

## **"Recognition and Protection of Patients Rights"**

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## Foreword

The promotion of patients' rights requires the support of different actors: public authorities taking legislative, administrative and judicial action; the healthcare professions in their own conception of their activities and in their everyday implementation of these activities; last but not least, the participation of the patients themselves.

The enunciation of patients' rights has been an important development in the course of the last decades. On the European level, the Convention on Human Rights and Biomedicine represents one of the most significant advances in this direction. The Convention establishes the principles of dignity, autonomy and protection of integrity and the other fundamental rights of the person. The additional Protocols being elaborated are to develop these principles in the form of regulations specific to each field of activity.

Healthcare professionals are becoming more and more conscious of the importance of acknowledging an active role for the patient. It is essential to encourage this evolution of mentality which contributes also to the establishment of a climate of confidence between the patient and the physician.

The associations for the defence of patients' rights are, I believe, called to play an increasing role, such as in the relations with the public authorities and in the everyday help to patients. The number and the importance of such these organisations varies greatly between countries. The public authorities need to acknowledge their role and promote the participation of the associations in the decisionmaking processes.

Without sincere cooperation between these diverse actors, respect for the fundamental rights of the patient cannot be effective.

Carlos de Sola  
Head of the Bioethics Division  
Council of Europe

## 1. Bio-ethical Convention; European Norms and National Legislation on Patients Rights

Toma Birmontiene<sup>1</sup>:

### ON THE CONVENTION ON HUMAN RIGHTS AND BIOMEDICINE AND LITHUANIAN LEGISLATION

Due to well-known historical circumstances, Lithuania did not participate in the development or application of international principles on human rights for many decades. After regaining its independence in 1990, Lithuania had to integrate a great number of international legal provisions in its legislation. The protection of the rights of patients came into focus of attention immediately after the restoration of independence when efforts were made to stop the abuse and denial of human rights in psychiatry, which had been widely practised under the soviet regime. The rights of patients as an important area of human rights were developed in Lithuania under the influence of international standards and human rights instruments and of other countries' experience.

The Constitution of the Republic of Lithuania was written, in 1992, with due regard to the respective documents of the United Nations and the Council of Europe, therefore it complies with the fundamental international requirements of human rights. This fact was confirmed by the Constitutional Court of the Republic of Lithuania in its opinion, adopted on January 24, 1995, on the conformity of the Constitution of the Republic of Lithuania to Articles 4, 5, 9, and 14 of the Convention on the Protection of Human Rights and Fundamental Freedoms, and Article 2 of its 4<sup>th</sup> Protocol.

Subject to the provisions of Article 138 of the Constitution of the Republic of Lithuania, international treaties ratified by the Seimas (Parliament) are part and parcel of the law of the Republic. The provisions of the Constitution are also interpreted in the Law on International Treaties of the Republic of Lithuania (1999). Rights deriving from treaties can be directly appealed to by the citizens before the courts and public authorities.

Lithuania became a member of the Council of Europe in 1993. In 1995, Lithuania ratified the European Convention on Human Rights, which has made a significant influence on the development of new legal doctrine in Lithuania. The European Convention on Human Rights is a particular sort of international treaty, different from other treaties on human rights. Its special character derives from its providing for an effective mechanism of implementation. A person who thinks that his rights enshrined in the Convention are violated can address directly to the European Court of Human Rights.

A number of laws on various aspects of the rights of patients in 1995-96 was determined by the concern of the politicians about the compliance of Lithuanian provisions on human rights with the requirements of the European Convention on Human Rights and other international documents regulating human rights.

In the above-mentioned period a series of legal instruments have been adopted in the domain of rights regarding health care, such as the Law on Mental Health Care (1995); the Law on the Rights and Injuries of Patients(1996); the Law on Transplantation and Donation of Human Tissues and Organs(1996); the Law on Blood Donation(1996); the Law on Registration of Death Cases and Critical Conditions(1997); the Law on the Prevention and Control of Communicable Diseases (1996); the Law on Health Insurance and some others (1996). Somewhat earlier (in 1994), the Parliament adopted the Law on Health Care System which is to be considered as an unsuccessful attempt of legislation. This is because the intention was for the Law to cover all the areas of health care, which is very difficult to do in a legal framework that is just emerging and taking shape. Although this law has been amended several times, some of its provisions are not properly effective even now. Amendments have been made to several other laws which have been mentioned here also.

The provisions of the Constitution of the Republic of Lithuania and the European Convention on Human Rights have been major sources of stimulation for the adoption of a number of laws. In 1995, Seimas adopted the Law on Mental Health Care that provides for a detailed regulation of the rights of mental patients, of conditions for the application of involuntary hospitalisation and treatment. The Law on the Prevention and Control of Human Communicable Diseases was passed in 1996. The Law defines the circumstances under which a person unwilling to undergo treatment for a dangerous communicable disease may be forcibly placed in hospital and treated.

1996 was the year when Seimas passed the Law on the Rights and Injuries of Patients. The Law covers a wide spectrum of patients' rights, including informed consent to treatment, confidentiality of information on the patient's health, etc. A lot of attention goes to the rights of under-age patients. Information to a patient who is a minor or to his parents and guardians must be provided in a form comprehensible to them. If there are disagreements between the minor and his parents or guardians in presenting the information, the physician providing treatment must be guided by the interests of the patient. A minor patient who, in the opinion of the physician, is capable of appraising properly the condition of his or her own health, shall have the right to address independently the case and decide upon the treatment that has been proposed for him. Upon the request of the parents or guardians of the minor, the physician must advise the legal representatives of the minor regarding the treatment. However, such information may

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<sup>1</sup> Director, Lithuanian Human Rights Center

also be withheld on the request of the minor if sharing it would do considerable harm to his or her interests, unless other legal acts provide for otherwise. If the minor is hospitalised, his parents or guardians must be informed of this (Article 6).

It is to be regretted that due to the changes in the insurance policy of Lithuania and also due to the insufficient funds allocated by the Government to public health care institutions, the provisions on the payment of damages for injuries done to patients' health on the no fault liability grounds, are not currently applied in practice. The Ministry of Health has been working on the draft amendments to this Law for several years, but we have not seen any practical results yet.

The Law on the Rights of Patients has been influenced by the Declaration on the Promotion of Patients' Rights in Europe (1994) and the legislation of Finland. The Law is in conformity with the provisions of Article 8 (Right to Respect for Private and Family Life) and Article 10 (Freedom of Information) of the European Convention on Human Rights. The Law on the Rights of Patients provides the basic principles of the rights of patients. It does not cover all the specific fields such as transplantation, artificial procreation, biomedical research, mental health issues and others.

The Law on Transplantation was passed in 1996. It provides for a detailed regulation of transplantation of tissues and organs removed from a deceased person or a living donor. The Law is based on the concept of consent. A person while alive can express his or her will regarding the transplantation of his or her organs. If a person dies without having expressed his or her will regarding transplantation (or has not given consent, but has not expressed any objection concerning the transplantation of his or her organs either), the permission to take the tissues or organs of such a person after his or her death could be given by members of the family of the deceased person.

This Law was amended in 1999, though, and some of its provisions are now formulated better from a legal point of view. The Law now includes some additional principles, mentioned by the Convention on Human Rights and Biomedicine. The practical conditions for transplantation have not been changed. The original intention in amending the Law was to provide for the right of an individual to declare his or her objection to the transplantation of his or her organs. If the person has not expressed any objection, the decision is taken by doctors. The legislative intervention was undergoing some changes as a result of public opinion on the issue having been revealed by a poll. (The public opinion poll was being held in May 1999. It was done on the request of the Parliamentary Committee on Health and organised by the Lithuanian Centre for Human Rights. 57.6 per cent of the respondents agreed that after their death the decision on the transplantation of their organs should be taken by their family members; 48.2 per cent preferred to take such decisions themselves by signing certain papers while alive; 83.9 per cent expressed their support for the idea of tissue and organ transplantation).

Thus, a considerable number of laws on the rights of patients had been passed in Lithuania before the Committee of Ministers of the Council of Europe adopted the Convention on Human Rights and Biomedicine on November 19, 1996 and before the Convention was submitted for approval and signature by the member states on April 4, 1997. Lithuania also signed the Convention. The Convention sets standards for the protection of the individual in the context of scientific and technological developments in biology and medicine. Some of the standards are new, particularly those on the protection of the embryo and foetus, and those elaborating upon legal norms and principles contained in general human rights treaties (non-discrimination, protection of physical integrity and privacy). The Convention gives international support to the legal position of the patient by setting a minimum level of protection with respect to individual human rights in the domain of health care. The lack of appropriate international legal enforcement will partly be compensated for by the jurisprudence under the ECHR.

It is important to consider the relationship between the European Convention on Human Rights and the Convention on Human Rights and Biomedicine. The well known 1969 Vienna Convention on the Law of Treaties defined the relationship between international agreements. Under the provisions of the Convention the general principle is that the provisions of an earlier treaty prevail over a later treaty on the same subject matter when the later treaty specifies that it is subject to or not to be considered as incompatible with the earlier one. It has been argued that this applies to the relationship of the European Convention on Human Rights and the Convention on Human Rights and Biomedicine and some other conventions. Due to the importance of the European Convention on Human Rights, more recent conventions do not take precedence over it. The more recent conventions can be assumed to have an effect on the interpretation of the older ones rather than replacing the latter.<sup>2</sup> The general principles of the European Convention on Human Rights provide for a scope of interpretation in the case law of the Convention. Due to such possibilities different aspects of patients' rights are present in the case law of the Convention and are of great importance. It is stated in the preamble of the Convention on Human Rights and Biomedicine, that this document elaborates some of the principles enshrined in the European Convention on Human Rights and other international human rights instruments (such as the Universal Declaration of Human Rights, the International Covenant on Civil and Political Rights, the International Covenant on Economic, Social and Cultural Rights, the Convention on the Rights of the Child, the European Social Charter, and also several instruments of a more specific nature adopted by the Council of Europe, such as the Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data). Thus, the adoption of a new convention should not necessarily supersede the provisions that have already been accepted internationally.

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<sup>2</sup> Oddny Mjöll Arnrdóttir, David Thor Björgvinsson, Vidar Mar Matthiasson: The Icelandic Health Sector Database, *European Journal of Health Law*, 6: p. 327, 1999.



In discussing the relationship between the Convention and national law, the principle enshrined in Article 27 of the Convention is of special importance. It says: “None of the provisions of this Convention shall be interpreted as limiting or otherwise affecting the possibility for a Party to grant a wider measure of protection with regard to the application of biology and medicine than it is stipulated in this Convention.” The Convention could be treated as the first provision and the initial standard which has to be accepted and complied with in the provisions of national laws.

In considering the relationship between the Convention on Human Rights and Biomedicine and Lithuanian laws, we can mention several aspects and possibilities. National laws can be amended with regard to the requirements of the Convention; in some cases, new laws can be adopted. It could also be the case that the area regulated by the Convention is not adequately covered by national legal acts or it is covered by legal acts of a different and inadequate level. For example, in cases when statutory regulation is necessary, the issue is covered by a mere governmental or ministerial decree, or the content of the national legal act does not comply with the content of the Convention.

At present, when an amendment of an existing law on health issues is discussed in Lithuania, the discussion takes into consideration the provisions of the Convention. Some of the provisions have become an integral part of Lithuanian national law. For example, the Law on Transplantation was amended, in 1999, in compliance with Article 19 of the Convention on Human Rights and Biomedicine which states that “Removal of organs or tissue from living persons for transplantation purposes may be carried out solely for the therapeutic benefit of the recipient and where there is no suitable organ or tissue available from a deceased person and no other alternatives of comparable effectiveness”. But the Lithuanian law does not provide for the exceptions spelled out in Article 20 of the Convention that “the removal of regenerative tissue from a person who does not have the capacity to consent (except for an under-age person) may be authorised provided certain conditions are met.” The Lithuanian law categorically prohibits the removal of organs or tissue from a grown-up person who does not have the capacity to consent. Thus, the Lithuanian law provides for stricter limitations on transplantation of organs from a living person. Conditions under which tissue or organs may be removed from a minor comply with the conditions indicated in Article 20 of the Convention (including the requirement that the recipient must be a brother or sister of the donor). If a minor is over 14 years of age, the law requires his or her consent in writing.

The Convention was a direct source of inspiration for the provisions of the draft Law on the Ethics of Biomedical Research, which was adopted by the Parliament on the 11 of May, 2000, and will come into force from the 1<sup>st</sup> of January 2001 on. Although work on this draft law started much earlier (in 1996), its content has changed radically several times. The content of the latest draft is harmonised with the

requirements of the Convention. While no such law was effective in Lithuania, biomedical research was regulated by the legal acts drawn up by the Lithuanian Ethics Committee and approved by a decree of the Minister of Health. The regulation of biomedical research at this level does not comply either with the requirements of the Constitution of the Republic of Lithuania or those of the Law on the Rights of Patients.

Article 21 of the Constitution of the Republic of Lithuania stipulates that no research or medical tests may be made on a person without his or her knowledge and free consent. Some of the aspects of this issue, for example, the consent of the persons undergoing research, are regulated by the Law on Mental Health Care and the Law on the Rights of Patients. Article 18 of the Law on Mental Health Care stipulates that experimental methods of clinical treatment may be applied only for the purposes of treatment on condition that the person has fully understood that his or her treatment is experimental and has given a written consent attested by two witnesses and the chief doctor of the health care institution. Article 7 of the Law on the Rights of Patients stipulates that “without the patient’s consent one may not use him or her in the scientific research in the field of biology and medicine. If the patient is a minor, such consent may be given by one of his parents or the legal representative and the authority for protecting the rights of the child.”

The development of the draft Law on the Ethics of Biomedical Research was influenced by Articles 15, 17 and 18 of the Convention on Human Rights and Biomedicine. The issue of research on embryos was giving rise to most heated discussions. The law permits only clinical observations on human embryos (i. e. non-invasive research). The creation of human embryos for research purposes is strictly prohibited (just as in Article 18.2 of the Convention). The law also includes a provision taken from the Law on Mental Health Care permitting biomedical research on mental patients only if they are capable of giving an informed consent. Their consent must be given in writing and it must be attested in the required way. The law indicates that research on psychiatric patients may be conducted also under some exceptional conditions, such as: research of comparable effectiveness cannot be carried out on other individuals; the results of the research have the potential of producing direct benefit for the patient’s health.

These principles of regulation are determined by Article 21 of the Constitution of the Republic of Lithuania and are much tighter than the interpretation of Article 17 of the Convention in the Explanatory Report to the Convention on Human Rights and Biomedicine on the Conditions of Research on Persons not Able to Consent.

Article 1 of the Lithuanian Law on Ethics of Biomedical Research enshrines one of the main principles – the principle of the primacy of the human being – which provides that the interests and welfare of the

human being shall prevail over the interests of society or science (this principle is transposed from Article 2 of the Convention).

The development of the Law on Ethics of Biomedical Research took a long time, more than any other draft law concerning Health issues, and it has been heavily criticised. The Law includes tighter requirements on control and responsibility. But the fact that Lithuania has signed the Convention facilitated the process of deliberation in Seimas in that it was not necessary to take steps to prove the importance of the Bill.

The provisions of the Law on Artificial Procreation caused a lot of discussions mostly due to the influence of the doctrines of the Catholic Church. This draft (i. e. one of the chapters of the Civil Code) transposes the provision of Article 14 (Non-selection of sex) of the Convention that “the use of techniques of medically assisted procreation shall not be allowed for the purpose of choosing a future child’s sex, except where serious hereditary sex-related disease is to be avoided.”

The problem of interpretation of the provisions of the Convention is also rather important. Under Article 29, the European Court of Human Rights may give, without direct reference to any specific proceedings pending in a court, advisory opinions on legal questions concerning the interpretation of the present Convention at the request of:

- the Government of a Party to this Convention, after having informed the other Parties;
- the Committees set up by Article 32, with membership restricted to the Representatives of the Parties to this Convention, by a decision adopted by a two-third majority of votes cast.

The Convention on Human Rights and Biomedicine covers various aspects of the rights of patients. A number of these aspects, such as access to health care, free informed consent to the intervention in the health field, protection of persons with mental disorders, respect for privacy and right to information, rights of a minor patient in the field of health care, prohibition of financial gain in disposing of parts of the human body, etc., were regulated by Lithuanian laws of the past to a varying degree. But until recently, Lithuanian laws did not spell out the principle of the prohibition of any form of discrimination against a person on grounds of his or her genetic heritage which is of a much broader scope than any other aspect of the patients’ rights and belongs to the level of constitutional rights, and could be discussed in a context of the provisions of the European Convention on Human Rights. There are other provisions in the Convention which will have to find their place in Lithuanian law. The Convention on Human Rights and Biomedicine will stimulate a review and improvement of certain provisions.

There is no doubt that in the field of medicine and biology regulation of human rights is as important as enforcement and implementation. But this could be a subject for another discussion. Implementation and

enforcement of laws on the rights of patients is a complicated process, which is not always taken a proper care in all the fields of health care in Lithuania.

Sjef Gevers<sup>3</sup>:

## MAKING LAWS ON PATIENT RIGHTS: THE DUTCH EXPERIENCE

### 1. Introduction.

In 1994, the Dutch parliament adopted an important law concerning the rights of the patient. The law - the Medical Contract Act - came into force in 1995. This paper provides first of all a picture of its backgrounds, and its main features and contents. Furthermore, it points out how the act relates to developments in Europe, and in particular to the international standards laid down in the WHO-declaration on Patient Rights (1994) and the Convention on Human Rights and Biomedicine (1997). More important than pure description is analysis of the approach adopted in the Netherlands. The second half of the paper addresses the main aspects of the Dutch approach: incorporating patient rights in contract law as part of the Civil Code; limiting the patient rights dealt with to the most important ones and enshrining them in general principles rather than in detailed rules; leaving the further elaboration to the courts and to self-regulation at different levels.

Making a law on patient rights is only one step in a long process. Implementation of the law is as important as, but much more difficult and complex than its formal enactment. Without large support from (the organisations of) patients, health professionals, hospitals and other establishments, health insurers, the government and the public at large, patient rights will not come to life. In this sense, patient rights legislation is as much a reflection, as it is an instrument of social change.

### 2. Development and basic features.

The idea to legislate on patient rights goes back to the 1980's, when the National Council for Public Health offered its advice on the status and further development of patient rights to the Dutch government in a number of successive reports. According to the Council, the safeguards provided by general civil and penal law, by the hospital accreditation requirements laid down in administrative legislation, by professional codes of conduct and by the case law developed by the courts, were insufficient to strengthen the position of patients vis-a-vis health professionals and to give the legal protection of the patient's right to privacy and physical and mental integrity required by the Constitution.

The Council acknowledged the existence of legal provisions on the position of the patient in some specific, atypical situations, such as the involuntary commitment of mental patients to psychiatric hospitals. Nevertheless, the Council recommended additional legislation addressing the legal position of patients in general. It took many years for a law on patient rights to come into existence. In 1990 a first draft was submitted to parliament. The Medical Contract Act was adopted in 1994 and enacted a year later.

A typical feature of the Dutch law is that patients rights are laid down in a law which modifies the Civil Code by introducing in that code provisions on the contract between patient and health care provider. The preference for a contractual approach reflects the prevailing perception of the doctor-patient relationship as a horizontal one, i.e. a relationship in which both parties should as much as possible have an equal position. Using contract law to strengthen the position of a weaker partner in a reciprocal contract is not new in contract law; the legislation on the labour contract, dating from the beginning of the 20th century,

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is an obvious example. By incorporating the doctor-patient relationship in the civil code, not only the special provisions of the medical contract apply, but also the general rules of contract law.

Whereas the main objective of the Medical Contract Act was and is to improve the legal position of patients in their relationship with health care providers, its aim is by the same token to protect their fundamental rights to privacy and integrity. In fact, as we will see, the Act can be considered an operationalisation in the domain of health care of these two basic rights.

Medical care is not just a matter of a principal who orders a certain service and a professional providing the requested service. In fact, what care is provided is not only determined by the patient's informed request, but also - and sometimes even in the first place - by the responsibility of health professionals to act according to their professional standards. A physician, for example, is expected to offer care which is medically indicated, and to act as a responsible physician, i.e. carefully and with sufficient expertise. The Medical Contract Act acknowledges this important role of professional responsibility, by requiring him to act as a 'good' care provider, but also allowing him to do so. This means that his professional standard can play a role in the way patients' rights are realised in practice.

### 3. Main contents.

The Medical Contract Act contains provisions on the following patient rights:

- the right to information;
- the right to give consent before a medical intervention takes place;
- the validity of an advance directive in which a medical intervention is refused;
- the duty to keep a medical record;
- retention periods for medical data;
- the right of the patient to have medical data deleted;
- patient access to medical records;
- confidentiality of medical data;
- the use of medical data for research purposes;
- the legal position of minors;
- the representation of incompetent adults in medical matters;
- the liability of health care institutions under civil law.

I will not discuss the relevant provisions in detail. For an more elaborate survey of the Act, see: L.F.Markenstein, The codification in the Netherlands of the principal rights of patients: a critical review, *European Journal of Health Law* 2 (1995) 33-44. Basically, the new act has brought no revolutionary change in the law. Fundamental rights of the patient, such as the right to informed consent, access to records and confidentiality, had already found recognition (in the literature, professional guidelines, court decisions etc.) before the new legislation came into force. This is not to say that the law has not introduced anything new, but on the whole it has codified, rather than modified, the already existing state of the art.

### 4. Relation to European standards.

The Netherlands is not the only European country that has adopted legislation on patient rights, although it has been one of the first. Several other countries have enacted specific patient rights legislation (e.g. Finland, Denmark, Norway, Lithuania, Iceland), while others have incorporated patient rights in general health laws (e.g. Spain, Hungary); finally, in some countries (for instance France and the United Kingdom) not legislation but patient charters are used to promote the position of patients. If one looks at legislation elsewhere, not the contractual approach adopted in the Netherlands would seem to be the dominant one, but the elaboration of patient rights in administrative rather than in civil or private law.

Also at the international level, in particular in Europe, standards have been developed. The two most important single documents in this respect are the Declaration on the Promotion of Patients' Rights in Europe of the WHO Regional Office for Europe, and the Convention on Human Rights and Biomedicine of the Council of Europe.

