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PÔVODNÉ PRÁCE / ORIGINAL ARTICLES

DISCRIMINATING AGAINST CHILDREN WITH HANDICAPPING CONDITIONS (2)*

Siegfried M. Pueschel

Child Development Center, Department of Pediatrics, Rhode Island Hospital, Brown University School of Medicine, Providence, Rhode Island, USA

The Reagan Administration's Response to Baby Doe and subsequent judicial involvements

The tragic Baby Doe circumstances did not only bring about a major reaction of the caring professionals involved with Baby Doe, but also the Reagan Administration was abruptly awakened to the problem of discrimination against handicapped infants [16]. The Baby Doe incident apparently touched President Reagan since he knew a youngster with Down syndrome well and was fond of him, namely, the son of columnist George Will and his wife Madeline. President Reagan felt that there must be some feder al civil rights law that would prevent such a situation. Hence, he ordered his Secretary of Health and Human Services as well as his Attorney General to take steps to prevent repetition of such an incident [16].

Shortly thereafter, on March 18, 1983, the Secretary of Health and Human Services sent a notice to most of the nation's hospitals stating that "The discriminatory failure of federally assisted health care providers to feed a handicapped infant, or to provide medical treatment essential to correct a life threatening condition" would violate Section 504 of the Rehabilitation Act of 1973 [16].

Later the Administration felt that this notice was a very mild measure and that a firmer stand needed to be taken quickly. The Administration then issued administrative rules that unambiguously extended the protection of the Federal Rehabilitation Act to handicapped newborns [18]. In doing so, the Administration was bypassing the customary procedures such as review at the special office in the OMB. A five-member task force drafted regulations indicating that hospitals and other health facilities are obliged to post a notice of nondiscrimination, that complaints had to be investigated, and that the violators faced the loss of federal financial aid [16].

The Administration saw an urgency to the problem because discrimination of handicapped individuals by refusing to render appropriate medical care could mean death or grave injury within days or even hours. The new regulations were published in the Federal Register on March 9, 1983 and were scheduled to take effect two weeks later [2].

The medical community was upset alleging governmental intrusion into medical practice and the parent/physician relationship. On March 21, 1983, attorneys for the American Academy of Pediatrics appeared before Judge Gesell in the United States District Court in Washington, DC asking for an injunction which was declined [16]. Judge Gesell, however, issued a decision vacating the rule on April 14, 1983, because he found that it violated the Adminis-

*Continued from ME&B, Vol. 3, No. 4.

trative Procedure Act. Moreover, the Judge indicated that Section 504 of the Rehabilitation Act of 1973 did not apply to medical care of newborns and that the Secretary of Health and Human Services failed to consider the disruptive effect of the Hot Line, the importance of the wishes of the parents, and the possible adverse effect of the rule on the interest of the child [2].

The Reagan Administration was surprised by the response of the medical community and Judge Gesell's dismissal of the regulation. Shortly thereafter, officials of the Department of Health and Human Services slightly modified the rules, and then followed procedural guidelines calling for public comments as well meeting with the representatives of the medical community. The modified regulations were published in the Federal Register on July 5, 1983 [18].

Subsequently, the American Academy of Pediatrics forwarded extensive comments to the Department of Health and Human Services on the newly proposed rules. The final rules, issued in January 1984, incorporated a committee review process which was to assist the health care provider in the design of procedures, policies, and standards for providing treatment to handicapped infants. The final rules were also designed to help health care providers to make decisions concerning medically beneficial treatment in specific cases [18].

Later, the American Academy of Pediatrics, together with other volunteer organizations representing infants with disabilities, developed a statement of "Principles of treatment of disabled infants" which pointed out "When medical care is clearly beneficial, it should always be provided and that when doubt exists, a presumption should always be in favor of treatment" [19]. The infant's medical condition should be the sole focus of the decision. It is important to note that the statement agree s that it is ethically and legally justified to withhold medical or surgical procedures that are clearly futile and will only prolong the dying process. However, supportive care should be provided, including sustenance and relief of pain and suffering [19].

The Department of Health and Human Services argued that the basic issue of equity requires that medically beneficial treatment must be rendered to handicapped infants who are "otherwise qualified" to receive it. Thus, if a "normal" infant would be provided with a specific therapy, it could not be lawfully withheld from handicapped infants simply because they are handicapped. Such rules would have required that the surgical repair of Baby Doe's esophagus should have been carried out and that Baby Doe would have been afforded the same kind of treatment as any other child [20].

Some of the criticisms which have been levied against the final Baby Doe rule include:

- that the only direct consequence for violating the rule, namely the withdrawal of federal funds, could penalize innocent infants and professionals,
- it only encourages hospitals to develop review committees,
- it does not provide specific standards and thus much inconsistency is likely to develop,
- it uses the concept of medical neglect instead of the best interest of the child's standards,
- no research on the effectiveness of the procedures has been done, and
- it will be difficult to ibe mplemented because of limited funds appropriated to carry out the procedures.

Most importantly, few medical services are provided to handicapped children and their families after infancy and many families will have to assume most of the responsibility and burden of the care. Thus, "we rush to defend the infant who has been denied treatment, we praise the courage of the parents who care for such a child at home, and we celebrate disabled individuals who achieve, however, there are poorly funded efforts to help handicapped children and their families" [2].

Baby Jane Doe

While the Department of Health and Human Services was working on the final rules, another handicapped infant who became known as "Baby Jane Doe," was born with spina bifida and hydrocephalus in Port Jefferson, New York [18]. In addition, the infant had microcephaly, spasticity in the upper extremities, and impairment of bladder and bowel functions. The infant was transferred to the University Hospital of the State University of New York at Stonybrook to undergo neurosurgery for spina bifida and hydrocephalus. The parents, however, decided not to have the surgery performed and to have the infant treated "conservatively" [18]. Although details of the physician's counseling are not known, apparently the parents were given a very bleak outlook and a poor prognosis for their infant [21]. They were told that the infant may have constant urinary tract infections, paralysis of her limbs, and would be unable to talk or respond to any emotions [21].

Subsequently, a Right-to-Life lawyer from Vermont went before the New York Supreme Court and asked that a guardian be appointed for the child and to order the appropriate neurosurgical intervention. Although the Court complied with both requests, the Supreme Court's Appellate Division reversed this ruling [22]. The Appellate Court felt that the parents had made an informed and intelligent decision based upon medical counseling and this "was in the best interest of the infant" [16]. The Court of Appeals of New York sustained the ruling of the Appellate Division [23]. In the meantime, Baby Jane Doe was treated "conservatively" [16].

Shortly thereafter, an anonymous informant complained to the Department of Health and Human Services that Baby Jane Doe was suffering "discriminatory treatment" since the parents and hospital were declining to treat her hydrocephalus. However, in order to investigate the reported concerns, the Department of Health and Human Services needed access to the infant's medical records. The hospital did not provide the infant's medical records to the Department of Health and Human Services since the parents did not give permission and the Department of Health and Human Services did not have jurisdiction in the matter. Later, on November 2, 1983, the Department of Health and Human Services went into court in order to gain access to the records. The Department charged that the hospital had violated its responsibilities under Section 504 of the Rehabilitation Act of 1973 [16].

On November 17, 1983, the United States District Court for the Eastern Division of New York concluded that the hospital could not be in violation of Section 504, because it lacked the legal authority to perform surgical procedures without parental consent [16]. Moreover, the court indicated that the parents' decision to refuse permission for surgery was reasonable, since it was based on due consideration of the medical options available and was in the best interest of the child [24].

Three months later, the United States Court of Appeals, Second Circuit, upheld the District Court's decision. The Court of Appeals main findings were that the medical treatment decision did not violate Section 504's prohibition against discrimination of the handicapped. Since the United States Court of Appeals for the Second Circuit upheld the District Court's ruling, the Administration appealed to the United States Supreme Court.

Legislative activities and the U.S. Civil Rights Commission's deliberations

During the time period when the courts were denying the Administration access to Baby Jane Doe's medical records, the House of Representatives was enacting legislation that incorporated several features of the Administration's rules [16]. Also, the Senate passed legislation relating to newborns with handicapping conditions. Eventually, in September 1984, a conference committee agreed on the *Child Abuse and Neglect Amendments* of 1984 (PL 98-457).

The Child Abuse and Neglect Amendments differed significantly from previous approaches of the Administra-

tion to interfere with medical management in the newborn period. In contrast to the federally controlled Civil Rights Authority, the Child Abuse and Neglect Laws are largely implemented by the states. The states were instructed to establish procedures to respond to reports of medical neglect.

In addition, the Amendments of the Child Abuse and Neglect Law attempted to define the scope and content of the physician's obligation to treat newborn babies with handicapping conditions. The Amendments also encouraged, but not required, that hospitals establish Infant Care Review Committees to aide parents and physicians in making their decisions with regard to therapeutic intervention of newborns with significant developmental disabilities.

The Child Abuse and Neglect Amendments specifically prohibit withholding of medically indicated treatment from infants with handicapping conditions. The Amendments stress that all infants with disabilities must, under all circumstances, receive appropriate nutrition, hydration, and medications, and must be given medically indicated treatment [25]. Medically indicated treatment is defined as the "treatment most likely to correct or ameliorate the condition based upon the reasonable medical ju dgment of the treating physician" [25]. Treatment, however, is not considered to be medically indicated and required when

- a child is chronically and irreversibly comatose,
- the provision of such treatment would merely prolong dying,
- the provision of such treatment would not be effective in ameliorating or correcting all of the infant's life-threatening conditions,
- the provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment under such circumstances would be inhumane [26].

Thus, the Child Abuse and Neglect Amendments attempt to insure that medical treatment is not denied except in the most extreme circumstances as mentioned above.

The U.S. Civil Rights Commission studied the Amendments and did not find any fault with provisions that created these exceptions to medical treatment requirements [26]. The Commission took the position that the failure to provide maximum medical treatment to infants with development disabilities is impermissible except in extremely limited circumstances. The report of the Commission emphasizes that the Child Abuse and Neglect Amendments are intended to set out a detailed standard of care that states receiving federal funds for their Child Abuse and Neglect programs must enforce [26]. The Commission, however, did not discuss the conflict with the general parental right to decide upon medical care for their children, handicapped or not handicapped. The report also did not address situations in which doctors recommend that lifesaving treatment be provided to an infant with developmental disabilities but when parents refuse to consent to such treatment. Moreover, the commission did not r ecognize that pain and suffering of an infant with developmental disabilities should be considered when determining whether to provide life saving treatment to that infant [26].

The U.S. Civil Rights Commission report constitutes a comprehensive analysis of the discriminatory treatment of infants with handicapping conditions and makes numerous recommendations for eliminating such discrimination. The Commission report however, ignores some significant opposing viewpoints. The Commission report also does not discuss aspects of "overtreatment" of infants with disabilities [26].

One could question whether mandatory treatment of all seriously ill newborns should be required by law. The Commission responds affirmatively to this question concluding that mandatory treatment should be required. This is based on the historical information describing blatant and oppressive discrimination against people with developmental disabilities in past decades. The Commission's conclusions are founded on the premise that prejudicial and stereotypical attitudes about the capabilities of persons with developmental disabilities should play no part in the decision of whether or not to allow infants with disabilities to live or die [26].

The aftermath of Baby Doe

The Reagan Administration's well-motivated but poorly conceived regulations that issued rules to insure that physicians and hospitals would not withhold treatment from seriously mentally and physically handicapped newborns and the medical community's reaction to governmental intrusion into medical care had a significant effect on many special interest groups in this country. Overzealous as it was, the Reagan Administration sensitized public and professional opinions to the medical problems of handicapped newborns. Although disfavored by the Administration, the judiciary effectively checked the workable and inadvisable means the Administration devised to promote its ultimate end.

When pediatricians specialized in perinatal care were asked for their views on the Baby Doe regulations and on whether the regulations had affected their practices, 76% believed that the current regulations were not necessary to protect the rights of handicapped infants, 66% felt that the regulations indeed interfered with the parents' rights to determine what course of actions was in the best of their child, and 60% mentioned that the regulations did not allow adequate considerations of infan ts' suffering [27]. The pediatricians also felt that the regulations ignored the traditional role of parental consent. Moreover, the pediatricians indicated that the regulations had altered the care of infants with handicapping conditions and the way they practiced medicine. Many pediatricians believed that the new regulations did not serve the best interest of infants [27].

In October 1984 House Representatives, professionals, such as physicians, attorneys, social scientists, and members of the press met at the State University of New York at Stonybrook [28]. This diverse group of people discussed ethical, social, legal, and medical issues concerning appropriate therapy of newborns with handicapping conditions. Members of this conference agreed that difficulties in medical decisions about treatment of significantly handicapped newborns include uncertainty about diagnosis and prognosis as well as the benefit of the treatment. Also, frequently the best interest of the child is difficult to assess. Five responsibilities physicians must attempt to pay attention to were identified by the conference participants:

- acting in the child's best interest: Judgments about the best interest of the child have traditionally involved judgements about the quality of life worth living. It was agreed that a handicap per se does not preclude a satisfying life any more than good health guarantees one.
- providing some form of medical care: Members of the conference indicated that appropriate care can and always should be provided to newborns with handicapping conditions. However, at times some form of medical treatment may be withheld.
- assisting parents in decisions about medical treatment: Because prognosis and diagnosis are frequently uncertain, it is often difficult to communicate this uncertainty and complicated medical information to parents. However, it is important that physicians do communicate with parents in a simple, understandable, and honest way to reduce the family's anxiety. Physicians should provide sufficient information to parents so that they can make appropriate decisions about treatment options [28].

