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# New Challenges in the Domain of Health Care Decisions

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## New Challenges in the Domain of Health Care Decisions

### Abstract

According to law, the ultimate decision on whether a proposed treatment should be used or not, lies with the patient. However, in Hungary, neither Parliament nor the Ministry of Health have initiated any enquiry into the way provisions on patients' rights are being translated into practice. Hungarian legal provisions concerning patients' rights are comparable to those of any legal system with long democratic traditions. However, there is a huge gap between law and practice, a gap which can be explained in relation to the paternalistic culture inherited from the previous regime that survived the collapse of communism. The paper asks what kind of institutional rules could help make available the new procedures created as a result of major progress in the bio-sciences. In addition, it endeavours to evaluate where Hungary is now with regard to the rights of patients, in particular, the right to their being able to give informed consent. It concludes by making some policy proposals on how to overcome the present, conflict-ridden situation and states that, it is of fundamental importance that patients' rights organizations are able to flourish. This requires public funding and a readiness on the part of the Legislature and the Executive to engage in an ongoing dialogue with civil associations.

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The views contained inside remain solely those of the author who may be contacted at [fridli@policy.hu](mailto:fridli@policy.hu). For a fuller account of this policy research project, please visit <http://www.policy.hu/fridli/>

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# 1 Introduction

This paper is dedicated to the problem of patients' rights. It will look at this problem in a special historical context: that of post-communist Hungary. Let us begin by saying a word or two on what makes this context so special from the point of view of our topic.

Around 1989-90, Hungary went through a process of transition from communism to democracy. At the same time, it left the sphere of interest of the collapsing Soviet Union, and joined the Euro-Atlantic community of democratic states. The transformation of the internal political system of the country and the change of its geopolitical situation gave strong impetus to a tendency towards an internalization of internationally recognized principles and rules of human rights and of the applications of these – including the rights possessed by persons who are subjected to medical treatment. In a very short period of time, the legal system of the country was subjected to a thoroughgoing review; legal provisions in conflict with patients' rights have been annulled or amended, and the international codes of patients' rights have been translated into internal law. Although Hungarian law continues to be deficient in many ways from this point of view, its written provisions concerning patients' rights are comparable to those of any legal system with long democratic traditions. However, if we shift the focus of interest from the written law to living practice via which the law is interpreted and applied to particular cases, we have to see that there is a huge gap between law and legal practice. This paper will describe the facts inherent in the gap, and it will explain them by the paternalistic culture inherited from the previous regime that survived the collapse of communism.

The above claims can be illuminated by a number of examples. Here are a number of recent news items to begin with:

- In November 2005, the second stem cell bank was opened in Hungary. It offers parents of newborn babies the possibility of keeping, in a frozen state, stem cells gained from the blood of the umbilical cord.
- In May 2004, the National Health Insurance (NHI) scheme announced a competition for funding hospice services.
- In its communications campaign conducted in August 2005, the government asked citizens a question: do people find it proper for prospective parents to have the right to choose the gender of their future child?
- In a ruling as of November 14, 2005, the Constitutional Court struck down, as unconstitutional, a legal provision that made access to artificial sterilization conditional on various specific facts – such as the number of children a person already has. The Court said that such provisions amount to an unjustifiable invasion of a citizen's self-determination (a

term that, in Hungarian constitutional law, fills roughly the same place as 'privacy' in the constitutional law of the US).

Compare, now, these announcements with the following research results from roughly the same period.

- Between 2002 and 2004, three independent inquiries were conducted to look into the state of patients' rights in Hungary: one initiated by the Parliamentary Commissioner of Civil Rights<sup>1</sup>, a second by the Public Foundation of Patients Rights Representatives<sup>2</sup>, and a third one by the Hungarian Civil Liberties Union<sup>3</sup>, a human rights group whose activities focus, among other things, on the issue of the rights of human persons in their role as medical patients. The reports of these inquiries invariably claim that:
- in the course of medical treatment, the right to human dignity of the people subjected to medical treatment is very often violated; the patient is treated as an object of medical intervention rather than as a subject who has the right to make the final decision about his/her treatment, and whose voluntary cooperation rather than passive resilience is to be sought,
- the most routine violation consisted of the withholding of information.

The items listed above and the reports cited next to them seem to be in conflict. The points suggest an image of Hungary as a country where the opportunities for citizens to make autonomous decisions with regard to medical techniques and practices are as open as they are in any other member state of the European Union. Public discussion on these opportunities seems to focus on the same subjects as in the older democracies, for the positions and the arguments marshaled on both sides seem to be the same as they are there. The question is: what kind of institutional rules could help to make available the new procedures created as a result of the major progress made in the biosciences so that patients have as much autonomy as possible in making use of them – while the potential dangers remain under control?

Yet if we examine research reports, the picture becomes less bright. Hungary will not appear any more as a country on a par with, say, Austria or the Federal Republic of Germany – but as one where the most elementary condi-

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1 Annual Report on the Activities of the Parliamentary Commissioner of Civil Rights and his General Deputy in 2003. Edited by the Office of the Parliamentary Commissioner of Civil Rights in May 2004.

2 Case Studies on the Rights of Patients, Children and People Cared for in Nursing Homes. Compiled by the Public Foundation on the Rights of Children, Patients and People in Nursing Homes, January 2005. See: [www.jogvedok.hu](http://www.jogvedok.hu)

3 Heuer, Orsolya, (ed.), (2002), *Patient Rights in Hungary- Rules and Practice*. Budapest: Hungarian Civil Liberties Union, 27.

tions of personal autonomy in the domain of healthcare may still be unavailable.

When, in the above paragraphs, I spoke about a gap between law and legal practice, I had confrontations between pronouncements and research results in mind. This paper will make an attempt to understand this gap and this tension; it will try to describe the way the conflicting facts fit together in a historic pattern in a country that recently emerged from a communist past to embrace constitutional democracy and to join the international community of democratic states. It will additionally endeavor to explain the facts inherent in the conflict, to evaluate the situation of where Hungary is now with regard to the rights of patients – and, in particular, the right to their being able to give informed consent. Finally, it will make some modest policy proposals on how to try to overcome the present, conflict-ridden situation.

In what follows, I will proceed in the following manner. First, I will spell out the hypothesis of this paper in somewhat greater detail (Section 2). Then, I will address more closely the paternalist heritage of the communist past, which plays a key role in explaining the gap between post-communist law and post-communist legal practice (Section 3). Next, I will offer a short overview of how the idea of patients' rights emerged and rose to the status of an official doctrine in the democratic West (Section 4). After this, I turn to the special conditions inherent in the democratic transition – and see how these conditions explain the legislative revolution in the area of human rights in general and patients' rights in particular (Section 5). This account will be followed by an in-depth analysis of the Health Act of 1997 (Sections 6 and 7). Sections 8 to 10 will be dedicated to the specific problem areas of legal competence in the context of healthcare decision-making, of rejecting/refusing life-sustaining treatment, and of informed consent. Finally, in the light of all this, Section 11 will suggest a number of modest policy proposals.

## 2 More on the hypothesis of this paper

In the preceding section, I suggest that we make a distinction between legislation and legal practice. Legislation is the easiest thing to adapt to norms and principles that are alien to past institutional practices. The resistance exerted by old habits and attitudes is strongest at the level of legal practice. Some factors that are favorable to human rights are temporary and tend to weaken

over time. The prestige of the Democratic Opposition and of the liberal ideas it represented was at its zenith at the beginning of the transition process, though gradually faded away during the following decade. The Constitutional Court was more determined about defending human rights in the first years of its existence than it was from the second half of the 1990s onwards. Thus, the first years of the new regime were exceptionally favorable for legal reform. Yet legal practice needed more time in order to adapt to the changes in legislation, and the years following the mid-nineties were less and less propitious for this process. Of course, the new legislation did not completely remain without practical effects – hence the facts cited at the beginning. Nevertheless, the gap between the law and actual legal practice is enormous.

To put it differently: legislative steps need to be combined with favorable institutional and social practices in order to attain their aim. Such practices are not automatically triggered off via new legislation; they are to be created through collective effort, and this task raises special problems for post-communist countries. This is because the most predominant patterns of behavior are shaped by a paternalist heritage and, because (and this is not unrelated to the survival of paternalistic attitudes) civil society input into policy decision-making remains very weak.

