Health care providers are usually asked to detect diseases in order to protect previously healthy individuals from becoming ill and to cure those who have become ill. Diagnosis, in these cases, is pursued in order to permit therapeutic intervention directed at returning people to health. This model, however, cannot be usefully applied to reproductive genetic testing. Because genetic disorders are inherited, fetuses or children who are found to be affected have never been “normal.” They may be asymptomatic, but they are not the same as other individuals who have a different genetic makeup. There are also limits on what can be done once genetic disease is detected. Not only is it impossible to change one’s genes, but there often are no truly curative or even largely ameliorative interventions for those disorders. In particular, there are very few effective therapies that must, or can, be begun in the prenatal or neonatal period.

As a result, while some people want reproductive genetic tests so that they can prepare themselves for the medical problems their children may have, the overriding reason these tests are offered and used is to prevent the birth of children with genetic disorders. The desire to use reproductive genetic testing for “prevention” will probably continue to play a major role, even when effective therapy becomes readily available, because
of the financial, emotional, and practical burdens associated with medical treatment.

The options available to avoid the birth of a child with genetic disorders depends on the point at which the woman and her partner are in the procreative process. If the woman is not yet pregnant, she and her partner may be able to use sperm or egg donation or may simply choose to avoid having children altogether. Once she is pregnant, however, the only way to avoid having children affected with these disorders is to use abortion—either selectively, if the disorder can be diagnosed prenatally, or generally.

Public discourse about reproductive genetic testing is heavily influenced and ultimately divided by the connections made between this sort of testing and the already controversial procedures affecting procreation such as artificial insemination by donor and egg donation on the one hand, and contraception and abortion on the other. People from many different political and religious perspectives are concerned about the use of reproductive genetic testing. Some, who profess to believe in a "right to life," argue that these tests are objectionable because all life is sacred, and they fear that the tests interfere with and may potentially threaten the lives of fetuses. Others view as immoral any form of (or influence upon) procreation besides unprotected coitus, a stance that excludes any use of genetic tests or new reproductive technologies (Congregation, 1990).

By contrast, some feminists and advocates for the rights of the disabled—including some of the contributors to this book—worry that the use of reproductive genetic tests may decrease our society's already poor tolerance of difference and may shift the onus of having a child with a genetic disorder even further away from society, onto families and in particular women instead (Rothman, 1986; Lippman, 1991). Other commentators point out that social structures that make it difficult to care for sick children can also make it difficult for potential parents to decline testing. There is little evidence, however, that legislators respond to the voices of these latter groups of critics.

At the other extreme, some people adhere to eugenic notions that the birth of children with genetic disorders places an inappropriate burden on society. The long history of such beliefs in
this country is evidenced by the thousands of people who have been involuntarily sterilized in the United States in this century.\(^1\) While present day eugenicists may not be willing to advocate openly for mandatory testing, contraception, and abortion because these notions are too unseemly in the wake of the well-known abuses here and abroad earlier in this century, they may support making testing widely available for the "public good" (Cunningham, 1990). And at some level, one has to acknowledge that reproductive genetic testing would not be made available, especially at public expense, unless people actually relied on the results to avoid having children affected by genetic disorders. The reassurance that most people feel when they get "good news" would certainly not be enough by itself to support the widespread application of these tests.

Still another group asserts that individual families ought to be able to make informed reproductive choices to suit their own goals. This sort of argument fits comfortably within the deference paid, if primarily only in words, to notions of autonomy and family privacy. Rhetoric of this kind is important, however, because of its prominent place in our public discourse.

These varying views have quite different implications in terms of policy that have the potential for conflicting with each other in fundamental ways. Thus, it is somewhat surprising that a large body of statutory, regulatory, and case law exists dealing directly and indirectly with the provision of genetic services. Many of these laws have evolved through state legislation, although the federal government has also played an important role. A close look reveals that there is indeed wide variation among the states in their approaches to reproductive genetic testing, with many states also having internal inconsistencies in their policies regarding genetics. In addition, the federal government has changed its position rather dramatically in the past 15 years. Taken together, these differences and conflicts demonstrate that there is little agreement about the appropriate use of prenatal genetic technologies.

The discussion that follows begins with an analysis of the present state of the law, looking first at cases, statutes, and regulations that directly address the provision of genetic services. Many of those statutes and regulations deal with issues of ac-
cess, most commonly by setting up state programs to provide some sort of genetic information and services to their citizens, and less frequently by requiring insurers to pay for the services. In addition, there is a burgeoning body of case law in which children with genetic disorders and their parents sue their health care providers arguing that the providers failed to supply adequate information for the parents regarding genetic risk. The families have often been at least partially successful in pursuing these claims, giving physicians added incentive to perform genetic testing and provide counseling. Some state legislatures have undermined these privately generated pressures by passing statutes that limit or eliminate families' causes of action.

The other major body of law directly affecting reproductive genetic testing is that dealing with abortion, since the main reason people use prenatal diagnosis at present is to allow them to choose whether to terminate the pregnancy if they receive an undesired result. Most current abortion statutes say little about this justification for wanting to terminate pregnancy. Their relative silence may have a substantial impact on reproductive genetic testing in the future, given the erosion of the United States Constitution's protection of the right to choose abortion. If states are once again allowed to regulate the reasons for which women may terminate pregnancies, it will be important to draw a distinction between those modes of testing that influence the decision of whether to conceive at all, and prenatal diagnosis, which almost inherently entails the possibility of abortion.

