

# Securing Human Rights in the Psychiatric Field by Utilizing Advance Directives

Peter Lehmann

**SUMMARY:** Psychiatry as a medical (and natural scientific) discipline cannot do justice to the expectation of solving mental problems that are largely of a social nature. Its diagnostic methods obstruct the view of the real problems of individuals in society. Its propensity and practice to use force constitutes a threat against the human right to bodily integrity. People with physical medical diagnoses have the right to say no; the same right is denied to people with psychiatric diagnoses. So they need to protect themselves by special means.

**KEY WORDS:** discrimination, citizens' rights, coercion in psychiatry, advance directives

'Laws on equality of treatment should be adopted' was one recommendation of the study *Harassment and Discrimination Faced by People with Psycho-social Disability in Health Services*. This study was conducted from 2001 to 2005 on behalf of the European Commission. Those involved were organisations of users and survivors of psychiatry and organisations of psychiatric workers and relatives of psychiatric patients, from numerous countries: Mental Health Europe, Pro Mente Salzburg (Austria), MIND (England & Wales), Clientenbond (The Netherlands), FEAFES (Confederación Española de Agrupaciones de Familiares y Personas con Enfermedad Mental – Spain), BPE (Bundesverband Psychiatrie-Erfahrener e.V. – Germany) and ENUSP (European Network of (ex-) Users and Survivors of Psychiatry), as well as the Belgian research institution LUCAS (Belgium). The result of the study was evidence that all over Europe, people with mental health problems (or people who are considered mentally ill or disabled) are discriminated against, i.e., treated less favourably than people with medical diagnoses; in doctors' practices of all kinds, in hospitals; in emergency

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units; and in psychiatric clinics. They experience discrimination in different forms: hostility; physical problems not being taken seriously; psychiatric drugs prescribed without informed consent; complaints dismissed as part of pathology; the right to access their own treatment records denied; and threats of discharge, separation, forced treatment, or higher dosages of psychiatric drugs if they do not accept prescribed treatment.

In order to enable people with mental health problems to enjoy full citizens' rights, their organizations should be involved in policy-making at all levels. Legislation on discrimination and boards of appeal were demanded from politicians, administrative authorities, and organized psychiatry:

Laws on equality of treatment should be adopted and funds provided so that these laws can be put into practice. One major objective is to adopt laws that guarantee the respect of human rights in a pro-active way. These laws should focus on the protection of human dignity, the right not to be violated, the right to self-determination, the right to privacy and the right to respect. For example through legal protection of advance directives ... (Action Project, 2005).

### **Legal protection of advance directives in Germany**

In Germany, people who want effective legal protection from violation of their bodily integrity – usually through violent administration of psychiatric drugs – or even protection from unwanted psychiatric examination can do this by executing advance directives. In 2009, when the national guardianship law was reformed, it included a provision for advance directives for health care. Under the revised law, an adult considered capable of consent has the right to affirm in writing ‘independently of the type and stage of an illness’ whether he or she ‘assents or disagrees with treatments, diagnostic procedures or medical interventions that are not immediately forthcoming at the time of this declaration.’ Literally, the German Civil Law Code states:

#### **Advance Directive for Health Care**

1) If an adult considered capable of consent declared in written form, whether he or she assents or disagrees with treatments, diagnostic procedures or medical interventions that are not immediately forthcoming at the time of the declaration (advance directive for health care), then the guardian will investigate, whether these determinations apply to the current situation of life and treatment. If this is the case, then the guardian has to enforce the will of the person under guardianship in its expression. An advance directive for health care can be withdrawn informally and at any time.

- 2) If no advance directive for health care is available, or if the determinations of an advance directive for health care do not apply to the current life situation and treatment situation, then the guardian must investigate the treatment wishes or desires of the person under guardianship to determine that individual's presumed will and decide on this basis whether he or she consents to a medical measure in accordance with section 1 or whether he or she forbids it. The presumed will has to be determined based on concrete indications. In particular, earlier verbal or written expressions, ethical or religious convictions and other personal moral values of the person under guardianship must be considered.
- 3) Sections 1 and 2 apply independently of the type and stage of illness of the person under guardianship.
- 4) Nobody can be obligated to establish an advance directive for health care. Production or execution of an advance directive for health care must not be made a condition of a contract (BGB, 2009).

