Genetic Dilemmas and the Child's Right to an Open Future

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GENETIC DILEMMAS AND THE CHILD'S RIGHT TO AN OPEN FUTURE

Dena S. Davis*

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I. INTRODUCTION

The Human Genome Project ("HGP"), combined with technological advances in assisted reproduction, raises a panoply of novel issues in law and ethics. Among the thorniest questions are those which appear to pit the autonomy of parents against the best interests of their present or future child. Whereas in the past, parents had no control over the genetic endowment of their children and little ability to predict which genetic diseases their children might fall prey to as they grew up, new technology now gives parents significant information and control. Parents affected by hereditary deafness can ensure that their children will not share their disability—or, they can use the new technology to ensure that their children will be deaf. Parents in families at high risk of Huntington’s Disease, which only shows itself in late adulthood, can now have their children tested for the gene and know the child’s fate before the child is old enough to have any say in the matter. These are only two examples of an almost infinite number of choices, decisions and interventions theoretically available as a result of the HGP.

The “gatekeepers” who mediate the access of laypeople to genetic information and technology have been primarily physicians and genetic counselors, along with Ph.D. geneticists. Ethical standards are spelled out in professional codes of conduct, discussed in Hospital Ethics Committees, and analyzed and promulgated by national bodies such as the President’s Commission for the Study of Ethical Problems in Biomedical and Behavioral Research.  

3. PRESIDENT’S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN BIOMEDICAL AND BEHAVIORAL RESEARCH, SCREENING AND COUNSELING FOR GENETIC CONDITIONS: A
Until recently, genetic medicine and genetic counseling have been characterized by a virtually unquestioned commitment to patient autonomy, expressed through the twin principles of nondirective counseling and value neutrality. Counselors prided themselves on giving their clients\textsuperscript{4} information which empowered them to make decisions based on their own values, with no evaluative comments from the counselors. Even when counselors feared that clients' decisions might lead to a great deal of avoidable suffering, they felt professionally required to hold their tongues. Now, however, this ethic of client autonomy is being challenged by the opportunities created by the HGP. In this paper, I examine three difficult issues raised by the HGP, and lay out an approach that takes seriously the interests of the child, present or future, while preserving the traditional commitment of professional geneticists to patient autonomy. The approach I take is based on Joel Feinberg's concept of "the child's right to an open future."\textsuperscript{5}

In Part II, I describe the Human Genome Project, as well as the advances in assisted reproduction which give people ways to make use of the information engendered by the HGP. In Part III, I discuss the ethics of medical genetics, especially the primacy of client autonomy and how it grounds the tenets of value neutrality and nondirective counseling. I describe three current issues that pose challenges to a professional ethic of value neutrality: (1) disabled parents who seek assistance in ensuring the birth of a child who shares their disability (e.g., hereditary deafness or dwarfism); (2) predictive testing of children for adult-onset genetic disorders; (3) sex selection. In Part IV, the heart of the paper, I construct a new approach to dealing with these issues, based on Feinberg's concept of a child's right to an open future.\textsuperscript{6} I argue that these issues should not be conceptualized as balancing parental autonomy against the welfare of the child, but as balancing parental autonomy against the autonomy (right to an open future) of the child, and I explain why this approach is more likely to yield constructive results. I then return to those questions in greater detail.

\textsuperscript{4}I use the term "patient" and "client" interchangeably in this article. On the one hand, persons seeking information about their genetic endowment, and certainly persons seeking assistance in influencing the endowment of their children, have a "doctor-patient" relationship in the social and legal senses of that term. On the other hand, the term "patient" carries troubling connotations of passivity which are particularly unfortunate in this field, where the person seeking information is often a woman and is (usually) not ill.


\textsuperscript{6}Id.
showing how the issues in Part III fare when subjected to the scrutiny of an approach based on the child’s right to an open future. Thus, in Part V, I discuss the case of deaf parents who ask for assistance in making sure that they have only deaf children. In Part VI, I look at the question of parents who request that their children be tested for genetic disorders that will not manifest themselves until later in life, and in Part VII I discuss parents who wish to select the sex of their offspring.

II. THE HUMAN GENOME PROJECT AND ASSISTED REPRODUCTION

A. The Human Genome Project

The Human Genome Project is an international effort to decipher the entire genetic blueprint of human beings, an undertaking that James Watson, discoverer of the “double helix” and past director of the National Center for Human Genome Research, has described as similar in magnitude to the effort to send a man to the moon. The goal of the 15-year Project, which began in 1988, is to map and sequence the roughly 100,000 genes that make up the human genome. The United States is a leader of this effort, with over $3 billion budgeted for the HGP, primarily channeled through the National Institutes of Health (“NIH”) and the Department of Energy (“DOE”). The medical applications of the HGP fall into three broad categories: increased ability to screen for genetic disorders, such as Huntington’s Disease; the potential to produce “genetic profiles” of


10. “Genome” denotes the complete genetic blueprint of a particular species, in this case, humans. “Mapping” a gene essentially determines its “address,” or location on one of 46 chromosomes, while “sequencing” a gene discovers its actual make-up. Thus, mapping tells us “where” it is, and sequencing tells “what” it is. Because mapping is easier than sequencing, the immediate goal of the 15-year HGP is to map the entire genome, while sequencing the entire genome will come later. NATIONAL INSTITUTES OF HEALTH, THE HUMAN GENOME PROJECT: NEW TOOLS FOR TOMORROW’S HEALTH RESEARCH (NIH-3190) 5 (1992).


individuals to predict their risk for a variety of diseases; and eventually the ability to reverse genetic defects and to use "gene therapy" to treat disorders.\textsuperscript{13}

Unfortunately, our ability to detect and predict genetic disease will precede by some decades any substantial ability to effect cures.\textsuperscript{14} However, even without the ability to "fix" a gene, there are a number of strategies people can employ to use the genetic information that is even now coming out of the Project on virtually a weekly basis.\textsuperscript{15} Whether our use of that information is for good or for ill, remains to be seen. A unique feature of the HGP is that the NIH and the DOE have set aside three percent of the total Project budget to support research on the ethical, legal, and social issues that this new information engenders.\textsuperscript{16}

\textbf{B. New Reproductive Technologies}

Until the late 1960s, all that medicine could offer to worried couples was to ascertain their risk of having children with genetic disorders, and to examine the children upon birth to see how the dice had fallen. Couples, in their turn, could either take their chances or refrain from reproducing. With the advent of ultrasound (which provides an image of the fetus in utero) and amniocentesis, parents were given a new option. Now, early in the second trimester, fetal cells could be drawn out of the amniotic fluid and tested for certain genetic defects, e.g., Down's Syndrome and Tay-Sachs Disease. Parents could then decide whether or not to terminate the pregnancy.

\begin{itemize}
\item \textsuperscript{13} Lori Whittaker, \textit{The Implications of the Human Genome Project for Family Practice}, 35 J. Fam. Prac. 294 (1992).
\item \textsuperscript{14} Genes are being localized far more rapidly than treatments are being developed for the afflictions they cause, and the human genome project will accelerate this trend. The acquisition of genetic knowledge is, in short, outpacing the accumulation of therapeutic power—a condition that poses special difficulties for genetic knowing.

\item \textsuperscript{15} Jacques Testart, \textit{The New Eugenics and Medicalized Reproduction}, 4 CAMBRIDGE Q. HEALTHCARE ETHICS 304, 305 (1995) ("[T]he new eugenics . . . will consist not of manipulation of the genome but in its selection.").
\item \textsuperscript{16} Collins, \textit{supra} note 11, at 264.
\end{itemize}
first, the number of disorders which could be detected were very few, but that number has grown exponentially with the advances of the HGP.  

Amniocentesis, however, has some obvious drawbacks. Although the procedure is considered safe and is routinely offered to women at risk for genetic defects (e.g., all women over 35 are considered at high risk for Down's Syndrome), there is a small risk of infection, injury to the fetus, or an unintended loss of pregnancy. Results cannot be obtained until the second trimester, when the woman may be obviously pregnant and when fetal movements have already been felt. This makes abortion medically more serious and psychologically more difficult. A procedure which is still experimental avoids some of these problems by isolating fetal cells which are present in the bloodstream of a pregnant woman; instead of having to invade the uterus to get at the amniotic fluid, all that is necessary is to draw blood from the mother.

17. When looking for certain kinds of information, one often finds out other things as unlooked for by-products, and these “secondary results,” to coin a term, often raise serious ethical issues of their own. The sex of the fetus, for example, is the most obvious thing the technician sees when performing a chromosomal analysis. This enables amniocentesis to be used for sex selection. Another problem arises when technicians discover very ambiguous information in the course of looking for some other piece of knowledge. For example, there was a time when a boy with an extra Y chromosome was thought perhaps to be at increased risk of violent, criminal behavior. But the link was never clear (it has now been repudiated), and there was an obvious risk of “self-fulfilling prophecy” if parents were warned that their children were at risk. Aubrey Milunsky, Know Your Genes 39-48 (1977). What should geneticists have done if they had discovered, perhaps in the course of doing a test to rule out Down’s Syndrome, that a fetus had this extra chromosome? Should the parents have been told, and perhaps given the opportunity to terminate the pregnancy, or to raise the child with extra care? Robert M. Veatch, The Unexpected Chromosome... a Counselor’s Dilemma, 2 Hastings Ctr. Rep. 8 (Feb. 1972).


19. Mark Evans et al., Genetic Testing and Screening: II. Prenatal Diagnosis, 2 Encyclopedia of Bioethics 986, 988 (rev. ed. 1995). Chorionic villus sampling (“CVS”) is preferable in some ways to amniocentesis because it is a first-trimester technique. The chorionic villi are fore-runners of the placenta and a sample can be obtained by aspiration between nine and twelve weeks of pregnancy. However, increased risk of miscarriage and fetal limb damage are drawbacks of CVS. Id. at 988; Chorionic Le Villus Sampling and Amniocentesis: Recommendations for Prenatal Counseling, 44 MMWR - Morbidity and Mortality Weekly Rep. (Centers for Disease Control) 1 (July 21, 1995).


Because abortion carries medical, emotional and economic costs, it would obviously be preferable to come up with a way to select or avoid genetic characteristics before pregnancy begins. One possibility, which is not yet effective but clearly on the medical horizon, is to sort out gametes before fertilization. This is more readily done with sperm, as they are more easily accessed and manipulated than eggs. Sperm could be collected, analyzed and sorted for the relevant characteristics, and then only the desirable sperm could be used for fertilization. For example, a couple at risk for hemophilia, a genetic disease which affects only males, could have the husband’s sperm sorted to exclude sperm with Y chromosomes (those which will produce male children).