### 3 The paternalist heritage of the communist past

Communist regimes made great efforts to make healthcare universally available. To some degree, these efforts were successful. Nobody was denied access to basic medical provision on the grounds that he/she was not able to pay for it. However, the universal provision of healthcare was not accompanied by a universally high level of medical assistance. As with any other types of service, medical services were marked by chronic shortages that, on their part, led to practices of corruption (labeled by the euphemistic term ‘parasolvency’). Thus, notwithstanding the notional availability of universal free healthcare, the average life expectancy at birth of men began to decline.<sup>4</sup> In 1990, according to the Hungarian Central Statistical Office, the average life expectancy at birth was, for men, 68.4 years in Bulgaria, 67.6 in the Czech Republic, 64.6 in Es-

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<sup>4</sup> The average life expectancy at birth of men was 66.3 years in 1970, 65.45 in 1980, and 65.13 in 1990. In other words, between 1970 and 1990 the average life expectancy of men went down by a little more than one year. After the regime change, between 1990 and 2000, it increased 3 years + in 2001, to become 68.1 years. See STADAT – 1.1.1. Népeség, népmozgalom. (Population and its Changes.), [www.ksh.hu](http://www.ksh.hu)

tonia, 65.1 in Hungary, 64.2 in Latvia, 66.6 in Lithuania, 66.5 in Poland, 66.6 in Romania, 66.6 in Slovakia, and 69.4 in Slovenia – as against an average of 72.8 in the 15 member states of the European Communities. In the same year, the average life expectancy at birth was, for women, 75.2 years in Bulgaria, 75.4 in the Czech Republic, 74.6 in Estonia, 73.7 in Hungary, 74.6 in Latvia, 76.2 in Lithuania, 75.5 in Poland, 73.1 in Romania, 75.4 in Slovakia, and 77.2 in Slovenia – as against a European Communities average of 79.4.<sup>5</sup>

These negative characteristics of the Soviet-type healthcare system were not unrelated to the regime's authoritarian character. The party-state utterly disregarded the value of personal autonomy, and nurtured a culture of collectivistic interference within personal decision-making. This tendency to interfere with self-regarding individual decisions was called "collectivism", when acts of intervention are justified by reference to the public good; and it is "paternalism" when the self-regarding decisions of an individual are interfered with on the grounds of a claim that the community or its political embodiment, the state, knows what is good for the individual better than the individual him/herself. Thus, one of the main aims of the legal and institutional reforms in new democracies had to be that of transforming the citizen-state relationship into one between an autonomous person and an institution that is expected to respect one's personal autonomy, and that sees itself not as designed to dominate the individual but to assist her or him in making informed decisions and then acting on them. The inherited culture of collectivism and paternalism resists this transformation, however – and it is more likely to resist it in certain domains than in others.

Paternalism was built into the hierarchical and authoritarian organization of communist societies. Wages and salaries did not reflect the contribution of people made to the national product: income earners received only a relatively small part of the value produced by them, in the form of disposable income; and so many of their needs were not covered by their own consumer decision-making but in the form of government-provided, collective services. This system generated attitudes of dependence in ordinary people and surrounded the state with the aura of a parental caretaker.

The same paternalism that pervaded all spheres of life also predominated in the physician-patient relationship. The patient was educated to see himself/herself as dependent on the physician, who has exclusive knowledge of what state he/she may/should be in and what treatment he/she will need. The asym-

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<sup>5</sup> See STADAT – 4.1.6. Születéskor várható élettartam (Life expectancy at birth), [www.ksh.hu](http://www.ksh.hu)

metry of their relationship was sanctified by the trust the patient was supposed to blindly invest in the physician. Trust in the physician as a superior authority was supposed to give the relationship a sort of exalted nature.

Paternalism rings nicely as a term: it tends to elicit associations of a warm, caring relationship. Actually, this expression covers practices that more often than not are cool and quite ruthless. Consider the practice of involuntary commitment of psychiatric patients. It would be wrong to claim that involuntary commitment is never, under any possible condition, permissible as a measure; but even if it may be justified under certain very special conditions, it still remains a most painful form of interference with somebody's personal right to self-determination – and, therefore, it cannot be allowed, except in exceptional and strictly limited cases. These are occasions where the patient's actual state gives rise to a well-founded judgment that he or she represents an imminent danger to his/her own life and bodily integrity or would be a danger to the life and bodily integrity of someone else. Thus, the procedure of involuntary commitment needs to be subject to very stringent rules, much more stringent than those that have to be followed in the case of other, less extreme forms of intervention. No such rules were legislated for under the communist regime in Hungary – and the reckless disregard of the special plight of those committed to a psychiatric ward against their will created opportunities for a wide range of abuses.<sup>6</sup> Some of these were politically motivated,<sup>7</sup> though the overwhelming majority of such procedures were initiated by relatives, neighbors or acquaintances of the unfortunate person, i.e. who was perceived by them as a nuisance.<sup>8</sup>

6 The Health Act of 1972 provided for a periodic review of cases of those involuntarily committed. The committee consisted of physicians. It was supposed to work in the presence of a judge, but the latter had no say as to the merits of a case – his or her role was reduced to bearing witness to the legality of the procedure.

7 The phenomenon termed “political psychiatry”, which was so widely used in the Soviet Union, was not unknown in communist Hungary. See the description of the 1981 incident of Károly Jakab, who was an activist of the National Peasant Party between 1945 and 1948 (*Beszélő*, an underground political magazine, N° 1, 1981 and N° 7, 1983), and the 1982 story of Tibor Pákh, a political prisoner between 1957 and 1970, (*Beszélő* N° 2, 1982).

8 In 1991, a legal committee organised within the Hungarian Association of Social Psychiatrists filed a petition with the Ministry of Justice asking for a review of the situation in the light of precedents set in the Strasbourg Court. The same document included a model law on institutional care provided to people with psychiatric illnesses. See 'Javaslat a pszichiátriai betegek intézeti (intramurális) gyógykezelésének jogi szabályozására' (Proposal for a Legal Regulation of the Institutional [intramural] Care of Psychiatric Patients), in: *Psychiatria Hungarica*, December 1991, pp. 403-418. It took three more years until there was a revision of the rules of involuntary commitment. This happened on February 15, 1995, when Parliament passed an amendment of the 1972 Health Act that made the involuntary commitment of a patient dependent on a judicial decision to be made upon a hearing having been given to the patient.

Even though Hungary was witness to two great cycles of economic reforms (in the late 1960s and, then, in the mid-1980s), the Soviet-type system of healthcare provision was left unaffected by both of them. The state remained the only healthcare provider, healthcare institutions remained subjected to a rigidly centralized hierarchy, and healthcare decision-making remained under the exclusive control of the medical profession and central agencies rather than being shared with patients. The latter did not have the opportunity to choose either the physician or the medical institution of their preference. Hospitals and outpatient clinics were assigned to geographic districts, and nobody had the right to seek treatment in a medical institution outside the district where he or she lived (the only exception being university clinics, i.e. which had the whole country as their “district”). Not even within their “district” did persons have a choice among the General Practitioners working there – each patient was officially assigned to one, and only one, G.P.

Healthcare is a domain having a strong internal motivation to adapt itself to the paternalistic/collectivistic patterns of thinking characteristic of a communist regime. The medical profession has vested interests in maintaining the hierarchical structure of health provision, where the providing units are directly subordinated to the state and get their funding from central sources. This is partly to be explained by the medical profession’s tradition of being, in itself, organized in a hierarchical manner, whatever the wider institutional framework of society. Physicians have to join a semi-public medical chamber; hospitals and clinics work under a strictly hierarchical regime of professors, adjunct professors and assistant professors, where a full professor is in all respects superior to the rest. Another source of the conservatism of the medical profession is the physicians’ traditional status of authority in society – and the strictly hierarchical organization of healthcare institutions supports this status; while decentralization and competition would threaten it with its being transformed into a mere service provider. Finally, once corruption had become endemic, this also contributed to the medical profession’s sticking to the system that produced – and goes on producing – it.

This is the background against which we have to understand the changes induced by the collapse of the communist regime and the transition to constitutional democracy.

Under communism, no voluntary associations could be legally formed with the aim of monitoring the activities of the party-state and its institutions, of forming alternative policy conceptions or of exercising pressure on the power-holder

in the interests of promoting change. The only independent organizations that were able to take root were dissident human rights groupings, such as the Moscow Helsinki Group and the Polish Workers' Defense Committee, established in 1976, Charter 77 in Czechoslovakia, and the Democratic Opposition in Hungary. As a result, there was no single organization specializing in patients' rights at the time when the transition to democracy was completed.

## 4 A brief overview of the rise of the patients' rights doctrine

The movement for the rights of the human person in his/her role as a patient has different historical sources. In the United States, it took inspiration from a growing sensitivity to human rights, being a notable result of the civil rights movement of the 1960s, and from a radically critical attitude towards consumerism as encouraged by the counter-culture movement of the New Left. In Europe, the New Left of the 1960s and the Green movements that made their appearance in the 1970s served as sources of general ideas that could, from their nature, also be applied to the domain of healthcare. (Consider, for example, the Foucaultian description of the institution of psychiatric asylums and of hospitals in general as vehicles of domination and oppression.) By the 1970s, human rights activism had expanded its horizons to the case of individuals subjected to coercive measures in the course of, or on the pretext of, their treatment.

The new awareness of the lack of autonomy in the context of medical treatment had yet another starting place. Since the 1960s, the general public has become ever more aware of the fact that, as consumers, people are seriously under-informed relative to the providers of the goods and services that they buy – and that this informational asymmetry makes them fatally dependent on the *providers*. One after the other, consumer protection groups have been established to get and disseminate information and to engage in litigation against firms for false advertising and secrecy about the harmful side-effects of their products. All this has contributed to raising the level of people's sensitivity as regards information gaining and informed decision-making.