The most important recommendation of this conference was that every institution that is involved in the treatment of newborns with handicapping conditions should have an explicit policy on how difficult treatment decisions will be made and how their institutional consequences will be managed [28].

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Ordering of the references is valid for the whole article; only the references cited in this part are given here.
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Address/Adresa: Prof. S. M. Pueschel MD, PhD, JD, MPH, Child Development Center, Department of Pediatrics, Rhode Island Hospital Brown University School of Medicine, 593 Eddy Street, Providence, Rhode Island (RI), 02903 USA.

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PREHĽADY

REVIEWS

GENETICALLY ENGINEERING DESIRABLE TRAITS: THE ETHICAL CHALLENGES

Robert W. Evans

"We used to think our fate was in the stars. Now we know, in large measure, our fate is in our genes."
- James Watson, *Time Magazine*, March 20, 1989

"We cannot think of any significant human social behavior that is built into our genes in such a way that it cannot be shaped by social conditions."
- *Not in Our Genes: Biology, Ideology, and Human Nature* by R.C. Lewontin, Steven Rose and Leon Kamin

Introduction

Genetic engineering concerns the practical application of DNA or their components. As a branch of the larger discipline of biotechnology, genetic engineering finds its historical roots in art, and was initially involved in the production of wines, beers and cheeses. Today, genetic engineering involves a constellation of advanced technologies including biology, chemistry and process engineering.

In recent years, advancements and innovations in genetic engineering have impacted significantly on the field of biotechnology. And today the applications of genetic engineering are varied and diverse, including the production of new drugs, transgenic organisms and biological fuels, gene therapy and the addressing of a host environmental concerns such as pollution. However, despite the many potential benefits of genetic engineering, the history, techniques and applications of this science are laced with serious ethical and moral issues of concern.

The purpose of this paper is three-fold. First, this paper will provide a brief overview of the origins of genetic research. Second, we will discuss what is presently occurring in modern genetics, and the underlying assumptions upon which these procedures are based. This will be done in order to more easily understand and evaluate current applications of genetic research. The various fallacies in reasoning and argument will also be exposed. And third, a Biblical-theological approach will be developed for the purposes of evaluating the promises and liabilities of genetic engineering from a Christian perspective.

Before we begin, a comment concerning the delimitations of this paper are in order. The field of genetic engineering and biotechnology is rapidly expanding and changing. It would be unreasonable to expect that the literature pertaining to such a topic could be exhausted in a single paper. And though every attempt has been made to be thorough, accurate, and timely, this paper will necessarily be limited to a review and consideration of that research data which was currently available.

Part One

A) Review of the History and Development of Genetic Engineering

A. What Are Genes?

Definitions of what constitutes a gene differ depending upon the kind of biologist that is asked the question. The molecular biologist, considers a gene to be a stretch of DNA that specifies thecomposition of a protein and may affect whether and at what rate the protein is synthesized, as well as sometimes affecting the synthesis of proteins specified by nearby genes. For the geneticist, a gene is a part of the living chromosome that mediates inheritable characteristics or traits. Population biologists offer yet another definition and consider genes as units of difference that can be used to distinguish various members of a population from one another. For the evolutionary biologist, genes are historical records of the changes organisms have undergone over time. All of these definitions share certain areas of overlap and complement each other, and which one a particular scientist focuses on "simply depends on his or her interest."

Despite these varying definitions, biologists are in agreement that genes are functional segments of DNA molecules, though the word "gene" predates that definition. The term "gene" was invented at the beginning of the 20th century to denote "particles that were thought to mediate the expression of hereditary traits in individuals and to transmit these traits from parents to their offspring." However, it later became clear that there were no such "particles", but that the functions once attributed to them were performed by portions of DNA molecules. This paper will make use of the term "gene" throughout for the purposes of economy and space, though "DNA segment" or "functional DNA segment" is the more accurate, and hence appropriate, label.

The ideological biases of those working in the area of genetic engineering may also be seen in the language that geneticists employ. Molecular biologists, as well as the press, will frequently use verbs like "control," "program," or "determine" when speaking about what genes or DNA do. And it is difficult to pick up a paper or turn on the television without hearing about the identification of a gene "for" this, or that "causes" that. However, given that DNA is an inert molecule, it doesn't do anything. Therefore, such descriptions as "for, " "causes," "determines," and "biologically-based" are all inappropriate as they assign an active role to DNA which it does not possess. Rather, DNA resides in dormant fashion in our cells and merely "waits for other molecules to interact with it."

However, given the language in which genetic information is wrapped when presented for public consumption, genes end up being looked on as some kind of absolute predictor. The following excerpts provide us with examples of common, yet grossly inaccurate, portrayals of the link between genetics and traits/conditions:

"Our research shows that male sexual orientation is substantially genetic." - B. Bower, "Gene Influence Tied to Sexual Orientation." *Science News*, 141, January 4, 1992.

"The possibility that persons at risk for alcoholism could be identified before they began drinking holds the

exciting promise of true primary prevention." - Theodore Reich, "Biologic-Marker Studies in Alcoholism." *New England Journal of Medicine*, 318 (1988) 180.

"... more than half of all juvenile delinquents imprisoned in state institutions and more than a third of adult criminals... have immediate family members who have also been incarcerated." - Fox Butterfield, "Studies Find a Genetic Link to Criminality." *New York Times*, January 31, 1992.

When the correlation between genetics and behavior are presented in such a way, an aura of inevitability and hopelessness is communicated which both limits and misleads us. The sense of personal responsibility that should rightly accompany our lives is lost and the unwary consumer of such biased information is placed into the awkward position of trying to contend for standards of conduct and decency that are "not the fault" of the one supposedly afflicted with the predictive gene.

Additionally, to lead others to believe that their capacities are predetermined and encoded in their genes can prevent them from taking available measures to change themselves or the conditions of their lives. Rather, genes function within an exceedingly complex matrix of interactions with biological reactions, social factors, and economic relationships. There is no "cause and effect" correspondence between genes and traits, and the processes involved in the expression of characteristics and behavior cannot be duplicated in a laboratory.

B. A Brief Review of the History and Development of Eugenics

In 1883, Francis Galton (who, incidentally, was the cousin of Charles Darwin), coined the term *eugenics*. Technically, the term "eugenics" means "well-born." Galton wrote that he invented the term in order to have, a brief word to express the science of improving the stock, which is by no means confined to questions of judicious mating, but which, especially in the case of man, takes cognizance of all the influences that tend in however remote a degree to give the more suitable races or strains of blood a better chance of prevailing speedily over the less suitable than they otherwise would have had.

Galton's class and race biases are readily apparent, as he expressed little doubt about who represented "the more suitable races or strains of blood." Galton would later help to found the English Eugenics Society and became its honorary president.

The history of the eugenics movement would take its next major step in 1912. At the inception of a long career as a geneticist, Hermann J. Muller wrote:

"The intrinsic interest of these questions [about heredity] is matched by their extrinsic importance, for their solution would help us predict the characteristics of offspring yet unborn and would ultimately enable us to modify the nature of future generations."

Muller was a politically progressive idealist. History reveals that he would later try to emigrate to the Soviet Union in the early 1930's because of his interest in helping to build "a better world."

Until World War II, there were many distinguished biologists and social scientists in Great Britain and the United States who, through either activity or silence, supported the eugenics movement. Even as late as 1941, the notable British biologist Julian Huxley, brother of Aldous Huxley, the author of *Brave New World*, wrote an article called "The Vital Importance of Eugenics." He begins his article as follows:

"Eugenics is running the usual course of many new ideas. It has ceased to be regarded as a fad, is now receiving serious study, and in the near future will be regarded as an urgent practical problem."

Later in the article, he argued that society must "ensure that mental defectives shall not have children." The blurring between the assumed integrity of the scientific endeavor and the realities of economic pressures are realized when Huxley goes on in his article to define as mentally defective "someone with such a feeble mind that he cannot support himself or look after himself unaided." Remarkably, these sentiments were expressed during a time when eugenic extermination practices were in full force in Nazi Germany.

And though similar feelings to those of Huxley continue to persist in some circles, the data concerning this issue is not supportive of the bias regarding the mentally retarded. For though most instances of mental retardation among the middle and upper classes do possess a genetic component, this is not the case among poor people. In the latter category, mental retardation is mediated in considerable measure by such environmental factors as inadequate nutrition and prenatal care, lead poisoning, and substandard school systems.

Like Muller, Huxley did not limit his concern to those persons who were demonstrably afflicted with "mental defects." Rather, he looked forward to a future when it would become possible "to diagnose the carriers of the defect [who are] apparently normal," since "if these could but be detected, and then discouraged or prevented from reproducing, mental defects could very speedily be reduced to negligible proportions among our population."

Huxley's views were by no means representative of a minority consensus. Eugenics societies had developed in both the United Kingdom and in America, and had been industrious in organizing "gene fairs" designed to educate the public about the dangers of inherited defects. These efforts were largely directed at the upper classes, and sensationally warned about the dangers of "class suicide" because the "best and brightest" were having too few children while poor people were having toomany.

While European eugenicists preoccupied themselves with an emphasis on class differences, those working with the eugenics movement in United States tended to focus more heavily upon ethnic and racial concerns. Lewis Terman was one of the principle engineers and advocates of IQ testing. He expressed some of his thoughts about the "link" between genetics and intelligence in an article he published in 1924, in which he worried that the fecundity of the family stocks from which our most gifted children come appears to be definitely on the wane.... It has been figured that if the present differential birth rate continues 1,000 Harvard graduates will, at the end of 200 years, have but 56 descendants, while in the same period, 1000 South Italians will have multiplied to 100,000.

Part Two

Current Trends in Genetic Engineering

A. The "New" Eugenics

After World War II, the societal interest in eugenics declined. By the standards of many, the emphasis upon class and racial demarcations had been over-emphasized to the point of becoming politically unacceptable. Within the scientific community it was also losing favor, though for more pragmatic reasons. The advancements of science began to catch-up with the folklore that was beingpropagated and scientists began to realize that nearly all inherited conditions were as a result of *recessive* genes, rather than *dominant* genes. What was discovered was that someone with a dominant genetic condition will pass it on to roughly half of her or his descendants. But to inherit a recessive condition, people must receive copies of the relevant *allele*, or form of the gene, from both their parents. If a person were to inherit only one copy from one parent, they will generally show no symptoms and are said to be *carriers* for that condition. But even if two carriers have children together, each child has only one chance in four of manifesting the condition.

Familiar examples of recessive conditions are *phenylketonuria*, or PKU (a metabolic problem that can result in mental retardation), *cystic fibrosis* (a glandular disturbance that leads to the accumulation of mucus in the lungs and to repeated infections), *Tay Sachs* disease (a fatal ne-

urological disease of young children), *sickle-cell anemia* (a blood disease that can be extremely painful and disabling), and *Gaucher Disease* (a chronic disorder of metabolism that is characterized by the enormous enlargement of the spleen).

Because these conditions are recessive, people who manifest them (those with two copies of the affected allele) represent only a fraction of those who carry at least one of the alleles. Detection of carriers is avoided because most alleles associated with recessive conditions are carried by people who have no symptoms and frequently would have no reason to suspect that they are carriers. In other words, recessive mutations which affect most genetically-mediated conditions are propagated by healthy, "normal" members of the population. Each of us carries alleles that would be either disablingor lethal if we or our children had two copies of them instead of just one. This discovery represents a significant blow to the eugenics movement because any genetic intervention measures which are directed at people who manifest these recessive conditions can only touch the tip of the iceberg at best. In short, genetic interventions cannot reduce the prevalence of the conditions it seeks to ameliorate or eliminate in the population at large.

Pursuant to this discovery, the idea of "race purity" died, as did the idea of building a strain of supermen. However, the notion that it is more beneficial for certain people to have children than others, and that a vast range of human problems can be cured once we learn how to manipulate our genes, remains very much with us today.

Selective eugenics can wear may faces. Helen Rodriquez- Trias, who served as the president of the American Public Health Association, cites a 1972 survey of obstetricians which found that "although only 6 percent favored sterilization for their private patients, 14 percent favored it for their welfare patients. For welfare patients who had borne illegitimate children, 97 percent... favored sterilization." Though this is an overt example of persistent eugenic thinking in our society, eugenics can also assume much subtler forms. From a Christian perspective, any suggestion that society would be better off if certain kinds of people were not born puts us on a dangerously slippery slope.

The increasingly-popular testing of prospective parents to see if they are carriers of genetic "defects" moves us a long way in the direction of labeling a large group of people as being somehow "defective." With the advent of indiscriminate testing, we have created a society in which not only the people who manifest the condition but also the carriers are likely to be considered "less than perfect." Many would argue that such tests are generally helpful because they increase a person's choices (the doctrine of autonomy), but this is practice without precept. It would be a mistake to ignore the underlying ideology that almost inevitably accompanies their use.

In 1971, Bentley Glass, retiring as president of the American Association for the Advancement of Science, wrote:

"In a world where each pair must be limited, on the average, to two offspring and no more, the right that must become paramount is... the right of every child to be born with a sound physical and mental constitution, based on a sound genotype. No parents will in that future time have a right to burden society with a malformed or a mentally incompetent child."

