Courts and Wrongful Birth

Can Disability Itself Be Viewed as a Legal Wrong?

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In 1990, the U.S. Congress launched a $3 billion scientific endeavor to uncover the specific links between genes and disease. The Human Genome Project was designed to map (that is, determine the location of) and sequence (or analyze the constituent parts of) each of the 50,000 to 100,000 genes in each human cell. Described by proponents as "biology's moon shot" and by opponents as "the Manhattan Project of science," the Human Genome Project's ultimate goal is to facilitate the development of genetic diagnostic tests and genetic treatment modalities for the nearly 5,000 diseases that have a genetic basis.

The Human Genome Project is producing an explosion of information. The genetic tests that are being developed determine the presence of genes signaling current and future diseases that may affect a person. People are able to learn of their risks of developing a particular genetic disease or of the possibility that they may develop a particular illness after exposure to certain environmental stimuli. They can also learn about the genetic makeup of their fetus, thus providing information that the couple can use to decide whether to continue or terminate the pregnancy.

As the volume of genetic information increases, prospective parents are beginning to expect health care professionals to inform them of genetic risks to their potential children due to their age, ethnic group and family history. Many couples seek genetic testing of themselves and their fetuses. They expect doctors to be able to predict genetic risk, to undertake genetic tests in a careful manner, and to convey the results accurately. When potential parents' expectations are not met—and they give birth to a child with a genetic disorder—they may sue the health professionals for "wrongful birth." In some cases, the child himself or herself might sue the health care provider for "wrongful life"; in such cases, the child's attorney claims the child would rather not have been born than have been born with the genetic-based disability.

The very notion of wrongful birth and wrongful life—conveying the idea that having a child with a disability that could have been "prevented" through abortion is a legal wrong—seems vastly at odds with the ideas about disability that serve as the foundation for the Americans with Disabilities Act. At the same time, however, some disability rights activists are strongly pro-choice and feel uncomfortable restricting women's rights to terminate a pregnancy. Moreover, because of altercations that people with disabilities have had with the medical system, they are sometimes troubled by taking the side of negligent doctors in these legal actions.

How, then, are we to reconcile the genetic tort actions with our goals in enacting and enforcing the Americans with Disabilities Act? To begin to answer that question, we need to analyze closely the social and legal context in which prenatal screening occurs and the perceptions of disability that undergird the wrongful birth and wrongful life cases.

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In large measure, the history of eugenics is a history of brutality against the disabled. People who were mentally disabled were involuntarily sterilized in the United States by the thousands at the turn of the century. In Nazi Germany, people with disabilities were systematically exterminated. Even today, much of the writing about genetic discoveries includes economic analyses about the cost of care for people with a particular genetic mutation, implying that society would be better off had they not been born.[1]

Genetic technologies have a major impact on people with disabilities. Indeed, genetic testing changes the very categories of "disabled." As bioethicist Paul Ramsey pointed out when amniocentesis was first introduced, "the concept of 'normality' sufficient to make life worth living is bound to be 'upgraded'"[2] as testing is increasingly offered for less and less serious disorders. Currently, some parents choose to abort for reasons that seem trivial or inappropriate to other people. Some parents abort fetuses with an XYY chromosomal complement, for example, even though research has disproven the hypothesis that this is a "criminal" gene. People with dwarfism "are incensed that by the idea that a woman or couple would choose to abort simply because the fetus would become a dwarf."[3] As time passes, an increasing number of women abort based on particular types of genetic information, which also changes the boundaries of normality. The percentage of women in Scotland who aborted fetuses with spina bifida rose from 21 percent in 1976 to 74 percent in 1985.[4]

Newer genetic technologies provide the opportunity for users to choose to avoid very minor deviations from some perceived normality. Consider the use of preimplantation screening, which Marsha Saxton refers to as "admission standards" for fetuses.[5] A couple undergoes *in vitro* fertilization, produces multiple embryos, and each one is genetically tested. If a couple has ten embryos in petri dishes, they might use different criteria to determine the "genetic worth" of the embryos to be implanted than they would in determining whether a single *in utero* fetus at four months of development should be aborted. While a couple may not be likely to abort a fetus based on its sex or based on being an unaffected carrier of a recessive disorder, they may, when faced with a high volume of embryos, only a few of which can be safely implanted in the woman, decide to implant only noncarrier embryos or embryos of a particular sex. With ten embryos, the couple must refuse implantation of some of the embryos for the safety of the woman and any resulting fetuses. If a couple chooses to move from randomly selecting the embryos to be implanted to doing so on genetic grounds, this may seem less morally problematic to them than aborting a particular fetus. The decision may be viewed differently for several reasons. The woman is not physically pregnant, so there has not been attachment to a particular fetus. She has not felt the fetus move or begun to bond with it. In addition, the process may be viewed less as choosing *against* a particular individual (the developing fetus) than choosing *for* a set of individuals (the embryos to be implanted).

Some genetic testing programs go even further than reporting known conditions; they also report any unusual genetic pattern, even where there is no clear indication about whether the genetic deviation has *any* health implications whatsoever. Thus couples may choose not to implant embryos and not to carry to term fetuses that do not meet some gold standard of normality, even in instances where the fetus would face absolutely no health risk.

