, and replace the neoliberal explanations of these themes.
- The capitalistic motives on the 'mental health market' should disappear, and the mental health branche should remain public, to be able to fully focus on the qualitative contents of mental health care, where the aim always is: to make mental health care superfluous. Mental health care therefore does not fit in the modern capitalistic and neoliberal marketing strategies. (**also see 6.1.3 psycho pharmaceutical industry should not be privatized*)

4.1 Patient movements and activities in the field of mental health

Independent Patient Organizations, which expresses the fundamental issues from the patients point of view, should exist in every country.

Independent Patient organizations enables the patients to :

- help, support, advise each other, if necessary anonymously (because of stigma)
- cooperate on topics and find recognition
- exchange information with society and professionals
- end taboos by getting more understanding for their illnesses
- get an empowering network, that contains valuable knowledge.

4.2 Mental health in member states

All member states should stimulate, protect and support the existence of various forms of independent patient organisations.

Patient organizations should be stimulated to play an important role in all mental health related topics, like mental health care itself (contributing: experience based knowledge, support, education), or on planning priorities, strategizing improvements, research and development, etc. ____

5 The need for an EU-strategy on mental Health

The need for a humane strategy on mental health in the European Union is very high.

6 Seeking solutions – Options for action

- **Stop the violation of fundamental human rights, rather today than tomorrow.**
- **Respect the patients and their fundamental rights.**

Mental health is an entity closely related to moods, character, perception and backgrounds of a person (both for the patient as the assistance) and therefore a careful treatment based on equality, trust and communication is necessary (*see also *forceful measures should be eliminated, paragraph 6.1.2*)

Effectiveness in mental health care is equal to carefulness towards the patients.

- **Good mental health care has to be established as soon as possible.**
- The good practices of mental health care should be valued by the patients, because the patients are the touchstones of the quality of care.
- The EU should provide funding for research on good practices,
- The EU should also stimulate development and continuation of good practices.

'Building on good practice' should mean that funding for effective mental health services, valued by the people who receive the service, is protected. This should include services which are not specifically for people with diagnosed mental health problems but which help people with social problems which can lead to mental distress- eg. helplines and services for specific issues, eg housing, or for specific groups, eg. refugees and migrants.

We have problems in the UK that money is available to start new projects for two or three years. At the end of that time, good new services often closed because they cannot get more funding; money is only available for new services. A lot of money and knowledge is wasted in this way.

- Prevention of all admissions by **integrating mental health care into society**, is probably the best option to end the stigma of mental health problems.
- Prevention also means elimination of the causes of mental health illnesses, which in fact means to stop violence, power abuse, social exclusion, and poverty (lack of chances). This all is not a core task of mental health care.

6.1 Improving mental health care

6.1.1 Group scheduling should be replaced by individual programmes

Forceful measures are an old-fashioned habit, based on the idea that patients who show different behaviour than others, should be trained to behave themselves. In the past, mental health care has established group-activity-schedules for patients daily life, for example: to get up at 7, eat at 8, go to creative therapy on 9. When the patient could follow this scheme, he would be cured enough to go back to society.

It is a well known fact that the patients social background is highly determining the mental state of health. For example child abuse, sexual abuse, traumatising events, loss of job or loss of friends, drug abuse etc. are all social circumstances which can lead to an outburst of psychic problems. Coping with these problems is a very personal process.

However, the group-activity-scheduling does not take any regard on the patients feelings. For example, the patient has to be creative at 9 am.

The reason for this scheduling is mainly, that mental health care institutions cope with severe poverty, a severe lack of personnel, lack of facilities and basically, a lack of investment, which leads to a poor standard of mental health care.

A group-activity-scheme is an easy way to claim the rules, and to keep the patients restricted, with the purpose underneath to maintain order inside the institutions without high costs, for example low expenses on personnel, and materializing mental health care. (* see also forceful measures should be eliminated par 6.1.2 and psycho pharmaceutical industry should not be privatised par 6.1.3)

An other reason why group-activity-schemes are still widely used is the lack of experience on recovering psychiatric problems. Patients are kept busy with activities on a random basis, based on an old-fashioned view on recovery.

Underneath also lays a main cultural problem, which we intend to call the neoliberal explanation of "Own responsibility", (* see 4 developing responses: policy initiatives on mental health)

In general scheduling-treatment, the main attention the patients get, is the dictation of the rules of the institution. When patients do not behave in accordance with the rules, they will be forced to do so. (*see forceful measures should be eliminated par 6.1.2)

In this way, the patients get drill-instructions, to fit into a standardised daily life scheme. There is no time to communicate on personal topics, because of the minimal amount of personnel. In the year 2006, a lot of psychiatric patients still have to become introvert by a mental-health-paralysing treatment, otherwise they will not be dismissed from the mental health institutions.

In Dutch practice (1994, mental health youth institution) there are still often only 1 or 2 assistants who go with a group of about 10 patients to an activity, like creativeness or sports, which is lead by 1 professional therapist. Patients who do not follow the scheme, stay behind at the institution, often accompanied by only 1 assistant. So, in several circumstances, the assistance personnel is facing a group of patients on their own, which makes it very hard for all to cope with the emotional and behavioural problems, and which leads to a variety of crisis inside mental health care.