In a similar tone, the situational ethicist Joseph Fletcher has written: "We ought to recognize that children are often abused preconceptively and prenatally - not only by their mothers drinking alcohol, smoking, and using drugs nonmedicinally but also by their *knowingly* passing on or risking passing on genetic diseases." Curiously, Fletcher absolves physicians of responsibility by singling out "nonmedicinal" drug use. This language of the "rights" of the unborn implicitly translates into obligations and responsibilities for future parents, and especially future mothers.

This ideal moves from implicit logic to explicit reasoning in the writings of Margery Shaw, an attorney and physician. In reviewing what she calls "prenatal torts" (a term that she has likely invented), she argues as follows: "Once a pregnant woman has abandoned her right to abort and has decided to carry her fetus to term, she incurs a "conditional prospective liability" for negligent acts toward her fetus if it should be born alive. These acts could be considered negligent fetal abuse resulting in an injured child. A decision to carry a genetically defective fetus to term would be an example.... Withholding of necessary prenatal care, improper nutrition, exposure to mutagens and teratogens, or even exposure to the mother's defective intrauterine environment caused by her genotype... could all result in an injured infant who might claim that his right to be born physically and mentally sound had been invaded."

B. The Presuppositions of Eugenics

The application and development of genetic engineering is predicated upon several assumptions which, though serious flawed, are encountered frequently and are widely disseminated. They are as follows:

1. The Fallacy of Genetic Prediction

Genetic predictions, whether they involve testing or screening, are based on the assumption that there is a relatively linear and straightforward relationship between genes and traits. However, genetic conditions involve a largely unpredictable interaction of numerous factors and processes. Even in those conditions in which the inheritance of certain genes follows a regular and predictable pattern are proving to be extremely difficult to define and localize. It is likely that in order to provide meaningful genetic information to prospective parents that scientists may sometimes need to work out the pattern of separate mutations for each of the different families, or even for each different individuals who manifest the "same" disease. This would make predictions impossible.

Furthermore, of what use would it be to have the entire gene sequence of a person? Divorced from the psychosocial context in which a person lives, the composite gene map is meaningless. Robert Cook-Deegan states it well: "A compact disk containing the DNA sequence of President Abraham Lincoln's genome would tell us very little about the President that we would really want to know. Whether or not he suffered from Marfan's syndrome, a genetic disorder not yet described in his time, would be a minor embellishment in his biography.... Blanket generalizations about the worth and danger of genetic information, robbed of their specific social context, render them almost meaningless. And that was the whole point of the genome debate."

2. The Fallacy that Detection will Lead to Cure

From a therapeutic perspective, it makes little sense to make any attempt to sort out the various genes involved with complex genetic conditions. Even if DNA is involved at some level, the condition could not ameliorated at that point. Yet, the faith that genes for all sorts of troublesome conditions can be identified and isolated, coupled with the hope that this will lead to profitable diagnostic tests, is likely to continue to fuel the search for relevant bits of DNA. Not only will this not cure or prevent the conditions, it will create a new class of stigmatized people, the "asymptomatic" or "healthy ill" who, though they have no symptoms, are considered likely to have a particular disability at some point in the future.

3. The Fallacy of Controlling Organism Functioning

The belief that genes cause traits in straightforward, predictable ways has also encouraged molecular biologists to undertake the Human Genome Project. This gigantic

project is designed in purpose to determine a base sequence for the DNA in all twenty-three human chromosomes. The Project is intended to first construct a map of the DNA "markers" associated with specific traits andeventually complete an entire sequence of nucleotide bases for a "human prototype." Unfortunately, the final product will be a composite of chromosomal regions obtained from the cells and tissues of different people. This will undoubtably cast serious questions upon the accuracy of the final composition.

Such an endeavor begs that question of why anyone would want to undertake the herculean task of identifying the fifty to a hundred thousand genes estimated to make up the human genome and then sequencing the approximately three billion nucleotide bases of which they are composed. Hubbard offers the simplest tongue-in-cheek answer when she replies, "because it is there." And certainly, scientists will discover some interesting things while undertaking this research. However, those reasons alone would not command the kind of funding that is needed for this massive a project.

The promise, therefore, is that scientists will be able to diagnose, treat, and eventually cure a large percentage of the "gene-linked" diseases once they have a complete DNA sequence. An even more grandiose reply is offered by James Watson and a number of other molecular biologists. They say that this will at last tell us "what it means to be human." Both of these assumptions are firmly grounded in the reductionistic assumptions that genes cause traits and that the more we learn about their composition, the more we will know about how organisms function.

However, neither of these assumptions are justified. The relationship between genes and traitsis much more complicated than the implied promises of the Human Genome Project would lead us to believe. The sequencing of a gene sequence would offer little information about the relationships between anatomical or physiological characteristics and specific genes because manifest traits are really the result of the interactions between genes and countless uncontrollable variables.

C. The Moral and Ethical Challenges

The issues which we have been talking about are also attenuated by a host of moral and ethical implications. The major ethical issues which arise from the advancement of genetic engineering would appear to cluster around several broad themes including human embryo research, the misapplication of genetic screening measures, the release of genetically manipulated organisms, plants and animals into the environment, and the alteration of the genetic sequence in the human gene-line. And though each of these areas is worthy of elaboration and comment, in keeping with the focus of our present discussion, we will restrict our discussion to the last of these.

Though the technology requisite to change or add genes in the human gene line is not currently available, the potential for such an advancement makes this prospect relatively immanent. The current thinking in this area is that the best way to ameliorate undesireable characteristics and promote those characteristics which are deemed as being of benefit is to alter the germ line, rather than to modify the somatic cells themselves. However, should this be an accurate representation of the current consensus, it fails to take into consideration that many of the defective characteristics which affect the human condition are as a result of mutuations in the genetic sequence and, therefore, "curing" the humans species of defective characteristics will be virtually impossible.

But even if we were able to employ such technology with precision, and control for those variable spontaneuos modifications which give rise to undesireable characteristics, genetic deterministic overreach remains accompanied by the danger of performing its work on the underlying assumption that there is a standard of normalcy (if not desirability) that all should have a "right" to possess. What is this "right to be born physically and mentally sound?" Who has such a right and who guarantees it? What are the essential elements of this "normal" condition and who is to establish them? Furthermore, who will decide who is to decide who is to establish them? Should the perceived needs of future human generations be established by individuals? By the State? By a committee of recognized experts? What if what is deemed as a desireable characteristic today is struck from the list years from now? What do we do with those genetically altered individuals who no longer conform to society's "new" standard of decency and desireability? What would prevent the standard from being asserted retroactively?

For those of us who embrace a Judeo-Christian ethic concerning our earthly mandate as followers of Christ, we find ourselves confronted by yet another host of ethical and moral dilemas, for how would we demonstrate our call to extend charity, graciousness, forgiveness, tolerance, patience, goodness, and winsomeness to a society who has been deprived of all those marginalizing "flaws" which would place them in need for such qualities of character to be exercised? Furthermore, would this search for "minimally acceptable standards" in the human genome be readily accepted by a society that is demonstrating a growing movement for disability rights?

Part Three

Toward a Biblical-Theological Approach to Genetic Engineering: Widely-Held Positions on Genetic Engineering and a Christian Response

Though many objections to a conservative approach toward genetic engineering have been advanced, only a few are encountered with significant regularity. They are as follows:

1. The Impediment to Scientific Progress

Proponents of a more radical application of genetic engineering techniques (including cloning and gene splicing), suggest that to halt the full application of these discoveries will retard scientific progress.

However, a Biblical-Theological approach differs from this line of reasoning. First, just because something is changing, does not mean that it involves progress. A morality that is based upon God's word is certain and not open for supposed "improvements." The flag of "scientific progress" may be flown in an effort to justify most anything. However, the claims of Scripture result in certain moral imperatives that do not change.

For example, the Hebrew term *nephesh* is most broadly defined as "breath" and is used to convey the sense of life or soul that God breathed into man, thereby giving humans unparalleled worth and precious value (e.g., II Kgs 1:13; I Sam 26:21). In contrast to the humanistic approach toward genetic engineering which can alter morality along with genetic substrates, a Christian approach recognizes the surety of God's intervention in the unique creation of man providing him with both dignity and unfaltering moral responsibility.

2. The Lack of Compassion for the Suffering

The proponents of a more radical application of genetic engineering might also suggest that the failure to employ the advancements to alleviate human suffering is cruel, discompassionate, and uncaring. If Christians truly cared for the suffering of others, they would not want those who could be identified through genetic screening/testing to be afflicted with genetic abnormalities to enter the world only to suffer.

However, a Biblical-Theological approach differs from this understanding in several important ways. First, good ends do not justify the evil means. While the Christian should be genuinely concerned with the suffering and misery of others, such cannot be accomplished through acts that disregard the dignity, sanctity and responsibility

that belongs to man as a result of being made in His Creator's image. Whereas the humanistic standard of good is based upon a utilitarian model, a Biblical-Theological ethic is one that is filtered through the grid of Scriptural mandate, the awareness of realities that will limit reasonable choices, and the motivation to love the one concerning whom decisions are being made.

The standard of a quality of life is not predicated upon the absence of suffering, but on the value which is derived from being a person in God's image. In this respect, a consideration of the Greek term, *zoe* (life) is informative. A comparison of Luke 12:15 and Mark 9:43 suggests that the quality of life is not to be found in the physical or material conditions of this world, but in the recognition that the *zoe* is to be found in one's relationship with Christ. The compassion that Jesus demonstrated for the weak and marginalized members of His culture should be our call, as well. God's desire is to have fellowship with those whom he has given *zoe*. Our medical practices should attempt to serve His creation in order that they may know His joy. We are to be custodians, not engineers, of life.

3. The Rule of Autonomy

Those who would advocate the more aggressive applications of genetic engineering may advance the notion that an external moral imperative should not be imposed upon their will. It is his or her life and, therefore, he or she should be able to make their own decisions concerning what is right for them. A practical area in which this might be asserted is in the gender selection of offspring. It may be argued that would-be parents have the right to choose the sex of their child.

However, a Biblical-Theological perspective recognizes the existence of certain moral imperatives concerning human life. The secularist is claiming a morality of choice that lacks a bases for its applicability. If an individual's will is sufficient for moral decisions, upon what basis is the humanist able to contend that it is their own will that is sufficient for this purpose? Why is not the objecting person's will with respect to another's choice sufficient to make the alternative choice equally, if not supremely, moral? It would appear that the humanist has erected a standard of morality based upon their own autonomy and without objective justification. As Geisler writes: "He has a moral prescription without a moral Prescriber."

Furthermore, the Scripture record is not at all clear that parents (or anyone else for that matter) has a *right* to choose the sex selection of their own children. Scripture *is* clear when it asserts that children are a gift from God (Ps 127:3). As Feinberg and Feinberg state, "...it seems rather strange to think of manipulating the nature of the "gift" that is given, let alone talk of having a right to do so."

Additionally, at what point along the continuum of choice and selection do we draw the line and say that we have gone too far? As Anderson argues, "At some point on the continuum childrencease to be a gift from God (cf. Ps 127:3) and begin to be a parental plaything."

Such a caution calls for wisdom and discernment, for the exact point along the continuum at which the line is drawn is not always clear. Nonetheless, at some point what is lawful and permissible becomes unprofitable and lacking in the ability to edify.

Finally, the *method* in which genetic interventions are employed carries with it serious moral and ethical implications. If sex selection were based post-conception, to employ genetic intervention strategies it would constitute infanticide or abortion. Likewise, to apply genetic engineering techniques *in vitro* and then discard unused or unwanted fertilized ovum would violate the doctrine of the sanctity of human life and death.

A Biblical-Theological approach toward genetic engineering, however, would not allow us to adopt this position. Ezekiel reminds us that God takes no pleasure in death (Hebrew word *mawet*), because it was His intent that we should live (Ez 18: 32). Genesis 3:3 also employs the same Hebrew word in God's instruction that death was not His original intent, but rather *hayyim*, or "life." But death was as a result of sin. Therefore, to employ genetic engineering techniques in an effort to bring about intentional, unjustifiable death, is contrary to God's intention and serves to underscore the reason for why and how death entered the human race; namely, sin.

Summary and Conclusion

Biomedical issues are replete with serious moral and ethical implications. The tension that exists appears to be at the point of interface between two competing world views -secular humanism, and Biblical Christianity. Having denied the existence of a God who has established order in His creation, there is a failure to recognize any imperative for moral or ethical conduct that would naturally derive from such an acknowledgment. Accordingly, the humanist is left with the assertion of moral imperatives that are based upon one of two key ways of thinking - utilitarian, and autonomous.

From the utilitarian perspective, the operative principle is to do that which will effect the greatest good for the greatest number of people. However, this fails to consider how the rights of the individual can be taken into account when making decisions, and renders questions about truth, morality, and justice to little more than a majority vote of those involved in deciding the question. The rule of autonomy is fraught with its own difficulties, as it fails to consider the need for balance between perceived "rights" and moral responsibilities. Furthermore, it is rarely the case that one's assertion of their perceived "rights" is done so without some consequence to others. Under such a rubric, where would one's "rights" leave off and the other's pick up? Such is wholly unsatisfactory and does not decide the question.