In addition to possibly making even less-serious departures from the model genome seem like a disability, genetic predispositional testing is creating a new form of disability in

Francis + Silvers (ed) Americans with Disabilities (2000) which currently "able" individuals are being treated by insurers, employers and others as "disabled" because of a potentially increased future propensity to illness.

Genetic tests are also stigmatizing existing people with disabilities as having slipped through the net of prenatal screening. The mere existence—and marketing—of genetic testing may seem like an affront to many people with disabilities, given the numerous ways in which "genetic" information was used in oppressive ways in the past, as with the mandatory sterilization laws at the turn of the century in this country, and the way in which disabled individuals continue to be discriminated against today.[6] The fact that the birth of children with certain disabilities can be "prevented" can aggravate the stigmatization of such children.

There is much in common between women who undergo genetic testing on themselves or their fetuses and people with disabilities. Both groups may suffer from medical manipulation. A woman whose genetic test results indicate that her fetus is affected with a genetic disorder—or that she herself is likely to develop a genetic disorder later in life—may be discriminated against by various social institutions such as insurers or employers. Yet despite certain commonalities, these two groups may appear to be at odds with each other. This is because some women's use of prenatal diagnosis to identify fetuses with particular disorders and abort them may be seen as devaluing existing people with those same disorders. In some—perhaps many—instances, the decision may be based on ignorance or even misinformation about what life with that disability is like, or even whether people with that condition consider it a disability at all.

PRESSURE TO USE GENETIC SERVICES TO ELIMINATE DISABILITY

"Prenatal screening seems to give women more power," says disability rights activist Laura Hershey, "but is it actually asking women to ratify social prejudice through their reproductive 'choice'?"[7]

Genetic testing creates an environment in which people believe that if a test is offered they should take it and act upon the information. "Women are increasingly pressured to use prenatal testing by claims that undergoing these tests is the 'responsible thing to do.' Strangers in the supermarket, even characters in TV sit-coms, readily ask a woman with a pregnant belly, 'Did you get your amnio?'" notes Martha Saxton.[8] Even a government agency, the Office of Technology Assessment of the U.S. Congress, exemplified this approach. After describing new genetic tests, an Office of Technology Assessment report stated "individuals have a paramount right to be born with a normal, adequate hereditary endowment."[9]

The way in which physicians describe a genetic condition may make it seem much more grim than it seems to a person with that condition. "Medical descriptions of Down's syndrome—rather than revealing the variability of the condition—selectively represent the condition in uniform, distancing, negative, ungendered, and static teams," notes Diane Beeson.[10] In the prenatal setting, as an increasing number of tests are being developed for less-serious disorders, parents may be pressured into feeling that something is "wrong" or "unfit" with their baby if there is the slightest departure from a socially conditioned perfection. Prenatal diagnosis, asserts McGill University epidemiology professor Abby Lippman, is "an assembly line approach to the products of conception, separating out those we wish to develop from those we wish to discontinue. . . ."[11]

Genetic testing may also "privatize" disability. Once prenatal diagnosis and testing are made available for a particular disorder, there may be a tendency not to continue to provide funds for research to help combat the medical problems for existing people with that disorder and not to continue social services for such individuals. Once genetic disease is no longer seen as a random characteristic, this may reduce our communal commitment to people with genetic disabilities.[12] This may be especially true in the coming years as wealthier women get access to prenatal diagnosis and abortion and poorer women do not.[13] If a disproportionate number of disadvantaged women have children with disabilities, their lack of clout in state legislatures may make it less likely that legal protections such as educational opportunities for people with disabilities will be continued.

Couples may be made to feel guilty by relatives, health care providers, insurers and other social institutions if they give birth to a child whose departure from "normality" could have been determined prenatally. This is particularly true in the case of mothers who already have children with a genetic disorder and who give birth to additional children with the same disorder.[14] Couples may be the subject of hostility for carrying a child with even a slight disability to term, as occurred with broadcaster Bree Walker-Lampley's decision to give birth to a child with ectrodactyly, a mild genetic condition which fuses the bones in the hands.[15]

Testing is being offered for such a wide range of conditions and disorders that the women being offered prenatal testing—and even some of the obstetricians ordering the tests—have no idea what the life of a child with such a genetic makeup would be like. They must increasingly depend on the people marketing the tests, such as biotechnology companies, for information about how serious the disorder being tested for might be. In the context of breast cancer genetic testing, a biotechnology company exaggerated the risk of cancer that women with the genetic mutation faced. Such tactics can push people into undergoing testing who otherwise would not have. Moreover, decisions may be made about terminating fetuses based on certain stereotypes about disability. Adrienne Asch, a disability rights activist and professor at Wellesley College, points to research studies which show that "whites and middle-class people in general showed more discomfort with Down syndrome and retardation, whereas people of color and those of lower socioeconomic status expressed more fear of physical vulnerability."[16]

Relying on physicians' assessments of disability can be problematic. Even those physicians who treat people with disabilities may have inaccurate impressions of the lives of such people if the physicians interact with such individuals only in a medical setting.

