The European Newsletter

of (ex-) Users and Survivors of Psychiatry

No. 12 (December 2003)

Special issue (Follow-up to special issue No. 11 from June 2003)

Action project to combat discrimination

Harassment and discrimination faced by people with psychosocial disability in health services. A European survey

The Newsletter of The European Network of (ex-) Users and Survivors of Psychiatry Peter Lehmann **ENUSP Desk**

www.enusp.org • e-mail: desk@enusp.org

With support from the European Community - The European Union against discrimination. The information contained in this publication does not necessarily reflect the position or opinion of the European Commission.

Content

| EDITORIAL | 1 | ESTABLISHING INDEPENDENT 7 |
|---|---|---|
| New Powers to combat discrimination | 2 | BODIES TO ASSIST IN COMBA- TING DISCRIMINATION |
| The action programme to combat discrimination | 2 | Recommendations from ENUSP to 8 the European Commission |
| by Anna Diamentopoulou Material and background informa- | 2 | The Psychiatric Will – A Special 9 Advance Directive |
| tion about the Action Programme to combat discrimination | 2 | In memoriam Hubertus Rolshoven 11 |
| Introduction: The anti-discrimination framework | 3 | Editorial Dear members and friends of ENUSP, In this new special issue of the ENUSP newsletter we give you some additional information about a project of the European Commission, ENUSP is participating. |
| BACKGROUND TO THE DIREC- TIVES ON RACIAL EQUALITY AND EQUALITY IN EMPLOY- MENT | 4 | |
| The directives on racial equality and equality in employment | 4 | |

Meanwhile the European Commission accepted the application for further funding the programme. And the German organisation BPE stands in for the French FNAP Psy.

We want to encourage you to make own programmes to combat harassment and discrimination in all fields, especially in the health field and in the psychiatric sector, and to support your national organisations who are partners in the project. Please distribute this newsletter and give us a response to our recommendations to combat discrimination.

Previous ENUSP newsletters can be found on our website:

www.enusp.org/documents/newsletter.htm

Many thanks for your ongoing support.

Peter Lehmann Newsletter-editor and Secretary of ENUSP

New Powers to combat discrimination

The European Union informed about the background of ist initiative "For Diversity – against discrimination:

"Fifty years ago, overcoming the nationalist and ethnic conflicts which had divided Europe was one of the driving forces behind the process of European integration. Today, the key objectives are to prevent people from being discriminated against in any way due to their racial or ethnic origin, religion or belief, disability, age or sexual orientation.

This is why the European Commission has launched a campaign with the slogan "For Diversity. Against Discrimination." to raise awareness of discrimination and to provide information about new EU rules to combat discrimination which are due to come into force in 2003."

The action programme to combat discrimination

by Anna Diamentopoulou (Commissioner for Employment and Social Affairs)

The European Union has come a long way since 1997, when Heads of State or Government gave it the power to take action to combat discrimination

on a whole new range of grounds. We have adopted strong and innovative legislation, which the Member States are in the process of transposing into their national laws. We have put in place a solid framework of supporting action, looking at the mechanisms we need to deliver equality objectives, developing thinking in sensitive areas such as data collection and public procurement, and reaching out to the new Member States to help them on their path to EU membership. We have put in place structures to exchange ideas and good practices between people fighting discrimination in the different Member States. And we have supported civil society at European level in its work to promote the values of equality and nondiscrimination in everyday life.

The primary responsibility for fighting discrimination lies within the Member States — with national, regional and local authorities, with civil society organisations and with us all as individual citizens. But Europe can give — and has given — a strong push in the right direction. This report provides an overview of what Europe is doing to support efforts in the Member States.

We have much to be proud of. But there is still a long way to go. Nearly 30 years after the directive on equal treatment of women and men in employment, we still cannot say that we have achieved real equality, even though we have made a lot of progress. It is important that we learn from our experience of striving for gender equality to make our progress in fighting discrimination on other grounds as quick as possible.

It is a serious challenge. Equality is simple in principle, but delivering it is complex in practice. I hope that this report will give readers a clear idea of some of the steps being taken right across the Union.

(from: "Annual Report on Equality and Non-Discrimination 2003", edited by the European Commission, Luxembourg: Office for Official Publications of the European Communities 2003, p. 3)

Material and background information about the Action Programme to combat discrimination

by Peter Lehmann

Dear members and friends of ENUSP,

here is the important background material to the EU-Action Programme to combat discrimination. I took over the – in my opinion – most important chapters from the "Annual Report on Equality and

Non-Discrimination 2003", edited by the European Commission, Luxembourg: Office for Official Publications of the European Communities 2003.