It is not my aim to describe here the history of the rise of sensitivity towards patients' rights in the US and in Western Europe. Suffice it to say that, by the 1990s, this process had reached the level of governments. In 1994, the so-called Amsterdam Declaration had been adopted by the representatives of

36 European states.<sup>9</sup> Yet before it became this official, one comparative study was conducted by Professor Henk Leenen and his associates, between 1988 and 1989, on legal rules affecting the state of patients' rights in 27 countries of Europe. The summary report based on the research data offered a general overview of available legal solutions via which to secure autonomous decision-making within the context of healthcare provision. It offered a way of improving governments' preparedness in recognizing and protecting the rights of the patient as regards informed consent-giving. As a particularly good example of this, many countries took steps to uphold the rights of the terminally ill to human dignity, even though the right to refuse life-sustaining treatment was not generally acknowledged at the time (as it is now in the majority of European countries). Also, an awareness that the will of a non-competent patient or her/his advance directive must be given a fair hearing made its appearance here, in examined legal documents.<sup>10</sup>

The Amsterdam Declaration, which counts as a European Charter of Patients' Rights, took as its starting point the report and recommendations of the Leeden Study. The legal solutions laid down and advocated by this study had, as their background, the principle that patients have a right to claim that a treatment that they are subjected to is based on their informed and uncoerced consent. This principle and some others closely related to it have been developed into a coherent document via the Amsterdam Declaration. Three years later, the Council of Europe officially adopted a convention on the application of biology and medicine.<sup>11</sup> Unlike the Amsterdam Declaration, the Convention is a piece of international law that has a binding force over the states that have ratified it.

To conclude this very short overview, I have to mention the role of the European Court of Human Rights (the so-called Strasbourg Court) in the development of the conceptual apparatus pertaining to patients' rights and as regards the rise of sensitivity towards them. Since its creation in 1959 (when it had an initially limited authority) and, then, with its elevation to its present status, in 1998, the Strasbourg Court has heard a large number of cases concerning patients' rights, especially in the area of liberty deprivation, to which psychiatric patients may be subjected. As we will see, the Court's rulings have had a major

9 *A Declaration on the Promotion of Patients Rights in Europe*, (1994), endorsed at the European Consultation of WHO, held on March 28-30.

10 Leenen, Henk, Gevers, Sjeff and Pinet, Geneviève, (eds.), (1993), *Promotion of the Rights of Patients in Europe, a Comparative Study*. Amsterdam: Kluwer Academic Publishers.

11 Council of Europe, (1997), *Convention for the Protection of Human Rights and Dignity of the Human Being with regard to Application of Biology and Medicine*. Oviedo, April 4. Incorporated into the Hungarian legal system by Act VI of 2002.

impact on legislative and other efforts in Hungary with regard to bringing the country's law and legal practices into line with European standards.

## 5 The transition to democracy

In 1989, the communist regime collapsed in Hungary, and a negotiated transition to democracy took place. The transition was presided over by principles of the rule of law and of human rights; it was not merely restricted to the introduction of a multi-party system and a practice of free elections. And its dominant ideology was that of constitutionalism.

After decades of arbitrary rule, the politically active part of the citizenry was adamant about having a regime based on the rule of the law. After decades of deprivation of freedoms, basic rights suddenly found themselves at the top of peoples' values. After decades where the constitution was nothing more than a piece of paper without legal force, a strong consensus emerged that the constitution must be enforced both against the executive and the legislative power – and because the Democratic Opposition, a human rights-based political movement, emerged as the most vocal adversary of the communist regime for more than a decade, human rights began to enjoy, at least in the years of the transition, a prestige beyond challenge.

The national roundtable agreement provided for the establishment of a strong Constitutional Court with wide powers of striking down legislation and governmental decrees, and the Court engaged in a project of actively raising the level of protection human rights enjoyed in virtue of legislation. It abolished capital punishment in 1990, as being incompatible with the constitutional right to life and to human dignity, and it laid down the principles for the protection of personal data, an important privacy right in 1991, for example.

All these factors contributed to create a climate, in the first post-communist years, which was extremely favorable to progressive efforts in the domain of healthcare-related rights, too. Yet this is only one part of the story, for external context provided strong stimuli in the same direction.

The transitions of 1989-90 were not restricted to internal changes for the post-communist countries. The collapse of the Soviet-type regimes proceeded on a par with the collapse of the Soviet empire. The Warsaw Pact and Com-econ were dissolved; the Soviet army withdrew from the countries of Eastern Europe that it had occupied for almost half a century. These countries thus

found themselves in a new geopolitical situation. The disappearance of the Soviet Union left these countries with no other alternative but to join the international organizations of the democratic West. NATO and the European Union are the most prominent among these, but there are many more – and human rights principles, including those applying to medical practices, are part and parcel of these institutional structures. And in order to become fully recognized members of the organizations in question, the new democracies must comply with these principles.

In the domain of healthcare, the situation is special. In the countries of Central and Eastern Europe and the former Soviet Union, the life expectancy of the adult population is not improving as compared to Western Europe. The average male life expectancy in Hungary rose between 1970 and 1990 by two years, the average life expectancy of women rose by a little more than four years – while the same figure for the 15 countries belonging to the EU before 2004 surpassed seven years in the same time period.<sup>12</sup> Thus, although the decade following the transition to democracy was marked by *some* improvement in the region, the same period was characterized by rising standards in the old member states of the EU as well, so the relative position of the post-communist countries has not changed significantly.

The position of Hungary seems to be particularly weak. In 2002, in terms of male life expectancy only the Baltic states and Romania were lagging behind it; in terms of female life expectancy, only Bulgaria and Romania lagged behind it; while some of those that rank higher are actually below it in terms of per capita GNP. A comparison of the 2003 data of the ten Central and Eastern European capitals shows that life expectancy at birth is still amongst the lowest (68.3 years for men and 76.5 years for women) in Budapest. The data for men is worse than this only in the Baltic capitals, while the equivalent data for women is better in all capitals of the region. The mortality rate is the highest (at 1.4%) in Budapest, the number of deaths per 10 000 inhabitants due to neoplasms is greatest (38.4) in Budapest, and only Riga surpasses Budapest in the num-

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<sup>12</sup> Consider again the Hungarian Central Statistical Office's data on life expectancy at birth in former communist countries (with a focus on those that have now acceded to the European Union or are in the course of acceding to it). In 2002, life expectancy at birth for men was 68.9 years in Bulgaria, 72.1 in the Czech Republic, 66.0 in Estonia, 68.3 in Hungary, 65.7 in Latvia, 66.5 in Lithuania, 70.5 in Poland, 67.8 in Romania, 69.9 in Slovakia, and 72.6 in Slovenia, as against an average of 75.9 in the fifteen member states of the EU. In the same year, life expectancy at birth for women was 75.9 years in Bulgaria, 78.5 in the Czech Republic, 76.9 in Estonia, 76.5 in Hungary, 76.8 in Latvia, 77.7 in Lithuania, 78.9 in Poland, 75.3 in Romania, 77.8 in Slovakia, and 80.4 in Slovenia – as against an EU-15 average of 81.8.

ber of deaths per 10 000 inhabitants due to diseases of the circulatory system (74.1, as against 69.4).<sup>13</sup>

Such sad data has one positive implication. Development assistance to efforts to improve health conditions is expected to be allocated to the post-communist countries.<sup>14</sup> Yet development organizations, including the agencies of the United Nations, consider the promotion of human rights in the domain of healthcare to be an integral part of any serious improvement.<sup>15</sup> This gives certain leverage to watchdog organizations that have a focus on the compliance of post-communist states with patients' rights standards. So we can expect that the pressure to comply better with these standards will not relent in the decade ahead of us.

## 6 Adoption of the new Health Act, 1997<sup>16</sup>

The Health Act adopted in 1972 said nothing about the rights of the patient to accept or refuse treatment proposed by his/her physician. This regulation (or the absence of it) did not run into trouble during the last decades of the communist regime – though the transition to democracy made it untenable.

The great value attributed to human rights in the post-transition decade also encouraged various civil initiatives in this field.<sup>17</sup> The Constitutional Court's practice in the first half of the 1990s served as another powerful engine of change. Initially, the Court understood its mission as being to raise the level of protection of human rights above the international baseline set by various human rights documents. In its rulings, it gave pride of place to the right to human dignity, which it interpreted as an abstract principle encompassing many specific rights not explicitly mentioned in the Constitution. Under this interpretation, different privacy rights and the right to personal self-determination were to be understood as so many specific instances of the more general right to human

13 'Demographic trends in east-central European capitals', (2005). *International Comparisons* 9. Budapest. Compiled by the Regional Dissemination Section of the Dissemination Department of the Hungarian Central Statistical Office.

14 Countries of CEE CIS have a high burden of adult mortality that needs to attract developmental assistance. Source: Suhrcke, Marc, et al, (2005), 'Development assistance for health in the central and eastern European Region'. *Bulletin of the WHO* 83(12), 920-926.

15 Mokhiber, Craig G, (2005), 'Towards a Measure of Dignity, Indicators for Rights-Based Development'. Sofia et al, (eds.), (2005), *Perspectives on Health and Human Rights*. New York: Routledge, 383.

16 Law CLIV of 1997.

17 For such an initiative regarding civil commitment see fn 4.

dignity.<sup>18</sup> This reading of the Constitution gave a big push to patients' rights legislation, because it was directly applicable to the problem of medical treatment and of the physician-patient relationship.