Physicians have very different views of particular disabilities from those of people with those disabilities. When asked to evaluate the quality of their lives, 80 percent of doctors said pretty good,[17] but 82 percent indicated that their life quality would be pretty low if they had quadriplegia. In contrast, 80 percent of people with quadriplegia rated the quality of their lives as pretty good. Consequently, as Adrienne Asch indicates, "those wishing to use the [genetic] technology should receive substantially more information about life with disability than they now do. . . ."

Laura Hershey is a poet and newspaper columnist. "I have a rare neuromuscular condition," she says. "I rely on a motorized wheelchair for mobility, a voice-activated computer for my writing, and the assistance of Medicaid-funded attendants for daily needs—dressing, bathing, eating, going to the bathroom."[18]

"My life of disability has not been easy or carefree," she continues. "But in measuring the quality of my life, other factors—education, friends, and meaningful work, for example—have been decisive. If I were asked for an opinion on whether to bring a child into the world, knowing she would have the same limitations and opportunities I have had, I would not hesitate to say, 'Yes.'"[19]

In 1999, a British philanthropic organization, RADAR (Royal Association for Disability and Rehabilitation) surveyed people with disabilities and genetic predispositions to a disability. Thirty-seven percent would ban abortion for Down syndrome, 53 percent for blindness and 72 percent for a correctable genetic condition such as cleft palate.[20]

Other people note the strange contradiction that just at the political moment when laws such as the Americans with Disabilities Act have been enacted to protect people with disabilities, genetic technologies are aimed at preventing their birth. "It is ironic," says Marsha Saxton, "that just when disabled citizens have achieved so much, the new reproductive and genetic technologies are promising to eliminate their kind—people with Down Syndrome, spina bifida, muscular dystrophy, sickle cell anemia and hundreds of other conditions."[21]

WRONGFUL BIRTH

Courts initially resisted recognizing a cause of action for wrongful birth.[22] The early cases befuddled the courts because, unlike traditional malpractice cases, nothing that the health care provider could have done would have prevented harm to the child.[23] The logic behind these early suits was that if the parents of the affected child had received proper counseling or diagnosis, they could have decided not to conceive or to seek an abortion. Early case law dealing with wrongful birth actions rejected the notion that the failure to warn the parents of a fetus's risk of an apparently serious genetic disease was actionable because the physician was not the proximate cause of the defect.[24] Seven states—Idaho, Minnesota, Missouri, North Carolina, Pennsylvania, South Dakota and Utah—currently statutorily bar wrongful birth claims.

However, wrongful birth cases are now recognized in 22 states and the District of Columbia.[25] In those states, the law creates a duty on the part of physicians to offer genetic services to high-risk patients. Physicians, genetic counselors or genetic testing laboratories may be found liable in a wrongful birth claim for negligent actions or negligent inactions. Since women have a constitutional right to reproductive choice, they are viewed as having a right to know about their increased genetic risks and the availability of genetic testing so they can either avoid conceiving a child with a particular genetic disorder or terminate a pregnancy with an affected fetus. Recognizing wrongful birth actions is also seen as an important way to deter physician negligence.

A variety of actions and inactions can give rise to a wrongful birth claim. Such a suit may be brought when a reasonable health care provider should have known of the risk because the couple's previous child had a genetic disorder. Or the negligence may consist of a health care provider's failing to offer certain tests, such as amniocentesis, to alert that the fetus has Down syndrome even though the health care provider should have known of the risk because of the woman's advanced age.[26] Other plaintiff parents have successfully brought wrongful birth claims against health care providers who actively discouraged use of genetic testing,[27] and against health care providers who failed to advise prospective parents of the risk that their fetus may suffer from a genetic disorder by virtue of one or both parents belonging to a particular ethnic or racial group.[28]

Wrongful birth claims have also successfully been brought against laboratories that performed a test negligently and against physicians who misinterpreted test results,[29] and such suits are likely to increase in the future. For instance, a recent study showed that one third of physicians misinterpreted genetic tests for colorectal cancer.[30] Thus, a test's predictability may depend not only on the actual ability of the test to identify the disease gene, but also on who is reading the results of the tests.

However, because hundreds or even thousands of genetic risks may become predictable, it may be unreasonable to assume that physicians will be able to warn each patient of all the potential risks and tests available to determine those risks. Thus courts have already begun to limit the types of genetic risks that physicians must disclose. Most states recognize wrongful birth cases only if the disorder is "serious." One court indicated, for example, that deafness was not sufficiently serious. However, parents have won cases in which the resulting child had Down syndrome, cystic fibrosis and polycystic kidney disease (which, to most people, would certainly not be considered so serious as to make life not worth living).