This report is available in all languages of the current member states of the European Union. You can read and download the report in your language under the URL

www.stop-discrimination.info

go to your language, click on "about discrimination" and see the link to the report on the right side.

Introduction: The antidiscrimination framework

A concerted effort is being made in the European Union to stamp out discrimination and to make the basic principle of respect for fundamental human rights a reality. New laws will soon come into force in all EU countries to protect the right of everyone in the EU to be treated equally and fairly no matter where they are from or where they live and work.

European laws — called directives — banning discrimination on grounds of racial or ethnic origin, religion or belief, disability, age and sexual orientation were agreed in 2000. Governments in every country must now modify their own national laws to bring them into line with these directives before the end of 2003. Each country can decide how best to do this according to their national traditions and legal systems.

One of the two directives concerned is about achieving racial equality. It prohibits discrimination against anyone because of their racial or ethnic origin and covers most areas of everyday life in which unfair treatment might occur. These areas include access to jobs, conditions at work, rates of pay and the rights and benefits linked to a job. They also include access to education and training, social security benefits and healthcare and equal rights to buy or rent goods and services, including housing.

Governments have agreed to introduce the measures necessary to comply with this directive by 19 July 2003. In some countries, this means passing new laws, in others amending existing ones. In all countries, governments also have to designate a body to provide practical and independent support and guidance to victims of racial discrimination, to help them follow up their complaints and get a just settlement. This means creating a body to perform this role if one does not already exist.

The second directive is about establishing equal rights and equal opportunity for people in employment and training, which is key to what people achieve in life and how well they live. The directive, therefore, outlaws discrimination on grounds of a person's religion, disability, age or sexual orientation. In this case, governments have agreed to make the necessary changes to their national laws by 2 December 2003, although they can ask for an additional period of up to three years to make the changes needed to deal with disability and age discrimination. But if they do this, they have to report each year on the steps they are taking to tackle discrimination on these grounds and the progress they are making to bring their laws fully into line with the directive.

Establishing an effective set of laws against discrimination is an essential part of stamping out unfair treatment. It not only gives protection to those discriminated against but it creates a climate in which people are discouraged from treating minority groups unfairly. But laws by themselves are not enough. If discrimination is to be eliminated, attitudes and behaviour have to change. This was recognised when the directives were agreed. An action programme aimed at helping to bring about these kinds of change was therefore launched at the same time. Its purpose is to support activities which combat discrimination and its underlying causes and which raise awareness of the problem and the measures being taken across the Union to tackle it.

The action programme runs until 2006. It finances studies aimed at improving our understanding of discrimination and at assessing the effectiveness of measures to promote equal treatment. It funds networks of people and organisations from across the EU to share information, especially about good practice, between one another. And it supports activities to raise the awareness of people, to inform them of their new rights and obligations under the law and to challenge discriminatory attitudes and behaviour.

Outline of the report

The publication of this report is one of the awareness-raising activities of the action programme. The first part of the report explains the main features of the directives and the measures they identify as being necessary to combat discrimination effectively. It also reviews what governments across the European Union are doing to put the directives into practice. It describes the legal changes being made to outlaw discrimination and the supporting action being taken to ensure that

victims have somewhere to go for help and suitable means of redress. The purpose is both to indicate what is happening and to draw attention to particular measures being introduced which can serve as examples of good practice to other governments trying to achieve the same objectives.

The second part looks at the action programme. It describes some of the cooperation projects being undertaken by people in different EU countries to tackle discrimination and its root causes. Again the purpose is to highlight practical examples of the kind of action which can be taken to reduce discrimination and to increase the chances of people being treated equally and fairly irrespective of their personal characteristics. It also reviews the activities of the networks of non-governmental organisations (NGOs) financed by the programme which link up bodies across the EU active in fighting discrimination in its various forms.

BACKGROUND TO THE DIRECTIVES ON RACIAL EQUALITY AND EQUALITY IN EMPLOYMENT

The EU directives (Council Directive 2000/78/EC establishing a general framework for equal treatment unemployment and occupation (27/11/00) and Council Directive 2000/43/EC implementing the principle of equal treatment between persons irrespective of racial or ethnic origin (29/06/00) combating discrimination follow directly from the Treaty of Amsterdam and were unanimously agreed by the EU governments within 18 months of the Treaty entering into force in May 1999. The Treaty, which sets out the principles and objectives of the European Union, affirms that:

'The Union is founded on the principles of liberty, democracy, respect for human rights and fundamental freedoms [...] principles which are common to the Member States.'