Yet the strongest pressure in the direction of giving patients' rights a legal expression perhaps came from the need to bring Hungarian law into harmony with international agreements signed and ratified by Hungary. In 1992-1993, the Ministry of Justice initiated a major project of legal revision to uncover those parts of the law that were not in harmony with the rules and principles established by these agreements. In the first round, such legal provisions that were found to be in blatant conflict with the European Covenant on Human Rights and Fundamental Liberties were amended.<sup>19</sup>

The new Health Act was adopted in 1997, in the same year that the Council of Europe took its landmark decision to issue a Convention for the Protection of Human Rights and the Dignity of the Human Being with regard to the Application of Biology and Medicine. The redaction of the Convention took seven years, so those who participated in preparing the Hungarian Health Act had the opportunity to become intimately acquainted with its guiding principles. The government's decree as of 1996 ordained that work to replace the Health Act of 1972 with a new piece of legislation should explicitly recognize the need for the new law to comply with patients' rights' norms as accepted by the international community.<sup>20</sup>

When it came to a discussion of the bill in Parliament, both the Amsterdam Declaration and the Convention were revealed to MPs as background materials for healthcare legislation – and this fact was of great significance, for the law in force and the traditions of legal practice in Hungary were widely off the mark as set by these two documents. Recognition of personal autonomy and, particularly, an understanding of the implications here were very underdeveloped in the country at the time the new Health Act was adopted. The pressure of civil movements was relatively weak; and the Constitutional Court, as I have tried to show, had done much to establish certain general principles that are relevant to the issue of patients' rights but – unlike in the domain of data protection or environmental protection – it did nothing to specify the consequences of these

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18 Tóth, Gábor Attila, (2003), 'Az emberi méltósághoz való jog és az élethez való jog' ('The Right to Human Dignity and the Right to Life'). In Halmai, Gábor and Tóth, Gábor Attila, (eds.), (2003), *Emberi jogok* (Human Rights). Budapest: Osiris.

19 Act LXXXVII of 1994 on the modification of Act II of 1972 on Healthcare. The amendment of procedures for involuntary commitment mentioned in fn 4 was part of this package.

20 Government Decree N° 1095/1996 (VIII.3.) on the main principles of the Health Act and on its preparation

principles for the physician-patient relationship. Thus, civil initiatives and Court directives have been, by and large, replaced by a felt need that the law of the country must be brought into line with *European* legislation. This circumstance explains both why the Health Act was able to make a great leap forward towards meeting the standards of patients' rights as set by countries with a long tradition of progress in this direction – why translation of the law into *living* institutional practice lagged behind, and why it proceeded so slowly and in such an uneven manner.

In Hungary, patients' rights have not received legal recognition owing to pressure coming from civil society. If the issue has received public discussion from time to time, it is because the press was ready to report on the most outrageous human rights violations committed against psychiatric patients. Such descriptions of individual cases were not, however, followed by a discussion of principle. The withholding of information about treatment and/or the non-availability of an option to refuse treatment was not put on the agenda. Treatment-related conflicts were not discussed from *this* perspective but from that of medical malpractice (such as a post-operation death caused by a towel being left in the wound due to negligence). Even these days, almost ten years after adoption of the Health Act, the issue of patients' autonomy is almost completely absent from the public sphere, while that of medical malpractice is more and more present, and the number of malpractice trials has seen a continual rise over the years.<sup>21</sup>

As an exception to the rule, the state of gynecology in Hungary – the difference between the quality of services in different hospitals, the issue of the freedom to choose non-conventional ways of delivery (giving birth at home, applying a Caesarian section) – are almost continuously discussed in public, and civil groups are formed to promote the right of the patients in this domain. This could be explained by such facts as the pregnant woman being a healthy, autonomous person, and not being dependent for her life on the physician. Also, the value of the child and general anxiety over the low birth-rate level may be making a contribution here..

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21 For a recent discussion of this topic, see Dobozi, Pálma, (2005), 'A sok ügyelet is okozhat műhibát' ('Too Many Night Duties May also be Responsible for Malpractice'). *Magyar Hírlap*, December 20.

## 7 A view on the law and on legal practice

The Health Act of 1997 gives due recognition to the right of a patient to have adequate information provided as regards a planned treatment and to their not being subjected to treatment in the absence of his/her consent (Section 3, Article 15). Thus, a patient may refuse treatment, although the expression of the refusal is bound to follow more stringent rules than is that leading to an eventual acceptance. If rejection is likely to result in a serious degradation of the health status of the patient, its expression is not valid unless it is made in a written statement that has been validated by a public notary or in the presence of two witnesses (Section 2, Article 20). Even more stringent are the rules dealing with a rejection of life-sustaining treatment. Such a rejection must be accompanied by a statement of a three-member medical panel, which is supposed to testify that 1. the patient is in a terminal state and that, 2. their mental condition allows them to make a competent decision; one with clear understanding of the consequences (Section 3-4, Article 20).

The Hungarian Data Protection Act gives pride of place to the right of the individual to exercise control over information held about them. In constitutional jurisprudence this is called the right of informational self-determination. The Health Act recognizes this right, and provides for its application in the area of healthcare. It says that patients have a right to know their medical data, to look into their medical files, and to request a copy of them (Article 24). Furthermore, the legislator took care to insert a provision in the Act that applies the constitutional principle of equal treatment under the law – and the Act mandates that patients are to be treated equally, without regard to their gender, health status, or personal convictions (Section 1, Article 7). The equal treatment article explicitly provides for non-discrimination in the case of the mentally ill (Articles 189 and 191). And mandatory treatment is made conditional, in conformity with the international standards, upon a decision made by a judge and also upon periodic judicial review (Article 199-200).

Thus, insofar as its broad outlines are concerned, the Health Act of 1997 can be said to comply with current international standards. Beyond any question, it represents a landmark as regards progress in the creation of a legal environment that is favorable for patient autonomy and self-determination. Nevertheless, as said earlier, there is a huge gap between legislation and legal *practice*. Progress made in legislation was not followed by a proportional prog-

ress in legal practice – so in most fields, the patients' rights provisions of the Health Act remained on paper only; while in some fields, there has even been some regression.

My contention is not that there was no further progress made. In some specific areas, the 1997 legislation was followed by progressive measures. For example, a ban on the use of cage beds in the institutions for people with mental disabilities has been adopted via ministerial decree (Decree of the Minister of Health and Social Care, July 6, 2004). This decision was taken against the stubborn resistance of the majority of the psychiatric profession; and in order to get to it, relentless pressure on the part of civil groups was required.<sup>22</sup> Yet the decisive push, again, came from international organizations, from the Committee for the Prevention of Torture and Inhuman or Degrading Treatment (CPT) of the Council of Europe, which, during its visit to Hungary in 1999, visited some psychiatric institutions. There, the Committee saw patients who were kept in cage beds – and, seeing the practice as a grave violation of human rights, it recommended strongly, indeed insisted, that the Hungarian authorities take instant measures to ban the use of cage beds<sup>23</sup>.

The 1997 Act laid down general principles but stopped short of elaborating on the procedures required to translate principles into practice. For example, it provided for three important institutions to enforce and protect patients' rights: one embodying a complaints procedure, one for patients' rights' representatives, and a mediating council. However, it left elaboration of the *specific* rules of these institutions primarily in the hands of the Ministry of Health and Social Care, which pointed to further legal action being needed; and such action proceeded in a ponderous and uneven manner, the rules adopted in the end proved to be highly deficient, and their practical implementation is unsatisfactory. Years passed before the authorities began a training process for personnel who were supposed to run these institutions. Although patients' rights representatives should, in theory, be available in every single hospital or clinic, the number of licensed representatives is so low that each of them has to divide his/her time between more than one institution. In consequence, rather than

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22 Gombos, Gábor, Kismódi, Eszter and Pető, Katalin, (2001), 'The Human Rights of Patients in Social Care Homes for the Mentally Ill'. A report Published by the Mental Health Interest Forum. Bads, Cage, (2003), 'Inhuman and Degrading Treatment in four EU Accession Countries'. A report published by the Mental Disability Advocacy Center.

23 See Introduction, Report to the Hungarian Government on the Visit to Hungary carried out by CPT from 5-16 December 1999 (March, 2000), 8.

being continuously available, they can be reached only once or twice a week, and then for just a couple of hours.<sup>24</sup>

The downgrading of the institution of patients' rights' representatives to near non-existence has inflicted major practical and symbolic damage on the concept of patients' rights; it deprives patients of an important tool of empowerment vis-à-vis a hospital, and of the support of an institutional authority. It also sends the message to all, including physicians, that patients' rights are to be treated as a window-dressing meant to appease the outside world rather than as a legal provision with a genuine regulatory force, and which should be taken seriously.

Here is a further example: The law specifies a number of cases where patients must receive written information on their rights. For example, psychiatric patients need to know the rules of civil commitment, and an important guarantee of their indeed being informed is that the requisite information is provided to them *in writing* (Section 2, Article 191). Three years after the coming into force of the law, a human rights organization made an inquiry into a number of hospitals on how widely the brochures on patients' rights are made available to medical institution patients. As it turned out, no single hospital had provided psychiatric patients with *any* kind of written information at their reception department.<sup>25</sup>

One last example to show that, up to the present, the official attitude of neglect and disregard towards patients' rights has not notably changed. In the fall of 2005, the government submitted its National Program to Combat Cancer for public discussion; the Program outlines a ten-year plan to improve the present, deplorably poor situation of the country with regard to treating cancerous illnesses. An earlier version of the document included a section on the problem of patients' rights in this particular field. In its unpublished, version, the document dealt extensively with the deficiencies in providing patients with information, and the ways those deficiencies might be overcome. It went as far as proposing that physicians should receive training to improve their communications capabilities. But even this attractive document failed to mention that patients need information so as to be able to make adequate decisions on whether they, as the ultimate decision-maker, need to accept treatment proposed by their

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<sup>24</sup> The Parliamentary Commissioner of Civil Rights announced, in 2003, that unless the salary of patients' rights representatives and the funds covering the costs of their services were raised, the system may become unworkable. See OBH 3155/2002.

