“The Good Mother”:
The Limits of Reproductive Accountability and Genetic Choice

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Bree Walker Lampley has discovered the meaning of the feminist truism that the personal is the political. A Southern Californian television news anchor, with a genetic condition that causes her to suffer missing or fused toes and fingers, Bree Walker Lampley became the subject of public discussion about whether it was appropriate to conceive a child who faced a 50–50 chance of inheriting the same condition. In a breathtaking display of insensitivity, a local radio talk show host held a two-hour call-in discussion of Walker Lampley’s decision on the issue. At the time, Walker Lampley was seven months pregnant.

Underlying the controversy surrounding the talk show, and indeed the amorphous fears surrounding the Human Genome Project, is the perpetual question of accountability. Should women be held accountable for the size, health, and demographic makeup of future generations? The question is asked in terms of women’s accountability because it is they who conceive, gestate, and give birth to these generations. Governments have often looked to women’s reproductive decisions as the mediating mechanism for enforcing a social policy on population size and structure. In many ways, fertile women are viewed as having the “last clear chance” (in the jargon of tort law) to perpetuate or stifle a genetic trait. The question is, does the public have a legitimate interest in that choice? If so, are women there-
fore accountable to the public for the choices they make? Are they accountable to their families and to the children with genetic disorders they bring into the world?

The question is more than hypothetical. A 1990 general population survey revealed that 39% feel that "every woman who is pregnant should be tested to determine if the baby has genetic defects," and 22% believe that, regardless of what they would want for themselves, "a woman should have an abortion if the baby has a serious genetic defect" (Singer, 1991). Nearly 10% stated they believe that poor women should be required to abort fetuses with genetic disorders rather than be allowed to turn to government assistance for the child's rearing and health care. With regard to specific disorders, surveys reveal that 95% of women would choose abortion following prenatal diagnosis of severe mental retardation, and 60% for moderate mental retardation, blindness, or paraplegia (Benn et al., 1985; Faden et al., 1987; Golbus et al., 1979).

On the other hand, parents of children with a genetic disorder such as cystic fibrosis are more tolerant. They tend to support both the choice to have more children with genetic disorders and the choice to terminate pregnancy upon request. For example, a substantial majority support the right to legal abortion in the first trimester following diagnosis of any of the aforementioned disorders, and 58% would themselves have an abortion in the face of a fetus with severe mental retardation. On the other hand, only 40% would themselves abort a fetus with a disorder leading to death before age five; 35%, a fetus predicted to develop moderate mental retardation; 20%, a fetus affected with cystic fibrosis; and 17%, a fetus predicted to develop a severe, incurable disease with onset at age forty (Wertz et al., 1991). This disparity between tolerating and choosing abortion among those with personal experience relating to a child born with a genetic disorder highlights the intensely personal nature of these decisions, and the inability of those most closely associated with such circumstances to agree upon bright-lined rules concerning responsible reproductive behavior.

This chapter first examines the question of personal accountability to one's family or children for reproductive deci-
sions. It concludes that while arguments can be made for moral accountability, legal accountability is inappropriate for the following reasons: First, conundrums concerning causation and calculation of damages make legal remedies difficult to fashion. Second, legal accountability adds little to the already significant emotional and financial forces constraining reproductive choice in the face of probable genetic disorder. Finally, legal accountability is premised on the notion that there are indeed objective standards measuring those lives that are worth living and those that are not, an assertion we reject. The chapter then shifts to the question of whether to hold women publicly accountable to the community for their reproductive decisions. Following an analysis of the political and ethical underpinnings of individual rights and community interests, we conclude that justifications to manipulate women's reproductive decisions are fatally flawed.

**Personal Accountability for Having a Child with Genetic Disorders**

A woman's decision to conceive, abort, or bear a child with genetic disorders may be subject to questions of personal, as well as communal, accountability. To argue for such a moral or legal accountability requires that one view the decision to use or forego genetic testing as a voluntary and informed choice that is causally related to some subsequent harm. Those assumptions, however, are not well founded.

Nondirective counseling and the informed consent process are based on our assumption that patient choice is a given. Proponents of reproductive genetic testing argue that with more genetic information there will be more choice. In fact, the availability of reproductive genetic testing assumes several levels of choice: whether to have a test, what to learn from the test, whether to live with uncertainty about its results, and whether to carry to term. But choice is not that simple. From the preconception stage forward, choice free of situational coercion may be an illusion. As an example, for those women who have little or no access to prenatal care, genetic services are not available. It is therefore inappropriate to speak of their "choice" to
forego genetically indicated abortion in the context of assigning moral or legal blame.

