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ARTICLES

SOCIETY AND THE NOT-SO-NEW GENETICS: WHAT ARE WE AFRAID OF? SOME FUTURE PREDICTIONS FROM A SOCIAL SCIENTIST

*Dorothy C. Wertz, Ph.D.**

I. INTRODUCTION: "THROUGH A GLASS DARKLY"

The Human Genome Project promises to identify each of the approximately 100,000 genes comprising the human genome. It also promises to "sequence" each gene, that is, list the order in which the four base proteins are arranged on each gene, a list that may easily be 10,000 letters long. The Human Genome Project ("HGP") probably will be completed by 2006, ahead of schedule.¹ It may take another 100 years, however, to figure out what each gene does in regard to the development and functioning of "normal" individuals. Only then will there be widespread therapeutic payoff from the project. In the meantime, there will be an increasing number of tantalizing bits of diagnostic information, most accompanied by a measure of uncertainty. Therapies that replace, supplement, or block the products made by malfunctioning genes, usually along

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1. For the estimated completion in 2005, see G.P. Schuler et al., *A Gene Map of the Human Genome*, 274 *SCI.* 540, 540-45 (1996). The original estimate was that the genome would be "mapped" (genes roughly located on the chromosomes) by the year 2000, and "sequenced" (the order of the protein bases: adenine, thymine, guanine, and cytosine in each gene identified) by the year 2005. See DANIEL J. KELVES & LEROY HARD, *THE CODE OF CODES: SCIENTIFIC AND SOCIAL ISSUES IN THE HUMAN GENOME PROJECT* 30 (1992). For the original estimate of completion of both mapping and sequencing by 2005, see Eric S. Larder, *The New Genomes: Global Views of Biology*, 274 *SCI.* 536, 536-37 (1996).

the lines of drug therapy, without transferring actual genes from one person to another will be developed.

As we enter this period of greater knowledge about genetics, we must recognize the considerable fear the public feels every time the words "genetics," "DNA," or "genetic engineering" appear. We need to ask ourselves what really is new about the HGP and what, exactly, we are so afraid of.

Two possibilities certainly are new: 1) we now can differentiate an individual's genotype (underlying genetic makeup) from the phenotype (visible characteristics); and 2) we can make predictions about the health of other family members on the basis of an individual's genotype. Even though these possibilities may not be conceptually new, the HGP ultimately may provide greater accuracy. People long have believed that they inherited health and other characteristics from their ancestors. Human beings have used the family tree as a predictor, but cultural and individual beliefs about the relative importance of different ancestors differ considerably from the scientific model.² Mankind's belief that "things invisible," as well as visible, shape our individuality and our fate also precedes the HGP. The description of these forces, however, may have changed from angels, to chemicals, to genes. We have lived for centuries with these unknowns.

What the HGP promises to do is to make the unknown known with a "scientific certainty" that is difficult to refute, at least for those who believe in the power of nature to determine people's fates. The potential horror of this certainty makes people shudder. Not only will they know their own futures, but anyone else who has the information will have some terrible power over them. Many Americans approach the HGP as a sort of last judgment: "For now we see through a glass darkly; but then face to face: now I know in part; but then shall I know even as also I am known."³

This "genetic essentialism"⁴ is at the heart of people's fears about the

2. See generally Martin Richards & Maggie Ponder, *Lay Understanding of Genetics: A Test of an Hypothesis*, 2-15 (Apr. 1996) (Center For Family Research) (on file with author); Martin Richards, *Families, Kinship, and Genetics*, in *THE TROUBLED HELIX: PSYCHOLOGICAL IMPLICATIONS OF THE NEW GENETICS*, 249-73 (Theresa Marteau & Martin Richards eds., 1996); STEVE JONES, *IN THE BLOOD: GOD, GENES, AND DESTINY* 378-82 (1996).

3. I Corinthians 13:12.

4. See generally DOROTHY NELKIN & M. SUSAN LINDEE, *THE DNA MYSTIQUE: THE GENE AS A CULTURAL ICON* (1995) (showing the influence of genetic essentialism on American popular culture). Genetic essentialism is the belief that we are our genes, or, in

HGP, and explains in part why society has tried to set separate legal and ethical standards for the use of genetic information, different from those for other medical information. Yet, neither essentialism, nor most of the specific ethical problems related to medical genetics, are really new. The nature-nurture controversy began with Darwin and probably will never be resolved, even after the HGP is completed. Efforts to explain crime biologically have gone on for over a century;⁵ genes simply add a new twist to deep-seated American cultural beliefs about "bad blood." The discovery of hormones in the 1930s, and chemical treatments for schizophrenia and depression in the 1950s, led to much discussion at the time of whether all behavior resulted from chemical states, or whether there was such a thing as "free will." It is questionable whether genetics will add to these earlier discussions.⁶

Most of the specific ethical issues related to genetics were dealt with prior to the establishment of the HGP. For example, many doctors and families have grappled with difficult reproductive decisionmaking for couples with family histories of inherited diseases. Before carrier testing and prenatal diagnosis, the majority of couples who had a child with a genetic disorder chose to have no more children.⁷ Employment and health insurance has been denied on the basis of risk for presumably in-

theological terms, that DNA is the goal, "a holy and immortal relic, a forbidden territory." *Id.* at 41. See also Abby Lippman, *Prenatal Genetic Testing and Screening: Constructing Needs and Reinforcing Inequities*, AM. J. L. & MED. 15, 15-50 (1991) (using the term "geneticization" to describe the increasing use of genetic explorations from medical and social phenomena); DOROTHY NELKIN & LAWRENCE TANCREDI, *DANGEROUS DIAGNOSTICS: THE SOCIAL POWER OF BIOLOGICAL INFORMATION* (1989) (describing changes of genetic testing generally).

5. See generally ARTHUR E. FINK, *CAUSES OF CRIME: BIOLOGICAL THEORIES IN THE UNITED STATES, 1800-1915* (1938).

6. See generally CARL N. DEGLER, *IN SEARCH OF HUMAN NATURE: THE DECLINE AND REVIVAL OF DARWINISM IN AMERICAN SOCIAL THOUGHT* (1991).

7. Carrier testing identifies people who carry one gene for an autosomal recessive disorder or women who carry a gene for an X-linked recessive disorder. Called "heterozygotes" (meaning that they have one gene for the disorder and one "normal" gene), those who carry a gene for an autosomal recessive disorder such as cystic fibrosis have no symptoms of the disorder and usually do not know that they are carriers unless they are tested or they have a child with the disorder. In order for a child to have an autosomal recessive disorder, such as sickle cell anemia or cystic fibrosis, both parents must be carriers. Women who carry a gene for an X-linked disorder such as hemophilia A on one of their two X chromosomes also have no symptoms. (There are a few X-linked disorders such as fragile X syndrome where women carriers may have symptoms, but these are milder than for males.) There are no male carriers for X-linked disorders; males, having only one X chromosome, are symptomatic. If a woman carries a gene for an X-linked disorder, each of her sons has a 50% risk of the disorder. Presymptomatic testing identifies people who have a gene for an autosomal dominant disorder if they live long enough. They are not called

herited conditions. Insurers always have asked about family history. The ethical issue of a doctor's disclosing false paternity goes back to the discovery of blood typing. The issue of disclosure of medical information about an individual to family members who may be at risk is probably as old as taking the family history.

This Article will discuss the current status of each of these issues at greater length. In considering the need for laws or regulations, it should be remembered that the issues are neither new, nor unique to genetics, and therefore should be considered in the general context of medicine and the law of privacy.

II. A THIRTY-SEVEN NATION SURVEY AS BASIS FOR DISCUSSION

In order to provide a basis for worldwide discussion of the issues, my esteemed colleague John C. Fletcher, to whom this Volume is dedicated,⁸ and I undertook two surveys of the ethical views of genetics professionals around the world. The first survey, conducted in nineteen nations, took place in 1985-86;⁹ the second survey, covering thirty-seven nations (in-

carriers because their asymptomatic stage is only temporary. Huntington disease is one example of an autosomal dominant disorder.

Prenatal diagnosis identifies fetuses with chromosomal disorders (such as Down's Syndrome), unborn errors of metabolism (such as Tay Sachs disease), or major malformalities (such as spina bifida and anencephaly). Prenatal tests are of several types. Some are "screens" that identify women at higher risks: maternal serum alpha-fetoprotein (a blood test), and the newer "triple test" (also a blood test) are examples. Ultrasound is another form of screening (although sometimes it gives non-definitive results). Usually a screen that is outside the "normal" limits requires a definitive test to get a diagnosis. Tests include chronic villus sampling ("CVS"), which is an investigation of fetal cells taken from the tissues that will later become the placenta, and amniocentesis, an investigation of fetal cells that have been sloughed off into the amniotic fluid surrounding the fetus. CVS can be done in the first trimester of pregnancy. Amniocentesis is done between 12 to 16 weeks.

The "screens" (blood tests and ultrasound) increasingly are being offered in all pregnancies. CVS and amniocentesis are offered only when a woman faces an increased risk, because of family history, of a genetic condition, advanced maternal age (35 or over, which gives an increased risk for chromosomal abnormalities), "abnormal findings" on the ultrasound or blood tests, or, in more instances, toxic exposures.

8. See Franklin G. Miller, Ph.D., *Dedicatory Essay*, 13 J. CONTEMP. HEALTH L. & POL'Y, ix-xiv (1996).

9. See generally Dorothy C. Wertz, *The 19-Nation Survey: Genetics and Ethics Around the World*, in ETHICS AND HUMAN GENETICS: A CROSS-CULTURAL PERSPECTIVE 1, 1-77 (Dorothy C. Wertz & John C. Fletcher eds., 1989) [hereinafter Wertz, *Genetics and Ethics Around the World*]; Dorothy C. Wertz et al., *Medical Geneticists Confront Ethical Dilemmas; Cross-cultural Comparisons Among 18 Nations*, 46 AM. J. HUMAN GENETICS 1200, 1200-13 (1990); Dorothy C. Wertz, *International Perspectives on Ethics and Human Genetics*, 27 SUFFOLK U. L. REV. 1411, 1411-56 (1993); John C. Fletcher & Dorothy C. Wertz, *Ethics, Law, and Medical Genetics: After the Human Genome is Mapped*, 39 EMORY

cluding the nineteen from the first survey), took place in 1994-95. Both surveys were conducted through anonymous questionnaires describing most of the ethical problems that occur in the practice of medical genetics, usually presented in the form of case vignettes. We included all countries known to have ten or more practicing medical geneticists.¹⁰ The anonymous questionnaires were distributed and collected by a geneticist colleague in each country. In the 1985 survey, all questionnaires were in English. In the 1994 survey, there were translations into Spanish, Portuguese, Chinese, Japanese, French, German, Hebrew, Czech, Russian, Polish, and Turkish. In 1984, 682 geneticists responded, sixty-two percent of those invited to participate. In 1994, 2,903 geneticists responded, sixty-three percent of those asked to participate, including 1,084 in the United States.

The 1994-95 survey included 499 board-certified primary care physicians from the United States, including pediatricians, obstetricians, and family practitioners, and 473 first-time genetics patients or their parents. Both groups were asked about their ethical views before and after genetic counseling and about the content of the counseling sessions. In addition, each geneticist or genetic counselor was asked to report on the content of these sessions. We also surveyed 988 adult members of the U.S. public.¹¹ All questionnaires covered the same ethical problems, though they were phrased to accommodate the knowledge level of the specific audience.

Patients had a median of thirteen years of education. Twenty-eight percent of patients were college graduates and thirteen percent high school dropouts. In addition, ninety-one percent were women, eighty-nine percent were white, and forty-four percent attended church at least once a month. Seventy-five percent of the patients or their spouses were in clerical, sales, service, or factory production occupations.

Because geneticists around the world face similar problems, the survey was conducted internationally. Most geneticists agreed that if a service were unavailable or illegal in their own country, they should offer patients a referral across international borders. Thus, it would make sense to have some international agreement about what services should be available and how they should be provided. Discussion can only proceed

L. J. 747, 765-809 (1991); Dorothy C. Wertz, *Ethical and Legal Implications of the New Genetics; Issues for Discussion*, 35 *Soc. Sci. Med.* 495, 495-503 (1992).

10. See Table 1.

11. This Survey was made possible with the help of Roper-Stassh Worldwide. See *infra* note 90.

in the light of full awareness of international perspectives. In each major section of this Article, international views will be presented.

In presenting our survey research, we do not mean to suggest that ethics should be conducted by professional or popular ballot. Indeed, the responses of the majority of professionals may contravene universal principles concerning genetics. This is the case in many nations, including the United States, with regard to prenatal diagnosis solely for gender selection.¹² Thus, while surveys cannot tell us what is right, they do serve to delineate the views of principal stakeholders.

Using these survey results, and earlier studies of genetic counseling, this paper outlines some concerns that will be more fully expressed in a book. In this Article genetic issues generally have been placed in the context of the value system of the United States, using results from other countries as a foil. From time to time reference will be made to overall survey results, but specific statistics and tables will be provided elsewhere.