<sup>25</sup> See Heuer, Orsolya, (ed.), (2002), *Patient Rights in Hungary - Rules and Practice*. Budapest: Hungarian Civil Liberties Union, 27.

physician. And when, in October of this year, the National Program to Combat Cancer was submitted for public discussion, the section on information provision was entirely absent from it.

To take stock: the 1997 Health Act was created in compliance with international principles dealing with patients' rights. Yet most of the questions left 'open' by the legislator, for a lower-level regulation and institutional practice, remain unresolved, or have been resolved in a spirit that is alien to that of the Act. This spirit is informed by the paternalistic heritage I have already referred to. The Health Act represents a new paradigm – that of patient autonomy and self-determination; though the legal and institutional practice continues to follow the old paradigm of paternalism. Rather than yielding to the new paradigm, therefore, it is assimilating existing concepts and ideas about patients' rights into the old paradigm.

With these preliminaries in mind, let us turn to the three specific problem areas noted in Section 1; the rights of people having no or limited competency, the right to refuse/reject treatment, and so-called reproductive rights, where the gap between legislation and legal practice is particularly wide and self-determination can be particularly limited.

## 8 Competency as a condition of the right to consent

### *8.1 The Health Act on competence*

In constitutional democracies, individuals do not have the 'protection' of coercive interference against their own choices/acts. There are only two types of cases where 'mistaken' decisions may be imposed against the will of the person involved: first, when the decision involves extreme and (usually) irreversible consequences – and, second, where the agent lacks the competence to foresee and to understand the consequences of their choice. In the latter case, however, the presumption of competence comes by default. Non-competence must be established via a strict procedure, one that protects the person under investigation against an assault on his or her personal autonomy.

Clearly, any regulation of such procedures must start out from an adequate definition of competency and, then, of its complete or partial absence. However, the Health Act fails to address the criteria of competence in this particular field

of decisions made with regard to treatment; it does not provide any definition of either competency or limited competency, or, indeed, a complete absence of competence. So law enforcement agencies will have to consult the Civil Code for a definition.

This gives some leeway to paternalism, for the following reason. As the Constitutional Court has ruled, when it comes to judging about competency in the context of medical intervention, the standard must be different from that of the Civil Code. “It should not be disregarded”, the Court says,

that competency, i.e. the decision-making capacity needed for the handling of one’s affairs, is originally and primarily defined by the Civil Code as a condition for making property-related declarations. When it comes to extending this system of concepts to other branches of the law, it is necessary to take the specific characteristics of these domains into consideration.<sup>26</sup>

Relevant questions of competency in the field of medical decision-making are as follows: is a patient capable of understanding the information given about their health status, on a proposed intervention, and/or on the consequences of either intervention or its being refused? Is he/she capable of balancing such considerations against each other in the light of his or her interests, values and convictions?<sup>27</sup> It is quite possible for these questions to be answered in the affirmative in the case of an individual who would count as being non-competent in the domain of property-related decisions; and the failure of the law to take on board such questions leaves open the possibility for declaring a patient who would count as competent under one area-specific investigation to be non-competent otherwise – so they would be dealt with according to old, paternalistic ways.

Additionally, the Act remains silent on the question of how to proceed when there is no judicial decision that would declare a patient non-competent, while the patient’s conduct makes it quite clear that he/she obviously lacks the relevant decision-making capacities; it is also silent on those cases where the physician is dealing with an adult who is not legally incompetent (to make a competent decision regarding his or her property, for example) but who is, nonetheless, unable to make competent decision concerning his/her treatment. The time needed for a judicial procedure to declare a person incompetent may

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<sup>26</sup> CC ruling N° 36/2000 (X.27.)

<sup>27</sup> “The competency to decide on medical intervention includes the capacity of the person to grasp the information necessary for their decision, the capacity to recognize all the possible consequences of such a decision, and the capacity to communicate the decision to the physician.” CC ruling N° 98/B/1992.

be one year in Hungary; yet in a typical case a decision regarding treatment would need to be made within a much shorter time period. There is no way to tell, on the basis of the law, *who* will possess the authority to declare a patient non-competent in an urgent case. These deficiencies serve to create further opportunities for paternalistic violations of patients' rights.

## *8.2 Treatment decisions in the case of non-competent patients*

The failure of the law to deal adequately with the problem of competence in the context of healthcare decisions has yet another unfortunate consequence. By the Civil Code, a person who is declared incompetent loses such decision-making rights completely; so a person who has been declared non-competent by a court before being taken to the hospital will not have any power to decide upon treatment – and there are no issues whatsoever upon which he/she could make a decision ultimately.

In the area of healthcare, as in other provinces of human life, rules concerning competence ought to be sufficiently fine-tuned so that a not fully competent person is not excluded from medical decision-making except for in those specific areas with regard to which he/she may be judged to lack the mental tools necessary for adequate decision-making. Even the less-than-fully competent person should be treated in such a manner as to maximally preserve his or her decision-making capacities<sup>28</sup>. Yet, unfortunately, the Act fails to provide sufficient guidance in this regard; it only says that a patient deprived of the power to decide about his or her treatment should still receive information on treatment and that his/her desires should be taken into consideration within the limits set by the professional requirements of treatment (Section 5, Article 13 and Section 5, Article 16). This is far from meeting the requirement that a choice of treatment should respect the values, convictions, and preferences of a patient. Again, there is room for paternalistic procedures' operations here, too.

There are further unjustified restrictions imposed on the legally incompetent. In the case of a non-competent patient, consent by a surrogate decision-maker<sup>29</sup> is not required by the law except in those cases where medical procedure will be invasive. Any other kind of intervention (for example, a diagnostic

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28 See Recommendation (99) 4 of the Council of Europe on Principles Concerning the Legal Protection of Incapable Adults.

29 Unless a non-competent patient has made an advance directive on who should decide on his or her behalf before it comes to a court declaring him or her non-competent, the right to decide in matters that regard him or her goes over automatically to their guardian as identified according to the law. Section 2, Article 16 of the Healthcare Act.

examination or therapy using neuroleptic drugs) can be performed *without* asking for the agreement either of the patient or of her/his surrogate (Section 4, Article 16).

### 8.3 *Persons with limited competency*

Hungarian law does not completely ignore the concept of limited competency, an intermediate stage between full presence and a complete absence of decision-making capacity. According to the Civil Code, somebody with a significantly reduced capacity to comprehend the circumstances under which he or she has to deal with his or her own personal affairs is a person with limited competence. If an individual is declared by a court, without any specification, to be someone of limited competency, and a custodian is appointed to him or her to run his/her affairs, then the presumption is that he/she cannot take legal steps in any regard without their custodian's consent.<sup>30</sup> This presumption still admits of exceptions, though. A person with limited competency can proceed autonomously in some of his or her affairs. They are free to make ordinary contracts having a lesser significance, for example; he/she has the power to proceed in the protection of his/her personality rights; and, in general, such a person is at liberty to engage in contractual relationships provided that these do not have anything but advantages for him/her.

A thoroughgoing amendment of the Civil Code, in 2001, empowered courts to declare someone lacking in sufficient comprehension of the conditions going with specific decision-making, so that there would not be a general limitation on his/her right to make autonomous decisions. If this is the case, a guardian needs to be appointed only for the aim of making specific decisions as delineated in the judgment.<sup>31</sup> For example, an individual may be declared to be of limited competency to deal with his or her movable and immovable property, in which case he or she is then left at liberty to make autonomous decisions in all other domains.

Such a regulation would involve, even for those declared to be of limited competency generally (and for persons aged between 14 and 18 years, who count as being of limited competency on the basis of their age), that such persons must have a right to make autonomous decisions with regard to their medical treatment so long as their decision does not come into conflict with

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<sup>30</sup> Hungarian Civil Code, Articles 12 to 15/A.

<sup>31</sup> Civil Code, Sections 5 and 6 of Article 14.

their interests. It is only in these latter cases that the guardian may be involved in the decision-making process.

The term “a person with limited competency” also makes its appearance in the Health Act. The Act, however, does not apply ‘limited competency’ to all contexts for which its use might be legitimate – nor does it determine with sufficient care the rights actually possessed by a patient with limited competence. Not unlike in the case of a person declared incompetent, a person with limited competency is totally deprived by law of the right to informed consent;<sup>32</sup> he/she cannot give or refuse consent as regards a proposed treatment – this will need to be done by a surrogate decision-maker. Such an interpretation of the limitations on the autonomy of an individual with limited competency leaves much less to the patient when it comes to their making a decision on his/her own; and it can be seen as unreasonable interference in the self-determination of persons whose competence is limited either by their age or their mental state.