Although gamete sorting is still in the experimental stage, the same goal can be achieved in a more burdensome fashion by combining in vitro fertilization (“IVF”) with preimplantation genetic diagnosis (“PIGD”). IVF is a technique which was developed primarily to help women who cannot achieve pregnancy because their fallopian tubes are blocked. Women with this condition are able to produce eggs, but the eggs cannot travel down the fallopian tubes, become fertilized, and continue their journey to the uterus. In IVF, one or more eggs are removed (by transvaginal aspiration) from the woman’s ovaries, and fertilized in the laboratory with sperm from the partner. The resulting embryos are then placed into the uterus, circumventing the blocked tubes. Because this is a cumbersome procedure with a relatively low success rate, it is now customary to increase the chances of success by hormonally inducing the woman to superovulate, producing an average of ten eggs. These eggs are retrieved and fertilized; three to six are put back in the hope that one or two will implant and grow; any extras are frozen for possible future attempts. The existence of a large number of in vitro embryos makes possible preimplantation diagnosis, in


24. Id.

25. The legal status of these “frozen embryos” has generated a great deal of scholarship and at least one major case, in which a divorced couple faced off over who had the right to determine the fate of their mutual frozen potential offspring. Davis v. Davis, 842 S.W.2d 588 (Tenn. 1992) Most fertility clinics now have the foresight to require clients to decide those issues before undergoing the procedure.
which cells are removed from the eight-celled embryos on the third day after fertilization and subjected to DNA analysis. The results are available within eight to twelve hours, and the individual embryos can then be transferred to the uterus, discarded, or frozen for another day. This technology has been available since the early 1990s. As of 1994, 29 healthy children had been born through the use of this technique, and 11 more pregnancies were in progress.

C. Summary

Because of the Human Genome Project, we are on the brink of being able to identify virtually every genetic aspect of the individual, as well as genetic predispositions which combine with environmental factors to create the added risk of disease. Through the techniques of assisted reproduction, we have the technology to put that knowledge to use by enabling parents to have significant control over the genetic make-up of their offspring. At present, this technology is expensive and cumbersome, which tends to act as a natural check on its use for all but the most serious of concerns (for example, to avert the birth of a child with a fatal genetic disease, such as Tay-Sachs). However, as the technology becomes more streamlined and accessible, questions will inevitably arise as to what constitutes an appropriate use. In III.C below, I describe three such dilemmas, but new ones arise every day.

III. THE ETHICS OF GENETIC COUNSELING

A. The Present Ethos

The genetic counseling profession is characterized by a respect for patient autonomy that is greater than in almost any other area of medicine.


28. See Human Embryo Research Report, supra note 23, at 25. Among the diseases which have been successfully avoided through PIGD are Tay-Sachs, cystic fibrosis, Lesch-Nyhan syndrome, and Duchenne muscular dystrophy.

29. Collins, supra note 11, at 262.
The Code of Ethics of the National Society of Genetic Counselors states that its members strive to:

** Respect their clients' beliefs, cultural traditions, inclinations, circumstances, and feelings.

** Enable their clients to make informed independent decisions, free of coercion, by providing or illuminating the necessary facts and clarifying the alternatives and anticipated consequences.30

Considering the uncertain and stochastic nature of genetic counseling, and especially in light of the difficulty physicians experience in sharing uncertainty with patients,31 it is remarkable that medical geneticists have hewed so strongly to an ethic of patient autonomy. This phenomenon can be explained by at least five factors: the desire to disassociate themselves as strongly as possible from the discredited eugenics movement;32 an equally strong desire to avoid the label of "abortionist" (a realistic fear if counselors are perceived as ones who advocate the abortion of genetically damaged fetuses);33 the fact that few treatments are available for genetic diseases;34 an awareness of the intensely private nature of reproductive decisions; the fact that genetic decisions can have major consequences for entire families.35 As one counselor said, "I am not going to be taking that baby home—they will."36

It should be explicitly stated... that one of the prime tenets of genetic counseling is patient autonomy. Counselors do not seek to tell patients whether they should obtain certain information or what they should do with it if they acquire it. The goal is to inform patients about what is possible and what their options are. Counselors help patients to work through those options and then to decide on their own principles what is the right choice for them.”

*Id.* at 262.


34. *Id.* at 29.


36. ROTHMAN, supra note 20, at 40.
The commitment to patient autonomy is expressed in the twin tenets of value-neutrality and nondirectiveness. The ethos of value neutrality finds expression in the practice of nondirective counseling. Counselors define their task as giving accurate information to clients in such a way that clients can use that information to act according to their own values. Barbara Katz Rothman and others have written about the social and medical pressure women experience to undergo amniocentesis. Nonetheless, even Rothman agrees that most counselors truly value nondirectiveness and "seek it as a goal," even if they do not always succeed in expressing that ideal.

B. The Challenge to Value Neutrality

Arthur Caplan has criticized value neutrality and nondirective counseling, what he calls a "just the facts, Ma'am" approach to counseling. Caplan's critique rests in part on counseling's "powerlessness" in the case of "what may be immoral requests" such as the desire to have a deaf child. Further, Caplan argues that the Human Genome Project makes it imperative that we drop the facade of value neutrality in order to confront the questions of what counts as disease or disorder, what kinds of disorders we wish to target for detection and treatment, and so on. Following Caplan, we might press further and ask, can a condition be defined as a disorder in one family and not in another? In a way, that is already true. One couple might define, e.g., Down's Syndrome, as a disorder so disruptive to family functioning that it necessitates abortion, while another couple would take it in stride. But can we be so value-neutral that a condition that is defined as a disorder in one family is actually an asset in another? Put another way, can we imagine basic health (e.g., normal hearing) being redefined as a disorder?

Imagine a deaf couple approaching a genetic counselor. The couple's goals are to learn more about the cause(s) of their own deafness, and, if possible, to maximize the chance that any pregnancy they embark upon will result in a deaf child. Suppose that the couple falls into the 50% of clients whose deafness has a genetic origin, and into the 33% whose deafness is autosomal recessive. As Walter Nance describes the challenge:

37. Bosk, supra note 33, at 27.
38. ROTHMAN, supra note 20, at 27.
It turns out that some deaf couples feel threatened by the prospect of having a hearing child and would actually prefer to have a deaf child. The knowledge that we will soon acquire [due to the Human Genome Project] will . . . provide us with the technology that could be used to assist such couples in achieving their goals. This, in turn, could lead to the ultimate test of nondirective counseling. Does adherence to the concept of nondirective counseling actually require that we assist such a couple in terminating a pregnancy with a hearing child or is this nonsense?41

The genetic counselor who adheres strictly to the tenets of value-neutral, nondirective counseling will respond by helping the couple to explore the ways in which they can achieve their goal: a deaf baby. (Thanks to the technology described in Part I, the couple’s goals can be realized without recourse to abortion, thus simplifying at least some of the ethical issues.) But as Nance’s depiction of this scenario suggests, the counselor may well feel extremely uneasy about her role here. It is one thing to support a couple’s decision to take their chances and “let Nature take its course,” but to treat as a goal what is commonly considered to be a risk, may be more pressure than the value-neutral ethos can bear.

Robert Wachbroit and David Wasserman offer a helpful but only partial answer to this dilemma in distinguishing value neutrality from nondirectiveness.42 The goal of nondirectiveness is patient autonomy. Value neutrality, they point out, is valued primarily because it appears to be a necessary condition for patient autonomy, the unstated assumption being that the open expression of the counselor’s values undermines clients’ abilities to make their own decisions. Wachbroit and Wasserman challenge that assumption, arguing that clients are not that fragile, and also that unspoken social biases may be more autonomy-threatening than those which are clearly put on the table.43 However, even this useful separation cannot extricate us fully from our dilemma. If a deaf couple approached a counselor looking not only for information but for practical assistance in creating a deaf child, the counselor might not be satisfied with a solution in which she expressed her moral reservations and then went on to help them anyway. What Nance and Caplan seek is a principled argument on which to base a refusal for assistance. This refusal need not rise to a legal prohibition, but

41. Walter Nance, Parables, in Bartels, Prescribing Our Future, supra note 1, at 92.
43. Id. at 108-09.
could become part of the ethical norms and standard of care for the counseling profession.\textsuperscript{44}

\section*{C. Three Genetic Dilemmas.}

(1) The first example of a dilemma occasioned by the new technology has been alluded to above: parents who wish to use the tools of genetics to ensure that they will have only children who share their disabilities. In addition to deaf parents, parents with achondroplasia (dwarfism) have expressed interest in such techniques, not only because it is difficult for dwarf parents to care for and discipline young children who tower over them, but also because people with achondroplasia tend to socialize primarily within a culture made up of other "little people."\textsuperscript{45}

(2) Another example is the controversy that surrounds testing of children for adult-onset genetic disease, e.g., Huntington's Disease ("HD"). HD, which tends to attack people in their 40s and 50s, is a neurological disorder which ends in dementia and paralysis. It is autosomal dominant, meaning that if one parent has the gene, each child has a fifty per cent chance of having the disease; there is no cure, and no way to delay or mitigate the disease. The vast majority of adults at risk for HD choose not to be tested.\textsuperscript{46} However, it is not uncommon for parents to request that their children be tested; their goals may be to set their minds at rest, to plan for the future, and so on.\textsuperscript{47} Should geneticists respect the parents' role as medical decision maker for their children by acceding to their wishes and testing the child, or should they insist that testing be postponed until the child is an adult and can make her own choices?

(3) A final dilemma has to do with sex selection. The technology described above makes it easier for parents to decide the sex of their offspring, without recourse to abortion. Critics of sex selection (when not used to avoid a sex-linked disease) object that it turns children into

\begin{itemize}
\item \textsuperscript{46} David Craufurd, \textit{Uptake of Presymptomatic Predictive Testing for Huntington's Disease}, The Lancet, Sept. 9, 1989, at 603.
\end{itemize}
commodities,\textsuperscript{48} that it could skew the cultural and political patterns of society,\textsuperscript{49} and that it tends to express and perpetuate a sexist preference for boys.\textsuperscript{50} But a significant percentage of genetic counselors (a majority of American counselors, in one study) have supported clients' right to use the techniques of amniocentesis and abortion to choose the sex of their children.\textsuperscript{51}

IV. THE CHILD'S RIGHT TO AN OPEN FUTURE

When moral challenges arise in the clinical practice of genetics, they tend to be understood as conflicts between the obligation to respect patient autonomy and other ethical norms, such as doing good and avoiding harm. Thus, a typical counseling dilemma exists when a person who has been tested and found to be carrying the gene for Tay-Sachs disease refuses to share that information with siblings and other relatives despite the clear benefits to them of having that knowledge,\textsuperscript{52} or when a family member declines to participate in a testing protocol necessary to help another member discover his or her genetic status.\textsuperscript{53}

This way of looking at moral issues in genetic counseling often leaves both the counselors and commentators frustrated, for two reasons. First, by elevating respect for patient autonomy above all other values,\textsuperscript{54} it may be difficult to give proper weight to other factors, such as human suffering. Second, by privileging patient autonomy and by defining the patient as the person or couple who has come for counseling, there seems no "space" in

\textsuperscript{50} Michael Bayles, Reproductive Ethics 34-36 (1984); John Fletcher & Dorothy Wertz, Ethics, Law, and Medical Genetics: After the Human Genome is Mapped, 39 Emory L.J. 747, 788 (1990) [hereinafter Fletcher & Wertz, Ethics, Law, and Medical Genetics].
\textsuperscript{51} In a study of medical geneticists in the United States and abroad, a majority in the United States said they would perform the diagnosis of sex for a couple planning to abort the "wrong sex" fetus, or would refer the couple to someone who would. Fletcher & Wertz, Ethics, Law, and Medical Genetics, supra note 50, at 772-73.
\textsuperscript{53} Bonnie S. LeRoy, When Theory Meets Practice: Challenges to the Field of Genetic Counseling, in Bartels, Prescribing Our Future, supra note 1, at 44-48.
\textsuperscript{54} In the Fletcher and Wertz study of geneticists in the United States and abroad "autonomy was found to be the dominant principle associated with reasoning about clinical decisionmaking;" this finding was especially strong in the United States. Fletcher & Wertz, Ethics, Law, and Medical Genetics, supra note 50, at 776.
which to give proper attention to the moral claims of the future child who is
the endpoint of many counseling interactions.