III. THE FIELD OF GENETICS

In the United States, there are 3,070 professionals certified by the American Board of Medical Genetics ("ABMG") or American Board of Genetic Counseling ("ABGC"). The ABMG certificates include M.D.'s, Ph.D.'s, and M.S.'s. In 1995, after the ABMG became a medical specialty accepted by the American Medical Association, the Master's-level counselors were certified separately by ABGC. Master's level counselors, full members of the National Society of Genetic Counselors, number about 1,100 persons, including about 800 who are board-certified. All have completed a special two-year postgraduate training program in genetics and counseling at one of twenty-two genetic counseling programs in the United States, two in Canada, and one each in the United Kingdom and South Africa. Ninety-four percent of the counselors are women, with a median age of thirty-four. Master's-level counselors provide most of the pre-test genetic counseling and a substantial amount of the counseling for those parents whose tests indicate the possible presence of a genetic condition that could influence their procreative decisions. Ph.D.'s in genetics

12. Dorothy C. Wertz, *Opinions des Généticiens de 37 pays sur la présélection du Sexe*, 28 *SOCIOLOGIE ET SOCIÉTÉS* 77, 78-80 (1996); Dorothy C. Wertz & John C. Fletcher, *Fatal Knowledge? Prenatal Diagnosis and Sex Selection*, *HASTINGS CTR. REP.*, May-June 1989, at 21. Genetic professionals may believe that in honoring requests for sex selection or offering referrals, they are respecting patient autonomy, but the principle of autonomy should not always prevail with the principle of justice or equality.

may conduct research or be responsible for laboratories, but many also see patients and provide counseling. About half of doctoral-level geneticists, both in the United States and around the world, are women.¹³ In the United States, ninety-four percent of all genetics services providers are white. Only twelve percent have extensive experience with support groups for those with disabilities.

There has been much discussion concerning the training of nurses or certified nurse-midwives ("CNM's") to do genetic counseling. Several graduate nursing programs exist for this purpose, but few nurses have been trained in genetics in the United States.¹⁴ Genetic nurses play a more prominent role in the United Kingdom, South Africa, and Poland. In Poland, midwives do much of the counseling about prenatal testing.

Genetics services providers may be responsible for screening of entire populations or groups, testing individuals or families who are known to be at higher-than-average risk because of family history or advanced maternal age, genetic counseling, diagnosing children or adults, or prenatal diagnosis. Medical genetics offers few treatments. It began as, and continues to be, a primarily diagnostic field. Initially the field of medical genetics concentrated on reproductive counseling: the providing of genetic information on which couples or individuals could base reproductive decisions. The counseling encounter was largely educational; this gave the patient greater equality with the physician than occurs in most medical encounters. Geneticists in North America and the United Kingdom, where genetic counseling originated, were hesitant to tell couples what to do. This was the result of the recent excesses of the Eugenics Movement, both in Nazi Germany and the United States. Genetic counseling began soon after these excesses, in the late 1940s. In the 1930s, counseling had been called "genetic hygiene" or "genetic advice."

In 1947, Sheldon Reed coined the term "genetic counseling" to replace eugenically tainted terms.¹⁵ Reed believed that prospective parents who

13. Dorothy C. Wertz, Ph.D., *Is There a "Women's Ethic" in Genetics: A 37-Nation Survey of Providers*, 52 *J. AM. MED. WOMEN'S ASS'N.* 33, 33 (1997).

14. Gwen W. Anderson, *The Evolution and Status of Genetics Education in Nursing in the United States 1983-1995*, 28 *IMAGE J. NURSING SCHOLARSHIP* 101, 102 (1996).

15. Sheldon C. Reed, *A Short History of Genetic Counseling*, 21 *SOCIAL BIOLOGY*, 332, 332-39 (1974). Reed thought that people who were sufficiently concerned about their potential offspring to consult a genetic counselor were usually above average in intelligence and responsibility. The value of transmitting these traits outweighed the risk of transmitting most diseases. Therefore, counselors should respect the potential parents' opinions. Sheldon Reed, *Heredity Counselling*, 1 *EUGENICS QUARTERLY* 47, 47-51 (1954). Reed also argued that counselors should "try to explain thoroughly what the genetic situa-

were responsible enough to seek genetic counseling would make such good parents that they ought to have children, and he urged counselors to support their decisions. In 1974, a committee of the American Society of Human Genetics suggested "nondirectiveness" as the norm for genetic counseling,¹⁶ thus diverging from all other medical specialties. It is unlikely that there would have been such emphasis on nondirectiveness had genetics begun as a pediatric or adult specialty outside the context of reproduction. In the future, as genetics becomes part of adult medicine and as preventive measures or treatments become available, the field likely will become more directive. Genetics may, however, retain the best element of nondirectiveness, namely respecting patients as equal members of the team in determining their own or their children's care. This is what patients attending focus groups indicated as a priority.¹⁷

United State's geneticists and counselors see a median of six genetics patients a week, a number that appears small compared to the 100-150 patient median of the primary care physicians in our survey. Given the small number of geneticists, this means that, in effect, most genetic information, and probably most genetic tests, will be provided to patients by their primary care physicians rather than by genetic specialists. Although inevitable, this is worrisome in view of the gaps in knowledge, even about

tion is," but that "the decision must be a personal one between the husband and wife, and this alone." SHELDON REED, *COUNSELLING IN MEDICAL GENETICS* 14 (1955). See also Harold Falls, *Consideration of the Whole Person*, in *HEREDITY COUNSELLING* 99 (H. Hammons ed., 1959) (encouraging such superior parents to have children if the gene to be transmitted did not impose too serious a hardship); C. Nash Herndon, *Heredity Counseling*, 1 *EUGENICS QUARTERLY* 64, 64-66 (1954) (believed couples should be evaluated in terms of "total genetic potential," not just the single gene).

16. F. Clarke Fraser, *Genetic Counseling*, 26 *AM. J. HUMAN GENETICS* 636, 636-61 (1974). The classic meaning of nondirectiveness, as described by Fraser in 1974, included the following elements: suggesting that while you will not make decisions for patients you will support any they make; telling patients that decisions, especially reproductive ones, are theirs alone and refusing to make any for them; helping individuals/couples understand their options and the present state of medical knowledge so they can make informed decisions; helping individuals/couples adjust to and cope with their genetic problems; the removal or lessening of patient guilt or anxiety; and helping individuals/couples achieve their parenting goals. From 97 to 100% of U.S. geneticists in the 1984 survey agreed with these elements. Wertz, *Genetic and Ethics Around the World*, *supra* note 9, at 34, 35.

Many counselors believe that this type of nondirectiveness is not possible. See, e.g., Seymour Kessler, *Psychological Aspects of Genetic Counseling, VII Thoughts on Directiveness*, 1 *J. GENETIC COUNSELLING* 9, 9-18 (1992).

17. Dorothy C. Wertz, Ph.D. & Robin Gregg, Ph.D., M.S.W., *Optimizing Genetics Services in a Social, Ethical, and Policy Context: Suggestions from Consumers and Providers in the New England Regional Genetics Group (NERGG)*, 10 *GENETIC RESOURCE* 1, 9-11 (1996).

relatively common genetic disorders, among the primary care physicians in our sample. Although most physicians got most things right on a knowledge quiz that was incorporated in our survey, some gave incorrect answers to questions of considerable importance to patients. For example, eleven percent thought that most children with Downs syndrome could complete regular (not special) high school; the majority thought that males with cystic fibrosis could father biological children (they are actually sterile); and fifty-two percent thought that "trisomy 52," a trick question, was prenatally diagnosable.

IV. GENETIC ESSENTIALISM: PRYING INTO THE SOUL?

Public fears about genetics are of a greater magnitude than those that accompanied previous, largely academic, discussions about the biochemical basis of the self associated with discoveries of chemical treatments for mental illness. People think that geneticists have uncovered the ultimate building blocks that make us what we are. The horror implicit in this point of view, unless one has a religious view of the soul, is that perhaps we are the sum of our genes and nothing more, and that science may now tell each of us exactly what we are and what we will become. This essentialistic view pervades popular culture. "I am my genes" is a phrase constantly used by questioners at public forums, despite the efforts of panelists to try to explain that "you" are not the same as "your genes." This "genetic essentialism," variously expressed as "good or bad blood," the Jukes and Kallikak families, Social Darwinism, or racial superiority/inferiority, has dominated over environmental views in America for over 100 years. According to Dorothy Nelkin, there were only two periods when environmental views had at least equal weight with genetic essentialism.¹⁸ The first was during the Great Depression of the 1930s, when middle-class people, themselves out of jobs, realized that other people were out of jobs through no fault of their own. The second period was immediately after World War II, when the eugenics movement was discredited because of the Nazis. In this period, social scientists believed that crime and mental illness could be prevented by proper nurturing in a two-parent nuclear family, with each parent fulfilling a prescribed gender role. Usually the mother was blamed if something went wrong.¹⁹ Many

18. NELKIN & LINDEE, *supra* note 4, at 33-34.

19. See generally BETTY FRIEDAN, *THE FEMININE MYSTIQUE* (1963) (describing mother blaming); FERDINAND LUNDBERG & MARYNIA F. FARNHAM, M.D., *MODERN WOMAN: THE LOST SEX* 270-271, 291-294 (1947) (purporting to be a psychiatric analysis of the woes of women who desert their true feminine and mothering roles); PHYLISS CHESLER,

mothers undoubtedly were relieved to see a return to biologically based thinking, because this absolved them from blame. Mothers again faced blame, however, when genetic information and new reproductive technologies placed difficult new choices on the parents.

Genetic essentialism has received more attention in recent years. Court decisions concerning child custody have given biological relationships more weight than the more traditional "best interests of the child." Thus, the courts have seemed to imply that there is something sacred about biology.²⁰ Couples whose embryos are carried by "surrogate mothers" have been declared the infant's parents on birth certificates, simply by virtue of their biological relationship. This fundamental view that we attach to biology and genetics is helping to determine our cultural view of genetic privacy, genetic disclosure, and genetic autonomy as somehow separate from other kinds of privacy, disclosure, and autonomy.

V. THINGS VISIBLE AND INVISIBLE: DOES GENETICS REQUIRE A NEW CONCEPT OF PRIVACY?

Around the world, insurance companies and employers are widely mistrusted by employees. Questions regarding their access to genetic information received the strongest consensus of all questions on our fifty-page questionnaire: virtually one-hundred percent of the geneticists in all thirty-seven nations, of U.S. primary care physicians, of patients, and of the U.S. public thought that employers and insurers should not have any access to genetic information without an individual's consent. Close to one-half of the respondents in each category thought that insurance companies and employers should have no access at all, even if the individual consents. It is unclear whether these responses resulted from particular feelings about genetic information or whether they resulted from an overwhelming distrust of insurers and employers. Human Immunodeficiency Virus, listed among a group of genetic conditions, received the same response.

There were fewer reports of refusals of insurance or employment on genetic grounds than we expected. In all, the 1,084 U.S. geneticists reported a total of about 550 individuals who were refused employment, let

WOMEN & MADNESS (1972) (explaining why these oppressive, feminine roles drive women to mental illness). For success in reducing the likelihood of complications in the newborn to less than one percent, *see, e.g.*, STEVEN G. GABLE, *OBSTETRICS: NORMAL AND PROBLEM PREGNANCIES* 962 (2d ed., 1992).

20. *See* Rochelle Cooper Dreyfuss & Dorothy Nelkin, *The Jurisprudence of Genetics*, 45 *VAND. L. REV.* 313, 324 (1992).

go from a job, or were refused life insurance on the basis of either being a carrier or having a genetic predisposition for disease or a disabling condition in the absence of symptoms. Most people would consider such refusals unfair discrimination, however, because carriers do not always develop the genetic condition. People with predispositions for cancer or heart disease, for example, may never develop the condition. In view of the fact that the 1,084 U.S. geneticists had a median of nine years experience, and saw a median of six patients per week, 550 such reports seem few. Many geneticists see their patients only once though, and sessions tend to concentrate on medical issues; therefore, it may be that genetics professionals are unaware of the concerns and risks facing their "clients" in a wider social context.

Primary care physicians in the United States, who see 100-150 patients per week and are likely to see their patients on an ongoing basis, reported only a few instances of refusals of employment or life or health insurance based on genetic information. There were a handful of reports from Canada. Geneticists in other nations seemed to think that such problems could occur only in the United States, because laws in their own countries protected the individual's right to work. Note that we did not ask about health insurance on the geneticist survey, because most industrialized nations have national health plans.

Survey questions for patients did not mention carrier status or predisposition, but simply asked "because of a genetic disability or disease, have you or a member of your family been refused. . . ." Approximately two percent stated they were refused employment, four percent health insurance, and six percent life insurance. Patients' explanations suggested that at least some of these refusals were justifiable, such as being denied a job as a firefighter on account of chronic bronchitis. We did not ask how many patients had applied for life insurance or for individually rated health insurance, as opposed to employer packages, which cannot exclude individuals. Therefore, we do not know what percent of those who actually applied for insurance were refused.

Among the general public, three percent reported being refused employment or fired from a job, three percent reported being refused health insurance, and five percent reported being refused life insurance "because of an inherited disease or condition." The percentages of reported insurance refusals approximates the overall percentage of insurance refusal. Thus, it is not clear from the data that genetics is a separate, or even a major, cause for such refusals.

Another study found far greater evidence of "genetic discrimination" by looking at select groups of experienced, college-educated consumers in genetic support groups.²¹ Perceptions of "discrimination," however, may depend on the social locus of the subject, as well as phraseology of questions: it appears that the phenomenon of discrimination based on genetic factors may be rarer than media reports suggest. However, the reports of our geneticist respondents document the existence of at least some discrimination. How these reports are interpreted will depend, in part, on the personal and political views of the interpreter in determining whether the glass is half empty or half full.