Access to Genetic Services

Although health care traditionally has been thought to be the responsibility of the states, the federal government has taken an increasingly prominent role in this area, largely by using money as an incentive to the states to provide health care services. Congress in the 1970s responded to the development of the "new genetics" by passing a variety of laws, culminating in the National Genetic Diseases Act in 1976, which provided separate funding for grants to the states to establish programs providing genetic services.²

In the 1980s, this practice changed. To begin with, the sepa-
rate funding provided under the National Genetic Diseases Act was repealed. Those programs were instead included within a special set-aside within the Maternal and Child Health Services Block Grant. The present statute has two important limitations. The Secretary of Health and Human Services can award support only to "special projects of regional and national significance, research, and training." More important, it provides that programs directed at genetic disease must compete for funding with initiatives for maternal and child health, children with special needs, individuals with hemophilia, and newborn screening, all at a time of decreased federal support for domestic programs. In addition, the detailed regulations promulgated under the National Genetic Diseases Act, which had made clear that a broad range of services were to be made available and which made no reference to abortion, were repealed in 1988.

The regulations that now govern speak of genetic testing only in the most general terms and make clear that those funds cannot be used to pay for abortion unless the pregnancy either presents a threat to the life of the woman or was the result of rape or incest, neither of which is likely to be the case for abortions for genetic indications. Under these restrictions, women who are poor or who have no way to pay for abortion can, theoretically, have prenatal diagnosis paid for with federal funds. But unless they are able to come up with some other funds to pay for abortion, they can use these technologies only to obtain reassurance or to prepare for what is to come.

What remains of the grant-making authority conferred by the National Genetic Diseases Act is that the Secretary of Health and Human Services is empowered to fund research, to educate professionals and the public, and to develop programs "for the diagnosis, control, and treatment of genetic diseases." The source of such funds is not clear, however, and preference is to be given in any event to sickle-cell anemia and thalassemia.

The federal government does provide some genetic services itself. The Public Health Service, for example, is directed to "provide voluntary testing, diagnosis, counseling, and treatment of individuals respecting genetic diseases." Moreover, some members of the armed services and their families can obtain genetic services as well. CHAMPUS, the health insurance
for military personnel and their families, for example, pays for prenatal diagnosis of both genetic and developmental disorders if the women is 35 years old or older or had rubella during the first trimester of pregnancy, or if the couple has a previous child with or a family history of a congenital abnormality. Its coverage explicitly excludes "routine or demand" prenatal diagnosis or tests to determine the sex or paternity of the child.\textsuperscript{10} Moreover, at least as of July, 1990, CHAMPUS covered the expense of most abortions,\textsuperscript{11} so that prenatal diagnosis would be a practical option for those personnel. Many veterans and their families, however, cannot obtain abortions at government expense in this setting.\textsuperscript{12} Thus, there is some, but incomplete, support at the federal level for enabling individuals to use the new genetic technologies.

The states, which have the primary responsibility for matters of health, vary greatly in their approaches to genetic services. (The details of those approaches are summarized in table 1 found in the appendix to this chapter.) Several state legislatures passed statutes providing for statewide genetics programs. Many of these were enacted in the heyday of the mid- to late 1970s, although California has revisited the topic several times, including passing several laws in the past two years. Some of the statutes are quite elaborate, providing in great detail, for example, that the services are voluntary and that the results are confidential.\textsuperscript{13} Others are quite brief, saying nothing at all about protection of the interests of the potential counselees.\textsuperscript{14} Indeed, some legislatures seem almost to have added statewide genetic services as an afterthought to their newborn screening laws,\textsuperscript{15} statutes that themselves have often been the object of little legislative attention (Clayton, 1992). Other states have created genetics programs by regulation, without a specific enabling statute.\textsuperscript{16}

Of particular interest is the fact that several states have established programs to provide prenatal diagnosis, most often by statute,\textsuperscript{17} but occasionally by regulation.\textsuperscript{18} Some of those states, however, have imposed substantial restrictions on the use of prenatal diagnosis. Minnesota and Missouri, for example, will provide testing in many instances but abortion rarely if at
Tennessee, which otherwise has a quite expansive program, provides that prenatal diagnosis will not be funded unless it would lead to treatment for either the pregnant woman or the child, stating that “the use of this program to abort unborn children is against the public policy of the state of Tennessee.”

A number of states have taken a more piecemeal approach to the provision of genetic services. To give a few examples, Pennsylvania provides funds to Jefferson Medical College to develop a program for Tay-Sachs disease, including counseling and “genetic diagnostic services.” Other states have directed that genetic screening be provided for families of individuals with mental disabilities. Still another approach is to require that applicants for marriage licenses be given information about genetic disorders and where to be tested. Finally, Kansas still requires that parents be given information about sickle-cell screening when their children enter school, despite the fact that children of that age are not the appropriate targets of genetic screening.

States ensure access to genetic services not only by acting as direct providers or by paying for the services outright in programs that are specifically directed at genetics, but also by requiring others to pay for testing when it is provided by health care professionals in the private sector. Washington, Minnesota, and California require at least some insurers who provide maternity benefits to include prenatal diagnostic tests within the benefits package. Louisiana mandates that those insurers who cover the care of people with cleft lip and palate include genetic assessment and counseling within the benefits provided, a service that that state’s insurers apparently are not required to offer to individuals with any other heritable disorder.