It emphasises the fundamental importance of nondiscrimination and extends this principle to other areas in addition to nationality and equal pay for men and women, which were dealt with before. In particular, it gave the European Union powers to take action against discrimination on a range of grounds. These powers are set out in Article 13:

'Without prejudice to the other provisions of this Treaty, and within the limits of the powers conferred by it upon the Community, the Council, acting unanimously on a proposal from the Commission, and after consulting the European Parliament, may

take appropriate action to combat discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation.'

The directives on racial equality and equality in employment

This part of the report is divided into two sections. The first explains the main features of the two directives on equality, the one dealing with racial discrimination and the other with discrimination in employment. The second section describes what national governments across the European Union are doing to put the directives into effect.

Main features of the directives

Scope of the directive

The two directives outlawing discrimination cover everyone living or working in an EU country, whether they are officially resident there or not. Protection, therefore, is not confined to EU nationals but extends to people from outside the EU who might be visiting for a period, whatever their nationality. (The directives do not, however, affect rules on immigration and do not cover differences in treatment on grounds purely of nationality.)

Both directives prohibit discrimination in employment and training, areas in which equality of opportunity is vital if people are to have a fair chance of fulfilling their potential, of attaining the standard of living they are capable of achieving, and of playing their full part in the economy and in social life. Under the two directives, therefore, everyone has the right to the same 'conditions of access' to jobs as other people, irrespective of their racial or ethnic origin, their religion or belief, their disabilities, their age or their sexual orientation.

This means that whatever their personal characteristics in these respects everyone has to be treated equally and fairly when they apply for jobs, seek promotion or set up in business for themselves. They also have the right to the same terms and conditions of employment as everyone else when they are in work, including, in particular, the same rates of pay and the same protection against dismissal. They have a similar right too to be trained, to gain work experience and to get career guidance. And they have the same right as everyone else to become members of trade unions or professional bodies (such as associations of lawyers,

doctors or architects) and the same entitlement to any benefits and privileges.

The ban on discrimination in employment and training applies universally, to people in the private sector as well as the public sector, no matter what size of firm or organisation they work in or apply for a job in. It applies to all 'occupations', which means every job which someone might be doing whether they are counted as being an employee or self-employed. It applies to people working part-time as well as full-time and whatever the contract of employment they have (including fixed-term contracts and those covering a period of training). It applies to employment agencies as well as other businesses and to bodies responsible for awarding qualifications, licences or permits which are required to do a particular job or undertake a particular activity (such as driving a taxi or trading from a market stall). And it also covers all place of work or in colleges, universities or specialist institutes, including the training needed to do different types of job or follow particular professions and including degree courses as well as lower level ones.

At the same time, the directives make clear that they do not force employers to take on anyone who is not competent to do a particular job or is incapable of undergoing the training needed to do the work involved.

The racial equality directive also covers other areas of possible discrimination, giving people from all ethnic backgrounds comprehensive protection against unfair treatment in their daily lives. According to the directive, therefore, someone's racial or ethnic origin should not affect their entitlement to social security and healthcare and to what are called 'social advantages' or their access to education and goods and services.

This means that no one should be discriminated against because of their racial or ethnic origin when it comes to pensions and other social benefits, as well as the full range of social advantages. These cover things like housing benefits, concessionary fares or fees, subsidised meals, grants for education or training, free prescriptions, reduced charges for services and so on. It also means that they have an equal right to attend school and undertake particular courses of study and to buy or rent all kinds of goods and services which are available to the public at large, including housing and entry to pubs and clubs.

Defence of rights and the right of redress

The directives make clear that everyone who is a victim of discrimination or who considers that they have been unfairly treated because of their personal characteristics should have adequate means of legal protection and an effective right of redress (i.e. they should be government in each country to decide whether this is through judicial procedures — i.e. through the system of criminal or civil justice — or through administrative arrangements, such as tribunals. Governments can also choose to encourage conciliation and set up a system for sorting out cases of unfair treatment voluntarily through discussion instead of through the legal route.