Once the issue of privacy goes beyond the areas of employment and insurance, there is a substantial divergence between the views of U.S. geneticists and patients. Patients appeared surprisingly unconcerned about many threats to privacy, especially outside a medical setting. For example, almost all patients surveyed, reported that they would tell a school system about a genetic test result showing that a child has a genetic condition that sometimes leads to antisocial behavior. The geneticist questionnaires said XYY which has been found to be associated with learning disabilities, excess height, clumsiness, and behavioral problems in some boys. The extra Y chromosome is not associated with violent crime, as was once thought. Most of these patients said that disclosure of the test results would help the child. When the surveyed patients were presented with a scenario where a school bus driver had a genetic condition posing high risk of heart attack or stroke, four-fifths thought the doctor ought to tell the man's employer if he refused to do so. Most geneticists would not disclose information in either case.

The responses of most patients to questions about DNA²² fingerprinting was very positive. Large majorities thought that DNA fingerprints should be required and kept on file for people charged with, although not necessarily convicted of, sex crimes (seventy-six percent); or other serious crimes (seventy-one percent); members of the armed forces (eighty-seven

21. E. Virginia Lapham et al., *Genetic Discrimination: Perspectives of Consumers*, 274 SCI. 621, 621-24 (1996); Lisa N. Geller et al., *Individual, Family, and Societal Dimensions of Genetic Discrimination; A Case Study Analysis*, 2 SCI. ENG. ETHICS 71, 71-88 (1996).

22. DNA (Deoxyribonucleic acid) is the molecule in the chromosome that contains the instructions for manufacturing specific proteins. DNA is made up of two strings of building blocks (protein bases) called nucleotides, with four varieties: adenine, thymine, cytosine, and guanine. These four are coiled into a helix, along with a phosphate molecule and a sugar called deoxyribose. The genes are spaced along the length of the DNA molecule like recordings on a tape. See Marcus Pembrey, *The New Genetics: A User's Guide*, in THE TROUBLED HELIX 63, 67 (Theresa Marteau & Martin Richards eds., 1996).

percent); and newborns (seventy-three percent). About half thought DNA should be on file for passport applicants, as well as people on welfare (to prevent fraud). Only when the questionnaire presented the issue of DNA fingerprinting for credit cards, which often meant the respondents themselves, was there any substantial hesitation, but one-third still approved. In both the questionnaires and three related focus groups, subjects were eager to get their entire medical and genetic record on a wallet-sized card.

In sum, most subjects appeared to believe that the benignity of medicine and disclosure of medical information extended outside medical settings. Most people in society seem unaware of common threats to medical privacy or to privacy in general. For example, many people willingly give out their social security numbers without knowing how much someone else can do with them. Most people are unaware of what can be done with the information on their drivers' licenses, information that many states sell. Most people do not know how many people, in an office, HMO, hospital, or business, have access to their medical records, or what kinds of sensitive material, such as psychiatrists' notes, may be in the record. In view of this overall lack of awareness concerning threats to privacy, however, it seems somewhat ridiculous to single out DNA for special treatment under the law. The rush to introduce "genetic privacy" laws, while ignoring overall medical privacy, especially psychiatrists' notes, makes sense only if one believes that somehow DNA is the soul. What we need are laws protecting medical privacy generally, not laws protecting just a subset of medical information. We also need laws guaranteeing individuals the right to insurance and employment.

In dealing with clinicians and researchers in other nations, we need to remember that privacy is largely a Western concept, originating from the eighteenth century Enlightenment Movement. The Enlightenment did not fully extend beyond Western Europe and North America. In most parts of the world people expect to know each other's business, especially on the family and community level. John Locke's concept of the body as property or surrounding oneself with private, inviolable space is simply unknown in most parts of the world.²³ Outside North America and Europe, confidentiality, not privacy, is the prevailing concern. Confidentiality, or the keeping of secrets that one has agreed to keep or which one's role requires one to keep (e.g., the priest in the confessional), is an an-

23. John Locke, *Two Treatises*, reprinted in *THE LOCKE READER* 289 (John W. Yolton ed., 1977).

cient principle and widely known. Doctors, recalling their one semi-sacred role, refer to the "medical secret" between doctor and patient. This differs from privacy, however, in that the patient has no ownership rights over the secret. The doctor may reveal the medical secret to other doctors, to family members, or sometimes to researchers.

VI. ALL IN THE FAMILY: TELLING RELATIVES

Whether or not to inform a patient's relatives that they may be at a genetic risk, against the wishes of that patient, was one of the questions geneticists found most difficult to answer. There was no consensus on this issue anywhere in the world. Overall, about forty-one percent of geneticists, including fifty-three percent in the United States and thirty-four percent outside the United States, would maintain the patient's confidentiality and not tell the relatives. The overall number who would maintain confidentiality has increased from thirty percent in 1985, thirty-nine percent in the United States, and twenty-nine percent outside the United States,²⁴ but there is still no consensus on this issue. The remainder would either tell the relatives if they ask (thirty-five percent, including thirty-two percent in the United States and thirty-seven percent elsewhere); tell the relatives even if they do not ask (twelve percent, including six percent in the U.S. and fifteen percent elsewhere); or send the problem back to the referring physician and let that physician decide (twelve percent, including nine percent in the United States and fourteen percent elsewhere). The major shift in responses since 1985 seems to be away from telling the relatives unasked, a decrease from twenty-four percent to twelve percent.

In many cases, telling unasked relatives is a practical impossibility because of the difficulty in locating them. Outside North America and Western Europe, the majority of doctors responding would tell the relatives of a patient that they are at genetic risk if they asked. The basis for this is that they had a duty to warn third parties of harm. Many respondents indicated in their written comments that they considered telling relatives who asked, quite compatible with maintaining individual confidentiality. Despite directions to check only one answer, many checked two or three, such as "respect patient's confidentiality," "tell relatives if they ask," and "send information to referring doctor." Respondents explained that this was their concept of preserving confidentiality.

24. Wertz, *Genetics and Ethics Around the World*, *supra* note 9, at 16.

In their view, only telling relatives who did not ask would be a breach of confidentiality.

The results of the international survey illustrate the differences between privacy and confidentiality described in the section above. In many parts of the world, the family, rather than the individual, is considered the unit of confidentiality. In these locations, genetic information belongs to the family, who not only share genes, but will be responsible for the care of children or other family members should they fall ill. If family members ask about genetic risk, the prevailing thought is that they "ought to know" or "deserve to know." The term "right to know" appears less often outside of North America or Europe. Sometimes family members may even have a "duty to know" and to use the information to prevent harm.

Some geneticists would pass the problem of disclosure on to the referring physicians, but they are not necessarily "passing the buck." In many nations, the geneticists assumed that the referring physician would know the family better and thus, be in a better position to weigh the harms and benefits of disclosure, or, according to most comments, to use his or her authority to persuade the patient to disclose the genetic risk voluntarily.

In the United States, many geneticists see genetic information in terms of "privacy." This means the absolute individual ownership of any information pertaining to the body, even though other family members may have the same genes. The absence of consensus concerning telling relatives of the genetic risk of a patient, after many years of discussion, suggests that this may be one truly new ethical issue posed by genetics.

In 1983, the President's Commission, an interdisciplinary group of geneticists, bioethicists, legal experts, and policy makers appointed by the President, provided that confidentiality could be overridden if four conditions were met: 1) reasonable efforts to persuade the patient to disclose voluntarily had failed; 2) there was a high risk of serious harm to the relatives if information was not disclosed, and the information would be used to avert this harm; 3) the harm suffered would be serious; and 4) only information directly germane to the relatives' medical/genetic status was conveyed.²⁵ In 1993, the Institute of Medicine reaffirmed this statement.²⁶ Neither group argued for a legal duty to inform relatives. They

25. PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, SCREENING AND COUNSELING FOR GENETIC CONDITIONS 44 (1983).

26. INSTITUTE OF MEDICINE, COMMITTEE ON ASSESSING GENETIC RISKS, ASSESSING GENETIC RISKS: IMPLICATIONS FOR HEALTH AND SOCIAL POLICY 267 (1994).

did, however, argue for an ethical duty and legal permission, although not an obligation, to inform in certain cases.²⁷ In 1995, bioethicist George J. Annas argued that there was no legal obligation to inform. In addition, it is probable that no case would ever meet the standards of the President's Commission or the Institute of Medicine for an ethical duty to inform.²⁸ They did not, however, argue for a legal prohibition against informing relatives in all cases.²⁹ Some of our geneticist respondents considered contractual obligations and argued that relatives who asked about genetic risk became patients themselves. Thus, the doctor faced a contractual obligation to tell them. These geneticist respondents' major reason for telling relatives, however, was in order to avoid harm.

Patients took a somewhat different viewpoint from geneticists on the question of informing relatives about their genetic risk. About three-quarters thought the doctor should tell the patient's relatives. This included about one-third who thought that doctors should try to find the patient's relatives and tell them even if they did not ask. About half the patients thought doctors should tell people about their genetic risks, even if the people did not want to know. Some of these answers appear to stem from a belief that information is somehow a good in itself; others stem from beliefs about family solidarity or physicians' duties to a wider whole.

Patients took a different view of the rights of spouses or partners to be informed about genetic risk. For example, two-thirds of U.S. geneticists would not tell a man that he is not the father of a child, even if he asked. Three-quarters of respondent patients, who were mostly women, thought that the doctor should tell a man who asked, but most thought the doctor should warn the woman first. Perhaps these patients, as first-time visitors to genetics clinics, rather than more experienced consumers of genetics services, have not yet heard the arguments about genetic privacy that are so prevalent in bioethics circles. It may be that their current consensus for informing relatives will dissolve in future years if discussions of ethical problems in genetics become part of high school education.

27. See *supra* notes 25-26 and accompanying text.

28. George J. Annas et al., *The Genetic Privacy Act and Commentary*, Health Law Department, Boston University School of Public Health, "Commentary" (1995) (appended to draft of model legislation on genetic privacy).

29. *Id.*

VII. MY RIGHTS VERSUS YOUR RIGHTS: THE TRIUMPH OF AUTONOMY

French respondents to our survey often said: "My rights end where other people's rights begin." Chinese respondents, along with many others from developing nations, said that individuals should act in terms of the welfare of the population as a whole. American respondents frequently spoke as if their rights, and their patients' rights, had no limits. The overwhelming majority of American geneticists, and patients, thought that withholding any service requested by a patient was a denial of patients' rights. About sixty percent of both geneticists and patients thought that patients are entitled to whatever services they ask for, as long as they can pay out-of-pocket.

In the United States, some argue that rights have no limit. Evidence for this view is found in two cases that appeared in both the 1985 and 1994 surveys. The first case is that of a twenty-five-year-old woman with no family history of genetic disorder who requested amniocentesis solely because she was anxious about the health of the fetus. This scenario typifies many patient requests for services that are not medically necessary. In 1985, seventy-eight percent of U.S. geneticists reported they would perform prenatal diagnosis, while eleven percent would offer a referral.³⁰ The figure was lower, sixty-one percent, outside the United States, because prenatal diagnosis was considered a costly resource.

By 1994, ninety-six percent of all geneticists in the United States would perform amniocentesis or offer a referral. This included fifty-eight percent who would perform the service only if the patient could pay out-of-pocket. This clearly substantiates our two-class system of medical care.

The second case illustrates the triumph of the principle of autonomy. In both 1985 and 1994 we posed the scenario of a couple with four healthy girls, who request prenatal diagnosis solely to find out the sex of the fetus. The couple say they will abort a female fetus. In 1985, thirty-four percent of U.S. geneticists would perform prenatal diagnosis for this couple, while twenty-eight percent would offer a referral. By 1994, thirty-four percent would perform, and thirty-eight percent would refer. This result exists despite much discussion in the bioethics literature that opposed sex selection. Sixty-two percent thought that sex selection should be performed only for patients who could pay out-of-pocket. Some U.S. geneticists stated in their comments that withholding insurance payments

30. Wertz, *Genetics and Ethics Around the World*, *supra* note 9, at 23. For a discussion of the ethics of sex selections, see Wertz & Fletcher, *supra* note 12, at 21.

had the effect of drawing some sort of moral line against the procedure. Geneticists stressed patient autonomy in giving reasons for their responses, both to sex selection and maternal anxiety cases. The nondirective ethos of genetic counseling maintains that patient requests should be respected, even where the counselor disagrees on moral grounds. Therefore, more genetic counselors than physicians would honor patient requests for sex selection.³¹

Almost as many patients as geneticists thought that doctors ought to honor a couple's request for sex selection, though their responses to questions about abortion suggest that almost none of them would ask for sex selection themselves.

Nonetheless, these patients and geneticists believed that other people had a right to services of which they personally disapproved. This finding is in line with National Opinion Research Center surveys going back to 1971.³² This was before the landmark decision of the U.S. Supreme Court in *Roe v. Wade*,³³ in which an eighty percent majority, with only three percentage points variance in all those years, believed that abortions should be available if there was a "serious defect in the baby," even though they would not use abortion themselves.³⁴

There is also a trend toward willingness to provide services on request in many nations outside the United States. In fifteen of the eighteen other nations surveyed in 1985, more geneticists would perform prenatal diagnosis for sex selection in 1994 than in 1985. The exceptions were France, India, and Sweden. Some respondents considered the sex selection cases hypothetical in nations where public insurance systems essentially regulate the availability of services, and payment out-of-pocket is rare. Nevertheless, in most nations, with the exceptions of Russia, Hungary, Israel, and Portugal, fewer respondents would accede to such requests than they would in the United States.