Finally, several states cover prenatal diagnosis under their program of medical assistance either directly as a matter of statute or by including such testing within their definition of family planning services. The latter course has been risky for state family planning programs, which typically rely heavily on federal money. Adopting such an expansive definition of family planning appeared to conflict directly with the Bush administration’s bans against mentioning abortion or providing anything
more than emergency prenatal care once pregnancy has been diagnosed, restrictions that the Supreme Court upheld in Rust v. Sullivan, but that were rescinded by President Clinton's executive order in January, 1993.

Analysis of the statutes and regulations that address genetic services suggests that there is little consensus about these programs. Many state legislatures and administrative agencies have attempted to extend reproductive genetic testing and counseling to their citizens through both direct provision of services and financial subsidy. Often these governmental institutions have devoted limited attention to the implications of such services, however. Relatively few statutes, for example, contain provisions for such fundamental protections as confidentiality and voluntary participation.

In addition, not all states appear to think that such services are desirable. Some states like Tennessee limit the services that they will provide. State legislatures have expressed ambivalence toward, if not disapproval of, genetic testing in other ways as well, some of which are discussed in the next section. And a number of states have been entirely silent on the subject, suggesting that these states provide genetic testing and counseling to their citizens, if at all, by relying upon their broad mandates to provide for the health of their population. It seems likely that many of these states simply do not supply those services.

**Wrongful Birth and Wrongful Life**

Federal and state statutes and rules focusing on genetic services are not the only bodies of law that affect the provision of genetic testing and counseling. Such activities come well within our society's current notions of health care and so are subject to the laws of medical malpractice. In the past 25 years, children with genetic disorders and their families have filed a large number of lawsuits in which they allege that their health care providers inappropriately failed to supply sufficient genetic information. Most commentators and courts now agree that such cases can be divided into two broad categories. The first are the claims of the parents, which are designated as causes of action for "wrongful birth." The second are the claims of the affected
children themselves, which are now termed "wrongful life" suits (Andrews, 1987; Wright, 1978).

Both sets of claims have essentially the same elements. The first is that the parents did not receive the relevant genetic information because of a health care provider's negligence. Negligence has a special definition in the legal system. It means not sloppiness or carelessness, but failure to meet the governing standard of care. This standard differs somewhat from state to state, but determining it usually involves asking whether the physician who was sued did something that other reasonable practitioners would not have done. Although the "reasonable practitioner" standard sounds straightforward, it can be elusive in practice. It almost invariably requires that the injured person obtain expert testimony verifying that the physician's care was inappropriate. The plaintiff's ability to provide this proof can be impeded by limitations on who can testify. In particular, the expert often must practice the same specialty as, and in a similar location to, the doctor being sued. Where this is true, an injured party may have difficulty finding a physician who is willing to testify against another practitioner whom she may know or from whom she may get referrals.

There are numerous ways in which a physician's negligence can prevent parents from getting appropriate information. Most commonly, the problem occurs in diagnosis. The physician can fail to realize that the couple is at increased risk, either by neglecting to take a genetic or even ethnic history, by not recognizing the implications of the history they did take, or by failing to make a diagnosis of heritable disease in a child previously born to the couple. Sometimes problems occur in the testing process—samples are mishandled or lost, for example—so that a diagnosis is not made. Less frequently, physicians appropriately determine the genetic risk but fail to inform the family adequately of the consequences. Such claims ought to be treated as suits asserting lack of informed consent to childbearing, although one court specifically rejected such an approach, stating that there had been no "affirmative violation of the plaintiff mother's physical integrity."

If the family can show that their provider deviated from the standard of care, they must then show that the negligence
caused them to suffer legally cognizable injury. For causation they must allege that had they been given the appropriate information, they would have chosen not to have the child. Where genetic disease was not discovered in an earlier child or where there was a problem in carrier screening, the couple need say only that had they been properly informed, they would have no more children at all or that they would have achieved conception in some other manner, such as using artificial insemination by donor, if that would have avoided the risk. Where the negligence allegedly occurred after the woman was already pregnant, she must say that she would have aborted the pregnancy either with or without prenatal diagnosis.

In some cases, alleging that the negligent failure to inform during pregnancy occurred prior to the Supreme Court's decision in *Roe v. Wade*, the courts refused to permit recovery—in part on the ground that the woman could not have obtained a legal abortion even had she known. This may become an issue again should some of the states succeed in their efforts to impose severe restrictions on access to abortion. Were that to occur, courts who favored families' claims in these circumstances might well return to a strategy used by some judges in the past who pointed out that prior to 1973 a woman who lived in a restrictive state could travel to states in which abortions were legally available.

While the existence of negligence and causation are essential elements of a suit alleging inadequate disclosure of genetic risk, such issues have not given rise to much reported appellate litigation, perhaps because they fit fairly comfortably within a traditional medical malpractice analysis. The major source of contention has been whether the birth of a child with a genetic disorder gives rise to any sort of legally compensable injury. (Table 2, found in the appendix to this chapter, contains a summary of many of the major cases and statutes that address this question.)

In considering parents' wrongful birth claims, the issue is what damages, if any, they ought to receive for having a child with a heritable condition whom they say they would have chosen not to bring to term. The majority of courts addressing this issue have concluded that parents may receive some sort of
compensation, although they differ widely as to what the measure of damages ought to be. Looking first at economic damages, a few courts have held that the parents may recover the full cost of raising the child. More frequently, courts have permitted parents to recoup the extraordinary expenses necessitated by the child’s condition, but often only until the child reaches the age of majority.