In contrast, a Biblical-Theological approach informs the ethical decision-making process by affirming that God specially created humans in His own likeness and, as such, moral imperatives for the preservation of the dignity and sanctity of life are derived. However, the Biblical-Theological approach also recognizes that reality will place necessary limitations on what can and should be done in a given situation and that Scripture does not provide a ready answer to every question. Hence, there is the need for both wisdom and love in the decision- making process. And whereas there may not be a right or wrong answer for a given question, there is a right and wrong way of approaching the questions that we face. Where God's Word is silent, we acknowledge the limitation which reality imposes and seek to do that which is most loving. Above all else, we should seek to do no harm. With these things in mind, may we heed the words of Geisler:

"Hence, the Christian obligation is to serve God, not play God. We are not the engineers of life, but merely its custodians. Medical intervention, therefore, should be corrective, not creative. We should repair life, not attempt to reconstruct it. Technology must serve morality, not the reverse."

(References given in the text, other references by the author.)

About the author: ***R. W. Evans, Ph.D.*** is a Licensed Clinical Psychologist and is currently completing his second Ph.D. in Systematic Theology at Trinity Evangelical Divinity School, Trinity International University. He has been awarded a Diplomate in Neuropsychology, a Diplomate in Medical Psychology, a Diplomate in Forensic Psychology, and a Diplomate in Forensic Medicine. He has also been elected a Fellow of the American College of Forensic Psychology, A Fellow of the American Board of Medical Psychology, and a Life Fellow of the American Board of Forensic Examiners. He is presently a Resident Graduate in Moral Philosophy and Ethics at Harvard University.

Address for correspondence: Dr. R. W. Evans, PhD., Post Office Box 7276, Libertyville, Illinois, 60048 U. S. A.
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LISTY REDAKCII

LETTERS TO THE EDITOR

ZAMYŠLENÍ NAD LÉKAŘSKOU ETIKOU V POSTMODERNÍ DOBĚ

Tomáš Lajkep

Oddělení lékařské etiky Lékařské fakulty Masarykovy University, Brno, Česká republika

Vážená redakce,

lékařská etika jako samostatný obor se vyvíjí ve Spojených státech od šedesátých let. U nás jsou její začátky mnohem pozdější, v podstatě těsně navazují na události roku 1989. Z dřívějších dob si většina z nás pamatuje na přednášky z marxistické etiky. Víme většinou, že byly, ale málokdo si vzpomene na jejich obsah. Stejně tak, jako pociťujeme jistý dluh vůči technické vyspělosti našich západních sousedů, pociťujeme i určitý nedostatek v etickém přístupu našich lékařů. Mnozí lékaři, si velmi často ani nechtějí přiznat, že v jejich oborech vůbec etické problémy existují, a to dokonce velmi závažné problémy. Zdá se jim, že dříve byla situace mnohem jednodušší a mnohdy se cítí nepříjemně dotčeni diskusemi o etice a připadá jim podivné, když se pacienti domáhají svých práv.

Na druhé straně však - když se podíváme na medicínskou praxi svých západních sousedů a na teoretická východiska současné bioetiky, můžeme se cítit poněkud rozpačitě i my. V Holandsku s klidem pokračují v eutanaziích, ve Spojených státech Dr. Kevorkian úspěšně asistuje u suicidií trpících pacientů. Ještě podivnější nám připadne skutečnost, že takové - z našeho zorného úhlu jednoznačně neetické počínání, není v příkrém rozporu s bioetickými fundamenty, které bioetika zatím definovala. I když tedy v tomto oboru máme zpoždění, zdravý rozum nám velí kriticky zkoumat a ne v oddaném údivu přebírat všechno, co nám západ k víře předkládá.

Hledání bioetických základů totiž probíhalo typicky americkým způsobem. Jako ideál byl vytyčen všeobecně přijatelný konsensus. Zpočátku však probíhala diskuse o roli lékaře a pacienta v terapeutickém procesu. To byly skutečně počátky bioetiky. Tuto vědu povolala k existenci sama nutnost. Paternalistický přístup přestal být únosný, technický pokrok pouze nastolil nové problémy, ale nepřispěl k jejich řešení. Nehledal se nějaký sjednocující výchozí moment, hledalo se už sjednocující konečné řešení praktických problémů. Tím však, že nebyly systematicky zkoumány základy etických rozhodnutí, bylo nesmírně těžké nalézt i konkrétní řešení stále nových situací, nehledě na to, že řada problémů - vlivem medicinizace, překračovala obor medicíny. I prostá shoda byla stále obtížnějším problémem. Z toho důvodu vytyčili Beauchamp a Childress alespoň čtyři základní body lékařské péče - *dobřečinění, neškodění, rovnoprávnost, autonomie*. Tyto body se staly jakýmsi základem bioetiky.

Autonomie v bioetice zahrnuje pacientovo právo na vlastní rozhodnutí. Zahrnuje právo svobodně jednat, právo svobodné úvahy a volby. Zahrnuje morální a legální principy s ohledem na osobnost a informovaný souhlas.

Dobřečinění: tento princip zahrnuje povinnost předcházet a zabránit poškození a povinnost zabezpečit dobro pro jiného. V bioetice se tím míní povinnost profesionální péče a hledání všeho dobrého pro pacienta.

Nonmaleficence - doslova tedy nečinění zla. Princip nonmaleficence zakazuje poškození, bezpráví a smrt druhých lidí a podporuje specifické morální směrnice, jako je zákaz zabití. Odvíjí se od maximy - *primum non nocere*, což je všeobecná zásada profesionální zdravotní péče. Povinnost nepůsobit zlo je mnohem striktněji daná, než povinnost působit dobro a je také morálním limitem autonomie.

Rovnoprávnost: teorie rovnoprávnosti zabezpečuje především spravedlivé rozdělení lékařské péče všem pacientům.

Tyto základy jsou ovšem velice sporné. První otázka, která se nabízí je "*proč?*" Proč zrovna tyto zásady a ne jiné. Z jakého důvodu je činěn pokus o jejich hierarchické sjednocení? Odpověď není jednoduchá a často v ní zaznívá odvolání se na jejich všeobecnou přijatelnost. Tím se ovšem etika ocitá v oblasti práva, takže s ním nakonec splývá. Právo je totiž dáno všeobecným konsensem. Pokud bude bioetika takto chápána, nenapadají mě jiné vyhlídky než ty chmurné. Víme, jak snadno lze manipulovat lidmi v zájmu ideologií, případně v zájmu trhu. Etika však, když už je obsažena ve slovu bioetika - musí z povahy předmětu svého zájmu usilovat o **ideál**, případně mít tento ideál na zřeteli. Teprve sledováním ideálu se ocitáme na poli etiky, a to jakékoli etiky. Odpovědi na otázky "*co?*" a "*jak?*" a "*proč?*" mám dělat se různí a podle toho můžeme mluvit o různých etických pojetích a směrech. Vzhledem k danému tematu se zaměřím na etiku postmoderní doby.

Postmoderní pojetí

Je dobré nejprve přiblížit **základní myšlenky postmodernismu**, protože tento myšlenkový směr má řadu inspirujících postřehů. Co je to postmoderní doba? To je doba ve které žijeme, je to historická změna způsobu života, jakou dnes prožíváme. S těmito změnami se setkáme ve vědě, v umění a v literatuře.

Postmoderní teorie vychází ze **strukturalismu**. Strukturalisté říkají, že smysluplné myšlení umožňuje *struktura jazyka*. Rozlišují mezi *signifikátem* - předmětem pojmu a mezi *signifikantem* - pojmem, označujícím slovem. V okamžiku, kdy se k sobě pojí signifikát a signifikant vzniká *znak*, který mimo tento proces nemá žádný smysl. Náš *jazyk* je znakový systém, který funguje především na základě operačního kódu binárních protikladů plus a mínus. S tímto poznáním je spjat rozvoj počítačů. Důležité ovšem je, že *význam* netkví ve znacích, ale vyplývá ze vztahů mezi znaky. Struktury významů zahrnují a implikují všechny svoje pozorovatele. Pozorovat znamená nechat na sebe působit, ale také působit na jiné. Vědecká nestranost je tedy nesmysl.

Zjednodušeně řečeno jakýkoli objev má význam jen proto, že k němu máme nějaký vztah. Význam objevu netkví v něm samotném, ale v našem vztahu k němu. Vůbec tedy není samozřejmé, že by hromadění objevů mělo vést k lepšímu životu. Naopak, zde vznikají konfliktní vztahy a dovolávat se objektivity objektů není vůbec k ničemu. Množství vztahových možností je téměř nekonečné, takže relativní je i identita vztahových objektů, protože není nikdy úplná. Je to v korelaci s Godelovou teorií o nedokazatelnosti bezrozpornosti i s Tarského větou o nedefinovatelnosti pravdy. Nikdy totiž neexistuje jen jeden význam.

Věřící člověk tomu může rozumět například takto: Bůh je pro mne úplně zbytečný pojem, pokud k němu nemám vztah. Samotný vztah k Bohu je tedy tím určujícím, a ne idea Boha. Pokud k Bohu nemám vztah, je pro mne jeho existence srovnatelná třeba s existencí planety Pluto. Postmodernismus se brání jednoduchému, universálnímu a hlavně dogmaticky jedinému kódování významu znaku. Neobrací se výhradně jen proti náboženství, ale také proti diktátu vědy. Podle Foucolta je vědění jen systémem myšlení, který získal moc, a je k jiným systémům stejně tak nepřátelský, jako náboženství. Vezměme si třeba *antropometrii*, která se zabývala měřením fysiologických parametrů, aby odhalila zločinecké subtypy. Známe i *eugeniku* - vědu o rasovém zdokonalování. To, co je vědecké, nemusí být nestranné.

Mezi lidmi stále panuje představa, že by **věda** měla vést k nějakému osvobození lidstva od jeho útrap, že věda představuje vrchol lidského úsilí. A přesto vědoucí člověk dneška by měl být především zdatný obchodník. Starý způsob, podle kterého osvojování **vědění** nelze oddělit od výchovy ducha, je zastaralý. Vztah, který mají k vědění jeho dodavatelé a uživatelé má formu vztahu mezi zbožím výrobců a spotřebitelů. Vědění je produkováno, aby bylo prodáváno, je konzumováno, aby bylo zhodnoceno v další

reprodukci. Z tohoto zorného úhlu je jedno, co je zkoumáno. Důležité je, jak tento proces může být využit a prodán. Vědecké úsilí se odtrhuje od reality, pouze finance jsou hyperreálné.

Co máme dnes v našem poznání k dispozici: **Novou informační technologii**. Počítačový svět mění i naše myšlení. Hledáme vysvětlující koncept všeho dění - to je podstatou tzv. **teorie všeho**. Na základě této teorie pochopíme podstatu manželských konfliktů, podstaty života, i třeba proč krachují burzy a psychologii pravěkých zvířat. Virtuální realita doplňuje tento svět o nové zážitky a opět zdůrazňuje odtržení od reality.

Projekt Human Genome. Na základě výsledků tohoto projektu budem vědět vše o genetické struktuře člověka. Budem znát nejen genetické lokalizace mnohých nemocí ale i místa, která jsou pro člověka nejzranitelnější. Kdo ví, o co bude mezi zákazníky větší zájem...

Přestože **postmoderní myšlení** vidí současnost kriticky, nemá často ani zdání o svém podílu na situaci, kterou tak koncizně postřehuje. Zdroj všeho zla vidí v *logocentrismu*, objektovém racionálním zaměření bez názorových alternativ, ale nechce chápat, že právě toto zaměření je skrytým zdrojem všech dosavadních kultur. Proč by ale pluralita měla být jediným legitimním vztahem k objektům? Zde je ve vší tichosti postulováno objektivní stanovisko, takže postmodernismus není popřením kultury, ale spíše svébytnou interpretací, kterou můžeme zkoumat jako kteroukoli jinou. **Postmoderní morálka** - ve které vše existující je skrytým zdrojem legitimity, v nás naopak vyvolává obavy z důsledků této teorie.

Vraťme se ale k našim problémům **lékařské etiky**. Z řečeného vyplývá, že v dnešní době je nesnadné mluvit o dobru pro pacienta, aniž by se nespecifikovalo, co se tím pojmem myslí a jaká je legitimita těch představ o dobru, které za jejím definováním stojí. Problém je totiž také v tom, jakou představu máme o fenoménu nemoci, smrti, jakou představu máme o smyslu utrpení, a podobně. Pokusil bych se o svůj výklad některých zásadních bioetických problémů.

Veškerá medicína sleduje za svůj cíl boj proti přirozeným stavům, které člověka oslabují, až nakonec umírá. To se nakonec týká i prevence. Zásah medicíny je zvenčí a působí proti přirozenému průběhu věcí. Otázkou zůstává, jak daleko člověk ve své snaze zabránit nepříznivému průběhu může dojít. Jsou pochopitelně stavy, kdy je to jednoznačné, ale jsou situace, kdy je to složitější - například při transplantacích, umělém oplození, interupcích, genetických manipulacích, a podobně. Těmito limity se zabývá etika a zákonitě při tom naráží na hodnotový systém akceptovaný společností a na ideál, o kterém jakousi představu každá etika má.

Kromě toho je zde ještě jeden významný fenomén, který má na myšlení lidí dnešní doby podstatný vliv, a to je **fenomén vědy**. Mezi lidmi panuje představa, že to, co je vědecké, je i mravné. Ba co víc, panuje představa, že věda sama se může vyslovit k problémům lidského štěstí. Nikde jinde nejsou tyto představy tak akcentovány, jako je tomu v medicíně. Podle těchto představ by lékaři měli bádat nad vším, co znesnadňuje a trápí lidský život, měli by experimentovat s ohledem na očekávaný efekt a vzhledem k tomu napnout všechny své síly. Lidé od rozvoje medicíny očekávají zbavení problémů, které je trápí, a medicína se tudíž zabarvuje jakýmsi mesiánským prvkem, aniž by pochopitelně mohla tomuto očekávání vyhovět. Mnozí vědci sami se domnívají, že limit jejich bádání tvoří jen technické možnosti, a vůbec se nezajímají o to, jaký etický dopad bude mít jejich objev.

