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INTRODUCTION

GENES AND DISABILITY: QUESTIONS AT THE CROSSROADS

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The articles contained in this issue spring from papers presented at a conference that we had the privilege of hosting in March of 2002 at the Florida State University College of Law. The conference, entitled “Genes and Disability: Defining Health and the Goals of Medicine,” was designed to elicit studied discussion of the relationship of genes to disability, genes to health, and genes to human well-being more generally. Assumptions about these relationships underlie nearly every legal and public policy decision relating to the subject of genetic medicine—from liability for negligent prenatal testing to statutory prohibitions of insurance discrimination on the basis of genetic information. Yet how we look at genetic conditions and their relationship to health and disability, or to notions of “normalcy” and “deviance,” is not strictly or even primarily a legal matter. Instead, the issues raised in this context involve ethical considerations and require an understanding of the social contexts in which those issues appear. For this reason we sought to include in the conference scholars from a variety of fields of study. The result was the gathering of sixteen scholars from the disciplines of law, medicine, medical ethics, history, philosophy, religion, sociology, psychology, and anthropology. While the conference was designed to be multi-disciplinary, it placed some emphasis on how various ethical responses can or should be reflected in law. The following collection of articles brings the insights of other disciplines to urgent questions regarding how the law should respond to advances in genetic medicine.

When and why are certain genes “undesirable,” who decides, and how? When does that “undesirability” constitute a “disability” for the person who carries that gene and what are the implications of deeming a genetic condition a disability? When does a genetic condition mean that a person or a person’s (potential) offspring is unhealthy and thus the appropriate object of medical attention? Should the medical response influence the legal response and, if so, how? These were the questions we posed at the outset to conference participants.

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As would be expected from the diverse academic backgrounds of the speakers, the questions were addressed in a number of different contexts and from varying perspectives. In reading the final manuscripts produced by participants for this issue, we have identified two broad themes emerging from the combined works that we would like to highlight. The first relates to line-drawing, the second to the social nature of genetic information.

That the issue of line-drawing in the context of prenatal testing practices would receive prominent attention at the conference was anticipated by the very questions originally posed to participants. This highly debated issue might be stated as follows: given that it is possible to test for certain genetic conditions for the purposes of aborting affected fetuses or selecting against certain embryos in the context of in vitro fertilization, is it appropriate for health care professionals to offer and society to support tests for only certain conditions and not for others? Are some genetic conditions clearly so undesirable that testing should always be offered (and perhaps encouraged)\(^1\) and some genetic conditions clearly so trivial that selection on the basis of them is inappropriate and should be discouraged or even unavailable? Testing for some conditions but not others, in particular, testing only for disabling conditions, risks harm to people currently living with disabilities by further stigmatizing impairment.\(^2\) It also potentially intrudes on reproductive choice to the extent that the mere existence of certain tests and not others suggests that a parent should want to avoid giving birth to a child with the disabling condition tested for.\(^3\) On the other hand, allowing parents to test and select for any trait, such as perfect musical pitch, risks commodifying children and weakening the parent-child relationship.\(^4\) Unrestricted choice in testing may also feed discriminatory attitudes toward people with certain behavioral traits, such as homosexuality, if parents in the future are able to test to avoid those traits.\(^5\) The question

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1. As Paul Lombardo asked at the beginning of the conference and in the opening article of this issue, three generations of (what) is enough? Reformulating Justice Holmes’s notorious statement in *Buck v. Bell*, 274 U.S. 200 (1927), that “three generations of imbeciles are enough,” *id.* at 207, Lombardo states that if there are good eugenic practices, then we need to figure out what kinds of conditions we are trying to avoid. See Paul A. Lombardo, *Taking Eugenics Seriously: Three Generations of ??? Are Enough?*, 30 Fla. St. U. L. Rev. 191, 217-18 (2003).


3. *Id.* at 340.

4. See David Wasserman, *A Choice of Evils in Prenatal Testing*, 30 Fla. St. U. L. Rev. 295 *passim* (2003) (preferring a regime of unrestricted choice to one that limits testing for only certain conditions even at the risk of such harms to the parent-child relationship because of the moral conviction “that the tendency to stigmatize physical and mental difference abnormality is deeply engrained and recalcitrant, whereas the tendency to treat children as commodities will be largely offset by the transformative effect of actually raising them.” *id.* at 313).

whether a line should be drawn between appropriate and inappropriate uses of testing and, if a line should be drawn, where it should be drawn and by whom, are complex issues that receive thoughtful analysis in a number of the articles in this issue.

Another, less anticipated theme that emerges from the pieces in this issue is the inherently social nature of genetic health and the challenge that medicine’s uses of genetic information pose for the preeminence of individual autonomy as a principle in bioethical reasoning. As one author points out: “genetic health is the ultimate notion of a relational concept of health because . . . [it] always involves a social unit.” In other words, no man or woman is a genetic island, and we cannot escape the implications of our genetic connections—to those who have come before us and those who will come after us, to the mate with whom we plan to mingle genetic material in reproduction, and to those with whom we simply share certain genetic traits—in making decisions regarding the use of genetic information. Moreover, beyond their obvious impact on our children and potential children, our choices about whether and how to use genetic information in reproductive decision making should also be made with a consciousness of our responsibility to the broader community those decisions may affect. Thus, we are challenged to exercise our reproductive autonomy with a sense of social responsibility. At the same time, however, individuals’ “autonomy” with respect to whether and how to use prenatal genetic testing may be seriously—if not obviously—constrained by the social and medical context in which the tests are developed and offered. While the broader debates over


7. John Jacobi’s article discusses a different sort of line-drawing issue. Recently enacted state statutes that prohibit discrimination by health insurers on the basis of genetic information appear to be premised at least in part on the notion that one cannot be at fault for one’s genetic make-up and therefore should not be denied health insurance on that basis. Drawing a line around genetic conditions to grant them exceptional treatment for this reason, however, would appear to be under-inclusive, for most illnesses are not attributable to the fault of a person’s behavior. See John V. Jacobi, Genetic Discrimination in a Time of False Hopes, 30 Fla. St. U. L. Rev. 363, 391-94 (2003).


9. Cf. Mary B. Mahowald, Aren’t We All Eugenicists? Commentary on Paul Lombardo’s “Taking Eugenics Seriously,” 30 Fla. St. U. L. Rev. 219, 224 n.22 (2003) (articulating concept of “relational autonomy” which suggests that “our ongoing relationships to others are inseparable from our autonomous decisions”).

10. See Janet Dolgin, The Ideological Context of the Disability Rights Critique: Where Modernity and Tradition Meet, 30 Fla. St. U. L. Rev. 343, 357 (2003) (characterizing disability rights critique of prenatal genetic testing as “valuing” choice but being cognizant of the risk of sacrificing communal responsibility to individual preference”; Holland, supra note 5, at 404 (asserting that the right of reproduction is bounded by social obligations, including that to vulnerable populations).

11. See Asch, supra note 2, at 334-35 (linking continuing discrimination against persons with disabilities and the development and funding of, and professional encourage-
abortion generally involve a tension between the individual autonomy to choose abortion and legal constraints limiting that autonomy, in the realm of prenatal genetic testing and termination, the tension is between social forces encouraging abortion of fetuses who would be disabled if born and the prospective parent’s autonomy to avoid testing and abortion. These social forces are far more elusive than legal constraints and have received too little attention. Finally, another aspect of the social nature of genetic information emerges when we consider the potential use of genetic information by health insurance underwriters. The widespread sense that it is inherently unfair to exclude a person from health insurance coverage because of a genetic trait may ultimately prompt a more profound recognition of the need to treat health insurance as a mechanism of social solidarity, and not merely an individual prepayment mechanism.

Related to these two themes that emerged during the conference—line drawing and the social nature of genetic information—is another issue that we believe worthy of mention, an issue that received considerable attention during the discussion and debate that took place during the conference but that is not reflected in the published articles to the same degree. When Paul Lombardo opened the conference with discussion of the Buck v. Bell case and the historical context in which it arose, he asked (paralleling the words of Holmes’s infamous opinion), if there are good eugenic practices, then what kinds of conditions are we trying to avoid? Three generations of ______ is enough? Mary Mahowald turned the question around at the end of her talk—and told the audience that three generations of mental retardation were not enough. This provocative statement questioned the wisdom and ethics of one of the most common uses of prenatal testing—the testing of fetuses for Down syndrome, with the expectation that selective abortion may follow. One of the most interesting developments at the conference, however, was that the statement was generally embraced. There appeared to be general consensus among participants that societal and institutional encouragement of the prenatal genetic diagnosis of fetuses with Down syndrome for the purpose of avoiding the births of such children is not “good eugenics.” In addition, while the emphasis was on the social context in which such testing and selection take place, rather than on the individual decisions of potential parents, there was also general recognition that even the latter was morally problematic.

The concerns that were expressed about such common testing and selection practices were many and varied. Modern selection practices against Down syndrome parallel in some disturbing ways universally condemned eugenic practices of the past aimed at eliminating mental

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12. See Jacobi, supra note 7.
retardation. While the means of such elimination differ greatly from the involuntary euthanasia programs of Nazi Germany or the state sterilization programs in the United States, the goals are hauntingly similar. Furthermore, to the extent such selection practices may appear to be based upon more laudable impulses to avoid suffering (rather than, for example, to relieve society of the economic burdens of caring for people with mental retardation), assumptions about the suffering of children with mental retardation should more honestly be understood as involving concerns about the ability to live independently. Much of participants’ objection to the widespread practice of aborting fetuses with Down syndrome stemmed from a criticism of the overvaluation within modern American society of ‘ableism’ and the capability to be independent of others’ care, or, to put it another way, to our society’s inhospitality to disability and dependency. Finally, the social and medical contexts in which decisions regarding testing for Down syndrome are made led many to question whether prospective parents’ choices reflect an exercise of true autonomy.

To the extent one concludes that genetic testing and selection to avoid Down syndrome shares disturbing characteristics with “bad eugenics” (as many participants in the conference appeared to agree), then what are the implications of this assessment? For government, for individuals, for society? First, there was no suggestion at the conference that the state should prohibit individuals from engaging in prenatal testing and selection. The autonomy of individual prospective parents in this regard was clearly favored over any actions the state might take in terms of barring testing and/or abortion. As Mary Mahowald pointed out, it was government action (although in the other direction) that made past eugenic programs so objectionable. Just as there was no suggestion that the government should bar prenatal testing and selective abortion for mental retardation, there was reluctance among participants to condemn individuals for deciding to test or to abort. Rather there was sympathy for prospective parents facing choices that formerly did not exist. Given that participants were not willing to say that parental choices should be limited or even condemned, the course that appeared most conducive to responding to the concerns about selection practices against Down syndrome was to change the social and medical context in which these decisions are made—among other things, to provide more social welcome for children with mental retardation and to appropriately educate prospective parents about the fulfilling lives such children can lead.

It seems indeed remarkable that scholars from such diverse backgrounds and experiences reached some degree of agreement regarding the problematic nature of society’s encouragement of prenatal testing for Down syndrome. Lest this be taken as an indication that it will be easy to achieve consensus on the numerous issues posed by
increases in genetic knowledge, however, we hasten to note that legal views on the appropriate use of prenatal genetic information and the apportionment of social versus individual responsibility for any burdens associated with genetic difference remain remarkably divergent. Several examples of this divergence appeared in the months following the conference and preceding the publication of this issue. In October 2002, a prominent law review published an article in which the author posed the question “Who should pay for bad genes?” and suggested that it would be unfair to require society to pay any costs associated with a child’s “bad genes” if the child’s parents could have avoided the genetic condition.14 This view, which suggests that parents should shoulder the economic costs of raising a child with an avoidable genetic condition, would seem to encourage parents to detect, if possible, and then select against disabling conditions. Only a few months later, though, an English court found that prospective parents were not allowed, under Britain’s Human Fertilisation and Embryology Act, to engage in preimplantation genetic diagnosis of an embryo.15 Thus, English law appears to prohibit the very type of preimplantation selection that the law review article suggests is desirable. Finally, on New Year’s Eve 2002, the Utah Supreme Court upheld the constitutionality of a statute prohibiting wrongful birth causes of action, finding that the inability to hold a physician legally liable for failing to advise prospective parents regarding genetic risks and testing options does not substantially burden a woman’s constitutionally protected right to choose to terminate a pregnancy.16 So in Utah, prospective parents have no legally protected right to receive competent advising about genetic risks and testing for genetic conditions.

Perhaps what the juxtaposition of these divergent views in the legal system with the degree of consensus that conference participants achieved suggests is the value of dialogue on the ethically appropriate use of genetic information. A central goal of the conference was to include voices of those with first-hand experience of disability, whether it be the voice of a person with a disability, a person with a disabled family member, a person who has experienced a “social handicap” or one who has worked with and advocated for persons with disabilities. Too often our legal and social conversations about the uses of genetic information have not invited the participation of these voices, but the level of discourse and agreement that occurred

15. Quintavalle v. Human Fertilisation & Embryology Auth., No. CO/1162/02, 2002 WL 31676428 (QB Dec. 3, 2002). This case involved parents who sought to engage in tissue typing of an embryo in order to determine whether the embryo would produce a child who would be a suitable stem cell donor for a sibling with beta thalassaemia. Id. The court suggested, without holding, however, that preimplantation genetic diagnosis for the more general purpose of selecting genetic traits would also be prohibited by the HFEA. See id.
at the conference indicate the value of respectful listening and dialogue.

Here are the voices to which you can listen in this issue.

In *Taking Eugenics Seriously: Three Generations of ??? Are Enough?*, Paul Lombardo, a law professor and historian who has studied extensively the history behind the Supreme Court’s notorious decision in *Buck v. Bell*, places the questions addressed by conference participants in an historical context. In this opening piece of the issue, Lombardo chronicles the media’s recent coverage of genetics, coverage that has related both to the culmination of efforts to sequence the human genome and to the State of Virginia’s legislative resolution expressing “profound regret” for state-sponsored eugenics policies in the early twentieth century. This review highlights the curious juxtaposition of contemporary scientific, medical and popular enthusiasm regarding the recent mapping of the human genome with the general opprobrium our society attaches to one of the forebears of genetic medicine, namely the early twentieth-century eugenics movement. Lombardo describes the efforts of several early adherents of the eugenics movement. His description reveals that while some supported coercive interventions to limit the personal freedoms of disabled persons—such as laws supporting the “sequestration or . . . sterilization” of persons with hereditary blindness—other supporters advocated genetic education as a means of improving health and preventing hereditary disease and disability. Thus, even in the early twentieth century, the “ambivalence of a brand of eugenics that was simultaneously sympathetic to the disabled and intent on eradicating disabilities” was apparent. Ultimately, Lombardo reminds us that today’s pursuit of advances in genetic medicine has too much in common with the eugenics movement—both in terms of motive and method—for us to dismiss the lessons of its history.

In *Aren’t We All Eugenicists? Commentary on Paul Lombardo’s “Taking Eugenics Seriously,”* Mary Mahowald, a philosopher who has previously examined from a feminist perspective the issues that genetics pose for equality, uses Lombardo’s article as a springboard for analyzing how to distinguish those eugenic practices that are morally objectionable from those practices that may be morally neutral or even praiseworthy. Mahowald notes that the negative moral connotation attached today to the term “eugenics” is associated with

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20. *Id.* at 205.
21. *Id.* at 213.
the coercive nature of past eugenic practices, but she emphasizes that coercion is not an inherent aspect of “eugenics,” which etymologically derives from the Greek for “well born.” By identifying the characteristics of an example of clearly morally reprehensible eugenics (Nazi genocide) and an example of clearly praiseworthy eugenic behavior (the health-promoting practices of most pregnant women), Mahowald constructs a framework for assessing the ethical acceptability of practices, such as prenatal genetic testing, that fall somewhere on the spectrum between these extremes. This framework includes, among other elements, examination of whether eugenic decisions are autonomously made by prospective parents or are somehow coerced and whether decisions seek to avoid a specific trait or instead seek to promote health. Specifically, Mahowald examines the widely socially accepted practice of prenatal testing and termination for Down syndrome, and concludes that the existing social support for the termination of fetuses because they would be mentally retarded illustrates an example of bad eugenics.

Larry Palmer, a law professor known for his application of an institutional perspective to questions of law and medicine, also looks to history for guidance in developing new theories of liability applicable to genetic health. In *Genetic Health and Eugenics Precedents: A Voice of Caution*, Palmer looks to the “eugenic precedents” of the Nazi Doctors’ trial at Nuremberg and the Tuskegee Syphilis Study and, while rejecting their usefulness as technical legal precedents, draws from them institutional lessons about ethical reasoning regarding the modern disease management process. In part, these lessons involve how genetically (and often ethnically or geographically) linked groups can participate in genetic research and efforts to prevent genetic disability. According to Palmer, these lessons regarding ethical reasoning from the eugenic precedents should be combined with the legal reasoning in existing genetic health (i.e., wrongful birth and wrongful life) cases to develop a theory of liability for modern disease management. Ultimately, he advocates for the development of a liability theory that recognizes the parameters of genetic medicine as going beyond the traditional doctor-patient dyad and thus implicating a public health perspective on improving the health of groups.

Jeffrey Botkin, a professor of pediatrics and genetics, returns in his article to the question of the ethical appropriateness of prenatal genetic diagnosis and the selection of children, and raises the specific question of whether some limits should be placed on what genetic information about a fetus or embryo should be offered to prospective parents. *Prenatal Diagnosis and the Selection of Children* adopts a

23. *Id.* at 223-24.
24. *Id.* at 233-34.
26. *Id.* at 242.
27. *Id.* at 243.
medical professional’s perspective and poses the question: “What tests should an ethical practitioner provide?” After examining wrongful birth and wrongful life actions as setting a minimum standard of risk communication, Botkin acknowledges but ultimately rejects proposals that practitioners provide prospective parents with risk information for all genetic conditions or traits for which testing is available. Botkin views such a comprehensive standard as posing logistical challenges for how such large amounts of complex information could be managed, as failing to distinguish between what information is ethically desirable and what is legally mandatory, and as being potentially harmful to the community of persons with disabilities. By contrast, he advocates an approach by which professional standards—rather than law or regulation—would determine what information and tests should be offered to parents, with the guiding principle being that only conditions often resulting in tangible harms to parents should be the subject of genetic counseling. According to Botkin, a genetic condition carrying a risk of an adult-onset disorder would not meet this standard (and thus should not be tested for prenatally), while a genetic condition associated with significant disability beginning in childhood would.

David Wasserman comes to a conclusion different from Botkin’s on the question of whether a line should be drawn between “testable” and “nontestable” conditions in the context of prenatal genetic diagnosis. Wasserman, who has written extensively on issues relating to disability, begins his article, A Choice of Evils in Prenatal Testing, by challenging the conventional understanding of prenatal testing as a medical procedure and depicting it instead as typically a procedure to identify and destroy unwanted organisms. Arguing that termination based on disability is not easily distinguishable from sex-selection abortion (in that neither practice typically serves to promote the health of an individual), Wasserman concedes that allowing testing and selection for a wide range of genetic traits may act to degrade the parent-child relationship and commodify children. Nonetheless, he views these possible harms as preferable to the further stigmatization of impairment likely to flow from the identification of only certain impairments as bad enough to test for. Moreover, he questions whether a professional standard for testing that focuses on family harm or burdens would be capable of drawing a clear line between testable and nontestable conditions, since questions of family harm depend not only on a particular family’s reaction to a genetic condition, but also on the contingent nature of social arrangements contributing to those burdens. Thus, his article concludes that a re-

29. Id. at 265-66.
30. Id. at 288.
31. Wasserman, supra note 4.
32. Id. at 297.
gime of unrestricted testing represents the lesser of two evils because it may “mut[e] the expressive significance of prenatal testing for people with disabilities.”

In *Disability Equality and Prenatal Testing: Contradictory or Compatible?*, Adrienne Asch, well known for her influential work within the disability rights critique of prenatal testing, asks whether it is possible for society to pursue the goal of social inclusion of persons with disabilities alongside the promotion of prenatal selection to avoid disabilities. She answers that these two pursuits are inherently in conflict, that assumptions that underlie the social endorsement of prenatal selection—assumptions (which she critiques as uninformed and narrowly conceived) about the quality of life of people born with disabilities—undermine the welcome of people with disabilities that laws such as the Americans with Disabilities Act purport to provide. The necessary, if unintended, consequences of institutional promotion of prenatal selection against disabilities are a devaluation of the lives of persons who live now and will live in the future with disabilities and an intrusion into the reproductive choices of women who will find it difficult to bring a child into the world knowing that society believes that the births of such children should have been prevented.

In examining the assumptions that surround the promotion of prenatal screening, Asch tackles a central question posed by proponents to justify institutional support of prenatal screening practices, which is this: isn’t it better not to have a disability than to have one, and that being so, isn’t it better to bring a child into the world who doesn’t have a disability than a child who has one? The answer, for Asch, is not self-evident, and her analysis rejects the presumptive responses to both parts of the question. First she points out the degree to which people with disabilities are often disadvantaged more by discriminatory attitudes and practices than by intrinsic limitations caused by their disability. Drawing on the social and minority group models of disability, Asch points out that most people with prenatally detectable disabilities are not hindered from leading fulfilling lives merely by virtue of the characteristics that distinguish them from people without disabilities. Assumptions to the contrary are misinformed. Asch then directly addresses the question of the good of having a capacity and the presumptive bad of not having it. Having a capacity may be good, she writes, “but the absence of capacity is simply not having it.” It is not, for one thing, a “loss” (as might be experienced by someone who had a capacity, but lost it), nor is it necessarily an absence of something of intrinsic value, as opposed to a

33. *Id.* at 300.
34. *Asch,* supra note 2.
35. *Id.* at 316-17.
36. *Id.* at 340.
37. *Id.* at 319-22.
38. *Id.* at 326.
“means to an end”—as visual capacity is a means to (but not the only means to) aesthetic pleasure. People can lead fulfilling lives without the full panoply of species-typical capacities. She writes, “[b]rief acquaintance with people who have disabilities and who work, play, study, love, and enjoy the world should demonstrate that very few conditions preclude participating in the basic activities of life, even if some conditions limit some classes of them, or methods of engaging in them.” Finally, Asch describes recent debates concerning whether prospective parents should be limited in their selection of the traits they might choose for their children, whether they should be allowed, for example, to select against blindness but not against color-blindness, against deafness but not against tone deafness—the latter traits in these pairs being viewed by society as trivial incapacities, the former being considered serious enough to warrant avoidance through selection. Asch counsels against any such “line drawing”: the construction of such a list sends a demeaning message to people living with the listed conditions and creates a value-laden counseling environment in an arena where reproductive choice has, at least in theory, been valued.

Janet Dolgin has written extensively on legal and social aspects of reproduction and family. Her article in this issue, The Ideological Context of the Disability Rights Critique: Where Modernity and Tradition Meet, is also centered on the disability rights critique of prenatal testing. But rather than discussing the strength of various claims made by adherents and opponents of the critique, she evaluates it as presenting a model of discourse outside legal and political contexts that might suggest new and valuable ways of discussing abortion and the scope and meaning of family more generally. Dolgin begins by pointing out that while most proponents of the disability rights critique are pro-choice—meaning that they remain committed to a woman’s legal right to an abortion—they nevertheless decry the social and institutional culture in which choices are made to avoid the births of children with disabilities. The choice to abort a fetus should be legally protected, but when the choice is made because of prenatally diagnosed disabilities, that choice is morally problematic. Because these concerns about choices made on the basis of the char-

39. Id.
40. A number of scholars have supported prenatal selection on the basis of the argument that it is better to bring a child into the world with more rather than fewer opportunities, with as “open” a future as possible. See, e.g., Dena S. Davis, Genetic Dilemmas and the Child’s Right to an Open Future, 28 Rutgers L.J. 549 (1997). Asch questions how “open” one’s future really needs to be considering that no one can possibly take advantage of every possible opportunity. But furthermore she challenges proponents of the “open future” as not appreciating what is valuable about capacities, which is that they enable experiences associated with the “good life” rather than that they permit unrestricted choice. Asch, supra note 2, at 325-26.
41. Asch, supra note 2, at 324.
42. Dolgin, supra note 10.
acteristics of the child who will be born cannot be addressed within the existing framework of abortion law—which focuses on the individual autonomy rights of the woman, on the one hand, as balanced against concerns about the ontological status of the fetus, on the other—the critique has been discussed and debated outside legal and political contexts. In this regard the critique has offered what is typically missing from discourse about abortion in general: it has offered a commitment to both individual autonomy and to community—in particular, the community of people with disabilities. It has merged and valued arguments (as to unrestricted choice and restricted choice) that as more generally applied to the abortion debate appear polarized. For this reason, Dolgin sees the critique as offering an “alternative frame for discourse” that suggests that opponents in the abortion debate may be more open to mediation than has been supposed. Just as within the disability rights critique itself, those who identify as pro-life and those who identify as pro-choice value to some degree both choice and community; an abortion discourse that takes place outside the context of courts and politics may reveal the degree to which there exist shared understandings between pro-life and pro-choice groups.

Suzanne Holland offers a unique perspective within this issue on the matter of prenatal selection of fetuses and embryos. As a professor of religious and social ethics, she draws on philosophical sources rather than legal ones. As a “homosexual person in a deeply heteronormative culture,” as she describes herself at one point in the article, she places herself quite personally as having deep and compelling interests in the future of genetic selection for undesirable traits. The focus of her article is on behavioral characteristics that might be selected against as “handicapping” (such as intelligence, alcoholism, aggression, homosexuality) although the points she makes are also applicable to people with disabilities as we commonly understand them. Since both types of characteristics are socially constructed as negative, the analysis applies similarly. Holland argues that reproduction is not an unbounded right, but carries social obligations, one of which is to support vulnerable members of society. What this means in the context of practices of genetic selection is that we must first listen to people who have reason to fear that, technology permitting, they might not have been born. In Holland’s view, the knowledge such people have achieved through their experiences must be appreciated and brought to bear on the practices and future regulation of assisted reproductive technologies (ARTs). Holland does not, however, leave her suggestions for reform of current practices of ARTs at this procedural level. Relying on Martha Nussbaum’s work identifying human capabilities and the obligation of a good society to

43. Id. at 358.
44. Holland, supra note 5, at 402.
45. Id. at 403.
promote them, Holland identifies a substantive responsibility on the part of American society: to discourage any future practice of selecting against behavioral traits. Such selection runs counter to society’s obligation to provide for all persons to flourish, whether “differently abled or stigmatized with social handicaps.”46

John Jacobi, an expert in health insurance finance and regulation, takes a look at the intersection of genes and disability in the context of health insurance in his article, *Genetic Discrimination in a Time of False Hopes.*47 He notes that although genetic discrimination laws were widely adopted by states in the 1990s, revealing broad support for “genetic equity” in health insurance, this country’s commitment to such antidiscrimination principles remain uncertain. First, the laws were adopted in anticipation of insurers using genetic information to classify risk, but before they have done so. Such laws have therefore remained largely untested. When the science advances to a point that genetic information is actually predictive of future illness, insurers will find it relevant for risk classification, and the strength of those statutes will be tested. Jacobi argues that for the promise of genetic equity contained in those statutes to be realized, they must be drafted (re-drafted) to avoid ambiguity of the sort that has met narrowed interpretation in the disability context under the Americans with Disabilities Act and they must be adequately enforced against covert discrimination practices through the use of consumer protection devices now being developed to protect consumers from some of the more unsavory practices of managed care organizations.

The commitment to genetic equity in health insurance faces another threat, however, which is the renewal of rapidly rising health care costs. Rationing in some form, Jacobi tells us, is inevitable.48 But it should not take the form of favoring established treatments over new ones and treatments valued by the majority over those valued by the minority.49 Such historical tendencies would unfairly disadvantage people with disabilities and people with expensive genetic conditions. In this vein, Jacobi suggests the impropriety of Daniel Callahan’s much-discussed proposition to ration on the basis of “sustainable medicine,” one goal of which is “a decent level of physical and mental competence” and “limited aspirations for progress and technological innovation.”50 Such a system would run counter to the egalitarian principles rooted in the disability rights history51 and should health insurance system has been incrementally been moving.52

46. *Id.* at 407.
47. *Jacobi, supra* note 7.
48. *Id.* at 394.
49. *Id.* at 396-97.
50. *Id.* 397.
51. *Id.*
52. *Id.*
TAKING EUGENICS SERIOUSLY: THREE GENERATIONS OF ?? ARE ENOUGH?

PAUL A. LOMBARDO*

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It will, I think, be clear to anyone who examines the records of the period from 1900 to about the middle thirties that the manner in which the eugenics movement developed cast a long shadow over the growth of sound knowledge of human genetics . . . .