Courts have had more trouble deciding what to do with parents’ claims for emotional injuries. Some courts have denied recovery altogether, reasoning that the parents are somehow bystanders to the child’s suffering or that the mother and father did not suffer physical injury. Other courts have permitted these sorts of damages, but some have required the recovery to be offset by the benefit that the parents receive from the child. The diversity of responses to the claims for emotional distress is the result, in part, of continuing judicial concern that psychological injury is more likely to be trumped up and less susceptible to measurement than physical or economic harms.

Courts have had less trouble deciding what to do with the child’s wrongful life claim. Since the essence of the parents’ claim is the missed opportunity to avoid childbearing, most judges interpret the children’s claims as assertions that they would be better off never having been born. For a variety of reasons, ranging from the metaphysical difficulty of comparing life with defects with no life at all, to judicial reluctance to say that life is ever not worth living, to views that the physician’s actions harmed only the parents, most courts have simply refused to allow these children to receive damages. A few courts, however, have permitted children affected by genetic disorders to recover a limited measure of damages, usually to the sum of the extraordinary costs of their care that would accrue after they reach majority.

Because so much of the judicial analysis in previous cases focused on the issue of damages, it rarely mattered whether the parents said that they would have avoided procreation altogether or whether they asserted only that they were denied the opportunity to have an abortion. The only exception was in discussions of causation. Recently, however, a growing number of legislatures have stepped in to limit wrongful birth and
wrongful life claims, and in some instances it makes an enormous difference exactly what choice the parents say was foreclosed to them. Although a few state legislatures have stated simply that parents and especially children cannot prevail in any cases involving allegedly inadequate genetic counseling, more have denied such claims only if they are based on allegations that had the parents been adequately informed, they would have had an abortion. In the latter states, parents can pursue their claims if they allege that had they been given the information at the appropriate time, they would have avoided having a child with a genetic disorder by using some of the new reproductive technologies or by not having any more children at all. This legislative approach demonstrates that the debate about abortion is much more powerful politically than is the discourse about contraception or alternative methods of procreation.

Judicial and legislative efforts to limit claims for wrongful birth and wrongful life have not gone unopposed in court. A number of litigants in recent years have argued that their due process rights were impaired by such restrictions. The complainants assert, in essence, that their rights to make informed procreative choices were unduly burdened because the bans on private causes of action encouraged physicians to be negligent in warning about the risks of having a child affected by genetic disorders. Such arguments have, however, been uniformly rejected.

In summary, parents who feel that they were inappropriately denied genetic information face several hurdles if they seek to sue their health care providers. The parents bear the burden of proving that their physicians were negligent and that the deviation caused the parents to suffer damages recoverable in their state, all this in a time when state legislatures are intervening to limit such claims. Parents also run into serious problems when statutes limit the period of time in which they can sue, and they frequently find that their claims are time barred. The children themselves almost never succeed in their lawsuits. Despite those difficulties, some parents do prevail and, when they do, can recover large amounts of money. This creates powerful incentive for individual practitioners to be diligent in taking genetic his-
tories, looking for indicators of increased genetic risk, and offering reproductive genetic testing.

The Role of the Law in Abortion

In the preceding discussion of legislative, administrative, and judicial efforts to deal directly with reproductive genetic services, the current debate about abortion casts a large shadow. Tennessee, for example, specifically refuses to provide prenatal genetic testing if there is no treatment available for the affected fetus, and a number of states forbid lawsuits based on the allegation that parents were denied the opportunity to choose abortion. Analysis of the abortion statutes themselves demonstrates that they, too, can affect the availability and usefulness of genetic testing. Such an inquiry also provides more insight into the acceptance particularly of prenatal diagnosis. To this end, my focus here is on the statutes that are actually on the books. Although many of these laws have been enjoined and so have no current legal effect, the Supreme Court in Planned Parenthood v. Casey recently made clear that substantial, if not unlimited, state regulation may be permissible.50

As is true of the laws dealing directly with the availability of genetic services, it is useful to begin by looking at federal law regarding abortion, even though most of the legislation actually occurs at the state level. Since the 1970s, the United States government has refused in most instances to permit its funds to be used to pay for abortion unless the pregnancy was the result of rape or incest or unless continuing the pregnancy would threaten the life of the woman.51 Current regulations now state explicitly that this ban applies to genetic testing funded within Maternal and Child Health Services Block Grants.52

The government also promulgated regulations stating that employers cannot be charged with sex discrimination if they refuse to provide "[h]ealth insurance benefits for abortion, except where the life of the mother would be endangered if the fetus were carried to term or where medical complications have arisen from an abortion . . . ."53 Employers are, however, free to provide broader benefits if they choose or if required to do
so by a bargaining agreement. Thus, Congress and the administration have done much to ensure that women who seek to abort fetuses with genetic or other anomalies will have to pay for the procedures out of their own pockets.

While the impact of these congressional and administrative efforts to erect economic barriers has been far-reaching, the most profound federal influence on the law of abortion has been the elaboration in *Roe v. Wade* of limited constitutional protection of a woman's right to choose to terminate a pregnancy. Before 1973, most states had restrictive statutes regarding abortion. After the decision in *Roe*, some states simply left their old statutes on the books. Other states took a different approach: Some simply repealed their old laws and put nothing in their place, others enacted new laws that essentially followed the trimester approach set forth in the Supreme Court's opinion (Hood, Kavass, & Galvin, 1991). Many state legislatures, however, began to test the limits of *Roe*. Until recently, the legislatures did not assault *Roe*'s basic framework directly, trying instead to attack it at the edges, passing laws, for example, requiring spousal and parental consent or notification, regulating the conditions under and methods by which abortions could be performed, or attempting to define viability. These efforts met with varying degrees of success in surviving constitutional scrutiny, but left intact the basic notion that women could obtain abortions for any reason until the fetus reached viability.