WRONGFUL LIFE

Courts have been much less willing to recognize wrongful life suits on behalf of the child, rather than on behalf of the parents. The claim of the child in a wrongful life case is that he or she would rather not have been born than be born with a particular disorder—and most courts have believed that was a matter for philosophers, rather than judges, to decide.[31]

Only three states—California, New Jersey and Washington—currently recognize wrongful life claims, and nine states statutorily bar such claims.[32] Jurisdictions that have refused to recognize the validity of wrongful life actions justify the decision by simply stating that they refuse to grapple with the philosophical and ethical implications of such an allegation. In a wrongful life action, "the child does not allege that the physician's negligence caused the child's deformity. Rather, the claim is that the physician's negligence—his failure to adequately inform the parents of the risk—has caused the birth of the deformed child. The child argues that but for the inadequate advice, it would not have been born to experience the pain and suffering attributable to the deformity."[33]

Courts *have* recognized a wrongful life cause of action in a few states when doctors failed to advise prospective parents of genetic risks[34] or provided erroneous information.[35] In such cases, the child may even be allowed to recover damages for "diminished childhood." In 1984, in *Procanik v. Cillo*, the New Jersey Supreme Court let the child recover damages for "diminished childhood" where the child sued her doctor for negligently denying her parents information regarding her health *in utero*. This court found wrongful life damages appropriate because it assumed that a child would rather not have been born than to have been born disabled and born to parents whose ability to care for her would be negatively impacted because of her disability.[36]

At least one court *in dicta* suggested that children may bring wrongful life actions against their parents in addition to, or instead of, against the negligent health care provider. A California court stated: "If a case arose where, despite due care by the medical profession in transmitting the necessary warnings, parents made a conscious choice to proceed with a pregnancy, with full knowledge that a seriously impaired infant would be born . . . we see no sound policy which should protect those parents from being answerable for the pain, suffering and misery which they have wrought upon their offspring."[37]

Thus far, no court has recognized a wrongful life suit by a child against a parent. Indeed, after the California decision, that state's legislature passed a law stating: "No cause of action arises against a parent of the child based upon the claim that the child should not have been conceived or, if conceived, should not have been allowed to have been born alive."[38]

The courts recognizing wrongful life claims have done so mainly because they find that the focus should not be on whether an impaired life is better than no life at all—which has been historically cited as justification for refusing to recognize wrongful life causes of action; instead these courts have focused on awarding damages for the child with the disability. In *Curlender v. Bio-Science Laboratories,* the court allowed a child born with Tay-Sachs disease to bring a wrongful life suit against a medical testing facility and a physician for negligently telling the child's parents that they were not carriers of the Tay-Sachs gene. The court stated: "the reality of the 'wrongful life' concept is that such a plaintiff both exists and suffers, due to the negligence of others. . . . The certainty of genetic impairment is no longer a mystery."[39] Similarly, a New Jersey court allowed a child to bring a claim of wrongful life and stated that a wrongful life claim "is not premised on the concept that non-life is preferable to an impaired life, but it's predicated on the needs of the living."[40]

Damages recoverable under causes of action for wrongful birth and wrongful life claims differ between jurisdictions. As a general rule, either the parents or the child—but not both—may recover the extraordinary costs associated with the child's illnesses. Furthermore, some jurisdictions allow the recovery of emotional-distress damages in wrongful birth or wrongful life cases and may award damages for "diminished parental capacity" or "diminished childhood."

The New Jersey supreme court allows damages for "diminished parental capacity" based on the theory that "[p]arents can suffer diminished parental capacity as a result of . . . being excluded from perhaps the most important decision in their lives—whether to give birth to a congenitally defective child. . . . Thus, parents victimized by negligent genetic counseling bear a multiple burden."[41] Another court allowed parents to recover for wrongful birth under the theory that such a holding would enhance, rather than disparage, the emotional well-being of the entire family.[42]

The legal cases view a child with a disability as a tragedy for the whole family. In some jurisdictions, siblings of a child with a disability may bring wrongful birth claims against a negligent doctor and may also be permitted to recover damages for "loss of parental services." In 1994, in *Batson v. U.S.,* the court held that the sister of a child born with neural tube defects could recover for loss of parental services. The court believed that the extra financial and emotional burden placed on parents by virtue of having a child whose doctor negligently failed to prenatally diagnose the disorder would cause the "healthy" sibling necessarily to lose out on "care, counsel, and training and education which a child might . . . have reasonably received otherwise."[43] An earlier court, however, refused to recognize a wrongful birth claim brought by parents and a child's siblings in part because the court felt the life of their sister did not constitute an actionable injury.[44]

In the first suit of its kind, a New Jersey appellate court held that a grandfather cannot bring a wrongful birth suit on his behalf to recover emotional distress arising from the birth of his grandson. The grandfather alleged that a grandparent is a "filament of family life" and that the birth of the child affected the entire family. Thus, he argued, he should also be entitled to recover damages for the emotional distress he suffered when the defendants failed to inform the mother of his grandson of fetal abnormalities.[45] The appellate court held that only the parents of the child may recover for pain and suffering resulting from the birth of the child.[46]

HOW DO JUDGES VIEW DISABILITY?

"There is reason for us to fear wrongful birth suits and oppose suits for wrongful life," says Adrienne Asch: "it is the message they send to the children themselves, disabled people, and society about the worth of life with impairments."[47]

An analysis of judges' opinions does give cause for concern about the social messages being sent about disability. Today's courts' willingness to recognize wrongful birth suits contrasts greatly with decisions in the 1960s when courts did not allow such suits, in part because it would devalue people with disabilities. In *Gleitman v. Cosgrove,*[48] a 1967 case, for example, the court stated:

> The right to life is inalienable in our society. A court cannot say what defects should prevent an embryo from being allowed life such that denial of the opportunity to terminate the existence of a defective child in embryo can support a cause for action. Examples of famous persons who have had great achievement despite physical defects come readily to mind, and many of us can think of examples close to home. A child need not be perfect to have a worthwhile life. We are not faced here with the necessity of balancing the mother's life against that of her child. The sanctity of the single human life is the decisive factor in this suit in tort. Eugenic considerations are not controlling. We are not talking here about the breeding of prize cattle. It may have been easier for the mother and less expensive for the father to have terminated the life of the child while he was an embryo, but these alleged detriments cannot stand against the preciousness of the single human life to support a remedy in tort.