Apparently both health care or genetic service providers and patients in the United States agree that autonomy should be unlimited. They believe that patients should have a right to know, a right to services, possibly even a right not to know, though patients are not so certain about the last, with about half believing that people who take a test have a duty to

31. Wertz, *supra* note 13, at 33.

32. NATIONAL OPINION RESEARCH CENTER, GENERAL SOCIAL SURVEY, 1972-1994: CUMULATIVE CODEBOOK (Nov. 1994).

33. 410 U.S. 113 (1973).

34. NATIONAL OPINION RESEARCH CENTER, GENERAL SOCIAL SURVEY, 1972-1994: CUMULATIVE CODEBOOK, *supra* note 32.

know the results. A recent publication by the Council of Regional Networks of Genetics Services Ethics Committee, which purports to be a code of ethics, reads like a paean to individual autonomy, with some paragraphs on justice attached.³⁵

On the other hand, the "common good" gets lost in this worship of autonomy. The implicit assumption is that society can pay for everything and therefore individuals have a right to everything. In practice, this assumption means that individuals should have almost unlimited rights unless they are poor. Two cases in the survey illustrate this view. In the first, most U.S. respondents, both geneticists and patients, would support the decision of a blind couple to have a blind child. When the prospective parent is described as a single blind woman on welfare who already has three blind children, however, almost half the patients and the primary care physicians thought the doctor should suggest sterilization, and about one-fifth thought the law should require sterilization. Respondents' comments indicated that they were responding to the prospective parent's social status rather than her disability.

Europeans sometimes snicker at American statements about "freedom of choice." They argue that Americans have choices only for those who can afford it. The Europeans claim, however, that laws limiting access to some services, or even prohibiting some services for everybody, are more fair than "freedom of choice" for a select group. France, for example, has restrictions on donor gametes and preimplantation genetic diagnosis, restrictions that probably would be unacceptable to most Americans. French geneticists, however, claim that this system is morally superior to the American system because the restrictions apply to everyone.

In many parts of the world, decisions are made by families or communities rather than individuals; the atomized, autonomous individual exists as a Western concept. Chinese geneticists commented that one does not become a human being except in the context of family and community. This reasoning leads to the conclusion that illegitimate pregnancies should be aborted, because the child, if born, never will become a person.

Americans ultimately will have to realize that not everyone can have everything; resources are not unlimited. One possibility is to maintain the status quo, with poor people bearing the brunt of curtailed services. This solution seems to satisfy many people who vote. This view is sup-

35. See generally Council of Regional Networks Committee on Ethics, *Code of Ethical Principles for Genetic Professionals: An Explication*, 65 AM. J. MED. GENETICS 179, 179-83 (1996) (collection of statements of ethical practice on which a consensus exists) [hereinafter *Code of Ethical Principles*].

ported by some of the primary care physicians in the survey. These physicians said they thought the two-class system of care was ideal, because if an individual could not afford medical services, that person probably did not deserve them. Another solution would be to distribute a more limited set of "choices" fairly, by requiring the foregoing of economic privileges and rejecting the demands of special interest groups.

VIII. IS KNOWLEDGE A GOOD IN ITSELF?: GENETIC TESTING

Sophocles said, "It is not wisdom to be wise, when wisdom profits not."³⁶ The dreadful knowledge was that King Oedipus had married his mother. Some genetic test results are of this caliber. One example is a test which indicates whether an individual will someday develop Huntington disease, an inevitable, untreatable, fatal neurologic disease. The Huntington test offers virtually one-hundred percent certainty, but does not predict the exact age at which the disease will appear. Most genetic tests, however, do not offer this certainty. Instead, like the weather forecast, they offer "percent chances" of variable outcomes that may or may not occur. Your life decisions, therefore, depend partly on your tendency toward optimism or pessimism about the chances, partly on the magnitude of predicted outcome, and partly on your faith in the power of the predictive process itself, a process that may be inaccurate.

Interpretation of risk is at the heart of genetic testing and counseling. Unless there is absolute certainty, either zero or one hundred percent, risk theory suggests that most people tend to overestimate low numeric risks and underestimate high numeric risks.³⁷ In a study of 1,369 genetic counseling cases conducted in the late 1970s, researchers found that patients interpreted the numeric risks they were given by geneticists as lower than the geneticists themselves interpreted the risks.³⁸ Patients in that study interpreted risks as high as fifty percent as "moderate" on a five-point scale, while geneticists interpreted risks over ten percent as "high."

Preliminary results from our new study suggest that this type of interpretation may no longer be the case. Patients seem to be interpreting

36. SOPHOCLES, *OEDIPUS THE KING*, line 316 (David Greene & Richmond Lattimore ed., David Greene Trans. 1954).

37. Amos Tversky & Daniel Kahneman, *Judgment under Uncertainty: Heuristics and Biases*, 185 *SCI. 1124*, 1124 (1974); Daniel Kahneman & Amos Tversky, *The Psychology of Preference*, 246 *SCI. AM.* 160, 164 (1982) (explaining risk theory).

38. Dorothy C. Wertz et al., *Clients' Interpretation of Risks Provided in Genetic Counseling*, 39 *AM. J. HUMAN GENETICS* 253, 256-57 (1986).

risks of twenty-five percent or more as "high" or "very high." In keeping with risk theory,³⁹ some of those given the lowest risks, one to three percent, tend to overestimate these risks as "moderate" rather than "low." Final results showing changes in risk perception may indicate that counseling has become more informative. Changes in risk perception also may result from the increased availability of prenatal diagnosis and other reproductive options which allow people to interpret their risks as high, because they may have a possibility of averting the risk.

How people interpret risks and approach testing may depend to a large extent on whether a condition is treatable or preventable. Geneticists tend to assume that once a test is available, people will rush to take it. So far, history has proved them wrong. Genetics centers are not flooded with people requesting carrier tests for cystic fibrosis ("CF"), as was the prediction when the gene was found. Huntington disease has not been eliminated in one generation, as was predicted when presymptomatic testing became possible. Some geneticists assumed that everyone at risk would be tested so that persons with the gene would refrain from having children.⁴⁰ Before tests became available, surveys suggested that most at-risk people would take a presymptomatic test. Once the test became real, people acted differently. About fifteen percent of those eligible actually got tested for Huntington disease; most people preferred not to know. Predictions of a public stampede for cystic fibrosis carrier testing likewise have proven false, another overestimate of the effects of a particular piece of genetic information on public health. Apparently, most people are interested in cystic fibrosis testing only if the issue is really salient,

39. See generally Tversky & Kahneman, *supra* note 38. Tversky & Kahneman's theory of risk points out that people employ three heuristics or biasing factors to expectations about outcomes: representativeness (the degree to which a particular outcome is regarded as representative of all outcomes); availability (whether one can easily bring to mind an example of the outcome); and anchoring (prior belief before viewing new information). Prior beliefs about one's experiences with the outcome reached (a child with a genetic condition) influence the interpretation, even if new and different information is provided in genetic counseling.

40. Seymour Kessler, *Attitudes of Persons at Risk for Huntington Disease Toward Predictive Testing*, 16 AM. J. MED. GENETICS 259, 266 (1987); Miriam Schoenfeld et al., *Potential Impact of a Predictive Test on the Gene Frequency of Huntington Disease*, 18 AM. J. MED. GENETICS 423, 423-29 (1984). For surveys suggesting that almost two-thirds of those at risk would use presymptomatic test for Huntington disease, and that almost half would use prenatal tests, see Gregory J. Messen & Roxanne L. Bechek, *Integrated Use of Predictive Testing by those at Risk for Huntington Disease*, 26 AM. J. MED. GENETICS 283, 283-93 (1987). See also Irene S. Markel et al., *At-Risk Persons' Attitudes Toward Presymptomatic and Prenatal Testing of Huntington Disease*, 26 MICH. AM. J. MED. GENETICS 295, 295-305 (1987).

usually if they are pregnant, and a health professional suggests testing.⁴¹ Even people with cystic fibrosis in the family sometimes must be “sold” on testing by having someone come to the home to do the counseling and testing.⁴² One reason for lack of interest is that the chances that both partners in a couple are CF carriers is rare; about one in 2,500 for whites, far less for Asians or African-Americans. Thus, testing is not salient in daily life. Knowledge of carrier status makes the disease no more treatable; it only adds to the difficulty of decisions about reproductive options for carrier-carrier couples who, in three out of four pregnancies would have been equally well off not knowing their carrier status. Nothing in the overall situation would predict a massive surge in testing unless profit-motivated commercial forces convinced primary care physicians to test patients, especially pregnant women, in order to protect themselves from lawsuits.

Geneticists could have anticipated the lack of interest in CF testing from earlier studies of families with CF.⁴³ Family members were eligible for DNA linkage testing and for prenatal diagnosis for several years before testing of the general public became possible, yet few took the opportunity.⁴⁴ Most considered prenatal diagnosis and abortion of fetuses with CF an unacceptable alternative for themselves, though they thought it should be available for others.⁴⁵ The knowledge simply was not useful. Treatment seems to be doing an “end run” around carrier testing. As people with CF live longer and healthier lives, due to improvements in conventional therapies, there may be even less interest in carrier tests.

Looking further back into history, one might have seen the future of

41. Susan Katz Miller, *Few Take up Offer on Gene Screening*, NEW SCIENTIST, Sept. 18, 1993, at 139; Frances A. Flinter et al., *Population Screening for Cystic Fibrosis*, 339 LANCET 1539, 1539-40 (1992).

42. Jeffrey R. Botkin, M.D., M.P.H. & Sonia Alemagno, Ph.D., *Carrier Screening for Cystic Fibrosis: A Pilot Study of the Attitudes of Pregnant Women*, 82 AM. J. PUB. HEALTH 723, 723-25 (1991). For a review of the current acceptance of cystic fibrosis carrier testing in the five studies sponsored by NIH, see *ELSI's Cystic Fibrosis Experiment*, 274 SCIENCE 489 (Oct. 25, 1996). Acceptance has ranged from one percent to seventy-seven percent, with the higher uptakes among pregnant women. According to Frances Collins, Director of the National Center of Human Genome Research, the public has responded “coldly” to offers of cystic fibrosis testing.

43. Dorothy C. Wertz et al., *Attitudes Toward Abortion Among Parents of Children with Cystic Fibrosis*, 81 AM. J. PUB. HEALTH 992, 992 (1991); Dorothy C. Wertz et al., *Attitudes Toward the Prenatal Diagnosis of Cystic Fibrosis: Factors in Decision Making Among Affected Families*, 50 AM. J. HUMAN GENETICS 1077, 1078 (1992).

44. See *supra* note 43.

45. *Id.*

CF testing by looking at sickle cell carrier testing, now available for twenty years.⁴⁶ There is no evidence that testing and counseling, although widespread under public health programs, have affected most people's lives in African-American communities. Some families have used the knowledge to make reproductive decisions; most have not. For some reason, many geneticists thought that whites would respond differently to cystic fibrosis carrier testing than African-Americans have responded to sickle cell carrier testing. So far they have not.

The issues raised by carrier testing are not new. In the 1950s, many high school health or biology courses taught students the pitfalls of Rh incompatibility. If you and your mate had the wrong combination, you could have at most two or three live children, at a time when the ideal family size for college-educated women was four or five.⁴⁷ Health and science fairs provided on-the-spot free blood tests so that people could know their type and Rh status. However, it is doubtful that many dating couples asked each other about blood types. They likely went ahead and hoped for the best, as most people do today.

In the future, much genetic testing will be risk estimation rather than presymptomatic or reproductive testing. Having a gene for breast cancer creates an elevated risk, but not a certainty; not having a breast cancer gene provides risk equal to that of other women. This is unless there happens to be some other gene for breast cancer that has not yet been found, or there exists some environmental or dietary exposure. Currently each test provides an "information gribble" that may be added to other little pieces of information to provide an incomplete and uncertain picture. If the information led to proven methods of prevention or early treatment, there might well be a stampede for testing. For example, the fact that women can "do something" to prevent breast cancer, namely have prophylactic mastectomies, unattractive and unproven as this option is,⁴⁸ has led to an interest in BRCA1 testing that may surpass interest in

46. For a history of sickle cell testing, see James E. Broman, *Genetic Screening Toward a New Eugenics*, in *IT JUST AIN'T FAIR: THE ETHICS OF HEALTH CARE FOR AFRICAN-AMERICANS* 165, 165-181 (Annette Dula & Sara Goening eds., 1994).

47. Gamma globulin injections to desensitize the mother after each birth now have virtually eliminated problems of RH incompatibility. For ideal family size in the 1950s, see Friedan, *supra* note 19.

48. There is, as yet, no scientific proof that prophylactic mastectomies prevent cancer or prolong life. Cancer still may occur in lymph nodes adjacent to the breast. In women with breast cancer genes, cancer also may occur in the ovary. *Report of the Working Group of the Stanford Program in Genomes, Ethics, and Society on Genetic Testing for Breast Cancer Susceptibility* 4, 6 Stanford University, Center for Biomedical Ethics, Nov. 1, 1996, Palo Alto, Cal. (on file with author).

CF testing.⁴⁹ To date, the volume of requests has fallen short of biotechnology company expectations.