### Looking back

After publishing, lecturing, and teaching lawyers and politicians for decades, mainly in the German-speaking countries, the campaign for legal protection of the psychiatric will, started in 1983, finally succeeded. Before people start to reply, 'Not possible in my country,' they should take a look at the developments in Germany. The campaign for the legal protection of advance directives took nearly a quarter of a century. People often said there was no chance of advance directives working in Germany.

In 1983, the independent self-help organisation Irren-Offensive (Lunatics' Offensive) – then an undogmatic group of survivors of psychiatry – received the article 'The Psychiatric Will: A New Mechanism for Protecting Persons Against 'Psychosis' and Psychiatry,' by Thomas S. Szasz (1982). Szasz proposed to translate the article into German and publish it. In his article, he referred to the idea of Walter Block, an Austrian school economist, anarcho-libertarian philosopher and Professor of Economics at Loyola University New Orleans, that it should be possible to apply the mechanism of protecting a person's last will to involuntary psychiatric treatment.

Unmentioned by – and perhaps unknown to – Szasz, two decades earlier the American former psychiatric patient Mary Ellen Redfield (1964) had drafted and published an advanced directive to protect herself from unwanted psychiatric treatment. In her article 'Upholding Psychiatric Advance Directives – 'The Rights of a Flea,' Laura Ziegler, past president of the National Association of Rights, Protection and Advocacy (US), recognised Redfield as the first to publish about this issue:

In 1964, Mary Ellen Redfield self-published *Will for Living Body*, a draft contract with doctors and lawyers that authorizes them to act as temporary guardians if she becomes comatose or of unsound mind. They are pledged to 'secure immediate remedial legal aid' should she fall into the power of doctors who will not honor its terms: refusal of all forms of psychiatric treatment, including those not yet invented. She exempts and welcomes consensual psychotherapy, and invalidates any consent given while drugged or of unsound mind. Declaring 'NO FAITH' in psychiatry she prohibits imposed alteration of her mind, in the expressed faith that she is sovereign over her psyche and soul (Ziegler, 2007, p. 318).

Nevertheless, Szasz' article was translated into German, and – supported by a grant of Netzwerk Selbsthilfe e.V. (Network Self-help, Inc.) – published and distributed as a booklet (Szasz, 1987). The booklet included a form, which had been discussed and developed with Berlin lawyer Hubertus Rolshoven (Lehmann, 2003). The form included a legal instruction to psychiatric workers, space for personal data, different options, and space for referring to personal experiences to justify and strengthen the decisions about specific desired or rejected forms of treatment – especially specific psychotropic drugs or classes of psychotropic drugs. There was no law to cite except the criminal law, which defines each intrusion on bodily integrity as a criminal act which loses its criminal character only if there is informed consent or if there is a life- and health-threatening emergency where people are unable to give consent and the psychiatrist believes that afterwards, when the person is in a rational state again, he or she would surely agree with the psychiatrist's decision. Probably this legal construction is similar in most countries.

The idea was, if there is a statement written by the person while in a state of unquestioned normality/rationality and the psychiatrist is aware of this statement (i.e., after it was handed over in the presence of a witness or sent by registered mail), it will be made absolutely clear to the psychiatrist that the person would not agree afterwards with the treatment without informed consent. Otherwise, the psychiatrist could be subject to civil and criminal liability. Since it would always be uncertain what a judge would decide, the psychiatrist would be aware of standing with one foot in prison.

In the decades that followed, information about the psychiatric will was distributed, articles were written, and booklets were published. Activists went to hearings, gave lectures at conferences and for political parties, and initiated and facilitated public discussions. Of course, the surprise was great when the German parliament finally integrated the concept into the guardianship law and recognized the psychiatric will.