. . . [T]he history of connections between eugenics and human genetics has a special relevance. The connections were very close, and were especially evident in the United States, where interest in both fields was widespread at the turn of the century. Human genetics was often treated as part of eugenics, or as it was often called, human betterment or race improvement. It was that part concerned with acquisition of knowledge of human heredity. The association tended to be maintained because both subjects were frequently pursued and often taught by the same persons.1

This selection was taken from the Presidential address of L.C. Dunn, delivered at the 1961 meeting of the American Society of Human Genetics. Dunn (1893-1974) was particularly well positioned to survey his field’s history for fellow geneticists, since his life and career spanned the entire period during which genetic study was initiated, developed, and took its place among the sciences. His comments on the role of eugenics were also especially noteworthy because he knew all of the major scientists who played a part in the early years of genetics, and many of them were the people he described as having “pursued and often taught” both eugenics and genetics.2

In the early decades of the twentieth century, Dunn noted, the excitement surrounding the scientific discoveries that seemed to have such a direct application to human development fed the eugenics movement. “Rapid translations of new knowledge into terms applicable to improvements of man’s lot is at such times,” Dunn warned, “likely to take precedence over objective and skeptical evaluation of the facts.”3 Dunn was concerned that this tendency, like other “de-

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1. L.C. Dunn, Cross Currents in the History of Human Genetics, 14 AM. J. HUM. GENETICS 1, 3-4 (1962).
2. Id. at 4.
3. Id. at 2.
fects seen in the adolescent period of human genetics,” had not dis-
appeared—even late in his own career.4 Much of what Dunn said
more than forty years ago is pertinent today, in the headlong rush to
apply the insights gleaned from genetic research.

Dunn’s 1961 speech reminds us of a point too often forgotten in
today’s excitement over the explosive growth of genetics as a subject
of scientific study, cultural fascination, and commercial potential.
The field of genetics has a history. Part of that history, so clearly de-
scribed by Dunn, is its simultaneous growth alongside and inextrica-
ble linkage to the eugenics movement. How we remember that his-
tory, or whether we choose to remember it at all, is a matter of con-
sequence in public policy debates about the uses of new genetic tech-
nologies and the insights derived from genetic research.

This Article begins by examining a recent milepost in the history
of genetics, and another in the history of eugenics. These events, the
sequencing of the human genome and a governmental apology for
eugenic abuses, were ironically juxtaposed by their coincidental, si-
multaneous occurrence within the recent past. The recent erection of
an historical marker commemorating the 1927 Supreme Court deci-
sion in *Buck v. Bell* is described in this segment of the Article. The
Article continues with an explanation of the popularity of eugenics at
the turn of the last century, and it details the involvement of some
early, hopeful adherents to the field. It then turns to the dark side of
eugenics, exemplified by the writing of Charles Davenport, revealing
how his colleagues, Lucien Howe and Harry Laughlin, planned to
advocate legal restrictions to prevent the marriages of blind people.

Next, the role of Harvey Jordan provides a link between infant
mortality prevention campaigns and medical education, yielding an-
other example of how varied the understanding of eugenics was. Cur-
rent uses of the word “eugenics” among geneticists and counselors
show how uniform the distaste for the term is today. The Article con-
cludes with a return to the *Buck* case and a discussion of the problem
of historic moralism.

I. GENETICS/EUGENICS IN THE PRESS

The second week of February 2001 saw the juxtaposition of two
significant mileposts in the history of genetics. The first involved the
ongoing drama of scientific conquest known to the world as the Hu-
man Genome Program. In prearranged, simultaneous publications,
the prestigious journals *Science* and *Nature* presented special edi-
tions announcing the completion of the sequencing of the Human
Genome.

4. Id. at 3.
Science said that sequencing of the genome provided a “powerful tool for unlocking the secrets of our genetic heritage and for finding our place among the other participants in the adventure of life.” The issue focused on the efforts of Craig Venter and the private sector entrepreneurs of Celera Genomics, whose work provided a competitive tension for researchers from government-funded laboratories. Science reminded its readers that the public announcement of this achievement coincided with the anniversary week of the birth of Charles Darwin, setting genetics in the historical context of evolutionary theory and emphasizing how the sequencing effort had “built on the scientific insights of centuries of investigators.”

Nature chose to focus on the publicly funded collaborative led by Francis Collins of the National Human Genome Research Institute of the National Institutes of Health. Like its counterpart, Nature also recalled the history of genetics. It described the “scientific quest” that began with the “rediscovery of Mendel’s laws of heredity” early in the twentieth century, launching the race “to understand the nature and content of genetic information that has propelled biology for the last hundred years.” Science and Nature led the coverage of the genome-sequencing story, and February 2001 was filled with an avalanche of headlines in the national and international press marking this milestone in genomic research.

Not surprisingly, a search of the text of the Genome editions of Nature and Science issued that triumphant week revealed no mention of the dark term “eugenics.” Yet the same week of the media’s genomania, the Virginia General Assembly passed a resolution that evoked memories of historical events also linked to genetic science, but attracting significantly less media attention. The resolution Expressing the General Assembly’s Regret for Virginia’s Experience with Eugenics was introduced by Mitch Van Yahres, who represents the

6. Id.
7. Id.
8. Id.
10. Id.
   Agreed to by the House of Delegates, February 2, 2001
   Agreed to by the Senate, February 14, 2001

   WHEREAS, the now-discredited pseudo-science of eugenics was based on theories first propounded in England by Francis Galton, the cousin and disciple of famed biologist Charles Darwin; and

   WHEREAS, the goal of the "science" of eugenics was to improve the human race by eliminating what the movement’s supporters considered hereditary disorders or flaws through selective breeding and social engineering; and
city of Charlottesville in the Virginia House of Delegates. Van Yahres argued that an examination of the past was critical at a time when we “face a future marked by great advances in understanding of genetics,” and he emphasized that education is needed to avoid similar scientific disasters in the future. Commentary accompanying the Van Yahres statement reminded readers that his “warning seemed especially topical amid news about the first analyses of the human genome being published in scientific journals.”

The legislative response followed an extraordinary series of page one articles in the Richmond Times-Dispatch by journalist Peter Hardin describing Virginia’s history during the eugenics movement.

WHEREAS, the eugenics movement proved popular in the United States, with Indiana enacting the nation’s first eugenics-based sterilization law in 1907, closely followed by Connecticut; and

WHEREAS, in 1924 Virginia passed two eugenics-related laws, the first, the Racial Integrity Act, defined a white person as having no trace of black blood and made it illegal for whites and non-Caucasians to marry; and

WHEREAS, the second 1924 measure permitted involuntary sterilization, the most egregious outcome of the lamentable eugenics movement in the Commonwealth; and

WHEREAS, under this act, those labeled “feebleminded,” including the “insane, idiotic, imbecile, feebleminded or epileptic” could be involuntarily sterilized, so that they would not produce similarly disabled offspring; and

WHEREAS, in practice, the eugenics laws were used to target virtually any human shortcoming or malady, including alcoholism, syphilis and criminal behavior; and

WHEREAS, still another regrettable aspect of the eugenics laws was their use as a respectable, “scientific” veneer to cover activities of those who held blatantly racist views; and

WHEREAS, in a landmark 1927 decision, the United States Supreme Court upheld Virginia’s involuntary sterilization of Carrie Buck, in an 8-1 ruling written by Justice Oliver Wendell Holmes; and

WHEREAS, from then until 1979, Virginia involuntarily sterilized some 8,000 people, with estimates of the precise number ranging from 7,450 to 8,300; now, therefore, be it

RESOLVED by the House of Delegates, the Senate concurring, That the General Assembly expresses its profound regret over the Commonwealth’s role in the eugenics movement in this country and the incalculable human damage done in the name of eugenics; and, be it

RESOLVED FURTHER, That the General Assembly urge the citizens of the Commonwealth to become familiar with the history of the eugenics movement, in the belief that a more educated, enlightened and tolerant population will reject absolutely any such abhorrent pseudo-scientific movement in the future.

Id.

12. Initial language for the resolution was suggested by Delegate Kenneth Plum, Virginia legislator from Northern Virginia. Personal communication from Kenneth Plum to the author (July 20, 2001).


14. Id. Stories also noted how anti-abortion advocates wishing to include language linking Planned Parenthood founder Margaret Sanger to the eugenics movement were disappointed in their attempt to amend the resolution. See Pamela Stallsmith, House ‘Regrets’ Eugenics, Richmond Times-Dispatch, Feb. 3, 2001, at A1; see also Va. Eugenics Victim Seeks an Apology, Daily Progress (Charlottesville), Feb. 6, 2001, at B1.
Hardin’s series analyzed the Virginia eugenic experience, including the “Racial Integrity” legislation that prohibited interracial marriage and was later used to erase whole tribes of the state’s Native American population from demographic records, and the state’s eugenic sterilization law, upheld by the U.S. Supreme Court in the infamous case of *Buck v. Bell*. The drama of Hardin’s story was heightened by an Associated Press reporter who provided a modern face to eugenic history when he located Raymond Hudlow, a man sterilized under eugenic laws who later won medals for heroism during the Korean War.

Looking forward to the November 2001 elections, three gubernatorial candidates pledged to issue a formal apology for Virginia’s eugenic past. The pledge was made particularly noteworthy by the comments of then-Lieutenant Governor John Hager, a man with paraplegia. He emphasized the potential for both the positive and negative impact of science: “While the advocates of eugenics felt they were on the cutting edge of science, it was a terrible example of how science can be misused.”

Charlottesville, Virginia was the hometown of Carrie Buck, a party in the 1927 U.S. Supreme Court case of *Buck v. Bell*, and the first person to be sterilized in Virginia following that decision. Press attention in Charlottesville echoed the debate on eugenics occurring in the halls of the Virginia legislature. Several stories detailed the controversy that arose when the original Van Yahres bill calling for an “apology” by the state was introduced. Some citizens who testified against the resolution had specific complaints. One descendant of Cherokee Indians rejected the measure for not going far enough in


19. Id.


23. *See, e.g.*, Hardin, supra note 13; Stallsmith, supra note 14.
condemning state officials who used eugenic legislation to persecute Native Americans. 24 From a dramatically contrasting perspective, a representative of the National Organization for European American Rights rejected any negative references to eugenics, particularly any condemnation of the “Racial Integrity” laws that had prohibited interracial marriage. 25

Legislators also raised opposition. Repeating a common objection, one lawmaker rejected the critique of past eugenic policies, since sterilization was “at the time . . . legal.” 26 Others saw no benefit in revisiting past injustices, and objected to “stirring up some history that none of us are proud of.” 27 According to the Washington Post, Virginia leaders usually prefer to celebrate the state’s role as the birthplace of Presidents, and rarely find time to recall the state’s “prominent role in such historic evils as slavery, segregation and forced sterilizations.” 28 That Virginia was addressing its eugenic history at all was a subject worthy of comment to the Post, which saw the legislative resolution as “a remarkable moment.” 29

Predictably, the compromise emerging from the legislative debate did not satisfy everyone. The General Assembly eventually deleted the word “apology” in favor of a diluted declaration of “profound regret.” 30 The resolution finally adopted by the Virginia Senate on February 14, 2001, was criticized as an inadequate response to living victims of eugenic laws. Highlighting the links that legislators made between old and new renditions of genetic science, a newspaper in Europe condemned eugenics as “genetic engineering at its very worst.” 31 That paper described the legislative resolution as Virginia’s attempt at “saying sorry, sort of.” 32

Thus, the connections between the historical misuse of science and the current rush of new technologies were made patent by news analysis and public comment. Local stories of Virginia’s eugenic history shared page one space with the Francis Collins and Craig

24. Hardin, supra note 13, at A1 (featuring comments of Deborah Skicism in opposition to eugenics resolution).
25. Id. (featuring comments of Ron Doggett of the Virginia Chapter of the National Organization for European American Rights).
29. Id.
30. Id.
32. Id.
Venter news conference on the sequencing of the human genome. \(^{33}\) Editorial writers, echoing *Heart of Darkness* author Joseph Conrad, spoke of “The Horror” of eugenics, characterizing it as a “past manipulation of the human gene pool.” \(^{34}\) They cheered potentially “wondrous and welcome” developments such as gene therapy, while warning against the “far more troubling” prospects of amniocentesis and genetic screening to “prevent the birth of children with serious physical defects—eugenics by pre-emption.” \(^{35}\)

In the months following Virginia’s resolution “of profound regret,” even more public attention was given to eugenics. \(^{36}\) A state committee stripped the name of Dr. Joseph DeJarnette from a building at a state mental hospital. DeJarnette ran the institution for more than fifty years, all the while publicly advocating sterilization of his patients. His most noteworthy comments included support of Nazi sterilization from 1933 until the beginning of World War II, in 1939. \(^{37}\) Removing the name of self-proclaimed “Sterilization DeJarnette” \(^{38}\) from the building led to protests that the state was “steriliz[ing] . . . history.” \(^{39}\) A newspaper in Virginia’s neighboring state of North Carolina considered the need for apologizing for its eugenic history; \(^{40}\) another in Maryland termed the Virginia saga “a lesson in ethics for our brave new world.” \(^{41}\) The legal press also weighed in, placing Virginia’s *Buck* decision, along with *Dred Scott v. Sandford*, \(^{42}\) *Plessy v. Ferguson* \(^{43}\) and *Korematsu v. United States* \(^{44}\) within a “dubious pantheon” as one of the Supreme Court’s “biggest blunders.” \(^{45}\) According to *Legal Times*, the movement for a Virginia apology raised “uncom-
comfortable reminders of the Supreme Court’s role.”

As 2001 drew to an end, popular attention to the history of eugenics continued. Newspapers in other parts of the country pursued the eugenics story, recounting the debate in Virginia and finding other people who had been sterilized. Disability rights groups pressed newly-elected Governor Mark Warner for the apology he promised during his gubernatorial campaign, and the coincident 75th anniversary of the Supreme Court decision in *Buck v. Bell* gave rise to more legislative activity. In the 2002 legislative session, a resolution was passed specifically honoring the name of Raymond Hudlow, a eugenics victim and war hero. A second resolution, calling the *Buck* decision the “embodiment of bigotry against the disabled,” was drafted to honor “the memory of Carrie Buck on the occasion of the

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46. Id.
   Commending Raymond W. Hudlow.
   Agreed to by the Senate, January 17, 2002
   Agreed to by the House of Delegates, January 25, 2002
   WHEREAS, the now-discredited pseudo-science of eugenics was based on theories first propounded in England by Francis Galton, the cousin and disciple of famed biologist Charles Darwin; and
   WHEREAS, in 1924, Virginia passed two eugenics-related laws, the second of which permitted involuntary sterilization, the most egregious outcome of the lamentable eugenics movement in the Commonwealth; and
   WHEREAS, under this act, those labeled “feebleminded,” including the “insane, idiotic, imbecile, feebleminded or epileptic” could be involuntarily sterilized, so that they would not produce similarly disabled offspring; and
   WHEREAS, in 1941, Raymond Hudlow, a 16-year-old boy who repeatedly ran away from home to escape an abusive father, was committed to the Virginia Colony for Epileptics and Feebleminded near Lynchburg; and
   WHEREAS, on June 17, 1942, an Amherst County Circuit Court judge granted the Virginia Colony’s request that Raymond Hudlow be sterilized; and
   WHEREAS, in October of 1943, Raymond Hudlow was released from the Virginia Colony, was drafted into the United States Army two months later, and in August 1944, was at Omaha Beach in France two months after D-Day; and
   WHEREAS, Raymond Hudlow saw combat in France, Belgium, and Holland, was wounded in the left knee and captured by the Germans, was in various prison camps for seven months before being liberated by the Russians, and was awarded the Bronze Star for Valor, the Purple Heart, and the Prisoner of War Medal; and
   WHEREAS, Raymond Hudlow, who served honorably in the United States Army and Air Force for 21 years, now lives in Campbell County; now, therefore, be it

   RESOLVED by the Senate, the House of Delegates concurring, That the General Assembly hereby commend Raymond W. Hudlow for his distinguished military career and for his service to the nation during World War II; and, be it

   RESOLVED FURTHER, That the Clerk of the Senate prepare a copy of this resolution for presentation to Raymond W. Hudlow as an expression of the General Assembly’s admiration for his courage, determination, and patriotism.

Id.
75th anniversary of the *Buck v. Bell* Supreme Court decision.” As the Virginia legislature debated memorial resolutions, other concerns about eugenics filled the legislative chambers. Lawmakers considered establishing a committee to study ethical, medical and scientific issues relating to stem cell research and highlighted “eugenic formulations” already used to screen stem cells.

The media also monitored the impending date of May 2, 2002, which provided an occasion for the dedication of a state historical marker recalling the Holmes opinion in *Buck* exactly 75 years earlier. As the anniversary date approached, the media again recalled the *Buck* case as a reference point for reflecting on uses of the new

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Honoring the memory of Carrie Buck.

Agreed to by the House of Delegates, February 1, 2000

Agreed to by the Senate, February 7, 2002

WHEREAS, in 1924 Virginia passed two eugenics-related laws, the second of which permitted involuntary sterilization, the most egregious outcome of the lamentable eugenics movement in the Commonwealth; and

WHEREAS, under this act, those labeled “feebleminded,” including the “insane, idiotic, imbecile, feebleminded or epileptic” could be involuntarily sterilized, so that they would not produce similarly disabled offspring; and

WHEREAS, May 2, 2002, is the 75th anniversary of the United States Supreme Court decision in the case of *Buck v. Bell*, in which Virginia’s 1924 Eugenical Sterilization Act was allowed to stand; and

WHEREAS, following the *Buck* decision, an estimated 60,000 Americans, including about 8,000 in Virginia, were sterilized under similar state laws, and the decision was applauded by German eugenicists who supported comparable legislation early in the Nazi regime; and

WHEREAS, in 1927 Carrie Buck, a poor and unwed teenage mother from Charlottesville, was the first person sterilized under the provision of the 1924 law; and

WHEREAS, subsequent scholarship has demonstrated that the Sterilization Act was based on the now-discredited and false science of eugenics; and

WHEREAS, legal and historical scholarship analyzing the *Buck* decision has condemned it as an embodiment of bigotry against the disabled and an example of the use of faulty science in support of public policy; and

WHEREAS, that scholarship has also pointed out the fallacies contained in the *Buck* opinion, noting, among other points, that Carrie Buck’s daughter, Vivian, the supposed third-generation “imbecile,” later won a place on her school’s honor roll; and

WHEREAS, the General Assembly in 2001 expressed its “profound regret” over the Commonwealth’s role in the eugenics movement in this country and over the damage done in the name of eugenics; now, therefore, be it

RESOLVED by the House of Delegates, the Senate concurring, That the General Assembly honor the memory of Carrie Buck on the occasion of the 75th anniversary of the *Buck v. Bell* Supreme Court decision.

Id.


genetic technologies.52 Journalists in other states focused on homegrown stalwarts of the eugenics movement, such as Harry Laughlin of Missouri, author of the Model Eugenical Sterilization Law, as they explored explicit parallels between the old eugenics and the new genetics.53 The day before the Buck memorial event, people gathered in Lynchburg, Virginia—not far from the site of the institution formally known as the Virginia Colony for Epileptic and Feebleminded—to present Raymond Hudlow with a copy of the legislative resolution passed in his honor.54

In Carrie Buck’s hometown of Charlottesville, a short drive from the cemetery where she was buried, the Virginia Department of Historic Resources erected a marker fronting a main thoroughfare just around the corner from the school Buck’s daughter, Vivian, attended. The text of the Virginia Historic marker commemorating Buck v. Bell carries this inscription:

BUCK V. BELL

In 1924, Virginia, like a majority of states then, enacted eugenic sterilization laws. Virginia’s law allowed state institutions to operate on individuals to prevent the conception of what were believed to be “genetically inferior” children. Charlottesville native Carrie Buck (1906-1983), involuntarily committed to a state facility near Lynchburg, was chosen as the first person to be sterilized under the new law. The U.S. Supreme Court, in Buck v. Bell, on 2 May 1927, affirmed the Virginia law. After Buck more than 8,000 other Virginians were sterilized before the most relevant parts of the act were repealed in 1974. Later evidence eventually showed that Buck and many others had no “hereditary defects.” She is buried south of here.55

Governor Mark Warner chose the Buck anniversary to fulfill his campaign promise. His official apology made Virginia unique among the more than thirty American States that performed sterilizations using laws validated by the Buck decision. His statement of apology was read at the dedication ceremony.56

55. Buck v. Bell Historic Marker, located at 800 Preston Avenue, Charlottesville, VA, 22903.

I am sorry that I am unable to be with you on this important occasion. In 1924, Virginia, like many states, passed a law permitting involuntary sterilization.
The history of eugenics and its contemporary genetic links reverberated through the articles commenting on the *Buck* marker.\(^5\) Charlottesville’s *Daily Progress* reported Delegate Mitch Van Yahres’ intention to expose the state’s school children to the history of eugenics.\(^5\) This coverage held particular poignancy because in 1927, the same paper applauded the *Buck* decision and praised the Holmes opinion as “a genuine classic,” while judging the sterilization law “sane,” “beneficial” and “progressive.”\(^5\) A similar turnaround was evident in the *Richmond Times-Dispatch*, which provided vigorous support for eugenics legislation in the 1920’s. In addition to the prominent placement of articles on the history of eugenics noted above, that newspaper ran an editorial entitled simply *Eugenics*. It condemned “[g]reat crimes . . . committed in the name of progress,” and “dubious theories” that provided justification for “state-sanctioned butchery,” as a part of recent history.\(^6\)

Just how recent was brought home by the presence of two people at the *Buck* marker ceremony who had endured sterilization at the Virginia Colony. As the guests of honor at the event, Mr. Jesse Meadows and Mrs. Rose Brooks helped to unveil the *Buck v. Bell* marker. Their photos and comments to reporters were distributed worldwide via news service reports and feature articles in papers such as the *Washington Post*\(^3\) and the *Los Angeles Times*,\(^6\) as well as

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In 1927, Carrie Buck was the first person sterilized by the Commonwealth pursuant to that law. Virginia’s actions were upheld by the Supreme Court of the United States, and the government ultimately sterilized approximately 8,000 people.

Last year, the General Assembly passed a resolution expressing profound regret for the Commonwealth’s role in the eugenics movement. Today, I offer the Commonwealth’s sincere apology for Virginia’s participation in eugenics. As I have previously noted, the eugenics movement was a shameful effort in which state government never should have been involved.

We must remember the Commonwealth’s past mistakes in order to prevent them from recurring. This highway marker will serve as a constant reminder of how our government failed its citizens and how we must always strive to do better.

news reports on National Public Radio\textsuperscript{63} and the British Broadcasting Corporation.\textsuperscript{64} Describing the marker ceremony, these stories noted that operations on Virginia Colony inmates continued from the time of Carrie Buck’s case in 1927 until 1979.\textsuperscript{65}

Despite the fact that more than 60,000 Americans were sterilized over seven decades in the twentieth century, Virginia is now alone among the more than thirty states where sterilizations took place to officially recognize and condemn past policy through a legislative resolution and the Governor’s apology.\textsuperscript{66} No U.S. State has compensated a sterilization victim.

II. WHY EUGENICS IS ONE OF HISTORY’S DIRTY WORDS

The Buck case and related laws to permit state-sponsored sterilization provide a touchstone for discussions of the eugenics movement. While the word itself had many meanings to the variety of people who used it early in the twentieth century, it is employed almost exclusively today as a pejorative term to signal coercive state measures.\textsuperscript{67} Connections between eugenic ideology and the Nazi Holocaust, along with the sterilization history recounted above, explain much of the contemporary negative reaction to the term “eugenics.” The racist focus of much of the eugenics movement provides even more reason for the negative connotations of the term. An instructive view of the dark side of the science concerned with “better breeding” can begin with a look at the careers of some U.S. eugenicists.\textsuperscript{68} Prominent among them was Charles B. Davenport.

Davenport represented the public face of eugenics in America


\textsuperscript{65} Blum, supra note 62; Smith, supra note 61.


\textsuperscript{67} DIANE B. PAUL, CONTROLLING HUMAN HEREDITY, 1865 TO THE PRESENT 3-4 (1995).

\textsuperscript{68} See generally CHARLES BENEDICT DAVENPORT, HEREDITY IN RELATION TO EUGENICS 1 (1913).
from 1910 until his death in 1944. 69 He was the Resident Director of the Long Island based Eugenics Record Office (ERO). 70 The ERO was the best-funded and most successful of the organizations that emerged to promote the ideas of the eugenics movement in the first quarter of the twentieth century. 71 Later it would also be associated with some of the most malignant members of the movement, described by today’s publications of the Cold Spring Harbor Laboratory (now a center of genomic research) as “self-righteously bigoted.” 72

Davenport was a credentialed member of America’s scientific elite. He took his Ph.D. at Harvard in 1892, taught there and at the University of Chicago, and was the Director of the Biological Laboratory of the Brooklyn Institute of Arts and Sciences. 73 He was a member of the National Academy of Sciences, the National Research Council and the American Association for the Advancement of Science. 74 He presided over the Sixth International Congress of Genetics in 1932. 75 He attracted funding for eugenics from the Rockefeller and Carnegie Foundations. 76

In the early years of the ERO, Davenport’s pronouncements on the need for research, education, and legal reform to advance the eugenic cause included extreme rhetoric voiced in strong tones. Davenport delivered a lecture at Yale University less than a year before the formal founding of the ERO that summarized his position on the aims and the format of his brand of eugenics. 77 He proposed a system that would survey family traits. Such a plan would “identify those lines which supply our families of great men.” 78 But

[w]e [should] also learn whence come our 300,000 insane and feeble-minded, our 160,000 blind or deaf, the 2,000,000 that are annually cared for by our hospitals and Homes, our 80,000 prisoners and the thousands of criminals that are not in prison, and our 100,000 paupers in almshouses and out.

70. Id. at 227.
71. Id.
75. Allen, supra note 69, at 228.
76. Id. at 264.
77. Id. at 230.
78. CHARLES B. DAVENPORT, EUGENICS: THE SCIENCE OF HUMAN IMPROVEMENT BY BETTER BREEDING 31 (1910) (read before the American Academy of Medicine, at Yale University, Nov. 12, 1909).
This three or four per cent of our population is a fearful drag on our civilization. Shall we as an intelligent people, proud of our control of nature in other respects, do nothing but vote more taxes or be satisfied with the great gifts and bequests that philanthropists have made for the support of the delinquent, defective and dependent classes? Shall we not rather take the steps that scientific study dictates as necessary to dry up the springs that feed the torrent of defective and degenerate protoplasm?\(^7\)

The results of the research on institutional records and the archives of schools and insurance companies would pave the way for eugenic legislation that would prevent “idiots, low imbeciles, [and] incurable and dangerous criminals” from having children.\(^8\) Preventative methods could include institutional segregation and surgical sterilization.\(^9\) The social prerogative for self-protection extended, according to Davenport, from executing criminals to taking other necessary steps to “annihilate the hideous serpent of hopelessly vicious protoplasm.”\(^10\)

Davenport predicted that preventive medicine—guided by eugenic principles—would replace palliative philanthropy. Bemoaning the “tens of millions” spent to “bolster up the weak and alleviate the suffering of the sick,” he argued for a way to check the “stream of weak and susceptible protoplasm.”\(^11\) Similar sums spent for eugenics would earn the donor the title of “world’s wisest philanthropist” and would “redeem mankind from vice, imbecility and suffering.”\(^12\)

Despite the warnings of other scientists that might have forestalled such a result, Davenport’s early sentiments would characterize the work of the Eugenics Record Office in later years. The malevolent face and horrific connotations of the word “eugenics” would become linked inextricably to the programs developed in this country at the ERO and to the Nazi Holocaust abroad.\(^13\) The careers of Davenport and his associates at the ERO typify what went wrong with eugenics. Its American incarnation became infected with class and race bigotry, and it pointedly ignored the developing scientific data generated through genetic research.\(^14\) Such data often contradicted links eugenicists made between heredity and medical conditions, not

\(^7\) Id. at 31-32.
\(^8\) Id. at 30-31, 33.
\(^9\) Id. at 34.
\(^10\) Id.
\(^11\) Id.
\(^12\) Id. at 35.
\(^14\) Herbert Spencer Jennings, Prometheus or Biology and the Advancement of Man 3, 16-17, 24-25 (1925).
to speak of the more expansive claims that blamed hereditary blight for diverse social problems such as crime and poverty. The agenda of the Eugenics Record Office embraced government coercion as the proper means to enforce a eugenically sanitized population and further stigmatized people with disabilities and their families. While Davenport and his ilk railed against the “socially inadequate,” others within the eugenics movement debated the proper uses of the law as a means of addressing disabling conditions.