It remains questionable whether knowledge is a good in itself, in the absence of clear usefulness. Although our culture says we have an obligation to know as much about ourselves as possible, this statement is based on the assumption that the knowledge will someday prove useful. For example, if it costs \$100 to make an individual fully aware of the facts about recessive carrier status for cystic fibrosis or sickle cell, should society pay for this? Should society expect something in return, like perhaps the judicious use of the knowledge to prevent the births of children with these conditions? Or is such an expectation eugenics? The \$100 estimate is not unrealistic, based on experiments in conveying information.

Knowledge is not necessarily always a good in itself, or even a good at all. Testing children for diseases that may occur later in life that are neither preventable nor treatable is a good example. In such a case, the child is presented with a "genetic destiny," unasked for and perhaps unwanted. Almost half of U.S. geneticists in our survey have faced such requests, usually from parents who think the knowledge is a good in itself and who want to do the best for their children. Most geneticists report they would refuse a parent's request to test minors under eighteen for genes for Huntington disease or Alzheimers disease. However, most patients and primary care physicians think parents ought to be able to have their children tested for these diseases, based on the good of the child, not parental autonomy. There have been statements opposing testing of minors unless there is a clear benefit to the minor, by groups including: the American Society of Human Genetics; the American College of Medical Genetics; the American Medical Association; and the Clinical Genetics Society in the United Kingdom.⁵⁰ These statements point to the possibility of lowered self-esteem, stigmatization, family conflict, and the shifting of family resources away from a child who may later develop a genetic disorder.⁵¹

In the future, there will be more tests providing pieces of information and showing different levels of risk for conditions that may appear at

49. *Gene Tests Get Tested*, 275 *SCI.* 782 (1997). Fewer than half, of the women offered BRCA testing at two clinical centers, accepted it.

50. American Society of Human Genetics Board of Directors and American College of Medical Genetics Board of Directors, *Points to Consider: Ethical, Legal, and Psychosocial Implications of Genetic Testing in Children and Adolescents*, 57 *AM. J. HUMAN GENETICS* 1233, 1233 (1995); Dorothy C. Wertz et al., *Genetic Testing for Children and Adolescents: Who Decides?* 272 *JAMA* 875, 880 (1994).

51. *See id.*

widely varying ages if at all, that may have symptoms varying from mild to severe, and that may have evolving treatments. Many of the ethical problems in counseling arise from these uncertainties. Some geneticists hope that very refined tests may solve many of our ethical problems by providing greater certainty. Such tests might, for example, tell people exactly the age they will develop breast cancer, or how tuberous sclerosis, which ranges from a few spots on the skin to severe mental retardation, in a fetus actually will express itself in a child.⁵² Although few medical tests are absolutely certain, development of greater predictive value will at least place genetic testing more firmly within the realm of medical testing generally. In time, it may become routine to have a "multiplex test"⁵³ for several hundred genetic conditions once in one's lifetime, probably in the context of family planning or pregnancy. If the once-in-a-lifetime multiplex test ever becomes reality, accompanied by increased knowledge of treatment, prevention, and responses to drug dosages, it may be possible to plan truly individualized medicine on the basis of genotype. This would fit into the context of "postmodern" approaches that emphasize the unusual and the individual, rather than applying one standard or routine to everybody.⁵⁴

IX. PROFESSIONAL-PATIENT INTERACTIONS: EXPECTATIONS AND REALITIES

Patients in the survey and consumers in the focus groups placed accuracy of information and respect for persons at the top of their wish list for "genetics encounters."⁵⁵ Of general importance were providers who know when to refer and are willing to do so, who know and admit their own limitations, who describe their expectations at the beginning of the counseling session, who avoid facile judgements about prognosis, who avoid making assumptions about people's choices and values, and who spend adequate time, including preparation for the counseling session

52. NEIL A. HOLTZMAN, M.D., M.P.H., PROCEED WITH CAUTION: PREDICTING GENETIC RISKS IN THE RECOMBINANT DNA ERA 232, 232-47 (1989).

53. Institute of Medicine, *Assessing Genetic Rides* 297-98 (1994); see also PHILLIP KITCHER, THE LIVES TO COME: THE GENETIC REVOLUTION AND HUMAN POSSIBILITIES 24-25 (1996), for a hypothetical description.

54. Adele Clarke, *Modernity, Postmodernity, & Reproductive Processes ca. 1890-1990*, or "Mommy, Where do Cyborgs Come from, Anyway?," in THE CYBORG HANDBOOK 139, 139-56 (Chris Hables Gray ed., 1995).

55. Betsy Anderson of the Federation for Children with Special Needs, Boston, Ma., originally coined this term to mean any situation where genetic information is transmitted. See Wertz & Gregg, *supra* note 17, at 3.

and follow-up.⁵⁶ Respondents also stressed the importance of educating ancillary medical personnel, such as office managers and receptionists; a team approach to care, with the patient/family as a member of the team; ongoing evaluation of performance; communication skills; awareness of familial aspects of genetics; and addressing all aspects, including social aspects, of the situation. Most of this sounds like a prescription for good medicine in general. The only item that may be more pertinent to genetics than some other specialties is the awareness of the familial aspects of the situation.

Two items of the greatest concern to bioethicists are missing from the list of patient's responses: privacy and nondirectiveness.⁵⁷ This does not mean that respondents had no interest in privacy; they certainly did not want insurance companies or employers to have access to personal information.⁵⁸ On the other hand, privacy was not among their major concerns in the clinical situation.⁵⁹ The issue of privacy arose in the focus groups only with regard to the difficulty of obtaining or transferring medical records to new specialists. This resulted in the frequent need to re-take tests, at the client's considerable expense, rather than wait for releases and delayed paperwork. Some respondents looked forward to the possibility of carrying their genotype and medical record on a credit-card-sized chip.

Nondirectiveness is another matter. As explained earlier,⁶⁰ genetic counseling has been "nondirective" in its philosophy ever since Sheldon Reed coined the term in 1947.⁶¹ Master's-level counselors in particular have employed this philosophy. A nondirectiveness philosophy requires medical professionals to support whatever decisions clients make, even if the medical professional personally disagrees with the decision.⁶² Nondirectiveness means helping clients determine what decisions are best for them, in view of their own values and goals, including their parenting goals. Medical professionals may help clients adjust to and cope with genetic conditions. Above all, doctors and counselors help clients understand their options, and the present state of medical knowledge, so that

56. Wertz & Gregg, *supra* note 17, at 5 (illustrating the "holistic awareness and approach").

57. *Id.*

58. *Id.* at 40-43.

59. *Id.* at 5.

60. See *supra* Part III and accompanying notes.

61. Reed, *supra* note 15, at 335.

62. See generally Fraser, *supra* note 16.

they can make informed decisions.⁶³ It is considered highly directive for a genetics professional either to tell his people what he would do in their situation, or to tell his clients what they ought to do.⁶⁴ In the 1985 survey, thirty-one percent of U.S. geneticists also rejected, as directive, the option of informing clients about what other people in a similar situation did.⁶⁵

Although belief in nondirectiveness is the "motherhood and apple pie" statement of U.S. genetic counseling, there is no evidence that this is what people really want. Both patient surveys and focus groups suggest that most people would be very angry if a counselor told them what to do in the context of reproduction, which is where nondirectiveness started. People also would be angry if they received purposely biased information presented as scientific fact. On the other hand, people want some sort of advice, direction, and guidance in addition to the plethora of "facts" provided in counseling sessions. Another speaker at the National Society of Genetic Counselors ("NSGC") conference described today's genetic counseling as providing pictures of foreign destinations, outcomes of possible decisions, without providing any maps or travel guides.⁶⁶ People want guidance in arriving at these destinations. They do not really want a value-neutral counselor who acts as an information machine. Videos and printed information, to be absorbed gradually after the session, might better perform this function. People prefer facing a human being who has a set of values and who cares about them and about their own values and concerns.⁶⁷ A few parent groups have even suggested that sometimes it may be appropriate for counselors to tell clients what the counselor would do in their situation.⁶⁸

Recently, nondirectiveness has come under professional scrutiny. Sey-

63. See generally James R. Sorenson et al., *Reproductive Pasts, Reproductive Futures: Genetic Counselling and its Effectiveness in 17 MARCH OF DIMES BIRTH DEFECTS FOUNDATION, BIRTH DEFECTS: ORIGINAL ARTICLE SERIES* (1981). This questionnaire survey of 1,369 genetic counseling cases is the largest study to date of clients' and counsellors' perceptions of the context of genetic counseling sessions. Clients filled out questionnaires before counseling, immediately after, and after six months. Counselors also filled out questionnaires after counseling. There were no questions about ethics or about prenatal diagnosis.

64. *Id.*

65. Wertz, *Genetics and Ethics Around the World*, *supra* note 9, at 35.

66. Sonia M. Suter, J.D., M.S., *A Fresh Look at Non-Directiveness*, paper presented at National Society of Genetic Counselors, Inc., Oct. 26-29, 1996, San Francisco, Cal. (on file with author).

67. Wertz & Gregg, *supra* note 17, at 13.

68. *Id.*

mour Kessler, who has trained a generation of genetic counselors, argued at a recent meeting of the NSGC that nondirective counseling might be bad counseling and that the time had come to de-emphasize nondirectiveness.⁶⁹ People want and need respect, understanding, and empathy. According to Kessler, telling people that as a medical professional you will support any decisions they make is highly directive because it preempts the moral high ground and denies the client any opportunity to express autonomy by differing from the counselor. Counseling does not change people's views on ethical issues, a statement borne out by "before-and-after" comparisons in our patient survey, and both client and counselor deserve a chance to express their views.

The vast majority of counselors in North America attempt to provide information that is "as unbiased as possible" after a prenatal diagnosis that indicates a genetic condition in the fetus. To their credit, these counselors also try to avoid letting their personal attitudes toward aborting or carrying to term influence how they provide this information. Outside North America, most counseling is directive: the counselor provides the client with intentionally slanted information in order to influence the client's decision. This is without the counselor's having suggested the course of action.⁷⁰

Giving purposely slanted information under the guise of medical/scientific "fact" or "truth" is morally worse than openly urging people toward a particular course of action. Clients given false "facts" have no opportunity to resist. Falsification is the foundation of successful propaganda. In some countries that offer few services for people with disabilities, providing pessimistically slanted information may serve unspoken social ends. There was, however, also pessimistic counseling in some nations with more advanced services, such as the Netherlands and Israel. Although the majorities in some nations of Northern and Western Europe would try to be unbiased for *some*, but not all, fetal conditions, most geneticists elsewhere would present slanted information, especially in Latin America and Asia. Thus, information may be optimistic or pessimistic, depending on the condition, the culture's view of the condition, and the respondent's

69. Seymour Kessler, Ph.D., *Non-Directiveness Revisited*, at the Dr. Beverly Rollnick Memorial Lecture at National Society of Genetic Counselors, Inc., Oct. 26-29, 1996, San Francisco, Cal. (on file with author). See also Seymour Kessler, *Psychological Aspects of Genetic Counseling VII: Thoughts on Directiveness*, 1 J. GENETIC COUNSELLING 9, 9-18 (1992).

70. Dorothy C. Wertz, Ph.D., *Ethical Views of European and Non-European Geneticists: Results of an International Survey*, paper presented at the European Society of Human Genetics, May 24, 1995, Berlin, Germany (on file with author).

personal view about the morality of abortion. Often there were no clear "culture areas."⁷¹ Geneticists in Spain differed from geneticists in Portugal, for example, with regard to the kind of information they would provide about most conditions. Many geneticists outside North America said that it was their duty to present information in such a way that patients would "do the right thing" or "prevent harm." They may have considered themselves nondirective, as did ninety-nine percent of international respondents to the 1985 survey,⁷² as long as they refrained from actually telling people what to do. No respondent reported that providing slanted information was dishonest.

What do clients in North America get from genetic counseling sessions? Apparently quite a bit of information about genetics, according to Kessler, often more than they can absorb in one session.⁷³ Clients also get as much empathy as there is time for under the social/economic constraints faced by medicine generally. Studies by geneticists James Sorenson in 1977-79,⁷⁴ and my own 1993-96 study, indicate that counseling concentrates on diagnosis and risk. Both studies asked clients and counselors to report on what was discussed during sessions. In 1977-79, few counselors discussed psychosocial issues such as the cost to a family for the care of someone with a genetic condition; the financial resources available to the family; how providing care for someone with a genetic condition may affect society; the potential effects of parent's marriage; changes in a family's quality of life; or the effects on other children in the family.⁷⁵ In 1993-96, despite the influx of Master's-level counselors trained in these areas, the situation remained much the same. Only two to four percent of patients reported having discussed these topics in counseling.

Other topics rarely discussed in today's counseling, despite all the legal and ethical emphasis on privacy, include telling your health insurer about a genetic diagnosis (two percent); telling your employer (one percent); or telling your blood relatives (thirteen percent). The major topics actually discussed in depth are why a genetic disorder occurs (sixty-three percent); treatment options (thirty-eight percent); carrier testing (thirty-three per-

71. "Culture areas" refers to geographic areas that are contiguous and share closely related languages.

72. Wertz, *supra* note 9, at 34, 35.

73. See Kessler, *supra* note 69.

74. Sorenson et al, *supra* note 63, at 2-3.

75. *Id.* See also Dorothy C. Wertz et al., *Communication in Professional-Lay Encounters: How Often Does Each Party Know What the Other Wants to Discuss?*, in 2 *INFORMATION & BEHAVIOR* 329 (Brent D. Ruben ed., 2d ed. 1988).

cent); development over a lifetime of an individual with a genetic disorder (thirty-three percent); and education for the person with the disorder (twenty-seven percent). For the fifteen percent of clients who discussed having children, major items discussed were their chances of having a child with a genetic condition (forty-seven percent); and prenatal diagnosis (thirty-seven percent).