### Not possible in your country?

In discussions with critical people in the psychiatric field, the reaction often was – and is – ‘Not possible in my country,’ because it has no special law that affirmatively recognises and protects a psychiatric advance directive. If you look at the German experience, it took some education to teach people, including lawyers, that although the criminal law could and should be the legal basis for advance directives, because of the usual discrimination against psychiatric patients, it is better if the law specifically recognises advance directives like the psychiatric will.

Additionally, in Germany, articles and books were published about the massive dangers caused by psychiatric drugs, especially by neuroleptics, the drugs mainly used for coercive treatment. In earlier years, jurists’ perceptions of the illegal violent administration of psychiatric drugs were undermined by the myth that ‘people with psychoses need neuroleptics like diabetics need insulin.’ Why should they fight for a right to say no to insulin treatment? But over the years, the interested public was educated about neuroleptic-induced obesity and disorders of fat metabolism; high blood pressure and insulin resistance (which may develop into an exceptionally dangerous metabolic syndrome associated with a high risk of massive vascular diseases, myocardial infarction, and apoplectic stroke); chronic deficit-syndrome (neuroleptic apathy syndrome or ‘broken wing’-syndrome); suicidality; delirium; breast cancer; malignant hyperthermia; neuroleptic malignant syndrome; cirrhosis of the liver; chronic diabetes; agranulocytosis; thromboses and embolisms; cardiac complications of all kinds; damage to the retina, the cornea and the optic nerve; loss of teeth; asphyxia; tardive psychoses and dyskinesias; apoptosis (death of brain cells) and increased mortality (Lehmann, 2013). So the argument that violent administration of psychiatric drugs is good for your health was finally doubted by judges.

Different judgments of the Federal Constitutional Court of Germany denied, in individual cases, psychiatrists the right to forcibly administer their drugs because of the substantial violation of the patient’s fundamental right to life and physical integrity. The court called this long-time practice illegal and demanded a new legal basis, which must conform to the stipulations of the UN Convention on the Rights of Persons with Disabilities (CRPD).

As a consequence, the Central Ethics Commission of the German Federal Medical Society now demands that more attention be paid to the patient’s moral values and beliefs. Patients’ subjective perspectives cannot simply be replaced by an ‘objective view’ and medical discretion. If the ‘illness’ impairs the patient’s assessment regarding the usefulness of a medical intervention, what is relevant then is ‘... the moral values the patient would have (or had previously), when in

a condition of capacity to give informed consent for medical treatment while they were not impaired by illness' (Zentrale Ethikkommission, 2013, p. A1336).

The UN CRPD, ratified by many countries' governments and thus legally binding, forbids legal discrimination against people with disabilities (including those with psychiatric diagnoses) and demands a move from substitute decision-making to supported decision-making (see Minkowitz, 2013).

In 'Article 12 – Equal recognition before the law', the UN CRPD, which entered into force on May 3, 2008, states:

- States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law
- States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life
- States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity (United Nations Enable)

Just like people with physical medical diagnoses, people with psychiatric diagnoses must have the right to refuse unwanted medical interventions. Rolf Marschner, a German lawyer explains:

In article 12 of the UN CRPD the prohibition of discrimination for the field of legal capacity and right to execute it is concretised, and thus the capacity to give informed consent for medical treatment. Namely, in article 12 the execution of force is not mentioned directly. But the recognition of the legal capacity of disabled persons and their right to execute it on an equal basis before the law with others means that disabled persons can decide like others about their residence and their treatment, and namely independent from the type and occurrence of their disability. Thus this works for mentally disabled and mentally ill persons. Insofar as the UN CRPD also forces a rethinking of familiar legal concepts in regard to the term of incapacity to give informed consent for medical treatment, because, from the consent for medical treatment by a legal guardian, direct legal consequences (legal limitations) can be deduced from the disability itself. (...) Article 12 section 3 of the UN CRPD demands to offer the formulation of an advance directive or the arrangement of a treatment contract (Marschner, 2013, pp. 220–1).