The court even went so far as to cite Jonathan Swift's "A Modest Proposal"[49] to support he last point.

A 1979 case similarly ruled:

> [One] of the most deeply held beliefs of our society is that life—whether experienced with or without a major physical handicap—is more precious than non-life . . . [the child] by virtue of her birth, will be able to love and be loved and to experience happiness and pleasure—emotions which are truly the essence of life and which are far more valuable than the suffering she may endure. To rule otherwise would require us to disavow the basic assumption upon which our society is based. This we cannot do.[50]

The way the judges today talk about people with disabilities has moved from a right-to-life analysis to the right of parents to use their best judgment about their future children. However, a discussion of the affected child's abilities is almost never discussed in the cases allowing some form of damages. Instead, the courts have focused on the child's disabilities and the degree to which this caused his or her parents, as well as the entire family, to suffer. The impact on the parents is seen as virtually unbearable. "The psychological trauma is much deeper and the impairment more pernicious than a seeming lack of love. . . . such parents 'are consumed with an awful sorrow. Not the surgical sorrow of death, but an hourly, daily, yearly sorrow—an agonizing shattering, tearing sorrow.'"[51] Another judge said: "No one can fail to deplore the anguish experienced by these unfortunate parents. A pecuniary award, regardless of its size, cannot compensate them for their sorrow."[52]

The diseases at issue are painted in gloomy terms. Cystic fibrosis is described as an "insidious and incurable disease. . . . The prospects for one suffering from cystic fibrosis . . .

are grim."[53] A child with a disability is seen as having "to bear the frightful weight of his abnormality throughout life."[54]

WHAT WOULD BE A DISABILITY-CENTERED APPROACH TO WRONGFUL BIRTH AND WRONGFUL LIFE SUITS?

What might an ADA-type approach to wrongful birth and wrongful life cases look like? One approach might be to eliminate such causes of action entirely. Courts recognize, for example, that a child cannot sue his father for being born illegitimate.[55] The California Court of Appeals, in the wrongful life suit, *Curlender v. Bio-Science*, said "it cannot be disputed that in present society such a circumstance [illegitimacy], both socially and legally, no longer need present an overwhelming obstacle."[56] It could be argued that, similarly, being born with a disability should no longer be actionable since the ADA and related laws remove many social and legal obstacles previously encountered by people with disabilities.

Even if wrongful birth and wrongful life cases were not eliminated entirely, people concerned about disability rights could try to ensure that they are not applied to less serious disabilities. Drawing such a line is obviously a sensitive and troubling matter. Perhaps it is hubris even to try. But there may be some disorders—painful, serious, causing early death, such as Tay-Sachs disease—where there may be fairly widespread support for parents' uncoerced and private decisions to undergo testing and abort to avert their child's pain and suffering. In all other instances, then, such legal actions could be forbidden.

There is at least some legal precedent for this second approach of line-drawing. Some early courts that entertained wrongful birth or wrongful life causes of action presumed that only children "born with gross deficiencies"[57] or "invidious and incurable" diseases would bring such suits.[58] For example, in *Turpin v. Sortini*, a wrongful birth case, the California Supreme Court asserted: "[i]n this case, in which the plaintiff's only affliction is deafness, it seems quite unlikely that a jury would ever conclude that life with such a condition is worse than not being born at all."[59]

Such line-drawing is appropriate if we do not want to require children to come with a genetic warranty. It seems totally inappropriate, for example, to screen a fetus for late-onset disorders, such as Huntington's disease or Alzheimer's.

The push to test—even for trivial or treatable conditions—is strong, in part because there is a financial benefit to the companies, patent holders and physicians who offer testing for less serious disorders. Yet certain tests should not be offered—because the condition is so trivial or is treatable after birth, or because the existence of the test seems to demean already-existing individuals with that condition. We discourage prenatal sex selection, because it is assumed that fetuses should not be aborted just because the individual will be discriminated against later in life. As we are flooded with new genetic tests, we need a societywide assessment about where to draw the line on the use of genetic services.

A third approach would focus not on limiting the legal claims but on trying to better inform potential parents about the nature of various disabilities so that they will not equate the birth of a child with a legal wrong. Disability rights activist Lisa Blumberg notes: "[t]oo often counselors do little more than provide future parents with a dreary laundry list of problems their child could have and express sympathy."[60] Before testing, an individual should be told about the genetic conditions for which he or she or the fetus is being tested, whether they are treatable, and about whether, in the prenatal context, the parents will be faced with a decision about whether to abort the fetus. He or she should have the opportunity to meet people with the disability for which testing is being done. Much thought should be given to the type of information that should be presented; this is an area in which disability activists can provide considerable aid to physicians and counselors.