The WHO Declaration provides a general framework for the development of patient rights by laying down general principles; these principles do not only relate to the protection of personal privacy and integrity, but also to a number of other issues such as the right to health care, the freedom of choice of a health care provider, the right to be treated with dignity and to die in dignity, the right to complaint and the right to participation in decision-making in health care.

The Biomedicine Convention does acknowledge such basic patient rights as the right to informed consent and to protection of private life, including the position of patients who are unable to decide for themselves, but many of its provisions deal with medical research and specific developments (the human genome, embryo research, organ transplantation further use of human tissue) rather than with conventional medical care.

When compared with these two international documents, although completely in accordance with the international guidance and standards offered by the WHO and the Council of Europe, the Dutch law limits itself mainly to the protection of patient rights in daily health care practice. Furthermore, its focus is on the participation in medical decision-making and on privacy protection; rights to receive care are not included in the law. The latter is not strange given the civil law approach adopted in the Netherlands.

#### 5. Other laws affecting the position of the patient.

If one wants to have a comprehensive picture of the law on patient rights in the Netherlands, other acts have to be taken into account as well:

- general privacy protection legislation (which is at present being revised in pursuance of the European Data Protection Directive);
- legislation on social health insurance (which lays down the right of access to specific forms of health care for the insured, and therefore is crucial in implementing the right to health care);
- mental health legislation (which contains rules of the protection of patients prior and after involuntary admission to mental institutions);
- patient complaint legislation (which obliges health care providers to enable patients to lodge complaints and to make arrangements for adjudicating complaints);
- legislation on organ and tissue removal from living and deceased donors for transplantation purposes;
- legislation protecting persons undergoing medical-scientific research;
- legislation of the protection of persons undergoing medical examinations prior to the conclusion of an employment or private insurance contract.

In other words: the Medical Contract Act contains only the general principles where patient rights are concerned. On the one hand, specific legislation has been enacted to deal with specific medical interventions (like research; transplantation; medical examinations) or specific groups of patients (mental patients). On the other hand, legislation with a wider scope (on social health insurance; on data protection) deals with important aspects of the legal position of the patient.

Regulating patient rights in different laws of a different nature has its drawbacks. For instance, in a particular situation (e.g. during the stay of a patient in a mental hospital), several laws will apply at the same time. Sometimes there may be overlap; if this does not create conflict and legal uncertainty, it can at least be confusing for health professionals. On the other hand, adopting a relative simple and straightforward general law on patient rights has obvious advantages: as the legislator can never regulate the many and complex situations arising in daily health care in an exhaustive way, health professionals can at least know (and remember) which principles they have to comply with.

#### 6. The contractual approach.

As I set out before, the Medical Contract Act has incorporated patient rights in the Civil Code, in particular in the part of that code which deals with contract law. At the basis of this approach is the perception of the doctor-patient relationship as a horizontal one. Although as a result of his disease the patient will find himself in a situation of dependency, he remains a free citizen with all the rights to decide for himself and to have his private life protected that he has in other domains of life. Furthermore, contract law gives the patient a direct claim to the health care provider to respect his rights. This means, that the patient can enforce the law at his own initiative and has not only to rely on the initiative of others, such as the health inspectorate or health insurers, or - in serious cases - the public prosecution. Finally, a civil law approach facilitates the acceptance by health care providers who are in general against direct state interference with the fiduciary doctor-patient relationship, but are less opposed against indirect forms of regulation like the contractual one.

This is not to say that the approach adopted in the Netherlands does not raise particular problems which - one way or the other - have to be resolved. I mention two of them.

The first one relates to the question with whom exactly the patient is to conclude a contract. If this is with a self-employed, independent practitioner, the situation is clear. However, nowadays much, if not most health care is provided by, or at least in the context of larger institutions. Who then is the contractual partner of the patient?

According to the Medical Contract Act, the contract can also be with the institution, e.g. a hospital. This will always be the case when the health professionals who take care of the patient are employed by that institution. It is also possible that a health professional, in particular a medical specialist, runs his own practice in a hospital under a contract of 'admission' with that hospital in stead of an employment contract. In that case, the contract will be between the patient and the medical specialist, at least as far as medical care is concerned. When medical care is provided in institutions (by employees or by 'admitted' health professionals), management has to see to it that the health personnel involved can and will act in accordance with the patient rights laid down in the Medical Contract Act.

The second problem has to do with situations in which the existence of a contract can not be assumed, for instance medical care in prisons, in the military, after involuntary commitment to mental hospitals, occupational medicine, medical examinations to assess claims to allowances and social benefits etc. On the one hand, the need for protection of persons will not be less in such situations; on the other, one cannot simply extend a contractual regulation to a situation which is usually governed by other, specific rules. The legislator has solved this dilemma by entering a general provision in the act which states that in non-contractual situations the rights of the patients have to be applied to the extent that the nature of the situation in question reasonably allows for that. This means that the principles laid down in the act have at least to be taken into account, and that there must be a justification for not (fully) applying them.

## 7. General principles and exceptions.

I have already explained that the Medical Contract Act contains general principles rather than detailed provisions. Does it than only provide a framework, or more than that? The answer is: mostly a framework. Take for example the right to be informed about the risks of a medical intervention. The act mentions information on risks as part of the information a patient is to receive in order to be able to give informed consent. However, it does not elaborate on this, apart from stipulating that the patient should be given the information which he reasonably needs to receive. Another example is medical-decisionmaking for incompetent patients. The act provides that in that case informed consent must be given by the patient's representative, usually a spouse or close relative; however, a doctor may carry out an intervention on an incompetent patient without that consent, if the care of 'a good health care provider' requires so.

Provisions like the ones mentioned are important, since they provide basic guidance to health professionals; at the same time, there is an obvious need for further elaboration with a view to specific situations.

A problem all law-makers have to face is the problem of how to deal with exceptions. This problem becomes only more pressing, as the provisions in a law become more general. Basically, there are two

ways to deal with this problem: either by exceptions written in the law in question itself, or by unwritten exceptions.

The Medical Contract Act uses both ways. As to written exceptions, a distinction can be made between specific exceptions (an example is the therapeutic privilege which is explicitly mentioned as an exception to the right to information) and general exceptions. As to the last kind of exception, this is to be found in the act on several places where it is provided that the care-giver should respect a certain right of the patient (e.g. act in accordance with an advance directive) unless the care due of a good health care provider requires otherwise.

Apart from that, a doctor (other care provider) can always fall back on unwritten exceptions which apply to all legal provisions, in particular by invoking a situation of emergency or 'force majeure'. If one looks at the way the duty to confidentiality has been regulated in the law, for example, the only exceptions which are mentioned are the consent of the patient and an unambiguous legal provision requiring a doctor to communicate medical information to a third person. In the legal doctrine, however, and in court decisions, it is generally accepted that in exceptional circumstances another duty of a health professional (for instance to protect the life and health of other persons) may prevail over the duty to remain silent. On the whole, the way the Medical Contract Act deals with exceptions is not at every point a model of consistency. This is not to blame the legislator. It is indeed difficult to make a good law on patient rights. At every point, one has to find a delicate balance between too general and too specific provisions. This applies also to exceptions.

## 8. Role of courts and self-regulation.

From what I have said before, it is obvious that a law on patient rights cannot replace the role of the courts and of other bodies in elaborating patient rights for specific situations.

In the Netherlands, the courts have always played an important role. A good example is the right of access to medical records. In a long series of court decisions, this right has been delineated by the courts and more or less imposed on the health care sector, in spite of the initial resistance of, inter alia, the medical profession.

A more recent example is the scope and meaning of confidentiality after a patient's death; over the last five years there is a strong increase in the number of cases in which courts have had to decide on whether or not to grant access to the medical record of a deceased person to his or her relatives.

If one looks at the number of decisions, most jurisprudence has been developed by medical disciplinary courts. Since the Medical Contract Act has come into force, their role has not diminished; one of the areas where disciplinary courts have an important input is that of rights and obligations with regard to medical records. Although the civil courts have always had a lower profile in this field, at some points their contribution is significant; a good example is the body of court decisions on the right to information, for instance where risks and alternatives are concerned.

Case law is insufficient to give flesh to the bones of the Medical Contract Act. Self-regulation remains essential. Basically, it may take place at three levels:

- at national level by all the parties concerned (e.g. the model agreement on patient rights concluded in 1990 by organisations of doctors and patients);
- by the professions (e.g. the extensive guidelines of the Royal Dutch Medical Association on the confidentiality of medical data);
- at institutional level (many institutions will have their own arrangements for complaint procedures, medical record keeping etc.).

Although voluntary regulation and practice guidelines are no substitute for sound judgement in individual cases, they are indispensable in supporting practitioners in making sound decisions on how to do justice to patient rights. An example are guidelines which elaborate which standard information should be provided to patients undergoing a certain medical intervention.

## 9. Implementation and enforcement.



"One of the major problems with patients' rights legislation is the issue of implementation", thus a recent comment on the development of patient rights (L.H.Fallberg. Patients' rights in Europe: where do we stand and where do we go? European Journal of Health Law 7 (2000) 1-3). It is not difficult to agree. Respect of patient rights in every day health care requires a lot more than legislation, even if it is made more operational by court decisions, guidelines and codes of conduct. In practice, a continuous effort is needed to ensure awareness, knowledge and commitment. Information and education of health professionals and patients are of particular importance. The Medical Contract Act is now being evaluated. Although the outcome of this official evaluation is not yet available, it is likely that if the law turns out not to be sufficiently effective, the recommendations will be on (further) implementation, more than on anything else.

Since very often health care is provided in institutions, one should not overlook the responsibility of management in facilitating and creating the necessary basic conditions for the implementation of patient rights. The circulation of medical data within hospitals, for example, is a matter which is hardly anymore controlled by the individual health professional.

The management of hospitals and other health care establishments has also a role in enforcing patient rights. They can do so, for instance, by stipulating compliance with patient rights in employment or 'admission' contracts and by seeing to it that health professionals abide with their contractual obligations. Usually, however, enforcement will have to take place at other levels. As I explained before, it is first of all to the patient to take the initiative for enforcement, either by lodging a complaint, or by addressing - if need be - a civil or disciplinary court. At the same time, the public authorities - in particular the health inspectorate - have their own responsibilities. They will sometimes have to take the initiative to enforce patient rights in the public interest, even if there is no patient complaining about an infringement of his or her rights.

## 10. Conclusion.

At the end of the introduction I said that patient rights legislation is as much a reflection as an instrument of social change. Another way to convey the same message is stating that - although such legislation can be instrumental in modifying the doctor-patient relationship - it has also an important symbolical function. Patients rights are the expression of changing social values, of a new understanding of human rights and citizenship which does not leave the medical sector unaffected.

Legislation on patient rights has also other latent functions. An important one is that it also reinforces and protects the position of individual health professions against external constraints. An example is the fear of the health professions that clinical autonomy may be eroded in a modern health care system. Patients rights can protect that autonomy, at least as long as it is in the interest of the patient.

A law on patient rights - such as the Medical Contract Act in the Netherlands - is no more and no less than an milestone on an ongoing journey.

Paula Kokkonen<sup>4</sup>:

## **Law on the Status and Rights of a Patient, the Finnish Experience**

### **Background of the "Law on Patient's Rights"**

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Following a long debate, almost 20 years, the Law on the Status and Rights of a Patient was finally passed in the Finnish Parliament and it entered into force March 1, 1993.

In all legislative work the history and cultural tradition of a country, as well as previously existing legislation and administrative systems and structures have to be taken into consideration. Legislation may be described as a safety net. If you are going to mend it you have to know where the holes are. Thus I want to emphasize that I do not offer our law as a global solution, applicable to all societies and all problems patients or the personnel may experience in the field of health care.

When I used to give lectures (since early 1970's) about patient's rights to health care professionals the very same questions would always be asked. Professionals were mainly concerned about patient's right to self-determination, right to information, medical secrecy and right to access to treatment as well as who makes that decision.

When we from the National Board of Health in 1979 made a proposal to the Ministry of Social Affairs and Health to draft a reasonably short and compact text on the "most essential" patient's rights, it was because of our experience that there remain many unanswered questions, which seem to create constant insecurity, and bring about varying interpretations and nonuniform practice. This of course was against the interests of both patients and health care personnel alike. Our standpoint was very practical. We knew that health care personnel would not carry around the heavy law books and get acquainted with interpretations of legal texts. Thus we needed a rather simple and clear cut text that would be easy to teach to the personnel and patients alike.

Before 1993 patient's rights (citizen's rights) were fragmented across a number of branches of law, even in the constitution. The provisions and sections needed often "creative interpretation" in order to come to a reasonable conclusion. Some of the rights were included in the codes of conduct of various health care professionals. The codes were, however, not officially recognized by the state. Hospital charters often included some patient's rights etc.

### **The content of the Law on Patient's Rights**

The law regulates inter alia the patient's right to good health care, to medical care or related treatment when needed, the right to access to treatment, to be informed and to self-determination, the status of a minor patients, emergency treatment, powers of the representative of the patient in certain situations, a new complaint procedure and it establishes a patient ombudsman institution. (See: Kokkonen, P. The New Finnish Law on the Status and Rights of a Patient: *European Journal of Health Law*, Volume 1, No. 2, 1994). The two real innovations are the local complaint procedure and the patient ombudsman.

At this point I wish to draw your attention to the fact that Finland has a separate law on Patient Insurance based on non-fault principle.<sup>5</sup> A uniform set of patient's rights aims at clarifying and strengthening those rights, and thus improving the safeguarding of those rights in the field of health care.

An exhaustive law covering all possible patient's rights was not considered feasible in our situation. Our law regulates the principles, that are to be followed in those situations that according to our knowledge

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<sup>5</sup> See Kokkonen, P. No Fault Liability - Patient Insurance; Patient Injury Act. *Vlaams Tijdschrift voor Gezondheidsrecht*, September-Oktober 1988. Jaargang IX, Nr 1: 1:15-22., or No-Fault Liability and Patient Insurance: the Finnish Patient Injury Law of 1986. *International Digest of Health Legislation*. 1989,40,1:241-246., or La loi finlandaise de 1986 concerne la responsabilité médicale sans faute et l'assurance contre les dommages causés aux patients. *Cahier de Droit Médical et Ethique Médicale*. Lyon, Cahier N 18, Décembre 1989:84-88.

had caused most of the problems experienced and expressed both by the patients and the health care personnel. Thus our law regulates the principles that we think to be central to patients' care and treatment.

Legislation on health care in Finland regulates separately the patient's responsibility to submit him/herself to care in certain situations, regardless of his/her will. This mainly comes into question in cases where there is an exceptionally strong physical intrusion on patient's person, or a disregard of his right to self-determination, in which case the procedure has traditionally been regulated under separate, special laws, the Mental Health Law for example. Our legislation has also regulated separately such matters as organ transplantation, induced abortions and sterilisation.

It may be worth mentioning that there is a universal public health system in Finland. Patient's right to economic support during illness is regulated under Social Security Law. In addition, the position of the patient would still be regulated by other special legislation in the field of health care that would remain in force, like law on induced abortions, sterilisation, non-fault patient insurance etc.

The need to state clearly and to legislate also about patient's responsibilities was considered. Some of the responsibilities proposed were that the patient follow the rules of hospitals and other health care units and for failing to do so pay for health care services ordered but not used where there was no sufficient reason. The responsibilities mentioned above were not felt to be suitable for inclusion in a proposal for a law on patient's rights.

### **Three years' compiled experience gained in the implementation of the law**

The Ministry of Social Affairs and Health of Finland set in 1996 a working group to compile the experience gained in the implementation of the law. The report was completed April, 10th in 1996 and it is published in English (Three years in force; has the Finnish Act on the Status and Rights of Patients materialized?, *Sosiaali- ja terveystieteiden tutkimuskeskus 1996:4*, ISBN 952-00-0161-1).

When the information for the report was collected, the Law on Patient's Rights had been in force almost three years.

### **Material and methods**

A questionnaire dealing with the training related to the law was sent to all known agencies arranging training for patient ombudsmen (N=28).

The complaints, made by patients or on their behalf, decided by the Provincial Governments from the beginning of 1995 to August 1995 and by the National Board of Medicolegal Affairs in 1993-1995 were examined. The purpose was to find out whether the law had been reflected in the decisions regarding the complaints.

Telephone interviews were made with several agencies in order to survey their opinion on the law. The interviewees were: physicians in leading positions in various types of hospitals and health centres (N=41, replied by 91 %). Patient ombudsmen of nine organizations of different types and eight representatives of professional and trade unions and patients' organizations.

Opinions on the law were also surveyed by means of a posted questionnaire that was answered by two members of the Central Association of Alternative Medicine and 23 members of the Hospital Contacts Committee of Jehovah's Witnesses (Negotiate about methods of treatment compensating for blood transfusion).

The Ministry of Social Affairs and Health arranged in September 1995 an expert seminar, to which representatives of patient ombudsmen, health care professionals' and patients' organizations and other interested parties were invited. The materialization of the law was discussed.

### **Results**

The law is considered already to have influenced practical functions within health care. However, there is still much to improve in patient's access to information and in the treatment of patients; the attitudes and traditions change slowly. The working group states that the fact that "living wills" have become increasingly general is a manifestation of people's willingness to use their right to self-determination even when they are no more able to express their will. Complaints that are processed at the local level are frequent, and each organization has a patient ombudsman. The principles of this system of local complaints and ombudsmen are considered good, but there is room for improvement. It takes time to change attitudes.

The law is considered important, even necessary, but we are still "running-in" the Law. No major changes are considered to the law for the moment.

It is worth to mention that a Law on the Status and Rights of Social Welfare Clients is being drafted along the same lines as the Law on Patient's Rights.

The study revealed that both the Law and the patient ombudsman institution was considered "important/necessary". The most central aspect of the law was considered patient's right to information and self-determination. The patient ombudsmen were of the opinion that the law has had a favourable influence on the development of patients' rights. However other interviewees pointed out that the principles of the law existed even before enacting the law. This is true to some extent. The real innovations are the local complaint procedure and the patient ombudsman.

The interviewees consider that the impact of the law is evident as far as patient's access to information and their treatment (conduct) and the confidentiality of patient documents is concerned. Procedures in facing minor patients have also been clarified. People are more aware of their rights and they know how to demand proper treatment.

There is still much room for improvement in health care professionals' attitudes, however. The chief physician of each unit plays a central role, the atmosphere of the unit depending largely on him/her. It appears that physicians and nursing personnel of the younger generation are more willing to adopt new patterns of behaviour towards patients.

According to Jehovah's Witnesses the conviction of adult patients is now better respected.

The Central Association of Alternative Medicine considers that the law has increased hearing of patients and reciprocity.

In the light of the complaint decisions the impact of the law is apparent primarily in patients' access to information and in their right to read their own case records. The result is only indicative, since much of the content of the law has been part of good care even before the entry into force of the law. The decisions given before and after the enforcement of the law have not been compared.

#### Right to care

According to the law, anyone who stays in Finland permanently is entitled to medical care without discrimination within the limits of the resources available to health care at the time in question. The patient has a right to qualitatively good health care and medical care. His/her dignity must not be violated and his/her conviction and privacy have to be respected. The mother tongue, individual needs and culture have to be taken into account as far as possible.

During the recession of the 1990's resources allocated to health care have diminished. Thus the provision on right to care within the limits of resources available has received much attention. This provision was originally designed with the notion in mind that society has the right to limit how much and what kind of care it provides for its citizens.

## Complaints

A patient who is not satisfied with his/her medical care or treatment has the right to make a complaint to the director responsible for health care in the health care unit in question. Making a complaint does not restrict the right of a patient to appeal to other authorities. If, when the complaint is dealt with it becomes obvious that the care of a patient may cause liability, taking legal action or disciplinary proceedings, the patient has to be advised as to how the matter can be initiated in a competent authority or organ.

The roots of an administrative complaint are in common law. Complaints in the field of health care are most commonly addressed to the National Board of Medicolegal Affairs or to the Provincial Departments of Social Affairs and Health. These authorities have tried to emphasize the importance of solving the patient's complaints, whenever possible, locally. It has not, before the law, been very popular as there has not been any established system in this field.

The new complaint method established by the Law on Patient's Rights has a potential to benefit patients because profound local knowledge as well as a call on the spot may be needed when taking a decision. By establishing this new complaint procedure it was also hoped that the amount of complaints to the central government would reduce.

That, however, does not seem to be the case. The amount of complaints to the National Board of Medicolegal Affairs and to the Provincial Governments has remained steady during the last few years, despite increasing numbers of complaints to the local health care units. The interpretation of the evaluators has been that there is either a lot of repressed dissatisfaction or the patient ombudsmen have not been sufficiently successful in their preventive work. One possible interpretation is also that there is an increased awareness of patient's rights. The truth remains, however, that this new tool has not diminished the amount of complaints to the governmental bodies.

According to the law, decision to a local complaint has to be given within a reasonable period of time. The recommendation is one month. All interviewees felt that it is important that the patient gets a written reply within a prescribed period of time. According to the report the period of time processing a complaint has been two to four weeks in 82 % of cases and one to three months in 18 % of the cases.

The report confirms an old truth. Complaints are most often related to human relation skills, or rather to the lack of them. Most complaints are estimated to relate to how patients are treated by the personnel. Further, issues relating to guidance and information, dissatisfaction with the result of the care and delayed access to care may result in a complaint.

With the rising level of education, patients have become more able to make independent decisions. According to the interviewees, patients have also become more ready to hold to their rights and also to express their dissatisfaction. All this partly owing to the new law.

## Patient ombudsman institution

The patient ombudsman is not only a channel for discharging patients' dissatisfaction. The purpose is also to promote the status and rights of patients in the organization. The work of patient ombudsman consists of advising and informing. By informing patients, their families and the personnel of the content of the law it is possible to influence attitudes, to prevent conflicts and thus to promote patients' rights.

The work of patient ombudsman requires sufficient knowledge of health care organization, its functions and professionals. Individual qualities, such as communication and interaction skills are of great importance for succeeding in the job. The personality of a patient ombudsman is his/her best tool.

The position of the patient ombudsman in an organization and his/her functions can be agreed upon independently by each unit. As a rule the tasks are attended to in addition to one's regular job. Patient

ombudsmen feel that lack of time is the most serious obstacle to succeed well in their job. Most of them would like to work on full time basis.

All parties interviewed regarded the job of a patient ombudsman as valuable and necessary. But there is still much room for development. The preventive role of the patient ombudsman in solving problems should be underlined and the quality viewpoint should be internalized. The ombudsman should be seen as a part of a care establishments quality assurance.