To describe the challenge primarily as one that pits beneficence
(concern for the child's quality of life) against autonomy (concern for the
parents' right to make their own decisions about these matters) makes for
obvious difficulties and frustrations. These are two very different values,
and comparing and weighing them invites the proverbial analogy of "apples
and oranges." In fact, the perennial critique of a principle-based ethics is that
it offers few suggestions for ordering principles when duties conflict.

Further, beneficence and respect for autonomy are values that will always
exist in some tension within the field of genetic counseling. For all the
reasons I listed above, counselors are committed to nondirective counseling.
But surely, most or all of them are drawn to the field because they want to
help people avoid or at least mitigate suffering. This is becoming
increasingly true as training programs in genetic counseling shift the
practice from a research to a social work model.

Faced with the ethical challenges of our new genetic capabilities, I
suggest a different way to look at these problems. I propose that, rather than
conceptionalizing them as a conflict between autonomy and beneficence, we
recast it as a conflict between parental autonomy and the child's potential
autonomy: what Joel Feinberg has called "the child's right to an open
future."

Feinberg begins his discussion of children's rights by noticing that
rights can ordinarily be divided into four kinds. First, there are rights that
adults and children have in common (the right not to be killed, for

55. An innovative approach to the question of parents who decline to avail themselves
of steps that would avoid the conception and/or birth of a disabled fetus is presented by Lois
Shepherd. Shepherd argues for a "right to attachment," based on the claim that making
decisions for their children is part of the parental-fetal bonding process, and "failure to respect
the boundaries around the parental-fetal relationship weakens the ties between parent and
child that are so important for the child's development and well-being." Shepherd, supra note
45, at 798-99. It is not clear whether Shepherd is arguing only for the right of parents with
inherited disorders to "let nature take its course," or also for the right to take positive steps to
ensure a disorder. Id. If the latter, I find her argument unsatisfactory because it ignores an
essential element of ethical parenting: respect for the child as an independent entity. See infra
notes 134-47 and accompanying text.

56. Albert R. Jonsen, Foreword to A MATTER OF PRINCIPLES?: FERMENT IN U.S.
BIOETHICS ix (Edwin R. DuBose et al. eds., 1994).

57. Joan H. Marks, The Training of Genetic Counselors, in BARTELS, PRESCRIBING OUR
FUTURE, supra note 1, at 16.

58. Feinberg, supra note 5, at 125.
example). Second, there are rights which are generally possessed only by children (or by "childlike" adults). These "dependency-rights," as Feinberg calls them, derive from the child's dependence on others for such basics as food, shelter, and protection. Third, there are rights which can only be exercised by adults (or at least by children approaching adulthood), e.g., the free exercise of religion. Finally, there are rights which Feinberg calls "rights-in-trust," rights which are to be "saved for the child until he is an adult." These rights can be violated by adults now, in ways that cut off the possibility that the child, when it achieves adulthood, can exercise them. A striking example is the right to reproduce. A young child cannot physically exercise that right, and a teenager might lack the legal and moral grounds on which to assert such a right—but clearly the child, when he or she attains adulthood, will have that right. Therefore the child now has the right not to be sterilized, so that the child may exercise that right in the future. Rights in this category include virtually all the important rights we believe adults have, but which must be protected now to be exercised later. Grouped together, they constitute what Feinberg calls, "the child's right to an open future."

Feinberg illustrates this concept with two examples, moving from the relatively uncontroversial to the more difficult. The less controversial instance is that of the Jehovah's Witness child who needs a blood transfusion to save his life, but whose parents object on religious grounds. In this case, the parents' right to act upon their religious beliefs and to raise their family within the religion of their choice conflicts with the child's right to live to adulthood and to make his own life-or-death decisions. As the Supreme Court said in another, less defensible, decision involving Jehovah's Witnesses:

Parents may be free to become martyrs themselves. But it does not follow that they are free in identical circumstances to make martyrs of their children before they have reached the age of full and legal discretion when they can make that decision for themselves.

59. Id. at 124-25.
60. Id. at 125.
61. Id.
62. Id.
63. Id. at 125-26.
64. Id. at 124.
65. Id. at 130.
66. Id. at 129 (quoting Prince v. Massachusetts, 321 U.S. 158, 170 (1944)). Of course,
The second example is more difficult. In 1972, in a famous Supreme Court case, a group of Old Order Amish argued that they should be exempt from Wisconsin’s requirement that all children attend school until they are either sixteen or graduate from high school.67 The Amish did not have to send their children to public school; they were free to create a private school of their own liking.68 But they framed the issue in the most stark manner: to send their children to any school, past 8th grade, would be antithetical to their religion and their way of life, and might even result in the death of their culture.69

The case was framed as a freedom of religion claim on the one hand, and the state’s right to insist on an educated citizenry on the other.70 Within that framework, the Amish won.71 First, they were able to persuade the Court that sending their children to school after 8th grade would potentially destroy their community:

because it takes them away from their community, physically and emotionally, during the crucial and formative adolescent period of life. During this period, the children must acquire Amish attitudes favoring manual work and self-reliance and the specific skills needed to perform the adult role of an Amish farmer or housewife. In the Amish belief higher learning tends to develop values they reject as influences that alienate man from God.72

68. Id.
69. Id. at 209.
70. Id. at 213.
71. Id. at 234.
72. Id. at 211-12.
Second, the Amish convinced the Court that the state’s concerns—that children be prepared to participate in the political and economic life of the state—did not apply in this case. The Court listened favorably to expert witnesses who explained that the Amish system of home-based vocational training—learning from your parent—worked well for that community, that the community itself was prosperous, and that few Amish were likely to end up unemployed. The Court said:

the value of all education must be assessed in terms of its capacity to prepare the child for life. It is one thing to say that compulsory education for a year or two beyond the eighth grade may be necessary when its goal is the preparation of the child for life in modern society as the majority live, but it is quite another if the goal of education [can] be viewed as the preparation of the child for life in the separated agrarian community that is the keystone of the Amish faith.

What only a few Justices saw was that the children themselves were largely ignored in this argument. The Amish wanted to preserve their way of life. The State of Wisconsin wanted to make sure that its citizens could vote wisely and make a living. By claiming that leaving school at eighth grade is not significantly different than leaving at age sixteen, the Justices ducked the question of whether the liberal democratic state owes all its citizens, especially children, a right to a basic education that can serve as a building block if the child decides later in life that she wishes to become an astronaut, a playwright, or perhaps to join the army. As we constantly hear from politicians and educators, without a high school diploma one’s future is closed. By denying them a high school education or its equivalent, parents are virtually ensuring that their children will remain housewives and agricultural laborers. Even if the children agree, is that a choice parents ought to be allowed to make for them?

Feinberg is right to question the Court’s reasoning. I go further than Feinberg, however, for I argue that the case was decided wrongly. If Wisconsin had good reasons for settling on high school graduation or age sixteen as the legal minimum to which children are entitled, then the Amish children were entitled to that minimum as well, despite their parents’ objections. In deciding the issue primarily on grounds that the Amish were

73. Id. at 222.
74. Id. at 223-29.
75. Id. at 222.
76. Id. at 239-40 (1972) (White, J., concurring).
not likely to create problems for the state if allowed to keep their children out of school, the Court reflected a rather minimalist form of liberalism. In fact, the abiding interest of this case for many political philosophers lies in the deep conflict it highlights between two different concepts of liberalism: commitment to autonomy and commitment to diversity,\textsuperscript{77} a discussion given new dimensions by the publication of John Rawls' \textit{Political Liberalism}.\textsuperscript{78} William Galston, for example, argues that:

A standard liberal view (or hope) is that these two principles go together and complement one another: the exercise of autonomy yields diversity, while the fact of diversity protects and nourishes autonomy. By contrast, my . . . view is that these principles do not always, perhaps even do not usually, cohere; that in practice, they point in quite different directions in currently disputed areas such as education. . . . Specifically: the decision to throw state power behind the promotion of individual autonomy can weaken or undermine individuals and groups that do not and cannot organize their affairs in accordance with that principle without undermining the deepest sources of their identity.\textsuperscript{79}

Galston goes on to assert that "properly understood, liberalism is about the protection of diversity, not the valorization of choice . . . To place an ideal of autonomous choice . . . at the core of liberalism is in fact to narrow the range of possibilities available within liberal societies."\textsuperscript{80} Against Galston, I argue that the autonomy of the individual is ethically superior to the autonomy of the group. Both ideals have powerful claims on us, but when group rights would extinguish the abilities of the individuals within them to make their own life choices, then the liberal state must support the individual against the group. This is especially crucial when the individual at issue is a child, who is particularly vulnerable to adult coercion, and therefore has particular claims on our protection. Unfortunately, of course, it is precisely where children are concerned that groups, understandably, most jealously protect their prerogatives to guide and make decisions. The Amish are an example of a group guarding its ability to shape the lives of its children and to assure the survival of the group; Deaf parents wishing to ensure Deaf children are an example of families pursuing the same goals. Of course, groups and families ought to—in fact, they \textit{must}—strive to shape the

\textsuperscript{77} William A. Galston, Two Concepts of Liberalism, 105 ETHICS 516 (April 1995).
\textsuperscript{78} John Rawls, Political Liberalism (1993).
\textsuperscript{79} Galston, \textit{supra} note 77, at 521.
\textsuperscript{80} \textit{Id.} at 523.
values and lives of the children in their care. Not to do so would lead to social and individual pathology. But when that shaping takes the form of a radically narrow range of choices available to the child when she grows up—when it impinges substantially on the child’s right to an open future—then I maintain that liberalism requires us to intervene to support the child’s future ability to make its own choices about which of the many diverse visions of life it wishes to embrace.

V. CHOOSING FOR DISABILITY: IS CREATING A DEAF CHILD A HARM?

A. The Wrongful Life Problem: A Red Herring

Returning to the discussion of genetic dilemmas, we confront two distinct issues. First, in what sense is it ever possible to do harm by giving birth to a child who would otherwise not have been born at all? Second, is being deaf, rather than hearing, in fact a harm?