In October 2002, the Constitutional Court struck down this regulation as unconstitutional, and mandated that Parliament come up with new rules on informed consent in the case of patients having limited competency.<sup>33</sup> Parliament did comply with the ruling, yet the new piece of legislation was not a notable improvement. As a small step forward, patients with limited competency can gain access to their medical files if they wish. However, insofar as participation in treatment decisions is concerned, the new regulation, rather than applying to all patients with limited competence, applies only to those whose competency counts as limited on the grounds of their age. A subgroup within this category – persons aged between 16 and 18 years – are now permitted to name their surrogate decision-maker or to exclude their legal representative from making decisions on their behalf with regard to medical treatment.<sup>34</sup>

To sum up here: The healthcare regulation in force subjects the self-determination of people with limited competency (whether for reason of age or any other reason) to unnecessary and disproportional restrictions. Three main concerns can be highlighted in support of this claim:

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32 Like the concepts of competence and non-competence, that of limited competence originates with the Civil Code. If competence is taken to mean a general decision-making capacity, then a person counts as having limited competence if she or he has not fully lost this capacity, to a greater or smaller degree. A non-competent person is someone whose decision-making capacity is completely absent. Section 4, Article 14 of the Civil Code (Act IV of 1957)

33 CC ruling No 36/2000 (X.27.) The ruling of the CC has noted that the Civil Code construes the protection of personality rights and of personal autonomy as applying to persons with limited competency, as outlined in the Health Act. A person with a limited competency has the right, according to the Civil Code, to take steps to defend his/her personality rights.

34 1997: CLIV. 16.§ (6) and 24.§ (6)

- First, the Health Act fails to provide any criteria so that one can draw a line between competence and non-competence in the context of various treatment-regarding decisions;
- Second, the Act fails to distinguish between different degrees of competence, and it denies the right to practice informed consent for all whose decision-making capacities are diminished;
- Third, even the surrogate decision-maker does not have complete control over issues pertaining to the medical treatment of a person with less than full competency; he or she is not allowed to make a decisive statement on treatment except in the case of invasive medical action – so all actions judged non-invasive will be subject to the exclusive authority of the physician.

## 9 Can the patient refuse life-sustaining treatment?

As mentioned already, the Health Act treats the right to reject a proposed treatment differently from someone's having a right to express acceptance. The rules going with a refusal are much more differentiated and restrictive. The more problematic the likely consequences of the omission of a certain treatment procedure, the more stringent will be the requirements laid down by the law for someone to have the right of refusal.

The most controversial of all such restrictions are those that apply to decisions regarding terminal states. Such decisions have two aspects, which need to be distinguished from each other.

- First, the evolution of medical techniques has clearly forged ahead in the last couple of decades, and there is now the medical profession's ability to prolong life almost indefinitely by applying previously unavailable life-saving and, in particular, life-sustaining methods. The availability of such techniques makes the problem of paternalism particularly acute, though, for it creates an opportunity for physicians to prolong the life of patients indefinitely – even against their will. Thus, the question of refusing/rejecting medical intervention becomes a central issue for patients in a terminally ill state. If they are denied the status of ultimate decision-maker on whether specific methods are to be used in their case, they lose control over themselves – and this control transfers itself to the providers of healthcare *completely*, with the latter now being in a position to prolong the patients' lives against their wishes. This raises the question of the right to refuse medical intervention even if it will have life-saving or life-sustaining functions; or, to put this differently, we are dealing with a question of passive euthanasia.
- Second, once in a terminally ill state, a human being may prefer to end his or her life quickly and painlessly, in order to avoid prolonged physical and/or mental suffering. Yet in such a state one may not be able to terminate one's life without a physician's assistance. This raises the

question of whether the right to life does additionally entail the right to decide about the timing of the *end* of one's life – and, if yes, whether this right entails a right to ask for assistance (usually by a physician) in carrying out one's will. This is a question of physician-assisted suicide, or even physician-performed euthanasia – or, put differently, is a question of voluntary, active euthanasia. Such a question reflects the conflict between the patient autonomy paradigm and the paternalistic paradigm, while it has a related, albeit slightly different, aspect too – that of the conflict between patient autonomy and a claim that, given the sanctity of life, humans have a duty *not* to interfere with the natural course of someone's dying.

The Health Act does not even mention active euthanasia. Instead, it provides for the right to pain relief and palliative care as a legitimate claim of the terminally ill against the healthcare system. Humane treatment in the final stages of the life of an individual is something that is due to him/her as a person possessing human dignity.

Thus, the provisions of the law on pain relief and palliative care remained a dead letter until, ironically, the issue of active euthanasia, which was, as mentioned, completely absent from it, became a topic of public controversy – and this is how it happened.

Public opinion in Hungary strongly supports euthanasia in both its passive and active forms. More than 60 percent of the adult population favor a physician-assisted termination of life, if the patient so desires.<sup>35</sup> In the early 1990s, a petition had already been filed with the Constitutional Court, asking, among other things, that the Court declare the absence of legal provisions that would permit and regulate voluntary, active euthanasia unconstitutional. The Court, even though it agreed to give a hearing to the case, evaded discussion of it for almost a decade. However (and not unrelated to public pressure), it put the issue on its agenda in 2003 – and, in April of that year, passed its ruling.<sup>36</sup> It rejected the claim that the absence in Hungarian law of a rule providing for the right to active euthanasia was unconstitutional; but it did not justify this negative ruling by appealing to the sanctity of human life, or by denying that the right to life *should* entail a right to decide about when and how to end a person's life. On the contrary, it stated that the general right to personal self-determination, which is a universal human right, includes a specific right to decide about how to end one's life. Though it then continued by denying that this claim could be translated into a legal right under all circumstances; it held that, under certain

35 'Nehéz kérdések a kegyes halálról' ('Difficult questions on mercy killing'), (2000). Budapest: Medián Public Opinion Center.

36 CC ruling N° 22/2003 (IV.28.) AB.

conditions, a person's choice of death is just a desperate reaction to the absence of adequate palliative care – and the law should not legitimize such a choice (the Court hastened to add). Legalization of a physician-assisted termination of somebody's life would not be permissible until the considered choice of the patient is one between accepting adequate palliative care – or terminating one's life, because it would not be worth continuing even if given such a humane alternative. Thus, the Court made the constitutionality of voluntary, active euthanasia conditional on the improvement of healthcare provision; and it made it an obligation of Parliament to oversee the progress made in this area so that it could, in due time, decide upon whether conditions were ripe for legislation to be made regarding active euthanasia.

Whatever the merits of this decision,<sup>37</sup> it had an unexpected consequence: immediately after public announcement of the ruling, civil groups approached Parliament's Committee on Healthcare with a demand to make an investigation into the state of palliative care in Hungary; and the Deputy of the Parliamentary Commissioner for Civil Rights announced that he, too, would make an inquiry. Thus, the poor state of the care of the terminally ill could not be neglected any more – and it was in response to this situation that the NHI decided to announce a competition via which to fund hospice services (see Section 1).

Let us now turn to the issue of passive euthanasia. Unlike active euthanasia, which is unmentioned by law, the right to reject life-sustaining treatment *is* explicitly recognized by it (Section 3, Article 20). And this is an important step forward, at least in principle. However, mere recognition of the fact that patients *do* have a right to refuse treatment, even if its omission or cessation makes death foreseeable, does not enable the bearers of this right to make use of it. Whether or not the right to refuse treatment has legal force therefore depends on the way its practice is regulated.

The Health Act does not stop at making a presumption that life-sustaining treatment can be rejected; it makes the refusal – that is, for it to be effective – conditional upon procedural requirements. By itself, setting such conditions does not count as an unconstitutional invasion of the right in question. Given the gravity and irreversibility of the decision, and the possibilities for abuse, it is reasonable to subject such a procedure to rules that will make the process transparent, so that any uncertainty as regards the will of the patient and a

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<sup>37</sup> It is certainly not lagging behind the European average, as there are only three countries in Europe where the law permits a physician to assist a dying person to terminate his or her life: in Belgium and the Netherlands voluntary, active euthanasia is legalized, while in Switzerland assisted suicide is immune from prosecution.

discontinuation of medical assistance against that person's will is done away with.<sup>38</sup>

Yet it is unreasonable and unacceptably paternalistic to subject the process to conditions of such stringency that they are nearly impossible to meet – and this is the case with the regulation provided by the Health Act. A patient has to make five different, consecutive statements requesting that life-sustaining support be withdrawn from him or her, on five different occasions. Not before she/he has made the fifth one can she/he hope for her/his will to be acknowledged – though not even after the fifth statement can they be certain that this is what is going to happen. The first statement comes when they announce their desire to the physician. The second follows when a written version of the statement is made. Next, a three-member medical panel examines the case, and the statement must be repeated in their presence. Fourthly, three days after the panel has made a positive verdict, a new statement needs to be made in the presence of two witnesses, in which the patient expresses his or her will to proceed rather than to change their earlier decision. Fifth, after the confirmation has been made, an in-depth interview must be conducted by the physician to explore the reasons *why* the patient wants the life-sustaining treatment to be withdrawn, rather than continued. The physician is supposed to make attempts to convince the patient, in the course of this conversation, that he or she should change the already made decision in favor of accepting a continuation of medical support. If, against all the arguments, the latter persists in his/her stance, the physician may still decide that the will of the patient is not sufficiently clear – and that the treatment should go on (Articles 20-23).