Nowadays we still see similar tendencies to the group schemes, for example in the Netherlands when talking about clientparticipation. Clientparticipation means that the patients should have the ability to have influence on their own treatment, by getting involved at the 'design level' of their treatment, and by the ability to choose whether a certain approach is suitable to their recovery. In the Netherlands these 'patient moments' are structured, often, by planning weekly patient participation hours, which is often only talking, and brings minimal influence for the patients.

Clientparticipation means there should always be time to communicate with patients, to give patients the opportunity to join the process of establishing recovery, and to be treated as equal human being who has something to say about his own life. Keywords are Empowerment, Equality and Participation to Recovery.

This means that, at all time, there has to be sufficient personnel for enabling communication between an individual patient and a member of the personnel.

- **Group-schemes are used to fight symptoms, and are not curing mental health illness.**
- **Mental health Care should focus on individual treatments, established with joined input from the patient and the assistance and eventually more people like friends, relatives etc (in accordance with the patient).**

6.1.2 Forceful measures and matters should be eliminated

- An assumption is: that all efforts will be done to stop the **genocide** on psychiatric patients (which happens especially in warzones and poor countries), rather today than tomorrow. This has got nothing to do with mental health care.
- The poor countries get the benefit of the doubt that all malpractices and abuse of forceful measures is caused by **poverty** and the lack of chances on establishing good mental health care. (* see 3. the situation - mental health, a growing challenge for the EU)

These poor countries are therefore in a certain way excluded from what we comprise by: the use of forceful matters. Like isolation cells, fixation, medication, restricted freedom, or any involuntary treatment. Also because poor countries often accept the richer countries as a guidance to their own practices.

The richer countries can economically afford to establish and to provide better mental health care, than the oppression, torture and exclusion, which is still happening.

Instead of good care, in a lot of circumstances excessive force is used. Even in some so called democratic, rich countries of the EU.

Some familiar forceful measures are mentioned:

- Physical restrictions, such as isolation cells, fixation straps and other measures to restrict freedom of movement etc. are **torture** towards the patients, which has more to do with severe neglect and oppression, than with mental health.
- Administering food involuntarily is experienced equal to rape.(as said by the organisation of Anorexia patients in the Netherlands)
- It is a severe violation of the integrity of the body.
- Administering psycho pharmaceutical drugs involuntarily is a severe violation of the integrity of the body and worse: the mind.

Even official studies on patients perceptions of involuntary treatment, point out that compulsory treatments can, among others, cause feelings of humiliation, loneliness, and anxiety. A lot of patients described compulsory methods as traumatizing.

It is clear that forceful measures are originally used too fulfil other needs than mental health, and these practices never really have stopped, which is a real tragedy.

Psychiatry denies the person and its role of moral agent, and violating the core of human existence. This is the most serious offence against human rights. (* also see 4 developing responses: policy initiatives on mental health)

The psychiatric profession should listen to what the patients think of their treatments (clientparticipation), and deal with it seriously. Because when the professionals, when using compulsory methods, have no regard for the feelings of the patient, it is very HARD for the patient to communicate on other traumatizing events in the patients life as well. When professional care-providers harm patients (which we call: **re-traumatizing**), instead of healing, the patients feel very misunderstood and lonely. They don't trust the personnel anymore, and their whole world collapses, because they don't want to be harmed, they want to be helped, and they get scared.

Compulsory measures are **painful oppositions** between targets and methods within psychiatry. Patients and staff should talk about different treatments, and cooperate on the treatments which lead to recovery, and should not oppose and force one another.

What is called: 'Active participation' and 'empowerment' of the patient are keywords to improving mental health care.

The psychiatric professionals should always have the ability in time and scheduling, to spend time with patients, to communicate with the patient and to show social compassion and support.

- **Involuntary treatment should be forbidden**, because it is torture. It is no 'good practice' and should therefore not be supported by the EU.
- **The patient has the right to deny a treatment.**

Psychiatric professionals have the ability to prevent incidents by more communication.

Prevention means: to pick up the early signals of a crisis, to start to care in the early stages, and prevent the real crisis. This is possible with a very good communication between patient and his surroundings, eg. with family and friends involved, or well-trained or specialized personnel. (which includes people with experience based knowledge)

Every communication means more **signs and signals**. So therefore a **sphere of openness** in society and in every mental health care facility is very important.

Talking to one another, share laughs, cosiness, music, sports, silence, every act is a reflection of feeling. And **there is no life without feelings** (* see 1 Introduction and 4 developing responses: policy initiatives on mental health)

More communication also gives more **insight** to the patients direction of recovery or rehabilitation.

The painful oppositions between targets and methods, is not caused by bad intentions of the nowadays mental health care-professionals.

There is a huge lack of specialization, caused by history.

6.1.3 Psycho pharmaceutical industries should not be privatised

The definition of mental health, is polluted by what we intend to call the neoliberal explanation of "wealth", which makes the population unwanting to accept imperfective features of their surroundings.