The topics patients were most interested in discussing paralleled those that counselors most wanted to discuss: why a genetic disorder requires treatment, chances of having a child with a genetic disorder, and carrier testing. Patient comments do not indicate any expectations about discussing psychosocial or economic issues, or any disappointment that these were not discussed. Whether they should be discussed in a really optimal session or a follow-up session is a matter for serious consideration among those establishing professional standards. Some practice manuals⁷⁶ and consumer statements suggest that much of a session's time should be devoted to these issues.

Between 1977-79, counselors were aware of what clients most wanted to discuss in only twenty-six percent of sessions. In fifty-two percent of sessions, counselors remained unaware of patients' interests even after forty-five minutes to an hour of counseling.⁷⁷ Preliminary analyses of the 1993-96 data suggest that communication may have improved, largely because both parties say they are now most interested in "why a genetic disorder occurs," a major interest of counselors in the earlier study.

Patients' ethical views ascertained through thirty-eight case vignettes on questionnaires before and after counseling in 1993-96 did not change after counseling. This is partly due to the fact that ethical issues rarely are discussed in counseling. Only four percent of patients reported that ethical or moral issues were discussed, even though the questionnaire explained what ethical issues were, as opposed to technical issues, for example.

In a 1977-79 survey, ninety-five percent of counselors reported that they were satisfied or very satisfied with counseling sessions.⁷⁸ Satisfaction was related to the counselors' perceptions that clients understood

76. DOROTHY C. WERTZ ET AL., WHO GUIDELINES ON ETHICAL ISSUES IN MEDICAL GENETICS AND THE PROVISION OF GENETICS SERVICES, HEREDITARY DISEASES PROGRAMME, WORLD HEALTH ORGANIZATION 63-65 (1995) [hereinafter WHO GUIDELINES]. See also Wertz & Gregg, *supra* note 17, at 5, 79-88, 94-96.

77. See generally *supra* note 73.

78. Dorothy C. Wertz et al., *Can't Get No (Dis)satisfaction: Professional Satisfaction with Professional-Client Encounters*, 15 *WORK & OCCUPATIONS* 36, 36-54 (1988).

etiology and prognosis, even if they actually did not, and to the client's level of education.⁷⁹ According to the 1993-96 survey, "Can't get no (Dis)satisfaction," the title of our earlier paper, is still the general rule. Satisfaction, as before, rests on counselors' perceptions of clients' understanding of information. In the United States, ninety-seven percent of geneticists would be satisfied as long as the patient understood the medical/genetic information; fewer, thirty-seven percent, would be satisfied if the patient received emotional support but then forgot the information. In the United States, most counselor satisfaction is not tied to whether or not patients have prenatal diagnosis or abort "defective" fetuses, though ninety-one percent of counselors would be dissatisfied if legal abortions were not available.

Around the world, there were important differences in the ethical views of male and female providers. In the United States, female M.D.'s were more likely than male M.D.'s to say they would perform prenatal diagnosis for sex selection, more likely to warn relatives at risk against a patient's wishes, and less likely to accede to parental requests to test children for adult-onset conditions.⁸⁰ There was no difference between male and female M.D.'s in directiveness or advice-giving.⁸¹

Outside the United States, female M.D.'s were more likely to offer pessimistic information after prenatal diagnosis, were more pessimistic about disability in general (probably because they knew that women would be the caregivers), were more likely to say they would have abortions, and were more likely to warn relatives of genetic risk.⁸²

Within the United States, the major differences in ethical views were between M.D.-Ph.D. geneticists and Master's-level genetic counselors.⁸³ Counselors were less directive, more optimistic about disability, less willing themselves to abort, more likely to maintain patient confidentiality rather than warning relatives at risk, and more likely to accede to requests for sex selection.⁸⁴ Although this nondirective, individual autonomy-based stance is at the heart of counseling theory, it may also serve to avoid professional turf battles.⁸⁵ Counselors practice, and usually receive, their payments under medical direction. They are also younger

79. *Id.*

80. Wertz, *supra* note 13, at 35.

81. *Id.*

82. *Id.*

83. *Id.*

84. *Id.*

85. *Id.*

than M.D.'s with a median age of thirty-four, as opposed to the M.D.'s median age of forty-two. Counselors also have fewer years in practice, nine as compared to fourteen, and are mostly female, ninety-three percent. A nondirective stance makes it virtually impossible to be criticized by the medical profession. Maintaining patient confidentiality is the traditional ethic. Overriding confidentiality to warn relatives is, however, perhaps easier for M.D.'s who are more firmly established in the professional hierarchy.

Discussions in North America and the United Kingdom focus mainly on patients' *rights* and providers' *responsibilities*. Although it is rare to speak of patients' responsibilities in bioethical discussions, counseling is a two-way street. Interaction depends on patients' honesty, openness, and follow-up. Discussion of patient responsibility is much more common outside of English-speaking nations. Instead of remarking "patients have a right to know" or "a right to decide," geneticists outside the United States state, in their comments, "patients have a responsibility to know," or "they must/ought to decide." Not only the phraseology, but the ethical mode of thought is different. Consideration of patient responsibility could add much to bioethical discussion in North America.

X. ENHANCING OURSELVES: CYBORGS AND HUMAN NORMALCY

The first cyborg was a mouse with an insulin pump.⁸⁶ Cyborgs include anyone who uses a mechanical or chemical assist or implant to improve the functioning of the body. In other words, cyborg includes just about everyone except for people who do not take medications or vitamins. Even so, most of us have had shots to enhance our immune systems. We have been enhancing ourselves since prehistory, through cosmetics, ritual operations, and drugs. An estimated one percent of American women have had breast implants, mostly for cosmetic purposes, rather than to replace a breast lost to surgery.⁸⁷ It is difficult to find anything morally "wrong" about such enhancements. Implants may be considered vain, stupid, or wasteful of medical resources, but most implants are paid for out-of-pocket so there is little likelihood that any resources are being shifted from the poor.

Exactly what is morally or ethically wrong about breast implants?

86. CHRIS HABLES GRAY, *THE CYBORG HANDBOOK* (1995). There currently is much discussion of cyborgs in the cultural studies literature and in feminist treatises.

87. MARCIA ANGELL, *SCIENCE ON TRIAL: THE CLASH OF MEDICAL EVIDENCE AND THE LAW IN THE BREAST IMPLANT CASE* 34 (1996).

Widespread use of such devices may change our concepts of human normalcy but this is not commonly used as an argument against breast augmentation. Similarly, use of human growth hormone to add height to short boys who are within the "normal" range could alter the normal range itself if the "treatment" effectively added to a boy's final height. A wide combination of medications, such as beta blockers, pneumonia immunizations, and cholesterol-lowering drugs, already have contributed to changing "average" life expectancy among the elderly. A medication that would raise IQ probably would receive wide acceptance. In fact, we have been enhancing ourselves for years without concern about changing what is average and without concern about people who are left behind because they cannot afford enhancements. Why should we stop now?

It is only when genetics enters the picture that people become afraid of consequences and bioethicists begin to say enhancement is wrong. Our fear of genetic enhancement is part of our belief that "we are our genes" or that our DNA is somehow equivalent to our soul.⁸⁸ Millions of people are willing to take mood-altering drugs to improve or even enhance their performance, but they balk at the idea of genetic enhancements. This is true even if these enhancements would not involve the gene line limited to one generation only. Using gene therapy to make up for a deficiency, or for treating disease is all right, but bioethicists are afraid of using it to make people "better" than average. Like the parents of Garrison Keillor's fictional Lake Wobegone, most parents desire "all the children [to be] above average."⁸⁹ There may, however, be limits to what parents will do to achieve this. The majority would object to use of prenatal diagnosis and selective abortion to have "perfect babies," or indeed, to prevent anything except severe mental retardation, at least according to our public survey.⁹⁰ Once a child is born, parents usually want that child to do as well as possible and will purchase whatever "enhancement" they can afford.

In some religious traditions such as Hinduism, it is a moral duty to be the best one can possibly be.⁹¹ Therefore, genetic enhancement might be

88. NELKIN & LINDEE, *supra* note 4, at 54.

89. Garrison Keillor's "Prairie Home Companion," a popular public radio program, used as part of its sign off from the fictional Lake Wobegone that "all the children are above average."

90. Using Roper-Stassh Worldwide, we surveyed 988 members of the U.S. adult public, using 20 of the same questions as in the patient survey. See *supra* note 11.

91. George E.C. Sudarshan, *Hinduism*, in *ON THE NEW FRONTIERS OF GENETICS AND RELIGION* 168, 168-69 (J. Robert Nelson ed., 1994).

seen as simply one more form of acceptable human striving.⁹² Asian bioethics does not draw a firm line between what is natural and artificial and does not denigrate the artificial.⁹³ The president of the East Asian Society of Bioethics argues that we should use recombinant DNA techniques to promote "artificial evolution," which he equates with "positive eugenics."⁹⁴

The countries with a potentially positive outlook on genetic enhancement, or at least with few internal cultural barriers to the idea, are Japan, China, and India. These countries possess advanced genetic technology and are active participants in the HGP.

It is probably only a matter of time before somebody, somewhere starts doing genetic enhancement. As Philip Kitcher said, "it is probably impossible to draw a line between making up for a deficiency, for example, susceptibility to pneumonia, and making a positive improvement over the average, like, an enhanced resistance to pneumonia."⁹⁵

When genetic enhancement does become available, it probably will be marketed under other names. The "genetic" likely will be played down: after all, no one wants to be "genetically engineered." The technique undoubtedly will be marketed as preventing a possible deficiency rather than providing an enhancement. If our definitions of "normalcy" change, we will look at this as an advance. Americans already look at history and count added years of life expectancy as a plus. Americans do not complain about increases in average height or express concern that a man as short as John Adams probably could no longer be elected president. Perhaps such concerns should be expressed, but this is unlikely so as long as enhancements are widely available to the middle class. It is not enhancement in itself that is so troubling, however. Rather, of real concern is the possibility of new social rifts associated with increased differences between members of different social classes.

Technologies have a way of sneaking up on us and appearing where not expected: chances are enhancement will appear under another name, yet unsuspected. When, and if, germline gene therapy or germline enhancement ever come, it may be in a form that society has not anticipated and

92. *Id.*

93. Hyakudai Sakamoto, *Towards the New Foundation of the Asian Bioethics*, paper presented at International Association of Bioethics, Nov. 22-24, 1996, San Francisco, Cal. (on file with author).

94. *Id.*

95. See KITCHER, *supra* note 53, at 124-25.

for which we are not prepared.⁹⁶ For example, one proposed technique of avoiding mitochondrial diseases, which are rare but may be severe, would be to use the egg of a woman without the disease and to replace the nucleus with the nucleus from the woman who has the disease. This would provide nuclear DNA from one woman and mitochondrial DNA from another.⁹⁷ Most people think of germline therapy as manipulating genes in the nucleus of an embryo or gamete, not as switching the mitochondria that surround the nucleus. Yet, switching mitochondria would make a permanent and irrevocable change in future descendants, although mitochondria may have little effect on the genotype, and the procedure may have been an offshoot of preimplantation diagnosis rather than of research on gene therapy. The procedure has not yet succeeded in animals and may never become reality. Nevertheless, it is an example of how new technologies appear in unexpected guises and win approval.

XI. EUGENICS AND THE COMING "DISAPPEARANCE OF DISABILITY"

Eugenics⁹⁸ is alive and well in many parts of the world. In China, the stated goal of human genetics is "improvement of the population quality and decrease of the population quantity." Every one of the Chinese geneticists responding to our survey used these words. Geneticists in many countries, especially in East European and developing nations, also expressed eugenic sentiments. "I hate substandard life," said one woman in India, who expressed a sentiment probably felt by many. In Western Europe and Latin America, geneticists eschew the term "eugenics" as meaning a state-sponsored, coercive social program. Instead, these geneticists use the word "prevention," speaking of this as a major goal of genetics. Prevention is supposed to differ from eugenics because it is based on individual and family choices. It also may be based on the purposely slanted information provided by geneticists, discussed earlier.

Yet the history of the Eugenics Movement shows that eugenics actually

96. Andrea Bonnicksen, Ph.D., J.D., *Nuclear Transplantation: Ethical and Policy Implications*, paper presented at the International Association of Bioethics, Nov. 22-24, 1996, San Francisco, Cal. (on file with author).

97. *Id.*

98. The word "eugenics" literally means "well-born" or "of noble heredity" in Greek. The term was coined by Francis Galton, a cousin of Charles Darwin, in 1883, as "a brief word to express the science of improving the stock." FRANCIS GALTON, *INQUIRIES INTO HUMAN FACULTY* 24-25 (1883). According to political scientist Diane Paul, eugenics has had many meanings, including government-mandated programs, socially coerced programs, and individual free choices that, taken together, create a eugenic outcome. KITCHER, *supra* note 53 (discussing eugenics).

has many meanings. It could be voluntary or coerced; government-sponsored or individual; a "science" or a social policy; or based on the welfare of individuals or based on the welfare of society.⁹⁹ Eugenicists included social reformers such as George Bernard Shaw and Bertrand Russell, and believers in individual autonomy such as John Stuart Mill, who urged "responsible parenthood" and said that "to undertake this responsibility—to bestow a life which may be either a curse or a blessing—unless the being on whom it is to be bestowed will have at least the ordinary chances of a desirable existence, is a crime against that being."¹⁰⁰ "Prevention" shades into eugenics, as long as eugenics is voluntary and individual. The word "voluntary" leaves the question, however, of *how* voluntary? Reproductive choices are not made in a vacuum. Economics, women's societal roles, services for children with disabilities, cultural expectations, availability of contraception, abortion, and new reproductive technologies all exert force on individual "choices." It may be said fairly that a woman has no choice about having a child with a genetic condition if an alternative is not available. For example, legal abortion is not available anywhere in Latin America, except Cuba. The same could be said about China and other nations where there are very few services for children with disabilities, or in the United States where services are unevenly distributed.