Patient ombudsmen need support and opportunity for job supervision as well as consultation with legal advisers.

It has been agreed upon that the National Board of Medicolegal Affairs organizes annually a national symposium for patient ombudsmen and that the Provincial Governments also organize annually a provincial symposium for them.

My deep conviction is that patient ombudsmen need strong support from the governmental bodies in order to be able to "survive" in a machinery where they often feel insufficiency as they try to fulfil the expectations of both patients and the personnel. According to our experience it is not easy for health care personnel to admit that they might have been negligent. Sometimes it is also difficult for a patient to admit that s/he cannot be fixed like an automobile and that health care personnel is not necessarily to be blamed for his/her ill health.

### **To conclude**

We are happy to share our experience of the Law on Patient's Rights. This law seems to be a suitable solution to our situation in Finland. By speaking "loudly" about patient's rights we have tried to prevent the kind of phenomenon that is common in the USA, where lawyers are harvesting in the hospitals.

Marcus Düwell<sup>6</sup>

## **The Convention on Human Rights and Biomedicine from an ethical perspective**

### **1. Introduction**

In the course of the last decade, the Convention on Human Rights and Biomedicine has become a central point of reference for the bioethical discussion. By means of the Convention, minimal standards are to be determined for the protection of human dignity in all of Europe. I would like to begin by discussing the political significance of the Convention; in the second part of my contribution, I want to examine several articles of the Convention more closely from an ethical perspective.

### **2. On the political relevance of the Convention**

The background against which the Convention was worked out can be viewed from three aspects.

1. The various developments in the field of biomedicine give indication of an increasing number of possible applications whose moral evaluation is not obvious. Examples of such applications are genetic

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diagnosis and therapy, research on embryos, transplantation medicine, medical experiments on subjects unable to give consent, and euthanasia. In each of these cases we are concerned with techniques, the moral assessment of which is not clear, techniques which, on the contrary, are morally ambiguous.

The knowledge which we gain through biomedicine and biotechnology changes the scope of our actions and decisions in dealing with our physical constitution in a very basic way. It changes our conception of human beings and the world, opens up a range of new possibilities for medicine, and contains at the same time the danger of functionalizing the human being to a previously unknown extent. Let us take as an example *genetic prenatal diagnosis*. Whereas previously many genetically determined diseases were experienced as a kind of fate, it is possible today to diagnose some of them in the womb. To this extent, such diagnosis represents a significant extension of the possibilities of medicine. Almost all of the diseases and handicaps which can be diagnosed, however, are unable to be treated. This means that a couple whose child has been diagnosed with a disorder of this kind has only the alternative between bearing the child and terminating the pregnancy. Thus, the emergence of a handicap of this sort becomes a matter of conscious decision. This opens up the possibility for many couples of sparing themselves a severe burden. At the same time, however, many couples, faced with the need to take this decision, are caught in an almost unbearable conflict of interests. Moreover, many people who suffer from a handicap which can today be prenatally diagnosed feel themselves threatened in their right to life and their existence called into question. "Why do you want to abort a human being who is like me?" is their question. The mere offer of this diagnostic technology leads to a situation in which many pregnant women experience their pregnancy in an entirely different way. So, for example, the number of pregnancies which in the context of prenatal diagnosis are assessed as "risk pregnancies" is many times higher than the number of children born with genetically determined disorders. This means that by offering this technology, fear and conflicts of interest can also be created.

It is furthermore becoming increasingly difficult to limit the range of applications of prenatal diagnosis. In principle, one can examine not only for serious genetic diseases; due to the progress of the human genome project and of the technical possibilities of diagnosis, an increasing number of genetically determined features are becoming diagnosable. In order to limit the application of prenatal diagnosis to serious genetic diseases, we would need a generally binding and clearly defined concept of "disease." But such a concept of disease we do not have. The question of whether a specific phenotypical phenomenon is assessed as a disorder is a question of the social construction of illness. And precisely this assessment as a disorder can, given the growing pluralism of lifestyles and value systems, be different from individual to individual. We can certainly agree in extreme cases about what a disorder is and isn't, but in controversial cases, we have no really clear and generally binding notion of illness or handicap. This means that it will be problematic in the long term to find cogent arguments for limiting the field of potential applications of prenatal diagnosis. Is, for example, achondroplasia an illness, a handicap, or simply a variation from the norm? According to what criteria is this to be decided? If we have no

generally accepted criteria, how are we going to argue that specific variations from the norm are a reason for selection? This example should demonstrate, just in very general terms, the difficulty and relevance of bioethical topics.

2. The second reason for the bioethical discussion, alongside the technological developments in biomedicine, lies in the fact that the basic principles of a generally accepted system of moral convictions is being increasingly called into question. The *plurality of moral convictions* is no longer a phenomenon limited to intellectual elites and moral-philosophical sceptics. On the contrary, an erosion has taken place of precisely those institutions which have traditionally been viewed as moral authorities. One does not need to mourn over this process, but one must take note of the fact that we are now in a situation in which our shared moral convictions do not reach very far. In this situation, one cannot simply point to existing legislation and say, "Morally we are of different opinions, but the law provides us with a binding framework." The difficulty consists precisely in the fact that we are dealing with questions and problems which require new legal regulations. Moreover, the law itself lays claims to moral legitimation. It is precisely because human dignity and human rights are of such major moral significance that they should be protected by law. If the law is to develop and evolve, we must constantly be asking ourselves what is morally right. Naturally, the binding force of law remains in place, but its moral quality is questionable. In my opinion the major question of bioethics therefore should be: what possible moral rights we could legitimize by ethical arguments as rights that should be protected. The pluralism of values forces us to the discourse about the content of a binding morality.

3. Against the background of the plurality of moral convictions and the moral ambiguity of biomedical techniques, the Convention is meant to define minimal standards which guarantee a minimal protection of human dignity in all European states. One reason for this lay in the fact that, particularly in Eastern Europe, many questions relating to biomedicine are not legally regulated at all or in a sufficient way, so that the Convention was to aim, at the very least, at a minimal protection. Article 27, however, states very clearly that every state has the right to prescribe higher standards of protection. This article was quoted repeatedly in Germany to convince the public that subscribing to the Convention would in no way undermine established moral and legal standards of protection.

So much for the background issues. One can now ask oneself whether the concept of the prescription of minimal standards represents an appropriate response to the challenges posed by biomedicine. One must remind oneself that in ethical questions relating to biomedicine, the concern is not primarily with the moral evaluation of single techniques. Biomedicine leads to possibilities for intervention which force us with particular urgency to clarify for ourselves what exactly the notion of human dignity entails. Is research on embryos an intervention which violates human dignity or not? The issue concerns not merely the question of fact. On the contrary, the specific regulation which we put in place to govern such research leads to a specific interpretation of human dignity becoming generally accepted. In questions of human dignity and human rights we are dealing with the core of our moral convictions. I think that it



ought to be worth arguing about this core content of morality. But in actual fact, the concept of a convention on minimal moral standards is having the effect of making this debate superfluous. In Germany, for example, the new survey commission on "Ethics and Law in Medicine" of the German parliament has been explicitly assigned the task of examining the extent to which the German legislation still correspond to these minimal standards. So they ask whether we should correct our regulations towards this minimal standards. The Art. 27 doesn't protect against such process of political deregulation. This means that we are currently experiencing a process of the following kind. The Convention prescribes minimal standards, but wins acceptance by maintaining that every member state can have more rigorous ones. These minimal standards are then used as a lever to ward off demands which would go further. The most disturbing thing about this, however, is that these minimal standards are not meant to be accepted because they are considered to be morally right, but rather because they express a minimal consensus. This means in effect, however, that we are no longer arguing about what human dignity and human rights actually mean. We are also no longer arguing about whether an ethics of human dignity is the right way of thinking about morality at all. The entire basis of our morality is being reduced instead to the content of practicable political compromises. It is not the mark of a democratic culture to tolerate this process in which the core of moral convictions can not be proved and discussed in the way of rational argumentation.

### **3. The Convention on Human Rights**

#### **a) Human dignity**

On what moral concepts is the Convention of Human Rights and Biomedicine based? Let me quote the first article of the Convention. Article 1: "The parties to this Convention shall protect the dignity and identity of all human beings and guarantee everyone without discrimination respect for their integrity and other basic rights and fundamental freedoms with regard to the application of biology and medicine." The first article thus appeals to the dignity, integrity, and rights of the human being. The concept of human dignity entails that the human being shall not be violated and the value of a human being could not be weight up against other values. That means that, regardless of the benefit which might result from using a human being as a means to an end, human dignity requires that it is not a legitimate moral option to suspend his or her basic rights. It remains, however, unclear quite how far this regulation is meant to reach.

It is controversial, for example, what consequences this has for the *moral status* of embryos and foetuses. On this subject we read, in Article 18.1 of the Convention: "Where the law allows research on embryos *in vitro*, it shall ensure adequate protection of the embryo." What exactly "adequate protection" consists of, however, is never defined. In an information paper issued by the German Ministry of Justice under the previous government, the assertion is made that this means that the regulation is to be interpreted in such a way that "an adequate protection entails the prohibition of such research projects on embryos." This

interpretation does not seem to me from the text of the Convention (and the explanatory report) to be warranted. The compromise formula "adequate protection" is completely unclear, because the point at which the protection of human dignity is meant to begin is left undefined. At Number 19 of the explanatory report, we find the following: "The convention also uses the expression 'human being' to state the necessity to protect the dignity and identity of all human beings. It was acknowledged that it was a generally accepted principle that human dignity and the identity of the human being had to be respected as soon as life began." The protection of dignity is therefore meant to take effect as soon as "life" begins, but we are not told when life begins. Moreover, this talk of "life" is extremely unprecise. Does it mean the coming into being of a living organism of whatever sort, or does it mean the beginning of an individual? We are certainly dealing here with extremely difficult moral-philosophical and anthropological questions. But it is clear that on this point the Convention is ambiguous.

In the European discussion about research on embryos, the position is often advanced that one has to take into account the fact that the moral status of embryos is differently evaluated in different moral traditions, and that, to the extent that this is the case, ethics must call for tolerance of the different points of view. I do not intend to answer the question here of whether this is true. Nevertheless, the demand for tolerance would have as its consequence that the answer to a controversial problem would be implicitly prejudiced. Tolerance can only be demanded for convictions and actions which are at least basically morally acceptable. The demand for tolerance implicitly entails the acknowledgement that the embryo is not to be seen as an individual bearer of human dignity. If the embryo were to be a bearer of dignity from the very beginning, then every form of research on embryos which leads to their being used up as raw material would involve the destruction of beings with the status of human dignity. The call for tolerance of such actions would be equivalent to the surrender of the obligations which are connected with the notion of dignity. Now, the thesis that the protection of embryos is only morally required to a limited degree can be defended with arguments. But these arguments must be presented before a call for tolerance can be morally legitimated. It does not seem to me to be a sensible solution to respond to this problem with unclear compromise formulas. It is furthermore completely unacceptable to tell the public that this compromise formula entails a clear prohibition of research on embryos. We have to debate the issue of whether we think that research on embryos is morally acceptable or not with arguments. But we dare not try to avoid the debate. Europe, on this point, is demonstrating a considerable degree of insincerity.

### **b) Public interest versus the interests of individuals**

So Article 1 protects human dignity. In Article 2, on the other hand, we read: "The interests and the welfare of the human being shall prevail over the sole interest of society or science." With this formulation, the point of view changes in a central respect, in that the interests of the individual and the interests of society are opposed to one another. It is clearly stated that the interests of the individual always take priority. To this extent, Article 2 follows from the formulation of human dignity in Article 1. But there is an essential difference. In this version of the text, the interests of the individual and those of

society are brought into a relationship in which they are weighed up against each other. The formulation of Article 2 is taken from the classic formulation of the Declaration of Helsinki-Tokyo, but with one important change. What has been added here is the expression "the sole interests" of society and science. Here, therefore, an interest of science and society becomes apparent which is no longer connected to individual interests. Whereas the scientific progress of medicine should of course always be related to its usefulness for concrete individuals, here a "sole" interest of science and society is constructed which can then be related to individual interests in such a way that it can be weighed up against them. The emphasis placed upon the priority of the individual perspective must not conceal the fact that here a problematic shift has taken place.

The relationship between *individual rights and public interests* runs like a thread through the Convention. The general force of the Convention tends towards protecting the individual from infringements of his or her rights by medicine. The central instrument of protection is here the "free and informed consent" of those affected (Articles 5, 15, 16, 19). (Significance of informed consent for medical ethics.) Because informed consent is given such central importance in the Convention, it becomes a separate task to regulate means of dealing with medical and scientific interventions in human beings who are not capable of consent (Articles 6–9, 17, 20). Protection of informed consent and regulation for cases where it is not possible is the central structure of the Convention. But informed consent only offers protection when dealing with technical possibilities which already exist. Many ethical questions are excluded by this concentration on informed consent: research ethics, for example. In research, the technical possibilities of future medicine are developed and thus the future potentials and problems preformed (e.g. xenotransplantation). We are developing now technologies which create special options for actions in the future. The ethical question is not only whether the patient involved in research for xenotransplants has give consent. The ethical question should be as well whether a technology with specific opportunities, risks and dangers should be developed at all. We do not know for example whether xenotransplantation have specific risks of creating new diseases and dangers for the public and there are limits for the prediction of such risks. This dimension is missing from the Convention almost completely. That informed consent as a standard of protection for individual rights is not sufficient can also be made clear, for example, in the field of prenatal diagnosis and other forms of pre- and perinatal medicine. In all of these techniques, decisions are made about the chances for life, about the selection and genetic disposition of a human being at a point in time at which the potentially affected party him- or herself is unable to consent. That means, however, that informed consent in these areas of regulation cannot function as a guarantee of the protection of individual rights. The decision taken on behalf of the affected party which is a borderline case in normal medicine becomes the normal situation. Particularly controversial was the question of whether in the interests of the further technical development of medicine, that is to say, in the public interest, experiments with human beings unable to give consent could be carried out. For experiments with human beings able to give consent, the Convention stresses informed consent and lists

the conditions which apply to the quality of the intervention: no alternatives, low risk, the quality of the research project, and the right to withdraw one's consent at any time. The scientific and ethical quality of the research project is checked by an appropriate commission. Here it is worth noting that in almost all countries the ethics commissions are dominated by medical practitioners, that they work only on the basis of the declarations of medical associations, and that often not even a single professional ethicist must be present. These kinds of commissions can lay absolutely no legitimate claim to the competence needed to determine whether a given project is ethically unobjectionable. With respect to experiments with human beings unable to give consent, the following is worthy of note: in contrast to those able to consent, neither they nor their appointed deputies have the right to withdraw consent to participate in the experiment at any time. Moreover, it is stated that this research should only involve a low risk for those taking part and high value for research, both of which are extremely vague statements. The regulations for the protection of those unable to give consent are here extremely inadequate. The danger is at least present that in actual fact the priority of the public interest over that of those unable to consent could be made possible.

I would like, just briefly, to mention one further example of the inadequacy of the regulations contained in the Convention: *germ line gene therapy*. The relevant points are contained in Article 13. There it is stated that: "An intervention seeking to modify the human genome may only be undertaken for preventative, diagnostic, or therapeutic purposes and only if its aim is not to introduce any modification in the genome of any descendants." There are several points in this regulation which need to be noted. Germ line gene therapy appears here to be prohibited. But this first impression requires a number of qualifications.

Alterations in the germ line as a *side-effect* of somatic gene therapy are not forbidden, because only those interventions are prohibited which "aim" at an alteration of the genome of the patient's descendants.

Alterations to the germ line would be thinkable if they applied only to the genome of the human being who emerges from the gene-therapeutically manipulated embryo, but not to his or her descendants. It could be argued that an alteration of the genome of the descendants is not the "aim" of the intervention. As a kind of thought experiment, one could also imagine that the affected person would have to refrain from having children. That, however, would be connected with a massive violation of personality rights. The binding of the aims of the intervention to therapeutic purposes does not have as clearly a restrictive character as one might initially think. If therapeutic purposes are to be clearly distinguished from "enhancement", the improvement of the genome, we need a clearly defined notion of illness. It would, for example, be questionable whether dwarfism was an illness or handicap which required therapy. The Convention on Human Rights, however, contains no such definition of illness. The articles dealing with general medical interventions concentrate exclusively on legitimising medical interventions by the "informed consent" of the affected parties or their deputies, so that the notion of illness remains tied to individual decisions. In the case of germ line gene therapy, a proxy decision is for this very reason the

only one possible. Because the Convention contains no clear notion of "illness", it will be very difficult to maintain the distinction between therapeutic purposes and enhancement in the long term.

#### **4. Conclusion: an ethics of human rights**

The Convention of the European Council links an ethics of human dignity with an ethics of the weighing up of interests. Although it emphasises the priority of the rights of individuals, it is nevertheless very sketchy in the details and it is doubtful whether it can really serve as a guarantee of the protection of human rights. Moreover, a procedure which codifies a minimal consensus is questionable. One can already observe in the political discussion that many are calling, for example, for the abolition of the more restrictive regulations on embryo research, in order to achieve legal standardization. Regardless of one's position on this research as such. The mere fact that other countries allow research on embryos is not an argument for doing so ourselves. No one should be released from the obligation to do the hard work of moral argumentation.

My thoughts on this issue have been intended to show that it is in many respects inadequate to attempt to protect human dignity by means of an ethics of informed consent alone. Furthermore, the weighing up of individual and public interests is constantly in danger of becoming unable to think of the unconditional nature of the protection of individual rights in an appropriate way. What is needed is an ethics which can formulate general binding human rights and find ways of arguing and discussing the content of such human rights. Such an ethics should be open for a plurality of notions of a good and successful life. Plural life-orientations are, however, dependant on an ethics of human rights for their protection. Particular goods are identified as rights for everyone. Such an ethics, however, should not only address the current threat to human rights. It must also ask critically whether by means of developments in science and technology we are guaranteeing human rights in the future or endangering them. And it must concern itself with the question of how we can learn to judge this, if we get to the point where we are no longer able to tell if we are doing the one or the other. The protection of human rights and human dignity is the best thing we can take with us into the twenty-first century.

## 2. Informed Consent, Decision Making Capacity, Rights of the Mentally Ill.

E. Gefenas<sup>7</sup>:

### **Informed consent within a transition society**

#### ***Introduction***

This paper deals with the specific features of implementing the principle of informed consent (IC) in various fields of health care in Lithuania. Hopefully, some of the considerations would also apply to the other transition societies (TS) of Central and Eastern Europe (CEE) in their implementing the principle of IC into their health care legislation. It means that many countries in the region have been moving from paternalistic to autonomy-based relationship between health care provider and patient. The shift from traditional paternalism to autonomy-based approach is, however, a rather complicated process.

The practice of implementing IC follows its legalisation with rather evident delay. This is quite understandable, taking into account that socio-cultural circumstances change rather slowly. That is especially the case when, to put it in the words of J. Katz, the tradition excluding patient's involvement is thousand years old, while the movement facilitating patient participation in their medical decisions started only a few decades ago<sup>8</sup> Therefore, the first section of the paper based on the data of Danish empirical study provides a detailed picture of the diversity of doctor – patient relationship in different regions of Europe.

In spite to the “socio-cultural resistance”, the need to introduce the practice of explicit and specific IC is especially urgent in such areas as biomedical research. The second part of the paper examines the pitfalls of running clinical trials in a paternalistic society.

The third section brings us back to the complexities of the doctor – patient relationship, which is especially evident when end of life decisions are made. To be realistic about the possibility of implementing IC within certain areas of health care

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<sup>8</sup> Katz, J. The silent world of doctor and patient, 1984, New York

decision-making we have to take seriously the fundamental moral dilemma between respect for personal autonomy and beneficence-based paternalism as a core of doctor-patient relationship.

Finally, the considerations mentioned above give us stuff for thinking about the relationship between law and ethics as well as about the peculiarities of legalizing competing moral principles in different socio-cultural contexts.

### **I. Legalization and practice of IC: contrasting pictures of the doctor–patient relationship**

The major obstacle to implement the principle of IC in a TS has been the prevalence of paternalistic health care practitioner-patient relationship which was being imposed during decades of totalitarian regime. It should be stressed, however, that Lithuanian health legislation has already made steps towards a “modern” ethos of personal autonomy. The law on the Rights of Patients and Compensation of Damage to Their Health (1996) has been explicitly based on the principle of IC. Lithuania and other post-communist countries have also signed the Convention on Human Rights and Bioethics (Bioethics Convention), which is explicitly based on the principle of respect for personal autonomy and says that IC “makes clear patients’ autonomy in their relationship with health care professionals and restrains the paternalistic approach which might ignore the wish of the patient”.<sup>9</sup>

These developments are gradually changing traditional paternalistic health care ethics. IC is getting more and more integrated in different fields of clinical decision-making. More and more often, patients are getting informed about the opportunity to refuse chemotherapy when their chances to increase life expectancy are negligible; likewise, they are allowed to choose conservative treatment of breast cancer instead of radical mastectomy. It seems, however, that there are still significant differences between the types of doctor–patient relationship practiced in the CEE countries as compared with countries of Northern and Western Europe. The following study reveals these differences in spite of the fact that it was conducted in the beginning of the nineties.

#### **Informing the patient and the spouse**

In 1993, Danish researchers conducted a study about the peculiarities of informing the patients and their relatives in different European countries<sup>10</sup> Gastroenterologists from all over Europe were asked to give the answers to the questions related to the situation of the patient suffering from a sigmoid colon carcinoma.

Here is a brief summary of the study:

The diagnosis is confirmed by microscopic investigation of biopsies. Further investigations show no signs of metastases in the liver and elsewhere. The doctor decides that it will be necessary to do a resection of the colon. These are the questions to the doctor:

Question 1. Would you tell this patient that s/he has a cancer if s/he asks no questions?

<sup>9</sup> Explanatory Report, Council of Europe, 1996, art. 5

<sup>10</sup> Thomsen O.O., Wulff H.R. et al. What do gastroenterologist in Europe tell cancer patient? *The Lancet*, 1993; Vol. 20, pp. 473-476.

British doctor: "Your biopsy shows that this is cancer of the bowel.... It makes for a serious problem, and it does need to be removed, but the overall chances of success are about 50-50 and they may prove somewhat better when the specimen has been analysed".