Providing more accurate information about an individual's life with disabilities, and assuring that people in general have more contact with such individuals in the course of their daily lives,[61] may help prevent some couples from being coerced into testing and abortion and may deter lawsuits. Personal knowledge of a particular disorder can lessen the tendency of people unthinkingly to seek a "genetic fix." Some genetic counselors, for example, find that after working with patients with cystic fibrosis, they are no longer willing to participate in counseling for prenatal tests (since they personally do not feel that such a child should be aborted).

CONCLUSION

Preventing the birth of an individual with a disease is morally different from preventing a disease. "It suggests that the lives of some persons with a disability or illness are not worth living, that such persons are to be understood only as social or economic drains and never as sources of either independent value or enrichment for the lives of others," says Ruth Faden, director of the Program in Law, Ethics, and Health at Johns Hopkins University.[62] To the extent that judges deciding wrongful birth and wrongful life convey the message that disability itself is a legal wrong, it is time to take action to address these misperceptions forcefully.

NOTES

[1] This problem is exacerbated by the fact that few people have contact with individuals with a disability and consequently may overestimate their cost to society and underestimate their contribution to society.

[2] Paul Ramsey, "Screening: An Ethicist's View," in B. Hilton, D. Callahan, M. Harris, P Condliffe, and B. Berkley, eds. *Ethical Issues in Human Genetics: Genetic Counseling and the Use of Genetic Knowledge*. 163 Fogarty International Proceedings No. 13, 1973: 147, 159.

[3] Marsha Saxton, "Disability Rights and Selective Abortion," in Ricki Solinger, ed. *The Fifty Years War: Abortion Politics, 1950 to 2000*. Berkeley, CA: University of California Press, in press.

[4] Dorothy C. Wertz and John C. Fletcher, "A Critique of Some Feminist Challenges to Prenatal Diagnosis," 2 *J. Women's Health* 173–188, 181 (1993).

[5] Saxton, "Disability Rights."

[6] Adrienne Asch, for example, points out that blind parents are sometimes denied custody and visitation rights based on their disability. Adrienne Asch, "Reproductive Technology and Disability," in Sherrill Cohen and Nadine Taub, eds. *Reproductive Laws in the 1990s* Clifton, NJ: Humana Press, 1989 (citations omitted), 69–123, 79.

[7] Laura Hershey, "Choosing Disability," *Ms.*, July/August 1994, 26–32, 29.

[8] Saxton, "Disability Rights."

[9] Office of Technology Assessment, U.S. Congress. *Mapping Our Genes* 84 (1988).

[10] Diane Beeson, "Social and Ethical Issues in the Prenatal Diagnosis of Fetal Disorders," in Benedict M. Ashley and Kevin D. O'Rourke, eds. *Health Care Ethics: A Theological Analysis*, 3d ed., St. Louis, MO: Catholic Health Association of the United States, 1989, 76–86, 81.

[11] Abby Lippman, "The Genetic Construction of Prenatal Testing: Choice, Consent, or Conformity for Women?" in Karen H. Rothenberg and Elizabeth Thomson, eds. *Women and Prenatal Testing: Facing the Challenges of Genetic Technology*. Columbus, OH: Ohio University Press, 1994, 9–34, 15.

[12] Adrienne Asch and Gail Geller, "Feminism, Bioethics, and Genetics," in Susan M. Wolf, ed. *Feminism and Bioethics: Beyond Reproduction.* London: Oxford University Press, 1996 (footnote omitted), 318–350, 330.

[13] In one study, "60% of urban white women over age 40 in Georgia, but only 0.5% of African women over 40 in rural areas used prenatal diagnosis." Wertz and Fletcher, note 4 at 178, citing D. C. Sokol, J. R. Byrd, A.T.L. Chen, M. F. Goldberg and G. P. Oakley, "Prenatal Chromosome Diagnosis: Racial and Geographical Variation for Older Women in Georgia," 244 *JAMA* 1355–1357 (1980).

[14] Id.

[15] See Lori B. Andrews, "Body Science," 83 *American Bar Association Journal* 44 (1997).

[16] Asch, "Reproductive Technology," 87.

[17] Hugh Gregory Gallagher, "Can We Afford Disabled People?" 14th Annual James C. Hemphill Lecture, September 7, 1995, Rehabilitation Institute of Chicago, 21.

[18] Hershey, "Choosing Disability," 28.

[19] Id., 30.

[20] "Disabled People Mixed Over Genetic Future," BBC News, September 28, 1999, available at http://news.bbc.co.uk/hi/english/health/newsid_459000/459330.htm.

[21] Saxton, "Disability Rights."