This lack of choice can be illustrated by an examination of available genetic screening services. Federal funds are available for limited screening, but not for the abortion that some women would choose in the light of certain results (Clayton, 1993; NARAL, 1992). The majority of states place similar limitations on the use of public funds (NARAL, 1992). And the *Webster v. Reproductive Health Services* decision upheld the constitutionality of prohibiting the use of not only public funds, but also public facilities or public personnel, for abortion services. Nor is adequate funding available at the state or federal level to ensure even minimal health care for every child brought to term despite prenatal diagnoses of genetic disorder. Thus, even if screening is available, financial considerations will constrain the resulting "choices" concerning procreation to the point that moral and legal responsibility for the outcome may be dubious.

Given those limitations, how can impoverished women be held personally accountable for reproductive decisions following genetic counseling? And if such parental responsibility could be assigned, should it not be shared by both parents, even if one parent—the mother—has a constitutionally protected veto power over decisions concerning abortion?

In an ideal world, carrier screening prior to pregnancy would be a joint responsibility of the couple. Obtaining information about probabilities of genetic risk may help to clarify decision-making about reproduction, and this is a shared responsibility. However, once the decision is made to conceive and the egg has been fertilized, the responsibility shifts exclusively to the woman. This is so regardless of whether she is the carrier of the risky genetic link. The decision to conceive, often tied to the need for genetic connection by both parents, shifts all responsibility related with genetic testing to the mother: she is the sole subject of testing. In this context, do her husband's or partner's desires make her choice less than fully voluntary? If so, then moral accountability and legal concepts of proximate cause are obscured.

A further compromise of autonomous decision-making arises from the problems involved in developing standards of prenatal
care practice. Providers, who set the standard of care, have a choice not to provide such testing. But some providers may feel compelled to encourage women to choose genetic testing, both out of concern for the outcome of the birth and for fear of legal liability (U.S. Congress, 1992). Ironically, the more the profession encourages genetic testing and increases consumer expectations, the more it will be trapped into providing the services due to the perceived threat of medical malpractice litigation. Nonetheless, the profession has the power and the responsibility to question risks and benefits of genetic testing in the broader context of comprehensive pregnancy care. One example might be to attempt to educate the public as to how rarely genetic abnormalities significantly impair a baby’s health.

Professional conflict of interest can also compromise genetic counseling. The counseling session is often scheduled just prior to the genetic testing itself so that the woman may sign a consent form. There could instead be a greater interval recommended between counseling and testing procedures, allowing the woman to consider fully all of the relevant issues. Genetic counselors should not feel that they have failed themselves or their employers if a woman chooses not to be tested, nor should a woman’s decision to forego testing have financial consequences for the counselors or their employers.

In addition, genetic counseling should make clear what options a woman will have after receiving test results. Obviously, there has been increasing concern that as both the use and scope of genetic testing are expanding, the constitutional right to choose to terminate a pregnancy is contracting. While protecting previability abortion decisions from many state restrictions, recent Supreme Court decisions still tolerate extreme limits on postviability abortion—even for genetic indications—and permit mandatory counseling throughout the pregnancy period as a condition of obtaining abortion services. This makes it likely that each state will set its own rules for categorizing those conditions that justify postviability abortion. Some states will allow such abortions for “fetal defect,” congenital anomalies and the like, but as reproductive testing increases, legislation will have to refine and adjust those definitions. For example, some genetic aberrations do not cause significant disorder of physical
health, but can create cosmetic problems that are likely to cause disorder of mental health due to societal reactions to the child's appearance. Whether they will constitute a "defect" poses a problem of enormous emotional and political dimensions.

The Supreme Court's decision in Planned Parenthood of Pennsylvania v. Casey also sheds light on the permissible range of State restrictions on abortion that may affect the use of genetic services. The Supreme Court held that mandatory counseling requirements are permissible expressions of state interest in the protection of fetal life and in preference for childbirth over abortion, so long as they do not become an undue burden on a woman's right to obtain previability abortions, which the court did reaffirm as an aspect of protected personal liberty. Mandatory counseling introduces the opinions of the physician, the genetic counselor, and, in the case of counseling directives written by the state, the opinions of the state legislature and regulators as well. The Casey decision specifically upholds the constitutionality of state measures designed to express a state preference for childbirth over abortion. This includes any form of counseling that presents objectively accurate information, even if it is an unbalanced presentation, so long as the counseling does not amount to an "undue burden." The politics of the disability rights movement and the anti-abortion movement could well result in a rash of mandatory counseling provisions designed to discourage couples from using prenatal diagnosis for selective termination of pregnancy. Twenty-five states already have mandatory counseling legislation (NARAL, 1992).