Když mám se studenty seminář o počátcích života a bavíme se o možnostech **umělého oplodnění**, uvědomí si mnozí studenti, že tomu tak skutečně je. Vezměme si otázku klonování lidských buněk. Výzkum na tomto poli je podněcován zájmem zvýšit šance na umělé oplodnění. Otázka zní: "Je umělé oplodnění tou největší hodnotou, které by se měli podřídit všechny etické zásady v medicíně?" Jistě, že ne. Jakou je tedy umělé oplodnění hodnotou? Kam až můžeme ve výzkumu, který je iniciován snahou pomoci neplodným párům, dospět? A tady už se zřetelně studenti rozchází. A jejich vzájemný rozpor je vposledku určen tím, jak se dívají na život od okamžiku početí.

Naprosto zřetelně tak můžeme vidět, jak se názory na konkrétní etické řešení rozcházejí podle toho, jaký kdo má názor na život a na pravdu. Je to nakonec důsledkem toho, že etické úvahy jsou až pozdním filosofickým rezultátem. To si málokdo uvědomuje a kategoricky přednáší morální soudy, přestože o filosofii neví vůbec nic. K tomu však nutí sám život. Přestože filosofickým úvahám se člověk v životě vyhnout může, nevyhne se úvahám etickým.

Simulakrum: toto postmoderní slovo vyjadřuje odpoutání od reality, kdy je nám místo původní reality simulována jiná realita, která se tváří jako ta původní, ale nemá s ní nic společného. Ve velké Británii byly v srpnu minulého roku ve velkém likvidovány lidské zárodky vzešlé z fertilizačních programů. Na počátku byla idea, která se zdála být velkolepá - umožnit neplodným párům početí. Z ideí o životě se stala skutečnost zkázy. Cožpak ale šlo těm, kdo iniciovali a podporovali výzkum o umělém oplodnění o tento fakt? Nikdy ne, to jen lékaři jsou naivní a jsou schopni bojovat o věc, kterou považují za dobrou. Těm, kdo iniciují a udržují tento výzkum, jde ve skutečnosti o peníze. Pokud bude pracoviště zkoumající umělé oplození prosperovat, prodáte ho na finančním trhu stejně tak dobře, jako fungující továrnu. Bude burzovní společnosti zajímat "co" se prodává a co se kupuje?

Z řečeného je jasné, že boj za etické ideály není snadný. Na jedné straně zde působí mediální vnucování a zásady svobodného trhu a spolu s tím neustále se prohlubující vzdálenost mezi etickým ideálem a právním stavem. Na druhé straně jsou zde však požadavky lidské přirozenosti, které nelze ignorovat. Vycházet z těchto požadavků je důležité pro výuku lékařské etiky a objevovat fundamenty esenciality je nutností pro filosofické zarámování bioetiky.

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Souhrn

Autor se zabývá lékařskou etikou z hlediska doby, která tvrdí, že pluralita názorů je základem současného myšlení. Sám se domnívá, že zkoumání esenciality je pro další vývoj bioetiky nutností. *Klíčová slova: lékařská etika, principy bioetiky, postmodernismus.*

Abstract

Author reflects on some pricipal ideas and notions of the postmodern position and their considerable influence on contemporary bioethics. He holds, that the inquiry into the very fundamental questions of contemporary thinking is necessary, rather than the mere seeking of the pluralistic consensus, for both the development of bioethics as a scientific discipline, as well as for its being able to help in solving the practical dilemas of contemporary medicine and health care. *Key words: medical ethics, principles of bioethics, postmodernism.*

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DOCUMENTS

Council of Europe

CONVENTION FOR THE PROTECTION OF HUMAN RIGHTS AND DIGNITY OF THE HUMAN BEING WITH REGARD TO THE APPLICATION OF BIOLOGY AND MEDICINE:

CONVENTION ON HUMAN RIGHTS AND BIOMEDICINE

(Adopted by the Committee of Ministers on 19 November 1996)

PREAMBLE

The member States of the Council of Europe, the other States and the European Community signatories hereto, Bearing in mind the Universal Declaration of Human Rights proclaimed by the General Assembly of the United Nations on 10 December 1948;

Bearing in mind the Convention for the Protection of Human Rights and Fundamental Freedoms of 4 November 1950;

Bearing in mind the European Social Charter of 18 October 1961;

Bearing in mind the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights of 19 December 1966;

Bearing in mind the Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data of 28 January 1981;

Bearing also in mind the Convention on the Rights of the Child of 20 November 1989;

Considering that the aim of the Council of Europe is the achievement of a greater unity between its members and that one of the methods by which that aim is to be pursued is the maintenance and further realisation of human rights and fundamental freedoms;

Conscious of the accelerating developments in biology and medicine;

Convinced of the need to respect the human being both as an individual and as a member of the human species and recognising the importance of ensuring the dignity of the human being;

Conscious that the misuse of biology and medicine may lead to acts endangering human dignity;

Affirming that progress in biology and medicine should be used for the benefit of present and future generations;

Stressing the need for international co-operation so that all humanity may enjoy the benefits of biology and medicine;

Recognising the importance of promoting a public debate on the questions posed by the application of biology and medicine and the responses to be given thereto;

Wishing to remind all members of society of their rights and responsibilities;

Taking account of the work of the Parliamentary Assembly in this field, including Recommendation 1160 (1991) on the preparation of a Convention on bioethics;

Resolving to take such measures as are necessary to safeguard human dignity and the fundamental rights and freedoms of the individual with regard to the application of biology and medicine;

Have agreed as follows:

CHAPTER I
General provisions

Article 1. (Purpose and object)

Parties to this Convention shall protect the dignity and identity of all human beings and guarantee everyone, without discrimination, respect for their integrity and other rights and fundamental freedoms with regard to the application of biology and medicine.

Each Party shall take in its internal law the necessary measures to give effect to the provisions of this Convention.

Article 2. (Primacy of the human being)

The interests and welfare of the human being shall prevail over the sole interest of society or science.

Article 3. (Equitable access to health care)

Parties taking into account health needs and available resources, shall take appropriate measures with a view to providing, within their jurisdiction, equitable access to health care of appropriate quality.

Article 4. (Professional standards)

Any intervention in the health field, including research, must be carried out in accordance with relevant professional obligations and standards.

CHAPTER II
Consent

Article 5. (General rule)

An intervention in the health field may only be carried out after the person concerned has given free and informed consent to it.

This person shall beforehand be given appropriate information as to the purpose and nature of the intervention as well as on its consequences and risks.

The person concerned may freely withdraw consent at any time.

Article 6. (Protection of persons not able to consent)

1. Subject to Articles 17 and 20 below, an intervention may only be carried out on a person who does not have the capacity to consent,
for his or her direct benefit.

2. Where, according to law, a minor does not have the capacity to consent to an intervention, the intervention may only be carried out with the authorisation of his or her representative or an authority or a person or body provided for by law.

The opinion of the minor shall be taken into consideration as an increasingly determining factor in proportion to his or her age and degree of maturity.

3. Where, according to law, an adult does not have the capacity to consent to an intervention because of a mental disability, a disesase or for similar reasons, the intervention may only be carried out with the authorisation of his or her representative or an authority or a person or body provided for by law.

The individual concerned shall as far as possible take part in the authorisation procedure.

4. The representative, the authority, the person or the body mentioned in paragraphs 2 and 3 above shall be given, under the same conditions, the information referred to in Article 5.

5. The authorisation referred to in paragraphs 2 and 3 above may be withdrawn at any time in the best interests of the person concerned.

Article 7. (Protection of persons who have mental disorder)

Subject to protective conditions prescribed by law, including supervisory, control and appeal procedures, a person who has a mental disorder of a serious nature may be subjected, without his or her consent, to an inter-

vention aimed at treating his or her mental disorder only where, without such treatment, serious harm is likely to result to his or her health.

Article 8. (Emergency situation)
When because of an emergency situation the appropriate consent cannot be obtained, any medically necessary intervention may be carried out immediately for the benefit of the health of the individual concerned.

Atricle 9. (Previously expressed wishes)
The previously expressed wishes relating to a medical intervention by a patient who is not, at the time of the intervention, in a state to express his or her wishes shall be taken into account.

CHAPTER III
Private life and right to information

Article 10. (Private life and right to information)
1. Everyone has the right to respect for private life in relation to information about his or her health.
2. Everyone is entitled to know any information collected about his or her health. However, the wishes of individuals not to be so informed shall be observed.
3. In exceptional cases, restrictions may be placed by law on the exercise of the rights contained in paragraph 2 in the interests of the patient.

CHAPTER IV
Human genome

Article 11. (Non-discrimination)
Any form of discrimination against a person on grounds of his or her genetic heritage is prohibited.

Article 12. (Predictive genetic tests)
Tests which are predictive of genetic diseases or which serve either to identify the subject as a carrier of a gene responsible for a disease or to detect a genetic predisposition or susceptibility to a disease may be performed only for health purposes or for scientific research linked to health purposes, and subject to appropriate genetic counselling.

Article 13. (Interventions on the human genome)
An intervention seeking to modify the human genome may only be undertaken for preventive, diagnostic or therapeutic purposes and only if its aim is not to introduce any modification in the genome of any descendants.

Article 14. (Non-selection of sex)
The use of techniques of medically assisted procreation shall not be allowed for the purpose of choosing a future child's sex, except where serious hereditary sex-related disease is to be avoided.

CHAPTER V
Scientific research

Article 15. (General rule)
Scientific research in the field of biology and medicine shall be carried out freely, subject to the provisions of this Convention and the other legal provisions ensuring the protection of the human being.

Article 16. (Protection of persons undergoing research)
Research on a person may only be undertaken if all the following conditions are met:
i) there is no alternative of comparable effectiveness to research on humans,
ii) the risks wich may be incurred by that person are not disproportionate to the potential benefits of the research,
iii) the research project has been approved by the competent body after indepedent examination of its scientific merit, including assessment of the importance of the aim of the research, and multidisciplinary review of its ethical acceptability,
iv) the persons undergoing research have been informed of their rights and the safeguards prescribed by law for their protection,
v) the necessary consent as provided for under Article 5 has been given expressly, specifically and is documented. Such consent may be freely withdrawn at any time.

Article 17. (Protection of persons not able to consent to research)
1. Research on a person without the capacity to consent as stipulated in Article 5 may be undertaken only if all the following conditions are met:
i. the conditions laid down in Article 16, sub-paragraphs (i) to (iv), are fulfilled;
ii. the results of the research have the potential to produce real and direct benefit to his or her health;
iii. research of comparable effectiveness cannot be carried out on individuals capable of giving consent;
iv. the necessary authorisation provided for under Article 6 has been given specifically and writing, and
v. the person concerned does not object.
2. Exceptionally and under the protective conditions prescribed by law, where the research has not the potential to produce results of direct benefit to the health of the person concerned, such research may be authorised subject to the conditions laid down in paragraph 1, sub-paragraphs (i), (iii), (iv) and (v) above, and to the following additional conditions:
i. the research has the aim of contributing, through significant improvement in the scientific understanding of the individual's condition, disease or disorder, to the ultimate attainment of results capable of conferring benefit to the person concerned or to other persons in the same age category or afflicted with the same disease or disorder or having the same condition;
ii. the research entails only minimal risk and minimal burden for the individual concerned.

Article 18. (Research on embryos in vitro)
1. Where the law allows research on embryos in vitro, it shall ensure adequate protection of the embryo.
2. The creation of human embryos for research purposes is prohibited.

CHAPTER VI
Organ and tissue removal from living donors for transplantation purposes

Article 19. (General rule)
1. Removal of organs or tissue from a living person for transplantation purposes may be carried out solely for the therapeutic benefit of the recipient and where there is no suitable organ or tissue available from a deceased person and no other alternative therapeutic method of comparable effectiveness.
2. The necessary consent as provided for under Article 5 must have been given expressly and specifically either in writen form or before and official body.

Article 20. (Protection of persons not able to consent to organ removal)
1. No organ or tissue removal may be carried out on a person who does not have the capacity to consent under Article 5.
2. Exceptionally and under the protective conditions prescribed by law, the removal of regenerative tissue from a person who does not have the capacity to consent may be authorised provided the following conditions are met:
i. there is no compatible donor available who has the capacity to consent,
ii. the recipient is a brother or sister of the donor,
iii. the donation must have the potential to be life-saving for the recipient,

iv. the authorisation provided for under paragraphs 2 and 3 of Article 6 has been given specifically and in writing, in accordance with the law and with the approval of the competent body,

v. the potential donor concerned does not object.

CHAPTER VII
Prohibition of financial gain and disposal of a part of the human body

Article 21. (Prohibition of financial gain)

The human body and its parts shall not, as such, give rise to financial gain.

Article 22. (Disposal of a removed part of the human body)

When in the course of an intervention any part of a human body is removed, it may be stored and used for a purpose other than that for which it was removed, only if this is done in conformity with appropriate information and consent procedures.

CHAPTER VIII
Infringements of the provisions of the Convention

Article 23. (Infringement of the rights or principles)

The Parties shall provide appropriate judicial protection to prevent or to put a stop to an unlawful infringement of the rights and principles set forth in this Convention at short notice.