III. LUCIEN HOWE AND THE CAMPAIGN TO ERADICATE “HEREDITARY BLINDNESS”

One medical application of eugenic principles involved proposals for eradication of hereditary blindness. Dr. Lucien Howe had written about the cost of institutional care for the blind as early as 1889, estimating an expenditure of over $25 million annually. His objective was to take steps toward reducing the number of “[the] most pitiable of human beings, the blind.”

In 1918, Howe wrote to Harry Laughlin, Superintendent of the Eugenics Record Office, asking for advice concerning a new committee that had been appointed by the American Ophthalmological Association. Howe wanted to survey superintendents of schools for the blind and colonies “to which defectives of any kind are sent” to ascertain the cost of people “afflicted with hereditary blindness.”

Howe had already taken a public position on the need for a practical plan “for prevent[jion] to some extent [of] hereditary blindness” in a paper delivered to the American Medical Association. Having surveyed the literature concerning the cost of supporting a blind person, he asserted that much of the “misery and expense could be gradually eradicated by sequestration or by sterilization” of the carriers of hereditary blindness, following the model of laws for the commitment and sterilization of the “feebleminded” already enacted in several

88. Lucien Howe et al., Report of the Committee of the New York State Medical Society on the Causes and Prevention of Blindness, 14 SCI. 268, 270 (1889).
89. Id.
In cooperation with the Committee on Hereditary Blindness of the Section on Ophtamology of the American Medical Association, which Howe chaired, the Eugenics Record Office completed a survey that was sent to institutions for the blind as well as ophtamologists in hospitals and private practice. Each respondent was asked to fill out a family pedigree for people who have “hereditary eye defect[s]” and describe “details of eye defect and associated personal traits.”

The results of the survey were incorporated in recommendations that could be used by the American Medical Association to support changes in state marriage laws. By 1921, records of several hundred families had been collected in which some forms of “hereditary eye defects” existed. Howe and Laughlin, though wary of endorsing “radical methods” such as sterilization, were ready with another legislative proposal to recommend “in justice to innocent taxpayers.” They surveyed a number of physicians to solicit their endorsement of a proposed law. The law would allow any taxpayer to demand an injunction to block the issuance of a marriage license to any applicant who had “a visual defect,” or family history of such a condition, making it apparent that “children of such a union are liable to become public charges.” Two experts were to be summoned by the court to examine the prospective spouses. If the experts agreed that there was a likelihood of transmitting familial blindness, the court could require posting of a ten thousand-dollar bond as a condition of the marriage license.

Survey responses varied from those who judged the law a “dead letter,” to others who felt the “abuses and injustice” of such a law

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93. Id. at 1997.
94. Letter from the Committee on Hereditary Blindness, to Principals and Superintendents of Institutions for the Blind and Ophtamologists in Hospital and Private Practice (Harry Hamilton Laughlin Papers, on file with the Truman State University Library).
97. Id.
could not justify the potential beneficial impact. Still others thought the law too tame and wanted an “inclusive law” to address all “unfortunate physical and mental inheritances.” Howe eventually despaired of getting a consensus of medical opinion in favor of the law, and conceded that while he favored sterilization of the blind, “the next best thing is this bonding principle.” Howe and Laughlin hoped that the bonding principle would complement the sterilization law Laughlin advocated. Howe noted that if bonding worked out with the blind, it could be used to prevent the marriage of “any type of socially inadequate offspring.” as Laughlin called his target population for a sterilization law.

When the Eugenics Research Association voted to promulgate the marriage bond law in 1928, the Boston Post reported Howe’s plan under the headline “Harvard Scientist Wants Married Couples Bonded.” Though no state adopted the Howe plan, as late as 1942, proposals for “banning marriages between nearsighted people” were made to the American Medical Association in the name of “eugenic mating[s].”

Today the criteria used by Howe and Laughlin to diagnose and/or “predict” hereditary features of blindness would probably evoke scorn from the scientific community. Their theories about the workings of genetics in a eugenics scheme would be labeled “pseudo-science.” But the eugenicists and their colleagues from the scientific establishment would have been astounded to hear that anyone considered eugenics


102. Letter from Dr. Lucien Howe, to Dr. Davenport and Dr. Laughlin (Feb. 10, 1923) (on file with the American Philosophical Society), available at http://www.eugenicsarchive.org/images/eugenics/normal/301-350/325.jpg (last visited Nov. 4, 2002) (on file with author). By the time Howe announced his proposal to his colleagues in ophthalmology, he had increased the amount of the required bond to $14,000. Lucien Howe, Concerning a Law to Lessen Hereditary Blindness, TRANSACTIONS AM. OPHTHALMOLOGICAL SOCY (June 25, 1926) (on file with the American Philosophical Society), available at http://www.eugenicsarchive.org/images/eugenics/normal/301-350/308.jpg (last visited Nov. 4, 2002) (on file with author).

103. See Legal, Legislative and Administrative Aspects of Sterilization, EUGENICS RECORD OFFICE BULLETIN NO. 10B, at 117-20 (1914) (Model Sterilization Law).

104. Memorandum on Marriage License Bond, supra note 98.


a mere “pseudo-science,” a term often used today to describe eugenics by those who wish to distinguish it from current scientific orthodoxy. Such a posture ignores the extraordinary attention and enormous support of mainstream scientists given to the eugenics movement early in the century. At the height of the eugenics movement, no major college or university in the United States ignored eugenics. In fact, the eugenicists themselves used the term “pseudo-science” to distance themselves from past missteps, such as phrenology.

Despite the dark turns taken by some eugenicists—favoring crude legal interventions to eliminate “defective” conditions—much of the language of eugenics was hopeful. It pointed to a time when scientific insights could lead to preventive medicine. Though their perspectives were often marked with prejudice, a clearly philanthropic motive was also often at work in those who endorsed the health policy initiatives of the eugenics movement. That is one feature of early eugenics that made it extraordinarily popular.

IV. POPULARITY OF THE EUGENICS MOVEMENT

Francis Galton, the man who coined the term “eugenics” defined it as “hereditarily endowed with noble qualities” or more simply “well-born.” Galton’s elaborated definition included “all influences that tend in however remote a degree to give the more suitable races or strains of blood a better chance of prevailing speedily over the less suitable than they otherwise would have had.” Within a generation, adherents to Galton’s scientific credo would include statesmen.

108. Daniel Wikler, Eugenic Values, 11 SCI. CONTEXT 455, 455 (1998) (“[Eugenic][e] programs are now generally regarded as pseudoscience, having roughly the same relation to genetics as alchemy to chemistry or astrology to astronomy.”).

109. HALLER, supra note 90, at 72 (“Nearly every college and university had one or more professors inspired by the new creed.”).

110. Harry Laughlin noted that many fields of study, such as anatomy, psychology and phrenology were drawn upon to constitute eugenics. Of phrenology he said, “Although this pseudo-science failed in its extravagant claims of correlation, it must be credited with a careful study of human characteristics.” Harry H. Laughlin, Eugenics Record Office Rep. No. 1, at 5 (1913); see also Pseudo-Science, 12 J. HEREDITY 431 (1921) (book review) (using “Pseudo-Science” as a headline for a negative review of a book characterized as “feminist literature.”).

111. FRANCIS GALTON, INQUIRIES INTO HUMAN FACULTY AND ITS DEVELOPMENT 17 (1883).

112. Id.

113. See, e.g., PROBLEMS IN EUGENICS: PAPERS COMMUNICATED TO THE FIRST INTERNATIONAL EUGENICS CONGRESS xi (1912) (showing “The Right Hon. Winston Churchill, M.P., First Lord of the Admiralty,” listed as a Vice President of the Eugenics Congress); see also Lombardo, supra note 85, at 801 n.385 (describing Elihu Root’s career as Secretary of War, Secretary of State and Senator of New York, as well as his connections to the eugenics movement).
and Presidents,\textsuperscript{114} as well as a Who’s Who of scientists and physicians who eventually embraced eugenics.\textsuperscript{115} Nobel Laureates, such as Theodore Roosevelt,\textsuperscript{116} (1906), Elihu Root (1912), Woodrow Wilson (1919) and Winston Churchill (1953), joined more than a dozen Nobel Prize winners from the sciences who openly supported some form of eugenics at one time during their careers. They included such noteworthy scientists and social scientists as Alexis Carrel (1912),\textsuperscript{117} Thomas Hunt Morgan (1933),\textsuperscript{118} Jane Addams (1931),\textsuperscript{119} H.J. Muller (1946),\textsuperscript{120} William Shockley (1956),\textsuperscript{121} Linus Pauling (1962),\textsuperscript{122} Joshua Lederberg (1958),\textsuperscript{123} Francis Crick (1962),\textsuperscript{124} Konrad Lorenz (1973),\textsuperscript{125}

\textsuperscript{114} For example, as Governor of New Jersey, Woodrow Wilson signed sterilization legislation that would apply to “the hopelessly defective and criminal classes.” See Gov. Wilson Signs the Sterilization Bill, N.Y. TRIB., May 4, 1911, at 1. Theodore Roosevelt wrote in reference to “the vital problem of the perpetuation of the best race elements . . . I wish very much that the wrong people could be prevented entirely from breeding.” Theodore Roosevelt, 

\textit{Twisted Eugenics}, 106 OUTLOOK 30, 32 (1914).


\textsuperscript{116} See, e.g., Roosevelt, supra note 114.

\textsuperscript{117} Reggiani, supra note 39.

\textsuperscript{118} GARLAND E. ALLEN, THOMAS HUNT MORGAN: THE MAN AND HIS SCIENCE 227-34, 369 (1978).

\textsuperscript{119} JANE ADDAMS, A NEW CONSCIENCE AND AN ANCIENT EVIL 130-31 (1912).

\textsuperscript{120} H.J. Muller, \textit{The Dominance of Economics over Eugenics}, in A DECADE OF PROGRESS IN EUGENICS: SCIENTIFIC PAPERS OF THE THIRD INTERNATIONAL CONGRESS OF EUGENICS 138-44 (Harry F. Perkins et al. eds., 1934).


\textsuperscript{122} Linus Pauling, \textit{Foreword}, 15 UCLA L. REV. 267, 269 (1968).

\textsuperscript{123} Joshua Lederberg, \textit{Molecular Biology, Eugenics and Euphenics}, 198 NATURE 428, 428-29 (1963). This incredibly prescient article foreshadows many of the newest developments in genetic research.

\textsuperscript{124} Sir Francis Crick has been quoted as saying “no newborn infant should be declared human until it has passed certain tests regarding its genetic endowment, and that if it fails these tests it forfeits the right to live.” Charles Frankel, \textit{The Specter of Eugenics}, 57 COMMENT. 25, 33 (1974). Crick also favored a scheme for licensing parenthood or a tax on children. Francis Crick, \textit{Eugenics and Genetics}, in \textit{MAN AND HIS FUTURE} 274, 275-76 (Gordon Wolstenholme ed., 1963). This would “encourage by financial means those people who are more socially desirable to have more children.” \textit{Id.} at 276. As for the problem with correlating financial means with “desirability,” Crick said: “It is unreasonable to take money as an exact measure of social desirability, but at least they are fairly positively correlated.” \textit{Id.}

\textsuperscript{125} Lorenz used language typical of the old eugenics movement, comparing the social effect of genetic abnormalities to the career of an unchecked cancer:

There is a close analogy between a human body invaded by a cancer and a nation afflicted with subpopulations whose inborn defects cause them to become social liabilities. Just as in cancer the best treatment is to eradicate the parasitic growth as quickly as possible, the eugenic defense against the dysgenic social effects of afflicted subpopulations is of necessity limited to equally drastic measures . . . . When these inferior elements are not effectively eliminated from a [healthy] population, then—just as when the cells of a malignant tumor are allowed to proliferate throughout a human body—they destroy the host body as well as themselves.

\textit{CHASE, supra} note 121, at 349.
and Gunnar Myrdal (1974).126

The popular face of eugenics was often a happy one, with the winners of “better babies” contests pledged to future “eugenic” marriages127 and county fairs rewarded the fittest families.128 Never too far behind a popular movement, even politicians jumped on the eugenics bandwagon. One Chicago politico is reported to have even invoked the new field on his own behalf, claiming a spot on the Chicago City Council as “[the] eugenic candidate.”129

Early critiques by Europeans of the scientific technique of leaders in American eugenics prompted a New York Times headline announcing an “English Attack on Our Eugenics.”130 The debate continued in the pages of Science, which quoted an indignant Charles Davenport, the soon dean-to-be of American eugenics, condemning the “stupid, captious and misleading” comments and “delusions” of a European counterpart who dared to question the scientific bona fides of the U.S. movement131 as it gathered public attention and approval.

Representatives of the government health establishment concurred in endorsing the validity of eugenics. The U.S. Public Health Service Surgeon General supervised eugenic examinations and issued eugenic marriage certificates.132 Dr. W.C. Rucker, the assistant surgeon general, said “Eugenics is a science. It is a fact, not a fad.”133 Social work leader and later Nobel Laureate Jane Addams applauded “the new science of eugenics with its recently appointed university professors. Its organized societies publish an ever-increasing mass of information as to that which constitutes the inheritance of well-born children.”134 Even disability rights icon Helen Keller agreed that some “defective” children should not be saved from a premature

130. David Heron, English Eugenics Expert Again Attacks Davenport, N.Y. TIMES, Jan. 4, 1914, at 14, 15; David Heron, English Expert Attacks American Eugenics, N.Y. TIMES, Nov. 9, 1913, at 7 (emphasis added).
131. C.B. Davenport & A.J. Rosanoff, Reply to the Criticism of Recent American Work by Dr. Heron of the Galton Laboratory, EUGENICS RECORD OFFICE BULLETIN NO. 11, at 3, 3-43 (1914); see Charles B. Davenport, A Reply to Dr. Heron’s Strictures, 38 SCI. 773, 774 (1913); David Heron, A Rejoinder to Dr. Davenport, 39 SCI. 24, 24-25 (1914).
132. See Gets Eugenic Certificate, N.Y. TIMES, Oct. 22, 1913, at 1 (describing architect Homer B. Terrill as the recipient of the first eugenic certificate issued by the United States Public Health Service).
death because of their propensity to criminality.135

The rush to endorse new ideas seemingly anchored in scientific truth was hardly unusual, and one should not make too much of the early popularity of disparate ideas labeled “eugenic.” However, the extraordinary success of proponents of some variety of eugenics in capturing the public’s moral imagination cannot be ignored. Despite the disfavor into which the “dark side” of eugenics has fallen, the seductive message of the eugenics movement is worthy of analysis. Early followers rallied to a fundamental eugenic premise: that science could be used to alleviate suffering and improve the human condition. The attraction to eugenics for many was that it promised, if not a medical Utopia, free of diseases, at least a future in which some debilitating conditions could be relegated to the dustbin of history.

Among the champions of this promise was the inventor of the telephone. Alexander Graham Bell asserted that the “chief object of eugenics” should consist in raising the general quality of health among the largest number of individuals.136 Bell was among the most prominent of eugenics supporters, and his endorsement extended to his role as chairman of the first Scientific Board of Directors of the Eugenics Record Office (ERO).137 Bell also served as chair of the ERO technical Committee on the Heredity of Deafmutism.138 When the Journal of Heredity became the flagship publication of the American Genetic Association, he wrote the introductory article, entitled “How to Improve the Race,”139 for the first edition.

Bell argued that it was most important not to prohibit marriage and childbirth among those with hereditary problems, but to encourage them to marry “normal” members of the population, thereby “dilut[ing]” the impact of “undesirable blood.”140 He believed that “it is more practicable to improve the undesirable strains than to eradicate them.”141 As early as 1914, he decried the trend among eugenic enthusiasts to concentrate on coercive legal measures in an effort to eliminate genetic disease.

[I]t is to be regretted that the efforts of eugenists have been mainly directed to the diminution of the undesirable class.

135. PERNICK, supra note 129, at 55.
136. See Alexander Graham Bell, How to Improve the Race, 5 J. HEREDITY 1, 6 (1914).
137. See Laughlin, supra note 110, at 29.
139. Bell, supra note 136, at 1. This edition represented a transition from an earlier publication named the American Breeders’ Magazine, which was published prior to 1914. The American Breeders Association was the earlier name of the American Genetics Association.
140. Id. at 7.
141. Id. (emphasis omitted).
So much has this been the case that the very word “eugenics” is suggestive to most minds of hereditary diseases and objectionable abnormalities; and of an attempt to interfere, by compulsory means, with the marriages of the defective and undesirable.142

While opposed to the most repressive measures (such as compulsory sterilization) that eugenicists would eventually champion, Bell proposed a resolution on behalf of the ERO Board in 1916 to require the names of parents of everyone counted in the 1920 Census.143 He wished to require the inclusion of the name and address of “each blind or deaf and dumb person” in a registry so that eugenicists could monitor and track family records of “dependent” persons from generation to generation, making the census a source of pedigree data available for genetic and eugenic analysis.144

He also contributed to techniques in drawing pedigrees, proposing a system borrowed from his own study of multi-nippled sheep.145 His mathematical technique represented a foolproof means of detecting, and thereby avoiding, consanguineous pairings that could lead to a genetic mismatch.146 Bell’s obituary in the *Journal of Heredity* celebrated his perspective—eugenics with a friendly face.

His first study [of deafness] has put him in the rank of earliest explorers in the field of eugenics, and his later work [on longevity] has marked him as belonging to the positive eugenicists who believe that the improvement of the human race will only come from the mating of the desirables and that to stop the mating of the undesirables will not advance the race . . . .147

Bell was joined on the Scientific Board of the ERO by William Welch. Welch was the first dean of the School of Medicine at Johns Hopkins University, and a giant in the development of public health policy.148 He has been called the “Dean of American Medicine” and father of American medical education.149 Thomas Hunt Morgan, student of the common fruit fly *drosophila* and later winner of the 1933 Nobel Prize for his work in genetics, joined the other scientists on the

142. *Id.* at 6.
144. *Id.* at 208-09.
147. *Fairchild, supra* note 145, at 198.
149. *See generally id.*
original ERO Board. The presence of Bell, Welch, and Morgan on the ERO Board shows the affinity of pioneers in genetics for practical applications of their science. Even Wilhelm Johannsen, the Danish scientist who coined the terms “gene,” “genotype,” and “phenotype,” was active in the eugenics movement. The perspective of Bell, who shied away from “negative eugenics,” and Morgan, whose dissatisfaction with the shoddy science of many eugenists lead him to an early break with the movement, can be contrasted with the attitudes of Davenport and Laughlin. Nevertheless, all these men were intimately involved in the early eugenics movement, and none would have completely discarded the hopeful premises upon which the movement was founded.

Those premises and the philanthropic goals to which they pointed were expressed in organizations like the American Association for the Study and Prevention of Infant Mortality (AASPIM). Every annual meeting of the AASPIM included a program on eugenics, and the organization was able to extend its influence by extensive publicity. The ambivalence of a brand of eugenics that was simultaneously sympathetic to the disabled and intent on eradicating disabilities is captured in the comments of AASPIM Chairman Harvey Earnest Jordan. Jordan was a faculty member at the University of Virginia School of Medicine for over forty years, and eventually led that school as Dean. He supported the proposition that every child “must be saved if possible” while those “grossly and obviously unfit” should be prevented from reproducing. However, in contrast to Davenport, who referred to “the beneficent agent of extensive infant mortality”

150. See Allen, supra note 118, at 228, 234, 369.
151. A strong critic of many early scientific missteps of eugenists, Johannsen nevertheless joined the Permanent International Commission on Eugenics in 1923 and even served on a Danish state commission on castration and sterilization. See Eugenics and the Welfare State: Sterilization Policy in Denmark, Sweden, Norway and Finland 26 (Gunnar Broberg & Nils Roll-Hansen eds., 1996).
152. Allen, supra note 69, at 250.
as a check on problem births, Jordan opposed “eugenic euthanasia.”

To enable doctors to understand the importance of the workings of heredity in daily practice, Jordan argued that eugenics should be part of the curriculum of every medical school. The doctor of the future would not be merely a “dispenser of medicines” but a eugenic advisor who could point the way toward the “elimination of as much of the physical, mental and moral sickness and weakness as can be prevented.” Jordan urged that health enhancing practices must be promoted toward an “ultimate ideal” of a “perfect society constituted of perfect individuals.” But because Jordan was aware of the expense of “social therapy” and environmental interventions to cure problems thought traceable to heredity, he favored a preventive strategy.

Eugenics provided the means to realize his prophylactic goal. “Medicine is fast becoming a science of the prevention of weakness and morbidity; their permanent not temporary cure, their racial eradication rather than their personal palliation . . . . Eugenics, embracing genetics, is thus one of the important disciplines among the future medical sciences.”

V. Conclusion: Three Generations of ??? Are Enough?

Historians of eugenics have demonstrated the variety of ways early geneticists were involved in eugenics. They have noted the difficulty of framing accurate generalizations about the eugenics movement, because it included people who represented an “enormous variety of ideas, researches, and viewpoints.” Nevertheless, one vari-

156. Davenport’s comments were reported from another meeting of the American Association for the Study and Prevention of Infant Mortality. See Erville B. Woods, Heredity and Opportunity, 26 AM. J. SOC. 1, 18 (1920).
157. E.g., Jordan, Eugenics: Its Data, Scope and Promise, as Seen by the Anatomist, supra note 155.
158. Jordan, Medical Curriculum, supra note 155.
159. Id. at 398.
160. Id. at 396.
161. Id.
ety of the old eugenics looked forward to its application as part of a revolution in medicine. The similarities between the rhetoric used by eugenicists and parallel rhetoric today describing such a revolution is obvious.\textsuperscript{164} Perhaps it is true that “[o]nce we have left the garden of genetic innocence, some form of eugenics is inescapable.”\textsuperscript{165} But, what form of eugenics is acceptable?

The eugenics of Davenport, Laughlin, Howe, or Hitler are clearly not acceptable. Their example is often chosen to show the danger of allowing the intrusive hand of government into the reproductive choices of individuals. Consistent with that critique, some emphasize that government is the villain we should attend to most, since it can do so much more harm than mere individuals ever could.\textsuperscript{166} Some bioethicists make a similar point, arguing that the worst feature of eugenics was its application through government coercion, not the choices made against allowing certain conditions or characteristics to be reproduced in a new generation.\textsuperscript{167}

\textsuperscript{164} Compare Harvey Jordan’s celebration of the power of eugenics, Jordan, Eugenics: The Rearing of the Human Thoroughbred, supra note 162, to this comment from a recent medical genetics textbook:

[A] major contribution of these new developments in genetics has been in the area of prevention and/or avoidance of disease, the aspect of medicine that must become the focus of modern medicine. Genetic screening programs to detect individuals at risk, improved genetic diagnosis, genetic counseling, and prenatal diagnosis are some of these current applications of new genetic knowledge to medical practice. . . .


\textsuperscript{165} PHILIP KITCHER, THE LIVES TO COME: THE GENETIC REVOLUTION AND HUMAN POSSIBILITIES 204 (1996).

\textsuperscript{166} Ruth Schwartz Cowan, Genetic Technology and Reproductive Choice: An Ethics for Autonomy, in THE CODE OF CODES: SCIENTIFIC AND SOCIAL ISSUES IN THE HUMAN GENOME PROJECT 244, 262-63 (Kevles & Hood eds., 1992). Ruth Schwartz Cowan clarifies the danger of attacking eugenics by rolling back the clock on patient autonomy:

The history of prenatal diagnosis thus seems to suggest that in order to prevent a future in which parents will be able to choose the characteristics of fetuses that will be brought to term we will have to alter the norms of the scientific profession, and return medical practice to paternalistic modes of operation, and restrict women’s rights to request and obtain abortions.

\textit{Id.} at 261.

\textsuperscript{167} For example, Art Caplan notes that “no moral principle seems to provide sufficient reason to condemn individual eugenic goals.” Arthur L. Caplan et al., What is Immoral About Eugenics?, 319 BRIT. MED. J. 1, 2 (1999). He considers futuristic choices such as eye color or a genetically engineered propensity for mathematics similar to today’s decisions to teach one’s children a different set of religious values or send them to summer camp for tennis lessons. \textit{Id.} Caplan goes on to say that if coercion and force are absent and individual choice is allowed to hold sway, then presuming fairness in the access to the means of enhancing our offsprings’ lives it is hard to see what exactly is wrong with parents choosing to use genetic knowledge to improve the health and wellbeing of their offspring.

\textit{Id.} To a certain extent, Caplan’s arguments about distributive justice echo what Buchanan et al. identify as the “greatest . . . flaw of eugenics”—the “failure to take justice seriously.” ALLEN BUCHANAN ET AL., FROM CHANCE TO CHOICE: GENETICS AND JUSTICE 100 (2000).
Thus laws mandating sterilization or prohibiting marriage among people of differing “races” represented the most egregious examples of government intrusion in the name of eugenics, and governmental involvement in coercive reproductive policies is the most objectionable feature of eugenics to most people today. If no eugenic laws had been enacted in the United States or Europe, we would have little reason to bemoan the “curse of eugenics” that plagues current genetic research.

Eugenic laws found their most dramatic expression in the case of *Buck v. Bell*; it is used as a symbol for our rejection of eugenics. The popular memory of the case is linked to the opinion of Oliver Wendell Holmes, Jr. condemning Carrie Buck to sterilization as the daughter of a “socially inadequate” mother and a mother herself of a similarly afflicted daughter. The opinion concludes with a splash of the trademark Holmesian rhetoric, criticized by his colleagues as a bit too caustic, condemned by history as a chilling expression of statist sentiment.

We have seen more than once that the public welfare may call upon the best citizens for their lives. It would be strange if it could not call upon those who already sap the strength of the State for these lesser sacrifices, often not felt to be such by those concerned, in order to prevent our being swamped with incompetence. It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind. The principle that sustains compulsory vaccination is broad enough to cover cutting the Fallopian tubes . . . . Three generations of imbeciles are enough.

Most people cringe at the Holmes opinion as an example of the worst tendencies of the eugenics movement. As often as not, their discomfort is exacerbated by the knowledge that the *Buck* case was a sham. *Buck* is certainly among the most cruel Supreme Court opinions, and as we now know, among the most false. Carrie Buck had no
diagnosable cognitive disabilities, nor did her daughter.174 She was the victim of a political movement that had the assistance of her foster parents, her doctors, and her lawyer; she was betrayed by each of them in turn.175 Perhaps this makes the case all the more tragic; often it simply makes our moral judgments about it too easy.

Because the Supreme Court got it wrong—to use Holmes’ language, Carrie was no “imbecile,” and no sound evidence of hereditary disease was demonstrated in her case—it is easy to generate scorn for the case and the movement it represented.176 But a moralistic, backward judgment about eugenics is not only naively ahistorical, it can be dangerous. To impute only corrupted motives to supporters of the eugenic agenda because of our disgust at the worst of those who claimed the label means to miss the myriad ways other motives guided their efforts, as well as the many ways our current practices and motives parallel them. It also may imply that had Holmes’ commentary been accurate, and if Carrie Buck actually was likely to pass on a genetically diagnosed disabling condition, we would endorse the Holmes conclusion and the type of law it affirmed as well.

What if we remove the specter of a governmentally mandated reproductive scheme? As the discussion above has made clear, many of those who happily embraced the banner of eugenics were also loathe to enact sterilization laws or other governmental programs but nevertheless endorsed the goals of eugenics in decreasing genetically transmitted disease.177 How different were their aspirations from those played out today in practices such as prenatal or preimplantation diagnosis and consequent abortion?

Today we can diagnose some forms of deafness, blindness, and numerous other diseases where the genetic contribution to disease is clear and the prognosis of genetic disease is firm. How much does it matter if we use a technique—less troubling to some than coercive surgery—to “cleanse the germplasm” as the eugenicists would have said? Does our embrace of techniques such as preimplantation selection of “normal” fetuses or prenatal genetic diagnosis and selective abortion make our motives in “eradicating defects” less suspect? Does homegrown retail eugenics differ in kind from the wholesale government variety?