As noted above, such provisions might also incorporate state attempts to define "genetic defect" in a way that manipulates parental responses to test results. States as diverse as Delaware and Texas have attempted in the past to limit abortions to cases of "severe" or "grave" malformations or defects (Clayton, 1993). Under Casey, it would appear states may still attempt to mandate counseling that characterizes some genetic conditions as minor and others as severe. A key question in such statutes is the definition of "severe defect." First, a number of test results from genetic screening can be ambiguous. Some forms of mosaicism or triploidy, for example, can be difficult to evaluate. Even in easily identified disorders, such as cystic fibrosis, the
expression of the disease can be highly variable, and the state of the art in treatment is still rapidly evolving. Whether such a condition represents a "severe defect" is a matter of interpretation.

Even more important in such a scenario is the identity of the person making the interpretation of "minor" versus "severe." In many cases this will be the physician, who will need to certify that the statutory counseling requirements were met before an abortion was performed. But the varying attitude toward abortion and disability among physicians will certainly make this judgment itself highly variable, even within a community, let alone among jurisdictions.

Furthermore, the *Rust v. Sullivan* decision upheld an interpretation of Title X regulations that prevents federally funded clinics from providing any sort of abortion counseling, except in cases of extreme medical need. Genetic abnormalities of the fetus would not provide an exception. Even following the repeal of the federal gag rule under the Clinton-Gore administration (APN, 1993), state legislation may continue to present such barriers. Louisiana, Missouri, and North Dakota, for example, have gag rules that mimic the federal restrictions on abortion counseling in publicly financed facilities (NARAL, 1992).

In addition to such financial and informational barriers, the profession itself often limits choice by abandoning the care of the pregnant woman midstream. The medical profession should ensure that providers making referrals for genetic testing or providing the genetic testing services also provide abortion services. The medical profession needs to better coordinate such services for the woman. At the same time that training in genetic testing is expanding, training in abortion services among residency programs is decreasing. At present, only 15% of the obstetrics-gynecology residents are trained in abortion procedures (O. Nordberg, personal communication, October 1992). Without such continuity, providers are in fact limiting choice for women.

Finally, lack of health insurance or information about disability services may also make some women feel they have no choice but to abort. Such women may worry that failure to abort will waive future support for the child born with disabilities. This fear may be real, as anecdotal reports continue to cir-
culate (albeit rarely) of insurance companies and HMOs threatening not to cover expenses for children born by choice with genetic disorders (U.S. Congress, 1992).

Even if a woman's decision regarding procreation is made free of the economic and psychological constraints described above, it is difficult to argue that her decision "caused" any harm. The questions raised by wrongful birth and wrongful life actions may help illustrate the point.

A wrongful birth action assumes that by the provider's failure to disclose information about genetic testing or to provide the correct test result, the provider caused a harm that requires compensation to the parents of a child born with a genetic disorder. The harm inflicted in this case is not that the child was born with a genetic disorder. Rather, the harm is the parents' deprivation of their right to know about a testable genetic condition and to then choose whether to terminate the pregnancy.

On the other hand, most courts have been unwilling to recognize a wrongful life action brought by a child against a provider for the same negligent conduct. In wrongful life, the child asserts it would have been better never to have been born than to live with such a severe disorder. Here, the provider has not actively harmed the child; that harm was caused by the accident of genetic disorder. The provider's action with respect to the child was at most a failure to "rescue" the child from a life of disorder by giving the parents timely information that would have led to an abortion. But the majority of courts are uncomfortable with any decision that hints that nonexistence might be preferable to a life with disability, and thus implicitly reject the notion that there is a duty to the child to rescue the child from such a life. Where there is no duty, there can be no cause of action or legal accountability.

These same considerations militate against legitimizing wrongful life actions by children against their parents. Unless one can find a duty to rescue a child from a life with unavoidable genetic disorders, one cannot hold the parent accountable for such a birth, even if the parent had sufficient options that the decision is correctly characterized as a "choice." Certainly, the goals of tort law are not served by holding mothers (as opposed to providers) accountable to children for the decision to
give them life. Even assuming that there is a legitimate public purpose in reducing the number of children born with significant genetic disorders, maternal liability is pointless. A woman who faces the prospect of rearing a child with significant physical problems due to a genetic anomaly already has as much cautionary information as she needs. Adding the prospect of financial liability will add little to the already inherent deterring factors.

Nor does making a mother compensate her child for the pain incurred by life with genetic disorders serve as more than a dollar-shifting mechanism, moving money from the parent to the child. As parents already owe their children a duty of adequate support, it adds little to the child’s opportunities for medical care. While lodging the suit against the parents’ insurers may offer the prospect of additional dollars flowing into the family, it hardly seems reasonable to argue that the opportunity for fraudulent use of the insurance system should be offered to a suffering child. This is especially true in the light of the real prospect, on much more solid conceptual grounds, of recovery against those medical professionals (and their insurers) who failed to give the information necessary to allow parents to avoid such a birth.