Nevertheless, "prevention of birth defects" is a major goal of genetics in most nations. A truly eugenic goal, cleaning up the gene pool or reducing "the number of deleterious genes in the population" also was considered "an important goal of genetic counseling" by more than forty percent of respondents in seventeen of the thirty-seven nations surveyed. Most of these were developing nations, including Brazil, China, Cuba, Czech Republic, Egypt, Greece, Hungary, India, Mexico, Peru, Poland, Portugal, Russia, Spain, Thailand, Turkey, and Venezuela.

For many years, "prevention" meant foregoing childbearing by couples at genetic risk. This was illustrated in families with cystic fibrosis, where the child with CF was often the last child born, especially if the couple already had a child without CF.¹⁰¹ Couples reported having changed

99. Diane B. Paul, *Eugenic Anxieties, Social Realities, and Political Choices*, 59 *SOC. RES.* 663, 663-83; Dorothy C. Wertz, *Prenatal Diagnosis and Society*, in *NEW REPRODUCTIVE TECHNOLOGIES: ETHICAL ASPECTS*, VOL. I OF THE RESEARCH STUDIES 191, 193-200 (1993).

100. JOHN STUART MILL, *ON LIBERTY AND OTHER ESSAYS* 120 (John Gray ed., 1991) (1855).

101. Michael M. Kaback et al., *Attitudes Toward Prenatal Diagnosis Cystic Fibrosis Among Parents of Affected Children*, in *CYSTIC FIBROSIS: HORIZONS: PROCEEDINGS OF*

their reproductive plans after the birth of such children.¹⁰² As treatments for CF and life expectancy improve, some of these plans might change once again. As carrier testing became available, other means of "prevention" opened, such as not marrying another carrier or using artificial insemination to prevent the birth of an affected child. These options are not attractive to most Americans.

Prenatal diagnosis has opened up another possibility: marry, conceive, and then selectively abort fetuses with genetic conditions. There is no more ethically troubling problem in genetics than which disorders to abort. Originally, prenatal diagnosis was aimed at "detecting" fetuses with Downs syndrome or open spina bifida, with the assumption that most couples would choose abortion. In the 1985-86 survey, over forty percent of geneticists in eight of the nineteen countries surveyed, reported they would refuse to perform prenatal diagnosis for couples who opposed abortion.¹⁰³ Most would now perform the service if such a couple requested it. In many places, though, it is still a matter for argument whether the service should be "offered" to people who are known to oppose abortion. Although many ethicists' statements about prenatal diagnosis say that genetic testing can be used to prepare for the birth of a child with a genetic condition,¹⁰⁴ this is usually not regarded as its major purpose. Choices are almost never easy. Education and training have improved the lives of some children with Downs syndrome,¹⁰⁵ and treatment has improved the lives of children with spina bifida. Furthermore, prenatal diagnosis is now possible for hundreds of genetic conditions, some of which involve neither mental retardation nor physical disability. Geneticists in the recent survey stated the most difficult questions in the survey concerned how to counsel after prenatal diagnosis and personal attitudes toward abortion found on a list of twenty-four fetal conditions. A majority of M.D. geneticists, both inside and outside the United States, reported that they would abort for fifteen of the twenty-four conditions. In the United States, eighty-five percent would abort for Downs syndrome, ninety-two percent for severe, open spina bifida, seventy-three percent for cystic fibrosis, seventy-two percent for Huntington disease,

THE 9TH INTERNATIONAL CYSTIC FIBROSIS CONGRESS, Brighton, England (David Lawson ed., 1984) (on file with author).

102. *Id.*

103. Wertz, *supra* note 9, at 23.

104. INSTITUTE OF MEDICINE, *supra* note 26, at 166; WHO GUIDELINES, *supra* note 76, at 53-54.

105. See generally MICHAEL BERUBE, LIFE AS WE KNOW IT: A FATHER, A FAMILY AND AN EXCEPTIONAL CHILD (1996).

and fifty-six percent for achondroplasia. A substantial minority, thirty-one percent, would abort for severe obesity in the absence of a genetic syndrome. A majority of U.S. Master's-level genetic counselors would abort for eleven of the twenty-four conditions, though the percentage was somewhat lower than for the M.D.'s. In counseling, the majority of M.D. geneticists in the United States would be "as unbiased as possible" for all conditions except anencephaly, trisomy thirteen, a disorder causing profound mental retardation and leading to death in early infancy, and where the child is not of the sex desired by the parents. (A majority of Master's-level counselors would be nondirective in all situations).

Outside the United States, the majority of M.D. geneticists would present purposely slanted information for all twenty-four conditions. The information was slanted pessimistically so that patients would terminate the pregnancy for most conditions, with the exceptions of cleft lip/palate, predisposition to mental illness or alcoholism, or Alzheimers disease, obesity, or where the child is not of the desired sex. There was, however, wide variation between nations with regard to particular conditions; sometimes there was an almost equal division between optimistic and pessimistic counseling for a condition. There was also substantial minority support for making abortion illegal for those conditions for which many would counsel optimistically. Some written comments from outside the United States gave the impression that some geneticists considered it their duty to provide slanted information, as long as they themselves had an opinion about the morally "right" answer. If they had no opinion or found the situation too difficult to decide, then it was up to the patient to decide, more or less by default. Some counseling reflected a religious opposition to abortion in several countries, notably Chile, Poland, and Spain.

Patients in the United States, ninety-one percent of whom were women, took a somewhat more conservative view toward abortion than did geneticists.¹⁰⁶ A small majority would abort for four of the twenty-four conditions, described as "child would be severely retarded, unable to speak or understand, with nearly normal lifespan;" "child would be severely retarded and would die within first few months of life;" "child would be born without a brain and would die soon after birth;" and "child would have a blood condition with periods of extreme pain and shortened life expectancy." On the geneticist questionnaire, these were Hurler syn-

106. See Dorothy C. Wertz, Ph.D. et al., *Attitudes Toward Abortion Among Parents of Children with Cystic Fibrosis*, 81 AM. J. PUB. HEALTH 992, 994 (1991).

drome, trisomy thirteen, anencephaly, and sickle cell anemia. The word "pain" in the lay description of the latter probably influenced many patients. We included a screening question in order to allow respondents who thought that most abortions should be illegal to skip over the abortion questions. Some of the twenty-five percent who thought abortions should be illegal except to save the mother's life answered the questions about abortions for fetal conditions anyway. Interestingly, their responses to abortion for genetic conditions paralleled the responses of those who did not oppose abortion. It is almost as if, in agreeing with the statement that abortion should be illegal, they had not previously considered the idea of fetuses with genetic conditions or other malformations.

In our survey of the U.S. public, there was only one fetal condition for which a fifty-six percent majority would abort: the child who would be severely retarded, unable to speak or understand.

Our results suggest that while geneticists would abort for the majority of disorders listed, patients would be reluctant to do so. There is considerable room for further research on how such different world views are mutually understood in the process of counseling, if indeed they are understood.

In recent years, opposition to prenatal diagnosis has come from some feminists and disability rights activists.¹⁰⁷ These individuals claim to support a woman's right to abortion for other reasons, but they argue that selective abortion after prenatal diagnosis keeps people with disabilities out of the world. They suggest that this is not only unfair, but devalues the lives of living persons with disabilities.¹⁰⁸ They are afraid that people with Downs syndrome, achondroplasia, cystic fibrosis, mental retardation, and deafness are going to disappear, eliminated before birth by a heartless, discriminatory eugenics process comparable to the Nazis' killing program for children with mental retardation.¹⁰⁹ People with disabili-

107. Ruth Hubbard, *Prenatal Diagnosis and Eugenic Ideology*, 8 *WOMEN'S STUD. INT'L. FORUM* 567, 567-76 (1985); Adrienne Asch, *Reproductive Technology and Disability*, in *REPRODUCTIVE LAWS FOR THE 1990's* 69, 107 (Sherrill Cohen & Nadine Taub eds., 1989); Adrienne Asch & Gail Geller, *Feminism, Bioethics, and Genetics*, in *FEMINISM AND BIOETHICS: BEYOND REPRODUCTION* 318, 331-339 (Susan M. Wolf ed., 1996); Marsha Saxton, *Born and Unborn: The Implications of Reproductive Technologies for People with Disabilities*, in *TEST-TUBE WOMEN: WHAT FUTURE FOR MOTHERHOOD?* 298 (Ruth Arditti et al. eds., 1984). For a response to these views, see Dorothy C. Wertz & John C. Fletcher, *A Critique of Some Feminist Challenges to Prenatal Diagnosis*, 2 *J. WOMEN'S HEALTH* 173, 173-88 (1993).

108. *Id.*

109. For a description of the Nazi killings of people with mental retardation, see

ties are saying, in effect: "Look at me. You are devaluing my life and telling me my life is not worth living, if you have a selective abortion."¹¹⁰

There are two issues here that should be considered separately before they are considered together: disability and abortion. Abortion actually may be the easier topic. Disability rights activists do not oppose preconception measures to prevent disability, such as immunizations to prevent rubella or folic acid to prevent spina bifida, even though these measures will greatly diminish some disability communities. Deaf Culture, in particular, will soon diminish with the virtual disappearance of rubella among pregnant women. Nor do disability activists oppose use of contraception or voluntary sterilization by couples at risk for having children with genetic conditions. Yet contraception keeps more people, including people with disabilities, out of the world than prenatal diagnosis ever will. Many couples at risk prefer to avoid having children rather than face decisions about prenatal diagnosis and abortion.¹¹¹ In the end, the result of all these measures is the same: people with disabilities are kept out of the world. It is only when the measure used is selective abortion that the feminists and disability rights activists become upset, however.¹¹² They argue that contraception is not discriminatory. It is the selection of a particular "person" for destruction, through abortion,¹¹³ that upsets opponents of prenatal diagnosis. This disserves their claim to reject the belief that the fetus is a person. Most of these arguments against prenatal diagnosis are based on an implicit belief in the personhood of disabled fetuses and sometimes on personal identification with these fetuses. This leads to some twisted logic, because most opponents of selective abortion also believe in a woman's right to choose.¹¹⁴ If a fetus is a person, then women should not be having abortions at all. Or does a fetus only become a person if it has some special characteristic, such as disability? I doubt that many families will subscribe to the rather convoluted logic of the arguments put forward by this small but vociferous group of opponents.

The issue of attitudes toward disability and keeping people with disabilities from being born is quite complex. Geneticists around the world,

MICHAEL BURLEIGH, *DEATH AND DELIVERANCE: EUTHANASIA IN GERMANY, 1900-1945* (1994).

110. *Id.*

111. See Kaback et al., *supra* note 101.

112. See *supra* note 107.

113. Opponents of prenatal diagnosis use exactly the same arguments against preimplantation genetic diagnosis.

114. See *supra* note 107.

with the exception of Master's-level counselors in the United States, take a generally dim view of disability. Most do *not* think that all disabilities can be overcome, even with maximum social support. Most do *not* think that "the existence of people with severe disabilities makes society more rich and varied." In twenty-five of the thirty-seven nations, not including the United States, majorities thought "it was unfair to a child to bring it into the world with a serious genetic disorder." In twenty nations¹¹⁵ majorities thought that "it is socially irresponsible knowingly to bring an infant with a serious genetic disorder into the world in an era of prenatal diagnosis."

The vast majority of geneticists, including Master's-level counselors, have very little experience with support groups for people with disabilities. Most geneticists probably would be quite happy to see most disabilities disappear. Quite rightly, this gives some people with disabilities the shudders as it strikes at the heart of their very being. In reality, however, disabilities will not disappear. This is because most disabilities arise not from genetics, but from poverty, low birthweight, absence of prenatal care, poor maternal or infant nutrition, environmental exposures, accidents, and war. Even in genetics, new mutations arise that will not be diagnosed prenatally. With increasing social disorganization in many parts of the world, we can expect that more, rather than fewer, children may be born with disabilities. In developed nations, prenatal diagnosis will keep a comparative few out of the world, but this will have a negligible effect on the overall proportion of the population with disabilities.

Nevertheless, there are some troubling questions. Many geneticists are discomforted by requests for prenatal diagnosis for what they regard as "minor" conditions. These minor conditions include hand deformities or treatable conditions such as cleft palate. Some geneticists might feel more comfortable if there were some general guidelines about offering prenatal diagnosis in these circumstances. Should the procedure be limited to only "serious" conditions? Who decides what is "serious?" A separate international survey of almost 1,500 geneticists demonstrated the impossibility of defining "serious," and making lists of serious conditions.¹¹⁶ The diversity of views, even within the profession of geneticists, simply is too great. Add to that the potential diversity of patients' views

115. These nations include Belgium, Brazil, China, Colombia, Cuba, Czech Republic, Egypt, Greece, Hungary, India, Israel, Mexico, Peru, Poland, Portugal, Russia, Thailand, Turkey, and Venezuela.