The first issue can be termed the problem of wrongful life. Imagine a couple: Carl and Karla. They are each deaf, with a form of hereditary, recessive deafness. With every pregnancy they face a one in four chance of producing a deaf child. Further imagine that this form of deafness can be detected by genetic testing. Knowing the odds, Carl and Karla decide simply to get pregnant and take their chances. One can expect that they would face some criticism for their decision, especially if the decision were “made public” by their actually having a deaf child. One argument made against them might be that they ought not to burden society with the extra needs of a deaf child if the situation could have been avoided. This argument is easy to refute, as deaf people are fully capable of becoming productive members of society.

But what about the second kind of argument: that for them to have a deaf child is wrong for the sake of the child itself? As Steinbock and McClamrock explain, this kind of claim can be sustained only in very horrible instances, because it relies on the assertion that the child’s life will be so terrible that it would have been better off if it had not been born.81 Remember that this particular child, call her Carol, could either be born deaf or not be at all. Deafness was a part of her DNA. Had her parents taken steps to avoid a deaf child, they would have had a different child altogether, not Carol. There may be perspectives from which we can argue that their laissez-faire approach was morally wrong, but we cannot claim to be

arguing that from Carol’s perspective (unless we are prepared to argue that being deaf is literally a fate worse than nonexistence).

For clarity’s sake, imagine another instance: a couple who is deaf for nongenetic reasons. This couple, of course, has no more likelihood than the general population of giving birth to a deaf child. If they want to ensure, or at least, increase their chances of having a deaf child, they will have to deliberately expose it to some teratogen like German measles. In this case, it is easier to argue that the child, call her Ann, has been harmed. Baby Ann had two possibilities: being born hearing or being born deaf. Her parents deliberately did something to ensure the latter condition. If (and this is something we still need to address) being deaf is less desirable than being able to hear, then Ann has been harmed.

Now imagine a third scenario. Again, we have Carl and Karla who each carry a recessive gene for deafness. For unrelated reasons, this couple needs to make use of in vitro fertilization to become pregnant. Like most couples using IVF, they try to produce a number of embryos, only some of which will be implanted. They decide to use preimplantation diagnosis and implant only those embryos that carry two copies of the gene for deafness. Looking into the petrie dish, and simplifying the situation somewhat, we see four embryos: A, B, C, and D. Embryo C has both copies of the deafness gene; the others do not. Carl and Karla choose to implant only Embryo C, who emerges nine months later as Carol, a healthy, deaf baby. Has Carol been harmed? As in the first scenario, Carol had only two possibilities: to be born deaf or not to have been born at all. It seems hard to argue that Carol has been harmed in this instance, for the same reasons that she had not been harmed in the first scenario, where her birth was a matter of chance. And yet, this is the scenario which so troubles Nance, and which Caplan uses as an example of an “immoral” use of genetic counseling. If the harm here is not to Carol, and not to society, who or what has been harmed?

All commentators seem to agree that there is no purely logical way out of what Dan Brock calls the “wrongful handicap” conundrum. In the case of a child whose life is arguably not worth living, one can say that life itself is a cruelty to the child. Steinbock argues that the life of a child with Tay-Sachs disease fits this category. But when a child is born in less than ideal circumstances, or is partially disabled in ways that do not make for a life of horrendous suffering, there seems no way to argue that the child herself has


been harmed. This may appear to entail the conclusion, counter to our common moral sense, that therefore no harm has been done "A wrong action must be bad for someone, but [a] choice to create [a] child with its handicap is bad for no one."  

However, most commentators agree that one can still support a moral critique of the parents’ decision. Steinbock and McClamrock argue for a principle of “parental responsibility” by which being a good parent entails refraining from bringing a child into the world when one cannot give it “even a decent chance at a good life.” Feinberg appears to agree, arguing that a parent “acts wrongly” in bringing a handicapped child into the world if in a month’s time she could have conceived a nonhandicapped child, despite the fact that her wrongdoing harmed no specific person. Brock, following Parfit, distinguishes same person from same number choices. In same person choices, the same person exists in each of the alternative courses of action the agent chooses, but the person may exist more or less harmed. Thus the parents who deliberately exposed Baby Ann to a deafness-inducing teratagen made a same person choice. In same number choices, “the choice affects who, which child, will exist.” Brock claims that moral harms can exist in both instances, despite the fact that in same number choices the moral harm cannot be tied to a specific person. Brock generates the following principle:

Individuals are morally required not to let any possible child . . . for whose welfare they are responsible experience serious suffering or limited opportunity if they can act so that, without imposing substantial burdens or costs on themselves or others, any alternative possible child . . . for whose welfare they would be responsible will not experience serious suffering or limited opportunity.

While agreeing with Brock, Steinbock and others, I locate the moral harm differently, at least with respect to disabled persons wishing to reproduce themselves in the form of a disabled child. Deliberately creating a child who will be forced irreversibly into the parents’ notion of “the good life” violates the Kantian principle of treating each person as an end in herself and never as a means only. All parenthood exists as a balance

84. Brock, supra note 82, at 271.
85. Steinbock & McClamrock, supra note 81, at 17.
86. Brock, supra note 82, at 272.
87. Id. at 273.
88. IMMANUEL KANT, GROUNDWORK OF THE METAPHYSICS OF MORALS 96 (H.J. Paton
between fulfillment of parental hopes and values and the individual flowering of the actual child in his or her own direction. The decision to have a child is never made for the sake of the child—for no child then exists. We choose to have children for myriad reasons, but before the child is conceived, those reasons can only be self-regarding. The child is a means to our ends: a certain kind of joy and pride, continuing the family name, and fulfillment of religious or societal expectations. But morally the child is first and foremost an end in herself. Good parenthood requires a balance between having a child for our own sakes and being open to the moral reality that the child will exist for her own sake, with her own talents and weaknesses, propensities and interests, and with her own life to make. Parental practices which close exits virtually forever are insufficiently attentive to the child as an end in herself. By closing off the child's right to an open future, they define the child as an entity who exists to fulfill parental hopes and dreams, not his own.

B. Is Being Deaf a Harm?

Having evaded the snares of the wrongful life conundrum, we must tackle the second problem: is being deaf a harm? At first glance, this might appear as a silly question. Ethically, we would certainly include destroying someone's hearing under the rubric of "harm"; legally, one could undoubtedly receive compensation if one were rendered deaf through someone else's negligence. Many Deaf people, however, have recently been claiming that Deafness is better understood as a cultural identity than as a disability. Particularly in the wake of the Deaf President Now revolution at Gallaudet University in March, 1988, which is to Deaf Pride as the Stonewall Riot is to gays and lesbians, Deaf people have been asserting their claims not merely to equal access (e.g., through increased technology)
but also to equal respect as a cultural minority. As one (hearing) reporter noted:

So strong is the feeling of cultural solidarity that many deaf parents cheer on discovering that their baby is deaf. Pondering such a scene, a hearing person can experience a kind of vertigo. The surprise is not simply the unfamiliarity of the views; it is that, as in a surrealist painting, jarring notions are presented as if they were commonplace.92

From this perspective, the use of cochlear implants to enable deaf children to hear93 or the abortion of deaf fetuses, is characterized as "genocide."94 Deaf pride advocates point out that as Deaf people they lack the ability to hear, but they also have many positive gains: a cohesive community, a rich cultural heritage built around the various residential schools,95 a growing body of drama, poetry and other artistic traditions,96 and, of course, what makes all this possible: sign.97 Roslyn Rosen, the president of the National Association of the Deaf, is Deaf, the daughter of Deaf parents and the mother of Deaf children. "I'm happy with who I am," she says, "and I don't want to be 'fixed.' Would an Italian-American rather be a WASP? In our society everyone agrees that whites have an easier time than blacks. But do you think a black person would undergo operations to become white?"98

On the other side of the argument, there is evidence that deafness is a very serious disability. Deaf people have incomes thirty to forty percent

93. Cochlear implants are permanent surgical hearing aids which the medical community considers to be a highly recommended intervention for profoundly deaf adults and children. NIH Consensus Development Panel on Cochlear Implants in Adults and Children, 274 J.A.M.A.1955 (1995).
95. Carol Padden & Tom Humphries, Deaf in America: Voices From a Culture (1988).
96. Ivers, supra note 91, at 469.
98. Dolnick, supra note 92, at 38.
below the national average. The state of education for the deaf is unacceptable by anyone’s standards; the typical deaf student graduates from high school unable to read a newspaper. Even among the brightest and most able deaf students, one reads heartbreaking accounts of the difficulties involved in tasks as simple as trying to sell an ad for the student yearbook.

However, one could also point to the lower incomes and inadequate state of education among some racial and ethnic minorities in our country, a situation we do not (or at least ought not) try to ameliorate by eradicating minorities. Deaf advocates often cite the work of Nora Ellen Groce, whose oral history of Martha’s Vineyard, Everyone Here Spoke Sign Language, tells a fascinating story. For over two hundred years, ending in the middle of the 20th century, the Vineyard experienced a degree of hereditary deafness exponentially higher than that of the mainland. Although the number of deaf people was low in noncomparative terms (one in 155), the result was a community in which deaf people participated fully in the political and social life of the island, had an economic prosperity on par with their neighbors, and communicated easily with the hearing population, for “everyone here spoke sign language.”

So endemic was Sign for the general population of the Island that hearing Islanders often exploited its unique properties even in the absence of deaf people. Old-timers told Groce stories of spouses communicating through Sign when they were outdoors and did not want to raise their voices against the wind. Or men might turn away and finish a “dirty” joke in Sign when a woman walked into the general store. At church, deaf parishioners gave their testimony in Sign.

As one Deaf activist said, in a comment that could have been directly related to the Vineyard experience, “When Gorbachev visited the U.S., he used an interpreter to talk to the President. Was Gorbachev disabled?”

100. Andrew Solomon, Defiantly Deaf, N.Y. TIMES MAG., Aug. 28, 1994, at 43.
102. Groce, supra note 99.
104. Id. at 3.
105. Id. at 4.
106. Id. at 65-66.
107. Id. at 67.
108. Id. at 62.
109. Dolnick, supra note 92, at 43.
Further, one might argue that, since it is impossible to eradicate deafness completely, even if that were a worthy goal, the cause of deaf equality is better served when parents who are proud to be Deaf deliberately have Deaf children who augment and strengthen the existing population.