The directives impose an obligation on governments to ensure that people bringing complaints of unfair treatment have the right to be supported and represented by their trade union or by specialist associations or organisations. At the same time, they have to make sure that the sanctions to be applied in cases where discrimination has occurred are 'effective, proportionate and dissuasive'. In other words, the penalties for discrimination should bear some relationship to the harm done and should act as a deterrent against behaviour of this kind.

To strengthen protection further, governments are required to introduce legislation under which the burden of proof in civil cases (i.e. where criminal charges are not involved) is shared between the person claiming to have been treated unfairly and the person against whom the complaint is being made. This means that the responsibility for proving or disproving the case is divided between the two. The person making the complaint has first to show that the facts are consistent with discrimination having occurred (that there is prima facie evidence of this) and that there is therefore a case to answer. The person accused of discrimination then has to demonstrate that they did not act unfairly and that there was a legitimate reason for what they did. The onus is, therefore, on the accused to convince the court or tribunal that they did not behave in a discriminatory way. And the person claiming discrimination is not expected to produce conclusive proof of this, something which they are unlikely to be in a position to do.

Governments are obliged, in addition, to ensure that people complaining about discrimination are adequately protected from victimisation or retaliation, which if unchecked could deter them from exercising their right to equal treatment. This also goes for witnesses in discrimination cases who need to receive the same protection from victimi-

sation to encourage them to give evidence. Governments are, therefore, required to put measures in place to dissuade those accused of discrimination from reacting in this way. These measures, in particular, need to protect employees against the possibility of dismissal if they lodge a complaint or take legal action against their employers or if they give evidence in cases of unfair treatment.

Bodies for the promotion of equal treatment

To increase the level of protection against discrimination even more, the racial equality directive requires governments to designate an independent body, or bodies, to help people suffering racial discrimination to pursue their complaints. Governments have to give these bodies the power to conduct independent surveys on discrimination and to publish independent reports on the subject, so that they can help increase understanding of the problem and contribute to finding solutions as well as providing practical assistance to victims.

Positive action

The directives recognise explicitly that outlawing discrimination will not necessarily be enough by itself to ensure genuine equality of opportunity for everyone in society. Specific measures might be called for to compensate for disadvantages arising from a person's racial or ethnic origin, age or other characteristics which might lead to them being treated unfairly. For example, ethnic minorities may need special training and specific help to have a reasonable chance of finding a job. Putting on training courses or making different arrangements especially for them are ways of improving their chances. The directives allow positive action of this kind to be undertaken and do not regard it as infringing the principle of equal treatment.

Reasonable accommodation

While positive action to compensate for the disadvantages of particular groups is optional, accommodating the needs of people with disabilities is a compulsory part of the directive on equality in employment. The reason is the same as the argument for positive action, only stronger. Without measures to accommodate their needs, people with disabilities could be so disadvantaged that they are unable to work at all. The directive, therefore, requires employers throughout the EU to take whatever steps are 'reasonable' to enable people with disabilities to work, advance in their

careers and participate in training, so long as this does not involve excessive financial and other costs. (...)

The definition of discrimination

The definition adopted in the directives of what counts as direct discrimination is a common sense one: it occurs whenever someone is treated less favourably than someone else 'is, has been or would be treated in a comparable situation' on grounds of racial or ethnic origin, age, religion or belief, disability or sexual orientation. Unfair treatment is most likely to occur because of a person's own characteristics but it also might be because of their association with someone, for example, of a particular ethnic origin. This is equally covered by the directives.

The directives also ban 'indirect' discrimination. This is where 'an apparently neutral provision, criterion or practice' results in people with particular characteristics, in terms of their ethnic origin, age and so on, being unfavourably treated compared to others. Indirect discrimination is outlawed unless it can be shown to be both 'objectively justified by a legitimate aim' and the means to achieve this legitimate aim are 'appropriate and necessary'.

The extension of protection to cover indirect discrimination is an important addition to the laws which at present exist in many countries. It means that people are protected against unfair treatment even when this is unintentional, when those responsible for introducing a particular practice, for example, did not realise the effect it would have on different people. What matters, therefore, is not the intention but the consequences.

The directives ban, in addition, 'instruction to discriminate', which is where someone orders someone else to act in a discriminatory way, and 'harassment', where someone behaves 'with the purpose or effect of violating the dignity of a person and of creating an intimidating, hostile, degrading, humiliating or offensive environment'.