Finally, there is little “justice” in holding women liable for choosing to give birth to afflicted children. In the tort system it is considered just when those who impose nonreciprocal risks upon others are required to pay for the privilege via compensation to the victim. But choosing to rear a child with disorders is not the imposition of a nonreciprocal risk: the risk is mutual. The parent risks deep regret at having taken on such a draining and difficult task. The child risks deep regret at having been given the opportunity to decide whether this sort of life is better than nonexistence. Admittedly, only one party can be in a position to make the choice; the as-yet unconceived child cannot have had any say. But absent an outright eugenic ban on having children while knowing they will be genetically disabled, the fact of the matter is that someone must choose; and that person can only be the parent. Indeed, who better than Bree Walker Lampley, herself affected by a genetic disorder, to balance the quality of her child’s life against the task of raising such a child?
Who better than Bree Walker Lampley who has herself experienced the kinds of challenges her child will face?

Public Accountability and the Manipulation of Reproductive Decisions

Women are often subjected to communal, as well as personal, pressures to shape their reproductive decisions. The justification is usually based on public health needs. Debates surrounding modern public health crises, such as the spread of HIV infection, often use an adversarial model focused largely on balancing a presumed conflict between individual rights against community rights. This adversarial vision may well be due to the decline of widespread communicable disease, the rise of the medical profession, and the development of an individualistic, rights-based system of justice (Parmet, 1989). For many public health issues such as genetic testing and screening, however, individual interests may be in harmony with public interests, and thus cooperative models of governmental and individual action may be more appropriate (Bayer, 1989; Parmet, 1989; Gostin, Curran, & Clark, 1987; Shilts, 1987).

Historically, governments have viewed preventing disease and providing medical care as core functions, whether that entailed disease reporting and sanitary engineering or quarantine and health care (Parmet, 1985; Rosenkrantz, 1972). The police power of the state to take such measures seemed to be based on long-held doctrines that the use of property (and in turn, individual action) was limited by the extent to which it created a public nuisance (Schwartz, 1974). Even after the mid-nineteenth century, when federal constitutional law guarantees of individual rights were applied, public health regulation was viewed as largely immune from constitutional challenge (Tribe, 1988; Tushnet, 1988; Schwartz, 1974). Even draconian quarantine measures have been upheld on the basis that “salus populi suprema lex” (the safety of the people is the supreme law).5 “The police power was, in short, the public’s right to self-survival” (Parmet, 1989).

Where the public health hazards were “democratic,” in other words, where they cut across class, race, ethnic, and gender
lines in the community, there was no apparent distinction between individual interests and community interests. When any member of the community might be the next to fall ill, there was a common need for defense against the spread of illness and a common need for compassion for those afflicted. As disease became viewed more as a sign of moral and spiritual failing, however, those who imposed restrictions (who assumed themselves of superior character) began to feel safe from suffering under such constraints themselves. This was particularly true as immigration rose, and the foreign-language-speaking, often impoverished newcomers were viewed as a distinct group bringing disease and moral impurity with them (Rosenkrantz, 1972; Rosenberg, 1962).

Courts eventually began to recognize that disease control could be used abusively to oppress certain economic, racial, and ethnic minorities, and slowly increased judicial scrutiny of public health measures (Parmet, 1985). With their newfound awareness, the courts needed a principle by which to distinguish legitimate from illegitimate public health interests. The medicalization of health helped to provide that principle: Advances in bacteriology and sanitation created a scientific basis for public health policy, and this increased the delegation of public health powers into the hands of scientifically trained individuals. Over time this evolved into a policy requiring that individuals follow the advice of medical professionals lest they be viewed as having caused their own illness and threatened to make others ill as well (Parmet, 1985; Rosenkrantz, 1972; Rosenberg, 1962).

As is discussed below, in the area of reproductive health the courts have often adopted an adversarial model in which they balance the right of the community to protect itself from individuals whose decisions threaten the health and makeup of the next generation (Bartrum, 1992; Johnsen, 1992; Oberman, 1992) against the individual's right to make reproductive decisions free of government coercion. Limitation on the community's right (such as the "right" to require genetic screening) is found only in those constitutional provisions designed to protect individuals against the excesses of government action: the Fourth Amendment's protection against unreasonable searches; the Fifth and Fourteenth Amendments' assurances of due pro-
cess and equal protection under the law; the First Amendment's protection of the exercise of religion; and the doctrine of fundamental rights with regard to marriage and procreation (Adelman, 1981). Yet ironically, it is in the area of reproduction where harmony may exist between public health and individual goals, obviating the need for such adversarial analysis (Johnsen, 1992).

As the story of Bree Walker Lampley demonstrates, there is strong public sentiment against bringing children into the world knowing they will suffer debilitating and painful illness. It is, however, the very people who make the choice whether to bring them into the world who will have the primary responsibility for their care and succor. Who better, then, to make the choice of whether to conceive such a child than the people who will be there to help the child, financially and emotionally, through every hospitalization or every physical therapy session.