Many of the problems that deaf people experience are the result of being born, without advance warning, to hearing parents. When there is no reason to anticipate the birth of a deaf child, it is often months or years before the child is correctly diagnosed. Meanwhile, she grows up in a world devoid of language, unable even to communicate with her parents. When the diagnosis is made, her parents must first deal with the emotional shock, and then sort through the plethora of conflicting advice on how best to raise and educate their child. Most probably, they have never met anyone who is deaf. If they choose the route recommended by most Deaf activists and raise their child with sign language, it will take the parents years to learn American Sign Language ("ASL"). Meanwhile, their child has missed out on the crucial development of language at the developmentally appropriate time, a lack associated with poor reading skills and other problems later.\footnote{110}

Further, even the most accepting of hearing parents often feel locked in conflict with the Deaf community over who knows what is best for their child.\footnote{111} If Deafness truly is a culture, rather than a disability, then raising a Deaf child is somewhat like white parents trying to raise a black child in contemporary America (with a background chorus of black activists trying to tell them that they can not possibly make a good job of it!).\footnote{112} Residential

\footnote{110. Id. at 40.}
\footnote{111. Solomon, supra note 100, at 65.}
\footnote{112. Deaf parents who are taken aback to find themselves with a hearing baby may exhibit many of the same fears, in reverse. The following is from an interview with a deaf woman, describing the birth of her daughter:  

When Barbara was born, it wasn’t until about three days later that I had this funny feeling about her. I started wondering if she was deaf or hearing . . . . My first child. I kept wondering to myself, Is she deaf or is she hearing? I was holding her in my arms near the metal food tray. I picked up a spoon and dropped it on the tray. I couldn’t believe it! I was really upset. I did it a second time because I just couldn’t believe it. I dropped the spoon again, and it was the same thing. I even did it a third time. I thought, Oh, my God, she’s hearing! What am I going to do? I have a hearing daughter! My husband came in and I said, My God, our daughter’s hearing! He was just as surprised but he told me it was fine, it was going to be okay. I’m the third generation deaf. There was no question but that we would have deaf children. Then I find out that my daughter was born hearing! What on earth am I going to do with her? I don’t even know how to talk to her. [“So you never thought that you might have a hearing child?”] No, never! It never occurred to me that my child would be hearing. I was really surprised. I was scared. I wanted to be close to my children. I’ve}
schools, for example, which can be part of the family culture for a Deaf couple, can be seen by hearing parents as Dickensian nightmares or, worse, as a "cultlike" experience in which their children will be lost to them forever.\textsuperscript{113}

By contrast, deaf children born to Deaf parents, "Deaf of Deaf" as they say, learn language (Sign) at the same age as hearing children. They are welcomed into their families and inculcated into Deaf culture in the same way as any other children are welcome into their own culture. By all accounts and perhaps for these reasons, the Deaf of Deaf are the acknowledged leaders of the Deaf Pride movement, and the academic \textit{creme de la creme}. In evaluating the parental choice to deliberately ensure having Deaf children, one must remember that the statistics and descriptions of deaf life in America are largely reflective of the experience of deaf children born to hearing parents, who make up the vast majority of deaf people today.\textsuperscript{114}

If Deafness is a culture rather than a disability, it is an exceedingly narrow one. One factor that does not seem clear is the extent to which children raised with ASL as their first language will ever be comfortable with the written word.\textsuperscript{115} At present, the conflicted and politicized state of education for the deaf, along with the many hours spent (many would say wasted)\textsuperscript{116} attempting to teach deaf children oral skills, makes it impossible to know what is to blame for the dismal reading and writing skills of the average deaf person.\textsuperscript{117} Some deaf children raised with ASL from birth do become skilled readers, but there is reason to question whether a deaf child has access to the wealth of literature, drama, and poetry that liberals would like to consider every child's birthright.

Although Deaf activists correctly show that many occupations are open to the deaf with only minor technological adjustments, the range of occupations will always be inherently limited. It is unlikely that the world

\begin{itemize}
\item always been very close to my family, and I wanted the same for me and my children.
\item The Hearing world and the Deaf world are such separate worlds. I worried that we would never connect, or that we would drift apart.
\end{itemize}

\textbf{Paul Preston, Mother Father Deaf: Living Between Sound and Silence} 17 (1994)

\begin{itemize}
\item 113. Dolnick, \textit{supra} note 92, at 52.
\item 114. "[O]ver 90 percent of the prevocationally deaf have two hearing parents." Beryl Leff Benderly, \textit{Dancing Without Music: Deafness in America} 12 (1990).
\item 115. ASL itself has no written analogue, and has a completely different grammatical structure from English.
\item 117. \textit{Id. See also} Ivers, \textit{supra} note 91, at 465-66; Dolnick, \textit{supra} note 92, at 40.
\end{itemize}
will become like Martha’s Vineyard, where everyone knew Sign. This narrow choice of vocation is not only a harm for its own sake but also is likely to continue to lead to lower standards of living.\textsuperscript{118}

\textbf{C. Choosing for Disability and the Child’s Right to an Open Future}

If deafness is a disability which substantially narrows a child’s career, marriage, and cultural options in the future, then deliberately creating a deaf child counts as a moral harm. If Deafness is a culture, as Deaf activists assert, then deliberately creating a Deaf child who will have only limited options to move outside of that culture also counts as a moral harm.\textsuperscript{119} A decision made before a child is born that confines her forever to a narrow group of people and a limited choice of careers, so violates the child’s right to an open future that no genetic counselor should acquiesce to it. The very value of autonomy that grounds the ethics of genetic counseling should preclude assisting parents in such a decision.

\textbf{VI. CHILDHOOD TESTING FOR LATE-ONSET GENETIC DISEASES}\textsuperscript{120}

\textbf{A. The Problem}

A number of serious genetic diseases do not show themselves until fairly late in life. A person with HD, for example, does not usually begin to exhibit symptoms of the disease until the fourth or fifth decade of life.\textsuperscript{121}

\textsuperscript{118} Certainly one reason why the Vineyard deaf had the same level of prosperity as their hearing neighbors was that farming and fishing were just about the only occupations available.

\textsuperscript{119} Even Galston, who argues that liberalism is about the protection of diversity rather than of individual autonomy, begins with the presumption that society must “defend . . . the liberty not to be coerced into, or trapped within, ways of life. Id. Accordingly, the state must safeguard the ability of individuals to shift allegiances and cross boundaries.” Galston, \textit{supra} note 77, at 522.

\textsuperscript{120} This issue was brought to my attention by Ronald M. Green and Thomas H. Murray.

\textsuperscript{121} Huntington’s disease is a movement disorder—causing uncontrollable jerking and writhing movements of all parts of the body, called chorea. Even more distressing to patients and families than the obvious movements, it is preceded or accompanied by cognitive changes leading to profound and frequently severe emotional disturbances, suicidal depression and occasionally hallucinations and delusions. The disease runs a course of about fifteen to twenty-five years and is inevitably fatal . . . . No treatments are known beyond some marginal and temporary palliation for the movements and antidepressants for the psychiatric symptoms.
New genetic knowledge has enabled scientists to devise tests for some of these diseases and for genetic predispositions to diseases, with many more advances on the horizon. So, for example, someone whose parent had HD and who is thus at a fifty percent risk of inheriting the gene (and therefore the disease), can be tested at any point after conception. The advantages to this kind of testing are obvious. Persons at risk can now make reproductive decisions knowing whether or not they will get HD and if they are at risk of passing it on to their children. The fifty percent who do not carry the gene will, presumably, be more relaxed and hopeful about the future, and will not interpret every passing hand tremor as the first sign of incipient HD. However, in the twenty years in which HD testing has been available, a number of disadvantages have become obvious as well. Discovering that one definitely has HD can lead to depression, social...

Huntington’s disease is a product of a gene transmitted in an autosomally dominant inheritance pattern—in other words, a gene that occurs on one of the twenty-two human chromosomes and whose effect dominates its normal partner. It is entirely penetrant, which means that if a gene carrier lives long enough, the disease is inexorably expressed.

Wexler, supra note 14, at 212.

122. Tests are currently available for predispositions to breast, colon, and thyroid cancer, as well as melanoma. Testing is also possible for familial Alzheimer Disease, although the Medical and Scientific Advisory Committee for Alzheimer Disease International has reached a consensus that the tests are not yet ready to be offered to the public. MEDICAL AND SCIENTIFIC ADVISORY COMMITTEE FOR ALZHEIMER’S DISEASE INTERNATIONAL, Consensus Statement on Predictive Testing for Alzheimer Disease, 9 ALZHEIMER DISEASE AND ASSOCIATED DISORDERS 182 (1995).

123. [The symptoms [of HD] can begin at any time, from very early to very late. So the worry is essentially lifelong. Every clumsy movement, every slight stumble, any momentary slurring of speech or fleeting unsteadiness of gait—trivial events most people would ignore—will, in the individual at risk for HD, arouse apprehensions: Is this it? Does the inexorable decline now begin?

Albert Rosenfeld, At Risk for Huntington’s Disease: Who Should Know What and When?, 14 HASTINGS CTR. REP. 5 (June 1984).

124. The first presymptomatic test for HD was developed and offered to the public on a research basis in 1986. Catherine A. Hayes, Genetic Testing For Huntington’s Disease—A Family Issue, 327 NEW ENG. J. MED. 1449 (1992).

125. In one 1984 study, patients with HD (diagnosed by symptoms and family history, not by DNA) were more likely to commit suicide than the general population. Miriam Schoenfeld et al., Increased rate of suicide among patients with Huntington’s disease, 47 J. OF NEUROLOGY, NEUROSURGERY, AND PSYCHIATRY 1283 (1984). Unfortunately, in my opinion, the medical literature persists in describing suicide as a “risk,” rather than as a rational choice.
stigma,126 and problems with insurance and employment.127 Even knowing that one does not have the gene can lead to "survivor guilt" and serious psychological problems if one or more of one's siblings were not so lucky.128 Thus, only fifteen percent of adults at risk have availed themselves of the opportunity to be tested and discover their status.129

This mixed reaction to the option of pre-symptomatic testing raises a difficult ethical question: how should health care providers respond to requests from parents who wish to have their children tested for adult-onset disorders for which there is no medical intervention130? At present, there is a consensus developing in the United Kingdom that predictive genetic testing of children "should generally not be undertaken" if there are no useful medical interventions.131 In the United States, it is too early to claim that a consensus has been reached, but opinion appears to be leaning toward the "no-test" position.132

B. Presymptomatic Testing and the Child's Right to an Open Future

There are many reasons why parents may request presymptomatic genetic testing of children for adult-onset diseases, even in the absence of any useful medical intervention.133 Parents may hope for a reduction in their

126. Wexler, supra note 14, at 234.
128. Wexler, supra note 14, at 236.
129. Genetic Testing of Children, supra note 47.
130. If some ameliorating intervention were possible, the ethical issue would become quite clear, as testing would almost certainly be in the child's best interest.
131. Theresa M. Marteau, Editorial, The Genetic Testing of Children, 31 J. MED. GENETICS 743 (1994). See also Sheila McLean, Genetic Screening of Children: The U.K. Position, 12 J. CONTEMP. HEALTH L. & POL'Y 117 (1995). This is a consensus of ethicists and working groups focused on this issue, not of practicing physicians and geneticists. For example, a 1993 survey in the U.K. showed that a majority of pediatricians and a substantial minority of geneticists would test children at the parents' request for late-onset genetic disorders or for unaffected carrier status. Dorothy Wertz et al., Genetic Testing for Children and Adolescents: Who Decides?, 272 JAMA 875 (1994). Presumably, the publication of policy statements by professional societies will bring the majority of medical practice into conformity with those guidelines.
133. Excluded from this category, of course, are diseases for which medical monitoring in childhood is shown to be helpful in catching the disease early. Conversely,
own uncertainty and anxiety, or they may use the information to make
decisions about whether or not to have more children or how to space
subsequent pregnancies. Parents may want to take genetic predictions into
account as they allocate resources for higher education or consider other
kinds of long-range planning. One genetics center had a man request
testing of his grandchildren in order to decide how to write his will.