What is evolving is a right for people who might become targets of forced psychiatric treatment to decide beforehand how they want to be treated and how they do not want to be treated, or who are the persons they trust to make decisions in states of mental emergency, when their own decisions are not accepted as

rational. So advanced directives are regarded as an effective way to create equal recognition before the law for people considered presently incapable of consent.

### **Self-help virtues of advance directives**

As described above, people now can protect themselves from unwanted psychiatric interventions, subject to limitations concerning the difference between law and justice, and the fact that the totality of all possible human and emotional conflicts cannot be solved in advance by a written statement.

To consolidate this success, it is advisable to base advance directives on individual experiences of adverse effects from psychiatric drugs (or electroshock), as well as propose how to respond to emotional crises with measures not involving psychiatry. By anticipating courses of crises and their resolution, advance directives also have important self-help virtues. People no longer see themselves as a function of disturbed genes, metabolism, families, neighbours, policemen and other entities. They now see themselves as subjects who can plan their lives themselves. They have a better chance of not ending up in the doctor's office again so quickly when they learn to understand their personal involvement in the creation of their life-history and how to manage their problems and ensure that their wishes are put into effect. Miriam Krücke, a German student of psychology, wrote a thesis about the use of advance directives, and interviewed some people who had produced advance directives about their failures and benefits. She stated:

Advance directives stimulate a more differentiated approach to the course of the crisis, including early warning signs, habitual responses and appropriate alternatives. In the same manner, the recourse to professional services can be organized before the event. The current development of an informed opinion results from a systematic review of past experiences. 'The idea was also to find out at what point the course had been set, to what extent I myself was involved, basically the point when I – and I can do this now looking back – could have already recognized what kind of conflict situations I was getting into. I have learned to see clearly how my crises have developed and how I can behave and which people can help me. My psychiatric will specifies what kind of support I want instead of psychiatric drugs. I certainly consider the possibility of a relapse ahead of time. I have given a great deal of thought to the causes of my madness and to alternative means of dealing with it.' (Krücke, 2007, pp. 99–100 / 2014).

Meanwhile, in Germany, there are various forms for advance directives, which are offered from different legal bodies. Some are useful, while others seem silly (Lehmann, 2014, p. 46). People have to be careful, and they should

mix components from different forms, according to their different personal experiences and values. Over the years, there have been both positive and negative experiences with psychiatric advance directives. The last two pieces of information about advance directives received by the author of this paper were about a psychiatrized psychiatrist whose advance directive was ignored and who subsequently sued for damages (the case is still undecided), and about another psychiatrist who expressed his fear that patients with advance directives forbidding examination and forbidding administration of psychiatric drugs could be committed to his ward. Implementing humane alternative treatment could solve so many problems (Stastny & Lehmann, 2007; 2014).

The development of advance directives in Germany demonstrates that not only is it sometimes possible to uphold autonomy through the judicial system and to overturn discriminatory statutes, but that advance directives have extraordinary potential in the struggle for self-determination and toward securing the human right to bodily integrity for people targeted for psychiatric intervention.

### **Update (October 2014)**

On September 23, 2014, the German Society for Psychiatry and Psychotherapy, Psychosomatics and Neurology (DGPPN) published an 'Ethical statement on self-determination and compulsion,' in which they publicly admitted the effectiveness of advance directives:

Advance directives are also obligatory in mental illnesses, as long as the legal conditions are fulfilled (among others, written form, given ability for self-determination at the time of the drawing up). Their legally binding effect protects patients so that their treatment options will not be ignored, but also highlights the high responsibility patients have for their own health and for the own treatment process (DGPPN, 2014).

### **Notes**

For more information on this subject see:

Jim Gottstein's Law Project for Psychiatric Rights (<http://psychrights.org/Research/Legal/AdvanceDirectives/AdvanceDirectives.htm>), especially 'Advance Directives in Various Countries' (<http://psychrights.org/Countries/AdvanceDirectives.htm>).

Peter Lehmann Publishing with a list of Danish, English, French, German and Greek articles on the psychiatric will and other advance directives ([www.antipsychiatrieverlag.de/info/pt-uebersicht.htm](http://www.antipsychiatrieverlag.de/info/pt-uebersicht.htm))



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