Central and Eastern Europeans usually withheld the diagnosis talking about "an ulcer", "inflammation", "colitis" etc.

Question 2. Would you tell the patient described above that s/he has a cancer if s/he directly asks you for a diagnosis?

This question is relevant for those escaping direct information to the patient asked about in Question 1. Most doctors in Central and Eastern Europe would still withhold information: "my answer would be the same if s/he were to ask no questions" - was the answer of a Polish doctor choosing the term "inflammatory process" to answer Question 1.

Question 3. Would you tell the wife/husband that her/his spouse has cancer? This is a question concerning the case when the doctor meets the patient's wife or husband (in the patient's absence). The wife/husband asks to be told the diagnosis.

Norwegian doctor: "The patient has all the information and s/he can inform the family members, if s/he wants to".

An answer by a Spanish doctor represented the opposite opinion prevalent also in Eastern European countries: "I would explain to the relative that the patient has cancer and I would also ask him/her whether the patient should know about it or not".

The answers of CEE doctors to the questions about informing the patient and his/her spouse about the diagnosis of cancer reflect a traditional type of HCP-patient relationship. Firstly, the decision is made in the absence of any participation by the patient. Secondly, there is very often a close relative intervening between the patient and the doctor. The relative helps the doctor to manage painful information about the health status and prognosis of the individual concerned. As has already been mentioned, many TSs are gradually shifting towards the autonomy-based model of doctor-patient relationship. The importance and complexity of this process are represented by the analysis of the two following cases.

## II. Clinical test of a spasmolytic drug: the necessity of IC

Here is the summary of the Patient Information Sheet of a test which has been run in several CEE countries.

Patients suffering from nephrolithiasis or ureterolithiasis were invited to participate in a randomised, double blind, placebo-controlled multicentric study on spasmolytic drug X. The drug was distributed in a random way among two groups: the first group was receiving the drug X, the second was just receiving placebo. Neither the patient nor the physician would be aware about the substance being used in any concrete case.

One of the requirements of inclusion criteria is typical signs of renal colic, namely, acute, moderate to severe pain of low back radiated into suprapubic, inguinal, or genital regions, haematuria, agitation, nausea, vomiting, paleness, sweat and weakness. The patient is informed about the possibility to receive, on a random basis, intravenous injection of X or injection not containing drug substance (placebo). The study lasts three hours and both injections could be



repeated once within a three-hour period. Following the administration of the injection, the participants of the study are asked to indicate the level of pain on a visual-analogue scale.

In spite of the fact that the patients are told that participation in the test is voluntary and, that, they are free to withdraw any time their agreement to participate, there are several questions to ask with regard to the principle of IC.

Firstly, taking into account the inclusion criteria of the study, is it realistic to think that a patient with acute, moderate-to-severe pain is able to read and understand the text of the patient information sheet?

Secondly, is it likely that a patient would voluntarily agree to take 50 percent of chance of receiving placebo and suffer the symptoms for three hours while indicating the level of pain on a scale even in case of treatment failure, which means that such a patient would spend three hours in pain and other related symptoms?

Finally, would it be possible to think about realising such a clinical test in any Western country and have it approved by research ethics committee functioning in these countries?

It does not seem so. The test in question reminds us the terrifying stories about doctors using their patients for all sorts of experiments, even those seriously harming research subjects (e.g. Tuskegee syphilis research). Taking into account the prevalence of the paternalistic doctor-patient relationship, this problem seems to be very important for all post-socialist countries because there is a serious danger that these countries might be used as a place for experimentation on human beings. The case of the reported clinical test highlights the necessity to follow an explicit and specific IC policy. At the same time, it shows how easily the requirement to follow IC could be manipulated and transformed into a formal procedure of signing an informed consent form.

### **III. Refusal to eat: the complexity of IC**

In contrast to the previous case, the present one shows the complexity of following the principle of IC in the domain of mental health and in that of the end of life decisions. It is a story (shared with me by the attending psychiatrists) of an old and blind man who was transferred from the institution for the elderly to the psychiatric hospital because of the refusal to take food and, thus, to a rapid loss of weight. The man, a childless widower, feels his existence to be totally meaningless. He is absolutely lonely after spending almost 20 years in the institution for the elderly where he moved when his wife died. All over these years, he has not been visited by his relatives, and a few years ago, after becoming blind, his ability to communicate with other residents of the institution significantly decreased. Moreover, there are no personnel available to spend more time with the man in the institution. His mental status examination reveals no major psychiatric problems. The old man articulates his wishes clearly, and

the attending psychiatrist faces the dilemma of following the old man's desire to be left alone or prescribing antidepressants, subjecting the patient to involuntary feeding, followed by his eventual return to the institution for the elderly.

This case reveals a particular aspect of respect for personal autonomy considerations which seems to be much more controversial within TSs as compared with affluent societies. Such situations arise when a patient's satisfaction with life drops below a critical level, and the patient refuses to accept simple life sustaining measures, because no appropriate treatment or care is not available due to poor economic circumstances. Applied to this case, IC would lead to rather different practical solutions and interpretations of the case by physicians in a TS and those in a welfare state. Many Western countries have clear guidelines forbidding any interference with the ultimate choice of a competent person. In these countries, however, before being left with such an ultimate decision, the person concerned is usually provided with psychological counselling or other kind of professional care.

Taking into account the real difficulties faced by many of the transition society's health care institutions (we could refer here to a huge gap in per capita annual expenditure for health care between welfare and transition society and the neglect of the mentally ill or the disabled within post-communist societies inherited from the previous regime), the consequence of strictly following the principle of IC would most probably be that the man is left alone with his authentic decision. What makes this and similar cases so controversial, is not only the traditional requirement to prolong the life of a human being but also the powerlessness of health care practitioners to change the situation which is at least sometimes manageable in such countries as Sweden or Norway.

#### IV. Concluding remarks

The interpretations of the cases presented in this paper direct us to more theoretical questions concerning the relationship between law and ethics in health care. The case of biomedical research stresses the necessity to separate those activities which should strictly follow the explicit, specific and written requirement of informed consent from those which are based on implicit rather than explicit consent. The analysis of health care decision-making within different socio-cultural circumstances also raises the question how far should the law go in interfering with the traditional doctor-patient relationship and enforcing the principle of informed consent.

Let us analyse some legal provisions related with the right not to know the information about one's own health status. The Lithuanian Law on the Rights of Patients and Compensation of Damage to Their Health (1996) gives a comprehensive explanation of the right to information (art. 6). It explicitly mentions the right not to know, saying that "the information should not be supplied to the patient against his will, however, his will must be clearly expressed and the history of his illness should contain a mention of this wish of his".

This is an example of the provision, which actually excludes the beneficence-based scenario from the doctor patient relationship. If a health care provider is obliged to have the patient's will to be "clearly expressed", the doctor is not allowed to practice "implicit" consent. In other words, it seems that the doctor is always obliged to ask the patient if she or he wants to know the truth. This is, of course, hardly compatible

with the situation where the doctor meets the patient who does not want to be informed about his poor prognosis. The Council of Europe Bioethics Convention is more sensitive to this situation because it only says that a wish not to know “must be observed” by the doctor<sup>11</sup>, rather than clearly expressed by the patient.

Two considerations should be stressed in this context. First, the clinical practice and HCP-patient relationship is based (to use somewhat simplistic interpretation of medical ethics) not only on the principle of respect for personal autonomy but also on the principle of beneficence. In many clinical situations these two principles require a similar course of action and do not contradict each other. The opportunity for controversies increases when the principle of IC is introduced in a traditional society. We have probably to be more sensitive to these circumstances; otherwise our legal provisions will be seen as the obstacles to good clinical practice. In this respect, laws should provide some space for the exceptions from the dominant trend. That is exactly the point where culture- and health care-specific ethical considerations get a prominent role in supplementing minimal legal standards.

Judit Fridli<sup>12</sup>:

### **Who Decides For Me When I Am Incompetent?**

Ten years ago communism collapsed in Eastern Europe. In the place of one-party states, constitutional parliamentary democracies emerged. Human rights have got a pride of place in the new constitutions. Among these rights, the right of the person to self-determination has been recognized.

The right to self-determination entails the right to decide about one’s body including those decisions related to medical intervention. This we commonly call „patient’s rights”. My talk will be dedicated to the question of how much the law and the institutional practices in present-day Hungary respect patient’s rights. I will focus in particular on the cases where the patient is restricted in his competence either because of his age, or because of some illness or mental disability. I want to discuss whether people with reduced competency are sufficiently protected by the law against undue interference with their right to self-determination. I want to see whether the law guarantees for such people that the surrogate decision, if needed, does not disregard their own interests and values. Finally, I will raise the issue of advance directives as a way to make competent decisions for a future case where the patient might lose her competent decision-making capacity.

#### **1. Legal stipulation of patient’s rights**

In Hungary, the basic rights of the patient found legal expression in 1997 with the adoption of a new Health Care Act. Before the bill got submitted to the Parliament, there were heated debates on whether the structure and workings of the health care system should be regulated by one single law or whether separate laws should be

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<sup>11</sup> Explanatory report, art. 10

<sup>12</sup> Chair, Hungarian Civil Liberties Union

enacted to deal with separate aspects of the system. Some of those who were pleading for the second solution, wanted to see separate laws on patient's rights and on the rights of the mentally ill. The Government decided for the first option.

The new Health Care Act includes a separate chapter on the rights of the patients. The main aims and principles of this chapter are in conformity with the international standards. One of the stated aims of the law is that of protecting the right of the patient to self-determination. The right to self-determination is not enumerated by the Hungarian constitution. The Constitutional Court decided, however, that the right to human dignity, an enumerated constitutional right, is to be understood as entailing the right to self-determination. Following this reading, the Health Care Act bases the individual's right to dispose freely over her body on the constitutional right of dignity.

Informed consent is made an indispensable condition for starting the treatment. The patient has the right to refuse treatment; this right includes, under certain conditions, the right to refuse life-sustaining treatment as well. It is a right of the patient to have access to her medical files and to see to it that her data are handled in a confidential manner.

The Health Care Act covers a wide range of more specific issues as well. For example, it includes dispositions on artificial insemination, on the particular rules of psychiatric treatment, on medical experimentation, and on organ or tissue removal.

The Health Care Act of 1997 created the framework for the regulation of the physician-patient relationship in conformity to the international standards and the Hungarian constitution. However, the same law subjects the rights of the patient to undue restriction in some respects. I will address cases of such restriction in my talk. Before entering into details, however, let me make some preliminary notes of a general character.

The Health Care Act offers a list of the institutions aiming to enforce patient's rights, but it fails to define their tasks or to describe their working procedures. For example, it gives the patient the right of complaint but fails to tell

- who are the persons under the obligation to give hearing to the complaint,
- whose complaint are they obligated to examine,
- how should they document the complaint, etc.

The same absence of regulation in detail characterizes the case of the mediating councils, an institution whose function is supposed to be to help to resolve conflicts between the hospital and the patient. Furthermore, the Act announces that the patient advocates will start their activities not earlier than one-and-a-half year after its coming in force. Never since 1997 did the legislature provide for the establishment and the rules of the institutions foreseen by the Act.

Another failing of the Act is that it gives employer's rights to the Surgeon General over the patient rights advocates. This arrangement was criticized during the Parliamentary discussion by both legal scholars and human rights organizations. The critics saw it as being a decisive condition for the independence of the patient advocate that his employer is an instance outside of the public health care system. Nevertheless, the original version has been passed as law. Nor did the Act provide for

a national center for the patient advocates which would sum up their reports with the aim of submitting the data to the political decision-makers and the wider public.

Experiences of the first two years of the Act have shown that these worries were not without foundation. The absence of institutions to enforce patient's rights contributes to erode the belief that these rights are to be taken seriously.

## **2. Patient's rights and people with limited decision-making capacity**

As I told you, patient's rights are enumerated and defined by the Hungarian Health Care Act in conformity to the international consensus. In certain respects, though, the Act is not sufficiently well thought through. One of its weak points is the way it treats persons with limited decision-making capacity. They are unduly restricted by the Act in the exercise of their right to self-determination.

In a way, this case is a test for the true intent of the legislator. If the legislator's aim was to shift the ultimate right to decide from the physician to the patient, then he should have made it sure that even people with limited decision-making capacities could participate in the decision over their treatment as much as their state permits this. Furthermore, he should have seen to it that if it comes to surrogate decision-making, desires of the patient are taken into consideration as much as possible. In the absence of such provisions, the right to self-determination of patients with limited decision-making capacity is likely to suffer. Two types of violations can be predicted in this case.

- a. So long as a patient with limited competence does *not* contradict the physician, nobody will ask whether he gave his consent on the basis of competent deliberation. In the absence of a representative capable of giving force to the patient's interests, the right to decide shifts back from the patient to the doctor. The treatment might fail to be in conformity to the interests of the patient who, however, is not in a position to recognize the mismatch.
- b. Or, conversely, the patient does contradict the physician. He refuses the treatment, upon which he is declared incompetent, and a surrogate decision-maker is appointed. The reason for taking this move might be nothing else but a desire to have somebody who could give valid consent. In such cases, the surrogate decision-maker ignores the expressed will of the patient who allegedly is incompetent to base his will on rational deliberation.

The first type of danger consists in that a move in the defense of the patient's rights will not be taken: The patient is not able to decide on the basis of rational deliberation, and there is nobody else but the physician to deliberate for him. The second type of danger consists in an undue restriction of the patient's power to decide: the real ground for the interference is not that the patient is not capable of making competent decisions but that his decision is contrary to the physician's judgement.

If we consider the Hungarian Health Care Act from the perspective of these types of danger, we will find it insufficiently circumspect. As we will see in a moment, the Act ignores the fact that competency admits of degrees; it makes a yes-no distinction between competents and incompetents, and it withdraws the right of consent from those declared incompetent. They are still assumed to have the right to information,

but the right to decide is reallocated to their representative. The only qualification added by the law is that the desires of the incompetent patient „should be taken into consideration to the degree permitted by professional requirements”. This seems to be a lip service to the principle of „maximum preservation of capacity” rather than a genuine guarantee for the participation of the incompetent patient in the decision about therapy.

There are a number of questions which are left without any answer by the law:

a. Who is to be treated as incompetent in the domain of decisions about treatment?

The Act does not address the conditions for competence in the particular field of decisions about treatment. Therefore, law enforcement agencies have to consult the Civil Code for a definition of incompetence. The Civil Code defines incompetence as total and definitive absence of deliberating capacity. Thus, a competent person is one who is in full possession of this capacity while an incompetent person is one who is fully deprived of it. In other words, competence is a yes-or-no property.

True, the Civil Code knows the concept of limited competence as well, and this concept permits to introduce distinctions of degree. A person is said to be of a limited competence if her deliberative capacity suffers lasting and significant impairment. But the grading this definition is after is not the one we are interested in. Not even the concept of limited competence does allow for distinctions between types of decision. For example, it does not permit to distinguish between the capacity to make economic contracts on the one hand and the capacity to decide about medical intervention on the other. Such distinctions within the general concept of competence are very important, though. This is because very often the various specific capacities can go separately: a person who is incapable of making responsible economic decisions, might still be able competently to decide whether to accept treatment. Only the second question matters for the aims of exercising patient’s rights.

Finally, the Health Care Act does not make use of the distinction between lack of competence and limited availability of it. Neither the incompetent nor the person with limited competency is allowed to practice informed consent. Rather than using such an undifferentiated concept of competence, the Health Care Act ought to have stipulated a more specific concept of capacity to make decisions regarding treatment. The relevant questions would be as follows: Is the patient capable of understanding the information on his health status, on the proposed intervention and on the consequences of either the intervention or the failure of performing it? Is he capable of balancing these information against each other in the light of his interests, values and convictions?

The rights of the patient with less than full competency are restricted in yet another way as a result of the failure to elaborate a specific conception of decision-making capacities in the domain of medical treatment. If there were to be such a conception available, it could possibly include the injunction that the court decision on restricting or withdrawing legal competence should be subject to periodic review. In the absence of it, periodic review is not part of the practice. Thus, somebody can be deprived of the right to refuse treatment on the grounds of a court decision taken years (perhaps decades) before.

Recently, the Ministry of Justice prepared, taking into consideration Recommendation (99) 4 of the Council of Europe on Principles Concerning the Legal Protection of Incapable Adults, a new conception on the guardianship rules of the Civil Code. Enshrining this conception into law would be a significant step forward. Unfortunately, though, the conception would leave the dispositions of the Health Care Act unaffected.

b. What is to be done in the absence of a judicial decision on incompetency when the patient obviously lacks the relevant decision-making capacities?

A person who has been declared incompetent by a court before getting to the hospital, does not have any power to decide on his treatment. Neither do those who are of limited competence because of their age, that is juveniles below 18. However, the law is silent on those cases where the physician faces an adult who is not legally incompetent but who is unable to take competent decision on his treatment. The time needed for the judicial procedure of declaring a person incompetent may be one year in Hungary. In a typical case, decision on treatment must be made within a much shorter delay. There is no way to tell who has the authority to declare the patient incompetent in cases of such urgency.

c. Who decides for the incompetent patient?

One legal possibility is to give the power of surrogate decision-making to a close relative. If, however, the patient had been put under guardianship at an earlier date, then it is the guardian's authority to exercise the rights regarding medical treatment on behalf of the patient. He is the person with the authority to accept or refuse treatment or to see the patient's medical files. The problem with this arrangement is that, in Hungary, about one third of the individuals declared incompetent by a court have a so-called 'professional guardian'. The professional guardian is not a trained specialist as the name might suggest but an employee of the municipal government who can have twenty-to-thirty wards at the same time. In general, he has no personal contact with his wards, having as his main assignment the handling of their finances. Such a guardian is not fit to make surrogate decisions in matters of medical treatment. He cannot be expected to decide on the basis of the interests of the patient as the patient himself sees them in the light of his values. He can only be expected to give automatic consent to the physician's proposal. Very often, he is not even easy to find.

d. What principles should the surrogate decision follow?

The Health Care Act remains silent on how one should proceed when deciding on behalf of an incompetent patient. It does not give any guidance on whether the surrogate decision-maker should decide

- on the basis of what *he* would prefer if he were in the place of the patient, or rather
- on the basis of what he believes *the patient* would prefer if she were in possession of her deliberating capacities.

Any acceptable regulation ought to see to it that the surrogate decision respects as much as possible the will of the incompetent patient. This cannot happen,

- unless the patient is being involved as much as possible in the process of decision-making, and
- unless efforts are made to reconstruct his statements made when he was still competent, which could give guidance as to his considered will with regard to the treatment and, finally,
- unless the surrogate decision-maker tries to find out his general values and convictions, so as to make the decision in the way as the patient would make it if she were to be competent.

Self-determination in the case of the legally incompetent person is void of any meaning if the decision does not depend at all on her views and values, but exclusively on the physician's and the surrogate decision-maker's judgement. If the legislative intent behind the Health Care Act was to make the patient sovereign over the ultimate decisions regarding treatment, then it is mandatory to give as much weight to the incompetent patient's own considerations in those decisions as possible. In other words, even the incompetent person must be treated in such a manner as to maximally preserve her decision-making capacity. Unfortunately, the Act is characterized by a conspicuous absence of any regulation in this sense.

There are further unjustified restrictions applied on the legally incompetent.

- a. In the case of the incompetent patient, consent by a surrogate decision-maker is not needed unless the medical procedure is invasive. Any other kind of intervention (for example, a diagnostic examination or a therapy by neuroleptic drugs) can be performed without asking for the agreement either of the patient or of her surrogate.
- b. The right of self-determination regarding medical treatment cannot be exercised by individuals below 18. In the case of those legally incompetent because of their age, it would have been better
  - o to demand joint decision by the juvenile and her legal representative between 14 and 16, while
  - o leaving the decision to the patient from 16 years on.

The involvement of a surrogate decision-maker in the decision of a juvenile over 16 has no justification but in the case where her own choice is in obvious conflict with her interests. The law in force in Hungary does not allow for a juvenile to take autonomous decisions in such trivial cases as asking for psychological counseling or for a consultation with a gynecologist.

- c. The surrogate decision-maker is never allowed to refuse treatment in the absence of which the state of the patient would suffer lasting deterioration. Thus, even if he knows that the patient would have denied consent to the treatment or operation in question while still competent, he cannot refuse it on her behalf. In the same manner, he cannot make an ultimate decision refusing life-sustaining treatment. Such a decision can be overruled by the consent of a court which the hospital may ask for and obtain. As we have seen already, the consent of the surrogate decision-maker is not necessary in the case of non-invasive treatment. The upshot is that the law stipulates his role rather as that of a person who is available to give the consent to the treatment.

Let me say a word or two on the way the Health Care Act's provisions on handling incompetency affect the cases where individuals are treated for mental



illness. In so far as hospital treatment is concerned, it does not make any difference for the status of a legally incompetent person whether she is treated for mental illness or for some other illness unrelated to her mental state. What is specific about the mentally ill is the procedure of their assignment to a 'social care home for the mentally ill'. Insufficiencies of the Hungarian system of psychiatric care make it by and large unavoidable for patients who frequently return to the hospital for treatment, or whose social conditions do not allow them to stay home, to get assigned to an institute of psychiatric care or to a 'social care home for the mentally ill'. Most of these institutions, although designed for people with psychiatric illnesses, lag far behind the hospitals as to the level of the medical care they are able to offer, the nurse-patient ratio is unusually low in them, and restrictions on the freedom of the inmates are unusually heavy. These institutions are generally located in buildings of a very poor shape, and they house hundreds of people for years, decades, often for their whole life.

Nevertheless, the rules of the assignment of patients to them are much more lax than those of a temporary assignment to a psychiatric clinic. In the case of hospital or clinic assignment, if the guardian asks for it against the will of the ward, a judicial review must follow, and it is up to the judge to decide whether the patient needs hospital treatment or she should be released. In the case of the assignment to an institution of psychiatric care or to a 'social care home for the mentally ill', there is no room for judicial review. An assignment for life of a human person is decided between her guardian and an official of the local government. Moreover, the local government has the power to appoint a temporary guardian to an individual whom no court declared incompetent. The temporary guardian is, then, in a position to consent to the assignment decided upon by a local government official. In other words, the law makes it possible to seclude for life, against her will, a person who is fully competent to take decisions about her own life.