There is, of course, a strong tradition in Anglo-American law and
culture of allowing parents great latitude in making medical decisions for
their children. Although exceptions to that rule have been made with respect
to mature minors, in research protocols, or when parents’ decisions
put children at great risk of losing their lives or their health, it is still
generally the case that a parental decision is considered both necessary and
sufficient for providing medical care for minor children. This tradition
began with the pre-twentieth century doctrine that the child was the father’s
property. Today it rests on two assumptions: that the parents are the persons
most able to make a decision about the well-being and best interests of their
children, and also that making decisions about children’s education,
medical care, and so on, is part of the autonomy rights of parents as heads of

knowing that the child does not have the gene for disease can spare the child burdensome and
unnecessary monitoring. ASHG/ACMG Report, supra note 132, at 1234-35.

134. Id. at 1236.

135. Another reason to have a child tested, perhaps as a teenager, might be to avoid
the psychological disruption of living an “at risk” role that is later repudiated. Nancy Wexler,
reporting on a pilot testing program with extensive counseling begun at the College of
Physicians and Surgeons of Columbia University, notes that,

It is almost as inconceivable for people to learn that they are not in harm’s way.
Identities have been built around being ‘at risk’: commitments abandoned, lives led
in the fast lane. Some people who learn that they are free of the long-dreaded gene
are stunned and unprepared. Suddenly they are ordinary; vulnerable now to other
diseases, responsible for their lives as never before. Friends and relatives who had
sacrificed for them in the past may feel cheated and vengeful or disturbed to find
themselves deprived of their role of tending to an invalid.

Nancy S. Wexler, The Tiresias Complex: Huntington’s Disease as a Paradigm of Testing for
Late-onset Disorders, 6 FASEB J. 2820, 2823 (1992).

136. Judith Granbois & Gail Vance, Ethical Issues in Late Onset Genetic Disorders:
Cases and Methods, Presentation Before the Association for Practical and Professional Ethics
(APPE) (March 1996).

137. ALLEN E. BUCHANAN & DAN W. BROCK, DECIDING FOR OTHERS: THE ETHICS OF


140. BUCHANAN & BROCK, supra note 137, at 233.
their families. Thus, when a genetic test has been placed before the public, geneticists are up against a powerful presumption if they refuse parental requests.

Geneticists make a number of arguments against acceding to parental requests for predictive testing. They fear that a child with a genetic defect will be subjected to increased medical tests and treatment regimens with no proven benefit, may suffer a loss of self-esteem, may suffer a loss of privacy if the diagnosis is disclosed outside the immediate family, may be stigmatized at school or in future employment, or may have difficulty in obtaining insurance later in life.

The Report of the Boards of Directors of the American Society of Human Genetics and the American College of Medical Genetics attempts to resolve this issue by relying on the basic tenet of all medical ethics: *primum non nocere*, or *first do no harm*, but acknowledges that where the benefits and harms “are primarily psychosocial rather than medical, such an assessment may be difficult.” Advocates of the parental right to make the decision rely on “the privacy of the family unit in our culture,” and frame the issue as one of tension between “the beneficence model of patient care and the rights of parents to their own autonomy and to the protection of their family units.”


142. One argument that will not withstand scrutiny is that genetic testing requires informed consent, and young children are incapable of giving it. This argument would preclude any pediatric care at all. *ASHG/ACMG Report, supra* note 132, at 1234.

143. *Id.* at 1235.

144. This report was also endorsed by the Alliance of Genetic Support Groups, the Council of Regional Networks for Genetic Services, the International Society of Nurses in Genetics, the National Society of Genetic Counselors, and the American Academy of Pediatrics. *Id.* at 1239.


146. *ASHG/ACMG Report, supra* note 132, at 1238.

147. Pelias, *supra* note 141, at 347. Pelias also argues that there are legal obligations on counselors, based on constitutional law, to comply with parental requests for testing. *Id.* However, Pelias’ assertions are based on a misunderstanding of the difference between negative rights (against interference by the state) and positive rights (which entitle one to certain services). Constitutional issues arise when the state intervenes against a parent’s wishes (e.g., forbids parents to send children to religiously-based schools, as in *Pierce v.*
In my view, the best way to resolve this issue is by recourse to the concept of the child’s right to an open future. Although the majority of adults at risk for HD have decided not to be tested, fifteen percent have chosen the other route. Thus, there is no common answer to the question of whether life is better lived with or without the knowledge of one’s HD status. Genetic counselors go to great lengths to protect the right of adults to make the decision for themselves of whether or not to be tested.148 Obviously, if parents have the child tested, then they preclude the child’s

Society of Sisters, 268 U.S. 510 (1925)), not when the state decides against providing a service (unless their refusal is based on unconstitutional reasons, such as race).

Ellen W. Clayton does an excellent job of laying the legal issues to rest in Removing the Shadow of the Law From the Debate About Genetic Testing of Children, 57 AM. J. MED. GENETICS 630 (1995). “[A]s we continue to debate the proper roles of physicians, parents, and children in deciding about genetic testing prior to adulthood, we need to recognize clearly that, far from conferring sweeping rights on parents to demand these tests, tort and constitutional law in the United States have little role to play in resolving these dilemmas.” Id. at 633. Although I am in near complete agreement with Clayton, I also think it is important to note that while the law has little role to play in shaping policy about genetic testing, once policy has been set, doctors can rely upon it as a “standard of care” which may protect them from tort litigation. Conversely, a maverick who persists in testing children for late-onset genetic disease in the face of a consensus in the medical community is more vulnerable if she is sued (perhaps by a child claiming that the testing caused stigma or depression). The standard of conduct becomes one of “good medical practice,” which is to say, “what is customary and usual in the profession.” W. PAGE KEETON ET AL., PROSSER AND KEETON ON THE LAW OF TORTS 189 (5th ed. 1984). See also Neil Sharpe, Letter to the Editor, Presympomatic Testing for Huntington’s Disease: Is There a Duty to Test Those Under the Age of Eighteen Years?, 46 AM. J. MED. GENETICS 250 (1993). Sharpe argues that failure to advise patients of the availability of a medical procedure may provide a cause of action for medical malpractice or a breach of the doctrine of informed consent. Id. However, there is little evidence that geneticists are moving toward a policy of not informing families that the test is available (which is impractical in any case, since adults know that the test is available for them); rather, the policy would be to share with families the information that the test exists, and why the policy discourages or precludes testing of minors. Id. Sharpe’s second point is that this issue should not be decided as a matter of policy, but on a case-by-case basis. Id.

148. Situations in which testing one person necessarily provides information about other people’s status are particularly troublesome to geneticists, who strenuously protect people’s right to privacy. Catherine Hayes, President of the Huntington’s Disease Society of America, is impliedly critical of researchers who agreed to test one identical twin for HD, despite the fact that the other twin did not want to know her status. Hayes, supra note 124, at 1450. The twin who wanted to know insisted that she would never reveal the results, but she did. Id. Since identical twins are genetically identical, the second twin found out her status as well. Id. Hayes comments, “One person’s right to know in this case did not necessarily outweigh her twin’s right not to know. When information was given to one twin, the other irretrievably lost the freedom to decide.” Id.
right and opportunity to make that decision for himself in adulthood.\textsuperscript{149} As we have seen, for those unfortunate enough to have a family history of a disease like Huntington's, the decision whether or not to be tested is profound and complex. Even the lucky half who discover that they do not have the gene are hardly "home free," psychologically speaking. This is a decision each individual can only make for herself. Thus, respect for the child's right to an open future supports the growing consensus in the United States against offering such tests for children.

VII. SEX SELECTION

A. The Problem

Sex selection through abortion has been available since the advent of genetic testing by way of amniocentesis, and in some countries, such as

\textsuperscript{149} A related issue deals with confidentiality. Genetic counselors will protect without exception the right of individuals not to share their genetic information with others, even in situations where not sharing the information puts others at risk or limits their options. We normally do not think of medical confidentiality as an issue between parents and children (except matters regarding older children and sexual or reproductive questions), because of the overriding assumption that parents need to know about their children's medical conditions in order to promote their health and well-being. Thus it would be ludicrous for a doctor to refuse to share with a parent the results of a child's test for TB or asthma. But in the case of HD, there is nothing the parent can do to prevent the disease from occurring, and arguably little the parent can do to prepare the child, younger than eighteen, for a disease that will not strike until middle age. Thus, it is not clear why the child's incipient right to privacy should not be a barrier to testing children and informing parents of the results. Jeffrey Botkin makes a related point with respect to the genetic privacy of the fetus. Jeffrey Botkin, \textit{Fetal Privacy and Confidentiality}, 25 \textit{HASTINGS CTR. REP.} 32 (Sept.-Oct. 1995). "[R]espect for the privacy and confidentiality of the fetus outweigh parental rights to information about the fetus." \textit{Id.}

The argument for confidentiality is even stronger with respect to testing children for possible carrier status for a recessive genetic disease, such as Tay-Sachs. Carrier status has no implications for one's health, except for reproductive decisions. The right of mature minors, and certainly of adults, to make their own reproductive decisions is a fixed point in our ethics and jurisprudence. John A. Robertson, \textit{Embryos, Families, and Procreative Liberty: The Legal Structure of the New Reproduction}, 59 \textit{S. CAL. L. REV.} 939 (1986). Thus, a child who is born into a family with a history of Tay-Sachs Disease needs to be informed about the problem at an appropriate time. Whether she wishes to be tested to find out her carrier status, whether she decides to share the results with her parents, and how she uses that information to make marital and reproductive decisions, are not for her parents to decide.
India, it is resorted to widely, despite sporadic attempts to make it illegal.\textsuperscript{150} In the West, amniocentesis followed by abortion of the “wrong” sex fetus occurs, but without hard data.\textsuperscript{151} In a 1989 survey, thirty-four percent of American geneticists said they would perform prenatal diagnosis for sex selection, and twenty-eight percent would refer the couple to someone who would.\textsuperscript{152} The only other method presently available by which one may reliably choose the sex of one’s offspring involves IVF and PIGD.\textsuperscript{153} Various methods of douching and the timing of intercourse have been put forward from time to time, but never with proven success.\textsuperscript{154} The least cumbersome method of sex selection, sperm sorting before insemination, is now on the horizon but is still in the experimental stage.\textsuperscript{155} In this article, I will discuss only those means of sex selection that do not involve abortion. The lengthy analysis of the law and ethics of abortion that would be required to ground a discussion of abortion for sex selection is beyond the purview of this paper and would detract from the focus on the child’s right to an open future. Thus, some of the familiar and weighty arguments against sex selection, e.g., that it discriminates against females by aborting primarily female fetuses, that it misuses costly medical resources, or that it is an ethically unacceptable reason for abortion, will not be relevant to this discussion. In that respect, I have made my task harder: what arguments against sex selection remain when there are no issues of destroying developing human life or risking the woman’s health?