[22] See, eg., *Gildiner v. Thomas Jefferson Univer. Hosp.* 451 F.Supp. 692, 695 (E.D. Pa. 1978); *Lininger v. Eisenbaum,* 764 P.2d 1202, 1212 (Colo. 1988); *Blake v. Cruz,* 698 P.2d 315, 332 (Idaho 1984); *Dorlin v. Providence Hosp.*, 325 N.W.2d 600, 601 (Mich. Ct. App. 1982); *Eisbrennery v. Stanley,* 308 N.W. 2d 2O9,213 (Mich. Ct. App. 1–981); *Azzolino v. Dingfelder,* 337 S.E.2d 528, 532033 (N.C. 1985), cert. denied, 479 U.S. 835 (1986); *Schroeder v. Perkel,* 432 A.2d 834, 840 (N.J. 1981); *Berman v. Allen,* 404 A.2d 8, 12 (N.J. 1972); *Gleitman v. Cosgrove,* 227 A.2d 689, 692 (N.J. 1967); *Alquijay v. St. Luke's-Roosevelt Hosp. Ctr.*, 473 N.E.2d 244, 245 (N.Y. 1984); *Becker v. Schwartz,* 386 N.E.2d 807, 812 (N.Y. 1978); *Ellis v. Sherman,* 478 A.2d 1339, 1342 (Pa. Sup. Ct. 1984), aff'd, 515 A.2d 1327 (Pa. 1986); *Nelson v. Krusen,* 678 S.W.2d 918 (Tex. 1984); *James G. v. Caserta,* 332 S.E.2d 872, 881 (W.Va. 1985); *Dumer v. St. Michael's Hosp.*, 233 N.W.2d 372, 377 (Wis. 1975); *Beardsley v. Wierdsman,* 650 P.2d 288 289–90 (Wyo. 1982).

[23] See, eg., *Procanik v. Cillo,* 478 A.2d 755, 760 (N.J. 1984) (plaintiffs could not assert that the physician's negligence caused the child's congenital rubella syndrome or that the child ever had a chance to live a normal life).

[24] See *Gleitman v. Cosgrove,* 227 A.2d 689, 692–93 (N.J. 1967) (holding that no casual link existed between a fetus's injury resulting from its mother's exposure to German measles and the doctor's failure to warn the parents of the risk of such an injury).

[25] See *Keel v. Banach,* 624 So.2d 1022 (Ala 1993); *University of Arizona Health Services Center v. Superior Court,* 136 Ariz. 579, 667 P.2d 1294 (1983); *Turpin v. Sortini,* 31 Cal. 3d 220, 182 Cal. Rptr. 337, 643 P.2d 954 (1982); *Lininger v. Eisenbaum,* 764 P.2d 1202 (Colo. 1988); *Haymon v. Wilkerson,* 535 A.2d 880 (D.C. 1987); *Garrison v. Medical Center of Delaware, Inc.*, 581 A.2d 288 (Del. 1989); *Kush v. Lloyd,* 616 So.2d 415 (Fla. 1992); *Arche v. United States Dep't of AM,* 247 Kan. 276, 798 P.2d 477 (1990); *Reed v. Campagnolo,* 332 Md. 226, 630 A.2d 1145(1993); *Viccaro v. Milun* 406 Mass. 777, 551 N.E.2d 8 (1990); *Greco v. United States,* III Nev. 405, 893 P.2d 345 (1995); *Smith v. Cote* 128 N.H. 231, 513 A.2d 341 (1986); *Schroeder v Perkel,* 87 N.J. 53, 432 A.2d 834 (1981); *Becker v. Schwartz,* 46 N.Y.2d 401, 413 N.Y.S.2d 895, 386 N.E.2d 807 (1978); *Owens v. Foote,* 773 S.W.2d 911 (Tenn. 1989); *Jacobs v. Theimer,* 519 S.W.2d 846 (Tex. 1975); *Naccash v. Burge* 223 Va. 406, 290 S.E.2d 825 (1982); *Harbeson v. Parke-Davis, Inc.*, 98 Wash.2d 460, 656 P.2d 483 (1983); *James G. v. Caserta,* 175 W.Va. 406, 332 S.E.2d 872 (1985); *Dumer v. St. Michael's Hospital,* 69 Wis.2d 766, 233 N.W.2d 372 (1975); *Goldberg v. Ruskin,* 128 111. App. 3d 1029, 84 111. Dec. 1, 471 N.E.2d 530 (1984); *Eisbrenner v. Stanley,* 106 Mich. App. 357, 308 N.W.2d 209 (1981); *Flanagan v. Williams,* 87 Ohio App. 3d 768, 623 N.E.2d 185 (1993). Georgia and North Carolina bar wrongful birth causes of action by judicial decision. See *Atlanta Obstetrics & Gynecology Group v. Abelson* 260 Ga. 711, 398 S.E.2d 557 (1990); see also *Azzolino v. Dingfelder,* 315 N.C. 103, 337 S.E.2d 528 (1985).

[26] See, eg., *Becker v. Schwartz,* 386 N.E.2d 807, 814 (N.Y. 1978) (noting the effect of a mother's age on the development of a fetus).

[27] See *Haymon v. Wilkerson,* 535 Acted 880, 881 (D.C. 1987) (finding liability when a couple followed a physician's advice discouraging genetic testing of their fetus and the fetus was subsequently diagnosed as having Down syndrome).

[28] See *Naccash v. Burg.* 290 S.E.2d 825, 837 (Va. 1982) (allowing recovery for a physician's failure to use a blood test to determine the risk that an Eastern-European Jewish couple had of passing Tay-Sachs disease to their children).

[29] See, eg., *Gallagher v. Duke University,* 822 F.2d 793 (4th Cir. 1988).