Article 24. (Compensation for undue damage)

The person who has suffered undue damage resulting from an intervention is entitled to fair compensation according to the conditions and procedures prescribed by law.

Article 25. (Sanctions)

Parties shall provide for appropriate sanctions to be applied in the event of infringement of the provisions contained in this Convention.

CHAPTER IX
Relation between this Convention and other provisions

Article 26. (Restrictions on the exercise of the rights)

1. No restrictions shall be placed on the exercise of the rights and protective provisions contained in this Convention other than such as are prescribed by law and are necessary in a democratic society in the interest of public safety, for the prevention of crime, for the protection of public health or for the protection of the rights and freedoms of others.

2. The restrictions contemplated in the preceding paragraph may not be placed on Articles 11, 13, 14, 17, 19, 20 and 21.

Article 27. (Wider protection)

None of the provisions of this Convention shall be interpreted as limiting or otherwise affecting the possibility for a Party to grant a wider measure of protection with regard to the application of biology and medicine than is stipulated in this Convention.

CHAPTER X
Public debate

Article 28. (Public debate)

Parties to this Convention shall see to it that the fundamental questions raised by the developments of biology and medicine are the subject of appropriate public discussion in the light, in particular, of relevant medical, social economic, ethical and legal implications, and that their possible application is made the subject of appropriate consultation.

CHAPTER XI
Interpretation anf follow-up of the Convention

Article 29. (Interpretation of the Convention)

The European Court of Human Rights may give, without direct reference to any specific proceedings pending in a court, advisory opinions on legal questions concerning the interpretation of the present Convention at the request of:

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

Article 30. (Reports on the application of the Convention)

On receipt of a request from the Secretary General of the Council of Europe any Party shall furnish an explanation of the manner in which its internal law ensures the effective implementation of any of the provisions of the Convention.

CHAPTER XII
Protocols

Article 31. (Protocols)

Protocols may be concluded in pursuance of Article 32, with a view to developing, in specific fields, the principles contained in this Convention.

The Protocols shall be open for signature by Signatories of the Convention. They shall be subject to ratification, acceptance or approval. A signatory may not ratify, accept or approve Protocols without previously or simultaneously ratifying, accepting or approving the Convention.

CHAPTER XIII
Amendments to the Convention

Article 32. (Amendments to the Convention)

1. The tasks assigned to "the Committee" in the present Article and in Article 29 shall be carried out by the Steering Committee on Bioethics (CDBI), or by any other committee designated to do so by the Committee of Ministers.

2. Without prejudice to the specific provisions od Article 29, each member State of the Council of Europe, as well as each Party to the present Convention which is not a member of the Council of Europe, may be represented and have one vote in the Committee when the Committee carries out the tasks assigned to it by the present Convention.

3. Any State referred to in Article 33 or invited to accede to the Convention in accordance with the provisions of Article 34 which is not Party to this Convention may be represented on the Committee by an observer. If the European Community is not a Party it may be represented on the Committee by an observer.

4. In order to monitor scientific developments, the present Convention shall be examined within the Committee no later than five years from its entry into force and thereafter at such intervals as the Committee may determine.

5. Any proposal for an amendment to this Convention, and any proposal for a Protocol or for an amendment to a Protocol, presented by a Party, the Committee or the Committee of Ministers shall be communicated to the Secretary General of the Council of Europe and forwarded by him to the member States of the Council of Europe, to the European Community, to any Signatory, to any Party, to any State invited to sign this Convention in accordance with the provisions of Article 33 and to any State invited to accede to it in accordance with the provisions of Article 34.

6. The Committee shall examine the proposal not earlier than two months after it has been forwarded by the Secretary General in accordance with paragraph 5. The

Committee shall submit the text adopted by a two-thirds majority of the votes cast to the Committee of Ministers for approval. After its approval, this text shall be forwarded to the Parties for ratification, acceptance or approval.

7. Any amendment shall enter into force, in respect of those Parties which have accepted it, on the first day of the month following the expiration of a period of one month after the date on which five Parties, including at least four member States of the Council of Europe, have informed the Secretary General that they have accepted it.

In respect of any Party which subsequently accepts it, the amendment shall enter into force on the first day of the month following the expiration of a period of one month after the date on which that Party has informed the Secretary General of its acceptance.

CHAPTER XIV
Final clauses

Article 33. (Signature, ratification and entry into force)

1. This Convention shall be open for signature by the member States of the Concil of Europe, the non-member States which have participated in its elaboration and by the European Community.

2. This Convention is subject to ratification, acceptance or approval. Instruments of ratification, acceptance or approval shall be deposited with the Secretary General of the Council of Europe.

3. This Convention shall enter into force on the first day of the month following the expiration of a period of three months after the date on which five States, including at least four member States of the Council of Europe, have expressed their consent to be bound by the Convention in accordance with the provisions of paragraph 2 of the present Article.

4. In respect of any Signatory which subsequently expresses its consent to be bound by it, the Convention shall enter into force on the first day of the month following the expiration of a period of three months after the date of the deposit of its instrument of ratification, acceptance or approval.

Article 34. (Non-member States)

1. After the entry into force of this Convention, the Committee of Ministers of the Council of Europe may, after consultation of the Parties, invite any non-member State of the Council of Europe to accede to this Convention by a decision taken by the majority provided for in Article 20, sub-paragraph d of the Statute of the Council of Europe, and by the unanimous vote of the representatives of the Contracting States entitled to sit on the Committee of Ministers.

2. In respect of any acceding State, the Convention shall enter into force on the first day of the month following the expiration of a period of three months after the date of deposit of the instrument of accession with the Secretary General of the Council of Europe.

Article 35. (Territories)

1. Any Signatory may, at the time of signature or when depositing its instrument of ratification, acceptance or approval, specify the territory or territories to which this Convention shall apply. Any other State may formulate the same declaration when depositing its instrument of accession.

2. Any Party may, at any later date, by a declaration addressed to the Secretary General of the Council of Europe, extend the application of this Convention to any other territory specified in the declaration and for whose international relations it is responsible or on whose behalf it is authorised to give undertakings. In respect of such territory the Convention shall enter into force on the first day of the month following the expiration of a period of three months after the date of receipt of such declaration by the Secretary General.

3. Any declaration made under the two preceding paragraphs may, in respect of any territory specified in such declaration, be withdrawn by a notification addressed to the Secretary General. The withdrawal shall become effective on the first day of the month following the expiration of a period of three months after the date of receipt of such notification by the Secretary General.

Article 36. (Reservations)

1. Any State and the European Community may, when signing this Convention or when depositing the instrument of ratification, make a reservation in respect of any particular provision of the Convention to the extent that any law then in force in its territory is not in conformity with the provision. Reservations of a general character shall not be permitted under this article.

2. Any reservation made under this article shall contain a brief statement of the relevant law.

3. Any Party which extends the application of this Convention to a territory mentioned in the declaration referred to in Article 32, paragraph 2, may, in respect of the territory concerned, make a reservation in accordance with the provisions of the preceding paragraphs.

4. Any Party which has made the reservation mentioned in this Article may withdraw it by means of a declaration addressed to the Secretary General of the Council of Europe. The withdrawal shall become effective on the first day of the month following the expiration of a period of one month after the date of its receipt by the Secretary General.

Article 37. (Denunciation)

1. Any Party may at any time denounce this Convention by means of notification addressed to the Secretary General of the Council of Europe.

2. Such denunciation shall become effective on the first day of the month following the expiration of a period of three months after the date of receipt of the notification by the Secretary General.

Article 38. (Notifications)

The Secretary General of the Council of Europe shall notify the member States of the Council, the European Community, any Signatory, any Party and any other State which has been invited to accede to this Convention of:

a. any signature;

b. the deposit of any instrument of ratification, acceptance, approval or accession;

c. any date of entry into force of this Convention in accordance with Articles 33 or 34;

d. any amendment of Protocol adopted in accordance with Article 32, and the date on which such an amendment or Protocol enters into force;

e. any declaration made under the provisions of Article 35;

f. any reservation and withdrawal of reservation made in pursuance of the provisions of Article 36;

g. any other act, notification or communication relating to this Convention.

In witness whereof the undersigned, being duly authorised thereto, have signed this Convention.

Done at ....., the .....(*) in English and French, both texts being equally authentic, in a single copy which shall be deposited in the archives of the Council of Europe. The Secretary General of the Council of Europe shall transmit certified copies to each member State of the Cuoncil of Europe, to the European Community, to the non-member States which have participated in the elaboration of this Convention, and to any State invited to accede to this Convention.

(*) The date of the opening of this Convention for signature will be fixed later on by the Committee of Ministers.

Rada Európy

KONVENCIA NA OCHRANU ĽUDSKÝCH PRÁV A DÔSTOJNOSTI ČLOVEKA V SÚVISLOSTI S APLIKÁCIOU BIOLÓGIE A MEDICÍNY: KONVENCIA O ĽUDSKÝCH PRÁVACH A BIOMEDICÍNE

(Prijatá Radou ministrov 19. novembra 1996)

PREAMBULA

Členské štáty Rady Európy, ostatné štáty a Európske spoločenstvo ako signatári Konvencie,

- berúc do úvahy Všeobecnú deklaráciu ľudských práv, vyhlásenú Valným zhromaždením Spojených národov 1O. decembra 1948;
- berúc do úvahy Konvenciu na ochranu ľudských práv a základných slobôd zo dňa 4. novembra 1950;
- berúc do úvahy Európsku sociálnu chartu zo dňa 18. októbra 1961;
- berúc do úvahy Medzinárodnú konvenciu o občianskych a politických právach zo dňa 16. decembra 1966;
- berúc do úvahy Konvenciu na ochranu osobnosti pri počítačovom spracovaní osobných údajov zo dňa 28. januára 1981;
- berúc do úvahy aj Konvenciu o právach dieťaťa zo dňa 20. novembra 1989;
- sú si vedomí, že cieľom Rady Európy je väčšia jednota medzi členskými štátmi a jednou z metód na dosiahnutie tohto cieľa je dodržiavanie a ďalšie uplatňovanie ľudských práv a základných slobôd;
- uvedomujú si rastúci rozvoj biológie a medicíny;
- sú presvedčení o nutnosti rešpektovať človeka ako jednotlivca i ako príslušníka ľudského rodu a uznávajú dôležitosť záruky rešpektovania dôstojnosti človeka;
- sú si vedomí toho, že zneužitie biológie a medicíny môže viesť k aktom, ohrozujúcim ľudskú dôstojnosť;
- sú presvedčení, že pokrok v biológii a medicíne by sa mal využívať pre prospech súčasných a budúcich generácií;
- podčiarkujú potrebu medzinárodnej spolupráce, aby biológia a medicína slúžili pre dobro všetkých ľudí;
- uznávajú význam verejnej debaty o otázkach, súvisiacich s aplikáciou biológie a medicíny, a odpovediach na ne;
- chceli by všetkým členom spoločnosti pripomenúť ich práva a povinnosti;
- berúc do úvahy prácu Parlamentného zhromaždenia, včítane Odporúčania 1160 (1991) k príprave o Konvencii o bioetike;
- rozhodli sa urobiť potrebné opatrenia na ochranu dôstojnosti človeka a základných práv jednotlivca v súvislosti s aplikáciou biológie a medicíny;

preto súhlasia s nasledovným:

KAPITOLA I.
Všeobecné opatrenia

Článok 1. (Návrh a cieľ)

Zmluvné strany budú chrániť dôstojnosť a identitu všetkých ľudí v súvislosti s aplikáciou biológie a medicíny a zaručia každému bez diskriminácie rešpektovanie jeho integrity, ostatných práv a základných slobôd.

Každá zmluvná strana urobí v rámci svojich vnútorných zákonov opatrenia, potrebné pre realizáciu článkov tejto Konvencie.

Článok 2. (Priorita ľudskej bytosti)

Záujmy a blaho človeka musia mať prednosť pred púhym záujmom vedy a spoločnosti.

Článok 3. (Spravodlivý prístup k starostlivosti o zdravie)

Zmluvné strany urobia v rámci svojej jurisdikcie vhodné opatrenia na zabezpečenie spravodlivého prístupu k starostlivosti o zdravie, pričom sa bude brať do úvahy tak potreba zdravotníckej starostlivosti, ako aj dostupné zdroje.

Článok 4. (Profesionálna úroveň)

Každý zásah do sféry zdravia, vrátane výskumu, sa musí robiť v súlade s príslušnými profesionálnymi záväzkami a odbornou úrovňou.

KAPITOLA II.
Súhlas

Článok 5. (Všeobecné pravidlá)

Žiadny zásah do sféry zdravia sa nesmie urobiť bez toho, aby osoba, ktorej sa týka, neprejavila k tomu slobodný a informovaný súhlas.

Predtým musí byť daná osoba primerane informovaná o účele a povahe zásahu, ako aj o jeho následkoch a rizikách.

Príslušná osoba môže kedykoľvek slobodne svoj súhlas zrušiť.

Článok 6. (Ochrana osôb, ktoré nie sú schopné vyjadriť súhlas)

1. Vzhľadom k Článkom 16. a 19. sa stanovuje, že zákrok u osoby, ktorá nie je schopná vyjadriť súhlas, sa vykoná jedine, ak ide o jej priamy prospech.