Implementation of the directives on equality in EU Member States

Governments in all EU countries are taking steps to comply with the directives on equality. This is as true in countries where legislation outlawing discrimination was already fairly extensive before the directives were agreed as in those where it was more limited. Even in countries where arrangements for combating discrimination were well established, these did not meet the requirements of the directives in every respect and needed some modification. This was particularly so as regards the directive on equality in employment which outlaws discrimination on grounds of religion, age, disability and sexual orientation. While laws had been introduced in several countries to protect people with disabilities and particular religious beliefs, this was much less the case as regards age and sexual orientation.

The steps taken so far vary a lot between countries. Differences in the legislation already in place and in the arrangements which exist for protecting and assisting the victims of discrimination mean the responses to the directives also differ. In a number of countries, including Belgium, Denmark, Ireland, the Netherlands, Sweden and the United Kingdom, a fairly extensive system of protection against racial and ethnic discrimination in particular has been in operation for some years. In others, the arrangements in place were more limited at the time the directives were agreed. Even though the right of people to be treated equally in these countries is included in their constitutions, this right has not always been fully guaranteed by more detailed legislation and by effective arrangements for protecting people against discrimination.

Partly because of these differing situations, there are also differences in the timetable adopted for making the legal and other changes to provide the protection required by the directives. In some countries, moves were already under way to extend the system of protection before the directives were agreed. In a number of them, new laws have already been introduced and existing ones modified to provide the level and extent of protection required. In Belgium, in particular, a new law was passed on 6 January 2003 prohibiting all forms of discrimination and going beyond the minimum requirements of the directives in a number of respects. In other countries, changes in legislation and the other measures required are still under consideration.

The purpose here is not to examine in detail what is happening in each Member State and to list the changes made or being considered in any exhaustive way. Instead, it is to describe selected measures introduced, or being introduced, in particular countries in order to illustrate the kind of action being taken. These measures and the arrangements adopted for putting them into place might also serve as examples to governments still in the process of deciding how best to meet their obligations under the directives.

This review of the action being taken begins with the process of consultation taking place to ensure that the views and interests of those most likely to be affected are taken into account before new laws are passed. This includes organisations representing those vulnerable to discrimination as well as employers and trade unions. It then considers the main features of the new laws which have been introduced or are planned as well as the measures taken to support them.

ESTABLISHING INDEPENDENT BODIES TO ASSIST IN COMBATING DISCRIMINATION

In Great Britain, the Commission for Racial Equality was established in 1976. Its functions include eliminating discrimination, promoting equality of opportunity and good relations, issuing guidance and advice to individuals and businesses about their legal rights and obligations and monitoring the effectiveness of legislation. More recently, the Disability Rights Commission was set up in 2000 with similar responsibilities following the passing of legislation to protect people with disabilities. In Northern Ireland, a single Commission for Equality was established in 1999. The government is exploring the possibility of moving towards a single commission for Great Britain in the longer term and is consulting widely about the merits of this.

In Belgium, the Centre for Equal Opportunities and Opposition to Racism (CECLR) was set up in 1993 to help combat racial discrimination. Its activities include carrying out surveys, publishing reports, submitting recommendations on discrimination issues to government, organising training and coordinating dialogue with NGOs. Under the new laws, it was given responsibility for dealing with all the other forms of discrimination covered in addition to that based on ethnic origin. Its role was also extended by enabling it to take up complaints from the victims of discrimination, mediate between the parties involved and monitor the implementation of the two new laws banning discrimination.

In the Netherlands, the Equal Treatment Commission was set up in 1994 as an independent body to deal with complaints of discrimination on grounds of religion, sexual and political orientation, nationality and marital status as well as ethnic origin. Its responsibilities will be extended to cover age and disability once the two bills being considered at present are adopted. It can undertake investigations on its own initiative to see whether

there is systematic discrimination in particular public services or parts of the private sector and it can take legal action, if necessary, to bring these to an end. It is required to publish annual reports on its activities and to report every five years on the way legislation is working.

In Ireland, the Equality Authority was established in 1999 as an independent body under the Employment Equality Act. Its mandate includes working for the elimination of discrimination and promoting equality of opportunity. It is also required to publicise the features of the legislation which exists against discrimination. An additional organisation, Comhairle, was set up in June 2000, as a network of citizen information centres, to advise disadvantaged groups, such as ethnic minorities, on how to exercise their rights to social services. It also provides information on equipment and the design of buildings to ease the problems of people with disabilities.