For the most part, legislators attempted to regulate the reasons for which women could seek abortions only after fetal viability. A few states passed statutes that explicitly or implicitly permit third-trimester abortions of fetuses with serious defects, but most that addressed the issue allow late abortions only if continuing the pregnancy would threaten the life or health of the woman. Although one state sought to restrict certain abortions prior to viability, the others that considered decisions made during this period took a more permissive stance, mentioning the presence of defects in the fetus only as a factor to be considered, and usually by the physician. (The language of the statutes that address the legal implications of finding defects in the fetus for abortion decisions are summarized in table 3 of this chapter's appendix.)
relative silence on the federal and state level about selective abortion has been that women can legally abort fetuses with defects before viability and sometimes thereafter.

However, beginning early in the 1980s and culminating in *Webster v. Reproductive Health Services*, a growing number of the justices on the Supreme Court expressed dissatisfaction with *Roe v. Wade* and essentially invited the states to pursue a more frontal assault on the earlier opinion. In response to this judicial rhetoric, as well as to growing political pressure, legislators began to devote much more attention to abortion, resulting in a spate of new laws. A few legislatures accepted the invitation of the discontented justices and enacted very restrictive statutes that fly in the face of *Roe*. Utah, for example, passed a law that would permit abortion only if the pregnancy threatened the life of the woman or was the result of rape or incest, or if the fetus was diagnosed with grave defects. Louisiana's new law is even more restrictive, allowing abortion only if the pregnancy was caused by rape or incest or threatens the woman's life. Guam's statute permits abortion only when the pregnancy is ectopic or when two physicians independently agree that "there is a substantial risk that continuance of the pregnancy would endanger the life of the mother or would gravely impair the health of the mother." Notably, the latter two statutes contain no provision for selective abortion of fetuses with anomalies.

For now, the validity of these restrictions must be assessed in the light of the Supreme Court's recent opinion in *Planned Parenthood v. Casey*. In that case, the Court held that while legislatures may regulate abortions prior to viability, they may not place undue burdens in the way of a woman's right to choose. Because requirements that married women notify their spouses and that minors notify both their parents have been held to be undue burdens, the scope of permissible regulation, while quite broad, is not unlimited. Indeed, Louisiana's and Guam's statutes have already been struck down. A district court in Utah, however, in an opinion handed down days before *Casey*, upheld the Utah statute, rejecting among other things an argument that the provision that abortions be permitted only when the fetus suffered from grave defects was unconstitutionally vague. In the unlikely event that the district court's ruling upholding limita-
tions on abortions of fetuses with defects survives appeal, it would open the door to other states that wish to limit women's ability to decide to abort fetuses with anomalies or other genetic disorders. Women who live in states that adopt laws as restrictive as Utah's may be forced to travel to another more permissive state if they seek an abortion after prenatal testing detects a problem in the developing fetus. While this additional hurdle is one that some women will not be able to surmount, other courts have found restrictions that force women to undertake burdensome travel not to be undue.71

The United States Constitution is not the only protection available to women opposing state legislatures' efforts to restrict access to abortion. Women increasingly assert, with varying degrees of success, that their state constitutions protect the right to choose,72 and the new Congress may well enact a federal statute guaranteeing some sort of access.73 But unless Congress and state courts step in, many women face the prospect that their state governments will curtail their ability to choose to abort a fetus with defects.

Even assuming that women retain some rights to choose abortion, many women already confront substantial economic barriers to such choices that the states have done little to address. A few states have chosen to provide public funding for selective abortion, often hiding such decisions in funding bills that do not make it into the statute books where they would be readily accessible for public scrutiny. (The language of these funding provisions is summarized in table 4 of this chapter's appendix.) Most states, however, do not permit their medical assistance funds to be used for this purpose, which is hardly surprising in the light of the federal restrictions.

Fourteen legislatures also accepted the invitation of the Title VII regulations to enact laws permitting private insurers to exclude coverage for most abortions except when the pregnancy threatens the life of the woman or when complications have arisen from an earlier abortion.74 While most of those statutes do allow insurers to offer these benefits if they choose, not a single state requires insurers to pay for abortions of fetuses with defects. Efforts are now underway to ascertain what insurers are actually doing within these legal guidelines.75 Many privately
insured women are probably covered for testing and abortion since, from the insurer’s perspective, those procedures may often be cost-effective when compared to the costliness of long term care for a child with a serious genetic disease. Indeed, what some women may need more than coverage is protection from insurers’ efforts to pressure them into aborting fetuses who are at risk for or who are determined to have a genetic disorder (Karjala, 1992).

Regardless of the context of private insurance, the result of most of the statutes regarding abortion is that many poor women cannot use prenatal diagnosis, even if it is offered by the state or some other party, because they cannot afford the abortion that they might want should the fetus be found to have a defect. Moreover, all women face the threat that the Supreme Court will not recognize a woman’s right to abort a fetus with genetic defects when the Court is directly confronted with the question. Were this admittedly unlikely scenario to occur and were states to act aggressively to restrict selective abortion while Congress remained silent, prenatal diagnosis would have little place, at least until gene therapy or other therapeutic interventions become available.