When we recall Howe’s attempt to eradicate blindness, we must also evaluate current efforts to search for genes that lead to impaired

174. Id.
175. Id.
176. Id.
177. See, e.g., John P. Dawson, 27 ILL. L. REV. 839, 842 (1932) (reviewing J.H. LANDMAN, HUMAN STERILIZATION (1932)) (“The eugenic movement will make greater headway by throwing its emphasis on private rather than public agencies, on persuasion rather than compulsion.”).
sight.178 Our memory of Alexander Graham Bell’s crusade to eliminate deafness must be placed alongside reflections on similar projects today.179 The search for the causes of mental retardation and developmental delay has not abated since the time of Davenport and Laughlin, and genetic markers for these cognitive impairments are currently under study.180 A review of Jordan’s attempt to inject eugenics into medical education “as part of genetics” to lower the social cost of disease,181 reminds us that neither our motives nor some of our methods are dissimilar to our predecessors.182 In order to take eugenics seriously, we cannot dismiss Holmes or any other advocates of eugenics as backward, benighted members of a deluded, defunct, social movement. We have too much in common with them for that tactic to be pursued in good faith. We must strip the Holmes opinion of the language that we may find offensive, then answer the hard question that remains. What genetic conditions shall we choose to eliminate? Three generations of ??? are enough?

180. See, e.g., Siobhán A. Jordan et al., Localization of an Autosomal Dominant Retinitis Pigmentosa Gene to Chromosome 7q, 4 NATURE GENETICS 54 (1993).
181. Compare id., with Francis S. Collins & Alan E. Guttmacher, Genetics Moves into the Medical Mainstream, 286 JAMA 2322, 2323 (2001) (“[G]enetic medicine will ultimately improve prevention initiatives, leading to greater emphasis on maintaining wellness and a reduction in health care costs over the longer term.”).
182. A recent article on preimplantation diagnosis for Alzheimer’s disease included this recommendation: “prospective parents . . . should be informed about this emerging technology so they can make a choice about reproduction.” Yury Verlinsky et al., Preimplantation Diagnosis for Early-Onset Alzheimer Disease Caused by V717L Mutation, 287 JAMA 1018, 1021 (2002). Similar recommendations were made for other parents who may be “determined by strong genetic predisposition to be at risk for producing progeny with severe disorders.” Id.
AREN'T WE ALL EUGENICISTS? COMMENTARY ON
PAUL LOMBARDO'S "TAKING EUGENICS
SERIOUSLY"

MARY B. MAHOWALD*

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The infamous statement of Justice Oliver Wendell Holmes, “Three
generations of imbeciles are enough,”1 has long been recognized as a
shameful example of how eugenics has been practiced not only in
horrendous situations such as Nazi Germany, but even in a country
founded on the principle that “all Men are created equal.”2 From the
start, the flawed wording of this principle was evident: “men” was in-
terpreted to exclude women and Negroes. Both groups were excluded
from voting rights and other civil rights that white men enjoyed for
many years thereafter. The United States Supreme Court ruling in
Buck v. Bell denied another group of people the same basic right that
Holmes and his colleagues enjoyed; apparently they did not think
that people with mental retardation were “men.”3

Paul Lombardo has made it abundantly clear that the decision in
this case was based on an empirically false claim; the three women to
whom Holmes referred were not imbeciles at all.4 Still, even if the
claim were true, the decision would still illustrate eugenics, nega-
tively defined as the effort to prevent the birth of “unfit” individuals.5
For Holmes, coercive sterilization of a retarded woman was justified
in order to ensure that her posterity would not be similarly affected.6

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rently Visiting Professor Emerita at Stanford University.
1. Buck v. Bell, 274 U.S. 200, 207 (1927). Hereafter, I shall refer to this decision ei-
ther as Buck v. Bell or as the Holmes decision.
2. THE DECLARATION OF INDEPENDENCE para. 2 (U.S. 1776).
3. See Buck, 274 U.S. at 207.
5. Daniel J. Kevles cites the work of Francis Galton, Karl Pearson, and other eugeni-
cists who “equated fitness with physique and mental ability, and assumed that it was cen-
tered in the middle, and particularly the professional, class.” DANIEL J. KEVLES, IN THE
NAME OF EUGENICS: GENETICS AND THE USES OF HUMAN HEREDITY 32 (1985). With Gal-
ton’s approval, C.W. Saleeby proposed the distinction between negative and positive eugen-
ics. Id. at 321. Negative eugenics was “intended to encourage the socially disadvantaged to
breed less—or, better yet, not at all.” Id. at 85. Positive eugenics “aimed to foster more pro-
lific breeding among the socially meritorious.” Id.
As Lombardo reminds us, however, Holmes was not a lone champion of this eugenic attitude. American presidents and Nobel laureates alike had been publicly associated with the eugenics movement, which had many supporters in the public-at-large. Apparently, some members of the movement distinguished between practices that were acceptable and those that were not, cautioning that governmental coercion should not be employed in the laudable pursuit of healthy offspring. But not until the Nazi atrocities demonstrated to the world the horrors to which a eugenic mentality and practice could lead did professional and public support for the movement decline and eventually grow silent.

Advances in genetics and possibilities for manipulating the human genome have resurfaced concerns about eugenics in our day. Typically, these concerns embody the same critique that has been directed against *Buck v. Bell* and against Hitler’s atrocities; namely, that they constitute an egregious disvaluing of human beings whose lives and progeny ought to be equally respected. However, one practice that arose between Holmes’s and our time has generally escaped concerns about eugenics, despite the similarity between its rationale and that of the Holmes decision. In some quarters this practice has become not only acceptable but expected, leading women who decline it to feel that they are disappointing others, especially their practitioners. I refer to the practice of prenatal testing and termination of affected fetuses.

Prenatal testing is mainly performed to identify fetuses with conditions considered undesirable by parents, practitioners, or society in general. The great majority of these conditions are incurable, although their symptoms or disabling impact may be reducible through treatment and social accommodation. The range of conditions that are identifiable in utero has escalated considerably since the human genome has been mapped and sequenced. Chromosomal anomalies and single gene disorders that affect infants or adults are definitively diagnosable through prenatal testing; well-known examples of these conditions are Down syndrome, cystic fibrosis, Tay Sachs disease, sickle cell anemia, and Huntington disease. Genetic susceptibility to complex disorders such as breast cancer and Alzheimer disease is also detectable in utero, and propensity for some behavioral traits is

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8. Lombardo cites Alexander Graham Bell as an example of those who distinguished between eugenic practices that were acceptable and those that were not. *Id.* at 211-13. Bell opposed coercive legal measures and advocated efforts to improve undesirable traits rather than eradicate them. *Id.* at 211. Even if the Buck women had actually been mentally retarded, he therefore would not have agreed with the Holmes decision. See generally *id.*
detectable or likely to be detectable in the near future.\textsuperscript{9}

Many fetal disorders are diagnosable through simpler means than genetic tests; these include spina bifida and cleft lip and palate, which are observable in utero through ultrasound. By far, however, the most common condition for which women are referred for prenatal testing, and for which they seek termination after a positive diagnosis, is Down syndrome, also called “trisomy 21.”\textsuperscript{10} The rationale that underlies testing and termination for this condition is similar to the rationale of the decision in \textit{Buck v. Bell}: to prevent the birth of a child with mental retardation. However, in contrast to the Holmes decision, which is broadly condemned on legal as well as moral grounds, prenatal testing and termination of a fetus with mental retardation is not only legal, but prevalently viewed as moral. Nonetheless, both practices illustrate the defining intent of negative eugenics: to limit the births of individuals or groups of individuals who are deemed unfit or undesirable.\textsuperscript{11}

Ironically, in the years between Holmes’s opinion in \textit{Buck} and today, prenatal testing and termination of “unfit” fetuses have been routinely requested and performed without acknowledging the eugenic nature of these practices. Genetic counselors, trained to guide their clients to make decisions in conformity with their clients’ own values, distinguish between their profession’s goals and those of

\begin{itemize}
\item Behavioral traits related to genetics include tendencies to alcoholism, obesity, sexual orientation, dyslexia, athleticism, and timidity. \textsc{Mary Briody Mahowald}, \textit{Genes, Women, Equality} \textit{246} (2000) (documenting these and other examples of behavioral traits attributed to genetics).
\item “Trisomy” refers to the fact that the affected person has an extra chromosome, i.e., three chromosomes instead of two; “21” indicates which chromosome pair is affected. See Cathleen M. Harris & Marion S. Verp, \textit{Prenatal Testing and Interventions}, in \textsc{Genetics in the Clinic: Clinical, Ethical, and Social Implications for Primary Care} \textit{59, 60} (Mary B. Mahowald et al. eds., 2001); Cynthia Powell, \textit{The Current State of Prenatal Genetic Testing in the United States}, in \textit{Prenatal Testing and Disability Rights} \textit{44, 45} (Erik Parens & Adrienne Asch eds., 2000). The condition is called “Down” syndrome after Sir John Langdon Haydon Down, who first described its symptoms, comparing them with those of “Mongols.” See \textsc{Rayna Rapp}, \textit{Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America} \textit{295-96} (1999). Rapp also cites Down syndrome as the most common condition for which women seek prenatal testing. \textit{Id.} at 223. The actual reason for referral in these cases is “advanced maternal age,” which generally means thirty-five years or older. Although the risk of having a child with Down syndrome increases with maternal age, most children with Down syndrome are born to younger women, who are not routinely referred for prenatal diagnosis as are the older women. Younger women are referred for prenatal tests if they have a family history of a hereditary disease, if they have already had an affected child, or if screening tests suggest a need for definitive testing. See Marion S. Verp, \textit{Prenatal Diagnosis of Genetic Disorders}, in \textsc{Principles and Practice of Medical Therapy in Pregnancy} \textit{159, 162-66} (Gloria E. Sarto ed., Appleton & Lange 1992); Glenn Schemmer & Anthony Johnson, \textit{Genetic Amniocentesis and Chorionic Villus Sampling}, 20 \textsc{Obstetrics & Gynecology Clinics N. Am.} \textit{497, 515-16} (1993).
\item See \textsc{Kevles}, \textit{supra} note 5, at 85 (discussing Saleeby’s distinction between negative and positive eugenics).
\end{itemize}
eugenics. Typically, they point to the nondirectiveness of genetic counseling and the autonomy of their clients as individuals or couples; eugenics, as they see it, is a coercive practice directed towards whole groups of people. As we will see in what follows, the assumed differences between prenatal termination for Down syndrome and coercive sterilization of the retarded are not establishable with sufficient clarity to support the claim that the latter, but not the former, constitutes eugenic practice. Even if both practices are eugenic, however, that in itself is not adequate grounds for claiming that they are legally or morally flawed.

As an example of the possible legal and moral acceptability of eugenic practice, consider the behavior of most pregnant women who intend to bring their pregnancies to term. Most of us who are mothers changed our behaviors considerably during pregnancy, intending thereby to improve the chances of having a healthy child. We took our vitamins faithfully, quit smoking (if we had ever started), avoided aspirin, abstained from ordinary drinks like coffee and Coke as well as alcohol, and, in some cases, endured prolonged bed rest or hospitalization to avoid premature birth. If positive eugenics is defined as the effort to promote the birth of “fit” individuals, these behaviors may well be characterized as eugenic. In contrast to forced sterilization of the retarded, however, the efforts of women to do everything they can to have healthy newborns is widely recognized as morally commendable rather than condemnable. Lombardo is right, therefore, to suggest that some eugenic practices are not only morally appropriate but praiseworthy.

Diane Paul has made it clear that the term “eugenics” can refer to very different kinds of behavior. Lombardo explores some of these meanings and recounts some of the high and low points in the history of eugenics, concluding with a challenge to find words to substitute for “imbeciles” in Holmes’s infamous statement so that the resultant formulation articulates a sentiment that is morally and socially acceptable. He thus suggests the need for line-drawing, by which we might distinguish between good and bad eugenics. In Part I of this Article I attempt to do this by approaching the line from both ends: the manifestly bad and the manifestly good expressions of eugenics.


13. See generally Lombardo, supra note 7.


15. See generally Lombardo, supra note 7.

16. Id.
My goal is to get as close as possible to where the line should be definitively placed. Preliminarily, however, I examine the broad array of meanings that the term “eugenics” embraces, and identify the variables that seem to be associated with these different meanings. To the extent that different variables are included in different meanings of eugenics, identifying them helps to clarify what makes some (most?) eugenics bad, some eugenics good, and some eugenics probably neutral.

In Part II, I consider the “disabilities critique” that must be rebutted in support of routine prenatal testing and selective termination of fetuses with disabilities. My analysis suggests a criterion by which to determine whether these procedures constitute good or bad eugenics. Finally, I focus on prenatal testing and termination for Down syndrome, a condition marked by the same disability attributed to members of the Buck family in the Holmes opinion. Although decisions to avoid having children with Down syndrome through prenatal testing and termination need not constitute bad eugenics, I argue that broad acceptance of the practice does support the disabilities critique, placing it on the lower end of the spectrum between bad and good eugenics.

I. Eugenics as a Spectrum of Concepts

Etymologically, the term eugenics comes from the Greek eugenes, which means “well born.” In light of this derivation, its meaning is as difficult as it has ever been to answer the perennial philosophical question, what is “the good”? Still, by its literal definition, eugenics does mean something good, not bad: well born, not ill born. Presumably, this meaning is what led some eugenicists of the past to think that the practice they advocated was good, even when others recognized it as good in name but not in fact. Francis Galton, who coined the term in 1883, probably thought he was doing “good” by championing eugenics as the “science of improving the stock.” Of course, thinking something is good does not make it so.

To the extent that eugenics is construed as morally objectionable, it is generally associated with coercion. As Paul observes,

17. This critique, also called “[the disabilit[ies] rights critique” is well-developed by Erik Parens & Adrienne Asch in The Disability Rights Critique of Prenatal Genetic Testing: Reflections and Recommendations, in PREGNATAL TESTING AND DISABILITY RIGHTS, supra note 10, at 12-13.
19. RUTH HUBBARD & ELIJAH WALD, EXPLODING THE GENE MYTH: HOW GENETIC INFORMATION IS PRODUCED AND MANIPULATED BY SCIENTISTS, PHYSICIANS, EMPLOYERS, INSURANCE COMPANIES, EDUCATORS, AND LAW ENFORCERS 14 (1993) (quoting FRANCIS GALTON, INQUIRIES INTO HUMAN FACULTY 24-25 (1883)).
the health of the population, but the means employed to achieve it.
From this standpoint, in the absence of coercion (as reflected in law or obvious forms of social pressure), policies designed with the good of the population in mind are not properly labeled “eugenic.”

Note, however, that coercion is not an element in the etymology of the term; neither is it included in scientific and dictionary definitions of eugenics as a science by which the human race is improved. Even if the concept or term were mentioned, what constitutes “coercion” is arguable in its own right. For some, coercion implies the presence of formal, legal barriers to choice; to others, practical impediments such as economic costs and social pressures function coercively. The Holmes decision was coercive in the first sense; in an age in which reproductive freedom is supported by law, women may nonetheless experience coercion in the second sense.

Although I am no more able to define “the good” definitively than philosophers throughout history have been, I believe it is possible to arrive at an approximate understanding of what constitutes good or bad eugenics by approaching the issue indirectly, starting from the extreme ends of a spectrum of practices that most people consider ethically reprehensible or ethically praiseworthy. Popular approval and prevalent practice do not confer moral validity, which is why the mere fact that prenatal testing and termination after positive diagnosis is widely accepted does not make the practice morally justifiable. Nonetheless, the extreme ends of the spectrum are not just widely endorsed, but universally upheld by reasonable people. This makes the argument for moral validity much more compelling than it would be if controversy prevailed regarding their moral or legal status.

Let us consider, therefore, some examples of activities undertaken or omitted in the name of eugenics that seem manifestly wrong, and some that seem manifestly right or good. On one side, put the genocide committed by the Nazis or other groups who kill classes of people whom they consider undesirable; on the other side, put the health promoting behavior of the great majority of pregnant women.

21. Paul illustrates this point with regard to the different political perspectives. A classical liberal or libertarian, she says, would consider the potential parents of a child with Down syndrome “free to abort the fetus or bring it to term,” whereas an egalitarian liberal or socialist would claim that the “downstream” costs of caring for a severely handicapped child may limit their freedom to bring an affected pregnancy to term. Id. at 146.
22. Feminist philosophers have recently formulated a conception of “relational autonomy,” which critiques a narrow or literal conception of freedom on grounds that individuals are not adequately definable atomistically; rather, our ongoing relationships to others are inseparable from our autonomous decisions. See generally RELATIONAL AUTONOMY: FEMINIST PERSPECTIVES ON AUTONOMY, AGENCY, AND THE SOCIAL SELF (Catriona MacKenzie & Natalie Stoljar eds., 2000). “Relational autonomy” also takes into account environmental limitations and social pressures on the decisions of individuals. Id.
tween these opposite ends of the spectrum are a range of behaviors that may be construed as eugenic—sometimes separately, and sometimes in combination;\footnote{23} they all fulfill in some way the literal meaning of eugenic as well-born. Many decisions about fertility, whether it is curtailment through contraception, sterilization, or abortion, or it is enhancement through various reproductive technologies, fall within the spectrum of eugenics; so do social policies, laws and cultural norms that affect such decisions. Perinatal decisions may also be eugenic—if their goal is to promote well-bornness.\footnote{24}

Prenatal testing and selective abortion are at neither end of the spectrum between good and bad eugenics. By broad social agreement, the \textit{Buck v. Bell} decision belongs closer to the bad end.\footnote{25} However, determination of where a particular behavior belongs on the spectrum depends on multiple variables, some of which are identifiable through examination of the practices that are clearly locatable at either end of the spectrum. The following characteristics distinguish between the two extremes:

<table>
<thead>
<tr>
<th>Nazi Genocide</th>
<th>Health-Promoting Behavior During Pregnancy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coercive intervention by state or government</td>
<td>Autonomous decisions by potential parents</td>
</tr>
<tr>
<td>Directed to born persons as a group</td>
<td>Directed to potential children as individuals</td>
</tr>
<tr>
<td>Terminating their lives</td>
<td>Supporting their lives</td>
</tr>
<tr>
<td>To avoid a specific trait or traits</td>
<td>To promote health or other conditions</td>
</tr>
<tr>
<td>Judged by state to be undesirable</td>
<td>Judged by potential parents to be desirable</td>
</tr>
</tbody>
</table>

\footnote{23}{Prenatal testing, for example, is separable from termination of a fetus, and may in fact be associated with the desire to treat rather than eliminate an affected fetus.}

\footnote{24}{Ironically, once an individual is ill-born, regardless of the degree in which well-bornness was pursued before birth, the medical options available are largely anti-eugenic rather than eugenic. By prolonging the lives of those who are not well-born so that they reach reproductive age, medical practitioners facilitate the births of more people who are ill-born. If germ line gene therapy is ever successful in humans, this anti-eugenic propensity of health care could be reduced; I doubt, however, that even then it would be overcome.}

\footnote{25}{As Paul Lombardo observes, "[m]any of the commentaries on \textit{Buck} describe the case as an aberration traceable to the 'eugenics craze' of the Progressive Era." Lombardo, \textit{supra} note 4, at 32. Presumably, an "aberration" of the "craze" would be even more problematic than the craze itself.}
Notice that one side opposes and the other respects the autonomy of those who are directly affected. Note too that one side involves people already born, while the other involves individuals that have not been born and may not even have been conceived. One side is eugenic practice through termination, not just prevention, of already-born individuals who are considered undesirable; on the other side is the avoidance of harms and promotion of benefits to intended offspring. On one side, the practice is driven by the state or government and directed towards an entire group of people who are defined by a single trait or set of traits. On the other side, the practice is driven by individual women or couples and directed towards potential children as individuals.

As Aristotle observed long ago, the good of society generally outweighs the good of the individual as such. Based on that priority, the implicit emphasis on social welfare in the left column is a good, but other characteristics in that column are not. In contrast, the characteristics on the right are generally understood in a positive moral light. Coercion, for example, carries a moral onus that respect for autonomy does not—even though both are sometimes justifiable and sometimes not. And decisions to terminate lives are obviously tougher (and for pacifists, impossible) to justify than decisions to extend life—because life is a prima facie good. Terminating lives is even tougher to justify when the individuals to be killed are already born, and the sole criteria for termination are single traits or sets of traits found in whole groups of people who may also be killed by those criteria. In contrast, the lives to be supported on the right are seen holistically, as individual potential children whose worth and right to life are not definable solely on grounds of any single trait or sets of traits.

The *Buck v. Bell* decision is on the left side of the eugenics spectrum because it fulfills all but one of the characteristics listed under Nazi genocide. The Supreme Court’s ruling in *Buck* authorized the forced sterilization, but not the killing, of “imbeciles.” Nonetheless, it constituted government endorsement of coercive intervention to avoid a specific trait deemed socially undesirable by state legislators. Worse, the Holmes decision purported to effect its eugenic goal by preventing individuals from exercising a right that is central to many

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26. See, e.g., ARISTOTLE, Politics, in THE BASIC WORKS OF ARISTOTLE 1129 (Richard McKeon ed., Benjamin Jowett trans., Random House 1941) (“[T]he state is by nature clearly prior to the family and to the individual, since the whole is of necessity prior to the part.”).

27. It is at least a prima facie good. Beyond that minimal claim, it may be argued that life is a necessary condition for all other goods attributed to living entities.
people’s lives, i.e., the right to have a child.\textsuperscript{28} Admittedly, some people with disabilities may be incapable of raising a child or, at least, raising one by themselves. Many are, nonetheless, capable of biological and social parenthood. So the Holmes decision is only as much removed from the far left as sterilization is from homicide. Moreover, as Lombardo makes clear, the assessment of someone as an “imbecile” or so impaired as to justify sterilization may be questionable even on empiric grounds.\textsuperscript{29}

Prenatal testing is of course separable from termination of affected fetuses. When it is considered separately, prenatal testing may be not only close to but at the right end of the spectrum of eugenics. Some women seek testing with no intention of terminating their pregnancies if the fetus is found to have an anomaly. They may request tests solely to identify a condition that is potentially and effectively treatable in utero, to determine a mode of delivery that is likely to optimize the outcome for the child, or simply to prepare themselves or other family members for the birth of an affected child. In such cases, the testing is either eugenically neutral or “good eugenics.”

When prenatal testing is undertaken to identify anomalies and terminate affected fetuses, it belongs closer to the left side of the spectrum. Two factors distinguish this from forced sterilization: the eugenic decision is made autonomously by the pregnant woman rather than by government imposition; and the life of the fetus, rather than the capacity for reproduction, is thereby ended. Governmental coercion puts sterilization closer to the far left, but direct killing of the fetus may be just as bad or worse if the fetus is imputed to have moral status. This brings us to the charge leveled by some people with disabilities against those who support prenatal testing and termination of affected fetuses. To them, these routine practices clearly constitute bad eugenics.

II. THE DISABILITY RIGHTS CRITIQUE OF PRENATAL TESTING AND SELECTIVE ABORTION

The link between genetics and advocacy for people with disabilities has precipitated “the disability rights” critique of prenatal testing and selective abortion, and “the expressivist argument” with
which the critique is associated. According to Erik Parens and Adrienne Asch, the critique involves three main claims. First, prenatal diagnosis undercuts recognition of the extent to which the meaning and impact of “disability” are socially constructed; second, it implies unwillingness of parents to accept an imperfect child; and third, it usually involves inadequate understanding of the disabilities it attempts to avoid.

Prenatal testing probably does undercut recognition that disabilities are largely socially constructed. Nonetheless, it is possible to support prenatal testing while reducing the disadvantaging impact of its social construction. Positive prenatal diagnosis generally leads to termination, but it is the termination rather than the diagnosis that is most problematic from a disability rights perspective. In fact, the diagnosis may be undertaken to facilitate interventions on behalf of the disabled or even to ensure that the intended child is affected with a specific disability. (I will ignore here the fact that some supposed “disabilities” are not viewed by people with those conditions as disabilities.)

The second claim, that prenatal testing implies parental unwillingness to accept an imperfect child is not necessarily true; rather, it implies the unwillingness of parents to accept a fetus with certain disabilities if this can be avoided through testing and termination or treatment. What is pivotal here, in part because imperfect newborns (and children) whose parents accept and love them are commonplace, is that the parents who terminate after positive diagnosis do not consider the fetus a child at all, whether perfect or imperfect. At most the fetus is a potential child, and the potential of having a child with disabilities is what is avoided. So long as the fetus is not morally comparable to a person who is disabled, testing and termination to ensure that ill-bornness is prevented may be morally equivalent to contraception for better spacing of offspring.

The third claim of the disability rights critique is that prenatal diagnosis usually involves inadequate understanding of the disabilities it attempts to avoid. This claim is true in most cases despite the efforts of genetic counselors to provide their clients with all of the information relevant to their decisions. It is hardly controversial that women or couples deserve to be maximally informed about the disabilities for which they may be tested. However, knowing more about

30. For a recent survey of different positions on the morality of abortion and arguments in support of them, see THE PROBLEM OF ABORTION (Susan Dwyer & Joel Feinberg eds., 3d ed. 1997).
32. Id.
33. Admittedly, requests to ensure disability in children are both legally and morally problematic.
a condition does not necessarily mean that a decision to terminate is less likely. For at least one condition, Down syndrome, the opposite seems to be the case. (I will return to this point later.)

The “expressivist argument” with which the disability rights critique is associated is stronger than the preceding claims. Simply put, the argument is that prenatal testing sends the message to people with disabilities that their lives are not worth living. As Asch observes: “a single trait stands in for the whole, the trait obliterates the whole” with “no need to find out about the rest.” However, support for a woman’s decision to terminate a fetus assumes the priority of her choice over the life of the fetus, regardless of whether it is disabled. It should be possible, therefore, to support a right to testing and termination without practicing the discrimination towards people with disabilities that apparently motivated the *Buck* decision.

Regardless of whether abortion is legal or moral, prenatal testing and selective abortion to avoid the birth of children who are disabled may exemplify bad eugenics. Although decisions to terminate an affected fetus are assumed to be made autonomously by individuals, the rationale for termination is to prevent the birth of a child whose trait, identified as undesirable, “stands in for the whole.” Occasionally, the rationale for the termination is the best interests of the potential child; in other words, it seems better for a particular fetus not to be born because its inevitable “ill-bornness” is so severe. Even with very severe anomalies, however, the predominant experience of the child is rarely, if ever, one of suffering unless he or she is not given adequate care after birth.

Provision of “adequate care after birth” is usually much more demanding and difficult for parents of children with disabilities than for other parents. Few have the resources, whether economic or psychosocial, to meet the challenge alone; yet society often seems to expect them to do so. A healthy woman who lacks the necessary resources for providing adequate care of a healthy infant may terminate her pregnancy solely on grounds of her inability to care or lack of social supports for doing so. While such decisions are morally problematic for various reasons, they do not constitute bad eugenics. If it is not bad eugenics for a woman to choose abortion because of her inability to care for a child who is not disabled, neither is it bad eugenics for her to choose abortion solely because she is unable to care for one who is disabled and no one else is willing or able to provide care.

34. Parens and Asch cite Allen E. Buchanan for developing the “expressivist argument” that they elaborate and critique. Parens & Asch, supra note 17, at 13-17 (citing Allen E. Buchanan, *Choosing Who Will be Disabled: Genetic Intervention and the Morality of Inclusion*, 13 SOC. PHIL. & POL’Y 18 (1996)).
35. *Id.* at 13.
36. *Id.*
Acknowledgment of one’s inability to care for another is not equivalent to rejection of another because of a condition or trait that renders the other unworthy of care. Accordingly, a criterion by which we may determine whether prenatal testing and termination of an affected fetus illustrates “bad eugenics” on the part of the woman who chooses these procedures is that the mere fact of the disability is not the pivotal reason for her choice. Other reasons may be adequate or inadequate in their own right but they do not constitute the bad eugenics of discrimination against the disabled, nor do they imply that life with disability is not worth living. Other possible reasons for testing and termination are the avoidance of health risks to the pregnant woman and her responsibilities for other children or adults.

If prenatal testing and termination are performed solely to avoid the birth of a child with a specific trait, the procedures are closer to the left end of the spectrum between bad and good eugenics. Down syndrome is a chromosomal anomaly associated with the level of retardation that the Buck court apparently wanted to avoid in future generations; it thus seems to illustrate this leftward leaning. Because Down syndrome is tested for so routinely in the prenatal setting, it merits careful scrutiny as a potentially acceptable substitute for “imbeciles” in the Buck case. Few people with Down syndrome are classifiable as “imbeciles.” Like the Bucks, they may be educated and live satisfying lives despite their mental limitations. When the justices formulated their ruling in the Holmes decision, they did not have the benefit of prenatal tests to determine whether the alleged retardation of Emma, Carrie, and Vivian Buck was hereditary; they apparently based their judgment on the (inaccurate) observation that the retardation had occurred in all three generations. Even if the Buck court had been correct about the alleged retardation and its hereditary character, it could not have definitively predicted its degree of impact on future generations. Today we can definitively diagnose Down syndrome and some other anomalies in utero; in many cases, however, we cannot definitively predict their impact on affected individuals or on society in general.