In Sweden, the Ombudsman for Ethnic Minorities was established in 1986 to give advice and assistance to people suffering discrimination, to help them take cases to court and to monitor compliance with legislation. The Ombudsman for Disability was set up in 1994 and that for sexual orientation in 1999 with the same functions.

In Finland, the Ombudsman for Minorities was established in January 2001 with similar functions as in Sweden. It is proposed to strengthen the powers of the office and create an additional body, the Board of Discrimination, with the ability to enforce decisions of the Ombudsman and forbid discriminatory action.

In Luxembourg, the inter-ministerial committee responsible for proposing the legislative changes required to comply with the two directives has suggested creating a specialised body to deal with discrimination on all the grounds specified in them.

Similarly in Austria, the draft amendments to legislation propose extending the responsibilities of the Commission for Equal Treatment (*Gleichbehandlungskommission*) and the Office for Equal Treatment (*Gleichbehandlungsanwaltschaft*) to cover all the grounds of discrimination. The Commission mainly examines general issues relating to discrimination but can pass decisions which are non-binding in individual cases of dispute between employers and employees. Its general concern is to settle cases through mediation. The Office for Equal Treatment advises and assists victims of discrimination.

Sharing the burden of proof

People suffering discrimination also need to feel that they have a reasonable chance of being successful if they decide to take action against the person or organisation responsible, that the odds are not stacked against them in any case they might bring. For this reason, the requirement in the directives for the burden of proof to be shared between the two sides involved is of major importance. It is not a common aspect of the legal system in EU Member States and so requires a departure from established practice. At the same time, it has already been introduced as a feature of gender equality legislation in many countries.

Preventing victimisation

It is equally important that those suffering discrimination are protected against victimisation or reprisals being taken against them if they take action to defend their right to be treated equally and fairly. This again is a new concept in many countries. Nevertheless, it is being included in the legislation being introduced across the Union. the person accused of unfair treatment to demonstrate that there are valid reasons for their behaviour. In Denmark, Spain, the Netherlands and Sweden, it is planned to include the same provisions on the sharing of the burden of proof in legislation banning discrimination on various grounds as those incorporated in gender equality laws.

Recommendations from ENUSP to the European Commission

by Peter Lehmann (November 4, 2003)

Quality standards

- ➤ Effective participation of legitimised and trained (ex-)users and survivors of psychiatry in the implementation and development of quality standards and research projects at all levels
- ➤ Pro-active guarantee of the respect of human rights (non-discrimination, protection of human dignity, right to inviolability of the person, right to self-determination, right to privacy) e.g. through legal protection of advance directives or loss of licence to practice in case of treatment without informed consent; introduction of a suicide register (with special consideration of associated psychiatric drugs, electroshocks, restraint and other forms of

compulsion, harassment and discrimination)

Organisations of (ex-)users and survivors of psychiatry

- Political and financial reinforcement of independent organisations representing (ex-)users and survivors of psychiatry and their projects (e.g. alternative crisis centres, counselling centres, public relations work, research projects, peer coaching, self-help centres) at all levels
- ➤ Participation of legitimised representatives of (ex-)users and survivors of psychiatry in decision-making bodies and in congresses and other events (at least for two, work should be paid)
- ➤ Financial support for networking and international exchange of organisations representing (ex-)users and survivors of psychiatry

Boards of appeal

- Organised nationally, regionally and locally
- Legally covered, controlled by (ex-)users and survivors of psychiatry, low barrier (anonymous upon request)
- Independent from medical and psychiatric institutions
- > Paid work
- ➤ With powers and structural guaranteed possibilities to sanction institutions and to influence the decision-makers

Any comments please send to: ENUSP Desk desk@enusp.org

The Psychiatric Will – A Special Advance Directive

by Peter Lehmann

Advance directives are one possibility to create equal opportunities. To explain its functioning, I repeat here parts of the lecture »Le testament psychiatrique« given in the name of ENUSP at the

Conference RESPONSABILITE, DROITS ET PROTECTION DANS LE CHAMP DE LA SANTE MENTALE EN EUROPE, Madrid 7. – 9. October 1994, organized by the Comité Européen: Droit, Ethique et Psychiatrie (C.E.D.E.P., Seccion espanola)