2. U maloletých, ktorí podľa zákona nie sú schopní vyjadriť súhlas, sa môže zákrok uskutočniť jedine so súhlasom ich zákonného zástupcu.
Názor maloletých treba úmerne k ich veku a stupňu zrelosti brať vo zvyšujúcej sa miere do úvahy.

3. Keď dospelá osoba v zmysle zákona nie je schopná vyjadriť súhlas, zákrok sa môže vykonať len so súhlasom jej zákonného zástupcu.
Daná osoba, nakoľko to je len možné, sa zúčastní na schvaľovacom procese.

4. Právny zástupca, uvedený v odsekoch 2. a 3., obdrží za rovnakých podmienok informácie uvedené v článku 5.

5. Schválenie, uvedené v odsekoch 2. a 3., môže byť kedykoľvek zrušené, ak je to v záujme danej osoby.

Článok 7. (Ochrana osôb s duševnou poruchou)

Podľa podmienok daných zákonom, ktoré zahŕňajú zákonný dohľad, kontrolné a opravné mechanizmy, môže byť osoba s ťažkou duševnou poruchou podrobená zákroku, zameranému na liečbu jej duševnej poruchy, bez svojho súhlasu len vtedy, ak by bez takejto liečby bola vystavená vážnemu poškodeniu zdravia.

Článok 8. (Naliehavé situácie)

Ak v dôsledku naliehavej situácie nie je možné získať zodpovedajúci súhlas, možno medicínsky potrebný zákrok v záujme zdravia danej osoby uskutočniť neodkladne.

Článok 9. (Predtým vyjadrené prianie)

U pacienta, ktorý je v čase vykonania zákroku v takom stave, že nemôže vyjadriť svoje prianie, treba prihliadať k prianiu, ktoré vyjadril ohľadom vykonania tohto zákroku predtým.

KAPITOLA III.
Súkromný život a právo na informácie

Článok 10. (Súkromný život a právo na informácie)

1. Každý má právo, aby sa rešpektoval jeho súkromný život vo vzťahu k informáciám o jeho zdraví.

2. Každý má právo na všetky informácie o svojom zdravotnom stave. Pokiaľ si však tieto informácie nepraje, treba to rešpektovať.

3. Vo výnimočných prípadoch môže byť právo, uvedené v odseku 2., obmedzené zákonom v záujme pacienta.

KAPITOLA IV.
Ľudský genóm

Článok 11. (Zákaz diskriminácie)

Akákoľvek forma diskriminácie osoby na základe jej genetickej vybavenosti je zakázaná.

Článok 12. (Prediktívne genetické testy)
Skríningové testy genetických chorôb, alebo také, ktoré slúžia na identifikáciu nosičov génu recesívnej choroby alebo detekciu genetickej predispozície alebo náchylnosti k chorobe, možno urobiť jedine pre zdravotné účely a vedecký výskum s nimi spojený, v rámci primeraného genetického poradenstva.

Článok 13. (Zásah do ľudského genómu)
Zásah do ľudského genómu možno vykonať len pre účely preventívne, diagnostické alebo terapeutické, a to len vtedy, ak jeho cieľom nie je zmena genómu u potomkov.

Článok 14. (Zákaz výberu pohlavia)
Použitie techník lekársky asistovanej prokreácie nebude dovolené pre účely voľby pohlavia budúceho dieťaťa, s výnimkou prípadu, kde by sa malo vyhnúť vážnemu dedičnému ochoreniu, viažúcemu sa na pohlavie.

KAPITOLA V.
Vedecký výskum

Článok 15. (Všeobecné pravidlá)
Vedecký výskum v oblasti biológie a medicíny sa má vykonávať slobodne, pokiaľ je v súlade s touto konvenciou a inými právnymi normami, zabezpečujúcimi ochranu ľudskej bytosti.

Článok 16. (Ochrana osôb, ktoré sú zaradené do výskumu)
Výskum na ľuďoch sa smie vykonať len vtedy, ak sú splnené všetky nasledujúce podmienky:
i) nie je iná porovnateľne efektívna možnosť získania poznatkov;
ii) riziká pre danú osobu nie sú v disproporcii s možným prospechom výskumu;
iii) výskumný projekt bol schválený kompetentnou nezávislou komisiou, ktorá zhodnotila cieľ výskumu, jeho vedecký prínos a multidisciplinárne posúdila jeho etickú prijateľnosť;
iv) osoby, vstupujúce do výskumu, boli informované o svojich právach a ochrane zabezpečenej zákonom;
v) potrebný informovaný súhlas podľa Článku 6. bol udelený výslovne a špecificky a je zdokumentovaný. Takýto súhlas môže byť slobodne kedykoľvek zrušený.

Článok 17. (Ochrana osôb, ktoré nie sú schopné vyjadriť súhlas s výskumom)
1. Výskum na osobe, ktorá nie je schopná vyjadriť súhlas podľa požiadaviek Článku 5., sa môže vykonať len vtedy, ak sú splnené všetky nasledovné podmienky:
i. sú splnené podmienky uvedené v Článku 16., pod-odseky (i) až (iv);
ii. výsledky výskumu poskytujú možnosť skutočného a priameho priaznivého účinku na zdravie danej osoby;
iii. výskum s porovnateľným účinnosťou nemožno vykonať na osobách, ktoré sú schopné dať súhlas;
iv. potrebné schválenie podľa Článku 6. bolo udelené špecificky a písomne;
v. daná osoba nemá námietky.
2. Výnimočne a za ochranných opatrení predpísaných zákonom, sa môže schváliť výskum, ktorého výsledky neposkytujú možnosť priameho priaznivého účinku na zdravie danej osoby, ak sú splnené podmienky uvedené vyššie v odseku 1, pod-odseky i., iii., iv. a v., ako aj nasledovné prídatné podmienky:
i. cieľom výskumu je výrazným zlepšením vedeckého pochopenia stavu, choroby alebo poruchy jedinca prispieť ku konečnému dosiahnutiu výsledkov, ktoré by mali priaznivý vplyv na zdravie danej osoby alebo iných osôb rovnakého veku alebo postihnutých tou istou chorobou alebo poruchou;
ii. výskum je spojený len s minimálnym rizikom a minimálnou záťažou pre danú osobu.

Článok 18. (Výskum na embryách in vitro)
1. Kde zákon dovoľuje výskum na embryách in vitro, musí sa zabezpečiť primeraná ochrana embrya.
2. Vytváranie ľudských embryí pre výskumné účely je zakázaná.

KAPITOLA VI
Odber orgánov a tkanív od živých darcov pre účely transplantácie

Článok 19. (Všeobecné pravidlá)
1. Získavanie orgánov alebo tkanív od živých darcov pre účely transplantácie je možné len vtedy, ak ide o priamy terapeutický prospech príjemcu, ak nie je možné získať vhodný orgán od mŕtvych osôb a nie je známa žiadna účinná alternatívna liečebná metóda.
2. Nevyhnutný súhlas podľa požiadaviek Článku 5., musí byť udelený výslovne a špecificky, a to v písomnej forme alebo pred zodpovedným orgánom.

Článok 20. (Ochrana osôb, ktoré nie sú schopné vyjadriť súhlas s odberom orgánov)
1. Žiaden orgán ani tkanivo sa nemôže odobrať od osôb, ktoré nie sú schopné vyjadriť súhlas podľa Článku 5.
2. Výnimočne a za ochranných opatrení predpísaných zákonom, sa môže povoliť odobratie regeneratívneho tkaniva od osoby, ktorá nie je schopná vyjadriť svoj súhlas, ak sú splnené nasledovné podmienky:
i. nie je k dispozícii kompatibilný darca, ktorý je schopný vyjadriť súhlas;
ii. príjemca je brat alebo sestra darcu;
iii. darcovstvo môže potenciálne zachrániť život príjemcu;
iv. povolenie, ako je uvedené v odsekoch 2. a 3. Článku 6., bolo vyjadrené špecificky a písomne v súlade so zákonom a so schválením kompetentnej inštitúcie;
v. potenciálny darca nemá námietky.

KAPITOLA VII
Zákaz finančného zisku a zaobchádzanie s časťami ľudského tela

Článok 21. (Zákaz finančného zisku)
Ľudské telo a jeho časti sa nesmú, ako také, stať predmetom finančného zisku.

Článok 22. (Pokyny pre zaobchádzanie s odstránenými časťami ľudského tela)
Ak sa počas lekárskeho zákroku odoberie nejaká časť ľudského tela, smie byť uchovaná a použitá pre iný účel, ako bol ten, ktorý viedol k jej odobratiu jedine vtedy, ak je to spojené s primeranou informáciou a súhlasom.

KAPITOLA VIII
Porušenie ustanovení Konvencie

Článok 23. (Porušenie práv alebo princípov)
Zmluvné strany v čo najkratšom čase zabezpečia primeranú právnu ochranu na zabránenie alebo zastavenie nezákonného porušovania práv a princípov uvedených v tejto Konvencii.

Článok 24. (Kompenzácia neprimeraného poškodenia)
Osoba, ktorá utrpela neprimerané poškodenie ako výsledok zákroku, má nárok na spravodlivé odškodnenie podľa podmienok a postupov, predpísaných zákonom.

Článok 25. (Sankcie)
Zmluvné strany zabezpečia primerané sankcie, ktoré sa použijú pri porušení ustanovení uvedených v tejto Konvencii.

KAPITOLA IX
Vzťah medzi Konvenciou a inými opatreniami

Článok 26. (Obmedzenia uplatňovania práv)
1. Práv a ochranných opatrení obsiahnutých v tejto Konvencii sa nebudú týkať žiadne iné obmedzenia, okrem

tých, ktoré predpisuje zákon a ktoré sú potrebné v demokratickej spoločnosti v záujme verejnej bezpečnosti, pre zabránenie zločinom, pre ochranu verejného zdravia, alebo pre ochranu práv a slobôd iných osôb.

2. Obmedzenia, uvedené v predchádzajúcom odseku, sa nesmú týkať Článkov 11., 13., 14., 16., 17., 19., 20. a 21.

Článok 27. (Širšia ochrana)

Žiadne z ustanovení tejto Konvencie sa nesmie interpretovať ako limitujúce alebo ináč ovplyvňujúce možnosti zmluvnej strany prijať v súvislosti s aplikáciou biológie a medicíny ešte ďalšie ochranné opatrenia okrem tých, ktoré sú zmluvne dohodnuté v tejto Konvencii.

KAPITOLA X
Verejná diskusia

Článok 28. (Verejná diskusia)

Zmluvné strany zabezpečia, aby základné otázky súvisiace s pokrokmi v biológii a medicíne boli predmetom primeranej verejnej diskusie a to najmä z hľadiska ich lekárskeho, sociálneho, ekonomického, etického a právneho aspektu, a aby sa možné aplikácie biológie a medicíny stali predmetom primeraných konzultácií.

KAPITOLA XI
Interpretácia a sledovanie Konvencie

Článok 29. (Interpretácia Konvencie)

Európsky súd pre ľudské práva môže poskytnúť poradnú mienku k právnym otázkam, týkajúcim sa interpretácie Konvencie, bez priameho odvolania sa na špecifické postupy príslušné súdu. Urobí tak na požiadanie:

- vlády zmluvnej strany po informovaní ostatných zmluvných strán
- Výboru, ustanoveného podľa Článku 32, v ktorom je členstvo obmedzené na reprezentantov zmluvných strán tejto Konvencie, na základe rozhodnutia, ktoré bolo prijaté dvojtretinovou väčšinou hlasov.

Článok 30. (Správy o aplikácii Konvencie)

Na základe žiadosti Generálneho sekretára Rady Európy každá zmluvná strana predloží vysvetlenie o tom, akým spôsobom jej vnútorný zákon zabezpečuje efektívne uplatnenie ktoréhokoľvek z ustanovení tejto Konvencie.

KAPITOLA XII
Protokoly

Článok 31. (Protokoly)

S cieľom rozvíjať v špecifických oblastiach princípy, ktoré sú obsiahnuté v tejto Konvencii, môžu sa v súlade s Článkom 32 vypracovať protokoly.

Protokoly musia byť k dispozícii na podpis signatárom Konvencie. Musia byť predmetom ratifikácie, prijatia alebo schválenia. Signatár nemôže ratifikovať, prijať alebo schváliť protokoly bez toho, aby predtým alebo súčasne ratifikoval túto Konvenciu.

KAPITOLA XIII
Pozmeňujúce návrhy Konvencie

Článok 32. (Pozmeňujúce návrhy Konvencie)

1. Úlohy, pridelené "Výboru" v tomto článku a v Článku 29., bude vykonávať Programový výbor pre bioetiku (CDBI) alebo Rada ministrov určí pre tieto úlohy iný výbor.

2. Výbor, uvedený v predchádzajúcom odseku, tvorí vždy jedna delegácia za každú zmluvnú stranu, schválená vládou danej zmluvnej strany. Každá delegácia má jeden hlas.

3. Každý zo štátov, uvedených v Článku 33. alebo vyzvaný, aby sa v súlade s Článkom 34. pripojil ku Konvencii, hoci nie je zmluvnou stranou Konvencie, môže byť vo výbore zastúpený pozorovateľom. Ak Európske spoločenstvo nie je zmluvnou stranou, môže byť vo výbore zastúpené pozorovateľom.

4. Pre zosúladenie s vedeckým pokrokom Výbor preskúma Konvenciu najneskôr do 5 rokov po tom, čo vstúpi do platnosti a neskôr v takých intervaloch, ktoré určí.