**Governmental Response to Reproductive Genetic Testing—Lacunae and Ambivalence**

It would be unrealistic to expect all states to have fully developed responses to technologies as new as reproductive genetic testing. Governments simply do not move that quickly. But the lack of well thought out programs is probably the result of more than mere reluctance to deal with technical matters or the press of other problems. For as noted at the outset, the inextricable linkage between reproductive genetic testing and alternative methods of procreation, contraception, and abortion raises profound and controversial issues.

The existence of such deeply divided beliefs has meant that many legislators passed laws not always consistent with one another. Examples of such inconsistencies abound. Tennessee passed a law in 1985 forbidding the use of public funds for prenatal diagnosis of conditions for which there are no effec-
tive therapy, saying that abortion was against public policy. Since 1989, however, that same legislature has provided public funds for abortions of fetuses "medically determined to have severe physical deformities or abnormalities or severe mental retardation."  

Louisiana established regional genetics clinics for its citizens and later passed the first statute in the continental United States since Roe v. Wade to forbid the abortion of fetuses affected with genetic disorders. Missouri will pay for "genetic diagnostic evaluations, treatment, counseling, and follow-up for families with or at high risk for a genetic disease," language that appears to include prenatal diagnosis, but forbids referral for abortion unless the life of the woman is threatened. That state also enacted a statute barring recovery for claims by parents alleging that they were denied genetic information that would have led them to choose abortion. The government of North Carolina provides an extensive set of genetic services to its citizens. Its highest court, however, held that neither parents nor children can receive compensation when the parents were inappropriately denied genetic information. A similar set of laws providing services but barring suits for wrongful birth and wrongful life were enacted by Colorado’s legislature.  

At the other end of the spectrum, the New Jersey courts provide among the broadest recovery for wrongful birth and wrongful life claims seen in this country. That state’s legislature, by contrast, has done almost nothing to provide genetic services to its citizens. Some of those laws can be reconciled with each other at least on a formal level, usually on the ground that preconception testing is more acceptable than that occurring after pregnancy has begun because of the more obvious possibility of abortion in the latter case. Thus a state could offer carrier screening while declining to provide prenatal diagnosis. Even so, it is hard to understand why a state would make available genetic testing and then deny private rights of action to their citizens when individual practitioners fail to provide the same services. Particularly in the light of the number of laws that have been enacted, it is remarkable how infrequently governmental bodies have created comprehensive sets of services and protections. Far
more frequently, the legislators established programs in little more than a sentence despite their far-reaching implications. Only a handful of legislatures took a broad look at the potential needs or desires of their citizens. Few regulate the genetic testing techniques to ensure that testing is actually being done accurately. Perhaps legislators are relying upon the litigation about wrongful birth and wrongful life, the efforts of private groups, and the Federal Clinical Laboratory Improvement Act to elaborate appropriate standards of care even though such mechanisms are not likely to be fully effective. These technologies are often expensive, yet only a small number of states have acted to ensure that adequate funding is available to those who wish to receive testing and counseling.

The lawmakers have said correspondingly little about abortions of fetuses with genetic disorders. Their silence may have been the result, until recently, of a sense that there was little reason to say anything because the law was clear. Now that the law is open to question, legislators from both ends of the political spectrum may be reluctant to address the subject of genetically indicated abortions. Perhaps some lawmakers who generally oppose choice are ambivalent when the fetus has serious defects. More likely, those who favor choice fear the consequences of opening the topic for discussion at all.

Legislators have said nothing about the use of alternative methods of procreation such as artificial insemination by donor and egg donation as possible methods to avoid having children with genetic disorders. This lack of activity is not particularly surprising since regulation of the new reproductive technologies has been an area that legislatures have hesitated to confront. Indeed, only one state requires physicians to obtain a genetic history from sperm donors, and that state only suggests genetic testing. Their silence, nonetheless, reveals yet another way in which lawmakers have failed to ensure that families have options in the face of information indicating that they may produce children with genetic disorders.

Finally, in addition to the inconsistencies and gaps within the policies of individual states, it is also obvious that the variation among the public policies of different states is enormous. California, which has worked on many levels to increase access to
reproductive genetic testing, has radically different policies from Louisiana, which has sought to ban abortion altogether in most situations. Taken as a whole, the frequency with which individual states have adopted conflicting or perfunctory policies, or no policies at all, and the wide array of approaches taken by the different states demonstrate that there is no consensus on the role of reproductive genetic testing.

Conclusion

The law affects reproductive genetic testing in a host of ways. Legislators, congresspeople, and administrators have sought both to provide and to limit access to genetic testing. When the government attempts to ensure access, it often provides services itself, and less frequently requires third-party payers to provide coverage. In those efforts, however, it is truly remarkable how rarely the links between reproductive genetic testing, contraception, abortion, alternative methods of procreation, and feelings of discomfort about the "new genetics" have actually been acknowledged. The implications have been more explicitly recognized when legislatures put barriers in the way of individuals' desires to obtain reproductive genetic testing. But no matter what form the discussion takes, the implications for women of this sort of testing are rarely considered.

The most powerful force driving the use of these technologies is not the direct interventions of governments to ensure access, rather it is the actions of individual litigants who bear a child affected with a genetic disorder and then sue health care providers and institutions. That genetic testing would be shaped more by lawsuits than by legislation is hardly surprising since litigants are not constrained by the same political pressures and public rhetoric that lawmakers face. The individuals who have sued physicians and health care institutions have alleged that they were entitled to information that can be revealed by reproductive genetic testing. The sense that those people were wronged by being denied this information has been supported, albeit to varying degrees, by the courts and only partially undermined by legislative efforts to limit such suits.