As the Human Genome Project continues to identify the genetic risks we all face in procreation, genetic diagnosis and counseling will become an aspect of personal health for the entire community, not just certain members or certain ethnic groups. The development of tests for cystic fibrosis is particularly significant because it heralds an era in which the Caucasian population is potentially subject to genetic screening and governmental influence regarding reproductive choices. Until now, the population groups thus targeted have largely been racial and ethnic minorities who are still working toward full acceptance and effectiveness within the political community. The earlier vision of public health, in which the entire community viewed itself at general risk, could therefore replace the present vision, in which only certain groups are at risk. This in turn could restore the inherent safeguards necessary to make majoritarian politics a more reasonable way for the community to make choices concerning the implementation of widespread genetic screening programs, and reduce the temptation to view public health models of genetic screening as a battle between community interests and individual rights.

Unfortunately, this commonality of interests is rarely recognized in reproductive politics. Instead, manipulating women's reproductive choices to meet community perceptions of inter-
generational need is a common phenomenon. While public interest in the size and composition of a population is certainly legitimate, it is not a sufficient justification for choosing the most interventionist and burdensome restrictions on women's freedom before seeking alternative solutions. The unusually interventionist population policies of China and Romania during the 1970s and 1980s illustrate the problem.

China's policy, still active in the 1990s, combines public information campaigns with tax and employment penalties for those urban women having more than one child and rural women having more than two. Those extreme costs are borne by women despite the fact that other means, such as enhanced education for girls, are powerful tools to meet public goals of reduced population growth without burdening women. Some argue that the urgency of the population growth in China required drastic measures with short-term returns. But the readiness with which the Chinese government chose to penalize women, rather than men, indicates a tendency to view women's bodies and reproductive propensities as legitimate tools of state policy.

The Romanian pro-natalist policies were equally interventionist. To ensure an adequate supply of labor for the postwar economy, women were forbidden access to contraceptives. Many were subjected to repeated pregnancy tests at their places of work. Those found pregnant were required to submit to follow-up examinations. A miscarriage would result in an investigation to determine if it had been induced. Induced miscarriage, of course, was a crime—not against the fetus, as is argued here in the United States, but against the state and the community. Once again, despite noninterventionist options for meeting state policy goals (such as increasing immigration from impoverished countries who have too many people to support), the community and government reaction was to look for a more immediate solution that entailed using women as a means to state ends.

Here in the United States, the Human Genome Project offers the prospect of an American-style debate over similar policies. Despite the rhetoric emphasizing the freedom to have children as a "fundamental" right (Robertson, 1986, 1983), the United
States has a long history of eugenic thinking and has often rushed to mold women’s reproductive decisions to meet state policy goals. In the United States the first eugenic sterilization law was passed in Indiana in 1907; twenty-nine more would follow (Reilly, 1991). The 1924 Johnson Act premised immigration policy on racist theories about the relative merits of peoples originating from various parts of Europe. Even Margaret Sanger, most influential of the early supporters of access to birth control, endorsed government offering monetary rewards to those who would be “unfit” parents if they would agree to sterilization (Gordon, 1990). More recently, state legislatures have begun to seriously debate whether to offer financial incentives—ranging from threatened withdrawal of existing social benefits to actual cash grants—to poor or drug-addicted women who choose to have a long-term contraceptive placed in their bodies. Several courts have ordered women convicted of child abuse to choose between a jail sentence and the implantation of the same, long-acting contraceptive (NYT, 1993; Southwick, 1992; UPI, 1993, 1992). Consistent with these interventionist approaches to furthering eugenic policies, American prosecutors and courts have shown a tendency to attempt to further the more general state goal of child protection by way of forced caesarean sections and prosecution of pregnant addicts.\(^8\)

With the prospect of better predictive diagnosis of disorder, there will be the temptation to ask whether we as a nation have an obligation to future generations to minimize their burdens, both personal and economic, from the presence of physical or mental disorders among them. Further, if the decision is made that such an obligation exists, there will be the temptation to protect those generations through state interventionist policies. Though the politics of abortion and the right-to-life movement probably forestall drastic policies such as that adopted in China, numerous indirect pressures could be brought to bear. These range from public service messages, to mandatory genetic testing as a condition for the granting of a marriage license, to differential insurance coverage in the semiprivate and public insurance markets.

It might be argued that we owe nothing to future genera-
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tions; after all, they consist of people who do not yet exist, may never exist, and cannot be known to us now as individuals. Furthermore, any rights they might have to protection are nonreciprocal (because they can do nothing for those of us currently living) and unenforceable. Indeed, our very actions taken on their behalf would change the genetic makeup of that future generation, thus resulting in the paradox of our taking actions on behalf of individuals who might well cease to exist as a result of those actions (Parfit, 1984, 1981).