5. Každý pozmeňovací návrh Konvencie a každý návrh či doplnok protokolu, predložený niektorou zo zmluvných strán, Výborom alebo Radou ministrov, sa musí oznámiť Generálnemu sekretárovi Rady Európy, ktorý ho poskytne členským štátom Rady Európy, Európskemu spoločenstvu, všetkým signatárom, každej zmluvnej strane a každému štátu, ktorý bol vyzvaný k podpísaniu tejto Konvencie v súlade s ustanovením Článku 33., ako aj každému štátu, vyzvanému k pripojeniu sa k tejto Konvencii, ako je uvedené v ustanoveniach Článku 34.

6. Výbor prerokuje návrh najskôr o dva mesiace po tom, ako mu bol v súlade s odsekom 5 predložený Generálnym sekretárom. Text, prijatý dvojtretinovou väčšinou odovzdaných hlasov, Výbor odovzdá na schválenie Rade ministrov. Po tomto schválení bude text predložený jednotlivým zmluvným stranám na ratifikáciu, prijatie alebo schválenie.

7. Každý pozmeňovací návrh, prijatý zmluvnými stranami, nadobúda platnosť prvým dňom mesiaca po uplynutí lehoty jedného mesiaca od dátumu, kedy päť zmluvných strán, zahŕňajúcich najmenej štyri členské štáty Rady Európy, informovalo Generálneho sekretára, že návrh prijali.

Ak niektorá zmluvná strana prijme pozmeňovací návrh neskoršie, vstúpi tento návrh do platnosti prvým dňom mesiaca, ktorý nasleduje po uplynutí lehoty jedného mesiaca od dátumu, kedy dotyčná strana informovala Generálneho sekretára o prijatí návrhu.

KAPITOLA XIV.
Záverečné ustanovenia

Článok 33. (Podpis, ratifikácia a nadobudnutie platnosti)

1. Táto Konvencia musí byť k dispozícii na podpis členským štátom Rady Európy, štátom, ktoré nie sú členmi Rady Európy, ale podieľali sa na vypracovaní Konvencie a Európskemu spoločenstvu.

2. Táto Konvencia musí byť ratifikovaná, prijatá a schválená. Ratifikačné listiny, ako i dokumenty o prijatí a schválení, budú uložené u Generálneho sekretára Rady Európy.

3. Táto Konvencia vstúpi do platnosti prvým dňom mesiaca, nasledujúceho po uplynutí trojmesačnej lehoty od dátumu, keď päť štátov, včítane najmenej štyroch členských štátov Rady Európy, vyjadrilo svoj záväzný súhlas s Konvenciou v súlade s odsekom 2. tohto článku.

4. Pre každého signatára, ktorý vyjadrí súhlas s Konvenciou neskôr, nadobudne Konvencia platnosť prvým dňom mesiaca nasledujúceho po uplynutí trojmesačnej lehoty od dátumu, kedy boli uložené jeho ratifikačné listiny a dokumenty o prijatí a schválení.

Článok 34. (Nečlenské štáty)

1. Keď Konvencia vstúpi do platnosti, môže Rada ministrov Rady Európy po konzultácii so zmluvnými stranami vyzvať ktorýkoľvek štát, ktorý nie je členom Rady Európy, aby sa k tejto Konvencii pripojil, ak toto rozhodnutie bolo prijaté väčšinou podľa Článku 20, pododstavec d Štatútu Rady Európy, a po jednohlasnom schválení zástupcami zmluvných štátov, ktoré sú oprávnené byť členmi Rady ministrov.

2. Pre každý štát, pristupujúci ku Konvencii, vstupuje Konvencia do platnosti prvým dňom mesiaca po uplynutí trojmesačnej lehoty od dátumu, kedy bol dokument o jeho pripojení sa ku Konvencii uložený u Generálneho sekretára Rady Európy.

Článok 35. (Teritóriá)

1. Každý signatár môže pri podpise Konvencie, alebo pri ukladaní ratifikačných listín, či dokumentov o prijatí alebo schválení, špecifikovať teritórium alebo teritóriá, kde bude táto Konvencia platiť. Každý ďalší štát môže učiniť rovnaké prehlásenie pri ukladaní listín o pripojení sa ku Konvencii.

2. Prehlásením, adresovanom Generálnemu sekretárovi Rady Európy, môže každá zmluvná strana kedykoľvek

neskôr rozšíriť platnosť tejto Konvencie na ktorékoľvek iné teritórium, za ktorého medzinárodné vzťahy zodpovedá, alebo je v jeho zastúpení oprávnená prijímať záväzky. Na tomto teritóriu vstupuje Konvencia do platnosti prvým dňom mesiaca po uplynutí trojmesačnej lehoty od dátumu, kedy zmienené prehlásenie prijal Generálny sekretár.

3. Každé prehlásenie, uvedené v niektorom z predchádzajúcich dvoch odsekov a týkajúce sa ktoréhokoľvek územia špecifikovaného v danom prehlásení, sa môže zrušiť oznámením Generálnemu sekretárovi. Odvolanie prehlásenia nadobúda platnosť prvým dňom mesiaca po uplynutí trojmesačnej lehoty od dátumu, kedy odvolanie obdržal Generálny sekretár.

Článok 36. (Výhrady)

1. Každý štát a Európske spoločenstvo môžu pri podpise tejto Konvencie alebo pri ukladaní ratifikačných listín vysloviť výhrady voči každému jednotlivému opatreniu Konvencie, ktoré nie je v zhode s platným zákonom na jeho území. Výhrady všeobecného charakteru podľa tohto článku nie sú prípustné.

2. Každá výhrada, uplatnená podľa tohto článku, musí obsahovať stručný výklad daného zákona.

3. Každá zmluvná strana, ktorá rozširuje platnosť tejto Konvencie na teritórium, uvedené v prehlásení podľa Článku 35., odsek 2., môže pre toto teritórium vysloviť výhradu v súlade s ustanoveniami predchádzajúcich odsekov.

4. Každá zmluvná strana, ktorá vyslovila výhradu, o ktorej je zmienka v tomto článku, môže ju odvolať formou prehlásenia, adresovaného Generálnemu sekretárovi Rady Európy. Odvolanie nadobudne platnosť prvým dňom mesiaca po uplynutí jednomesačnej lehoty od dátumu, kedy ho obdržal Generálny sekretár.

Článok 37. (Vypovedanie zmluvy)

1. Každá zmluvná strana môže túto Konvenciu kedykoľvek vypovedať oznámením Generálnemu sekretárovi Rady Európy.

2. Vypovedanie nadobúda platnosť prvým dňom mesiaca po uplynutí trojmesačnej lehoty od dátumu, kedy oznámenie o vypovedaní obdržal Generálny sekretár.

Článok 38. (Informácie)

Generálny sekretár Rady Európy je povinný informovať členské štáty Rady Európy, Európske spoločenstvo, každého signatára, každú zmluvnú stranu a každý iný štát, prizvaný k pripojeniu sa ku Konvencii, o:

a) každom podpise;

b) každom uložení ratifikačnej listiny, alebo dokumentu o prijatí, schválení, či pripojení sa ku Konvencii;

c) každom dátume, kedy táto Konvencia nadobúda platnosť v súlade s Článkom 33. alebo 34.;

d) každom pozmeňovacom návrhu, prijatom v súlade s Článkom 32. a o dátume, kedy tento pozmeňovací návrh nadobudol platnosť;

e) každom prehlásení, urobenom podľa ustanovenia Článku 35.;

f) každej výhrade alebo odvolaní výhrady podľa ustanovenia Článku 36.;

g) akomkoľvek akte, oznámení alebo správe, týkajúcej sa tejto Konvencie.

Na dôkaz súhlasu s uvedeným textom my, nižšie podpísaní, riadne oprávnení, podpisujeme túto Konvenciu.

Vyhotovené v....., dňa.....(*), v jazyku anglickom a francúzskom. Oba texty sú autentické a zhotovené v jednom exemplári, ktorý bude uložený v archíve Rady Európy. Generálny sekretár Rady Európy odovzdá overené kópie každému členskému štátu Rady Európy, Európskemu spoločenstvu, nečlenským štátom, ktoré sa podieľali na vypracovaní tejto Konvencie a každému štátu, vyzvanému k pripojeniu sa k tejto Konvencii.

(*) Dátum podpísania tejto Konvencie bude ustanovený neskôr Radou ministrov.

(Konvencia bola slávnostne podpísaná v apríli 1997 v Španielsku. Medzi signatárske krajiny Konvencie sa zaradila aj Slovenská republika. Pozn. redakcie.)

Z anglického originálu: **Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine**, Directorate of Legal Affairs, Council of Europe, Strassbourg, November 1996 (pozri s. 11 - 14 tohto čísla nášho časopisu), preložili: Doc. PhDr. Magdaléna Kouřilová, CSc, Prof. MUDr. Ladislav Šoltés, DrSc., MUDr. Jozef Klepanec.

K NÁVRHU KONVENCIE O ĽUDSKÝCH PRÁVACH A BIOMEDICÍNE

Ústav medicínskej etiky a bioetiky v Bratislave sa podieľal na formulácii niektorých ustanovení Konvencie, keďže jeho pracovníci sa ako vyslaní experti pravidelne zúčastňovali rokovaní prípravného výboru. Naše stanoviská vychádzali predovšetkým z rešpektovania Ústavy Slovenskej republiky, zákonov platných na našom území (vrátane Liečebného poriadku MZd SR), ako aj mravných tradícií nášho obyvateľstva.

Konvencia predstavuje materiál, ktorý sa rodil dlho a ťažko, keďže bolo náročné prísť ku zhode postojov k zásadným bioetickým problémom, pretože tieto odrážali odlišné tradície, súčasné postoje verejnej mienky, ako aj národné, v rôznom stupni prepracované a odlišné legislatívy. Výsledný návrh preto definuje len určitý rámec pre národné legislatívy, určité minimá na ochranu ľudských práv a dôstojnosti človeka, pričom sa ponecháva zákonodarcom jednotlivých štátov priestor na prijatie riešení, ktoré by boli v zhode s mravným a právnym cítením daných národov.

V krajinách strednej a východnej Európy bude po rokoch totality a paternalistického prístupu k chorým treba prijať viaceré legislatívne opatrenia na realizáciu Konvencie. Zástupcovia týchto krajín prispeli k formovaniu konvencie silným sociálnym cítením, ktoré je odrazom humanitných a kresťanských tradícií týchto národov.

Hlavné témy posledných zasadaní expertov boli najmä z oblasti širokej problematiky genetickej informácie, najmä skríningu geneticky podmienených chorôb. Išlo o to, či identifikáciu nosičov daného génu možno robiť výlučne pre zdravotné účely a vedecký výskum s nimi spojený, alebo aj len z vedeckého záujmu. Hlasovaním prišli experti k záveru, že tento zásah je možný len zo zdravotných dôvodov. Osobitnou otázkou boli metodiky včasnej detekcie pohlavia a ich oprávnenosť. Upozorňovali sme na nebezpečie demografických disproporcií, ak by sa voľba pohlavia stala reálne dostupnou pre potenciálnych rodičov, ktorí by sa pre pohlavie budúceho dieťaťa rozhodovali na základe vlastných preferencií. Takýto výber by snáď, za určitých podmienok, bol oprávnený u geneticky podmienených chorôb, viazaných vo svojom prenose na pohlavie.

Medzi najzávažnejšie problémy pripravovanej Konvencie patrili otázky spojené s lekárskym výskumom, a to nielen u osôb kompetentných, ale najmä u osôb nekompetentných, napríklad u duševne chorých alebo u ľudských plodov. Umelé oplodnenie v skúmavke dáva vznik početným ľudským zárodkom, ktoré po úspešnom prenesení časti z nich do tela matky, zostávajú ako nadpočetné v zmrazenom stave. Základnou etickou otázkou je, či možno tieto zárodky využívať pre vedecké účely a súčasne zabezpečiť ochranu a dôstojnosť ľudského života. Experti sa zhodli na stanovisku, že vytváranie ľudských embryí pre vedecké účely musí byť zakázané.

Ďalším okruhom problémov, diskutovaných prítomnými expertami, boli otázky transplantácie orgánov a tkanív.

Vychádzalo sa z jasne definovaných kritérií pre transplantáciu a slobodného, informovaného, špecifického súhlasu darcu, danému v písomnej forme alebo pred zodpovedným orgánom. Osobitný článok Konvencie by mal zabezpečovať ochranu osôb neschopných súhlasiť s odberom orgánov.

Konvencia obsahuje aj články, ktoré boli prijaté bez dlhších diskusií: ide najmä o záverečné paragrafy a články, ktoré vychádzajú z preambuly a sú skôr administratívneho charakteru.

Bude vecou odbornej diskusie, ako aj potrebného legislatívneho, informačno-propagačného, výukového a výchovného úsilia, na ktorých by sa mali podieľať predovšetkým Ministerstvo zdravotníctva, Slovenská lekárska komora, Slovenská lekárska spoločnosť, lekárske fakulty, Inštitút pre ďalšie vzdelávanie pracovníkov v zdravotníctve, atď., ako aj celá odborná zdravotnícka a laická verejnosť, aby sa táto konvencia dostala do povedomia nášho obyvateľstva a vhodne zapracovala do našej legislatívy.

Bratislava, 27. 2. 1997 ***Prof. MUDr. L. Šoltés, DrSc.****

** vedúci Ústavu medicínskej etiky a bioetiky v Bratislave, predseda Etickej komisie Ministerstva zdravotníctva SR*

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