The wealth of articles and books in the genetics literature as
well as informal conversations with geneticists and genetic counselors suggest that the private lawsuits are viewed as powerful incentives for encouraging the use of genetic testing. Indeed providers seem to have been driven, by their fear of liability, to expand the care they deliver. This more sophisticated level of practice has elevated the standard of care, thereby, almost ironically, increasing individual practitioners' potential exposure to claims that they failed to provide appropriate care.

One might argue that these cases demonstrate that women very much want reproductive genetic testing. But before one accepts this hypothesis too readily, one must recognize that individuals' reasons for claiming can be quite complex, ranging from anger at a physician's lack of communication skills or the desire for genetic information, to pressure from others or the simple need for money (Hickson, Clayton, Githens, & Sloan, 1992; Sloan et al., 1993). Thus, more scrutiny of the events that led families to pursue claims for wrongful birth and wrongful life is necessary. Even if the people who sued did feel that they were wronged by being denied access to genetic information, it is also possible that they would have been troubled by their options had the information been provided. And there is no reason to think that most people hold the same views about the desirability of reproductive genetic testing as those who filed claims.

The result of legislative and administrative actions and private litigation is a two-tiered system. People who are poor have some access to genetic services, limited in many instances by debate and ambivalence within the political arena. Their ability to obtain access via court, seeking damages for wrongful birth or wrongful life, is limited because they cannot prove causation should they not have been able to pay for the services they say they were denied. Individuals who can pay, by contrast, have greater access to genetic testing—access facilitated by patterns of medical practice driven by the pressures of litigation and by a wish for cost-efficiency by insurers.

The gap between the two levels of service may narrow in the future. The poor may be given greater access, perhaps for unspoken eugenic reasons or perhaps due to greater political activism by those who are pro-choice or who view procreative decision-making as a personal matter. An alternative scenario is
that legislatures will limit or bar the claims of individuals who do not receive genetic information, thereby limiting the incentives of practitioners to provide genetic testing. Another more distant possibility is that legislatures will successfully limit the use of abortion in cases where fetuses are determined to have genetic or other disorders.

Given the dramatic increases in genetic knowledge, it seems likely legislatures will continue to address reproductive genetic testing. But if inconsistent and incomplete policies are to be avoided, the implications of this technology for contraception, abortion, and alternative methods of procreation, and ultimately for the ways in which we regard others must be confronted directly. It will also be necessary to decide what interests ought appropriately to be considered and what weight those interests should be given. The role of promoting reproductive genetic testing for eugenic purposes and for avoiding burdens on the public fisc must be explicitly addressed. A major challenge will be to ensure that the various views of women are heard in the debate.

ACKNOWLEDGMENTS

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NOTES

18. 77 Ill. Admin. Code § 630.30 (1985) (MCH project to cover genetic screening and prenatal diagnosis); Md. Admin. Code tit. 10, §§ 39.02.01-.10, 39.03.01-.06, 52.01.01-.06 (genetics programs and MSAFP); Ohio Admin. Code §§ 5101:3-4-07&08 (1989) (genetics within family planning and obstetrical services).
31. Howard v. Lecher, 366 N.E.2d 64 (NY 1977) (alleging failure to recognize risk that parents who are Ashkenazi Jews may have child with Tay-Sachs disease).


51. 42 U.S.C.A. § 300a-6 (1991) (no funds to programs in which abortion used as method for family planning); 28 C.F.R. §551.23(b) (1990) (prison inmates); 42 C.F.R. § 36.54 (1990) (Indian Health Services; mentions only life of the woman); 42 C.F.R. §§ 50.304, 50.306 (1990) (Public Health Service).


75. Moseley R. “Insurance Implications of a Complete Genome Map,” 1 R01 HG 00402-01.


What the Law Says


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# APPENDIX

## TABLE 1 Statutes and Regulations Addressing Genetic Services

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**LEGEND**

- **be** calling for bioethics commission
- **c** confidentiality
- **ch** parents to be told about possibility of testing children for sickle-cell trait upon their entry to school
- **cl** required only for families of patients with cleft lip &/or palate
- **d** antidiscrimination law addressing genetics
- **e** eugenic language
- **educ** provides for education in schools
- **f** far reaching statement of protection of patients
- **fp** family planning services include genetic counseling
- **m** information regarding genetics given to applicants for marriage licenses
maternal child health program

physicians to test marriage applicants for sickle-cell disease or trait

no statement regarding protection of patients

cannot do prenatal diagnosis of diseases for which there is no treatment

cannot refer for abortion unless continuing pregnancy would threaten life of mother

"program of prenatal diagnosis for the purpose of detecting the possible or handicaps of an unborn child will not be used for screening, but rather will be utilized only when there are medical or genetic indications which warrant diagnosis"

neural tube defects/MSAFP

prenatal diagnosis

regulation

statute

surcharge placed on insurers to pay for state genetics program

voluntary

* comprehensive program including education in schools

discusses hereditary diseases but does not really address screening and counseling

STATUTES AND REGULATIONS REFERRED TO BY STATE

Alabama (statute)

California (statute)

Colorado (statute)

Florida (statute)

Georgia (statute)

Hawaii (statute)
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Iowa (statute and regulation)
1990 Iowa Senate Joint Res. 2003 (genetic factors among those contributions to developmental disability that can be “prevented or minimized”).