If followed word for word, such an absurd regulation makes it technically impossible to recognize someone's wish to reject life-sustaining treatment – and it conveys the message that the general principle recognized by the law is not to be taken seriously: the patients' rights paradigm must not be abided by, and medical practice is allowed to go on – following the paternalistic paradigm. No wonder that the three-member panels of physicians do not exist in hospitals; nor are any written statements asking for a discontinuation of life support to be found; nor is any data available on the number of cases of a patient rejecting life-sustaining treatment. The author of this policy paper put a question to leading representatives of the Hungarian Medical Chamber and of the Ministry of Health about how many cases there have been, since the law's coming into force, when a patient *insisted* on the withdrawal of life support – and nobody

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38 See the reasoning of the CC ruling N° 22/2003 (IV.28.) AB.

was able to give even an informed guess. Apparently, if such discontinuations do occur, they do not follow the procedure laid down by law. The Deputy of the Parliamentary Commissioner on Civil Rights made an attempt to look into this problem, but hospitals denied him any access to their medical files. Ironically, they justified this refusal by appealing to the right of patients to retain control over their personal data.<sup>39</sup>

## 10 Informed consent and reproductive rights

The awareness of people that they are the bearers of rights that others have to respect – and that the state has to enforce – is not even. Hungarian citizens are not overly conscious of some of their rights, though are well aware of others. Furthermore, their attitudes towards their rights have been changing over time – and rights that the public was not aware of in the past may now be highly visible. The transition from communism to democracy dramatically raised the public's rights-consciousness. Yet people are exceptionally keen about some of their rights, and less so about others. I have mentioned already the right to euthanasia, both passive and active, which commands the support of almost two-thirds of the adult population in Hungary. Even higher is the support for reproductive rights. First, more people insist on such rights than on rights related to the end-of-life decision-making; and, secondly, they are more intense and vocal about the first than about the latter. In modern, secularized societies many people (whether religious or not) put a high premium on limiting the risk of unplanned pregnancy – and Hungary is no exception in this regard.

In countries where abortion on demand is legally banned, the key issue is to get the ban repealed so that women are free of legal obstacles as regards gaining access to an abortion in the first three months of their pregnancy. Thus, the first task concerning the right to abortion is to secure control over one's own body as a *negative* freedom, i.e. as the freedom for a woman to seek a service of her choice, which will be unimpeded by government interference. Once this freedom from legal obstacles has been secured, however, a new question emerges: whether reproductive rights are merely negative, or do they also include *positive* components? In other words, the second issue is whether a government has an obligation to make sure that the conditions for self-determination are equally available to all. Once this second question is raised, the

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<sup>39</sup> 'Adatvédelem gátolja a betegjogi ellenőrzést' ('Data protection in the way of checking whether patients' rights are being respected by hospitals'), (2002). *Magyar Hírlap*, February 1.

scope of reproductive rights is enlarged from being access gained to an abortion to access to other services (such as sterilization, contraception or IVF).<sup>40</sup>

The issues of reproductive health are not subject to a special regulation under Hungarian law. All reproduction-related issues – except for those of abortion – are supposed to be dealt with by the Health Act. Insofar as the issues of positive reproductive rights are raised at all, the services in question and the conditions for a woman (or, occasionally, a man) to have access to them are listed in this law – while the question of charges is looked at in health insurance regulations.<sup>41</sup>

A key issue in the field of positive reproductive rights is whether contraceptives should be made available free-of-charge to certain groups of women, such as the poor and persons aged below 18. This issue is not being attacked as one of rights, though, but as a problem of social policy. As the level of general sexual education is being raised and as effective forms of contraception are available to those able to buy them, the rate of abortions is continually going down. While, in Hungary, it was around 80 thousand per year in the 1980s, the average number of abortions is down around 54 thousand in this decade.<sup>42</sup> However, there is no similarly steep decrease for the below-18 age group. Governments on the right tend to explain this problem by referring to a weakening of the virtue of abstention – while governments on the left see it as evidence of the failure of sex education and say that there is an insufficient availability of contraceptives for these age groups. Thus, Christian-nationalist governments make attempts to restrict access to abortion – but, in the face of vigilant public opinion, they still need to proceed very cautiously; Socialist-liberal governments, on the other hand, promise to make contraceptives for those of below 18 years free-of-charge – although, up to the present, this promise has not come true. And even though the Professional College of Gynecologists supported introduction of the abortion pill as an alternative to surgical intervention, no such steps here have been made.

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40 Cook, Rebecca J, Dickens, Bernard M and Fathalla, Mahmoud F, (2003), *Reproductive Health and Human Rights*. Oxford University Press, 8.

41 The Constitutional Court did not address the issue of positive reproductive rights specifically, but it made in other contexts a general ruling to the effect that the state's obligations do not stop at respecting and taking account of the negative rights of citizens - it has a positive obligation to create an institutional framework that makes such negative rights meaningful to all. See CC rulings N° 64/1991.(XII.17.), N° 43/1995(VI.30.), and N°52/1995(IX.15.).

42 The number of abortions per one hundred newborns was 90 394 in 1990, and had dropped to 52 539 by 2004. See Hungarian Central Statistical Office, STADAT – 1.1.1. Népeség, népmozgalom (Population and its Changes).

Access to assisted reproduction is another hotly debated issue, with positive-rights implications. The rate of infertility in Hungary is 15%, being close to the European average. Nonetheless, the rate of test-tube fertilizations is way below the European one: in Europe, 3-4% of newborn babies come via test-tube fertilization, while in Hungary this proportion is 1.4% (being less than half the European average).<sup>43</sup> The Civil Association for Test-Tube Babies, an NGO working in this field, filed a petition with the Legislature in Spring 2005 to convince MPs that access to test-tube fertilization is a *right*, and that the government should ensure that this right can be made use of by increasing the number of fertility centers, by raising the level of financial support for test-tube programs (at present, the Health Insurance Caisse covers 50% of the program's costs, up to a maximum of five attempts at fertilization and implantation), and by making data related to the success rates of specific centers publicly accessible.

Furthermore, the Health Act does not provide for access to test-tube fertilization to anyone but married couples and those living in 'civil union'. Marriage is an institution available to heterosexual couples only; and although, since the mid-nineties, civil union has been made available to same-sex couples as well, the latter are not eligible, under law, to access to test-tube fertilization, not even if they are willing to cover the full costs of the program. Nor do single women enjoy eligibility under any condition – or at least this was the case until very recently, when the law was amended in this regard.<sup>44</sup> Moreover, couples (married or not) where one of the partners is declared to be of limited competency, are excluded from eligibility, whether or not the infertile partner is the same as the one whose competency is declared to be limited. The justification for this is based on a procedural requirement that the couple should make a consensual request for a test-tube experiment. So even if the member of the couple who needs the assistance in fertilization is fully competent, the consent of the other would be needed too – even though persons with limited competency are deprived by law of the having any power to give valid consent (see Section 8). Yet again, paternalism gets the upper hand in its conflict with patient autonomy.

When, in November of 2005, a package of amendments to the Health Act was tabled for the legislature, the Hungarian Civil Liberties Union filed a petition

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43 Kulcsár, Hajnal, (2005), 'Elbocsátás fenyegeti a "lombikos" szülőket' ("Test-tube" Parents Threatened by Dismissal'). *HVG Online*, April 4.

44 From July 1, 2006, single women can also have access to assisted reproduction provided that "for reasons of age or condition (infertility) she is unable to give birth to a child in a natural way". Health Act, Section 4 of Article 167.

with MPs proposing to alter the discriminative provisions.<sup>45</sup> Yet the Ministry of Health refused to support the proposal, and no MP expressed any willingness to translate it into an official amendment motion.<sup>46</sup> Nevertheless, when it came to Parliamentary debate of the bill in December 2005, MPs from the Government majority submitted a proposal aiming to allow single infertile women to have access to reproductive services. (This proposal, adopted by the Legislature, left same-sex couples, however, deprived of any access to assisted reproduction.)

The Health Act, as adopted in 1997, included a provision allowing for surrogate motherhood. However, when the Christian-nationalist right came to power in 1998, it proposed an amendment (adopted in 1999) that banned having recourse to surrogate mothers. This move, a clear violation of the right to reproductive health in the case of women whose womb has been removed, was never repealed. When it returned to power, the Socialist-liberal coalition promised to restore the articles on surrogate motherhood as soon as an amendment of the law came on the agenda. Since 2002, the year of the Socialist-liberal government's formation, the Health Act has been twice subjected to amendments, though nothing has happened in the area of surrogate motherhood.

We will now take a look at the abortion law (it is called, tellingly, the Law on the Protection of Fetal Life).<sup>47</sup> Even a cursory glance at the law will show that the reproductive rights of women are unduly restricted in this domain, too. The law secures more or less adequate access to abortion in cases where a need for it is based on medical reasons; though it fails to provide for abortion on the grounds that a pregnancy is not wanted. If the pregnant woman has no medical reasons to support her request, she must support it by reference to a "situation of social crisis". In this case, she will have to attend a counseling session, where the counselor (usually a nurse) may ask her to reveal her reasons and to discuss them with her – and where the job of the counselor is to try to convince the woman that, given the seriousness of her moral responsibility towards the fetus, she should *not* seek an abortion. Counseling would not come into conflict

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45 Statement 26 of HCLU. See: [www.tasz.hu](http://www.tasz.hu).

46 Hungarian law is no exception in this regard. A new fertility law was adopted in Italy in 2004 that bans the donation of sperm and eggs, defines life as beginning at conception, and allows fertility treatment only to married heterosexual couples. A referendum was held in May 2005 upon the initiative of the Radical Party with the aim of overturning the key provisions of the law. Although several polls showed that Italian voters largely supported the repeal of the sections in question, the referendum ended up as invalid because of low participation. 'In Political Step, Pope Confronts the Law on Fertility', (2005). *The New York Times*, May 31.