This is an overly simplistic view, though, at least as it is premised on an atomistic, individualistic view of rights and obligations. Those future people, as yet undefined and unknowable, may be viewed as part of our moral community because they will eventually become sentient, actual people, linked to us in time if not necessarily in space. Looked at collectively, “[society] is a partnership in all science . . . art . . . virtue, and . . . perfection. As the ends of such a partnership cannot be obtained in many generations, it becomes a partnership not only between those who are living, but between those who are living, those who are dead, and those who are to be born” (Burke, 1959). As members of a common moral community, we who are living ought to abide by that implicit social contract because our obligation to the future stems from our debt to the past. One commentator likens this notion to the Japanese concept of “on” (roughly, obligation), in which “[o]ne makes payment on ‘on’ to one’s parents by giving equally good or better rearing to one’s children. The obligations one has to one’s children are merely subsumed under ‘on’ to one’s parents” (Benedict, 1946).

Accepting the notion of obligation to future generations does not, however, imply limitless duties. It would appear excessive to argue that we who are living owe them more than we owe ourselves. The reason for their claim on us (that they will be living) is no more pressing than the claim we make upon ourselves. After all, we too are living. Furthermore, their claims upon us are still conditioned upon their coming into existence and choosing to press a claim. Our claims upon ourselves are not conditional; they are already real. Thus, to some extent, the claims of members of the current generation upon the re-
sources and liberties of society are superior to those of future generations.

Given this limitation, one might realistically claim that the current generation, as a community, owes future generations a degree of restraint, such as a willingness to refrain from doing things we know will be significantly harmful. But even this does not go far enough. After all, we do some significantly harmful things to ourselves because there are economic or moral imperatives that drive our decisions. Each new interstate highway harms the aesthetic and biological values of the terrain in the name of economic development. To borrow again from the jargon of tort law, then, we can probably argue that the current generation owes a duty to refrain from negligent acts harming future generations. Such negligence can roughly be defined as engaging in behaviors that put future generations at an unreasonable risk of harm in the light of the purported benefits to be accrued by so acting. And, again as in tort law, we can look to custom as a rough and ready, though by no means irrebuttable, presumption of reasonableness. To the extent that we treat future generations no differently than we treat ourselves, we have probably fulfilled our obligations. Our own sense of the fairness of the trade-offs we are making for ourselves provides the best available guide to how future generations are likely to view similar choices. Boiled down to a formula, we who are now living probably owe those who will be living a world perhaps different in kind but not significantly worse in degree than the one we ourselves occupy. Thus, until we demand for ourselves a world free of all avoidable genetic, or indeed physical, disorders, we can hardly be said to owe the same to future generations.

The question then must be asked, how can or should we create a world for ourselves and for future generations that minimizes our burdens? The answer must be that we make sacrifices and trade-offs. The public health doctrine of quarantine requires a sacrifice on the part of the infectious person for the benefit of the community as a whole. It involves a trade-off between individual autonomy and community well-being. But the fact that such a trade-off can be made does not suggest that it need not meet minimal standards of justice. Vaccination re-
fusals are permitted in order to honor our commitment to principles of bodily integrity, parental authority, and free exercise of religion. Tuberculosis isolation is chosen only after proven medicines and directly observed therapy fail to halt the spread of infection. And quarantine is completely eschewed when, as with the epidemic of HIV infection, it would entail an enormous, lifelong burden on those who are infected and only marginally improve upon other methods of protecting the public interest in controlling the spread of the disease.

Similarly, with regard to eugenic uses of information emerging from the Human Genome Project, any sacrifice demanded of specific individuals for the benefit of current and future generations must meet standards of justice. It is pointless to try to ensure intergenerational justice by violating principles of intragenerational justice. Looked at over a continuum of time, such a trade-off does nothing to further the goal of achieving a morally responsible community across generations. And that in turn means a just distribution of sacrifice not only between generations but within generations.

One influential concept of justice discussed among law professors today is that presented in John Rawls's *A Theory of Justice*. Rawls sets out a social contract procedure designed to arrive at those principles of justice that appear imperative. He argues that valid principles of justice are those we would agree upon if each of us were to freely and impartially consider the situation from a standpoint removed from any actual society (the "original position") and from which we each bargain with others similarly rendered impartial by virtue of this "veil of ignorance." Ignorant of our own biological attributes or position in whatever sort of society we were to create, Rawls argues that rational bargainers would inevitably agree upon a certain set of principles (Rawls, 1971). Concerned with utilitarianism's propensity for looking at maximization of total social good with little attention to its distribution, Rawls concludes that there is an inevitable set of principles of justice that any set of rational negotiators would agree upon. They would, he argues, create a society based upon permitting the maximum amount of liberty for each individual compatible with liberty for all, and in which inequalities in primary social goods (income, rights, opportu-
nities) are allowed only if they ultimately inure to the benefit of everyone. This latter principle he refines to mean that inequalities are tolerable only if they most enhance the position of the least advantaged.