116. B.M. Knoppers et al., *Defining "Serious" Disorders in Relation to Genetics Services: Who Should Decide?*, 57 AM. J. HUMAN GENETICS A296 (Supp. 1995).

and you have an impossible situation, in which the definition of serious is perhaps best left to individual patients.

If prenatal diagnosis can be used selectively to abort a fetus with a disability, is it ethical to turn the tables and use it to selectively abort a "normal" fetus for a couple who specifically desires a child with a disability? In the questionnaire we posed the case of a deaf couple who want a deaf child, like themselves, and who would abort a hearing child. Is it fair to deny this couple, who do not consider themselves disabled, the right to have a child like themselves, while allowing hearing couples the right to abort deaf fetuses? On the other hand, if prenatal diagnosis is provided, is it fair to the child that the deaf couple ultimately will decide to carry to term a child with what most people regard as a considerable disadvantage when compared to hearing children? My colleague, John Fletcher, who is a hearing child of deaf parents, may discuss this case in a future publication. A large majority of geneticists in all countries, except the United States and Canada, would refuse this request. These geneticists cite it as a perversion of prenatal diagnosis to use it to bring a disabled child into the world. Is this a "eugenic" view?

XII. WILL ETHICAL CODES WORK?

Starting with the Nuremberg Code,¹¹⁷ international organizations have put forth general statements about human dignity and human rights.¹¹⁸ Most international codes of ethics in medicine pertain to the ethics of research on human beings. Individual nations have incorporated elements of these codes, especially informed consent, into laws or regulations.¹¹⁹ Funding agencies have enforced these regulations through economic control, such as withholding or withdrawing research funds from researchers.

Codes for clinical practice present a greater challenge. Such codes typically are drawn up by professional organizations without enforcement power. Professionals often regard proposals for codes as restrictive, especially in the United States. This is because these professionals want to

117. The Nuremberg Code arose as a result of the Nuremberg Trials after World War II, during which the Nazis conducted medical experiments on prisoners. It was the first international code of medical ethics and the first international requirement for informed consent.

118. For a brief description of existing codes, see Dorothy C. Wertz & J. C. Fletcher, *Proposed: An International Code of Ethics for Medical Genetics*, 44 *CLINICAL GENETICS* 37, 40-41 (1993).

119. See RUTH R. FADEN & TOM L. BEAUCHAMP, *A HISTORY AND THEORY OF INFORMED CONSENT* 114-226 (1986) (tracing development of informed consent principles):

be able to serve individual patients in unique situations. A code that prohibited such as a specific practice—sex selection—is unlikely to be accepted by U.S. geneticists. A code that says nothing specific and allows many individual interpretations, one that describes different types of relationships rather than actions or principles, would likely find greater acceptance in the United States. The NSGC's Code of Ethics is such a code.¹²⁰ Another example, based on principles rather than relationships, is the CORN "Code of Ethical Principles,"¹²¹ which is a paean to autonomy. These codes have the advantage of flexibility, but inherently are weak and unlikely to have much effect on practice. Another type of code that many professionals find acceptable is what might best be described as the "feel good" statement that puts forth lofty generalities with which it is virtually impossible to disagree but which have little relationship to practice. The UNESCO statement on the Dignity of the Human Genome is an example of such a code.¹²²

There is, however, hope for more concrete codes. The World Health Organization ("WHO") recently has published *Guidelines on Ethical Issues in Genetics*.¹²³ While this is a more concrete code, it is not an official WHO publication.¹²⁴ A team of consumers and providers in the New England Regional Genetics Group also has published comprehensive guidelines for provider-consumer interactions, including a substantial section on ethics.¹²⁵ The NSGC hopes to develop detailed standards of practice.

It remains to be seen whether these codes and guidelines will have any effect. Canada is the one nation that has a longstanding professional code of ethics. According to responses to our survey, Canadian geneticists, however, are not adhering to provisions of the Canadian College of Med-

120. *National Society of Genetic Counselors Code of Ethics*, 1 J. GENETIC COUNSELLING 41, 41-43 (1992).

121. See *Code of Ethical Principles*, *supra* note 35.

122. UNESCO, Preliminary Draft of a Universal Declaration on the Human Genome and Human Rights (Mar. 4, 1995) (on file with author).

123. See generally WHO GUIDELINES, *supra* note 76. The WHO document is an extensive code of practice for clinical genetics, running over 100 pages and covering most ethical problems that appear in practice. Compiled by a small group of WHO advisors, it was designed for use in developing, as well as developed, nations. After a larger consultatory conference, it may become an official WHO publication.

124. Although this is not a code of ethics or standard of care that only can be set by professional groups, the NERGG includes a detailed ethical section relevant to every area of practice. It was designed for use in training health care providers and consumer groups.

125. See generally Wertz & Gregg, *supra* note 17.

ical Geneticists Code¹²⁶ that specifically forbids sex selection.

Another problem is that not only is there no enforcement for professional codes, but also codes developed by one medical specialty may be ignored by another. As genetics becomes part of general medicine, obstetricians, pediatricians, family practitioners, and internists will not necessarily feel bound by a code put forth by the American College of Medical Genetics.

The alternatives, laws and/or regulations, are unattractive because they may be restrictive and difficult to change. In genetics particularly, laws could serve political purposes that are not in people's best interests. For example, Norway has restricted the number of prenatal diagnoses that can be done each year.¹²⁷ Sometimes, laws itemize people's worst fears, like prohibiting the creation of human-animal hybrids, procedures that no one wants to do anyway. A proposed Canadian law forbids such procedures, along with some medically useful procedures.¹²⁸ Sometimes, however, laws may be useful. France has specified the minimum content that should go into counseling before prenatal diagnosis, for example.¹²⁹ In the United States, however, legislating medicine is likely to be dangerous for all concerned.

In the future, the most enforced codes of practice may be based on standards developed by unseen committees at managed care organizations and based on cost-effectiveness analyses rather than on ethical considerations.

XIII. SOME PREDICTIONS FOR THE FUTURE: AMERICAN VALUES AND THE LESSONS OF HISTORY

Although it may seem presumptuous to make future predictions about genetics, I would like to suggest the following will occur:

126. Dorothy C. Wertz, *Professional Perspectives: A Survey of Canadian Providers*, 3 HEALTH L. J. 59, 78-86 (1995).

127. K. Berg & K. E. Trandy, *Ethics and Medical Genetics in Norway*, in ETHICS AND HUMAN GENETICS: A CROSS-CULTURAL PERSPECTIVE 317, 325 (Dorothy C. Wertz & John C. Fletcher eds., 1989).

128. Bill C-47, An Act Respecting Human Reproductive Technologies and Commercial Transactions Relating to Human Reproduction, House of Commons (Canada), 2nd Sess., 35 Parl., 45 Elizabeth II (1996).

129. For a full discussion of current European laws relating to genetics, see Bartha Maria Knoppers & Sonia LeBris, *Ethical and Legal Concerns: Reproductive Technologies 1990-1993*, in CURRENT OPINION OBSTETRICS & GYNECOLOGY 630, 630-34 (1993); Bartha Maria Knoppers, *Professional Norms: Towards a Canadian Consensus*, 3 HEALTH L. J., 1-18 (1995); WHO GUIDELINES, *supra* note 76, at Annex 2.

1) Genetics will become part of general medicine, and the ethical problems that seem so specific to genetics today will be recognized for what they are: problems that pertain to medicine as a whole. This does not mean that we will be closer to resolving these problems. It may be that careful ethical reflection on the need for “genetic privacy” will awaken policymakers to the need for “medical privacy” in general or that genetic counseling’s “nondirective” ethics will spill over into other types of provider-patient relationships. It is perhaps more likely that most genetics services will be provided in the same manner as other types of medicine. In managed care systems, this may mean hurried, assembly-line encounters that focus on tests and treatments rather than on providing information and counseling. Most primary care physicians may be ill-equipped to provide the information and counseling needed, in any case. Genetics will be no better and no worse than other types of medicine in providing unbiased information or helping people make decisions. Many will wonder why genetics was ever expected to produce superior provider-patient relationships, to uphold superior ethical standards, or to allow greater patient autonomy than other fields of medicine. Most counseling will be done by obstetricians, pediatricians, internists, and family practitioners. The small number of certified genetic counselors will be overwhelmed by the need to understand and explain genetic components in most areas of medicine.

2) As time goes on, the public’s fear of genetics will lessen, partly because of greater education about genetics, but mostly because genetics will come to be accepted as just one more area of general medicine. New labels that remove terms like “genetics” and “genetically engineered” will help to decrease fears of new tests and treatments. We already have “genetically engineered” insulin, made by bacteria. There has been no public outcry about this, partly because companies have downplayed the genetic element. When genetic enhancement comes, it will be provided and marketed under other labels.

3) Improved technologies will not solve ethical problems. Even with tests that are one-hundred percent accurate and that predict the severity and age of onset of genetic disorders, people will still face the same agonizing decisions.

4) The future of genetics will be shaped by commerce. Free enterprise, together with democracy, has always been seen at the top of the list of

enduring American core values, even above religion.¹³⁰ Medicine in America has always been, and remains, a business, in spite of statements by ethicists and high-minded professionals that it should not be so. Private enterprise is integral to the HGP, just as it is integral to almost every aspect of American life. At this point, there is no economically feasible alternative to the role of these enterprises, as government cannot support the entire HGP. Commercial interests have a way of restructuring scientific enterprises for their own benefit. This may be neither good nor bad in terms of effects on patients or society. It may mean, however, that some avenues are chosen for exploration over other possible, perhaps equally good or even better avenues. We will not know the full effects of commercialization for perhaps fifty to one hundred years. Meanwhile, all we can do is try to be aware of avenues not taken and to make note of them for future researchers and historians. We also can attempt to limit exploitation of patients and the public through regulations that would require full disclosure of conflicts of interest and ensure that all tests and treatments are accompanied by adequate understandable information.

5) The nature-nurture problem will never be resolved, even after completion of the HGP. We will learn that genetics affects vastly more areas of life than most of us imagined. We also will learn that genetics explains much less about our health and behavior than many people anticipated. In the long run, it may not matter whether we solve the nature-nurture problem. It is not which side one takes that counts, but rather how one uses the information. Believers in nurture can be just as determinist, racist, fascist, and "eugenic" as believers in nature. Therefore, it might be wise to put the nature-nurture problem behind us and to work toward a society that respects human differences.

6) We will use genetics to enhance ourselves, or at least to enhance what society considers desirable characteristics. We have been enhancing ourselves for generations. Self-improvement is a fundamental American value and is a keystone of American-founded religious groups such as Christian Science and the Church of Jesus Christ of the Latter-day Saints (Mormons). Enhancement will creep in slowly, unannounced, without frightening labels such as "germline gene therapy," and will become part of general medicine.

7) Some genetic disorders will become rarer, largely due to prenatal diagnosis. Most of these disorders will be untreatable and will involve

130. See ROBIN M. WILLIAMS, *AMERICAN SOCIETY: MAJOR VALUE ORIENTATIONS IN AMERICA* 454 (1970) (discussing free enterprise as a dominant American value).

mental retardation, death in infancy, intractable pain, or severe physical limitations. Many more disorders, however, will become treatable, though not necessarily by genetic means. Parents who would now forego having another child in order to avoid having one with cystic fibrosis may, in the future, decide to go ahead because treatment for cystic fibrosis has improved. As treatment for a disorder improves, there will be less interest in carrier testing or prenatal diagnosis for that disorder. Both cystic fibrosis and sickle cell anemia will remain with us, as chronic but treatable conditions.

8) America will export its ethical values along with its technology, ultimately leading to world cultural hegemony in bioethics. This is not necessarily "bad" or an example of cultural insensitivity or colonialism. Together with Canada, the United Kingdom, and some other nations, we have some good safeguards, such as informed consent, that are not present in much of the rest of the world. Somewhat greater emphasis on individual autonomy and greater equality in the doctor-patient relationship would not harm most of the world's people and might improve both medical care and the position of women. Of course, we also have some ethically dubious practices, such as patenting of genes and inequality of access to care, that we should probably not try to export. Nevertheless, we need to remember that we are in fact exporting and sometimes imposing our ethics on others, just as we do in business. This is all the more reason to examine our ethics carefully.

TABLE 1
SURVEY RESPONSE RATES

Country	Invited to Participate	Responded	% Responding
Argentina	20	19	95
Australia	26	15	58
Belgium	40	15	138
Brazil	131	74	56
Canada	212	136	64
Chile	15	16	64
China	392	252	64
Colombia	27	15	55
Cuba	96	14	16
Czech Republic	137	81	59
Denmark	54	28	52
Egypt	2	2	100
Finland	53	22	42
France	102	75	74
Germany	418	255	61
Greece	12	12	100
Hungary	78	36	46
India	70	23	33
Israel	27	23	85
Italy	23	22	96
Japan	174	113	65
Mexico	89	64	72
Netherlands	41	26	63
Norway	18	9	50
Peru	16	14	88
Poland	250	151	60
Portugal	22	11	50
Russia	66	46	69
South Africa	21	16	76
Spain	82	51	62
Sweden	15	12	80
Switzerland	10	6	60
Thailand	38	25	66
Turkey	30	22	73
UK	217	102	47
USA	1538	1084	70
Venezuela*	22	16	73
<i>Total</i>	<i>4594</i>	<i>2903</i>	<i>6</i>

* Data from Venezuela are not yet entered