### **3. Can one make an advance directive on medical treatment?**

I would like to make, towards the end of my talk, some notes on an issue closely related to the problem of incompetence. People in full possession of their mental capacities may have strong views about what kinds of treatment they would accept or refuse in a hypothetical state of incompetency. Or they may think they are unable to foresee those future situations in a sufficient detail, but they have confidence in a particular person's judgement and solidarity. For such people, it may be of utmost importance to be able either to refuse in advance certain treatments they find particularly odious, or to name in advance the person who would serve as proxy decision-maker for them. Thus, the possibility to make advance directives enhances the scope and meaning of the right to self-determination.

The Hungarian Health Care Act does provide for this legal institution. The formal conditions for the statement are more simple in cases where the individual designates the person who should be informed or should give consent on her behalf. Advance directives on refusing treatment (for example, life-sustaining treatment) are subject to more strict formal regulations. They are to be made in the presence of a public notary, and an expert opinion of a psychiatrist is to be attached to the effect that the person making the directive is in full command of

her mental capacities. The advance directive prepared in this way remains in force for two years; after the end of the second year, it has to be renewed and reinforced by a new expert opinion. The requirement of periodic renewal serves the aim of preventing old directives from deciding issues of treatment at a time when the patient is increasingly likely to have changed her views. However, the cost of this safeguard is that much less people will make use of the opportunity to decide in advance certain aspects of their future treatment, because few people are sufficiently conscious in the domain of medical treatment as to make periodically repeated efforts to determine the way hypothetical future situations may be handled.

The Act allows the individual to withdraw her advance directive without any formalities. It also permits to the medical institution to go on with the treatment even in the presence of an advance refusal provided that it has grounds to doubt whether the patient's will remained unchanged in the meantime.

Let me address, in conclusion, the question,

4. Is it possible to apply in the medical practice the provisions on patient's rights of the Hungarian Health Care Act?

**Transition to democracy made it a task of great urgency to pass a new Health Care Act. This is because the law in force was twenty years old and truly outdated, while the hoped-for admission of Hungary to the Council of Europe and the European Union made the updating unavoidable. The contemporary international standards of patient's rights were well known to legal experts and human rights activists but not for the medical profession and the wider community. The media was prepared to discuss issues of medical malpractice but not issues related to the right to informed consent. The patient-physician relationship remained presented according to the traditional model: the patient places his trust in the doctor who proceeds in his best interest anyway. The only demand expressed on behalf of the patients was to provide them with more information on what is going to happen to them. It did not occur to opinion makers that the patient could make use of the information in order to decide on the kinds of treatment he would accept.**

**Thus, there is a gap between the Act's spirit and the attitude of the general public. Public opinion does not exert any serious pressure on the medical and governmental authorities to bring practice in line with the law. Patient interest groups are mobilized rather by the aim of making medical treatment or certain types of it available for particular categories of ill people. At the same time, physicians were to be expected to resist to the new regulations. They were likely to see the shift the ultimate decision from the doctor to the patient not as a step towards optimal decision-making on treatment but as a restraint on their own professional authority. They were also likely to be afraid of the rising number of malpractice litigation. These are serious problems which it is the responsibility of the government to handle by mobilizing a complex mix of political, legal, and communications instruments.**

4.

However, the government which submitted the Health Care Bill to the Parliament in 1997 failed to make the necessary steps. In 1998 it fell, and the new government was quick to send the message that it was not giving priority to patient's rights. The head of the Chamber of Physicians got to be appointed as Minister of Health Care. (The Chamber was mounting a relentless attack on the Bill during its discussion in Parliament.) Since 1998, the government initiated two amendments to the Health Care Act: the first time it proposed to restrict the right of the patient to control the use of his medical files, and the second time it proposed to abolish the legal provision for surrogate motherhood. Both proposals passed, although the first with significant changes, and the second in the midst of heated public debates.

Up to these days, patient rights advocates are not active in the hospitals. The ministerial order regulating their activities has been promulgated in December 31, 1999. It provides that the patient rights advocate is supposed to spend one day a week in the hospital. Rather than assigning more than one patient rights advocate to one hospital, the government intends to assign more than one hospital to one patient rights advocate. Contrary to the spirit of the Act, the ministerial order stipulates only symbolic presence, making the patient rights advocate incapable of providing personalized help to particular patients. Mediating councils did not come into existence, although the Act foresees their establishment by January 2000.

So long as the government does not commit itself publicly and explicitly for the enforcement of patient's rights, so long as it continues to refuse mobilizing material and human resources to publicize patient's rights and to establish the requisite institutions, no change can be expected in this domain. Respect for patient's rights may go eroding, and the public may get convinced that, yet again, something has been introduced on paper in order to please the European Union but without any intention to be taken seriously.

**Simon Foster<sup>13</sup>:**

"TRUST ME, I'M THE PATIENT"

I am a lawyer working in a specialist mental health charity, so what I want to say relates specifically to issues of mental disorders and also incapacity. However, I believe these issues relate closely to everything we have been discussing during this conference.

I would like to begin with a short account of the English legal system; although what I want to say will, I think, relate to everyone else's work, some of it arises particularly because of our laws. As you may know, we have no written constitution. Instead, we work within a **common-law system**, whereby traditional legal principles are applied to specific cases by judges. Unlike other systems, for example the Civil Code, judges

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in the High Court, and more particularly in the appeal courts, set binding precedents which must be followed by other judges until they are overruled by a superior court, or until Parliament legislates on the issue.

In most areas of law, in fact, the common-law has been largely replaced and superseded by legislation, which takes priority over it. For example, the law relating to the detention and treatment of people with mental health problems is contained in the **Mental Health Act 1983**, which is the key legislation in this area.

Our legislation tends to be very detailed, because of the power to judges to include their own binding interpretations of clauses which are not clear. The Mental Health Act alone is around 150 pages long; the standard text-book which includes this and also covers common-law rights, guidance and regulations is over 600 pages long.

However, the common law is still very important. For example, the Government has put forward proposals for an Incapacity Act, but there is no timetable for its introduction; in the meantime, the area of incapacity is largely governed by common law. This means that

**incapacity is judged by a ‘functional’ test according to the particular activity concerned**, rather than by a general declaration of incapacity. The test is, is the person capable of:

- (i) comprehending and retaining treatment information;
- (ii) believing it (for example, you do not think that the person who tells you is a devil who is trying to mislead you); and
- (iii) weighing it in the balance to arrive at a choice.

Let me give you an example of this test in practice. In 1994, a detained patient in Broadmoor High Security Psychiatric Hospital, who has a diagnosis of paranoid schizophrenia, developed an infection in his foot. He refused to allow it to be treated. The infection got worse, to the point where gangrene developed. The doctors said to him: “Your foot has now deteriorated to the point that we must amputate it- otherwise the gangrene will spread and you are likely to die.” Mr ‘C’ said, in effect, “I understand what you say, but I am not prepared to let you cut my foot off, even if I do die.” Under the Mental Health Act doctors can forcibly treat someone for their mental disorder; however, in this case it was clearly a physical condition, so the question was whether or not he had sufficient capacity to make his own decision. In a situation such as this, doctors are expected to refer the case to the High Court for a decision. The judge considered statements by the doctors and by Mr ‘C’. In his view, although Mr ‘C’ had paranoid schizophrenia, he plainly understood what was meant by amputating his foot, including the risks of not doing so. He did not want it to happen. The judge ruled that Mr ‘C’ had sufficient capacity in these circumstances, and accordingly amputating his foot without consent would be unlawful.

The final note on the case is that, since the doctors were not able to amputate, they were forced to treat the foot in different ways, and it recovered from the gangrene!

As will be apparent, this means that we have no fundamental rights and freedoms which are automatically available to citizens. However, we signed up to the European Convention on Human Rights and Fundamental Freedoms in 1950; in October 2000 this will finally be incorporated into our domestic law, so that the Convention rights

will be directly accessible through UK courts. (This has already happened in Scotland, which has its own devolved Parliament.) The advent of **the Human Rights Act** will have a radical and dramatic effect upon our legal system. Much of our existing mental health legislation is not compatible with Convention rights, as the Government is well aware. They are currently consulting on proposals for a new Mental Health Act; however, this is unlikely to be introduced before the next election. (In many ways this is a good thing, as otherwise changes would be influenced by the wish to appeal to populist sentiment. See later.)

That was by way of background. Let me now tell you a story, which many of you will know. A woman collapses in the street. Her husband calls a doctor. When he arrives he quickly examines the woman and tells the husband: "I'm sorry to say that your wife is dead." The wife sits up and says "No I'm not!" Her husband replies: "Be quiet, dear, the doctor knows best."

I have told this story to illustrate three points. The first is the most obvious: the doctor is assumed to 'know' more than the patient. Second, notice that the family member supports the doctor against the views of the wife. Third, if you know the original story you will see that I have changed the sexes round, so the wife collapses, not the husband. This is because, in our experience, such attitudes oppress women even more often than men.

Why is the doctor so powerful? He or she is, of course, a professional. But I am a professional lawyer, and my clients don't think I know more than they do about their own lives. In my opinion a doctor- especially a psychiatrist- is not seen as a normal professional but rather as a magician. He (in England psychiatrists are usually men) has supernatural powers to know the hearts of men and women, and to create health from illness. In the same way we grant magical powers to car mechanics: we don't understand what they do, but we think they can bring a sick car back to life. The difference, of course, is that doctors are not dealing with machines but with people who have feelings, wishes, and generally the ability to make their own choices. However, in England as in most other countries, the patient is the last person to be consulted.

I should make it clear that this responsibility is as stressful for the doctors as it is disempowering for the patients. Many doctors, particularly the younger ones, do not want the burden of this God-like position, particularly since it means that they are not allowed to make mistakes without a public outcry. However, like all power, it is hard to give up; too many doctors, including many psychiatrists, positively enjoy it and expect their opinions to be accepted without question. Small wonder that alcoholism and drug use is common among the medical profession, in the UK at least.

Why has this attitude been allowed to prevail? I suggest two reasons. First, a psychiatric patient is generally assumed to lack capacity to make his or her own choices. Even when the patient expresses a clear view, doctors frequently assume that, because they do not believe that what the patient wants is in his or her interests, their capacity is flawed.

Suppose that a patient does not want to take the medication proposed by the psychiatrist, either because she does not like its side-effects or because she does not

accept that she is ill. When this happens, many psychiatrists report: ‘The patient lacks insight into his or her illness.’ (Presumably ‘having insight’ means ‘agrees with me’.) Anyway, ‘lack of insight’ can be used as evidence of lack of capacity to give an informed consent. Under English common law, as developed through the courts, doctors can treat patients without capacity in the way that they believe is necessary in the interests of their welfare. They have to make a ‘reasonable clinical judgement’. And how is the ‘reasonableness’ of the judgement assessed? By reference to what a ‘reasonable body’ of other doctors would have done (the so-called ‘Bolam’ test, named after a case of this name). In other words, the fact that four or five psychiatrists agree on a form of treatment is likely to make it ‘reasonable’.

Let me give you another example. Under our Mental Health Act of 1983 there is a provision that a person may not be detained in a hospital for treatment unless their ‘nearest relative’ has been consulted, and that person does not object. This can be a useful safeguard. But the patient has no choice over who this ‘nearest relative’ is- it’s laid down by law. So if I have been abused by my father, and this has provoked my mental health problems, it is still possible- indeed it’s very likely- that my father will be the very person who has the power to agree to my detention in hospital. Even if this does not happen, most of my relatives will assume, once again, that the doctor knows best.

The Mental Health Act permits an application to be made to court to remove the powers of a ‘nearest relative’ who has acted inappropriately. But one person is not allowed to make this application: guess who? Yes, the patient. The European Court of Human Rights recently heard an application challenging this provision (JT v United Kingdom); the UK Government settled the matter by promising to reform the law. But when this will happen remains to be seen.

There is, I believe, a second reason for this imbalance of power. A hundred years ago psychiatrists assumed a new role: as state guardians for the mentally disordered. Before that time psychiatry was essentially a private contract between the doctor and the patient’s family. People in mental distress were a danger to themselves, sometimes to others; perhaps they also caused difficulty and embarrassment to the family. But more recently, it was recognised that such behaviour also threatened the social order; patients needed to be protected from themselves, but the state also had to be protected from them.

Of course, this change of approach had some advantages, not least by removing the individual from the arbitrary power of his or her relatives (in theory at least). However, in the days when a doctor was hired under a contract he could be dismissed when the family no longer had confidence in him- and if the patient responded to treatment, she could dismiss the doctor herself. Under the present system, which operates across Europe as far as I know, that is no longer possible; Professor Gevers has already spoken of the limit to the usefulness of a ‘contract’ model in mental health.

Section 3 of the English Mental Health Act, for example, requires a psychiatrist to assess not only whether someone has a mental disorder of as nature or degree such as to require treatment in a hospital, but also whether such treatment is ‘necessary for the health or safety of the patient or the protection of other persons’. These are not

medical but social judgements. At present we do not even have an independent hearing before detention for treatment, though the Government accepts that this should be introduced.

Detention in hospital is not, of course, simply custody or confinement; it is supposed to be ‘to help the patient get better’. At the heart of the system lies a belief that someone in mental distress, even if he or she retains capacity, can legitimately be forced to take medication, in a way that would not be permitted if the patient had a physical illness. If I have diabetes, I must take insulin regularly. If I choose not to take it, I will start behaving erratically, and eventually pass into a coma, which could be dangerous both for me and for others. But the law has no power to force me to take insulin, until the point when I lose capacity to make a free choice. But if I have schizophrenia and refuse to take my medication, I am seen as placing myself at unacceptable risk, and my doctor will try to get me into hospital. I believe this is because of a subconscious fear which is partly primitive, partly Christian. The Christian part says: “If this person suffers harm, you are guilty if you do not help him.” The primitive part says: “If this person behaves abnormally, he will infect the whole group and society will suffer.” The doctor therefore acts as the priest who contains the contagion on behalf of society.

We see this particularly in England with those who are diagnosed as having a dangerous severe personality disorder. Currently they cannot be detained in hospital unless their condition is capable of being treated. Under new proposals they can be detained under the care of a psychiatrist, even if no treatment is available for them, and even if they have committed no crime. Thus the doctor is no longer the supervisor of the ill but the jailer of the dangerous.

You may think that this is an attitude of the past, and is well behind us. Unfortunately our experience in the UK is that it is still with us. Every so often someone with a psychiatric history attacks and kills as member of the public. This has always happened; the statistics show that the number of homicides by people with mental health problems has not increased for 50 years. However, every time a killing is reported, the more right-wing papers and media use it to whip up a public panic about ‘dangerous mad people’ coming to attack us all. This is particularly potent if the killer is black, as has happened two or three times recently. Given this pressure, and the wish of our present Government to follow public opinion, I would be very concerned that any reform to the Mental Health Act should not be rushed through before the next election. Any politically-sensitive proposals would most probably be designed to protect the public, rather than to ensure proper help for the person with mental health problems.

What, then, are the alternatives? I would suggest a simple change to the law. If a person’s health or safety appears to be at risk, because of his or her mental health condition, he or she should be offered a choice of treatments he or she may be willing to accept. In a civilised and prosperous country we should be prepared to spend as much on psychiatric treatment as on defence, for example. If a patient with capacity still says “no”, then the doctor may not intervene, any more than with treatment for a physical condition. If he or she clearly lacks capacity to make choices, his or her views should still be respected unless there is clear evidence that his/her health or safety is in serious danger, in which case the doctor should be permitted to apply the

treatment which seems necessary. But this must be time-limited, and if the patient regains capacity- which usually happens with fluctuating mental health conditions- it must stop unless he/she agrees to it continuing. Finally, if the treatment is forbidden in a valid advance directive it may not be applied, even if the doctor thinks it is in his or her 'best interests'.

This expression- 'best interests'- is I think the key. Is it in my best interests to be forcibly given treatment which I have said clearly I do not want, even if you believe that it will relieve the symptoms of my mental distress? What then happens to my dignity, my integrity, my humanity? I suggest that, just like Mr 'C' and his gangrenous foot, doctors are not entitled to make this sort of decision for me. Only I can judge where I believe my best interests to lie.

I am speaking of treatment and not detention. Those who are a clear danger to the public would probably still need to be detained, following a proper process. But there is still no excuse for treating them against their will. At best we could say: "We cannot release you while your condition is not treated, but if you agree to take this medication we will be able to consider it". If the detainee consistently refuses, that is the end of the matter.

This is not so radical. It happens all the time with the treatment of alcoholics, for example. Those with lung cancer as a result of smoking are taken into hospital when they collapse, but if they choose to leave hospital and resume smoking there is no legal power to compel them to stop.

No doubt this proposal would lead to an increase in the number of those in mental distress in public and in private, which would be alarming and upsetting for the family and doctors alike. But if there is no legal power to treat someone compulsorily, I believe new initiatives will arise to encourage and not compel the individual to look after his or her health. We can be very creative when the easy options are removed. For a start, doctors could practise telling patients about their own cases in a way that they can understand- and listening to their responses. It's usually better to know the information than to be aware that some information is available but is being withheld.

But what if my health deteriorates and I become suicidal, while still refusing intervention? This is not easy, but I believe it is the sign of a mature society that we can make such choices. We often see friends and loved ones on a path of self-destruction, through alcohol, drugs or a dangerous lifestyle. We try to persuade them to do otherwise, by every means that we have, but ultimately we accept that they have chosen the pattern of their lives. This is fundamental to respecting the dignity and the integrity of the individual.

So I suggest that we should give the authority for making decisions back where it belongs, to the person at the centre of the whole picture: the patient. Don't trust the doctor- trust me- I know more about my life than you will ever know.



### 3. Patients Rights Protection in Practice

**ELKE BEERMANN:**<sup>14</sup>

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**PATIENTS RIGHTS PROTECTION,  
MENTAL HEALTH LEGISLATION AND  
PATIENTS' ADVOCACY SERVICE IN AUSTRIA**

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It's a great pleasure to have been invited to this conference in order to present to you the practice of patients rights protection, of mental health legislation and the Patients' Advocacy System in Austria.

My name is Elke Beermann, I am a patients' advocate in the psychiatric hospital and the psychiatric university clinic in Graz. I work for the "Association for Guardianship and Patients Advocacy" with its management in Vienna.

First of all I'd like to give you an overview of what I'm going to talk about during my following presentation.

I've divided my talk into three main parts:

1. I will start with a short introduction into the Austrian **system of patients rights legal protection in general**. Thereby I want to give you an overview of the Austrian situation.
2. Then I want to make you familiar with the **main parts of legal protection** concerning mentally ill people in Austria.
3. And lastly I will tell you something about the **Austrian system of Patients' Advocacy**.

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<sup>14</sup> Magistrate, Patient's Advocacy Service Graz, Austria

## SYSTEM OF PATIENTS RIGHTS PROTECTION:

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Patients rights are a form of personal rights, of human rights.

Personal rights form the basis of patients rights. The possibility of a violation of patients rights is what makes it necessary to establish and legally to protect patients rights.

There is a general tendency to increase efforts to protect rights by legal provisions in many various domains. This tendency also concerns the public health system. In Austria for a long time there wasn't any law definitely defining patients rights. There were several laws and acts that regulated the duties of doctors, of nurses, of pharmacists, of midwives, of hospitals. In this way, the law provided for patients rights, but only indirectly.

Nowadays we have got two Acts that definitely define patients rights. Hospitals particularly are legally obliged to respect patients rights and to enable the patients to assert their rights.

These two Acts are:           the "Krankenanstaltengesetz" ("Hospital Laws")  
and  
  the "Unterbringungsgesetz" ("Commitment Law").

- The "**Bundes-Krankenanstaltengesetz**" ("Federal Hospital Law") includes framework legislation on the subject of patients rights. As the organization of hospital care is incumbent on the Lands in Austria, the Lands had to pass implementing laws called "**Landes-Krankenanstaltengesetze**" ("Lands Hospital Laws"). Therefore all nine Lands within Austria have their own regulations concerning hospital care in general and concerning patients rights in particular. Anyway, the patients rights regulated by the "Krankenanstaltengesetze" ("Hospital Laws") relate to in-patients in general.

All Lands are bound by law to establish patients' representations, patients' ombudsmen. Most Lands already have set up such institutions. However, the legal foundation of the patients' ombudsmen, their sphere of functions and their competencies differ from Land to Land.

- The “**Unterbringungsgesetz**” (“Commitment Law”) is a specific law for psychiatric hospitals; it’s a federal law regulating the legal protection of patients committed in psychiatric hospitals. This law has established the patients’ advocacy service as an independent institution that works for the legal protection of psychiatric patients and for safeguarding patients rights in psychiatric treatment.

To sum up:

<p>There is general <b>patients rights</b> legislation for all in-patients, with federal framework legislation and implementing laws by the Lands.</p>	<p>In addition there is a <b>special federal legislation</b> for mentally ill patients called "Commitment Law".</p>
<p>And there are <b>Patients Representations</b> established by the Lands that work for the safeguarding of these general patients rights.</p>	<p>And there is the <b>Patients Advocacy Service</b> that works for the safeguarding of patients rights in psychiatric treatment.</p>

As we already heard a lot about general patients rights, I'd like to turn straightly to the specifics of mental health legislation in Austria.

## **MENTAL HEALTH LEGISLATION - LEGAL PROTECTION SYSTEM:**

### **Historical Background:**

The Austrian Commitment Law is a **federal law**, it's effective all over Austria. The act only deals with mentally ill patients whose personal rights are restricted during an enforced stay at a psychiatric hospital. The Commitment Law went into effect in 1991.

It was a unending and hard way to its enforcement.

The discussion on the subject of guardianship and commitment started in the 1970s. The aim was to make distinction between guardianship and commitment and to come to a new legal basis for both.

Nevertheless, the negotiations about guardianship and commitment took several years. In 1984, the new Law for Guardianship went into effect. The reform of the Commitment Law took another 6 years.

During this time, a test project of patients' advocacy was established in two Austrian psychiatric hospitals; this test project was run by our association at that time called "Association for Guardianship" and was evaluated by a sociologist.

In March of 1990 the Commitment Law was passed and went into effect on the 1<sup>st</sup> of January, 1991.



The **most important differences** between the old Confinement Law and the new Commitment Law were:

1. court proceedings are made mandatory on every case of involuntarily commitment,
2. the fixed periods within court proceedings are being shortened,
3. a patients' advocacy service is established, and
4. the patient has got the right to ask for a judicial review in case of further restrictive measures.