The interest in sex selection, especially if it were freed from its present dependence upon abortion, is easy to document, even if we confine our observations to the industrial West. The sheer amount of resources scientists have invested in the search for sperm-sorting techniques\textsuperscript{156} suggests that

\begin{itemize}
\item \textsuperscript{150} Dorothy Wertz & John Fletcher, \textit{Fatal Knowledge? Prenatal Diagnosis and Sex Selection}, 19 Hastings Ctr. Rep. 21, 25 (May-June 1989) [hereinafter Wertz & Fletcher, \textit{Fatal Knowledge?}].
\item \textsuperscript{151} \textit{Id.} at 21.
\item \textsuperscript{152} \textit{Id.} The figures for those who would perform the procedure or who would refer were sixty percent in Hungary, forty-seven percent in Canada, thirty-eight percent in Sweden, and thirty-three percent in Israel.
\item \textsuperscript{153} \textit{See supra} text accompanying notes 22-28.
\item \textsuperscript{154} BAYLES, supra note 50, at 34; COREA, supra note 48, at 199-201.
\item \textsuperscript{155} \textit{See Sex Selection for Non-medical Reasons, supra note 22, at 8.}
\item \textsuperscript{156} COREA, supra note 48, at 199-201.
\end{itemize}
there is a market. In this country, the most common reason given is to "balance" a family by having at least one child of each sex.

B. Arguments for and against sex selection

One cluster of arguments against sex selection is rooted in the assumption that, if parents were able to choose their children's sex, the population of the world would become skewed. Myriad studies support the long-held assumption that there is a strong preference for boys. If true, this would lead to fewer women in the population. Some commentators

157. Amitai Etzioni, Sex Control, Science, and Society, 161 SCIENCE 1107 (1968). "If a simple and safe method of sex control were available, there would probably be no difficulty in finding the investors to promote it because there is a mass-market potential." Id.


159. I ignore the special situation of a family at risk for a sex-linked genetic disease, e.g., hemophilia, where the goal is not to avoid a boy per se, but to avoid the birth of a baby at high risk for hemophilia.

160. ROTHMAN, supra note 20, at 133; COREA, supra note 48, at 190-92.

161. Other studies show that, at least in the U.S., the most common preference is for a "balanced" family of two children, with a boy first. NANCY E. WILLIAMSON, SONS OR DAUGHTERS: A CROSS-CULTURAL SURVEY OF PARENTAL PREFERENCES 47 (1976). This strong preference for first boys, coupled with studies that purport to show that the oldest child in the family is more likely to be ambitious and assertive, and that girls are more likely to have high-esteem if they have older sisters than older brothers, see COREA, supra note 48, at 206-07, has caused some writers great concern. Tabitha Powledge, for example, writes that:

If [sex selection] is widely used to achieve the storybook two-child family (a boy first, a girl second) then a pernicious pattern already present in these (industrialized) countries—anxious, overachieving men and passive, accommodating women—might be substantially reinforced, because those personality patterns also tend to be characteristics of, respectively, first- and secondborns.

Tabitha Powledge, Toward a Moral Policy for Sex Choice, in Sex Selection of Children (Neil G. Bennett ed., 1983) (quoted in ROTHMAN, supra note 20, at 137). Willard Gaylin, a psychoanalyst who has studied Vietnam-era war resisters, noted that at the time of his research, of the twenty-six resisters (not including Jehovah's Witnesses) imprisoned in the two institutions he studied, twenty-one were eldest sons. WILLARD GAYLIN, IN THE SERVICE OF THEIR COUNTRY: WAR RESISTERS IN PRISON 284-85 (1970). If one looked only at the white resisters, twenty out of twenty-two were eldest sons. Id. At the same point in our history, it was also true that every single astronaut was an eldest son. Id. Thus, whatever path being an eldest son takes one, it appears to suggest an unusual degree of independence and assertiveness. Id.

Mary Anne Warren, however, after an exhaustive review of the literature, asserts that any conclusions about the psychological effects of birth order are due to errors in study design. MARY ANNE WARREN, GENDERCIDE: THE IMPLICATIONS OF SEX SELECTION 141 (1985).
think that this might improve the status of women by making them more desirable. However, most think that women would come to be valued primarily for their reproductive potential and would be forced into ever more narrow roles, kept in purdah, and so on. Other writers argue that in time the pendulum would come to rest in the middle, reverting back to the virtually equal number of girls and boys we start off with today. One writer suggests that, if we started off with more males, the elderly population would be less disproportionately female, giving rise to better social opportunities. On the other hand, fewer men would have the opportunity to marry, which would have a negative impact on their health and longevity. A different version of the skewed population argument focuses not on the status of women, but on the effect on society. Because women commit fewer violent crimes, are more likely to attend church, and are more active supporters of cultural events than men, a world with fewer women would likely be more violent and less cultural, a sort of “wild West” society.

Another societal argument claims that if everyone were able to choose their children’s sex, we would lose the lessons that come from having to “make the best of” the “wrong” gender; lessons that often lead to increased openness and decreased sexism. Barbara Rothman speaks of how her father, not having had a son, was forced to make the best of it and take his daughter on fishing trips, and how those turned into her fondest memories of her father. Philosopher Michael Bayles uses the same argument to critique the desire for a “balanced” family:

One might reply that someone . . . need not be sexist or irrational to want a boy. He has two daughters, and he would simply like to have a boy as well. Had he had two boys, he might have wanted a girl. But why would two daughters and one son be preferable to three daughters? Someone . . . might respond that he would like a son so that he could have certain pleasures in child rearing—such as fishing and playing ball with him. But that too is probably a sexist assumption. As the father of two daughters, I have fished and played ball with them, watched my daughter play on a ball team, and

162. Rothman, supra note 20, at 136.
163. Holmes, supra note 158, at 149.
165. Bayles, supra note 50, at 36.
166. Holmes, supra note 158, at 153.
167. Etzioni, supra note 157, at 1109.
gone camping and hiking with them, as well as cooked, cleaned house, done laundry, and engaged in various other so-called women’s activities with them.  

Bayles concludes that, “[w]here children allowed to develop freely their own interests and talents, children of the same sex would probably exhibit as much diversity as children of opposite sexes.”

An argument that has particular potency when applied to underdeveloped countries involves the efficacy of sex selection for population control. One version of this argument proposes that if there were fewer females in the next generation there would obviously be fewer “breeders,” and therefore fewer children born, a boon in overpopulated countries which have had only qualified success with more conventional avenues of family planning. A different version of this argument takes the tack that people often have larger families than they really want in an effort to have children of the desired sex. Thus, in India, for example, where male children are all-important and a woman’s status, health, and even life may depend on producing sons, giving people the opportunity to preselect their offsprings’ sex would result in smaller families. Since societies which highly value boys and devalue girls tend to be the same societies struggling with high population rates, sex selection could have a powerful impact. Against these arguments, critics assert that eliminating females to control population is inherently sexist, racist, and misogynist, and will not necessarily work. If it is true that a society with fewer women will tend to restrict their societal roles, we may discover that—with only childbearing to define them—women in these societies will have larger families.

169. Bayles, supra note 50, at 35.
170. Id.
171. Corea, supra note 48, at 210. This argument is made by, among others, John Postgate.
172. Holmes, supra note 158, at 152.
173. This is not a coincidence. Studies in India and elsewhere show that the most effective strategy for lowering the birthrate is to educate and empower women. Gerald Meier, Leading Issues in Economic Development 577-78 (1984) Another effective strategy is to improve the infant and child mortality rate, thus reassuring parents that the children they have will live to maturity. Id. at 576-77. It is no surprise that, to improve the infant and child mortality rate, it is important to educate and empower women. In fact, one argument against sex preselection might be that it provides a “quick and dirty” solution to a problem, overpopulation, which is better solved by improving the lot of women.
174. Holmes, supra note 158, at 153. See also Warren, supra note 161, at 163ff.
A different type of argument is agnostic about the causes and consequences of sex selection, but asserts that as the technology becomes available, choosing the sex of one’s baby is part of a couple’s basic right to reproductive choice. In a 1985 study, Wertz and Fletcher presented 295 American geneticists with the case of a couple who have four daughters and requested prenatal diagnosis so they can abort a fifth pregnancy if the fetus is a girl.\textsuperscript{175} Sixty-two percent of the geneticists surveyed responded that they would accede to the couple’s request.\textsuperscript{176} When asked why, the geneticists stated that they perceived sex choice as “a logical extension of parents’ rights to control the number, timing, spacing, and quality of their offspring.”\textsuperscript{177} This is in line with the focus on client autonomy that is pervasive in genetic counseling.

In the case of arguments which rest on parental choice, we see that opposition focuses on the dangers of turning children into “commodities.” Parents become consumers whose goal is the “perfect” child, with the assumed corollary that less than “perfect” children will be devalued. Thus, just as “yuppie” consumers purchase the perfect house, the perfect car and the perfect wine, they may also purchase the perfect baby. Wertz and Fletcher fear that if sex selection is permitted, it will be a precedent for other requests to avoid short children, nearsighted children, or children whose IQs are merely average.\textsuperscript{178} The result could be a return to the excesses of the eugenics movement.\textsuperscript{179} Maura Ryan, in a feminist critique of unlimited parental choice, points out that assisted reproduction is expensive and burdensome and wonders “how parents might look upon offspring when

\begin{itemize}
\item \textsuperscript{175} Wertz and Fletcher, \textit{Fatal Knowledge?}, supra note 150, at 21.
\item \textsuperscript{176} Id. Thirty-four percent of the geneticists said they would perform the prenatal diagnosis themselves, and 28% answered that they would refer the couple to someone who would perform the diagnosis. \textit{Id}.
\item \textsuperscript{177} Id. at 21.
\item \textsuperscript{178} Wertz and Fletcher, \textit{Fatal Knowledge?}, supra note 150, at 24. As in Lake Wobegon, in the world of genetic selection all the children are above average.
\item \textsuperscript{179} “The term eugenics refers to efforts to improve the inborn characteristics of the human species by applying rules of heredity to human propagation. In the first part of this century many eugenicists called for regulated marriages, sterilization, immigration restrictions, and permanent confinement of individuals considered ‘misfits.’” President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, Screening and Counseling for Genetic Conditions: A Report on the Ethical, Social, and Legal Implications of Genetic Screening, Counseling, and Education Programs 10 (1983).
\end{itemize}
they enter the process with the belief that a certain kind of child is owed to them, and after they have paid a high price for that child.180