How can this concept guide decisions about fulfilling our collective duty to future generations, particularly with regard to women’s obligations to fashion their reproductive lives to meet current community goals about the size and structure of future populations? Although Rawlsian principles of justice cannot be blindly applied to measure the merit of a particular social program within an actual society that was not derived through his thought experiment, it can provide some clue as to whether, in an ideal world, such a program would be tolerated.

Few could argue with the proposition that women are consistently disadvantaged in society. State policies that rely on control of women’s bodies and reproductive decision-making to promote community preferences for future generations free of genetic disorder would certainly not appear to maximize each person’s liberty consistent with the liberty of others. Rather, they single out one group, fertile women, for special restriction of liberty on behalf of community interests. Further, this curtailment of liberty does not inure to the benefit of the least advantaged; rather, it inures to the benefit of the community as a whole (assuming that having fewer persons with genetic disorders in the population really is a benefit) at the expense of the least advantaged.

The result, then, is that fertile women are conscripted to serve the reproductive preferences of the leadership in the community. In Planned Parenthood of Pennsylvania v. Casey, Justice Blackmun argues in his dissent that this is an equal protection violation, created by abortion restrictions:

By restricting the right to terminate pregnancies, the State conscripts women’s bodies into its service, forcing women to continue their pregnancies, suffer the pains of childbirth, and in most instances, provide years of maternal care. The State does not compensate women for their services; instead, it assumes that they owe this duty as a matter of course. This assumption—that women can simply be forced to accept the “natural” status and incidents of
motherhood—appears to rest upon a conception of women's role that has triggered the protection of the Equal Protection Clause.

The inequalities in reproductive choice should be no more tolerable when proposed as simply making women accountable to the public for their reproductive decisions. Such accountability can range from the seemingly benign mandatory testing for genetic conditions (in order to ready a woman to make a decision about reproduction) to the draconian forced sterilization of the genetically "unfit," such as was authorized in well over half of the United States during this very century.

Rawlsian analyses of justice aside, there are good and traditional legal grounds upon which to criticize proposals that make women accountable to the public for their reproductive decisions. Faced with a credible public policy, enforcement mechanisms must nonetheless be tested against distinct criteria. First, does the enforcement infringe upon a fundamental right or a protected class of persons? If so, does the public policy represent a compelling governmental purpose? Is the chosen enforcement mechanism the most effective, least restrictive alternative? It is worth noting that this legal formulation resembles elements of the Rawlsian principles of justice. It tolerates infringements upon individual liberty only when for a compelling purpose (here somewhat broader than the Rawlsian concept that only maintenance of liberty for others qualifies as such as purpose). Further, it incorporates a protection against inequalities in rights or benefits when they disproportionately burden a disadvantaged class (somewhat more tolerant of inequality than Rawls, who permits it only when it benefits the disadvantaged class).

Manipulation of reproductive decisions does infringe upon a fundamental right. The right to procreate is grounded in both personal liberty and the integrity of the family unit and is viewed as fundamental to notions of ordered liberty and justice (Robertson, 1992, 1990, 1986, 1983). Although the *Casey* decision abandons the language of "fundamental" rights with regard to abortion decisions, it does leave untouched—for the moment—the line of cases implying that the decision to *have* a child is fundamentally protected under the due process and lib-
And the grounding of this right in the early-twentieth-century decisions concerning family autonomy (such as parental control over childhood education) argues in favor of interpreting the right to procreate as not only the right to have children but also the right to make some choices about what kind of children one will have (Robertson, 1986, 1983).

Given, then, that reproduction holds an exalted place among implicit constitutional rights, can state interests in reducing the number of children born with genetic disorders pass muster? Most means to promote this goal will impair women's reproductive freedom. Even mandatory screening laws impose a burden. They require individuals to learn things about themselves they may have no wish to know and potentially threaten their economic security by putting them at risk of social stigmatization as well as employment and insurance discrimination. These laws can, in the end, have a chilling effect on the exercise of the right to procreate. Past experience coupled with pilot projects on cystic fibrosis carrier screening in the United Kingdom and the United States demonstrate that such screening efforts will be directed primarily at women rather than at men or at couples (U.S. Congress, 1992). Thus, even mandatory screening programs place a burden on the exercise of a fundamental right by women, a group that is historically disadvantaged. If states wish to reduce the purported burden of genetic disorders, the goal must be compelling and the means chosen must be the most effective and the least restrictive possible. The implementation of mandatory screening fails to meet these criteria.