### **The Objectives of the Commitment Law:**

The main aim of the Commitment Law is written down in its first paragraph: **"The human dignity of the mentally ill is to be respected and protected in all cases."** It is on this legal basis that the Law works for the protection of the mentally ill patients committed to psychiatric hospitals.

Psychiatric hospitals have a double aim: that of healing patients, but also of protecting society from mentally ill people and of protecting the latter from themselves. Committed patients have a special legal status which differs from that of other patients. Doctors at psychiatric hospitals are allowed to hold mentally ill people against their will at the hospital and to restrict their freedom of movement under certain circumstances.

This situation is made even more difficult by the fact that mentally ill patients may be unable to enforce their rights, or may be able to do so in a limited way only, this being due to their mental condition and their dependence on the hospital. Therefore, the Commitment Law provided for the establishment of a patients' advocacy service as a special representational body especially for committed patients.

Just in order to give you an overview of what domains find themselves under the regulation of the Commitment Law, I will **list the main subjects:**

### **The Commitment Law regulates:**

- the requirements for commitment,
- the compulsory transportation of mentally ill persons to a psychiatric hospital,
- the commitment proceedings within the hospital,
- the court proceedings, the periods of judicial review, the right of application, the right of recourse,
- the conditions under which compulsory treatment or further restrictions of freedom of movement are legal,

- the patients' advocates' mandate and rights.

### What does the term "commitment" mean in Austria?

I've already used the word **commitment** for several times. I think it's time to let you know what the term commitment means in Austria.

The term "**committed**" describes anyone who is confined in a closed area or otherwise subjected to restrictions of his/her freedom of movement in a psychiatric hospital.

- Thereby the freedom of movement is restricted to specific areas within a psychiatric hospital, to closed areas for instance.
- If patients are told, that they must not leave the hospital on their request, they are committed.
- Even if patients only think that they are not allowed to leave the hospital they are considered "committed".

We have to realize that commitment of mentally ill patients in Austria counts as an exceptional case within psychiatric care. In fact we've got about 60.000 inpatients a year; about 20% of them are committed.

Prior to commitment in a psychiatric hospital **three requirements** have to be met, which have to be regularly checked during the period of commitment:

- The patient has to suffer from a mental illness,
- as a result, he/she has to be at risk of seriously and severely endangering his/her life or health, or the life or health of another person and
- it must be the case that no other adequate form of medical treatment and care is available.

The commitment is thought to be an ultimate recourse to avoid imminent danger to life or health. Just being in need of treatment is no reason for commitment, neither is it the danger to property.

### The way commitment works:

A person can be committed at different points in time:

- at the time of admission to the hospital regardless a person comes to the hospital voluntarily or involuntarily and
- during hospitalization when the conditions on commitment arise.



A person can only be taken to a psychiatric hospital against his/her will if prior to the hospitalization a **physician employed by the government** (e.g. a doctor of the administrative authority, a police doctor) provides a written statement to the effect that the above mentioned conditions have been met.

In the mental hospital **two doctors** separately have to re-examine whether the commitment requirements have been met (para 10 Commitment Law). Only if both of them arrive at the conclusion that this is the case, can a patient be committed against his/her will.

Hospitalization against a patient's will has to be immediately reported to the district court and the patients' advocacy. Thus, the patient's advocate will be able to get in touch with the patient as soon as possible.

At this stage, it is often possible to settle concerns and complaints without court assistance, for example by talking directly to the responsible doctor.

If mentally ill persons have the capacity to judge and understand their situation, they themselves have the possibility to ask for commitment in writing. On request, patient's advocates also offer advice and assistance to voluntarily committed patients. However, such patients can withdraw their voluntary request for commitment at any time (para 4 Commitment Law).

To sum up, there are three different statuses of being inpatient in a psychiatric hospital:

- A patient can stay there voluntarily without being restricted in any way,
- a patient can be voluntarily committed and
- a patient can be involuntarily committed.

As I already told you, about 60.000 persons a year are admitted to hospital, nearly 80% of them stay there voluntarily without being restricted, just very few are voluntarily committed, and about 20% of the inmates are involuntarily committed.

### **The Commitment Proceedings - The System of Legal Protection:**

Doctors decide whether a person will be committed in a psychiatric hospital or not. Judges decide during the commitment court proceedings whether a commitment is legal or not.

The court proceedings themselves are organized in a very complex manner; in order to avoid misunderstandings, I will try to explain them in a simplified way.

**Within four days** of the district court being informed of a commitment a judge has to come to the hospital, hear the patient in person, hear the responsible doctor and the patient's advocate, and has to review the legality of the commitment for the first time. If the commitment requirements are met (mental illness, danger to oneself or someone else, no other treatment available), admissibility of commitment is declared, and an independent expert is appointed to give a psychiatric opinion within 14 days.

**Fourteen days after the first review** by court, a further court review is held. During this court-hearing the judge questions the patient, the patient's advocate, the medical head of the ward, the psychiatric expert and sometimes also family members or the guardian (should the person find himself/herself under guardianship). On the basis of the objective findings, the court has to decide whether the commitment requirements have been met and whether commitment is legal or not. If the mentally ill patient has to remain involuntarily in psychiatric hospital, a further follow-up is held at court not later than after three months; following this, a review is held after half a year, and after another half a year.

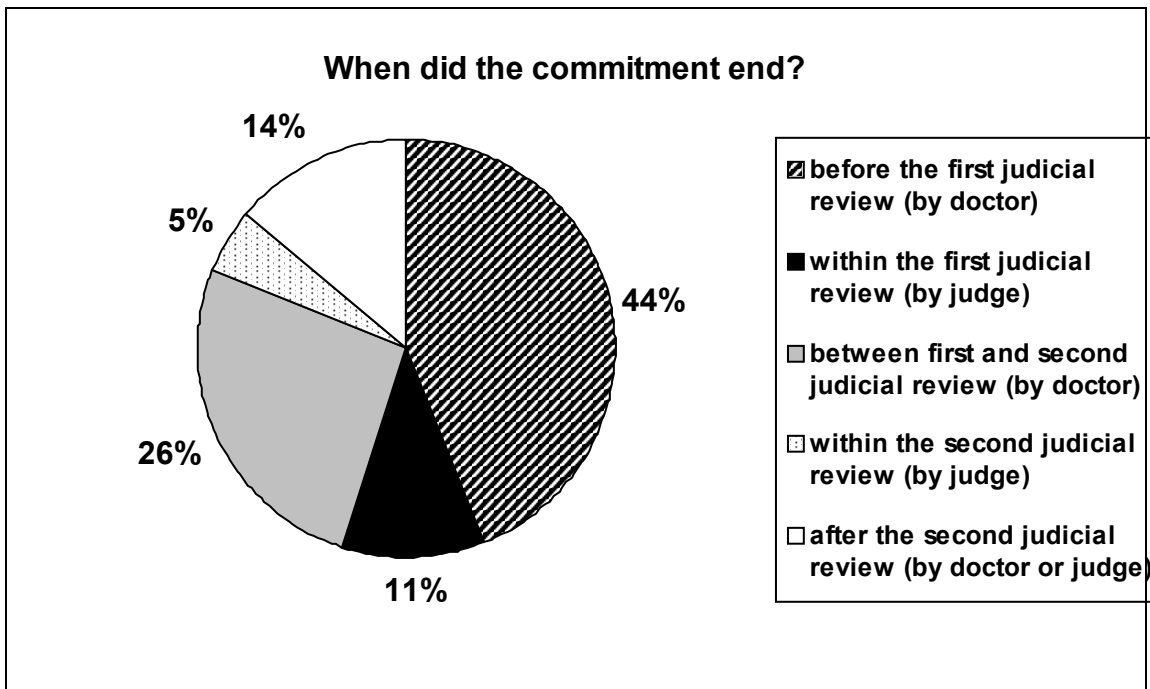
The follow up judicial review is split into two steps. The patient's advocate has to be informed of and involved in all procedural steps. All parties have the right to appeal against the court decision.

The judicial review on the commitment and the expert's medical opinion are obligatory and free of charge for the patient.

Just to give you an impression of the dimension, I'd like to give you some figures.

**In 1999, in the psychiatric hospital and the psychiatric university clinic of Graz only, 3.444 commitments** were reported to the patients advocacy.

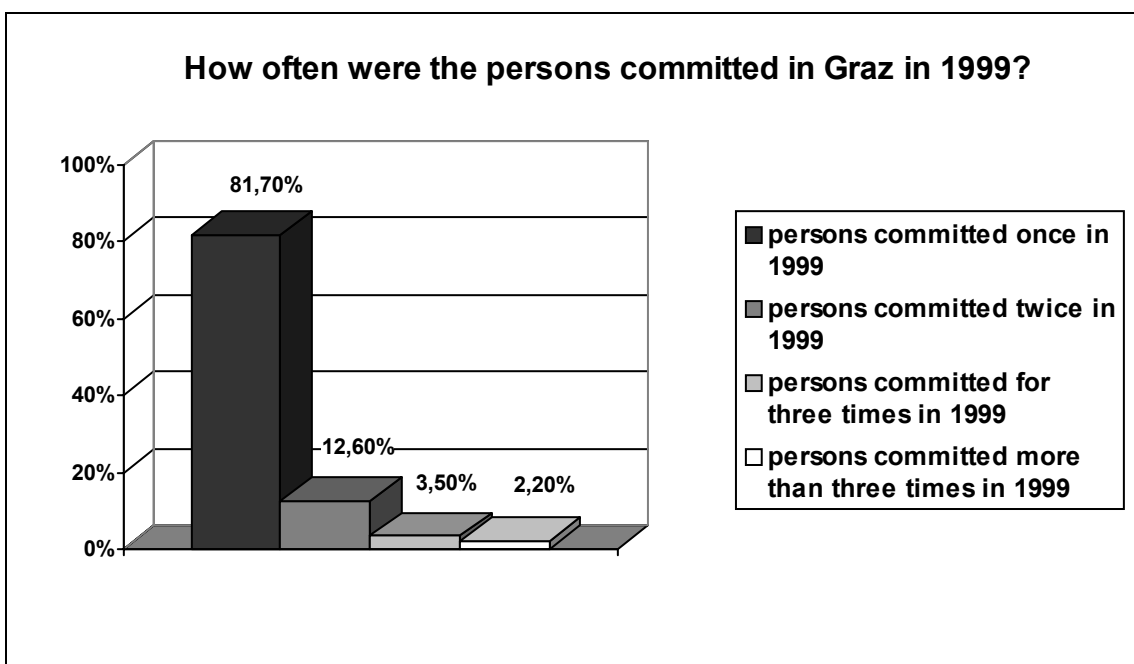
Most of these commitments ended by the decision of the hospital doctors. The following diagram is meant to show you the proportional share, when and by whom the commitments actually ended.



Beermann E., Scherf M.: The Commitment Law in Practice, Graz 2000

Some more facts:

The Commitment Law is often said to be a law raising the number of recurring commitments. In fact more than 80% of the 2.654 committed persons in Graz were only committed once in 1999.



Beermann E., Scherf M.: The Commitment Law in Practice, Graz 2000

## **Further restrictive measures:**

### **1. Restriction of freedom of movement:**

The Commitment Law makes a distinction between general restriction and further restrictions of freedom of movement:

- **General** restriction of freedom of movement is called commitment. Thereby freedom of movement is restricted to several rooms or specific areas within a psychiatric hospital; the commitment has to be reported to the court and to the patients advocacy and is obligatorily reviewed by court.
- **Further** restrictions of freedom of movement mean special measures within commitment like locking a patient in one room, confining him to a security bed, or fastening or tying him up.

These further restrictive measures are not allowed unless they are the only way

- to prevent an extraordinary danger to the patient or someone else and
- to ensure medical treatment and care.

Only doctors are authorized to order such further restrictive measures; they are obliged to document the kind of measure and the reasons in the case history, and have to inform the patients' advocacy immediately. Both the patient's advocate and the patient himself have the right to apply for judicial review against the restriction.

### **2. Compulsory Treatment:**

To talk about medical treatment is even more difficult.

Generally, "informed consent" forms the legal basis of every medical treatment.

As mentally ill patients do not always have the capacity to give "informed consent", specific provisions on the medical treatment of committed patients were incorporated into the Commitment Law.

The doctor always has to check the patient for ability to understand his situation and the meaning and consequences of a medical treatment. If the patient is capable of understanding and his situation and to make a judgement about it, the doctor has to accept the patient's decision whether it's for or against the treatment.

Only if the patient isn't able to understand and judge the meaning and consequences of the treatment, is the doctor authorized to order simple

medical treatment without the patient's consent. Compulsory treatment has always to be proportional to its purpose.

On the patient's or the patient's advocate's request the court has to review the legality of compulsory treatment.

There are special provisions for persons under guardianship and for infants and also for special treatments as electro convulsory treatment for example.

## **THE PATIENTS ADVOCACY SERVICE:**

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The Patients' Advocacy Service is an institution that has been established by the Commitment Law in January 1991.

Austrian patients' advocacies are non-profit associations. The service is run by two associations, namely the "Association for Guardianship and Patients' Advocacy" and the "Institute for Social Services". These associations are responsible for training, guiding and supervising patients' advocates and are funded and supervised by the Austrian Federal Ministry of Justice.

We work in teams and have diverse professional backgrounds. About half of the patients' advocates are lawyers, the rest are psychologists, sociologists, educational experts and social workers.

In order to receive an assignment, the association proposes patients' advocates at the responsible districts court; this court then assigns them to the patients of a specific psychiatric hospital. Patient's advocates are not nominated for specific individuals, but rather for certain wards of a psychiatric hospital.

The **patients' advocates' activities** include:

- the legal representation of committed patients in psychiatric hospitals,
- the representation of patients in court proceedings reviewing the permissibility of their compulsory commitment or compulsory treatment,
- counseling and information on patients rights for all patients as well as their families and friends and also for interested people in general.

In addition to these activities, patients' advocates are also involved in public relations in order to increase social acceptance of the mentally ill and mentally handicapped.

Although patients' advocacies are independent of the psychiatric institutions, psychiatric hospitals have to provide us with adequate rooms within the hospital area, and have to grant us free access to the patients.

We ourselves contact the committed patients, inform them on their rights and on the court proceedings and talk to them about their view of the commitment. In addition, patients can call us during regular working hours (Monday to Friday); they can ask us to come to their hospital wards, or they can meet us in our office which is easily accessible.

The services of patients' advocates are **confidential** and **free of charge** for the patients.

In Austria, all involuntarily committed patients automatically get a patients' advocate. Patients are only allowed to replace the patients' advocate if they appoint a lawyer or a notary. In this case, the competence of the patients' advocate towards the court expires; the competence of representation towards the hospital still remains.

The law affords the patients' advocates a strong position vis-a-vis the hospital and the court.

The patients' advocates ... :

- ...have an **unrestricted access to the patients**,
- ...have **to be informed** on important restrictions of patients rights,
- ...have **free access to records**, files and case histories of committed patients,
- ...have a **monitoring function**,
- ...are authorized to **apply for judicial review** against further restrictive measures,
- ...have the **right of recourse**, and
- ...are **obliged to inform the patient** of the planned actions and to get his consent.

Even though patients' advocates are the legal representatives of the patients during commitment court proceedings, their role does not diminish the patients' legal competence and capacity to be a party. Thus, patients have the right to enforce their rights themselves, and in this, they are supported by the patients' advocates. It is the aim of patients' advocates to protect the interests and needs of patients and to support them in their relationships with the psychiatric hospital.

It is the objective of the Patients' Advocacy Service to ensure conditions enabling informed and enlightened patients to have a say in both their commitment in psychiatric hospitals and the course of their treatment.

Patients' advocates have a monitoring function in psychiatric hospitals: they communicate with patients, doctors and nurses about the issues involved in commitment and compulsory treatment in order to clarify if compulsion is necessary or not. As legal representatives, they ensure that compulsory treatment and restrictive measures are documented and can be reviewed by the court. They are authorized to apply for judicial review against compulsory medical treatment and restrictive measures.

To come to a conclusion, establishing the patients' advocacies was one main pillar of improving the legal protection of mentally ill inpatients.

Courts have a controlling function, but they are located outside the hospital and come there only twice a week.

The patients' advocacies are located within the hospital areas. The advocates have free access to the psychiatric wards, and their office is easily accessible for patients in order to get support.

**Fons Dekkers<sup>15</sup>:**

## **Implementation of Patient Policy in Health Care**

### **The Dutch Model**

All participants in the health care system have a shared responsibility in giving shape to the primary process in cure and care: professionals, politicians, managers and insurance companies as well as patients and consumers themselves. Each one from his own perspective. There is no harmony in the system if only one perspective prevails, which usually is identical with the professional or the financial perspective. The main question here is: how can the patients' perspective become a significant aspect of the primary process? In other words: how can health care be driven by **supply as well as demand**?

In all cultures and nations patients and consumers have to be facilitated and encouraged to take their own responsibilities in the primary process, since this does not come naturally. The patient has a paramount interest in the outcome of the therapeutic process, but at the same time he has often too little knowledge and too little influence to really take his share in the process itself. And professionals usually do not treat patients as their real counterpart, since this is not the easiest way.

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<sup>15</sup> Director, National Institute for Client-centered Care/National Federation of Patients and Consumers (NP/CF), The Netherlands

Government should enable citizens/patients to take this fundamental responsibility once they need medical assistance or care. They should realise it is not realistic to make oneself completely dependant on a merely paternalistic (medical) system. That is not in line with basic democratic values, nor with the existential freedom of individual citizens.

And also, the primary processes of cure and care will not be sufficiently effective if the main subject is not allowed or if he will not be able to act as an active participant and as the one who bears ultimate responsibility for his own body and mind.

The political system, the government, health care institutions and the insurance system of a nation cannot provide the conditions for shared responsibility and especially for empowerment and education of patients and consumers in this respect unless they act in a concerted and systematic manner.

I shall use the case of the so-called **patient policy** in the health care system of the Netherlands as an example for methods and techniques that could be introduced as a cohesive package by government and other actors in this field.

### **Cornerstones of patient policy**

- 1 Enact and implement patients rights.
- 2 Support and acknowledge patients organizations.
- 3 Promote and facilitate patient participation.
- 4 Promote adequate patient information.
- 5 Introduce patient perspective in quality of care.

Concerning patients rights in the Netherlands I refer to Mr Gevers' lecture, focusing on the Medical Contract Act, which is an interesting concept of legislation. In addition I want to mention the Medical Quality Act, the Patients Participation Act and the Complaints Act. Together with some other Acts they are providing a systematic framework of legal measures to safeguard and promote patients rights and equity in the health care system.

The Medical Quality Act is interesting and unique in requiring formal quality systems in all health care institutions. The main criteria for good quality as stated in this law encompass patient centeredness and taking into account patients needs. Every year a quality report has to be delivered to regional health care authorities and representatives consumer organizations. This at least gives an opportunity to discuss measures to be taken in that institution to improve overall quality.

But this has little meaning if there are, for example, no grassroots organisations to deal with the impact of the reports and to induce as well as work out other means to improve quality and strengthen the patients' perspective.

### **Grassroots Organisations**



Thus, in order to enhance the implementation of patients rights and to provide citizens and patients with appropriate means to make the right choices and to take responsibility for their own health, it is necessary to promote and support grassroots organisations dealing with the interests and perspectives of patients and consumers. This should be a social and even ‘political’ factor in society, enabling citizens to participate in healthcare, on collective as well as individual levels, detached from commercial and professional interests as such.

In the Netherlands, again as an example, we have combined in a National Federation all such organisations dealing with the perspectives and interests of consumers, patients and health care users in general. This Federation counts up to 2 million members, which is about 20% of the adult population in the country. With these numbers, citizens interests can be defined in legitimate ways. But also with less numerous grassroots support, one can call for legitimate representation of users’ interests, as long as claims and visions are based on reliable surveys and research concerning the needs of relevant target groups in the population.

Main clusters of interest groups consist of:

- a. Categorical (disease related) organisations, including self-help groups and organisations for handicapped people.
- b. Citizens’ organisations and consumers’ organisations, including associations for women, elderly people and people in nursing homes.
- c. Family organisations, including associations for parents of mentally handicapped children or family members of psycho-geriatric patients.

These clusters usually have activities or branches on national level and/or on regional and local levels. Influence and participation are needed at all levels.

Looking at these grassroots organisations and their role in improving patients’ position and implementing patients rights in everyday practice, one could consider different areas of interest which are mainly effective as part of concerted and continuous activities aimed at improving health care services or complementary to them.

### **Main Areas of Interest**

1. Forming and supporting peer groups of patients and care users according to expressed needs.
2. Building national and regional infrastructures for participation in health care decisions and individual support by these peer groups.
3. Implementing and supporting patient oriented services in cure and care, including quality improvement from a patients’ perspective.
4. Developing and distributing objective patient information, supporting informed decision making by consumers and comparing quality of products and services in health care.

5. Education of patients as well as health care professionals in expressing and considering reasonable patients' needs as one of the main points of reference in health care.

6. Lobbying from the patients' perspective on all decision-making levels: political, professional and managerial. Improving awareness for a patients' individual autonomy and responsibility.

### **Flexible Targets**

In order to be able seriously to contribute to improving the system, it is necessary to avoid unnecessary polarisation. It should not be patients against doctors or patients against government. In many ways one can support and reinforce each other in improving the system and the primary process. For 70 or 80%, health care services can be in harmony with the patients' expectations and needs. If so, it is good to recognise that and concentrate on what is lacking or just wrong.

Grassroots organisations should distinguish between conflict and harmony. They also need different coalitions for different targets. For example, it is good to co-operate with professional organisations of physicians and nurses on ethical codes and socially acceptable guidelines for diagnostic procedures and treatment. Or to co-operate with government and politicians on equity and access, and on planning procedures. Conflict and opposition is only effective when the tools of harmony are exhausted or when the patient perspective is ignored and marginalized by others from the beginning.

The main challenge is to make the experiences of patients and their contribution to the health care system useful and needed for providers and politicians alike.

Citizens' participation should not be seen as bureaucratic excess in democracy, but as a substantial and indispensable dimension of:

- a. recognizing basic human rights and individual autonomy,
- b. planning and decision-making in the health care system,
- c. sharing responsibility in the primary process of diagnostic procedures, treatment, self-help and life-style,
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Josef Mrázek<sup>17</sup>:

### **LACK OF LEGAL INSTRUMENTS FOR THE PROTECTION OF PATIENTS RIGHTS IN THE CZECH REPUBLIC.**

#### **Article 31 of the Charter of Fundamental Human Rights and patients rights in the law of the Czech Republic**

Article 31 of the Charter which has been made part of the Constitution of the Czech Republic, provides for a relatively firm basis to patients rights, although the sense of it is subject to controversies, especially so are the principle of solidarity and the extent to which the state is supposed to guarantee health care to its citizens: these ideas are heavily attacked by right-wingers. In any case, the system of laws and regulations related to patients rights is being under reconstruction these days, and this work is expected to come to completion by the end of March 2001.