A. Prenatal Testing and Termination for Down Syndrome

Down syndrome, the most frequently identified cause of mental retardation, occurs in about one in 770 newborns. This incidence is lower than it was prior to the advent of prenatal testing and the

37. I developed the rationale for this criterion in ANITA SILVERS, DAVID WASSERMAN & MARY B. MAHOWALD, DISABILITY, DIFFERENCE, DISCRIMINATION: PERSPECTIVES ON JUSTICE IN BIOETHICS AND PUBLIC POLICY 236-39 (1998).
availability of selective abortion. However, because the lifespan of affected individuals has improved considerably during the past few decades, the actual number of people with Down syndrome in the general population has been increasing, just as it has with regard to other conditions associated with a shortened lifespan. Although referrals for prenatal testing may be based on general screening tests or positive family history, most referrals are based on maternal age of thirty-five years or more. The latter rationale stems from the fact that the risk of chromosomal anomalies increases with age, and thirty-five is the approximate age at which the risk of fetal loss or damage to the fetus through amniocentesis itself is about equal to the risk of having an affected fetus. The actual risk of Down syndrome in a woman who is thirty-five is one in 385; the risk of her having a fetus with other anomalies is one in 434, making her total risk of chromosomal anomaly one in 204. The fetal loss rate for mid-trimester amniocentesis is 1%, and for transcervical chorionic villus sampling is 0.5%-1% over the general population risk.

In comparison with the symptoms of other prenatally diagnosable anomalies, the common symptoms of Down syndrome are well known to most people. Most notable is mental retardation, found in all affected persons, but the degree of retardation, ranging from moderate to severe, is not predictable prenatally. Most people are also familiar with facial features associated with Down syndrome; they are less likely to be aware of medical problems that occur more frequently in

40. In the United States, for example, the median age at death of people with Down syndrome increased from twenty-five years in 1983 to forty-nine years in 1997. Quanhe Yang et al., Mortality Associated with Down's Syndrome in the USA from 1983 to 1997: A Population-based Study, LANCET, Mar. 23, 2002, at 1019.

41. Cystic fibrosis is another condition for which improvements in treatment have led to increased lifespan in affected individuals. Although the fertility rate of women with cystic fibrosis is less than that of their healthy counterparts, many who survive into their reproductive years have children. In contrast, men with Down syndrome or with cystic fibrosis are generally infertile, and very few cases of pregnancy in women with Down syndrome have been reported. Regarding fertility in people with cystic fibrosis, see Robert C. Stern, Cystic Fibrosis and the Reproductive Systems, in Cystic Fibrosis 381 (Pamela B. Davis ed., 1993). Regarding fertility in people with Down syndrome, see PAUL T. ROGERS & MARY COLEMAN, MEDICAL CARE IN DOWN SYNDROME: A PREVENTIVE MEDICINE APPROACH 196-98 (1992).

42. Verp, supra note 10, at 161-63.

43. Id.

44. Id.; see also Schemmer & Johnson, supra note 10, at 515-16.

45. Moreover, the majority of people with mental disabilities are only mildly retarded. According to Anita Silvers, citing Justice Thurgood Marshall in City of Cleburne v. Cleburne Living Center, 473 U.S. 432, 461-66 (1985) (Marshall, J., concurring in the judgment in part and dissenting in part), over 90% of people labeled with mental retardation would not have been considered disabled in other periods of history, and the capabilities of many in this group are more comparable to those of nonretarded people than to the capabilities of severely retarded individuals. E-mail from Anita Silvers, Professor of Philosophy, San Francisco State University, to author (May 10, 2002) (on file with author).
those affected (e.g., about 40% have congenital heart disease).\textsuperscript{46} Most of these medical problems are as treatable as they would be in other patients.

People with Down syndrome are described as having “warm, loving personalities and enjoy[ing] art and music.”\textsuperscript{47} Some parents claim they are easier to raise than their unaffected offspring.\textsuperscript{48} Because children with Down syndrome are apparently happy, preventing their birth can hardly be justified as a means of preventing suffering. A more honest rationale is prevention of the burden of their care to their family members or to society. While this rationale may also be morally problematic, it is not equivalent to a claim that their lives are not worth living. Consistent with the criterion I have suggested, so long as the reason for prenatal testing and termination is not the disability as such, testing and termination for Down syndrome does not belong on the left side of the eugenics spectrum.

While individuals are unable to care adequately for a child in some instances, the same is hardly true for society as a whole, at least in the developed world. Collectively, society has all the resources necessary to care adequately for all of its people: healthy newborns, those with disabilities, or anyone who needs care that is not available through parents or other family members. Accordingly, society in general does not have the justification that some pregnant women may have for testing and abortion of fetuses whose subsequent care may be impossible for them to provide. So why has prenatal testing and termination of affected fetuses, particularly those with Down syndrome, become so widely accepted by society? One reason is that fetuses do not count as persons under the law of the

\textsuperscript{46} Other potentially life-threatening disorders with a higher-than-normal incidence in people with Down syndrome are gastrointestinal disease and leukemia. Rogers & Coleman, supra note 41, at 78-81. One of the gastrointestinal disorders more prevalent in infants with Down syndrome than in other infants is esophageal atresia. In 1982, parents in Bloomington, Indiana refused consent for surgery to correct this life-threatening condition in their newborn with Down syndrome. Litigation regarding the refusal (which led to the infant’s death on the sixth day of life) provoked various efforts of the federal administration and Congress to mandate life-saving treatment in similar circumstances. For a summary of the case and related legislative efforts, see Mahowald, supra note 28, at 170-72, 181-82.

\textsuperscript{47} Lewis, supra note 39, at 210. That this description is rather stereotypical should be acknowledged. Gibson observes that people with Down syndrome are widely imputed to have traits that are contradictory; they are alleged, for example, to be “affable, mischievous, docile, aggressive, affectionate, stubborn, pleasing and self-willed.” David Gibson, Down’s Syndrome: The Psychology of Mongolism 111 (1978). Of course, individuals with Down syndrome vary considerably in their manifestation of these traits, and stereotypes are not necessarily applicable to all members of a class.

Although some fetuses are developmentally older and healthier than some premature infants, they do not have rights comparable to those of born individuals. As long as a clear line can be drawn at birth, decisions to terminate the developing organism prior to that time are separable from those made after birth, regardless of whether it is well-born or ill-born.

Another reason is that society, through its policy makers and those who influence public opinion, really does want to reduce the number of people who are mentally retarded in the general population; it may focus on Down syndrome because its presence is more easily recognizable than other conditions associated with mental retardation. In general, it wants to “improve the stock” and perhaps avoid the costs of care by eliminating or at least reducing the numbers of a particular group of people by encouraging testing in women and supporting the abortion of fetuses that test positive for Down syndrome. That this rationale has been effective seems clear from the fact that most women who are told that their fetus has this anomaly choose to terminate their pregnancies more quickly than when they are given other fetal diagnoses, some of which have more devastating medical consequences.

Broad acceptance of testing and termination for Down syndrome is thus triggered by a society that generally supports the termination of lives considered undesirable because of a specific trait, namely, mental retardation, and possibly because of the appearances that are characteristic of people with Down syndrome. Although decisions for prenatal testing and termination are usually thought to be autonomous, some individuals report that they feel pressured by physicians and others to undergo prenatal testing and encouraged to terminate when the result is positive. To the extent that this is so, prenatal testing and termination of affected fetuses cannot be considered

49. The legality of abortion assumes that fetuses do not have rights comparable to those of born individuals. See generally Roe v. Wade, 410 U.S. 113 (1973). However, damages and insurance payments are sometimes awarded to pregnant women on grounds that their fetuses are harmed or prevented from being born. See, e.g., Transamerica Ins. Co. v. Bellefonte Ins. Co., 490 F. Supp. 935 (1980).

50. According to Rapp, abortion after a prenatal diagnosis of Down syndrome is “almost automatic” because the women whose fetuses are affected are generally familiar with symptoms of the condition. RAPP, supra note 10, at 223-25. With other diagnoses, they tend to seek more information before making their decisions. Id.

51. Unlike genetic counselors, the obstetricians who routinely offer and provide prenatal diagnosis to women of “advanced maternal age” are trained to be directive rather than nondirective with patients. The goal of these physicians is to ensure that the woman and her potential child are both healthy; to many, accomplishing that goal may require testing and termination of an affected fetus. Given the usual power discrepancy between pregnant patient and physician, and the woman’s dependence on him or her for care, this attitude entails at least a subtle form of pressure to do what the physician wishes.
“good eugenics.”\textsuperscript{52} If the decisions are imposed by others, the principal difference between Nazi eugenics and prenatal testing and termination for a fetus with Down syndrome is that fetuses are not born persons. Obviously, this is an important distinction, but one that still places it with the \textit{Buck} court on the left side of the eugenics spectrum. In other words, with regard to routine testing and termination for this particular anomaly involving mental retardation, the decisions of individuals or couples are eugenically neutral, so long as conditions other than the disability itself form the rationale for the decision to terminate. Depending on the other reasons for the testing and termination, and assumptions about the moral status of the fetus, these decisions may be ethically justified.

Social attitudes and practices regarding prenatal testing for Down syndrome are another matter. I believe these illustrate bad eugenics for a number of reasons. Principal among these reasons is a deep seated ableism on the part of society’s leaders, who, having benefited by the abilities they currently enjoy, rarely recognize that these are mainly a matter of luck or fortune rather than deserved or earned. Even in a culture of political correctness, where attempts to ignore differences are manifest, this ableism prevails. Ironically, it is reinforced by ignoring differences and therefore doing nothing to correct the inequalities associated with them. This ethos of ableism no doubt influences individual women and couples to conform to its standard by avoiding the birth of a child who is disabled.

III. CONCLUSION

Recall the expressivist argument with which the disability rights critique is associated: prenatal testing sends the message to people with disabilities that their lives are not worth living. This argument is well-supported, I believe, in the encouragement pregnant women typically receive to undergo prenatal testing when they are thirty-five years or older. Some women report that they are more than encouraged; they are \textit{expected} to undergo prenatal testing because of the supposedly high risk of a chromosomal anomaly, especially Down syndrome.\textsuperscript{53} To a lesser degree women are expected and encouraged

\textsuperscript{52} Presumably, this is why the American Medical Association (AMA) warns against the “subtle or passive eugenics brought about through a combination of social pressures” to employ existing genetic reproductive technologies. Council on Ethical and Judicial Affairs, American Medical Association, \textit{Ethical Issues Related to Prenatal Genetic Testing}, 3 ARCHIVES FAM. MED. 633, 633-35 (1994). The AMA Council acknowledges that these technologies already provide the basis for decisions about the worth of individual lives, and that this “may constitute an extremely dilute but acceptable form of eugenic selection.” \textit{Id.}

\textsuperscript{53} During pregnancies in my late thirties, I experienced this expectation on the part of clinicians. Some authors affirm the importance of having this option. See, e.g., Mary Ann Baily, \textit{Why I Had Amniocentesis, in Prenatal Testing and Disability Rights}, supra note 10, at 64-71; RAPP, \textit{supra} note 10, at 3-5. However, whether prenatal testing is truly or
to terminate the pregnancy if the fetus is affected. In other words, the single trait of mental retardation and other traits associated with Down syndrome stand in for the whole of the potential person, and as Asch puts it, there is no need to find out about the rest of the person because “the trait obliterates the whole.” In the Holmes decision, the trait of mental retardation obliterated the right of three people to become parents. In prenatal testing and termination for Down syndrome, the trait of mental retardation obliterates the person that the fetus may become. In this narrow context, then, I propose a substitute for Holmes’s infamous statement, one that I consider not only legally supportable but morally demanded: Three generations of people with mental retardation are not enough.

Fully an option depends on the parties involved, the quality of the relationship between the woman and her physician, the adequacy and accuracy of the information provided, and on the availability of social and economic supports for continuing or discontinuing an affected pregnancy. That younger women may also be influenced by the expectation of clinicians that they undergo prenatal screening is clear from a survey of pregnant women in South Wales. Layla N. Al-Jader et al., Survey of Attitudes of Pregnant Women Towards Down Syndrome Screening, PRENATAL DIAGNOSIS, Jan. 2000, at 20, 23-29. All of the women were less than 35 years of age. Id. About half were not well informed about the tests, and the majority were unaware that they were voluntary. Id. The few (5 out of 101) who refused screening tended to be better educated and of higher social class. Id.

54. The anticipated cost of raising a child who is mentally retarded, and lack of social supports for doing so, constitute a kind of “passive eugenics,” especially for women or couples whose financial situations are already in jeopardy. Bowman uses the term “passive eugenics” to apply to the denial of appropriate medical care to the poor. James E. Bowman, The Road to Eugenics, 3 U. CHI. L. SCH. ROUND TABLE 491, 493 (1997). He imputes an inevitable connection between active and passive eugenics: “[A] society that countenances passive eugenics,” he writes, “provides fertile ground for both clandestine and overt active eugenics.” Id.

55. Parens & Asch, supra note 17, at 13.
I. INTRODUCTION

Genetic health is a confusing but increasingly important cultural construct. A little over a decade ago, I delineated the difference between a social or relational definition of health, which is embedded in any given society’s basic beliefs about the nature of illness and death, and a biological conception of health and illness as the absence of disease. The growing prevalence of genetic explanations for disease means our contemporary concept of biological health includes the idea of an individual’s risk of disease or even death. A genetic definition of health thus incorporates the idea of the absence of the risk of illness processes, not necessarily in ourselves, but in those to whom we are genetically related. The goal of “genetic medicine”—if we start to use that term—would be to reduce or eliminate the genetic risks to health. Ironically, genetic health is the ultimate notion of a relational concept of health because the risk of disease or ill health is not individual, but social. Thus, the concept of genetic health—or in its negative form, “genetic disease or defect”—always involves a social unit: the family, a couple contemplating having children, an individual planning single parenthood, or an ethnic or geographically de-
fined group. Let me illustrate this point with a bit of personal history.

A. A Narrative

When my youngest son, Reid, was in utero in 1982, his mother’s physician informed us that the routine blood tests he had ordered indicated an antibody reaction that was troublesome. After consulting with several specialists, we had a diagnosis—a genetic incompatibility between Reid’s blood and his mother’s blood that created risks of stillbirth or elevated bilirubin\(^3\) at birth. After he was born he became jaundiced and blood tests indicated high levels of bilirubin with risks of mental retardation, physical impairments, or death.\(^4\) After a complete blood transfusion and ten days in the special care nursery, he was able to come home.

Reid’s condition at birth—“little C/big C incompatibility on the RH factor”—is extremely rare. Even twenty years ago, health care practitioners knew that the more familiar RH factor was really a matter of three different genes.\(^5\) The hemoglobin shot usually given to mothers with the RH factor did not deal with the C gene problem.\(^6\) Reid’s pediatrician advised us that bilirubin problems tended to get worse with each subsequent pregnancy. He hypothesized that the mild jaundice we saw in our first child, Barry, might have been caused by the same incompatibility. Since Reid was our third child, he advised us to consider the consequences of having more children.

Fortunately, there were no disability issues to confront with Reid due to the genetic mismatch between his mother and myself. Reid is a healthy 20-year-old college junior. At some point I will have to talk to Reid and his two older brothers about the genetic risks that they may have inherited from their biological parents. At the very least, they and any prospective mates are entitled to know what I discovered in 1982, and any new knowledge that might be available in the

\(^3\) “[A] reddish bile pigment . . . resulting from the degradation of heme . . . in the liver; a high level in the blood produces the yellow skin symptomatic of jaundice.” RANDOM HOUSE WEBSTER’S UNABRIDGED DICTIONARY 207 (2d ed. 1999).


\(^6\) Id.
Human Genome Era\(^7\) about the risks of stillbirth, disability, or death in their progeny. I live with the implications of notions of “genetic health” for me and my three sons. As genetic knowledge grows, the number of families coping with genetic risks and emerging notions of genetic health will increase.\(^8\) To put the point another way, genetic health makes us think of illness, disease, and death in terms of reproductive partners, who our parents were, and our memberships in various ethnic, social, or even geographical groups.\(^9\)

**B. The Genetic Health of the Society: Eugenics**

The ethical and legal risks of using a concept of genetic health in social decisions is captured by the term “eugenics,” the idea that certain individuals are genetically too risky for the society to tolerate. Eugenics has bad—even “evil”—social connotations. No respectable scientist today would endorse eugenics. The mainstream mantra of the Human Genome Era, however, is that there is really only one “race” of any biological significance, the “human race.”\(^10\) Although the study of ethical, social, and legal aspects of genetic advancement was made a part of the Human Genome Project\(^11\)—scientists seem to be saying, “Let us get on with the job of helping health care professionals develop new ways of managing disease processes. Health care professionals can be trusted to implement these new genetic treatment modalities in accordance with prevailing legal doctrines and ethical standards respecting individual autonomy.” Our culture, however, has a long history of eugenic practices and genocides that were not recognized by cultural, social, and legal institutions as such until long after the practices have taken place.\(^12\)

To take the most infamous of these practices, the Nazi experiments on concentration camp inmates were not the work of a few

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7. Defined as “[a] period in which biomedical research will be dominated by the assumption that genetic knowledge will improve health care delivery and presumably overall health status—not only in this country, but throughout the world.” Larry I. Palmer, *Disease Management and Liability in the Human Genome Era*, 47 VILL. L. REV. 1, 2 (2002).


physicians and scientists gone awry. Social, historical, and legal contexts certainly played a role in the ability of the scientists to carry out their atrocities, as recent—albeit controversial—scholarship on the Holocaust demonstrates. But the cultural antecedents of the Nazi Doctors have their roots in our collective experience of Doctor Frankenstein as an icon of evil rather than simply a nineteenth-century novel by an 18-year-old woman. But as Daniel Kevles, a historian of science, and Paul Lombardo, a bioethicist and lawyer, have pointed out to legal and non-legal audiences, respected scientists in this country, not just scientists in Nazi Germany, endorsed governmental policies to eliminate certain groups of individuals on the hypothesis that they were “genetically” and socially too risky.

Justice Holmes—a powerful intellectual influence on legal realists—gave constitutional blessings to some of these governmental policies in his famous, but scientifically inaccurate, retort in *Buck v. Bell*: “Three generations of imbeciles are enough.” *Buck v. Bell* is cited primarily to question its standing as “good law” by legal scholars, but our awareness of social misdeeds in the name of the genetic and biological social defense, or the pursuit of scientific knowledge,


17. 274 U.S. 200, 207 (1927).

encourages legal actors to establish certain events as “precedents” that law should prevent from recurring. Thus, “eugenic precedents” are cases that legal decision makers should avoid. The Nazi Doctors Case and the Tuskegee Syphilis Experiment on the Negro Male are often cited in the bioethics literature as prototypical cases of eugenic precedents that should be used as the backdrop for judicial decision-making.19

C. A Recent Case: A Voice of Caution

The highly celebrated case of Grimes v. Kennedy Krieger Institute, Inc.,20 indicates that bioethics scholarship is starting to influence courts. The judges in this case used the Nuremberg Judgment in the Nazi Doctors Case (the origins of the Nuremberg Code) and the Tuskegee Syphilis Experiment to support their holding that a biomedical research institution, internationally known for its research and care of children with a variety of disabilities,21 could be held liable for flawed informed consent processes in a lead abatement study involving children.22 There is thus a growing confidence on the part of bioethicists that vigorous enforcement of informed consent by judges, supposedly established in these eugenic precedents, will help us achieve the appropriate risk-benefit ratio as genetic health23 is used as a guideline for disease management and research.

Although I agree with the Court’s result in Grimes, I seek to provide a voice of caution against embracing the Grimes court’s approach during our Human Genome Era. That voice of caution comes partially from my understanding of how the institutional arrangements of a given society can influence ordinary people—those who reflect the society’s basic and almost unspoken premises about the nature of evil—to react or fail to react to the genocides of their time.24 We should recall, for instance, that many “ordinary people” knew

21. The Kennedy Krieger Institute’s (KKI) stated goal is the training of practicing professionals and the discovery of new treatments and prevention of developmental disabilities in children. It was originally founded to treat cerebral palsy as the Children’s Rehabilitation Center in 1937. KKI has expanded to assist parents and legal guardians who care for children with disabilities and to conduct research on various disabilities as well as maintaining a seventy-bed pediatric hospital. KKI enlists professors of Johns Hopkins University from a variety of fields including medicine (mainly the field of pediatric neurology), psychology, education, physical and occupational therapy, audiology, speech and language therapy, as well as social work, child development, nutrition, and nursing. See The Kennedy Krieger Institute: A Comprehensive Resource for Children with Disabilities, http://www.kennedykrieger.org (last visited Aug. 25, 2002) (on file with author).
22. See Grimes, 782 A.2d at 813.
23. See GEORGE J. ANNAS ET AL., INFORMED CONSENT TO HUMAN EXPERIMENTATION: THE SUBJECT’S DILEMMA 49 (1977); Annas, supra note 19, at 24-25.
24. See GOLDHAGEN, supra note 13, at 375-79.
about the Tuskegee Syphilis Study, but did nothing until 1972. My caution also comes from my view of the limits of law in imposing a certain ethical vision on the institutions of science and medicine.25

These so-called eugenic precedents do, however, contain important institutional lessons—but not precedents in a technical sense—or helpful guidelines for the type of decisions institutions and individuals must face in the Human Genome Era. Genetic knowledge and its use and misuse are not likely to arise as they did in the clearly horrific examples of the past. More likely, use and abuse issues will arise in the increasingly common situations in which individuals encounter scientists and healthcare professionals on the fuzzy boundary between the search for new knowledge and traditional notions of disease management as a mere cure for disease. I use the term disease management, however, to describe the range of activities that modern health care professionals perform: research, treatment of diseases, management of chronic illnesses or conditions, and even palliative care for terminally ill patients.26

The eugenic precedents provide guidance for ethical reasoning about the modern disease management process, but the social values underlying ethical reasoning cannot readily be translated into judicial analysis because of the institutional arrangements of law, medicine, and science. As I have stated elsewhere, a comparative institutional analysis of the “eugenics problem” requires some difficult political and social tradeoffs that neither legislatures nor courts have heretofore been able to make upon behalf of society.27

I will argue that our focus should be on how genetic knowledge shapes disease management and on how courts, using liability doctrines, should respond to the risks and benefits of emerging notions of genetic health. My approach is essentially incremental, suggesting that law may not be the primary factor in preventing the horrors of past eugenic practices from recurring. On the other hand, my approach should help illuminate some issues that a variety of social institutions, such as families, must face and resolve as notions of genetic health start to dominate public and private discourse. The ge-


26. Traditional approaches to liability have separated attempts to distinguish between liability for mishaps in attempts to cure and liability for accidents in clinical research. While there are important doctrinal distinctions having to do with differences between negligence and “strict liability,” I propose to use the more inclusive term of disease management to determine the purposes and contours of a generalized theory of liability. See Palmer, supra note 7, at 3-4. I am thus assuming that a major cultural event such as the incorporation of genetic explanations into everyday explanations of illness, disease, and death, will eventually force a rethinking of legal doctrine.

netic health cases—wrongful birth or wrongful life—are currently separated in literary and judicial reasoning from the “eugenic precedents” that are relevant to the underlying ethical reasoning, if not the precise legal holdings of the cases emerging in the Human Genome Era. The way to link the ethical reasoning of the eugenic precedents and the genetic health cases is through a theory of liability for modern disease management. Thus, this Article provides an outline of an ongoing project to propose a theory of liability in medical management for the Human Genome Era.\footnote{Other aspects of this project are discussed in my recent piece, Palmer, supra note 7, at 13-33, and Larry I. Palmer, Medical Liability for Pharmacogenomics, in PHARMACOGENOMICS: SOCIAL, ETHICAL, AND CLINICAL DIMENSIONS (Mark A. Rothstein ed., forthcoming 2003).}

My argument has four parts. Part I reinterprets the lead abatement study case as a social, if not strictly a biological, genetic case. A public health perspective on the liability issues involved in \textit{Grimes}\footnote{See Larry I. Palmer, Patient Safety, Risk Reduction, and the Law, 36 Hous. L. Rev. 1609, 1635 (1999).} provides a means of arriving at the court’s holding without invoking the eugenic precedents of the Nazi Doctors or Tuskegee. Part II provides an institutionalist analysis of liability cases when parents seek to impose liability on physicians for failure to warn them of the risk of disability from an inherited condition in their offspring. I will thus seek to answer the question: Is there a standard of care for genetic health? Part III suggests using the Tuskegee Study and the Nazi Doctors Case as sources of institutional lessons rather than as legal precedents. The most important lesson derived from this analysis is that political action—an apology for the Tuskegee Study by the President of the United States\footnote{See President William J. Clinton, Remarks by the President in Apology for Study Done in Tuskegee (Mar. 16, 1997), at http://clinton4.nara.gov.textonly/New/Remarks/Fri/19970516-898htmt (last visited Jul. 26, 2002) (on file with author).}—institutionalized the notion that the ethics of scientific research aimed at better disease management will be judged in hindsight.\footnote{See Palmer, supra note 7, at 25; Jeffrey J. Rachlinski, A Positive Psychological Theory of Judging in Hindsight, 65 U. Chi. L. Rev. 571, 576 (1998).} Part IV argues that the informed consent doctrine in liability cases needs to be reformulated in terms of disclosure rather than in terms of promoting individual autonomy in the Human Genome Era. A recent case illustrates the view that judges should start using liability doctrines to provide incentives for physicians, scientists and their related organizations to share genetic knowledge with consumers, patients, and their representatives. In effect, I will propose a theory of liability for dealing with disease management not simply as physicians treating patients, but in terms of research to improve overall health of defined groups,
i.e., from the perspective of public health.32

Ironically, in the end, it will be genetically, socially, or ethnically identified groups of individuals who will have the greatest stake in minimizing the risks and optimizing the benefits of genetic knowledge. As notions of genetic health emerge, it is the small genetic difference among individuals that might affect health status, which is of interest to both scientists and to each of us as citizens.33

D. Public Health, Groups, and Genetic Health

Grimes v. Kennedy Kreiger Institute, Inc.,34 held that public health research could lead to liability of research institutions for failure in the consent process or in its selection of research subjects. Describing the context—the surrounding “facts”—of this ruling of potential liability depends upon one’s frame of reference.35 Since I will argue that Grimes is about genetic health in at least the popular, if not the scientific, sense I will first present the facts and the policy debate about modern research from the narrowest of legal perspectives—what the appellate court believed the “facts” were from the sparse record.

In the two cases involved in the Grimes appeal, parents of minors who had agreed to participate in a study of lead abatement in Baltimore filed an action for negligence against the research institute conducting the study.36 The plaintiffs claimed the research organization breached its duty of care when it failed to promptly inform them of the elevated level of lead in the minor’s blood sample and thus of the risk of lead poisoning from the environment in which the plaintiffs lived. The plaintiffs also alleged that the defendants had a duty to warn them of the risks of lead poisoning when the defendants’ tests indicated the presence of elevated levels of lead dust in their respective residences. In both of the cases, lower courts ruled that the research organization was entitled to summary judgment.37


33. See Palmer, Medical Liability for Pharmacogenomics, supra note 28, at 199.

34. 782 A.2d 807 (2000).


36. Appellant Ericka Grimes and her mother resided in a dwelling that researchers claimed had already been completely abated. See Grimes, 782 A.2d at 824-26. Appellant Myron Higgins and his mother resided in a dwelling deemed to require Level III ($6000-$7000) abatement, but received only Level II abatement ($3500). See id. at 828.

37. The research organization filed a third party complaint against the owners of the property. The plaintiffs first sought to add the owners of the property as defendants in an
The nature of both the written form—used to obtain the parents’ consent—and the research were important to the court’s holding. The study was sponsored by a grant from the Environmental Protection Agency (EPA). Its purpose was to determine if measures short of full “lead abatement” were as effective in reducing the risks to children as full-fledged lead abatement. To achieve a differential level of lead abatement in various groups of dwellings, the state of Maryland provided loans to property owners. The investigators recruited families with at least one child to live in these various dwellings and obtained the parents’ consent to participate in the study over a two-year period. Kennedy Krieger’s written consent form informed the parents of the purposes of the study, promised free blood tests for the children, and provided periodic inspections of their premises.

The majority of the court treated the case as one of first impression, but eventually held that summary judgment was improperly granted. Thus, a determination of the facts necessary to support an ultimate holding that the research institution is liable would await a trial. Furthermore, in response to a motion for reconsideration, the court clarified its holding regarding the legal inability of parents to consent to “non-therapeutic” research involving their children.