In 1983 I received an article from USA about legal protection against involuntary psychiatric treatment. The author, a psychiatrist, had written in 1982, that a new legal mechanism accommodating the interests of both those who support and those who oppose such interventions was proposed. Referring to the model of the last and the living will, the psychiatric will would provide a mechanism, so that individuals could plan, while undoubtedly rational and sane, how they wish to be treated respectively not treated in the future, should others consider them to be irrational or mad. Individuals who dread psychoses and desire protection from them by embracing, the use of involuntary psychiatric interventions could execute a psychiatric will in keeping with their beliefs. Individuals who dread psychiatry and desire protection from it by rejecting, regardless of »need«, the use of involuntary psychiatric treatment could execute a psychiatric will in keeping with their wishes and beliefs. Thus, no one who believes in psychiatric protections would be deprived of its alleged benefits, while no one who disbelieves in it would be subjected to its policies and practices against his or her will. So psychiatric patients would have equal possibilities like socalled normal patients.

The legal situation in the psychiatric institution

You all know the legal situation in psychiatry. There is a wide violation against the European Human Rights' Convention. The important one here is the mistreatment with chemical substances and with electroshocks: The neurotoxic psychodrugs, used too in totalitarian states to torture political opponents, lead to a reduction of the absorbtion of oxygen of the brain cells. The hormone system and the transmitter system are blocked; there is an organic disease of the brain, nearly identical to the symptomatology of encephalitis lethargica. Under neuroleptics about 90% suffer from brain atrophical states, brain cells die; 90% suffer from movement disorders; 30% from fever attacks; up to 100% from pathological changes of the electroencephalogram; 50% from inflammation of the gums, often combined with loss of teeth. And there are other damages of the autonomous system, like liver disease, diabetes, obesity, sterility, absence of menstruation, impotence, pigment deposition in the eyes and in the

heart muscle, breaks and splits of chromosomes, which may lead to identical mutations as caused by thalidomide (Contergan). Other damages are psychic deadening (called »zombie-effect«) loss of will, states of desperation and danger of suicide, dizziness and delirium. All these disorders are caused by all neuroleptics, low and high potent ones, by low and »therapeutical« doses, by short and prolonged duration of administration. It is an illusion to separate dangerous doses from harmless ones. Even minidoses, one time administered, can lead to extremely dangerous dystonic attacks, i.e. means people might die of suffocation.

Electro- and insuline-shocks are still in use; they are just as bad or probably even worse. Neuroleptics like these shocks lead to an artificial brainorganic psychosyndrome. Electroshocks cause epileptical fits. There is an internal damage to the brain cells by electrical current and by bleedings in the brain; nerve cells are damaged and die.

In the psychiatric institution

If you are committed in the psychiatric institution and claimed to be mentally ill, you cannot decide freely to accept or reject offered treatment methodes, as it is in a normal hospital for normal ill people. In the psychiatric institution the legal situation looks like this: If you accept the administration, you are called »understanding the illness«. They accept your decision. There is no information about risks, no informed consent. The same situation, another scenario: You say no, but now they do not accept your decision, they call it »lack of understanding the illness«, typical symptom of mental illness, they may give you a special additional diagnosis »Noncompliance of medical treatment« (DSM-III-R [Revisited] No. V15.81, and forcibly they administer their injections. No information, no decision, no consent. You have no choice there. – You have to decide previously. In form of the Psychiatric Will. But be careful, there

Special Psychiatric Wills

Since 20 years psychiatrists write about the necessarity to previous-decisions about psychiatric treatment

- to give previously consent to trials with new chemical agents
- to give previously consent to forced treatment with neuroleptics and electroshocks
- to give previously consent to forced commitment

 to annul previously all declarations of will, done later in the psychiatric institutions.

You may laugh about these special forms of Psychiatric Wills. But in any way: even typical psychiatrists see eh possibility of previously decisions, and of course each decision includes a proand contra-tendency.

In Germany, where the Psychiatric Will now (1994) is quite famous, after the magazine *Spiegel* published about it in 1993 (»Chemische Knebel, Vol. 23, No. 23, p. 83), psychiatrists offer a special treatment contract: For the case, that they do not longer want to wait to administer their neuroleptics, you can set priorities previously, what they should do first and what latest. You can choose between forced carceration, forced neuroleptic administration, forced fixation and forced isolation. What a liberty of choice.

All the Psychiatric Wills, written by members of the institutional psychiatry, know only one will: their own. Never ever even they think theoretically at an opponent will. Not to confuse readers, in Germany we use the term psychiatric testament, to make clear, that we and not a psychiatrist make a decision.