47 Act LXXIX of 1992.

with the principles of autonomy or self-determination if it were to be offered on a voluntary basis. In such a case, the counselor is supposed to provide the pregnant woman with information and to offer her support in her search for a decision that would reflect her values and informed desires. However, mandatory counseling, where the counselor's job is to try to make the woman seeking an abortion give up that intention, is not a form of assistance but, rather, an unacceptable invasion of the woman's privacy. It is violating the principle of patient autonomy in the name of paternalism and of a moralistic claim that seeing through a pregnancy is a duty that society has a right to remind a woman to do.

Autonomy of choice entails that any decision is *not made dependent* on the consent of a third-party. Teenagers aged below 18 need to have this autonomy in a number of issues, with as wide a range as possible, and this should certainly increasing with someone's age. Abortion belongs to this category – and a pregnant girl has a strong claim to autonomy here. However, bowing to the paternalistic principle, the abortion law refuses to allow this autonomy to the girls of under 18 years. Although the presence of a parent at the mandatory counseling is not required, the abortion cannot be performed unless parental agreement is expressed in writing. The requirement of parental notification – not even allowing for medical exceptions – thus makes it hard for pregnant girls to seek a physician's assistance.<sup>48</sup>

We can, however, note that some progress has been made in the area of reproductive rights.

- In 1995, the Constitutional Court struck down a legal provision concerning artificial sterilization. That provision made access to physician-performed sterilization conditional on the woman's having three children already or, alternately, on her having reached the age of 35 years.<sup>49</sup> The Court declared this requirement unconstitutional, and as a disproportional interference with someone's right to self-determination.
- Also in 2005, the healthcare authorities gave a license for the establishment of stem cells banks.
- Finally, sperm and egg donations by identified persons were legalized

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<sup>48</sup> The US Supreme Court heard arguments in a New Hampshire abortion-related case on November 30, 2005, revisiting the question of whether the parental notice law in force in New Hampshire was unconstitutional. (Of the 43 states that require parental involvement in a teenager's abortion decision, New Hampshire is one of only five *not* to include an explicit health exception in the text of the statute; while all laws *do* make exceptions for life-threatening medical emergencies.) The justices appeared to be in broad agreement on two propositions: that laws regulating a teenager's access to abortion must make allowances for medical emergencies – and that the New Hampshire law, requiring notice to one parent and a 48-hour waiting period, failed to do this. See *New York Times*, December 1, 2005.

<sup>49</sup> See Section 2 of Article 187 of the Health Act.

this year, making it possible for close relations, or ‘kin’, to donate sperm or eggs to each other.

As to reproduction procedures facilitated by recent discoveries in genetics – such as the genetic profiling of babies, the creation of sperm and eggs from stem cells, the cloning of human embryos, the creation of human embryos with genetic material from two mothers – these have not yet given rise to much public debate in Hungary. Even though these issues are hotly debated in bio-ethical committees and even in the science sections of newspapers in Western Europe, they remain, for the time being, beyond the horizons of the Hungarian public. As an early exception, the issue of sex-selection of fetuses was raised in a media campaign coming from the government in the summer of 2005. The campaign failed to elicit great interest, though – only three thousand people volunteered to respond to the question; yet a large majority of this relatively small number supported the proposition that parents should have such a choice in the case of their third child and afterwards.

## 11 Policy proposals

### 11.1 *In the domain of legislation*

When it came to an amendment of the Health Act, the Legislature made significant steps towards transforming the paternalist model of the physician-patient relationship into a model based on informed consent. According to law, the ultimate decision on whether a proposed treatment should be used or not, lies with the *patient*. Nevertheless, neither Parliament nor the Ministry of Health, responsible for submitting the draft of the law to the Legislature, initiated any inquiry into the way provisions on patients’ rights were being translated into practice.<sup>50</sup> Given that treatment decisions affect the constitutional rights of patients to self-determination, the issue is serious enough to justify a joint initiative by the Health Committee and the Constitutional and Legal Committee of the Parliament, to launch an investigation into:

- whether the institutions foreseen by the law as being the ones to guarantee that patients’ rights are duly respected have actually respected

<sup>50</sup> The Legislation Act mandates that “the organs of legislation and of law application must examine the impact of the application of legal rules, they must uncover the circumstances that prevent the law’s provisions from being followed in practice, and experience must be made use of in the legislative process”. Law XI of 1987, Article 44.

- this – and, if the answer is yes,
- whether they work with sufficient efficacy;
  - whether the rules in force are capable of securing personal self-determination in the domain of healthcare; and, finally,
  - whether patients have an opportunity to exercise, in practice, the rights the Health Act recognizes them as possessing.

It is time to initiate this investigation *now*, and it is highly desirable for it to be conducted with an eye to whether the law's provisions on patients' rights *are being translated* into living legal practice. Such an inquiry could lead to a proposal to amend the Act, with the aim of giving specific regulatory content to the general principles of patients' self-determination – and of rectifying the rules of the law that run against those principles.

The inquiry need not start in a void. Even before it is completed, one can identify a number of issues where significant change will be needed.

- It is against the spirit of the Constitution to treat, as the law does, *patients with limited competency* on a par with those who count as incompetent. To subject the first to the same restrictions that apply to the second is an unnecessary and disproportionate restriction of patient autonomy; it amounts to a paternalistic interference with personal self-determination in the field of healthcare. The concept of competence needs to be given a specific, treatment-related definition. The law should provide different rules for different aspects of decision-making concerning treatment, even for the same categories of patients with limited or no competence. The surrogate decision-maker must have the same powers to make decisions on behalf of the person represented by him or her as any fully competent patient would have in his/her own case.
- It is against the spirit of the Constitution to completely deprive *young people under the age of 18* of the right to make decisions concerning their treatment. Those aged above 16 must have the right to choose the institution and the physician of their preference, and to make the ultimate decision as regards whether to accept or reject a proposed treatment. Notification of parents and a having their agreement to go ahead with an abortion for someone aged below 18 years should not be a requirement. Patients aged below 16 must have the right to take part *actively* in any process leading to a decision being made on their treatment.
- It is against the spirit of the Constitution to have prohibitively burdensome practices for the terminally ill with regard to someone's right to *refuse life-sustaining treatment*. The procedure must be simplified, so as to make this option freely accessible.
- It is against the spirit of the Constitution to discriminate between clients asking for medical assistance in reproduction on grounds that are unrelated to their health condition (such as marital status, sexual orientation, etc.). Thus, the rules on assisted reproduction need to be changed in such a way as to bring them in line with the constitutional principle of *non-discrimination*.
- The law should anticipate the emergence of *new medical procedures*, at least those that are likely to become available in the foreseeable future. As Hungary's ambiguous experience with stem cells' banks shows, it is

not a fortunate situation to have a technique available for use *before* the relevant legal regulation is in place.

- *Genetic data* should be treated separately, as a category of unusually sensitive personal data that requires special regulation. The collecting and storing of *such* data will have a lot more serious consequences for the data subject than will be collecting and storing of *other* medical data. Thus, the individual's right to privacy and his or her right to have control over genetic data require special rules, with a particular stringency. These rules should be created *before* the obtaining of genetic data becomes general practice.

## 11.2 *In the domain of advocacy*

Legal practice is affected by many factors beyond just legislation itself. Most of these cannot be dealt with directly – for the action must target the social environment. There is one special aspect of this environment that plays a particularly important role in shaping legal practice though, and that is the institutional and cultural framework of legal advocacy – and it is an attack on this framework that the second group of my policy proposals recommends.

- The *Parliamentary Commissioner for Civil Rights* must have legal powers to conduct unobstructed inquiries into hospitals and clinics. According to the present regulations, the Commissioner cannot gain access to the files of a patient unless the latter has filed a complaint with him or her.
- The system of *patients' rights' representatives* needs to be revised. The law should insist that each medical institution has its own patients' rights representative – and each representative will serve one, and only one, institution. It should be made a legal requirement that the patients' rights' representative should have contact hours on a daily basis.
- Patients' rights' representatives should be required to make a report on their experiences year by year. Individual reports should be united into a *general yearly report* by the public trust responsible for the co-ordination of the activities of patients' rights' representatives. This report should focus on systemic problems existing in the area of patients' rights. It should be put before Parliament for discussion and endorsement – and it should be made available to the wider public.
- *Information on patients' rights* must be made widely accessible. Hospitals and clinics need to be held accountable for their readiness (or non-readiness) to make available written materials that explain to their patients what rights they possess and what remedies they have should those rights be violated.
- Procedural means must be established to enable a patient *to name a surrogate decision-maker*.
- With regard to a *refusal to have life-sustaining treatment* (beyond the legal simplification mentioned in the above subsection) it is necessary to make sure that the *physicians' panels* foreseen in the law as attesting the validity of a patient's decision are set up in all relevant medical institutions.
- A *consultative body on bioethics* should be set up to help the government

act, where this is necessary, to promote and to regulate the application of the new results of bioscience. This body would make statements on innovations in this field. The positions it takes on the welfare-related and ethical aspects of these innovations could stimulate public discussion. It is important for it to have members who are not scientists or physicians but who represent the considered views of the *general* public.

- In Hungary, as elsewhere, *patients' organizations* have been created with the aim of facilitating self-help for groups of patients with a particular illness or disability – and of lobbying for the interests of that group with Parliament and other relevant governmental authorities. As health-care system reform cannot be delayed any more, the need for a robust presence of such organizations is acutely felt. It is very important that they get public funding and other support so that they can step up their activities.
- It is of special importance that *patients' rights organizations* are able to flourish. This, again, needs an availability of public funding and a readiness on the part of the Legislature and the Executive to engage in an ongoing dialogue with civil associations.