Kansas (statute)

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## Table 2 (continued)

<table>
<thead>
<tr>
<th>State (Level of Authority)</th>
<th>Citation</th>
<th>Full Economic Damages</th>
<th>Extraordinary Damages</th>
<th>Emotional Damages</th>
<th>Minus Benefits</th>
<th>Wrongful Life</th>
</tr>
</thead>
<tbody>
<tr>
<td>WA (S) Harbeson v. Parke-Davis, 656 P.2d 483 (1983); Harbeson v. Parke-Davis, 746 F.2d 517 (9th Cir.) (1984)</td>
<td>Y</td>
<td></td>
<td></td>
<td></td>
<td>Y *</td>
<td></td>
</tr>
<tr>
<td>WV (S) James G. v. Caserta, 332 S.E.2d 872 (1985)</td>
<td>Y</td>
<td></td>
<td></td>
<td></td>
<td>N</td>
<td></td>
</tr>
<tr>
<td>WI (S) Dumer v. St. Michaels Hosp., 233 N.W. 2d 372 (1975)</td>
<td>Y</td>
<td></td>
<td></td>
<td></td>
<td>N</td>
<td></td>
</tr>
</tbody>
</table>

**Legend**
- S state supreme court
- I state appellate court
- F federal court
- Y yes
- N no
- D dicta
- NA not appealed
- P pending, awaiting trial below
- r reversed by later opinion
- * extraordinary expenses after majority
- # no lost earning capacity
- @ children barred from bringing claims only against parents
- ~ abortion only
- † occurrence of genetic defect not foreseeable
- ^ can recover only for the emotional injury of not being warned that fetus had congenital defects
- + negligence occurred before Roe v. Wade
- = medical expenses recoverable only until parents’ death
TABLE 3 Statutes that Address Abortion of Fetuses with Defects

BEFORE VIABILITY

<table>
<thead>
<tr>
<th>State</th>
<th>Statutory Language</th>
</tr>
</thead>
<tbody>
<tr>
<td>Del. Code Ann. tit. 24, § 1790 (1991)</td>
<td>permissible reasons for abortion include “substantial risk of the birth of the child with grave and permanent physical deformity or mental retardation”</td>
</tr>
<tr>
<td>Idaho Code § 18–608 (1991)</td>
<td>factors physician is to consider in deciding whether to provide first or second trimester abortion include “that the child would be born with some physical or mental defect”</td>
</tr>
<tr>
<td>Kan. Stat. Ann. § 21–3407 (1991)</td>
<td>physician justified in performing abortion “if there is substantial risk that . . . the child would be born with physical or mental defect”</td>
</tr>
<tr>
<td>Tex. Rev. Civ. Stat. Ann. art 44956 (1991)</td>
<td>physician can perform abortion if “the fetus has a severe and irreversible abnormality, as identified through reliable diagnostic procedures”</td>
</tr>
</tbody>
</table>
### THIRD TRIMESTER ABORTIONS

<table>
<thead>
<tr>
<th>State</th>
<th>Statutory Language</th>
</tr>
</thead>
<tbody>
<tr>
<td>Idaho Code § 18–608 (1991)</td>
<td>if abortion not performed, “pregnancy would terminate in birth or delivery of a fetus unable to survive”</td>
</tr>
<tr>
<td>Kan. Stat. Ann. § 21–3407 (1991)</td>
<td>can perform abortion if “there is substantial risk . . . that the child would be born with physical or mental defect” [no mention of viability]</td>
</tr>
<tr>
<td>Md. Pub. Health Code Ann. § 20–208 (1991)</td>
<td>can perform abortion if “[t]here is substantial risk of the birth of the child with grave and permanent physical deformity or mental retardation” until 26 weeks' gestation</td>
</tr>
<tr>
<td>Tex. Rev. Civ. Stat. Ann. art 44956 (1991)</td>
<td>can perform abortion if the fetus “has a severe and irreversible abnormality, as identified through reliable diagnostic procedures”</td>
</tr>
<tr>
<td>State</td>
<td>Statutory Language</td>
</tr>
<tr>
<td>-------</td>
<td>--------------------</td>
</tr>
<tr>
<td>Colo. Rev. Stat. §§ 26-4-105.5 &amp; 26-15-104.5 (1991)</td>
<td>“presence of a lethal medical condition in the unborn child . . . which would result in the impending death of the unborn child during the term of pregnancy or at birth”</td>
</tr>
<tr>
<td>1991 Iowa Acts 267, §§ 103, b &amp; 210, o(2)</td>
<td>“fetus is physically deformed, mentally deficient, or afflicted with a congenital illness”</td>
</tr>
<tr>
<td>1992 Md. Laws 64, § 1, 32.17.01.02</td>
<td>“genetic defect or serious deformity or abnormality”</td>
</tr>
<tr>
<td>1992 Tenn. Pub. Act. 1018, § 10, Item 4(3)</td>
<td>fetus is “medically determined to have severe physical deformities or abnormalities or severe mental retardation”</td>
</tr>
<tr>
<td>Va. Code § 32.1-92.1 (1991)</td>
<td>“any case in which a physician who is trained and qualified to perform such tests certifies in writing, after appropriate tests have been performed, that he believes the fetus will be born with a gross and totally incapacitating physical deformity or with a gross and totally incapacitating mental deficiency”</td>
</tr>
</tbody>
</table>