[30] See F. Giardiello, J. Brensinger, G. Peterson, M. Luce, L. Hylind, J. Bacon, S. Booker, R. Parker, and S. Hamilton, "The Use and Interpretation of Commercial APC Gene Testing for Familial Adenomatous Polyposis," 336 *N. Eng. J. Med.* 823–27 (1997).

[31] See, eg., *Gleitman v. Cosgrove,* 227 A.2d 689 (N.J. 1967); *Becker v. Schwartz,* 386 N.E.2d 807 (N.Y. 1978).

[32] See Idaho Code § 5–334 (1995) (statutorily barring both wrongful life and wrongful birth claim); Ind. Code Ann. § 34–1–1–11 (1996) (barring wrongful life causes of action); Minn. Stat. § 145.424(l), (2) (1993) (barring wrongful life and wrongful birth claims, respectively); Mo. Rev. Stat. § 188.130 (1995) (barring both wrongful life and wrongful birth claims); N.C. Gen. Stat. § 14.45. 1 (e) (1996) (conscience clause used by courts to bar both claims); N.D. Cent. Code § 32 03–43 (1995) (barring wrongful life causes of action); 42 Pa. Cons. Stat. § 8305 (1993) (barring both wrongful life and wrongful birth claims); S.D. Codified Laws Ann. §§ 21–55–1 & 21–55–2 (1987) (wrongful life, birth and conception claims explicitly barred); Utah Code Ann. § 78–11–24 (1993) (barring wrongful life and wrongful birth claims).

[33] See Thomas D. Rogers, "Wrongful Life and Wrongful Birth: Medical Malpractice in Genetic Counseling and Prenatal Testing," 33 *S.C. L. Rev.* 713 (1982).

[34] See, eg., *Turpin v. Sortini,* 643 P.2d 954, 965 (Cal. 1982) (bringing a claim against a health care provider for failure to advise parent of a hereditary hearing defect).

[35] See *Curlender v. Bio-Science Lab.*, 165 Cal. Rptr. 477, 479–80 (Ct. App. 1980) (bringing suit against a laboratory for negligently conducting genetic tests).

[36] See 478 A.2d 755, 764–66.

[37] See *Curlender v. Bio-Science Lab.*, 165 Cal. Rptr. 477, 488 (Ct. App. 1980).

[38] See Cal. Civ. Code § 43.6 (West 1998).

[39] See 165 Cal. Rptr. 477, 488 (App. Ct. 1980).

[40] See *Procanik v. Cillo,* 478 A.2d 755, 763 (N.J. 1984).

[41] See *Procanik v. Cillo,* 478 A.2d 755, 766–67 (N.J. 1984) (Handler, J., concurring in part and dissenting in part).

[42] See *Marciniak v. Lundborg,* 450 N.W.2d 243, 246 (Wisc. 1990).

[43] See 848 F.Supp. 962, 973 (U.S. Dist. Ct. 1994).

[44] See *Azzolino v. Dingfelder,* 337 S.E.2d–528, 537 (N.C. 1985).

[45] See Molly J. Liskow, "Grandfather of Tay-Sachs Baby Cannot Sue for Wrongful Birth," *New Jersey Lawyer,* May 11, 1998, 46 (citing *Michelman v. Erlich,* N.J. Appellate Division, A-3846–96T1, May 6, 1998).

[46] Id.

[47] Asch, "Reproductive Technology," 94.

[48] 44 N.J. 22, 227 A.2d 689 (1967).

[49] Jonathan Swift, "A Modest Proposal" in *Gulliver's Travels and Other Writings.* New York: Modern Library, 1958, 488–496.

[50] *Berman v. Allan,* 404 A.2d 8, 12–13 (1979).

[51] *Procanik v. Cillo,* 97 N.J. 339, 363 (Handler, J., dissenting) (quoting G. Stigen, *Heartaches and Handicaps* 6 (1976)).

[52] *Naccash v. Burger,* 223 Va. 406,420 (1982) (dissent).

[53] *Schroeder,* 87 N.J. at 58–59.

[54] *Gleitman v. Cosgrove,* 227 A.2d 689, 704 (1967) (Jacobs, J., dissenting).

[55] *Zepeda v. Zepeda,* 190 N.E.2d 849 (111. App. Ct. 1963).

[56] *Curlender,* 106 Cal. App. 3d 811, 825 (1980).

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[57] See *Becker,* 386 N.E.2d 812 (consolidated case where children suffered from Down syndrome and polycystic kidney disease).

[58] See *Shroeder v. Perkel,* 432 A.2d 834, 836 (N.J. 1981) (child suffered from cystic fibrosis).

[59] See 643 P.2d 954, 962 (Cal. 1982).

[60] Lisa Blumberg, "Eugenics vs. Reproductive Choice," *The Disability Rag and ReSource,* January/February 1994, 5.

[61] This could be a benefit of the Americans with Disabilities Act, which provides legal protections to assure that individuals with disabilities are better integrated into society.

[62] Ruth Faden, "Reproductive Genetic Testing, Prevention, and the Ethics of Mothering," in Karen H. Rothenberg and Elizabeth Thomson, eds. *Women and Prenatal Testing: Facing the Challenges of Genetic Technology*. Columbus, OH: Ohio University Press, 1994, 92.