C. Sex Selection and the Child’s Right to an Open Future

In many Western nations, where genetic counseling embodies a culture of respect for autonomy and where population control is not a pressing issue, a subtle but powerful argument can be made that sex selection is wrong because it abrogates the child’s right to an open future. Why, after all, do parents have strong preferences for girls or boys, even if that preference is merely in the context of family “balance,” the one rationale that some ethicists are prepared to find blameless, if not compelling?181 Parents whose preferences for one sex or the other are compelling enough for them to take active steps to control the outcome must, logically, be committed to certain strong gender-role expectations of the children they will raise. If they want a girl that badly, whether they are hoping for a Miss America or the next Catherine MacKinnon, they are likely to make it difficult for the actual child to resist their expectations and follow her own bent. Sociologist Barbara Rothman states:

[W]hen you start from the premise that one can “determine” fetal sex in the sense that it can be chosen, then the stereotypes predict the choice: people who want an active, vigorous, achieving child will have boys. And when they want a sweeter, quieter, more loving child, they will have girls.182

Rothman’s point holds even for those who would argue that gender stereotypes have been breaking down dramatically in the ten years since her book was published. For example, the 1996 Olympics exhibited exhilarating performances by women athletes, and the United States Supreme Court has just decided that Virginia Military Institute and The Citadel will no longer be able to exclude women.183 But such optimism does not invalidate


181. Wertz and Fletcher, Fatal Knowledge?, supra note 150, at 23. “We find no moral reasons to condemn the desire to balance gender in families, especially if used by parents who want their children to respect sex-based differences and to learn fairness to the opposite sex by practicing it at home.” Id.

182. ROTHMAN, supra note 20, at 138.

Rothman’s point. If stereotypes are breaking down, why is it so important to have a child of the “desired” sex? If someone wants a daughter so that she can be groomed to be the first female navy admiral, that is still perceiving her primarily in terms of gender. As Rothman says, “[i]f our sons are chosen as sons and our daughters as daughters, we will see them entirely through their gender.”

Because gender is only one among many characteristics, but one that carries very heavy baggage in our society, to view a child primarily through its gender narrows the child’s ability to choose his or her own path in life. The same would be true if we could choose children’s height, musical ability, or intelligence. At present, however, the one trait we can pinpoint and control is gender. Maura Ryan, arguing more generally against unfettered procreative liberty, challenges a framework where a desire for a particular type of child . . . is seldom weighed appropriately against the reality of the child-to-be as a potential autonomous human being. At what point does a being, who has been conceived, gestated, and born according to someone’s specifications, become herself or himself? And if a child comes into the world primarily to fulfill parental need, are there limits to what a parent may do to ensure that the child will continue to meet the specific expectations?

D. Knowledge of Fetal Sex and the Child’s Right to an Open Future

In the process of doing a chromosomal analysis to rule out Down’s Syndrome and other problems, it is impossible for a lab technician not to determine the fetus’s sex. The custom in our country at this time is for this piece of information to be transmitted from the lab to the physician, who typically asks the couple if they wish to know the sex of their baby-to-be. Although women have reported mixed feelings on this subject, the vast majority of women who have had amniocentesis do end up learning the sex of their fetus. Because all women over thirty-five are counseled to consider amniocentesis, as well as younger women with medical indications or family histories of genetic disease, this means that a great many women in America today know their baby’s sex well before it is born. In fact, it is quite common for people to ask a pregnant woman if she is carrying a boy or

184. **ROTHMAN, supra note 20, at 139.**
185. **Ryan, supra note 180, at 86.**
186. **ROTHMAN, supra note 20, at 121-123.**
187. **Id. at 121.**
a girl, or for parents to announce their baby’s name when he or she is still months away from being born.\textsuperscript{188}

Few commentators see this practice as an ethical issue (or at least when parents have no plans to act upon their knowledge to abort a fetus of the undesired sex). It is certainly a strange development, in that it calls into question many common customs. Of course, friends and relatives will still be delighted to get that dramatic phone call from the happy parents, telling them that mother and baby are healthy, but without the news that it’s a girl or a boy, the announcement lacks a certain something. And the obstetrician does not say, as he holds the baby up for the mother to see, “It’s a baby!” However strange these issues seem, we will leave them for the anthropologists (and marketers of infant goods) to worry about.

However, there is an ethical issue here, even though it is subtle. There is some evidence to show that, for parents who know the sex of their fetus, sexual stereotyping begins even before birth. Joan Callahan describes a conversation with a woman whose daughter had recently learned that the baby she was carrying was a boy:

The woman had no discernible preference for a boy grandchild over a girl grandchild, but she was delighted to know that her grandchild would be a boy because, she said, she could now “begin getting ready for him.” When asked what that meant, she saw immediately that it meant certain colors for blankets and sweaters, certain sorts of toys and room decorations. Long before he was even born, this child would be started on a “boy track,” surrounded by blues and trains, never pinks and dolls.\textsuperscript{189}

Pregnancy, perhaps especially when amniocentesis has freed one from at least some of the attendant anxieties, is a time rich with dreaming. If the fetus is quiet while one is listening to Bach, that shows great musical talent, while every fetal kick means that an Olympic soccer player is in the making. Just as the very early developing embryo is “totipotent,”\textsuperscript{190} the very early developing parent entertains a vast range of possibilities. In our heavily gendered culture, many of those dreams are lost, and others become locked in, the minute the baby is born and the sex is known.

\textsuperscript{188} Id. at 124-127.
\textsuperscript{189} Holmes, \textit{supra} note 158, at 136.
\textsuperscript{190} \textit{Human Embryo Research Report, supra} note 23, at 107. Totipotent means that each of the embryo’s cells has an unlimited capability of differentiating into different tissues and organs. \textit{Id.}
Most social scientists agree that gender socialization begins at birth and studies show that adults treat babies they think are male or female quite differently from the first days of life. However, with amniocentesis it is possible for gender socialization to begin before birth. Barbara Rothman, in an ingenious study, asked women to describe the movements of their fetus during the final trimester. Women who did not know their baby’s sex before birth used a variety of adjectives, without any pattern connected to the sex of their baby. However, when women knew their fetus’s sex, a distinct pattern emerged. The movements of female fetuses were much less likely to be described as “strong” and “vigorou..." The word “lively” was used often to describe females, but never males.

While some more masculine-sounding descriptions were given for female fetuses’ movements, there were never feminine-sounding descriptions for male fetuses’ movements. This is a common enough observation regarding gender—it is more acceptable for women and girls to be in some ways masculine than it ever is for men and boys to be ‘effeminate.’

Thus, one may make the argument that knowing the baby’s sex before it is born encourages the kind of gender stereotyping that threatens to limit the child’s right to an open future. This is such a subtle argument that it hardly justifies frustrating a parent’s right to know if they demand access to the information. However, Rothman points out that the urge to know the fetus’s sex often arises from the parents’ knowledge that the doctor or the lab technician already knows:

It is not simply that the information is now knowable. It is also that it is known. It is known to the medical personnel, and once the sex of the fetus becomes part of the medical record, it makes sense to treat it just as one would other information on that record. Nancy said she asked the sex because: “I want all the information available to the physician to be available to me.”

191. Jeffrey Z. Rubin et al., The Eye of the Beholder: Parents’ Views on Sex of Newborns, 44 AMER. J. ORTHOPSYCHIAT. 512 (July 1974).
192. Rothman, supra note 20, at 130.
193. id.
194. id.
195. id. Parents who did not know the sex of their fetuses were equally likely to describe male or female fetuses as strong or lively. id.
196. id.
From knowable information, to part of the medical record, the sex of the fetus finally becomes part of the “patient’s condition.” Spelling it out most clearly, Martha says she asked to know the sex of her fetus because “I believe a patient has the right and moral responsibility to know as much as possible about his or her condition.” In this way sex itself is medicalized. The pregnant woman by virtue of her pregnancy is a patient, and the sex of her fetus, by virtue of its place on the medical record, is part of her condition. Sex is a diagnosable chromosomal condition.197

One way to discourage the practice of reporting fetal sex, while still respecting the rights of parents who insist on knowing, is to adopt a policy suggested by Wertz and Fletcher in the context of discouraging actual sex selection. They propose that information about fetal sex remain in the lab and not be routinely reported to the doctor.198 Therefore, the doctor also would not know, and fewer patients would be prompted to ask for the information. The information would be available for parents who ask, but reporting would no longer be considered routine.199 This would also avoid the now rather common occurrence of parents who asked not to know being told by overenthusiastic nurses and physicians.200

E. Conclusion

Sex selection, even in the absence of abortion, limits the child’s right to an open future because it promotes gender role stereotyping and encourages parents to invest heavily in having certain types of children. This combination of investment and stereotyping makes it more difficult for the child to grow and develop in ways that are different than, perhaps even in conflict with, parental expectations. Just knowing the fetus’s sex, even outside of any attempt to predetermine it, may exacerbate gender stereotyping by allowing parents to begin the “tracking” process before the baby is born. Thus, policies which encourage sex selection or predetermination should be discouraged.

197. Id. at 122-23.
198. Wertz and Fletcher, Fatal Knowledge?, supra note 150, at 27.
199. Id. at 26-27.
200. ROTHMAN, supra note 20, at 122.
VIII. CONCLUSION

As the Human Genome Project continues its string of successes, and as assisted reproduction becomes ever more innovative, new challenges arise for social policy and for the medical and allied professions. The law is too blunt an instrument to be an appropriate vehicle of social policy in this area. As experience with sex selection through amniocentesis and abortion has shown, couples can always get around the law. Further, genetic counseling is such a subtle and sensitive art, and the counselees are in such a state of anxiety and often grief, that to burden counselors with being legal watchdogs would cause substantial harm for very little gain. Thus, the appropriate engine for expressing social policy in this area is in the codes and policy statements of the professionals themselves.

In this article, I have argued that healthcare providers should refuse to participate in endeavors to assist parents in deliberating creating disabled children, and should also refuse to participate in sex selection (unless it is for the purpose of avoiding a sex-related disease). I have also argued that providers should be extremely wary of parental requests to test children for adult-onset genetic disease. Finally, I suggest that the practice of informing parents of the sex of the fetus should be gently discouraged. All of these proposals can be implemented through policy statements by professional organizations.

In order for genetic counselors, medical geneticists and others to adopt these policies, they must be convinced that they are not in conflict with the powerful norm of respect for autonomy that virtually defines these professions. Thus, arguing that parental wishes should be overruled due to considerations of beneficence (the well-being of the child) or justice (the well-being of society) is likely to be unpersuasive. The concept of the child’s right to an open future offers a new way to resolve these issues by focusing on the autonomy of the child (present or future) as a limit on the autonomy of the parents. Thus, counselors and others are challenged, not to compromise or soften their commitment to autonomy, but to deepen and broaden it by taking the autonomy of the child into their range of moral vision as well.