By the way, the Psychiatric Will is not comparable with the Crisis Card, coming from England, where you can write down wishes, or with treatment contracts in any form: The Psychiatric Will is a declaration of your will, which is legally binding. The right of self-determination is protected by the general human rights' declarations and is more than a wish or a subject under negotiation.

The Psychiatric Will in Germany

Together with lawyers (ex-)users and survivors in Berlin developed a model declaration, which you can use as basis for the declaration of your will. The time is to short to read the whole 12 pages. You may have a look in the German separately, see: www.faelle.org/pt.pdf

This form includes a general information how to use the Psychiatric Will, a general model text including an legal information, even for psychiatrists, so that they know about their possible very illegal treatment, a declaration about persons of your own trust, who organize lawyers to fullfil your Psychiatric Will or who should take treatment or other guardianships, if a judge thinks it is necessary, and a part of declaration, where you can write down your individual wishes. May be, you can say, only 1/2 mg of thioridazine (Melleril), or anything you think you can stand, even electroshock by force (not more than 1 a day) –

it's your decision, or you say No to psychiatric treatment methods.

Experiences

In all the years from 1987 to 1994, if the Psychiatric Will was written correctly and a lawyer and the assigned persons of trust have been active to enforce the written will of the inmate, no psychiatrist has risked violating the Psychiatric Will. In 1990 the first leader of a Berlin psychiatric institution promised publicly, that in his institution Psychiatric Wills would be accepted without any discussion. Judges explained that they would not and could not impose any treatment-guardianships upon inmates, if these resist treatment but have a Psychiatric Will written well before commitment to suppose a different will of the so-called psychotic subject.

Limitations of the Psychiatric Will

Until today (2004) no court had to decide about the legal binding state of the Psychiatric Will. There was no violation, I correct: we did not hear about its violation. There could be limitations, f.e., in the text is a part, where you can decide previously, that in the supposed state of madness all your declarations you do inside a psychiatric institution are invalid. We have such a passus, to make it more difficult for psychiatrist to try any extortions of consent: What is, when, under such conditions, a subject previously rejects and later accepts? Is the consent valid then? Not to give a poor minded judge the chance to make a bad decision, and all later cases are decided in the same way, as it is typical in the law system, we adviced all survivors not to fight for compensation in such a situation. And there is a paragraph in all national laws, that forces physicians to treat in case of vital indication and unconciousness. They are allowed to suppose that the treated persons later would give their conset in the state when they can make a non-doubted rational decision. But in this case a psychiatrist had to proof that the forcibly treated person would have died in case of no treatment. I cannot imagine how a psychiatrist could give any proof that a person dies if he does not inject haloperidol in its backside.

Who can make a Psychiatric Will?

Declarations respective the own body are no legal transactions. These are most personally declarations. Even a person who is considered legally incompetent and cannot make a contract of sale, is considered by law to make his or her own decisions about the own body. The premiss is only the required ability to insight and to build a will. Not-

adults may fullfil this premiss in the same way as persons under guardianship.

What now?

The majority of psychiatric inmates is with poor legal protection against forced treatment, without information about the risks of neuroleptic and other psychiatric drugs and shock-methods. The legal situation should be the same one like in normal ill or healthy persons. But as long as our human rights are considered to be dependend from psychiatric diagnoses, and in consideration of the psychiatric assault and the lack of interest by nearly all politicians and judges in the structural human rights' violations, we have to protect ourselfes foresighted planning. I mean all of us, because everybody can get mad, and in elderly homes, where we all can come to, the use of neuroleptics is very widespread.

Finally, the early reflection on possible future problems (Who will help really if help is needed? What do I need if I go crazy? etc.) has a big therapeutical value and may result in a decrease of danger becomming a psychiatric patient. And a correct Psychiatric Will makes the life still more secure against psychiatric assault. As a result of the Psychiatric Will's convincing logic – the international movement of (ex-)users and survivors of psychiatry took on this exemplary strategy of self-defense and self-responsibility.

In memoriam Hubertus Rolshoven

by Peter Lehmann

A sad information: The Berlin lawyer Hubertus Rolshoven died on February 24, 2003. It was he, who in the early 80s developed with independent (ex-)users and survivors of psychiatry in Berlin the Psychiatric Will. Unimpressed by white coats, academic degrees and psychiatric ideology not only in his job, but also as a private person, he always was on the side of the disadvantaged discriminated and people.



Hubertus Rolshoven * July 27, 1946 † February 24, 2003