#### **The Czech Association of Patients and patients rights**

The legislative process invited the Czech Association of Patients to mobilize in order to save the patients rights already codified, to improve their definition, and to introduce those rights which are still absent from the law.

A particularly demanding task is that of making sure that the institutions of health care abide by the laws which stipulate patients rights. Low level enforcement is the main culprit for weak legal protection of patients rights in our country. Unfortunately, this might remain a problem in the future, too. Most probably, patients rights commonly recognized by EU member states will be legislated in the Czech Republic as well but, in this country, there will be a more stringent need for instruments of enforcement than elsewhere.

**The ombudsman** is a newly created institution in the Czech legal order, and there is no experience yet with regard to it. We can only hope that the problems of health care will be among the important subjects of the ombudsman's attention, and that the ombudsman's authority will be high enough.

#### **The right to choose the physician and the insurance company**

After the political changes in 1989, two of the patients rights have been newly introduced into the health care system of the Czech Republic. One of the new rights was that of choosing the physician, the specialist and even the hospital of one's preference. This right is not an absolute one, to be sure: the patient might be refused

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<sup>17</sup> Project director, Czech Association of Patients

on the grounds that the health care establishment selected by him/her finds itself outside of his/her home region or that there was no free capacity. However, there are at present discussions about restricting the patient's opportunities to choose so that they do not include more than the choice of the generalist physician (within some limits). This is called the model of controlled health care.

Another newly introduced right was that of choosing a particular insurance company to take care of the mandatory health insurance. Unfortunately, the rules for the insurance companies were too loose in the first years, and a large amount of money got lost without involving any effect on the quality of health care services.

### **The right to access to one's medical files**

It is highly important for a patient to be able to see his/her medical files and to ask for a copy of any document on them. However, this right has never been made concrete enough by the law. Sometimes, the right to obtain information is respected, sometimes it is not. EU legislation helps a lot in promoting this issue in the Czech Republic.

### **The Czech Association of Patients comments the Laws**

Interestingly, the Association of the Physically Disabled has, since very long, the right to take part in the legislative process concerning health care, but no other group of patients enjoys such a privilege. The Association of the Physically Disabled does a very good job, but its interests are restricted. Three years ago, it agreed to enter into effective co-operation with the Czech Association of Patients which contributed to an enlargement of its focus.

Since the end of 1998, the comments of the Czech Association of Patients are officially taken into account by the Ministry of Health.

### **Patients rights in the laws under preparation**

The list of patients rights to be found in the bills under discussion includes those rights recognized in the year 1992. This list has been set up by physicians and, therefore, some additions and amendments seem to be necessary, but the work done is to be appreciated, particularly as against the background of the attacks it became subject of recently.

### **The desires of the citizenry and the deafness of politicians**

More than 80% of the citizens expressed their desire that health care be guaranteed by the state for everybody on the principle of solidarity at a level usual in Europe and, that, its financing be managed by the state. The respondents agree that the redesigning of the health care system should start by defining the required extent of health and, that, costs and the way their coverage is raised (by means of taxation and insurance) are to be determined accordingly.

Interestingly enough, there are only a few politicians who agree that citizens have the right to choose the form of the health care system they want to participate.

Besides, there is a tendency among the physicians to interpret the difference between the health care before the year 1989 and after it in such a manner as to attribute some of the present difficulties to the fact that doctor's paternalism has been abandoned in favor of decision-making by the patient himself or herself.

### **Some key problems**

To sum up, the main problem does not lie in an absence from the Czech law of the classical patients rights, but in the fact that the instruments of application and enforcement are weak. A serious problem is the lack of respect for the desires of the citizenry as concerns the general conception of health care, especially the right to choose the level of the solidarity and to determine the part of the state in managing the health care system.

### **Health care in the Constitution of the Czech Republic.**

Article 31 of the Charter of Fundamental Human Rights, which has been made a part of the Constitution of the Czech republic ensures the necessary health care for each citizen without direct paying on the basis of the common health insurance and under the conditions specified by the law.

### **Patients rights in the law 20/66 Sb., 48/97 Sb. and 256/92 Sb.**

1. Right to free preventive tests in order to preserve or improve one's health.
2. Right to a minimum of drugs from each basic group of similar drugs without additional paying.
3. Right to an access to the emergency health care system and to continuous services.
4. Right to secrecy in treating personal data related to health care.
5. Right to full information about one's own health state, provided that it does not endanger the psychical state of the patient.
6. Right to the necessary information before deciding on a new diagnostic or therapeutic treatment.
7. Right to refuse health care after being told the possible consequences of doing so.
8. Right to privacy in the course of the health care process.
9. Right to take part in the control of the providing of the health care.
10. Right to get a copy, once in a year, of one's account at the insurance company if so requested.
11. Right to get a report on one's health files preserved at the provider of the health care, once a year without payment - the extent is not determined.
12. Right to a provision of health care such that the patient's sensitivity and dignity are respected.

Appendix:

**„The Czech Association of Patients defends your interests.“**

Excerpts from a leaflet



- The Association takes part in preparing the new laws, regulations and other legal documents in co-operation with the Ministry of Health with the aim of improving the position of the patients;
- the Association represents patients in organs exercising control over the establishments of health care;
- the Association represents patients in the organs exercising control over insurance companies;
- the Association is in a continuous contact with the Committee for Health and Social Issues of the Parliament and comments on the proposed laws;
- the members of the Association work in various official and consulting organs with the aim to protect there the interests of the patients;
- the Association provides legal advocacy and legal aid to patients suffering harm as a result of a bad health care.

Krzysztof J. Filipiak<sup>18</sup>, Małgorzata Szeroczyńska<sup>19</sup>

### **Experiences in teaching medical law and patients' rights to medicine and law students**

Three years ago the Warsaw Medical Academy together with the School of Law and Administration of the Warsaw University launched a seminar on aspects of bioethics, medical law and especially patients' rights. The seminar met with a great interest and was visited by a considerable number of both medical and law students. The last semester the formula of the seminar was slightly changed. The Philosophy Faculty of the Warsaw University was invited to cooperate. The number of participants increased as a result, and it came up to about fifty people in a class. At present the seminar is carried on by doctor Krzysztof Filipiak from the Medical Academy, criminal law professor Eleonora Zielińska and philosophy professor Zbigniew Szawarski.

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<sup>19</sup> Institute of Criminal Law, School of Law and Administration, Warsaw University, Poland

The seminar on bioethics and medical law entered into the program of studies of all the three faculties as an optional subject. Unfortunately, it is a one-semester class only which results in a strict limitation of the questions for discussion. The program was focused on four main issues:

1. patients' rights, among them the rights of the mentally ill – with the special attention for the problem of patient's consent to the medical treatment;
2. physicians' liability – in its three aspects: civil, criminal and professional;
3. permissibility and legality of controversial medical treatments – selected for the purpose of the seminar according to the students' interests (e.g. assisted conception, abortion, euthanasia, genetics, experiment on embryos, cloning, tests on new drugs, transplantation, sex correction etc.);
4. the recent Polish reform of medical service and health insurance.

Thus, the seminar is conducted with the participation of professors and students from three separate schools representing three various styles of education and providing completely different knowledge about medical issues, and so it is a truly multidisciplinary seminar. This allows to approach its questions from three points of view: ethical, legal and practical. Of course, the framework for discussion is constituted by the physicians' Code of Ethics and the acts of internal and international law dealing with medical problems (such as the Act on the Physicians' Profession, the Health Care Institutions Act, the Act on Protection of Mental Health, the Act on Transplantation of Cells, Tissues and Organs, the Act on Family Planning, Embryo protection and Legal Conditions for Abortion, the Health Insurance Act, the European Convention on Human Rights and Biomedicine of 1997, etc.). However, the main goal is not that of explaining the content of these regulations (which is obviously necessary to prepare the ground for discussion for the non-law students), even less is it that of conducting a jurisprudential debate on their possible legal interpretations, it is rather that of comparing the abstract standards with real practice, and of considering the reasons why the two so often do part company, and what is morally wrong in case of their discordance: is it the law or practice or perhaps both (especially in such delicate cases as that of abortion and euthanasia).

This field of interest is ordinarily enlarged by the issues which are only vaguely mentioned in the legal texts or which are not covered by Polish law at all (such questions as: genetics, cloning, production of embryos for the purpose of research, drug testing, sex correction, sterilisation and so on). The fact that these domains

remain, for the time being, without legal coverage, requires to focus on ethical standards in order to decide whether this kind of procedures are or are not admissible. A further step goes into deciding if the issues in question should be covered by the law and if so, how their legal regulation should look like.

Usually, the discussions have been very hot with sharp conflicts between law and medicine students. In most of the cases, their attitudes to the issues in question have been fundamentally different. Most probably, this reflects two different systems of values held by the two groups.

Medical students tend to focus on the patient's welfare, while law students (and also philosophy students) tend to give priority to the patient's autonomy and his/her will. The problem starts when we are placed in a situation where one must choose between these two values.

The law is explicit on requiring the patient's consent for any treatment, even a life saving one, and on making a crime if medical intervention is carried through without proper consent by the patient. However, medical students often treat this as a formal obligation, which is fulfilled by patient signing a very schematic agreement form. The patient's right to be adequately informed before deciding on treatment and the corresponding obligation of the doctor to tell the truth, usually meets their questions concerning two aspects:

1. How to deliver the diagnosis in order not to make the patient break down and resign from any treatment?
2. How to explain the proposed treatment – whether to show other alternatives (especially when only one of the alternative options is supposed to be adequate in this case); how deeply to enter into the details with regard to complications which may result from the proposed treatment, so that the patient chooses the procedure preferred by the physician, and in order that the physician is protected against later accusations of causing damages the patient has not been previously warned against.

Another point on which medical students are strongly opposed to legal principles is the one of unconscious patients who previously declared their refusal to treatment – which is a case, for example, of suicides or DNR demands (according to the Polish law the “living will” has no valid force). They usually assume that such a patient should be saved even against his/her will after losing conscience because he/she could have changed his/her mind which is impossible to verify now. However, it can be

observed that medical students adopt a pro-life attitude rather in order to protect themselves from an eventual accusation of causing death – as they deal with the situation of death risk, their liability for acting without an express patient’s consent is excluded. Such an attitude is understandable taking into consideration the lack of precision in the legal provisions concerning this issue and even contradictions between the physicians’ Code of Ethics and the Criminal Code.

In general, medical students are more interested in learning the conditions of their liability than anything else. They seem to look for precise knowledge about legal requirements to which their professional conduct is subjected – they want to know how they should behave, what they should say and what obligations they should meet in order to avoid criminal accusation and civil responsibility or fault in front of the Chamber of Physicians. On the one hand, they want lawyers to give them accurate and full receipts what to do to comport with the law – what should be included in the agreement form, what are conditions under which they can oppose the patient’s refusal to the treatment, what are the situations in which they can appeal to the conscience clause. To put it briefly, they want to know what they must do and what they must not do to be sure they would not be prosecuted.

On the other hand, when it comes to legal principles which are supposed to constrain the physician’s action, they almost invariably declare that such principles are impossible to follow under the conditions of medical care reigning in Poland, under circumstances of highly inadequate funding of treatment, scarcity of equipment, of staff, of hospitals beds, under circumstances where the physicians are overloaded and have simply not enough time for giving to individual patients all the required information.

Law students have an opposite attitude. They usually take the letter of the law for the only standard, and maintain that real life conditions cannot serve as an excuse for non-compliance except for very exceptional cases (comparable to the situation of duress). In general, they take the patients’ side, and commit themselves for an absolute protection of their rights and autonomy. At the same time, they are not able to give any precise indication for how the physician should act in specific situations, and refuse to discuss doubts raised by medical students from any perspective other than that of the patient.

Philosophy students are situated somewhere between the two opposite groups. They usually raise sceptical questions with regard both to medical practice and to

legal standards. They usually try to take a relativistic view on any general rules and values, and do not accommodate themselves with simplistic answers.

Such a diversity of attitudes toward essential issues regarding the standards of medical care make the seminar discussions often violent and always exciting. And this gives to our students not only the opportunity to acquire knowledge on medical law, but above all to improve the skills of logical argumentation in such a delicate field as that of bioethics which we think is much more important than establishing somebody's right or wrong.

#### **4. Legal Aid Services, Ombudsman Programs**

##### **Viktor Pickl<sup>20</sup>: "Legal aid services and Ombudsman programs for patients in Austria"**

Within the European Union, the Treaty of Amsterdam has opened the door to a European health care policy, but — with the exception of the issue of transplants — it has left the regulation of health care services in the hands of individual states. Up to now, the attitude of the EU and the member states towards harmonization of health care rights for European citizens and patients has been very restrictive.

Nevertheless, a network consisting of the World Health Organization, the European Partnership for Patients Rights and Citizens Empowerment tries hard to promote the principles of the Declaration on the Promotion of Patients Rights and to provide the Member States of WHO with technical support in the process of drafting patients rights.

This agency will be organizing and leading the 3<sup>rd</sup> Forum session on Patients Rights at the European Health Forum Gastein 2000 in Bad Hofgastein, Austria, from 27<sup>th</sup> - 29<sup>th</sup> September 2000.

The Committee of Ministers of the member states of the Council of Europe adopted, on 24<sup>th</sup> of February 2000, the Recommendation on the development of structures for citizen and patient participation in the decision making process affecting health care.

The Committee recommends, that the governments of member states

ensure that citizens participation should apply to all aspects of health care systems;

create legal structures and policies that support the promotion of citizens participation and patients rights.

The right of citizens and patients to participate in the decision making process affecting health care must be viewed as a fundamental and integral part of any democratic society.

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<sup>20</sup> Prof. Dr. Viktor Pickl: Patients Advocate and Healthcare Commissioner Vienna, Austria

Citizens should participate throughout the legislative process in health care, in the drafting of laws, in their implementation and follow-up, including future modifications procedures. This can be achieved through participation in commissions and public debates, whenever appropriate.

Citizens/patients should have the possibility of participating in setting priorities in health care. For this purpose, various aspects of priority setting should be clearly explained to ensure responsible and informed participation by citizens. Aims, outcomes and responsibilities attached to these choices must be clearly set out, as well as implications of these choices as regards the allocation of resources, reorganization of the health system and relations between the different components of the health care system.

Patients' viewpoints and expectations should be taken into account when assessing the quality of health care. Patients should have a say in internal evaluation, and should also be involved in external evaluation via patients associations.

In order to be effective, these mechanisms should have a broad range, providing for forms of conciliation and mediation. Complaints procedures and conflict resolution mechanisms should be easily accessible. Financial barriers to access to these mechanisms should be removed by making access free of charge.

We cannot underestimate the impact of improving citizen education on the promotion of patient rights, nor can we underestimate the need for being involved in their care. This is leading to growing expectations as to the quality of treatment. Patients don't accept authoritarian models any more. Citizens rightly demand technically top quality health care – and one provided in a humane way. Health systems must be able to provide "high-tech-high-touch" care. Better understanding of health will enable people to adopt healthier behavior patterns. At the same time, our knowledge on health determinants gets more detailed and complex. This places obvious requirements on the communication of health facts.

The catch word is "empowerment" which means giving resources for individuals and communities to manage their life and actions. The Jakarta Declaration on health promotion, drafted by participants of a WHO conference, puts this as follows: "Health promotion is carried out by and with people, not on or to people. It improves both the ability of individuals to take action, and the capacity of groups, organizations or communities to influence the determinants of health."

Citizens and patients should be actively involved in the decision making process on organizing and monitoring measures of health promotion and health care. Health care means joint rights and joint responsibilities. Respecting the rights of the patients increases their involvement and responsibility. The more people are aware of their autonomy, the higher the need for patient participation in the health care systems.

Now let me say a word about the situation in Austria with special regard to Vienna. As you know, Vienna is a medical Metropolis with 11.000 physicians and 40 hospitals. In 1992, the city already started efforts for a more effective protection of patients by setting up the Agency of the Vienna Health Care Commissioner. The independent Vienna patients' advocate and Health Care Commissioner are obliged by law to protect the rights and interests of the patients in all areas of health in the city of Vienna. The rights and interests of the patients are safeguarded individually or in general. About 7.000 people a year contact the Vienna patients' advocacy

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about complaints, suggestions, information requests and assistance and support for health services but also claim compensation for medical damage. Up to now patients advocacy in Vienna successfully claimed compensation for patients to the amount of about 60 million Schillings or provided support in this direction by non judicial means.

In view of the fact that medical damage is often difficult to prove, the city of Vienna provides an annual budget of about 10 million Schillings which, upon recommendation of the patients' advocate, will be paid unbureaucratically and without court proceedings in cases of special hardship as no fault compensation to patients.

The Vienna patients' advocate is a contact partner and spokesman for all medical self-help groups.

As a guardian of the rights and interests of the patients in general the Vienna patients' advocate has seat and voice in all public agencies concerning the health care system as

member of the health reform commission,  
member of the hospital financing commission,  
member of ethics commissions,  
an expert on draft bills and projects in the health care sector, an expert contributing to numerous information campaigns and publications.

Public Agencies of patients' advocates are up to now in Austria established in 8 of 9 states, but with different jurisdictions. There are strong efforts to harmonize patients rights and the jurisdictions of the patients advocates Austria-wide.

Patients and citizens need an independent and trustworthy institution for information and support. In most European countries ombudsman-institutions are well known and accepted by the citizens. Patients suffer; they need a person to turn to but no anonymous administrative machinery.

Apart from patients suffering from chronic diseases, the state of a patient is a temporary occurrence; health promotion and health care concern all citizens. In Austria a law on health promotion has recently been enacted, in order to support measures and initiatives for health promotion, education and information.

With these few words I wanted to show that Austria and especially Vienna have already started their way towards patient orientation, participation and protection in health care.

**Mihael Cigler<sup>21</sup>:**

## **LEGAL AND INFORMATION CENTRE FOR NGOs**

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<sup>21</sup> Project director, Legal and Information Center for NGOs, Slovenia

On the initiative of OSI Slovenia and in co-operation with it, a Legal and Information Centre for NGOs (PIC) has been established by joint efforts of the following organizations: Amnesty International Slovenia, Regional Environmental Centre Slovenia, Peace Institute, the Association for Development of Preventive and Voluntary Work, Retina - Institute for Support of Civil and Social Initiatives and Labeco - Centre for Ecological Research.

#### AIM OF ACTIVITY

The aim of PIC's activity is to strengthen legal security and to enlarge the autonomy and initiative of civil society in the field of legal issues, and to achieve greater influence of NGOs on both legal regulation of their status and on legal regulation of the fields within the scope of activity of NGOs. By uniting of NGOs and by directly engaging them in legal advocacy and monitoring, PIC aims to secure that legislation comes as close as possible to NGO projects. An additional aim of PIC is to co-operate with university Faculties of Law, other legal institutions and experts of high reputation, as well as with law students, in order to promote specialization within the legal profession on essential fields lacking specialists.

#### ACTIVITIES IN 1997

From Spring 1997 on, PIC has been conducting its activities on the premises of former barracks at the address Metelkova 6, which are being converted into a multicultural centre. It offers free legal aid and consulting to NGOs and individuals in the fields of human rights, humanitarian law - including field work at refugee centres, conscientious objection, family, labour and social law, environmental protection and registration of associations, institutes and institutions. In 1997, in all the fields mentioned, 1764 consultations including telephone conversations and advisory visits in the field were performed, 400 associations were informed of deadlines and requirements for registration under the new statute, and the documentation required for registration of 23 institutes and 8 associations has been prepared. As a rule, legal aid and consulting is rendered by undergraduates of law under the supervision and with the assistance of law experts engaged in practical work and experts from the Faculties of Law, while in more complicated cases PIC has established co-operation with individual solicitors.

In addition to regular advisory activities, in 1997 PIC was engaged in organizing round tables and workshops (Free Legal Aid - February 1997; Rights of Women and Children in Family Law - May 1997; Sexual Harassment - December 1997), as well as in preparing and publishing pamphlets on the above-mentioned topics. In the frame of the project »Do you know your rights?« PIC has formed a group of law students and students of Police Academy and, in co-operation with the Association for Non-violent Communication and Amnesty International Slovenia, made young people from nine high schools in Ljubljana and Maribor acquainted with their rights in case of being arrested. In co-operation with the Peace Institute and with the



Association of Conscientious Objectors, a comparative analysis was being conducted on the legal conditions of civil service, and public campaign has been launched on the topics of improvement of those conditions in Slovenia. PIC promoted the participation of environmental NGOs in defining the regulations of the Ministry of Environmental Affairs related to accessibility of information to NGOs. PIC also participates in the international project Security Services in Constitutional Democracy, carried out under the sponsorship of the Center for National Studies in Washington and the Helsinki Foundation for Human Rights in Warsaw. It co-operates with the Canadian Foundation for Human Rights and with the European Bureau for Conscientious Objection

#### ACTIVITIES IN 1998

In 1998 PIC continued its advisory activities and started or continued its work on the following projects:

1. Regulation of offering free legal aid;
2. Conscientious objection to military service;
3. Status and financing of NGOs;
4. Access to information;
5. Access to the information on environmental protection;
6. Children`s Ombudsman;
7. Roma rights;
8. Sexual Harassment;
9. Initiatives for the reform in the field of local self-government;
10. Advocacy;
11. Informing (young) people of their rights in contact with the police;
12. Do you know your rights?;
13. Establishing database and setting up a web page;
14. Humanitarian law.

In the frame of the projects we collected information on inadequately regulated areas, prepared detailed analyses of the current system, and conducted comparative analyses of the systems established in foreign countries, in order to prepare the ground for legislative changes in these areas. We informed the experts and the public of our findings and tried to offer possible solutions which should contribute to making adequate changes in legislation or to adopting new statutes regulating inadequately regulated areas.

We co-operate with numerous NGOs, governmental institutions, experts from Faculties of Law, foreign experts, solicitors, courts of law and law experts in the implementation of our projects.