However, it was what the court said in arriving at its holding that is important to genetic health scholarship. The court’s use of the Tuskegee Syphilis Study and the Nazi Doctors Case to bolster its wide, sweeping opinion has placed an ethical question mark on public health research involving disadvantaged or low-income urban dwellers, most of whom are members of minority groups. So while

amendment to their complaint, but later dismissed the actions against the owners. Id. at 826, 829.

38. Id. at 822.

39. While the consent form indicated that the blood tests were not to replace the “regular medical care your family obtains,” id. at 824, this fact does not affect the broad theory of liability for which I will argue (see discussion infra Part IV). Some might argue that the lack of a physician-patient relationship means there is “no duty,” but this reflects a narrow view of the duty and does not incorporate the various ways in which liability doctrine operates.

40. Grimes, 782 A.2d at 824.

41. Id. at 858.

42. The case is still awaiting trial.

43. The court claimed that its use of the words “any risk” meant “any articulable risk beyond the minimal kind of risk that is inherent in any endeavor.” Id. at 862. The majority’s implication that parents could not consent to putting their children at risk has caused a great deal of concern among members of the research community. I do not directly address those concerns in this Article.

44. It is worth noting that Johns Hopkins felt compelled to defend Kennedy Krieger. See Kennedy Krieger Institute Lead-Based Paint Study, http://www.hopkinsmedicine.org/leadpaint.html (last visited Aug. 5, 2002) (on file with author). It is interesting to note that in the amicus brief that Johns Hopkins signed, it highlighted its role in dealing with minority health issues. For example, in regard to sickle cell anemia it stated that: “Johns Hopkins Medical School faculty are engaged in important research to find a cure or treat-
in a technical sense minority groups—particularly those defined as such by their race—are not a genetic group, historically and currently race is constructed biologically.\footnote{Rothstein & Epps, supra note 9, at 229.} Since the court’s result in \textit{Grimes} could have been arrived at on a much narrower ground,\footnote{The concurring opinion by Justice Raker stated that summary judgment was improperly granted because sufficient facts supported appellants’ contention that a special relationship existed between the parties. \textit{Grimes}, 782 A.2d at 859. This special relationship gave rise to a duty of care that if breached would constitute negligence. \textit{Id.} Thus, there was no need to broach the issue of contract. \textit{Id.} at 859-61.} one might wonder if the majority’s invocation of eugenic precedents was driven by an underlying fear of racial neglect that leads to institutional neglect and eventually the notion of genocide.

Consider the various ways \textit{Grimes} could be viewed as one considers facts not cited in the record before the appellate court. At one level, \textit{Grimes} is about environmental health, not genetic health. But if we go back and examine the social and economic justification for the study, we can see that the research community, judging from their briefs,\footnote{See Brief, supra note 44, at 10.} saw a “public health crisis” in the city of Baltimore. They suggested that the poor and disadvantaged were faced with the dilemma of living in “unhealthy housing” or no housing, at least in the city of Baltimore.

This is not the first time that a disease metaphor was used to justify certain government housing policies such as urban renewal.\footnote{Berman v. Parker, 348 U.S. 26, 34 (1954). In upholding the constitutionality of legislation authorizing the taking of non-dilapidated housing as part of redevelopment or “renewal” of inner city “slums,” Justice Douglas also rejected a commercial owner’s claim that his otherwise safe and “healthy” property could not be publicly condemned and turned over to a private developer. For a discussion of the importance of metaphor in legal writing, see Larry I. Palmer, \textit{Writing Law}, in \textit{Writing and Revising the Disciplines} 113, 122-124 (Jonathan Monroe ed., 2002). I am indebted to the late Donald A. Schön for bringing this issue to my attention. \textit{See} Donald A. Schön, \textit{Cornell: Marrying Science, Technology, Artistry, the Humanities, and Professional Practice, Keynote Address at the Cornell Conference on Professionalism, Vocationalism & Liberal Education} 4 (Apr. 9, 1988) (transcript and audio cassettes available in the Cornell University Library).} Justice Douglas’s opinion, written in 1954, illustrates how deeply science and medicine have since shaped our public discourse:

\begin{quote}

The experts concluded that if the community were to be healthy, if it were not to revert again to a blighted or slum area, as though possessed of a \textit{congenital disease}, the area must be planned as a whole. It was not enough, they believed, to remove existing buildings that were insanitary [sic] or unsightly.\footnote{\textit{Parker}, 348 U.S. at 34 (emphasis added).}
\end{quote}
There are many reasons today to question the effectiveness of urban renewal as a housing policy for inner city areas, but Justice Douglas’s enthusiasm for “technical rationality” as a guide for evaluating legislative determinations continued for many years. Twenty years later, in Village of Belle Terre v. Booras, Douglas relied upon his urban renewal decision to uphold a definition of “family” in a local zoning ordinance that prevented unrelated individuals from living in a village on Long Island. As Justice Marshall’s dissenting opinion pointed out, the effect of Douglas’s Belle Terre opinion is to allow the local government to use traditional definitions of family in zoning ordinances that have adverse effects on various individuals or groups.

Today, equally well-meaning researchers see the risks of lead poisoning to disadvantaged children as minimal compared to what the researchers see as the children’s alternatives. There is in fact no forum in which the policy framework can be challenged, particularly by these modern-day urban dwellers, since the policy framework for lead abatement has been institutionalized in law and in real life such that lead is no longer used in new housing construction. But when middle and upper-middle class families move into older city neighborhoods, does their “renovation” or “gentrification” of these older homes involve complete lead abatement? How can we know?

So Grimes is a “genetic case” in a social sense, but with a twist on what risks certain groups ought to bear. To reduce the biological risks of the environment, some individuals must be put at risk, however slight, in order to gain the knowledge necessary to make the environment “healthy.” Those at risk—economically disadvantaged children in inner cities—are positioned as the beneficiaries, not necessarily as individuals but as a group, from the increase in scientific knowledge.

Researchers who are motivated by a sense of morality that focuses on the good of random and unidentified individuals—the future

50. Donald Schö


52. Id. at 9.

53. Id. at 12-20.


55. See Chapman v. Silber, 760 N.E.2d 329 (N.Y. 2001) (holding that landlords in New York State are required to remove lead paint if they know of its existence; thus, it is implicit that lead paint cannot be used in New York State).
good—as opposed to traditional professional health care ethics that focus on the good of the patient, find it easy to do the cost-benefit balance for research subjects. The public good, and in this case, public health, becomes the objective. Researchers have very little incentive to consider if those outside of science and its affiliated institutions, such as modern research universities, perceive science as aiming for the betterment of the common good. Although perhaps politically infeasible at the moment, one might wonder if a better social strategy might involve dispersing low-income residents throughout metropolitan areas. It is also possible that the long-term consequences of the partial lead abatement program is first abandonment of older dwellings, but then rebuilding or remodeling of properties into housing that only higher income individuals can afford. Or put another way, from the record before it, the appellate court perhaps assumed that the researchers established a framework for improving the housing conditions of those at risk for lead poisoning from their dwellings without the active participation of those groups in formulating research policy.

Viewed thus, we can understand the moral outrage of the Grimes majority that led them to yield to the temptation to invoke common

56. See Robert S. Morison, Bioethics after Two Decades, HASTINGS CENTER REP., Apr. 1981, at 8, 9-10 (arguing that in the future ethics will face an increasing number of unforeseen possibilities due to advances in science, thereby forcing society to grapple with fundamental ethical questions in a new way).

57. For a recent attempt to place professions in the context of the growth of the modern research university, see generally WILLIAM F. MAY, BELEAGUERED RULERS: THE PUBLIC OBLIGATION OF THE PROFESSIONAL (2001).

58. Cf. Spallone v. United States, 493 U.S. 265 (1990) (involving an attempt by the U.S. Justice Department to force the City of Yonkers to change its public housing policy as a means of desegregating the public schools). Framing the “homelessness” policy might also be a similar problem of social policy in urban areas that might have a “health component.” See SCHÖN & REIN, supra note 35, at 141-45.


60. There is perhaps a growing awareness of the need to “democratize” research through community participation. See DAVYDD J. GREENWOOD, INTRODUCTION TO ACTION RESEARCH: SOCIAL RESEARCH FOR SOCIAL CHANGE 175-78 (1998). Even the federal government is calling for “Community-based Participatory Research.” In a recent request for proposals to establish multidisciplinary centers to study health disparities, the funding agencies required that each center have at least one project that develops, evaluates, or implements one such participatory action research project. See Centers for Population Health & Health Disparities, NIH, RFA: ES-02-009 (April 1, 2002), at http://grants2.nih.gov/grants/guide/rfa-files/RFA-ES-02-009.html (last visited Aug. 13, 2002) (on file with author). At least one of the researchers involved with the lead paint reductions study in Grimes v. Kennedy Krieger Institute, Inc., Farfel, appears to be involved as a technical consultant to a community based group. See COMMUNITY ENVIRONMENTAL HEALTH RESOURCE CENTER, TECHNICAL CONSULTANTS AND ADVISORS, http://www.aeclp.org/consultants.html (last visited Aug. 26, 2002) (on file with author). Whether his involvement constitutes the kind of “participatory action research” as defined by Greenwood, however, cannot be determined.
law reasoning to relate its cases to Tuskegee and the Nazi Doctors. The *Grimes* court, however, forgot two significant differences between the cases before it and these eugenic precedents. First, as I have noted before,61 the eugenic precedents are “negative precedents” in the sense these “cases” represent policies the court, along with most members of society, are trying to avoid, not follow. Normally, when the courts claim to be using precedent, it is with the idea of furthering some fundamental policy or maintaining some appropriate balance the court has achieved. Second, whatever the holdings of these infamous cases, neither of them directly involve issues of civil liability and are not necessarily relevant to the *Grimes* court’s task of developing a theory of liability at the frontiers of science, medicine, and law.62

The *Grimes* majority should have asked the larger question regarding liability theory in relation to science and medicine: Under what circumstances should courts empower individuals to exercise social control over professionals and their organizations?63 The narrower issue raised by the lower court’s granting of summary judgment is whether the plaintiffs as a group should be granted access to courts, not whether in fact the plaintiffs can convince a judge and jury of the validity of their liability theory under the facts as alleged. The former is in fact an institutional question,64 of particular importance when there are few reported cases involving liability for research miscues.65 Rather than write about the eugenic precedents in relation to delineating the liability risks in research, the *Grimes* court should have used the cases as an opportunity to upgrade liability theory in several important respects.66

First, the court should have been explicit about the structure of research that gives rise to liability by allowing its readers to see its underlying assumptions about how researchers, physicians, and research organizations ought to relate to each other in a normative sense. The court does not say much about the principal investigators

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61. See supra pp. 4-5.

62. I borrow the phrase “frontiers” from LAW, SCIENCE, AND MEDICINE 687 (Judith Areen et al. eds., 1996).

63. Id. at 235-312.

64. Such a question frames social issues in terms of institutions such as “family formation rather than in terms of a particular social goal, such as procreative liberty.” Larry I. Palmer, *Life, Death, and Public Policy*, 81 CORNELL L. REV. 161, 178 (1995) (book review).


66. There is no reason to believe that the *Grimes* court was liberal in its interpretation of the scope of the so-called “informed consent doctrine.” See *Wright* v. Johns Hopkins Health Care Sys. Corp., 728 A.2d 166, 179 (Md. 1999) (discussing the Maryland Court of Appeals decision which held that physicians are not liable to the estate of an AIDS patient who was resuscitated despite a living will, which expressly stated a desire not to be resuscitated). For a discussion of the case see Palmer, supra note 7, at 18 n.86.
since they were apparently not named as defendants, but their backgrounds and professional affiliations are illustrative of how the modern biomedical research enterprise must operate. Both of the lead researchers held academic positions at Johns Hopkins, one in the school of medicine and the other in the school of public health. 67 Both also held important positions at Kennedy Krieger, but the court does not explain why this multi-layered set of relationships might be relevant to a particular theory of liability.

One possible theory of liability is that only physicians have a duty to warn individuals of the risks discovered through diagnostic interventions such as blood tests. The Grimes court rejects this theory and the implicit idea that lack of informed consent liability is based on contract rather than liability theories, 68 but fails to tell us why. I believe that the court is assuming that the researchers have an obligation to have access to physicians whenever they know there are physical risks to the subjects. The court need not assume that the researchers have an obligation, in fact, to provide subjects with access to health care professionals. 69 As a result, at the very least, the Grimes court requires researchers to inform subjects of any increased physical risks the researchers discover and advise the subjects to seek immediate professional health care.

Second, the court should have been more explicit about why it is appropriate to link public health researchers to physicians in its theory of liability. More generally, medicine and related professions such as public health, nursing, dentistry and pharmacy, are distinguished from other professions by their ethical and legal authority to routinely intrude into the human body or obtain information about the

67. Although the Grimes opinion cites Dr. Mark Farfel as the researcher in charge, 782 A.2d at 813, the Baltimore Sun op-ed piece cites the late Dr. Julian J. Chisholm and Dr. Mark Farfel as the researchers. See Don Ryan, Researcher on Lead Hazards is Solution, Not Problem, BALT. SUN, Aug. 28, 2001, at 19A. The late Chisholm was a founder of the Kennedy Krieger Institute’s Lead Clinic and then Professor of Medicine at Johns Hopkins University School of Medicine. See Jim Haner et al., Pioneer in Lead Study, Julian Chisholm, dies: Kennedy Krieger researcher treated poisoned children, BALT. SUN, June 22, 2001, at 1A. Dr. Mark Farfel is Director, Lead Hazard Abatement Research Department at Kennedy Krieger, see Kennedy Krieger Institute: A Comprehensive Resource for Children with Disabilities, http://www.kennedykrieger.org (last visited Aug. 25, 2002) (on file with author), and Associate Professor, Department of Health Policy and Management at the School of Public Health at Johns Hopkins University, see Johns Hopkins Bloomberg School of Public Health, http://www.jhsph.edu (last visited Aug. 5, 2002) (on file with author).

68. See Peter H. Schuck, Rethinking Informed Consent, 103 YALE L.J. 899, 956-57 (1994) (discussing different manifestations of informed consent doctrine and advocating contractual view of medical liability).

69. The language in the consent form which states that the study is intended only “to monitor the effects of the repairs and is not intended to replace the [family’s] regular medical care,” Grimes, 782 A.2d at 824, is not problematic under my analysis. In theory, allowing for independent medical care protects the interests of subjects as well as investigators, although social, economic, and geographical factors may limit the access of the Grimes subjects.
functioning or malfunctioning of the human body. Although the investigators were not named in the lawsuit, the court assumes that health care professionals are linked in some way, probably through a variety of organizational and, ultimately, economic relationships that are so sufficiently institutionalized that they need not be discussed. For instance, Johns Hopkins’ Institutional Review Board oversaw the research protocol in Grimes even though the Krieger Institute is a legally distinct entity. Despite the legal form of the various not-for-profits involved in some way with the research, the Grimes court viewed the professionals in these various organizations as connected by their professional ethos. Although perhaps holding different types of licenses or educational credentials, health care professionals are viewed as united through their commitment to “technical rationality” in defining and solving problems, especially when it comes to research.

Third, and perhaps most important, the Grimes court shifts the focus from the liability of individual researchers to the liability of the organization. Traditionally, liability theory in health care is centered in the special standard of care established for physicians in negligence law—malpractice. With the idea that most physicians and surgeons in this country are legally independent contractors, liabil-

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70. There is, of course, no easy way to explain why some individuals who routinely touch and intrude upon the human body—hair stylists, for instance—are licensed, but not thought of as “health care professionals.” For the purposes of my discussion in this Article, it is sufficient to point out that those whom we think of as “health care professionals” are judged by the standard of negligence, even when they use products that injure clients, whereas hair stylists are strictly liable for the products they use on their clients’ bodies. Newmark v. Gimbel’s, Inc., 258 A.2d 697 (1969) (holding that a beauty parlor operator could be held strictly liable for injuries caused by the use of a product to give the “customer” a permanent wave, even though a dentist was only liable in negligence for using a needle with a latent defect).

71. Kennedy Krieger Institute, Inc. is the only defendant named in the opinion. Grimes, 782 A.2d at 813-14.


73. The nature of professionalism or even health care professionalism is a matter of considerable debate. The traditional notion of professions as “self-regulating” is being challenged on a number of fronts, including health care. See, e.g., E.J. Emanuel & L.L. Emanuel, What is Accountability in Health Care?, 124 ANN. INTERNAL MED. 229, 229-39 (1996); L.L. Emanuel, A Professional Response to Demands for Accountability: Practical Recommendations Regarding Ethical Aspects of Patient Care, 124 ANN. INTERNAL MED. 240, 242-43 (1996).

74. See definition of technical rationality, supra note 50.

75. For the classic statement on the standard, see Allan H. McCoid, The Care Required of Medical Practitioners, 12 VAND. L. REV. 549, 558 (1959).

76. There are economic and social forces encouraging physicians to become “employees” or even beholden to third party networks or health plans, but the idea of physicians as independent contractors is deeply embedded in liability doctrine, at least in the United States. See, e.g., Sword v. NKC Hospitals, Inc., 714 N.E.2d 142 (Ind. 1999) (struggling with
ity of hospitals for the mistakes of physicians has been rare until fairly recently. 77 But the Grimes court allows a suit against the research organization without explicitly stating that research is governed by principles of what has been referred to as “enterprise liability.” 78 The principal investigators in Grimes may turn out to be employees of the Institute as the facts are later developed, making the case for vicarious liability clear. But there are some general features about modern research that the Grimes court does not explain that make enterprise liability the norm for research, even if individual researchers remain liable in some situations.

Under federal regulations, the entity receiving federal research funds is responsible for the overall conduct of the research. 79 It is the research organization that is ultimately accountable for the research to the federal government. In the current regulatory scheme, the institution is supposed to supervise the investigator, who in reality does the actual study or experiment; the institution provides oversight for the consent process through its Institutional Review Board. More explicitly, the investigator has an ethical obligation to protect the subject in his or her study, but the organization has at least a regulatory obligation to protect human subjects generally. The Grimes court, with explicit support from the regulations, 80 simply held that the organization’s failure to provide that protection, in vio-


78. Enterprise liability has been defined generally as “[a] legal regime in which manufacturers are liable for the costs of all product-caused accidents.” Jon D. Hanson & Douglas A. Kysar, Taking Behavioralism Seriously: Some Evidence of Market Manipulation, 112 HARV. L. REV. 1420, 1423 (1999). Enterprise liability is defined in health care as “various circumstances when an organization, for instance a hospital, health maintenance organization, or even a health plan is potentially liable to injured patient.” William M. Sage et al., Enterprise Liability for Medical Malpractice and Health Care Quality Improvement, 20 AM. J.L. & MED. 1, 1-28 (1994) (discussing medical malpractice and reform theories of liability). For example, the hospital might be liable for failure to fulfill its obligations to patients by not providing appropriate staff in the emergency room. In another example, a hospital might be held legally responsible for the injuries caused by a non-employee, such as a surgeon, who is considered an independent contractor. See id. at 18-20. For the use of enterprise liability in attempts to reduce medical error and assuage provider concerns about “malpractice” see William M. Sage, Principles, Pragmatism, and Medical Injury, 286 JAMA 226, 227 (2001).


80. Many clinical researchers and their lawyers believe that IRB approval provides immunity from lawsuits, but the federal regulations are specific:

No informed consent, whether oral or written, may include any exculpatory language through which the subject or the representative is made to waive or appear to waive any of the subject’s legal rights, or releases or appears to release the investigator, the sponsor, the institution or its agents from liability for negligence. 45 C.F.R. § 46.116 (2001) (cited in Grimes v. Kennedy Krieger Inst., Inc., 782 A.2d 807, 847 (Md. 2001)). See Palmer, supra note 7, at 32.
lation of a court-established duty, could potentially constitute negligence. From a systems perspective on accountability for subject protection in research, allowing the liability to fall on the research organization rather than on the investigator or physician makes sense.81

More generally, “enterprise liability,” as opposed to “professional liability,” as the locus of a liability theory82 makes sense in an era of genetic health for two reasons. First, enterprise liability encourages organizations to exercise some degree of control over the physicians and investigators operating within the organization. While professional liability and its accompanying professional/client dyad is the ethical foundation for liability doctrine, enterprise liability acknowledges the multidisciplinary reality of modern health care. In cases involving genetic health, as demonstrated in Part II, it is apparent that research and treatment involved in genetic health are complex and involve patient and family member interaction with a number of different professionals—for example, physicians, nurses, lab technicians and genetic counselors—who have various levels of related competencies.

Second, enterprise liability acknowledges what was only implicit in the earlier “wrongful birth” and “wrongful life” cases: genetic health requires a degree of specialization or a special branch of professional knowledge to be acquired by health care providers. In effect, liability doctrine can be used to encourage only certain providers (with the appropriate expertise)—academic medical centers—to deal with genetic health. Although not all individuals or groups have equal access to academic health centers, it is not clear that universal access to genetic health practitioners is in fact a social good, given the eugenic risks.83


82. Sage et al., supra note 78, at 28.

83. A “rights” approach to access to health care might lead one to argue for greater access to genetic research and interventions on the part of disadvantaged individuals. But an institutional approach poses questions of access in terms of trade-offs. Given a choice between new genetic therapies and access to primary health care, it is not clear what disadvantaged individuals might choose. It has been said that the US has the “best” medicine or health care in the Western World, but it is not clear that the overall health status of the entire population is poor when compared to other industrialized countries. In point of fact, the US ranks near the bottom in terms of health status indicators when compared to socie-
II. IS THERE A STANDARD OF CARE FOR GENETIC DISEASE?

Although there is a great deal of scholarship and numerous judicial opinions dealing with so-called “wrongful life” or “wrongful birth” cases, I propose to treat these as raising one larger question: Have courts established in liability law a standard of care for how health care professionals should deal with issues of genetic health? By framing the question in this manner, I seek to situate the issues of genetic health within the traditional specialized standard of care for health care professionals in liability doctrine. Such juxtaposition immediately highlights the fact that traditional malpractice standards are built on the paradigm of physical injury and physically invasive treatment.

Most of these genetic health cases arose after judges introduced ties with more drinkers and smokers than ours such as France or Sweden. See Barbara Starfield, Is US Health Really the Best in the World?, 284 JAMA 483, 483 (2000).


another theory of medical liability, the doctrine of lack of informed consent. Thus the prototype case relating to genetic health arose in the 1970s and later involved not the issue of whether the health care provider performed a procedure or intervention in accordance with “prevailing medical standards,” but whether the parent should have been informed of certain genetic risks. The emerging standard of care for genetic health issues in law is thus a post hoc determination by judges and juries that a physician should have told the parents of the risk of some inherited disorder in their child.

The underlying assumption of these genetic health cases is that the prospective parents have been deprived of the opportunity to decide not to have a child with the disease or disability, or the opportunity to prepare themselves for a child with such a disability. Of course, without a woman’s legal right to have an abortion, as the New Jersey courts have pointed out, these genetic liability claims would not be theoretically possible. But I believe the better articulation of the assumption is in terms of the lack of opportunity to choose whether to risk having a child with a disability. Recall the story of my son’s birth. The knowledge that he might need a complete blood transfusion when born helped at least this parent endure the four hours that the blood transfusion took and the subsequent days and nights in the special care nursery.

The latest permutations of this line of cases involves whether the duty to disclose imposes an obligation on the health professional to inform a patient’s child or relative of the risk of inheritable disease.

87. See Canterbury v. Spence, 464 F.2d 772, 787 (D.C. Cir. 1972) (holding that test for determining whether potential peril must be divulged is its materiality to patient’s decision); Cobbs v. Grant, 502 P.2d 1, 11 (Cal. 1972) (analyzing physician’s duty to patient and determining that there is a duty of reasonable disclosure concerning available choices with respect to proposed therapy and dangers inherently and potentially involved).

88. See Pate v. Threlkel, 661 So. 2d 278, 280 (Fla. 1995) (holding that a physician has a duty to warn a parent of the genetically inheritable nature of his or her disease); Schroeder v. Perkel, 432 A.2d 834, 842 (N.J. 1981) (holding that doctor was liable for failing to recognize cystic fibrosis in the first child and inform the parents that they were carriers of disease, which deprived them of informed choice to assume risk of second child). For a discussion of Threlkel see Palmer, supra note 7, at 15-16.

89. See, e.g., Hummel v. Reiss, 608 A.2d 1341, 1343 (N.J. 1992). Indeed most courts acknowledge that the right to procreative choice stems from a woman’s right to an abortion established in Roe v. Wade, 410 U.S. 113 (1973).

90. Without that knowledge, I suspect there is a greater risk on the part of at least some parents in the shock of discovery of “problems” to stigmatize the child as “sick,” “disabled,” and perhaps “unlovable,” at least until the child is restored as “healthy.”

91. See Threlkel, 661 So. 2d at 282 (holding that patient’s children were within foreseeable zone of risk and patient can ordinarily be expected to pass on warning). See L.J. Deftos, Genomic Torts: The Law of the Future—The Duty of Physicians to Disclose the Presence of a Genetic Disease to the Relatives of Their Patients with the Disease, 32 U.S.F. L. Rev. 105, 106 (1997) (describing cases and statutory law regarding genetic information as developing into area of law dubbed “genomic torts” and proposing that genomic concepts of
These cases are an indication that the very notion of genetic health and disease pushes the parameters of the assumption of the traditional standard of care. Or put another way, if the justification of a special standard of care for health care professionals was based in part on preserving the special social function of the professional/client relationship, issues of genetic health question that basic assumption. Another way of stating this point is to suggest that knowledge-flow in the traditional understanding of standard of care is from the professional to the client.\textsuperscript{92}

But once the notion of genetic health is institutionalized in health care practices through genetic screening of prospective parents, fetuses, and embryos,\textsuperscript{93} the flow of knowledge must be from professional to some type of genetically defined group. While there is a risk to traditional notions of client/professional confidentiality in this suggestion,\textsuperscript{94} recall that I am only making an argument for cases involving aspects of genetic health.

In making this argument, I should also note that there is no uniformity among courts about the theoretical basis of liability for failure to disclose information to patients.\textsuperscript{95} Furthermore, legislatures have reacted to the so-called “first revolution” of informed consent\textsuperscript{96} and limited the circumstances under which individuals can recover.\textsuperscript{97}

\textsuperscript{92} See JAY KATZ, THE SILENT WORLD OF DOCTOR AND PATIENT 48-59 (1984) (arguing that the doctrine of informed consent cannot protect patient autonomy).

\textsuperscript{93} Some of the papers in the symposium issue will make this point.

\textsuperscript{94} See Janet L. Dolgin, Choice, Tradition, and the New Genetics: The Fragmentation of the Ideology of Family, 32 CONN. L. REV. 523, 551 (2000) (noting that the doctrine of informed consent is “[a]ttractive . . . in part because it placates concerns about variations of privacy while interfering less with the goals of industry and science than rules defining genetic information as property”).

\textsuperscript{95} See Duttry v. Patterson, 771 A.2d 1255, 1257 (Pa. 2001) (holding that a surgeon’s personal characteristics were irrelevant to a patient giving informed consent).

\textsuperscript{96} The decision in Johnson v. Kokemoor, 545 N.W.2d 495 (Wis. 1996), has been called the second revolution in informed consent doctrine. See generally Aaron D. Twerski & Neil B. Cohen, The Second Revolution in Informed Consent: Comparing Physicians to Each Other, 94 NW. U. L. REV. 1 (1999) (discussing changes that might occur due to Kokemoor); Ketler, supra note 86, at 1052 (discussing Kokemoor and new cases which further expand informed consent in Wisconsin in therapeutic settings). For a more moderate perspective on the expected effect of Kokemoor, see Lynn M. LoPucki, Twerski and Cohen’s Second Revolution: A Systems/Strategic Perspective, 94 NW. U. L. REV. 55 (1999) (arguing that effect of change will be moderate rather than revolutionary, and that Twerski and Cohen focus on legal issues that the Kokemoor court left undecided).

\textsuperscript{97} See Hecht v. Kaplan, 645 N.Y.S.2d 51, 52 (N.Y. App. Div. 1996) (holding that under New York statutes on informed consent, plaintiff must prove that there was “unconsented-to affirmative violation” of her physical integrity in order to sustain cause of action). In Hecht, the physician drew an extra vial of blood and performed a blood test for Human T-Cell Leukemia Virus (HTLV), a contagious disease, while his patient only consented to have her blood tested for cytomegalovirus (CMV). See id. at 52 (discussing plaintiff’s claim that testing of blood for HTLV amounted to “human research without her consent”). Although the HTLV test result was positive, the physician failed to inform the pa-
As a consequence, some courts, relying upon statutory definitions regarding lack of informed consent and legislation protecting genetic privacy, might well hold that physicians have no duty to inform relatives of the risks of genetic disease. This lack of uniformity in approaches to disclosure liability cases generally should remind us, first, that court-developed liability doctrine is always subject to political reaction or even reformulation. Second, and perhaps just as important, liability doctrine remains primarily local in the sense that it is a function of state law in our system, but the ethical and social impact of notions of genetic health will be global.