The goal of reducing genetic disorder in the population may be founded upon several propositions. First, it may reflect an economic concern that genetic disorder is costly. Second, it may reflect a desire to reduce human suffering. Third, it may be part of a teleological scheme for moving the population toward some “better” level of species functioning. None of these goals, however, is effectively served by screening laws, let alone by more drastic or harsh measures. While genetic disorders impose costs on the population through cost-sharing health and social welfare programs, they do not approach the costs incurred for other disorders, including those caused by trauma (crime, accident, workplace injury), undetected or untreated disease, and
even illiteracy. Human suffering is far greater due to malnutrition, lack of shelter, and community violence than to relatively rare genetic disorders. And improvement of the population's capacity to engage in intellectually demanding work would take place far more quickly via universal literacy than via the reduction in the number of individuals with Down syndrome. State interests in "improving" the population and reducing suffering can be met far more effectively in areas having little or nothing to do with reproductive decision-making.

Voluntary screening programs, whether directed at women exclusively or not, offer a means of enhancing personal liberty (by making it easier to make an informed choice about procreation) while simultaneously serving governmental objectives that would otherwise go unmet. Mandatory education about basic genetics and the availability of screening services, like hygiene courses in high school, can empower women without manipulating them. Focusing on the personal liberty of those making reproductive decisions, rather than on the dubious public goal of eugenic cleansing of the gene pool, puts limits on the techniques that can be used by the government to promote genetic screening or to penalize women who make unpopular decisions regarding procreation in the face of genetic risk. It puts women's bodies back in the service of their own life goals, rather than the service of the government's most immediate objectives.

Conclusion

The Human Genome Project promises to vastly increase the amount of knowledge available to us concerning the likely birth outcomes of our children. History demonstrates that the state will be sorely tempted to use that knowledge for eugenic purposes, employing the most interventionist methods possible, if only because historically there has been little regard for women making reproductive decisions on their own behalf and for their own interests. Rather, women's reproductive decisions have consistently been viewed as being made for the benefit of others, whether their husbands, their families, or the state. Yet since women will inevitably be the main targets of genetic informa-
tion, screening, and planning, as well as the primary caretakers of those born with genetic disorders, justice dictates that increased freedom of action accompany this increased degree of responsibility. That freedom includes adequate information about the availability of genetic testing, sensitive counseling and guidance in its use, and equal support for pregnancy termination or continuation.

It is essential that we take advantage of the current state of constitutional law that has allowed pro-natalist aspects of reproductive freedom to rise to the level of a fundamental right. With this official nod from the Supreme Court, it is possible to resist most state interventions on the basis that they unduly burden unfettered exercise of this right. Overall, it is worth remembering that we do not owe our children or our children’s children an endless sacrifice of personal interests. Intergenerational justice dictates that we leave future generations no worse off than we are ourselves. While we might aspire to more, we cannot demand it.

In the end, the legal response to expanded reproductive genetic testing will determine who controls the technology. The assumptions we make, for example, about causing or preventing harm may well affect the development of relevant law. To the extent that women’s choices, autonomous or otherwise, are viewed as “causing” harm, those choices will be subject to significant limitation. If the passage of a deleterious gene from a parent to a child is considered “causing” harm, then women’s decisions about genetic screening and pregnancy termination could well be the subject of state interest. On the other hand, if these are viewed as decisions simply not to “prevent” harm, the decisions are more likely to be left unfettered. Of course, the biggest risk in the light of expanded opportunities for genetic testing is the development of an affirmative duty to prevent all avoidable harms to future children from whatever cause. This is exactly the sort of theory used in numerous forced caesarean and fetal protection policy cases.

Both providers and consumers must recognize there are limits on control over reproduction and the duty to rescue members of the next generation from the results of the genetic lottery. The expansion of genetic testing may give the impression
we can and should take complete control and responsibility for the
results of birth. But in the end we must recognize that conditions beyond our knowledge or grasp may cause results that we cannot control. Law cannot change this biological reality.

NOTES

5. Seavey v. Preble, 64 Me. 120 (1874).
10. Of course, the Supreme Court has not explicitly considered whether there is a positive right to procreate. It has, however, considered a wide range of related issues, including the right of the state to interfere with procreative ability by forcible sterilization (Skinner v. Oklahoma, 316 U.S. 535 (1942)), the right of individuals to prevent conception or continued pregnancy (Eisenstadt v. Baird, 405 U.S. 438 (1972); Griswold v. Connecticut, 381 U.S. 479 (1965); Roe v. Wade, 410 U.S. 113 (1973); Planned Parenthood of Pennsylvania v. Casey, 112 S. Ct. 2791 (1992)); and the right of individuals to rear children and to form nontraditional families (Loving v. Virginia, 388 U.S. 1 (1967); Meyer v. Nebraska, 292 U.S. 390 (1923); Pierce v. Society of Sisters, 288 U.S. 510 (1925)).

BIBLIOGRAPHY


"The Good Mother"