## **HEALTH ADVOCACY NETWORK PROJECT - HANP**

### **LEGISLATIVE REFORMS AND LAWS - ADVOCACY PROJECTS:**

#### **Legislative reforms:**

Human rights, patients', social and other citizen's rights of the persons with mental disabilities, of those with developmental disabilities, of handicapped persons, of patients in health care institutions are being routinely violated in Slovenia and also in other Central and Eastern European countries. The violations of those rights are due to governmental bodies, health, social and other institutions, families, etc. and they often occur as a result of bad law. Therefore, legislative reform and adequate laws are needed to ensure that those rights are being paid respect. Persons whose rights are violated are often in great need of professional support by lawyers capable of appropriately advise them on their their rights.

The Legal and Information Centre for NGOs – Health Advocacy Network Project team proposed different legislative reforms and draft laws regarding problems of persons with mental or developmental disabilities, and of handicapped people, and presented the model of advocacy in different laws proposals.

When I am writing this, the Slovenian Parliament is discussing the regulation of advocacy for persons with mental disabilities in mental health institutions.

The Slovenian government included in its National Program for Social Care the establishment of advocacy for mental health.

#### **The Advocacy Model:**

The Legal and Information Centre for NGO's - Health Advocacy Network Project is already providing special advocacy (legal consulting) for people with mental or developmental disabilities, and for handicapped people in general. Our interdisciplinary advocacy team is made up by experts in various professions: social workers, lawyers, attorneys at law, medical doctors, psychologist and psychiatrists. The team is consulting individuals in pairs. A social worker and a lawyer or a medical doctor and a lawyer provide individuals with help to solve their problems relating to health, mental health, social and disability legislation.

The rights of the persons with mental disabilities (psychiatric consumers), persons with developmental disabilities and handicapped person in general are being easily violated on the part of the health institutions, social institutions, the government, ministries, families and other social institutions. That is why the special help and advocacy services are of vital importance for them.

The problems that these clients face are often of a very complex nature. The team is handling clients' problems in an interdisciplinary manner with the help of various professionals – social workers, lawyers, medical doctors, psychologists, psychiatrists and sociologist. Each problem of the client is discussed within the team. As I have already indicated, the first interview is made by a pair of team members (e.g., a social worker and a lawyer). Lawyers are invariably involved because the client usually thinks that his/her problem is of a legal nature, which is often not the case: as a rule, the source of the problem is of a social or psychological nature (family disputes, institutional conflict, etc.). This is why a social worker is needed for the interview. Sometimes the client is afraid of the staff of the institutions (the health institution), and is complaining against their services – again the help and the action of both the social worker and the lawyer is necessary.

The client is sometimes not getting enough or adequate information from health care, social and other institutions about his/her problem. At other times, clients want to file a complaint against an institution and particularly against failures of medical assistance. In such cases a physician is needed, too: he is competent to judge the conflicting diagnoses and the medical services against which complaint is being made, and is able to help the advocacy lawyer to conduct the complaint procedure against hospitals and their staff.

Disabled people have poor access to legal and other institutional remedies in Slovenia. Lawyers and social workers in the advocacy team help to protect their rights, whenever this is needed and if the client so wishes. Psychiatrist and psychologists in the advocacy team help mental health clients to understand their diagnosis, the nature of the drugs prescribed for them and the side-effects of their use; they provide information about mental illnesses, especially when the clients' psychiatrist hides such information from them.

Psychologists often provide help to clients by means of translating their problems for the team and discussing the situation with the clients' family members, and informing these people about the clients' wishes and needs whenever the communication in the family is poor.

The advocacy team's priority is to settle conflicts outside of court, but if attempts at a non-litigation settlement fail, it files the complaint and provides the client with legal representation.

We aim to promote the making of a special disability law and the establishment of a disability centre in Slovenia. The centre would provide interdisciplinary and advocacy help dealing with legal/social and medical problems of clients and protecting their legal rights.

## **International co-operation**

The advocacy team is co-operating with the NGO-s and institutions in the countries of the European Community and in the United States. It is very active within the Alps-Adria Association that consists of professionals in the area of Mental Health from Italy, Austria, Hungary, Bosnia, Croatia, Germany, United Kingdom, etc.

Djula Rusinovic-Sunara<sup>22</sup>:

### **THE CROATIAN ASSOCIATION FOR PATIENTS' RIGHTS AS A RESULT OF TRANSITIONAL ACTIVITIES**

The war in Croatia and the transition from communist Yugoslavia to separate nation-states aggravated those challenges which human society has to face in general at the verge of the New Age. The World tries to manage the recent achievements in technology in general and in communications technology in particular, and to find its way between traditional moral standards and the banalization of all spiritual values which cannot be measured in terms of money.

In the course of the last century, the humanistic vocation of the physician has been brought down to materialistic values in the Western hemisphere. The value of the medical service, its professional quality included, was being translated into the price the physician is able to charge for it. On the other hand, societies and countries that cherished honour and humanity as values never to be expressed in money, got a charming seducer, the communist idea, that served as a façade for the maximisation of power by the few. For many decades, a monstrous regime of "the equals" ignoring any "leaders" was reigning in Croatia as in the whole region. The few privileged were untouchable idols to whom everything was allowed. They didn't answer for anything and took the advantage of efforts by others. They presented their own self-interest as the needs of the society, failed to recognize the value of individuality, and denied reward to personal effort.

The fall of the Berlin's wall dissolved the myth of common merits and common faults. The Croatian physician, who previously had been rewarded on the grounds of the reputation of and respect for his profession, and was being brought up according to the values of humanity, found himself unable to deal with the materialization of his work. At the same time, the authorities, starting to place value in market relations, demanded that all services, including medical services, should cover their costs.

They didn't take into consideration that over five decades, practice followed the teaching that health care is a public good, and no particular consumer can be charged for its services. In the meantime, the idea that health care is an unprofitable activity of high social importance appears in Croatian law. It is forbidden to advertise medical services because it is not and shouldn't be provided for profit. This nonsense hasn't been removed from Croatian law yet.

The interest in private medical institutions, that is, in private property in health care facilities, is not protected by law. A hilarious example is that, according to the standing law in Croatia, women cannot engage in private medical practice if they have children. A wide range of absurdities made the earlier way of medical practice impossible. During the fifty years of socialism, the consumers of medical services could expect those services being equally available to all, and this expectation remained with us. Moreover, the legislator laid the

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<sup>22</sup> MD , M.Sc., Croatian Association for Patients Rights

burden of privatisation on those who engaged in private practice, by forcing them to offer patients extra services beyond those covered by the state health insurance. Naturally, patients couldn't and still can't understand what kind of "extra" service this is because, in the past, everything was covered by the health insurance. Besides, physicians themselves couldn't understand what exactly is this contract that they make with patients. Consequently, a gap was being wide-opened between what a physician could be after and what a patient could expect to be a physician's obligation.

This discrepancy badly shake the basis of the physician-patient relationship, based for decades on quite different values. It took more than ten years for someone raising the paradoxes of this relationship sincerely and with comprehension.

The health of the nation is endangered, although the danger may seem exaggerated. The growing incidence of malignant tumors with women cannot be caused only by war stress. Another causal factor is the circumstance that the obligatory preventive medical check-up of women has been abandoned in the last five years. Before the war, women had been asked for a check-up every year. As a result of the abandonment of regular check-ups, a considerable growth of late diagnosed carcinoma of breast and uterus has been noticed just now - after the five years of war and an additional five years of not asking women for regular screenings. This is the subject of a special medical debate. The Croatian Association for Patients' Rights participated actively both in preparing the program and in conducting the discussion of the First Breast Congress in Croatia. It is not unusual in Croatia to see exulcerated and uncared of breast carcinoma, and this means that there is no social attention given to that problem. I would also like to mention that the so-called "dispensaries" or clinics that, in the past, were dealing with problems of certain groups of patients have been closed, too. The approach to the nation's health formulated by Andrija Štampar in 1910 (before he graduated in 1911) suddenly became unwanted in Croatia: equal health services for all was declared an expensive luxury. At the same time, the project "Promoting Health" appeared in WHO. It was made on the basis of the old pages written by the above-mentioned Andrija Štampar. Over the last ten years, the operation of the Croatian government has been characterised by a neglect for and ignorance of that view which considers human life as one of the most valuable goods. The lip service paid to humanity is nothing but hypocrisy on the part of the modern world because human life has got to be valued in dollars and in gold. It's been a problem not only for Croatia or Europe, but for the whole world.

People working in the health services are compelled to say to patients bluntly that their lives are worth exactly as much as they can pay for them. It's a very awkward situation, one you have to get used to if you want to do your job as a physician. When people employed in health services will start resisting to this thought then, eventually, the New Age will take its beginning. My personal thesis is that the new social order has to be based on health insurance for all. The basis of such an approach was clearly being laid down in the great ideas and visions of Andrija Štampar. The path Croatia had been made during the fifty years of darkness has also a bright side in that public health services and social medicine were enjoying strong social and political support. The path I can see today should be made by means of co-operation between physician and patient for a common aim: healthy man - healthy society.

At present, the Croatian Association for Patients' Rights has about seventy members, mostly university professors, medical professional, experts in law, ethics and sociology from all over Croatia. Only a year after its foundation it became an acknowledged partner in shaping health care policy in Croatia, the newly elected government appointing a representative of the Association as a member of the House of Representatives Board of Health Services, Work and Social Policy in the. For members of our Association, this way of progressing towards patients' rights means, at the same time, a way towards the rights of health care employees and towards a healthy society.

**Angela Antonova<sup>23</sup>:**

### **Legal aid services for Bulgarian users of mental health care**

Point of view of the Bulgarian members of the Association of Reformers in Psychiatry

Ever since psychiatry has emerged as a separate field, psychiatric practices have been subject to detailed scrutiny, to contradictory viewpoints and vigorous public debates in most civilised societies. Transitional periods in European societies have been also marked by a re-evaluation of social attitudes towards mental illness and professional practices utilised to contain it. Being in a period of transition in the last 10 years, the countries of Central and Eastern Europe and the former USSR are now also undergoing a process of re-evaluation of their psychiatric practices, institutions and services with a view to bring them in line with the values of democracy and civil society.

The community of European democracies became cognisant about the problem of mental health services in Eastern Europe at first mainly due to the issue of political abuse of psychiatry in some of the countries of the region. Now, ten years after the changes in Central and Eastern Europe and the former USSR have started, reports on cases of political abuse of psychiatry have ceased. However, a deeper analysis of the mental health scene indicates that its reality is grave: there is no sensitivity for the needs of the patient as an individual. No programmes facilitating the human social participation of mental patients have been developed to foster the sense of human dignity. Community care programmes for both patients and relatives are scarce if available at all. Psychiatric institutions violate the human rights of the individual through institutional practices and procedures that have been so deeply and rigidly entrenched in everyday life that creative attempts to introduce changes are met with enormous and furious resistance on the part of the psychiatric establishment.

Gradually, the understanding has emerged that the problem of mental health shall prove to be very complicated and burdened with many levels of meaning, anxieties and fears. There do not seem to be easy solutions developed elsewhere which would work in Eastern Europe, although there is a widely shared agreement about mental patients having human rights, the professionals are trying to broaden their understanding about their patients, and trainings have been organised over the years to fill the enormous gaps in treatment approaches.

The Association of Reformers in Psychiatry (ARP) is an international body, which would like to undertake the task to facilitate and co-ordinate international efforts for development and reform in the field of mental health, bringing together non-governmental organisations as well as statutory institutions and structures working on the problem. It is based on the Network of Reformers which has been developed with the support of the Geneva Initiative in Psychiatry – a non-governmental organisation dealing with issues of the political abuse of psychiatry and the rights of the mental

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patients which has piled a lot of experience in working on the scene of mental health in Eastern Europe and the Former USSR over the last 20 years.

What changes do the Bulgarian ARP members deem necessary?

When appropriate, reforms are needed to encourage the autonomy of patients and their integration into the community. Reforms attempt to provide opportunities for integration through provision of more opportunities for a meaningful life for mental patients. From a practical point of view, reforms in mental health reduce the use of institutions for the mentally ill and encourage their involvement in the community. Reforms include the following:

Most care should take place outside the hospital.

Patients should spend less time in hospital and more time living in the community.

Interactions within groups lead to more genuine and friendly relations for psychiatric patients.

Psychiatrists should obtain informed consent from patients when offering services.

The mental health staff should assure confidentiality to patients and should not disclose facts about them without their knowledge and consent.

Employers, relatives, helping professionals, policemen, public administrators, and others working with mental health patients should take personal responsibility for helping them with everyday problems related to their illness.

A broader network of relationships with professionals and people in the community are needed to help meet the needs of the mentally ill.

More people with mental health problems should be encouraged to seek legal aid.

Greater skills need to be developed by professionals and people in the community to handle mental illness.

Reforms unleash many changes in the mental health scene. Specifically, the processes in the use of human resources are improved.

Bulgaria - The State of Transition and Transition of the State

After 8 years of unsuccessful attempts to conduct radical economic reforms, in 1997 a Currency Board was introduced in Bulgaria. When the first stabilisation program started in 1997, drastic measures were undertaken for the transition towards market economy like liberalisation of prices on the domestic market and the foreign trade regime, creation of a currency market, floating exchange rates depending on the demand and the supply. Shock therapy measures in the economy were accompanied by serious changes in the international economic relations of the country. The collapse of the commerce among the ex-communist countries through which Bulgaria conducted 2/3 from its trade, caused an abrupt decrease in the domestic production.

The change in the payment conditions created obstacles for the supply of major resources and fuels, which are of crucial importance for the Bulgarian economy.

Under the conditions of the economic stabilisation policy, an improvement of the social status of the population could be sought only within limited financial resources. It is necessary to reach new decisions for more rational utilisation of these limited financial resources, for a consistent application of the principles of social solidarity and for a correspondence between contributions and social security payments. These directions have been considered in the new social legislation and the envisaged reforms in the social security network.

The new Unemployment Protection and Employment Promotion Act creates favourable legal environment for the implementation of *active labour market programs and measures*, which are some of the most important and efficient forms for overcoming the most intense social problems of the unemployment. At the same time, these programs could not be expected to balance the demand and supply of labour as a whole. In conditions of economic problems and structural adjustment, these programs could have only a relatively temporary effect for a certain labour market segment.

The reform in the *pension insurance* revises the old and very low norms for retirement age and working years, and will aim to restore the link between the amount of the present pension and the contribution of the insured people during their active life. The architecture of the future pension system will include three pillars: mandatory social insurance; mandatory occupational insurance; and voluntary supplementary insurance. There is no doubt that the access conditions will be more strict and more universal. They will be closely linked with the insurance years and the age, the retirement age will be raised, the earlier retirement privileges will be limited, and the pension system will be relieved from many payments which have a social assistance nature.

The *Health Insurance Act* also introduces considerable changes in the budget transfers for health services, which are an important element in the social security network. Mandatory health insurance will be introduced, the insurance burden being equally shared by the employers and the insured. The need to balance the revenues and the expenditures requires to limit the inefficient spending of funds, which could lead to a limited scope of the services especially in the beginning of the health network restructuring.

*Social assistance* aims to maintain the income of individuals and their families at the level of a guaranteed minimum set by the state. The new legislation in this area provides modern administrative framework and reliable fulfilment of the social rights of the citizens. Universal benefits are granted for taking care of child and child allowances, whose parameters will be updated according to the draft of the Family Assistance Act. The benefits and the preferences for the physically disabled people are codified in a special Act for Protection, Rehabilitation and Integration of Physically Disabled People. Despite the modern legislative base, the social assistance system cannot cope with the increasing poverty. There is an obvious contradiction between the regulated rights and the opportunity of their real fulfilment, which is mainly due to the limited financial resources.



There is no social security network that could cope alone with the extremely high social price of the transition. The reforms in the state social security schemes, conducted in extremely short terms due to the pressure of the fiscal restrictions, complicate additionally the social security level of the population. Under these conditions, the *NGOs* play a very important role for maintaining the vitality of the social security system. The importance of the *NGOs* for the social sphere results from the fact that they are very close to the individual needs and problems, and can ensure transparency in the spending of the resources. They would be also trusted by the donors as well as by the consumers of social services.

Let me introduce to you the Bulgarian Members of the ARP with their aims and activities.

### **NATIONAL ASSOCIATION FOR MENTAL HEALTH, BULGARIA**

Founded in 1997, the Association consists of individual and organisational members working in the field of mental health - psychiatrists, psychologists, social workers, mental health users and their families.

One of its main objectives is to raise the status of mental health as a basic value for both the individual and society; to improve the mental health of the Bulgarian citizens and the quality of mental health services; to protect the rights and interests of the citizens and to preserve, improve and restore their mental health.

Some of the current projects of NAMH are: “University education for mentally disabled people”; a project for the institutional stabilisation of the organisation; a project for the creation of new regional associations in Bulgaria.

### **BULGARIAN PSYCHIATRIC ASSOCIATION**

A Bulgarian association registered in 1993. The objectives of BPA are the following:

- to achieve the common goals in preserving the differences in the name of the purity and the honour of the psychiatric profession, the well-being of its members and society as a whole;
- to promote the mental health of the Bulgarian citizens and to improve the mental health care;
- to support the independent and honest practice of the psychiatric profession.

The BPA is a non-governmental, non-profit corporation of societies of psychiatrists and other professionals who are involved in medical treatment, training, research and other professional activity in the field of mental health and psychiatry, who accept the association’s constitution, who meet the requirements for membership and who have declared their free will to participate in the organisation.

Projects in progress:

- Publishing program - translation, printing and distributing of professional literature in collaboration with GIP;
- Tutoring Ukrainian nurses with the collaboration of GIP, UPA, and The Ministry of Foreign Affairs of the Netherlands.
- Research of the attitudes and needs of psychiatric help - in collaboration with Open Society - Sofia.

Teaching and practising of clinical supervision - in collaboration with GIP.

## **BULGARIAN ASSOCIATION OF SOCIAL WORKERS**

A Bulgarian organisation founded in 1996 in Sofia, composed of social workers, tutors, students, and NGO members; the number of members –300.

The main objectives of BASW is to unite the efforts of its members around the concept of social work as a free profession, meeting the international standards, as well as taking into consideration the specifics of the agencies, practising social work; to contribute to the process of improvement of the social care system; to contribute to the free and dignified practice of the profession of the Social Worker.

The projects, currently in progress are: a program for psychosocial help for unmarried parents, psychosocial care for old people, a program for working with the parents of children with impaired hearing, social work with the Romany ethnical minority; projects in partnership –psychosocial help for children with learning disabilities, their families and teachers, education of social workers for working with Romany people; psychosocial consulting for integration of children suffering from epilepsy in the comprehensive schools; developing ethical standards in the field of social work.

## **BULGARIAN ASSOCIATION OF PSYCHIATRIC NURSES**

The Bulgarian Association of Psychiatric Nurses was registered in 1997. The objectives of the organisation are:

- To change the attitudes towards the mentally ill people.
- To take care for psychiatric patients in a totally different way: pending the course of the treatment the main focus should be on the entire (whole) personality of the patient; our professional care should conserve or recover the patients' social functioning;
- To improve the education of psychiatric nurses.
- Some of BAPN main activities are the creation of new modules of care the purpose of which is to satisfy the needs proclaimed by the patients themselves; education: conferences - in co-operation with the Sofia Mental Health Society, the

"Animus" foundation, the Association of Ukrainian Nurses, BPA, "Neurosciences and behaviour foundation". Some of the current projects are in tutoring Ukrainian psychiatric nurses in new, reformed ways of treating psychiatric patients; another very important project is the project for specialisation in psychiatric nursing;

- BAPN is the organiser of the workshops of the program for post-graduate qualification.

#### Users and Relatives Involvement

In Bulgaria there is no well-organised group of users of Mental Health Services that can represent their interest and lobby for legislative changes that will guarantee recognition and protection of patients rights.

A study on patients' feedback about the quality of mental health services held in Sofia Plovdiv and Bourgas showed that more than 20% of the approached users claim that they understand and know their rights, but there is no clear understanding about basic human rights. 95% of the approached people do not expect that something can depend on their activity and have no idea that they can start a legal procedure to protect their rights.

A positive sign was the conference, devoted to the *11th April*, the World Day dedicated to schizophrenia and organised by a Bulgarian member of the ARP - the **National Association for Mental Health (NAMH)**. For the first time in Bulgaria, at this conference the users of mental health care were in the position of organizers and moderators at the panel discussions.

#### Unspoken Violence or Limited Financial Resources

In 1997, the Bulgarian Helsinki Committee published a Report for recognition and protection of mentally ill patients' rights in Bulgaria.

Some of the most shocking pictures are from the so-called "social homes for mentally ill people"

Concerning the Report in the social home "Last stop" near the village Terter "The residents of the home are often deprived of food when in the isolation room. There is no medical or psychiatric treatment in the home, it just provides shelter for the people cast away by life. People die there because they kill each other, because they are infected with severe colds; the prescribed medicines are not written in their medical files; a public prosecutor has come to the home only a few times, when a murder was stated".

In the Varna psychiatric clinic, patients are living on extremely poor meals, and they have no access to any modern drugs. The patients from the home in the village of Radovets have not seen a psychiatrist for 18 months.

The staff of the mental health clinic in Radnevo says: "Our clinic is not a prison, but not a sanatorium either".

According to the report, "in the village of Gorno Varshilo is the Bulgarian hell". The village school, transformed into a clinic, the patients live mainly on porridge. 48

women are starving, walking barefoot in the snow. They are not wearing in clothes, but are dressed in rags.

“This associate professor has been lying downstairs for several days, chained to the bed”, says the psychiatrist, “she is a smoker and needs about 60 cigarettes a day, when she has none she becomes aggressive”. Next to her, chained, is lying a former nurse. She used to be a drug addict, now has an alcoholic problem. She is actually disabled, cannot get out of the bed, she is chained because she might fall out, but manages to find some alcohol within the home”.

A long way to go...

There is still a long way to go till the Bulgarian users of mental health services start to recognize their rights and start to search for legal aid services. Also there are mountains to climb till legislators, lawyers, legal advisors, mental health professionals unite their efforts to build an working system for the protection of patients rights.

This grim picture can be seen as an indicator for the challenges you meet when trying to be a Bulgarian user of mental health services, a Bulgarian psychiatrist, a psychiatric nurse, a social worker, or an active citizen who wants to influence and take part in the reshaping of the system of service delivery.

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