III. ARE THE TUSKEGEE SYPHILIS EXPERIMENT AND THE NAZI DOCTORS CASE PRECEDENTS FOR THE DUTY TO DISCLOSE IN GENETIC DISEASE CASES?

The Grimes court was undoubtedly aware that neither the Nuremberg Judgment in the Nazi Doctors’ trial nor the Tuskegee Syphilis Study involved issues of civil liability. When litigation was commenced on behalf of the Tuskegee survivors, the theory of the lawsuit was based on a violation of the survivors’ constitutional rights, and the suit was brought against governmental entities, not research organizations such as the Tuskegee Institute. The Nazi Doctors Case involved criminal adjudications under international law, a long way from the kinds of cost-benefit analyses we associate with modern liability theory. It might be appropriate to extract some broader principles from these cases were one convinced there were no other way

tient of the results of the test for several months. See id. (stating that failure to inform endangered the health of the plaintiff’s husband); see also N.Y. PUB. HEALTH LAW § 2805-d(2) (McKinney 2001) (stating that “right of action to recover for medical . . . malpractice based on a lack of informed consent is limited to those cases involving either (a) non-emergency treatment, procedure or surgery, or (b) a diagnostic procedure requiring invasion or disruption of the integrity of the body”).

98. See Hecht, 645 N.Y.S.2d at 52 (challenging the notion that informed consent is rooted in the right to bodily autonomy).


100. One might consider if the Grimes court wrote such a broad opinion in order to shape the legislative debate. Notice that the legislature, with appropriate lobbying by a variety of interest groups, enacted a statute requiring the disclosure of the minutes of all IRBs in Maryland. H. Res. 917, 416th Sess. (Md. 2002).

101. See Palmer, supra note 27, at 609.


103. See RONALD DWORKIN, TAKING RIGHTS SERIOUSLY 232 (1977) (attempting to justify extraction of non-utilitarian principles from the Constitution for judges to apply).
to arrive at the court’s result, or if there were no negative consequences to attempted extraction. The Nazi Doctors Case and the Tuskegee Syphilis Study provide two different kinds of perspectives on issues related to genetic health and liability. Before outlining the doctrinal innovations we need for genetic health and disease, let me begin with the institutional lessons Tuskegee imparts.

A. Institutional Lessons from the Tuskegee Study

It is tempting to dismiss the Tuskegee Study in legal discourse because there was no binding legal precedent from the litigation following discovery of the study in 1972. It is equally tempting to place too much emphasis on the Tuskegee Study because it has become part of our ethical discourse in popular and political culture because of the prize winning play and made-for-television movie, Miss Evers’ Boys. I want to draw some enduring lessons from each perspective.

Technically, the theory of the lawsuit filed on behalf of the Tuskegee “subjects/patients” was that they were chosen by state and federal agencies because of their “race.” Since the federal government paid a settlement to the survivors and their representatives, one might argue that the claim had some plausibility. But what if one asks: Were the African-American professionals and health care institutions involved with the study somehow exempt from any form of legal liability? Are they to be excused ethically for their participation because of their race?

Rather than engaging in a kind of comparative “badness” analysis, I have suggested in previous publications that all of the participants in the Tuskegee Study should be viewed as “good” individuals unable to see that they practiced medicine . . . under what were bad institutional arrangements.” So viewed, Tuskegee vividly illustrates how the professional ethos of science may be more powerful than any socially imposed notions of race or ethnicity. In the contemporary context, just because members of so-called minority or stigma-

104. As I have noted elsewhere, there is a straightforward analysis of liability doctrine for arriving at the Grimes court’s result, as demonstrated by the concurrence. Grimes v. Kennedy Krieger Inst., Inc., 782 A.2d 807, 859-61 & n.45 (Justice Raker found that facts existed supporting appellant’s contention that a special relationship existed that created a duty on behalf of appellee—thus, there was no need to broach any other issue).


106. See Palmer, supra note 27, at 608-10.

107. PALMER, supra note 25, at 7.
tized groups are involved in pushing the medical frontiers does not prevent eugenic abuses from occurring. 108

More pertinent for this symposium, the underlying scientific and public health problem that led to the Tuskegee Study—syphilis—was at the time a “chronic disease” or at least an “incurable” disease. Medical progress as defined a half-century ago, primarily the intervention of powerful pharmaceuticals, led to an effective treatment. With the growth in knowledge about the genetic nature of disease and proposed treatment modalities, the current thrust of public policy is to ensure participation by minorities so as to avoid some of the “bad institutional arrangements,” such as treatments with adverse and less effective results in specific minority groups.

The second important lesson of Tuskegee comes from political institutions. When President Clinton apologized for the Tuskegee Study, he established that medical and scientific interventions are to be judged by current ethical understandings rather than those operative when physicians and scientists undertook the interventions—or in the case of Tuskegee, failed to intervene. 109 On the other hand, Clinton also helped to institutionalize the bioethics profession when he authorized funding for a National Bioethics Institute at Tuskegee. This act was in keeping with a long tradition in this country of labeling minority-focused professional activities “National” and majoritarian professional groups “American,” for example the National Bar Association as distinct from the American Bar Association. The work of legal institutions will in some respect have an overseer body—the bioethics profession and its institutional form will be the multidisciplinary bioethics commissions.

**B. Issues of Jurisprudence from the Nazi Doctors Cases**

I will not describe the Nazi Doctors Case except to say several Nazi physicians were executed and others imprisoned by a United States-sponsored international tribunal for their participation in experiments using concentration camp inmates. 110 Since a court had judged their conduct as “bad” even for the conditions of war, the Grimes court, like many of the commentators it cites, starts with the proposition that the Nuremberg case is the “most complete and au-

108. See PALMER, supra note 25, at 4-7; Palmer, supra note 27, at 611-13.

109. Failure to intervene in genetic health cases has come up before in the DES litigation. See Mink v. Univ. of Chi., 460 F. Supp. 713 (N.D. Ill. 1978).

Authoritative statement of the law of informed consent to human experimentation.” Such statements lull legal actors into believing that courts might be able to halt “eugenic” uses of the growing body of genetic knowledge without examining all of the problems that surround treating those ethical guidelines as “law.” Thus the first problem: What were the Nazi Doctors’ crimes in a legal sense?

The repulsion that we feel in even hearing about the atrocities committed makes us very comfortable lumping all these actions under the rubric of “war crimes.” In point of fact, the Nazi Doctors were convicted of both “war crimes” and “crimes against humanity,” which raises the question: What is the distinction between the two types of crimes under international law? In experiments aimed at aiding the war efforts, such as finding better treatment for malaria, I have argued the defendants were guilty of “war crimes.” Asking for the inmate’s informed consent would not have made the experiments legal, in my view, since the essence of the complaint and the evidence against the doctors was that they caused “excessive deaths” by the manner in which the doctors carried out their studies. Furthermore, the Nazi Doctors’ malaria experiments were similar in some respects to American wartime malaria experiments on incarcerated prisoners, according to the prosecutors who attempted to distinguish the two through an American “ethics expert.” These “war crimes” charges are not sources of principles for the emerging issues of genetic health.

The “crimes against humanity” portion of the Nuremberg Judgment, however, does provide some principles that could inform judicial attempts to develop doctrines relevant to genetic health. The prototypical crimes against humanity used by the Nazi Doctors involved the use of powerful drugs and x-rays on Russians, Poles, Jews and other groups. The object of these experiments was elimination of groups of civilians. The crimes against humanity doctrine might provide a principle for the civil lawsuits or legislation, whereas I doubt the relevance of the war crimes to civil lawsuits. But the principle one might derive from the crimes against humanity might be only a weak one: there should be some institutional checks on science and medicine, and in some circumstances liability rules provide the appropriate check.

112. See Palmer, supra note 7, at 28-31.
114. Whether or not the so-called expert, Dr. Ivy from the American Medical Association, succeeded in distinguishing the two types of studies in his testimony is subject to some debate. See Jon M. Harkness, Nuremberg and the Issue of Wartime Experiments on U.S. Experiments, 276 JAMA 1672, 1673 (1996); Jon M. Harkness, The Significance of the Nuremberg Code, 338 New Eng. J. Med. 995, 996 (1998).
115. See Palmer, supra note 7, at 28-31.
My concern with the use of the eugenic precedents by the *Grimes* court is twofold. First, I worry that the legal actors, including many scholars, will assume that the Nazi Doctors Case and the Tuskegee Study are clearly the eugenic type of precedents legal actors could use to prevent misuse of the growing body of genetic knowledge about the nature of disease. Second, I am concerned that a failure to understand the true legal response to these socially and ethically horrific events blurs the need for true legal innovation. There are institutional lessons to be learned and a weak principle to be derived from these events, but these lessons are mere frameworks for decision makers, many of whom may not be courts or bodies that rely upon “precedents” in the way common law judges do.

IV. HOW DO SOCIAL GROUPS PARTICIPATE IN ELIMINATING GENETIC DISABILITIES?

The laboratory, or more specifically the gene sequencing facility, is crucial to the development of genetically-informed treatments or even “cures,” but eventually the physicians and scientists need human subjects. The combination of the legally imposed duty to inform prospective parents of genetic risks, along with the scientific imperative of alleviating disease and disability, creates a new set of tools in health care delivery: genetic screening and what some have called “eugenic abortions” to avoid disability. As this new type of disease management takes hold, the distinctions between liability for experimentation and liability for breach of duties in treatment will break down. At some point, otherwise “healthy”—in the sense that they do not (yet) have any manifestations of the disease—individuals who may have a certain “gene” must become a part of the search for a cure.

Since some of the early genetic health cases involved Tay-Sachs, I will use a pending case involving a similar disease, Canavan Disease, to illustrate what is on the frontier of legal liability and disease management in relation to genetic health.

Canavan Disease is a genetic disorder that affects the growth of brain fibers leading to death in its patients, mostly children before the age of ten. Through the efforts of some individuals, organizations,

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116. See Gleitman v. Cosgrove, 227 A.2d 689, 694 (N.J. 1967) (Francis, J., concurring) (originating the term “eugenic abortion”). “Eugenic abortion” refers to abortion intended solely to eliminate a potentially defective fetus and is used to differentiate that form of abortion from “therapeutic abortion” which is an abortion performed to protect a woman’s health. See Hummel v. Reiss, 608 A.2d 1341, 1343 (N.J. 1992) (citing lower court opinion defining “eugenic abortion” versus “therapeutic abortion”).

117. See Howard v. Lecher, 366 N.E.2d 64, 65 (1977) (holding parents were not entitled to recovery against doctor for his failure to warn them of the high risk that their child would suffer from Tay-Sachs disease).
and researchers and their related organizations, a genetic test has been developed allowing for the screening of prospective parents, embryos, and fetuses. The lawsuit, Greenberg v. Miami Children’s Research Institute, Inc.,118 involves a dispute between the parents of children who either died from or have Canavan Disease and their organizational supporters, and the researcher who discovered the “Canavan gene” and the holder of the patent for the gene and the related genetic tests.119 The underlying issue is that the holder of the patent, the research organization, threatened the organizational plaintiff’s goal of virtually free screening for one of the groups most severely affected by the disease—Ashkenazim or persons of East European Jewish descent—when it insisted upon licensing fees to use its tests.

The essence of the plaintiffs’ complaint in Greenberg is that the researcher should have informed them of his intention to patent that gene, if discovered, when he took autopsy tissues of their dead children, and blood and other sources of DNA from them and their relatives. The plaintiffs further allege that they provided the seed money for the researcher’s foray into genetic medicine and access to potential donors of tissues. The defendants have argued that the complaint should be dismissed on a number of grounds.

Since the question still remains whether the plaintiffs have stated a cause of action, I have argued that a proper reading of Moore v. Regents of the University of California,120 where the California Supreme Court held there was a fiduciary duty on the part of a physician to disclose both his research and pecuniary interests in a patient’s DNA, should lead to the plaintiffs’ surviving the motion to dismiss or a motion for summary judgment.121 The result of such a ruling is that the lack of informed consent doctrine in genetic health cases protects the rights of groups of individuals to participate in the dissemination of genetic knowledge.

Essentially, I am arguing that individuals, with the obvious support of organizations, have the legal right to prevent the birth of a child with what they consider a disability. The issue then is: Does supporting this right to eliminate disability through genetic testing and selective abortion or destruction of embryos increase the likelihood of stigmatization of the disabled? The answer is “yes,” but it needs to be qualified by the following observations.

First, the individuals who might be afflicted with Canavan Disease are now socially linked either through genetic knowledge or

118. 208 F. Supp. 2d 918 (N.D. Ill. 2002). The United States District Court for the Northern District of Illinois, Eastern Division, has recently transferred the case to the United States District Court for the Southern District of Florida. Id. at 928-29.
119. The Canavan Disease case is described in detail in Palmer, supra note 7, at 8-13.
120. 793 P.2d 479 (Cal. 1990).
121. Id. at 498.
their own ethnic and religious self-definition. The social definition might lead to less drastic means of avoiding the risk of disability by advising against having children between two prospective parents with a high risk of creating a child with Canavan. Thus, a bit of counseling and discussion could decrease the incidents of “eugenic abortion.”

Second, in an ethical sense, abortion is preferable in my view to even voluntary sterilization to avoid disability. I make this point of a continuum from contraception, to abortion, to sterilization because the most important eugenic precedent in this country is *Buck v. Bell*, which has never been overruled. Political institutions in this country still have the theoretical right to use scientific knowledge to eliminate the disabled. But we should not confuse the authority of political institutions with the legal and ethical rights of individuals to form families in accordance with their own values, including their views of genetic risks.

V. CONCLUSION

Given this lack of constitutional prohibition against sterilization of the supposedly genetically unfit, I suggest that the legal efforts to prevent the abuse of genetic knowledge in pursuit of genetic health must take place in other forums: legislatures and liability doctrine development. We can use the Tuskegee Syphilis Study and the “crimes against humanity” portion of the Nazi Doctors Case as guidelines for legal developments. At the moment, courts could use these guidelines in disease management cases to allow private individuals to exercise some control over genetics-oriented physicians/scientists. These processes of liability can be used to optimize the risks and benefits of the use of genetic knowledge.

On the legislative front, the tortured history of sickle cell anemia should remind us that legislatures may not be good social optimizers of the risks and benefits of genetic knowledge. We should

122. 247 U.S. 200 (1927); see also supra note 17 and accompanying text.

123. However, it has been almost entirely repudiated. See, e.g., Fieger v. Thompson, 74 F.2d 740, 750 (6th Cir. 1996).

124. This explains why I believe it is better to view the woman’s constitutional right to abortion as part of family formation instead of a “right” of privacy or autonomy. See *Palmer*, supra note 25, at 19-37; Palmer, *supra* note 64, at 167-73.

125. Screening for carriers of the disease began in the United States in the 1970s. The majority of programs were voluntary; however, a few states enacted legislation requiring screening for those with sickle cell anemia and the sickle cell trait. Congress passed the National Sickle Cell Anemia Control Act of 1972, Pub. L. No. 92-294, 86 Stat. 136, which provided funding for research and education. The act prompted many states to reverse their earlier call for mandatory screening. This act was then revised, updated, and renamed the National Sickle Cell Anemia, Cooley’s Anemia, Tay-Sachs, and Genetic Diseases Act of 1976, Pub. L. 94-278, 90 Stat. 407; see James E. Bowman, *Genetics and African Americans*, 27 SETON HALL L. REV. 919 (1997).
try to encourage a political agenda based on voluntary rather than mandatory participation in screening programs and resist attempts to immunize physicians/scientists from liability for failure to share genetic knowledge in hindsight adjudication.\textsuperscript{126} There is some risk that the private market could exploit consumers/patients, but we should not allow our fears to prevent us from seeing that there is a separate but linked issue, that of equal access to health care. No matter how “good” our motives or intentions, we could adversely affect equal access to health care by trying to stop the attempt to eliminate genetic disability. To do so would be yet another example of “good” people creating “bad” systematic responses.

I hope that we will strengthen other social institutions, such as the family, to cope with the prospect of genetic disease management as we attempt to understand what is meant by “genetic health” for ourselves and for future generations.

\textsuperscript{126} The current “malpractice crisis” in some states has caused organized medicine to put “tort liability” back on its political agenda. \textit{See Peggy Peck, AMA Declares War on Malpractice Crisis} (June 26, 2002), at http://my.webmd.com/content/article/1691.51255 (last visited Aug. 7, 2002) (on file with author). Whether there is in fact a liability crisis is, of course, subject to debate as it has been in previous so-called malpractice crises in the 1970s and 1980s.
PRENATAL DIAGNOSIS
AND THE SELECTION OF CHILDREN

JEFFREY R. BOTKIN*

I. INTRODUCTION

For many adults, a central concern in life is the health and welfare of their children. A new baby ushers in decades of dedicated work and anxiety to foster the child’s life, to limit the inevitable pain, and to provide every advantage parents can reasonably afford. For most of human history, this work began at birth because, until recently, pregnancy was a black box, largely beyond parental influence other than through prayers and wholesome living. This situation has changed profoundly over the past twenty-five years. An array of technologies now can provide a detailed examination of the embryo and fetus, genetically, biochemically, and anatomically. The day is not yet here when we can effectively change the embryo or fetus from these perspectives, but we can effectively choose to accept or reject what we find. The ability to select our children based on detailed biologic characteristics is new. Efforts to provide the child with every advantage may begin with choosing the desired child at the very beginning. Questions over whether our society should promote or restrict this power also are new. These new capabilities will likely create one of the most difficult and divisive social debates over the next century.

This Article examines the debate from a professional perspective. Because those in the medical profession are gatekeepers for prenatal diagnostic technology, one approach to these questions is to ask what

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1. Pregnant women throughout recorded history have attempted to protect and foster their children before birth by eating good food and avoiding alcoholic drinks and physical labor during pregnancy. Until the last century, the medical community thought that maternal experiences could affect the developing child in quite specific ways. For example, a negative influence might be the sighting of a rabbit that was thought to result in a “hare lip.” Alternatively, by exposing pregnant women to beautiful art and music, children gained positive influences. This tradition continues today in the recent fad over encouraging women to expose their developing fetuses to classical music.
tests and technologies the ethical practitioner should provide. The answers to this question can be guided by professional, ethical and legal standards that are emerging in genetic medicine. This Article begins by offering three hypothetical clinical scenarios to frame the issues.

Case #1: Molly and Bert are pregnant with their third child. Molly is 36 years of age, Bert is 39, and both are in good health, as are their two other children. The pregnancy proceeds uneventfully under the guidance of their obstetrician, Dr. Owen. Dr. Owen is religiously and philosophically opposed to pregnancy termination other than for the protection of the life of the mother and, given the smooth course of this pregnancy, he does not discuss prenatal diagnosis with the couple. Dr. Owen recognizes that this failure to offer prenatal diagnosis is contrary to the prevailing standard of care. Women who will be 35 years of age or older at the time of delivery are at increased risk of bearing a child with Down syndrome and other syndromes caused by an increased number of chromosomes. Therefore, it has been standard practice for at least two decades to offer prenatal diagnosis to women of “advanced maternal age” to detect these conditions, if the parents so choose. Molly’s pregnancy proceeds to term, at which time she delivers a small infant girl, Alexandra, with the stigmata of Down syndrome. Chromosome analysis confirms the presence of Trisomy 21. Additional evaluation also confirms the presence of complex congenital heart disease in the infant.

Molly and Bert are shocked and saddened at the realization of Alexandra’s diagnosis and of the difficult challenges ahead for them and for their child. As they learn that prenatal diagnosis could have predicted this outcome, they become increasingly angry. Had they been offered prenatal diagnosis, they would have accepted. Upon

2. A separate approach would be to ask what sorts of prenatal tests and technologies should be used by an ethical couple. This question is less well explored than the professional standards question. Also, the question for prospective parents often becomes mired in abortion politics.

3. Down syndrome is also termed Trisomy 21. Kenneth Lyons Jones, Smith’s Recognizable Patterns of Human Malformation 8-13 (5th ed. 1997). Humans normally have a total of forty-six chromosomes in each cell, twenty-three from the person’s mother and twenty-three from the father. Lynn B. Jones et al., Medical Genetics 7 (Emma B. Underdown ed., 1995). The chromosomes are numbered from one through twenty-two plus the X and Y chromosomes that determine gender. Id. Therefore each of us normally has two #21 chromosomes. In Down syndrome, three #21 chromosomes are present, two from one parent and one from the other. Jones, supra, at 8-13. This extra chromosome causes the common characteristics of Down syndrome that include mild to moderate mental retardation, characteristic faces, and heart and/or bowel abnormalities. Id. Other less common trisomy syndromes include Trisomy 18 and Trisomy 13, both of which cause profound mental retardation and typically an early death. Id. at 14-23.

4. The term “prenatal diagnosis” encompasses a range of technologies. Amniocentesis is perhaps most familiar; a needle is inserted into the amniotic sac surrounding the fetus at about 16 weeks gestation. Fetal cells are isolated from the fluid and their chromo-
learning of the affected fetus, they would have regretfully, but surely, terminated the pregnancy. Molly and Bert choose to bring a legal claim against Dr. Owen for his failure to provide timely information about their reproductive risks and options.

The question for our analysis is whether the parents should have a valid legal or ethical claim. Should Dr. Owen be held legally or ethically responsible for the birth of this impaired child?

Case #2: Alice and Jack are pregnant with their first child. In their initial prenatal visit with Dr. Owen, he took a brief family history of both sides of the family to identify genetic risks to the developing child. However, Dr. Owen failed to take an adequate family history concerning cancer. Jack’s sister developed breast cancer at age 37, his mother died recently of ovarian cancer at age 59, and his maternal aunt had breast cancer at age 46. This family pattern is suggestive of a heritable mutation in either the BRCA1 or BRCA2 genes. Women who are mutation carriers for BRCA1 or BRCA2 have a lifetime risk of up to eighty-five percent for breast or ovarian cancer. While there are no significant health risks to a man who is a mutation carrier for either of these genes, he can transmit the mutation to his daughters and sons. Genetic testing for BRCA1 and BRCA2 mutations has been available clinically for about seven years.

Alice’s pregnancy proceeds uneventfully to term. A vigorous, healthy baby girl, Anastasia, is born. Six months later, Jack’s sister learns through genetic testing that she has a BRCA1 mutation. Jack and, subsequently, Anastasia obtain genetic testing, revealing that they both carry the BRCA1 mutation. Alice and Jack are devastated. After watching the difficult death of Jack’s mother and the suffering of his sister and aunt with breast cancer, they can only look forward with dread to the future of their beautiful little girl. Why didn’t Dr. Owen take an adequate family history? Had they learned of their risk in a timely fashion, they would have done BRCA1 testing on the fetus and terminated the pregnancy without hesitation. They bring suit against Dr. Owen for his failure to provide timely information about their reproductive risks and options.

The question for our analysis is whether the parents should have a valid legal or ethical claim. Should Dr. Owen be held legally or ethically responsible for the birth of this child?

Case #3: Susan and Jim Jingle are pregnant with their fifth child. At only eight weeks gestation, Susan and Jim are thrilled but not ready to announce the pregnancy to the family or the public. They

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somes are analyzed. Chorionic villous sampling (CVS) can be performed earlier in the pregnancy. CVS involves insertion of a needle or catheter to sample cells from the fetal side of the placenta which contain the same chromosome structure as the fetus itself. Ultrasound is available to provide a detailed anatomic examination of the fetus.
recognize that this news would be met with some public fanfare because the Jingle family is a highly popular singing and musical group called, appropriately, “The Jingles.” Both Susan and Jim have perfect musical pitch, as do all of their four children. This innate talent has allowed the children to develop extraordinary musical skills at young ages, albeit with intensive training and practice beginning by age 3. There is a strong family history of perfect musical pitch on both sides of the family, and both families have had noted musicians and entertainers for generations. This kind of family history is unusual, but not so rare that it escaped the attention of geneticists. Imagine for the purposes of this Article that a molecular biologist in England recently identified a gene variant that confers perfect musical pitch in the majority of individuals who carry this variant. A prominent medical journal published the finding and, subsequently, several other investigators have confirmed the association in additional families.

Susan and Jim are hopeful that this new baby will fit in the family mold. Indeed, they are a little fearful of how they would raise a child that could not be an integral member of the family activity—and not to mention the creative and financial possibilities of a cute new Jingle in the band. They ask Dr. Owen, Susan’s obstetrician, about the possibility of having another child with perfect musical pitch. He chuckled, “Oh, who knows? These kinds of things are mostly just plain luck, although you folks have been awfully lucky with the other kids. So, I guess the chances are pretty good this one will be talented, too.” Sadly, though, this one was not talented. Susan and Jim learned of the genetic test for the “musical pitch gene” through a magazine interview late in Susan’s pregnancy. It was too late to do prenatal testing but they had their baby tested while he was a newborn. He had not inherited the trait from either parent, and so, while he was healthy, he would have no more innate musical talent than any random kid off the street. Their disappointment was further fueled by the knowledge that Susan could have had prenatal diagnosis for this trait well before the public knew she was pregnant. Dr. Owen had given them false information and he obviously did not have enough professional good sense to look up the correct answer to their question. Music is the lifeblood of their family, not some trivial trait like blue eyes or big ears. This was too important to leave to dumb luck. The Jingles brought suit against Dr. Owen, claiming that had he accurately informed Susan and Jim about the availability of a genetic test, they would have used it and terminated the pregnancy upon detection of the undesirable fetus.

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The question for our analysis is whether the parents should have a valid legal or ethical claim. Should Dr. Owen be held legally or ethically responsible for the birth of this child?

II. THE LEGAL CONCEPTS OF WRONGFUL LIFE AND WRONGFUL BIRTH

Over the past twenty years, the courts have provided a partial answer to the questions posed by these cases. Wrongful life and wrongful birth are two related medical malpractice actions that have arisen since the 1973 *Roe v. Wade* decision to address claims of negligence leading to the birth of an impaired child. Health care providers are the usual defendants in these suits after the birth of a child with congenital malformations or a genetic disease. Wrongful birth actions refer to suits by the parents who claim harm to themselves from the birth of an ill or disabled child. Parents in these suits typically claim that, had they been adequately informed of their reproductive risk, they would have taken measures to prevent the pregnancy or birth of the affected child. Wrongful life claims are brought in similar clinical circumstances; however, these claims arise from the child who asserts harm from birth in an impaired condition. But for the negligence of the health care provider, the child claims she would not have been born to suffer with her condition. Neither of these claims is based on allegations that the defendant caused the impairment through negligent actions as, say, through the use of a teratogenic drug. Wrongful life and wrongful birth claims are based on allegations of inadequate or incorrect information that would have permitted the parents to avoid pregnancy or to detect the abnormality prenatally and terminate the pregnancy.

The wrongful life and wrongful birth suits have become increasingly prevalent over the past three decades for at least two reasons. First, *Roe v. Wade* established constitutional protection for abortion decisions through the first two trimesters of pregnancy. Second, medicine is offering an expanding array of technologies to evaluate the health of the fetus. In light of these developments, health care providers are seen to have parallel obligations to offer testing in a variety of clinical circumstances, and to adequately warn couples who have an increased risk of bearing a child with a heritable condition or congenital malformation. Failure to provide timely, accurate infor-

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8. Id.
9. Id. at 494.
10. Id.
mation according to the standard of care may leave providers liable under wrongful life and/or wrongful birth suits.

The wrongful life claim has met with limited success. To date, five state courts have recognized the wrongful life claim, while nineteen have rejected this tort. The primary difficulty for the wrongful life claim has been the implicit claim that a child would prefer non-existence to existence in an impaired condition. In these circumstances, existence without the condition was never a possibility for these children. So, the choice on behalf of the child was existence with impairments or non-existence through contraception or pregnancy termination. The children must assert that, but for the negligence of the defendant, they would not exist. In response to this dilemma, most courts have adopted the reasoning first articulated in the New York case of Becker v. Schwartz, in which the fundamental philosophic problem with wrongful life suits was described:

The first, in a sense the more fundamental [problem with wrongful life claims], is that it does not appear that the infants suffered any legally cognizable injury. . . . Whether it is better never to have been born at all than to have been born with even gross deficiencies is a mystery more properly to be left to the philosophers and the theologians. Surely the law can assert no competence to resolve the issue. . . . Not only is there to be found no predicate at common law or in statutory enactment for judicial recognition of the birth of a defective child as an injury to the child; the implications of any such proposition are staggering.