This view also stimulates psycho pharmaceutical industries to establish a growing variety of different diseases and medicaments. These medicaments often have harmful side-effects on humans and the environment.

The focus on visible features of diseases and universal solutions, is encouraged by the market and by cultural-economic interests (* see 3 the situation - mental health, a growing challenge for the EU and 4 developing responses: policy initiatives on mental health)

This is contrary to the well known fact, that social context of a person enduring his/her life is very highly determining for his mental state of health (for example in regard to violence, power imbalances, child abuse, sexual abuse, traumatizing events, addiction recovery etc.).

The neoliberal industrial approach is to analyse the people as a standardised medical persons, and to conquer the market with universal products for all of us. The industries sponsor the medical mental health investigations, and the market maintains itself by finding diseases for their pills.

- **By privatizing the sector of psycho pharmaceutical industry, the medicalization of mental health care will probably not be stopped.**
- 'Developing diseases' in mental health industry strengthens the neoliberal explanation of 'wealth', which leads to individualism and harms the society. (* *also see 4 developing responses: policy initiatives on mental health*)

Also, psycho pharmaceutical and medical drugs is frequently tested illegally on the population of the poorest countries of the world, like India, or across Africa, to lower the costs for such testing. But ironically, when this poor population suffers diseases themselves, it is a matter of luck if they survive. The chance that they will die in poor institutions is evidently higher.

- **The illegal drug testing should be stopped immediately.**

Since privatization leads to companies striving to make more interest, it is to be expected that these companies will search for the darns of the legislation, to find the cheapest options to make their interests.

Therefore we think the complete mental health sector should be public, and not privatized.

- In the last analysis, capitalism and neoliberalism, when executed in society, and especially in mental health care, leads to more mental health problems of the population.

6.2 Promoting the social inclusion of mentally ill or disabled people and protecting their fundamental rights and dignity

The patients with a mental health illness should not be excluded from society, and should not be put in large hospitals, where re- traumatizing evidently takes place.

6.2.1 Our priorities for the EU agenda on mental health care:

1. Stop poverty
2. Stop violence
3. Stop violation of human rights
4. Prevent mental health illnesses

5. Close psychiatric hospitals where patients do not survive their so called treatment, and replace the institutions by smaller sized facilities with better quality of care.

6. As much recovery and rehabilitation as possible

7. Involuntary treatments must be forbidden
8. Patients should be the touchstones of the quality of care.
9. Make use of experience based knowledge.
10. Support patient organisations

11. Focus on the human mental health, which is more than external features of diseases.
12. Accept mental diversity and pluralism
13. Accept intercultural mental diversity and pluralism
14. Give all patients the right to refuse their treatment.

15. Make special efforts to provide good care for psychiatric patients in poor countries, war zones and also for refugees and migrants.

16. Psycho pharmaceutical industry must not be privatized.
17. Mental health care must be a public service.

18. Eventually mental health care should completely take place inside the society, and by the society.

6.2.2 Our priorities for quality improvement inside mental health institutions:

19. No large scaled mental health institutions with hundreds of patients.
20. Small scaled community based mental health care facilities with regard for individual needs.

21. No group-schemes but individual plans, put together by joined efforts.
22. Make use of experience based knowledge and client participation.
23. Client participation should be possible at all time: Assistance should always have time to talk about anything.

24. Eliminate the use of forceful measures,
25. Patients decide whether a form of care is helpful.
26. Patients have the right to deny a treatment.
27. Try to maintain communication based on equality between the patient and staff.
28. Base the mental health treatment on communication, equality, trust, be careful with feelings, and aim for recovery, rehabilitation and integration.

29. No exclusion, but more company for the people with mental health illnesses
30. More accessibility for sharing contacts and more possibilities for the patients to participate in daily life of society.

6.3 Improving information and knowledge on mental health in the EU

For any information you can always contact the following patient organisations:

Miss Jolijn Santegoeds, Actiegroep Tekeer tegen de isoleer!

Address: Tellegenstraat 78 , Postal Code: 5652 NT , City: Eindhoven

Country: The Netherlands

Telephone: +31/ 040-2515342 or Mobile: +31/ 06-47018432

E-mail: tekeertegendeisoleer@hotmail.com

English website: http://home.tiscali.nl/antiisosite/international_message_board.htm

Full website (NL): <http://www.antiisosite.tk>

Mrs. Marietje Lemmens, Stichting Time-Out

Address: Prinses Christinalaan 14 , Postal Code: 6301 VX , City: Valkenburg aan de Geul,

Country: The Netherlands

Telephone: +31 / 043-6013857

E-mail: marietjelemmens@xs4all.nl

Full website (NL): <http://www.stichting-time-out.nl>

**Mr. Drs. Jan Verhaegh, Clienten Centrum Limburg /
Deputy Board Member for the North West Region of European Network Users
and Survivors of Psychiatry (ENUSP)**

Address: Prinses Christinalaan 14 , Postal Code: 6301 VX , City: Valkenburg aan de Geul,

Country: The Netherlands

Telephone: +31 / 043-6013857

E-mail: janverhaegh@xs4all.nl

Full website (NL): <http://www.stichting-time-out.nl>