The few courts that have recognized the wrongful life claims often have been willing largely to overlook the philosophical problems inherent in the claim and to support the suits based on the medical needs of the child and/or the public policy advantages of deterring

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15. Id. at 812.
negligent medical care. A California court in 1980 concluded:

The reality of the “wrongful life” concept is that such a plaintiff both exists and suffers, due to the negligence of others. It is neither necessary nor just to retreat into meditation on the mysteries of life. We need not be concerned with the fact that had defendants not been negligent, the plaintiff might not have come into existence at all.

While the trend has been against the wrongful life concept, courts in both Massachusetts and Connecticut have supported the tort within the past few years. A 1997 decision by the Connecticut Superior Court, quoting a 1983 decision, stated: “There is nothing illogical in a plaintiff saying ‘I’d rather not be suffering as I am, but since your wrongful conduct preserved my life, I am going to take advantage of my regrettable existence to sue you.’” A Massachusetts court was faced with a case in which a suit was brought against a physician who failed to report abnormalities on a fetal ultrasound and to repeat the examination. The mother gave birth to a child with heart and bowel abnormalities, and the parents relinquished the child for adoption. The court concluded:

Corey’s parents are not entitled to recover against the defendant for the ongoing extraordinary costs that Corey will incur because of the defect (due to the fact that they are no longer his legal guardians or official parents). Nor will Corey’s adoptive parents be entitled to recover, since the defendant owed them no duty. Therefore, this Court must consider whether Corey should have this cause of action since no one else can recover the extraordinary costs. In this situation, it appears fair to require the negligent Doctor to pick up these costs if negligence is proven.

Therefore, in order to assure adequate care to a child with disabilities, some courts have been willing to recognize wrongful life claims without explicitly declaring that life with disability can be worse than non-existence.

The New York Court of Appeals in Becker v. Schwartz deferred to philosophers and theologians on the basic question of whether ex-

17. Id. at 488.
20. Id. at *2.
21. Id. at *9-10.
istence confers a harm for some children. Bioethicists, theologians, and physicians have offered a range of opinions on this question. John Lorber, a British surgeon, wrote in 1975 of the deliberate non-treatment of some severely affected children with spina bifida:

There are ethicists and moralists, as well as doctors, who consider that life must be maintained at any cost, because any life is better than no life. It may be legitimate to adhere to such principles within their own family, but is it not right to enforce such a philosophy on others who do not hold with it. To my knowledge none of the world’s great religions or religious leaders believe that a severely defective innocent newborn infant would be worse off in heaven or wherever they believe their souls will go after death. Is it therefore humane to inflict an immense amount of suffering on such infants and on their families to ensure that they reach this heaven or haven in the end?\(^2\)

Margery Shaw, a geneticist and attorney, argued that “fetal abuse,” through knowingly bringing a child to birth with a genetic condition, should be made analogous to child abuse in the law.\(^2\) She would sanction not only wrongful life suits against negligent physicians, but similar suits against parents.

\[\text{Parents should be held accountable to their children if they knowingly and willfully choose to transmit deleterious genes or if the mother waives her right to an abortion if, after prenatal testing, a fetus is discovered to be seriously deformed or mentally defective. They have added to the burdens of the other family members, they have incurred a cost to society, and, most importantly, they have caused needless suffering in their child.}\(^2\)

In fact, the wrongful life claim raises this odd question of the parents’ responsibility for the birth of an affected child. When prenatal diagnosis detects a fetus with a genetic condition or congenital malformation, some parents choose to continue the pregnancy. Also, parents at risk for bearing a child with a genetic condition may choose to forego prenatal diagnosis and accept the risk of an affected child. As argued by Shaw, might the affected child have a wrongful life claim against the parents? The State of California was concerned enough about this possibility after the success of a wrongful life claim in the case of Curlender v. Bio-Science\(^2\) that it passed legislation barring suits by children against parents for the harm of their existence.\(^2\)

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\(^{23}\) John Lorber, Ethical Problems in the Management of Myelomeningocele and Hydrocephalus, 10 J. ROYAL C. PHYSICIANS 47, 58 (1975).

\(^{24}\) See Margery W. Shaw, Conditional Prospective Rights of the Fetus, 5 J. LEGAL MED. 63, 111 (1984).

\(^{25}\) Id.


\(^{27}\) CAL. CIV. CODE § 43.6 (West 1982).
In contrast to these authors, James Bopp, Barry Bostrom, and Donald McKinney argue from a “right to life” perspective that one of the very foundations of modern law and civilized society is that life has enormous intrinsic value.28

Wrongful birth/life claims . . . require a new legal theory, in that life itself is considered a wrong, and death is preferred over life with disabilities. By deviating from the general principle, historically found in civilized law, that life, even with disabilities, is valuable and that only wrongful death is compensable, wrongful birth/life actions are a radical departure from fundamental legal philosophy.29

Similarly, authors writing from a disabilities rights perspective assert that it is simply wrong that those with disabilities lead lives of hopeless despair.30 The greatest difficulties for those with impairments, it is claimed, are often not due to the condition per se, but to the discriminatory attitudes and barriers in society. Wrongful life (and wrongful birth) suits are seen by many of these authors as reflective of an inaccurate and inappropriate attitude in society toward life with a disability.

Finally, some bioethicists claim that the assertion that life with impairments is worse than non-existence is only justifiable for a few extremely severe conditions.31 From the perspective of the child, even the most rudimentary awareness and existence might be sufficient to experience a life of value. According to these authors, the kinds of conditions for which wrongful life suits have been brought, such as Down syndrome or congenital rubella syndrome, would not be justified from the perspective of the child.

The limited success of the wrongful life suits is not likely to change in the next decade or two. The primary challenge to these claims is the philosophical conundrum they pose. Some courts have been willing to overlook this problem in search of support for a disabled plaintiff when adequate support for medical expenses is not otherwise available.32 We might expect this pattern to continue in the

29. Id. at 514.
future, at least until we have a more comprehensive health care financing system. But the other reason wrongful life suits are recognized or pursued is the existence of the wrongful birth claims that usually speak to the same set of events.

The wrongful birth claims have been considerably more successful in the courts. To date, twenty-six states, the District of Columbia, and five federal courts have recognized a cause of action for wrongful birth. One state has enacted legislation recognizing the validity of wrongful birth suits. In contrast, five state appellate courts have rejected the claim and six states have enacted legislation barring wrongful birth suits. Two state laws banning wrongful birth suits have been upheld as constitutional. Although the national trend is clearly toward the recognition of the claim, wrongful birth remains controversial.

Several courts and scholars argue that the wrongful birth concept is an extension of the constitutionally protected right to privacy in abortion decisions. The claim is that abortion decisions are depend-


36. ME. REV. STAT. ANN. tit. 24, § 2931 (West 1988).


40. See Robak v. United States, 658 F.2d 471 (7th Cir. 1981); Haymon v. Wilkerson, 355 A.2d 880 (D.C. 1987); Hickman v. Group Health Plan, Inc., 396 N.W.2d 10, 18 (Minn. 1986) (Amdahl, C.J., dissenting); Smith v. Cote, 513 A.2d 341 (N.H. 1986); R. Keith John-
ent on information about the welfare of the fetus. Therefore, reproductive choice is limited if inadequate prenatal diagnostic information is provided. It is argued that the harm in these cases is not the birth of the impaired child, but the infringement on free choice in reproductive decisions.

In contrast, other commentators and courts argue that there is no basis for wrongful birth suits under the umbrella of privacy as articulated in *Roe v. Wade*. The constitutional right of privacy in reproduction and abortion only prevents state interference with abortion decisions, it is argued, and imposes no positive duties on health care providers to provide information about the fetus. Two state courts (Minnesota and Pennsylvania) have examined these arguments and held that the state laws barring wrongful birth suits are constitutional. Therefore, to date, the provision of prenatal diagnostic information has not been held to be a protected right under the Constitution.

Other commentators and courts argue that wrongful birth suits fall more appropriately under the patient’s right of informed consent. Informed consent relates specifically to the amount and type of information that health care providers must provide to patients about medical options. It is argued that, in the context of the medical condition of pregnancy, couples should be told the risk of a problem for the child in order to decide whether to obtain prenatal diagnosis. Under the current foundation for wrongful birth, as recognized by the majority of the courts, physicians are held to the prevailing standard of care for the provision of timely and accurate information about the welfare of the child.

While there is prevalent support for the wrongful birth claim in the judicial system, there remains a debate over the appropriate calculation of damages in courts recognizing the tort. Courts have considered several options that attempt to balance the benefits and costs

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41. See Bopp et al., supra note 28, at 466-68; John Lyons, Recent Development, To Be or Not to Be: The Pennsylvania General Assembly Eliminates Wrongful Birth and Life Actions, 34 VILL. L. REV. 681 (1989).
42. Lyons, supra note 41, at 694-95.
43. *Hickman*, 396 N.W.2d 10; *Dansby*, 623 A.2d 816.
of having and raising an impaired child.\textsuperscript{46} One method of calculation is to award the parents a monetary sum equal to the costs of the continued pregnancy, the delivery, and the medical costs incurred by the child’s impairment. These are seen as the additional costs directly incurred because of the claimed negligence of the physician. An additional award might be added to compensate for the emotional pain and suffering of bearing and raising a child with a disability. A third element that courts have variously considered is an offset to either of these damages for the benefits that a child brings to a family. Therefore, the damages for emotional pain might be reduced by the jury’s estimate of the child’s positive value to the family.

Clearly, the emotional pain from bearing and raising an impaired child and the emotional benefits of raising any child are highly value-laden. As a result, many courts have been unwilling to allow these kinds of calculations (or, in some circumstances, state law does not permit these kinds of awards or offsets).\textsuperscript{47} The majority of the courts have awarded damages for the medical costs incurred by the child’s unwanted medical condition while the child is a minor.\textsuperscript{48}

The broad recognition of the wrongful birth claim reflects and confirms the responsibility of physicians to provide timely and accurate information about reproductive risks to prospective parents. But this is a vague standard. What information must be provided to prospective parents? Court decisions have not articulated a broad standard because the cases deal with individual claims and circumstances. The single largest number of wrongful birth cases have been brought for failure to provide information about the risk of Down syndrome to women of “advanced maternal age.”\textsuperscript{49} Other conditions that have led to wrongful birth suits include congenital rubella syndrome,\textsuperscript{50} spina


\textsuperscript{47} Bogdan, supra note 46, at 136-38; Scheid, supra note 46, at 68-78.


bifida, Tay-Sachs disease, sickle cell anemia, cystic fibrosis, and a number of other rare conditions. Many of the conditions for which wrongful birth cases have been brought have only one case for that condition. Clearly there are only a few general rules emerging from this pattern of tort litigation to guide practitioners.

The alleged negligence in these cases falls into three categories. First, there are relatively well-defined population groups that are at increased risk for certain genetic conditions. Examples include sickle cell disease in individuals of African origin and Tay-Sachs disease in Ashkenazi Jews. The other prime example is women of advanced maternal age. The professional error here is not identifying couples who are at risk for conditions amenable to prenatal diagnosis and providing them timely information about test availability. A second category involves errors in making a correct diagnosis when suggestive signs or symptoms are present. Pregnant women who contract a rubella infection (German measles) are at risk for delivering a child with congenital malformations. A misdiagnosis of this subtle infection in the pregnant woman has been the event leading to a wrongful birth suit in several cases. A third category is comprised of cases in which an older child or other family member was misdiagnosed or misinformed about a genetic condition. The *Shroeder v. Perkel* case was brought after a physician failed to make a timely diagnosis of cystic fibrosis in a boy before the birth of a second affected child. Occasionally, suits will arise from simple laboratory error as well, that is, prenatal diagnosis was provided but the information returned to the couple was wrong.

Within each of these categories, there is a range of information that might be provided to prospective parents. For the purposes of this discussion, we will focus primarily on the question of risk notification. What kinds of conditions should prompt an alert from the physician? I have framed the discussion thus far primarily in the

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context of tort litigation. A description of the case law permits several basic conclusions. First, there is a clear tradition supporting a minimum standard of risk communication, at least in many jurisdictions. There is a reasonably broad social consensus that, for example, an older pregnant woman should be informed of the increased risk of Down syndrome and other aneuploid syndromes. Or, we can conclude that Ashkenazi couples should be warned of their risk of bearing a child with Tay-Sachs disease. But the second conclusion is that we cannot rely on tort litigation alone to provide sufficient guidance to health care providers. This is true in part because case law is primarily reactive. Further, and perhaps most importantly, the law speaks to the minimum standard of professional behavior. What the professional must do to avoid successful litigation is a different standard than what we would expect professionals to do to promote informed decision-making for couples during pregnancy. The primary standard should be based on our analysis of personal, professional, and social ethics, which may be a different standard than that dictated by law. However, the law asks the correct questions in addressing the ethical issues involved in defining a professional standard.

The remainder of this Article examines the concept of risk from two perspectives. The first relates to the probability of the occurrence of an adverse event. The second relates to the severity of that adverse outcome. We might decide that it is important to warn prospective parents about a serious potential outcome even when the probability is remote. In contrast, a common but relatively trivial outcome may not be deemed worthy of mention.

The knowledge at the base of each of these categories will enlarge with the expansion of genetic knowledge and prenatal diagnostic technology. Before returning to the arguments about limits on professional responsibilities to provide information in this context, this Article will briefly review current developments in prenatal diagnosis.

III. THE TECHNOLOGY OF PRENATAL DIAGNOSIS

Prenatal diagnosis requires the ability to image the fetus or to have access to embryonic or fetal tissue for analysis. The most familiar techniques are ultrasound, amniocentesis, and chorionic villous sampling. Ultrasound involves the transmission of sound waves into the body through an external probe and the measurement of the returning waves as they bounce off tissues in the body. The images created produce a depiction of the external anatomy of the developing fetus as well as internal structures like the brain, heart and kidneys.

Ultrasound is thought to be entirely safe. The primary limitation of the technology is that the fetus must be large enough and sufficiently developed to analyze the structure of the major organs. The remarkable advancement in recent years has been the advent of three-dimensional ultrasound. This technology combines two-dimensional images through digital addition to create stunning three-dimensional images of the fetus. These images look much like true photographs. From a medical perspective, these images provide detailed information about external and internal anatomy and can detect abnormalities of the brain, spine, limbs, bowel, heart, and kidneys. As this technology continues to improve, prospective parents can expect to have detailed color images of their child from mid-pregnancy onward.

Amniocentesis involves the insertion of a needle through the mother’s abdomen or through the vagina into the amniotic fluid sack surrounding the fetus. Several cc’s of fluid are removed for analysis. This fluid contains cells that have been sloughed by the developing fetus. These cells, in turn, contain all the genetic material of the fetus. Therefore, a genetic analysis of the fetus can be performed without removing tissues directly from its body. Amniocentesis generally is performed at about fifteen to eighteen weeks gestation. The primary reason to perform amniocentesis is for chromosome analysis. However, other genetic tests can be performed on the cells. As the number of genetic tests available expands, the number of conditions for which the fetus can be tested through amniocentesis will expand in parallel. The procedure carries a small risk of inducing labor and the subsequent loss of the pregnancy. The usual figure quoted is one pregnancy loss for every two hundred procedures. While this risk may seem relatively low, it should be remembered that amniocentesis as a screening tool is conducted on a large number of women who will not have affected fetuses. Therefore, an expected “cost” to screening programs is the occasional loss of a normal fetus in the effort to detect fetuses with specific abnormalities. Of course, it also must be remembered that amniocentesis only detects conditions for which professionals are specifically looking. That is, a normal amniocentesis does not warrant the general conclusion that the fetus is healthy.

Chorionic villous sampling (“CVS”) involves sampling of tissue where the placenta interdigitates with the wall of the uterus. Since the placenta is a product of conception, it has the same genetic material as the fetus. CVS is conducted by inserting a needle through the abdomen or a catheter through the cervix under ultrasound guidance to suction the tissue. The primary advantage of CVS is that it can be

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conducted at nine to twelve weeks gestation, although it can be performed as early as six weeks and as late as fifteen weeks. Recall that amniocentesis is usually conducted at fifteen to eighteen weeks. Therefore CVS permits an earlier diagnosis if an abnormality is detected. It is generally thought that an earlier termination is associated with less physical and psychological trauma for the woman. The risk of pregnancy loss for CVS is thought to be slightly higher than for amniocentesis—approximately one percent.60

Fetal cell isolation is a fascinating new approach to prenatal diagnosis that has yet to emerge into clinical practice. Research has shown that a tiny number of blood cells from the fetus leak through the placenta and into the mother’s circulation during the early weeks of pregnancy.61 These cells can be distinguished from the mother’s cells and successfully separated in the laboratory. This means that by eight weeks gestation, a simple blood test from the mother can provide a sufficient number of fetal cells to do a genetic analysis. Not only does this procedure eliminate the risks associated with amniocentesis and CVS, it also provides an even earlier diagnosis. To date, it has been easier to detect the cells of male fetuses in the maternal circulation due to the presence of the Y chromosome in males. The accuracy of fetal cell isolation has not yet been considered great enough to use this approach outside the research context.

As these brief descriptions illustrate, a goal of prenatal diagnostic technology has been to move the point of diagnosis earlier and earlier in pregnancy. Preimplantation genetic diagnosis (“PGD”) takes this effort to the logical extreme by enabling genetic testing in the embryo before it is even implanted in the uterus. This approach requires fertilization of the egg in the laboratory, that is, in vitro fertilization (“IVF”). The fertilized egg is permitted to grow to an eight to twelve cell mass at which point a cell is removed for analysis. This cell removal does not injure the embryo. The single cell can then be analyzed to determine if there are any genetic abnormalities. Typically during IVF, approximately ten to twelve embryos are created. Using PGD on several of the embryos permits a determination of which embryos are “affected” and which are not. One or more embryos

60. See Mark I. Evans et al., Prenatal Diagnosis of Chromosomal and Mendelian Disorders, in FETAL DIAGNOSIS AND THERAPY: SCIENCE, ETHICS, AND THE LAW 17, 27 (Mark I. Evans et al. eds., 1989); Canadian Collaborative CVS-Amniocentesis Clinical Trial Group, Multicentre Randomised Clinical Trial of Chorion Villus Sampling and Amniocentesis, 1 LANCET 1, 6 (1989); George G. Rhoads et al., The Safety and Efficacy of Chorionic Villus Sampling for Early Prenatal Diagnosis of Cytogenetic Abnormalities, 320 NEW ENG. J. MED. 610, 615 (1989).

without the genetic condition would be transferred to the uterus in hopes of initiating a pregnancy.

Initially PGD was done primarily for couples at high risk for bearing a child with a genetic condition. Some couples chose PGD in order to avoid the choice of pregnancy termination. Of course, PGD generally involves the discarding of embryos but many couples still feel that PGD is less ethically troubling than other forms of prenatal diagnosis. In more recent years, PGD has become common in couples undergoing IVF for fertility reasons as a way of checking the genetic health of the embryos prior to transfer to the uterus. Although PGD often costs tens of thousands of dollars, more than 700 children have been born world-wide following this procedure. To date, there do not appear to be risks to the children who are produced from PGD.

PGD offers particularly interesting possibilities in the future for the genetic selection of children because it may reduce the ethical burdens of such selections. Pregnancy termination is a profoundly important decision in a woman’s life so it is unlikely that many women would choose to terminate a pregnancy for what might be considered trivial reasons. Of course cultural norms and pressures have a strong influence. For example, prenatal ultrasound for fetal gender identification followed by pregnancy termination for female fetuses has become relatively common in India and China. Data from a 2000 census in China indicates that the male to female ratio for newborn infants is as high as 135 males per 100 females in some of the more prosperous provinces, due primarily to the availability of prenatal ultrasound.\textsuperscript{62} Requests for prenatal diagnosis for gender selection in the United States are uncommon but not entirely unfamiliar. Anecdotally, these requests are often from individuals with a cultural background that favors male children. Nevertheless, it is unlikely that cultural norms in the United States will change so significantly in the foreseeable future that pregnancy termination for mild or trivial conditions will become commonplace, even with the advent of chemical abortions that may reduce the physical burdens and increase the privacy of termination decisions.\textsuperscript{63}

PGD offers an interesting alternative to pregnancy termination with several significant advantages. The obvious advantage is the avoidance of pregnancy termination. Again, embryos are often discarded or frozen indefinitely in the process, but many couples find this less ethically troubling than abortion. The other key advantage


is the ability to select from a number of embryos. Following hormone stimulation of the woman, approximately ten to twelve oocytes (eggs) can be retrieved through a laparoscopic procedure. Following fertilization and removal of the embryos that fail to develop properly, a couple may have their choice of half a dozen embryos. In this context, gender selection can be performed as well as selection based on any other genetic criteria for which testing is available. While a couple might be primarily interested in avoiding use of an embryo with serious deleterious mutation, the technology offers the opportunity for much more fine-grained selections.

While this technology is available now, two other technical advances will increase the power of PGD. The first is the potential ability to harvest eggs in large numbers from tissue samples of the ovary. Currently a woman’s ovaries must be stimulated with hormones to produce mature eggs capable of fertilization. In the foreseeable future, it will be possible to mature eggs in the laboratory. The prospect is for the ability to take a slice of ovary through laparoscopic surgery and to mature dozens or hundreds of eggs through hormone stimulation in a dish. Following fertilization with her partner’s sperm and subsequent PGD, the couple would have a wide selection of potential children from which to choose. Why not a baby girl for the first pregnancy with one set of traits, and a boy for the next pregnancy with a different, desirable set of biologic characteristics?

The second set of emerging technologies, and the potential weakness in this hypothetical scheme, is the genetic tests themselves. The sequencing of the human genome is virtually complete. This sequence, along with the genome sequences of a number of experimental organisms, will permit rapid progress in the identification of genes associated with diseases, physical traits, physiologic characteristics and, potentially, mental characteristics. Along with the sequence information comes the ability to conduct tens of thousands of genetic tests simultaneously. Therefore, to the extent that we understand how gene sequences function separately and together in the body, we can potentially gain enormous volumes of genetic information from small tissue samples and possibly even single cells.

The challenge in predicting this kind of capability is the current uncertainty over the relative contributions of genes, environment, and random variation in the development of complex characteristics. It is well recognized that for many “simple” genetic conditions involving only one gene locus, the disease severity in siblings can be quite different even though siblings share much of the same genetic background and similar environments. It is clear that the expression of single genes is profoundly influenced by other genes (perhaps many other genes), environmental influences, and random variations as organisms develop and age. On the other hand, we know that genes
play a significant role in complex traits such as intelligence. Children having bright parents are not guaranteed to be bright themselves, but they have a significant statistical advantage compared to children of parents with average or less than average intelligence. So, it is important to dismiss simple notions of “genetic determinism,” that is, the belief that genes are the essential determinants of biologic characteristics. Yet, to my mind, it is a mistake to dismiss genes as a significant component of complex traits.

The important question for this discussion is whether a detailed knowledge of an embryo’s genetic makeup will permit any accurate predictions of the future traits of that individual as a child or an adult. Are there simply too many intervening influences between implantation and, say, grade school to make predictions meaningful? My own guess is that such predictions will be much like predicting the weather. The weather, too, is the result of an enormous number of factors that interact in complex ways. So it may be impossible to predict the weather in a given location at a given time with great accuracy, but with more data and more knowledge about interactions, some reasonably accurate predictions are increasingly possible. In two or three decades, the embryologist could say to a couple,

“With a healthy pregnancy, no significant injuries or illnesses as an infant, and a stimulating early environment, embryo #56 has an eighty percent chance of achieving an IQ above 120, and a thirty percent chance of an IQ above 140. He also is likely to have limited athletic ability and a seventy percent chance of moderate obesity by adolescence. Embryo #31 on the other hand . . . .”

IV. ETHICAL ISSUES IN THE BIOLOGIC SELECTION OF CHILDREN

We can now return to the central question of this discussion. What should be the professional’s responsibility to provide prenatal diagnostic information? In addressing this set of issues, we should assume that professionals are functioning within a broad social context that determines professional norms. That is, these questions are too important to leave to physicians alone. Physicians act as the gatekeepers but we can hope they will fulfill this role with the general guidance and approval of society.

The history of wrongful birth litigation offers some general parameters. We can say with assurance that prenatal diagnosis is here to stay and that there are definitive obligations in many jurisdictions to offer services to certain at-risk groups. There are also a few well-articulated professional standards that have their roots, to some degree, in the fear of litigation. As noted, it is well-accepted that obstetricians should alert women of “advanced maternal age” to their increased risk for bearing a child with Down syndrome or other ane-
uploid syndromes and make them aware of prenatal diagnostic capabilities. Similarly, the American College of Obstetrics and Gynecology’s Department of Professional Liability issued a statement in 1985 indicating that obstetricians should immediately begin to advise women about the availability of the alpha-fetoprotein test (“AFP”). This tests the pregnant woman’s blood to provide predictive information about whether the fetus might be affected with a neural tube defect such as spina bifida. The statement advised: “It is equally imperative that every prenatal patient be advised of the availability of this test and that your discussion about the test and the patient’s decision with respect to the test be documented in the patient’s chart.”

On the other hand, based on legal liability considerations, we cannot claim that all potential prenatal diagnostic information must be provided to couples. As noted, a challenge to the constitutionality of a state law prohibiting wrongful life and wrongful birth torts has not been supported in two cases. This means that prenatal diagnosis is not tightly linked to the notions of privacy or liberty in the abortion context. Women have a constitutionally protected right to make a decision about pregnancy termination in the first two trimesters of pregnancy. At least according to the two courts which have decided this issue, there is not a parallel constitutional right to ob-

64. Physicians need not provide these services themselves. Professionals can fulfill their obligations through the provision of information alone. It may then be up to the woman to find someone who provides the service, or who would provide the service at a price or location that the woman can manage.

65. Spina bifida is one form of “neural tube defect” that is characterized by an abnormality in the development of the coverings of the spine. Supra note 3, 608-09. Children born with spina bifida (also termed myelomeningocele) typically have a protruding sack or open tissue at some location along the length of the spine. Id. The skin and bony protection of the spine are missing due to the failure of the neural tube to close early in fetal development. The spinal cord is exposed, leading to abnormal development and malfunction. Id. These children usually lack motor and sensory function in the areas of the body served by that portion of the spinal cord and below.

Another form of neural tube defect is anencephaly, in which the scalp, upper skull, and cerebral hemispheres of the brain are missing. Id. Children with anencephaly are either stillborn or die within days of delivery unless artificially supported. Id. Neural tube defects during fetal development lead to leakage of a chemical called alpha-fetoprotein into the amniotic fluid and subsequently into the pregnant woman’s blood stream in small concentrations. Aubrey Milunsky, Maternal Serum Screening for Neural Tube and Other Defects, in GENETIC DISORDERS AND THE FETUS, supra note 59, at 635-701. An increase in the pregnant woman’s blood alpha-fetoprotein level can indicate that the fetus is affected with a neural tube defect, although there are a number of other normal and abnormal causes of such an elevation. Id. Currently, a battery of three or four chemical tests is performed on maternal serum to evaluate the pregnancy for risk of neural tube defects and several other conditions, including Down syndrome. Id.


tain any and all information on which a termination decision might be based. More specifically, women have a right to decide whether they wish to remain pregnant at all; they might not have the right to decide whether they wish to remain pregnant with a specific fetus.

From an ethical perspective, there also is no discernable right to be offered or to obtain a full genetic analysis of the fetus. Privacy rights are typically framed as negative rights, that is, one has the right to be left alone or to prevent access to personal information. Privacy rights cannot be used to compel the assistance of others or compel the provision of information, even if the subsequent use of the information is a private matter. More plausibly, the ethical foundation of prenatal diagnostic information is the right to make an informed decision about important health issues like reproduction. If so, then prenatal diagnostic choices are akin to many other choices in medical relationships. Typically in other areas of medicine, providers are required to provide some information but not all conceivable information about available choices.

Some authors contend that the ethical standard for the provision of prenatal diagnostic information should be all-inclusive. That is, all information that each individual woman or couple requires to make a decision should be provided. Adrienne Asch argues that such a standard permits full choice and avoids the divisive and destructive task of "line-drawing" whereby some conditions are deemed sufficiently severe to warrant prenatal diagnosis while others are not. She would prefer to limit the adverse consequences of prenatal diagnosis per se on those with disabilities by improving education about life with disabilities and otherwise fighting inaccurate and discriminatory attitudes. She trusts that, with time, couples will choose not to use or abuse prenatal diagnosis without the need to place artificial limits through professional standards.

There are at least several difficulties in promoting what I will call a "comprehensive standard." The first is the simple pragmatic concern over how such extensive and complex information could be managed in a professional encounter. Presumably this standard requires that all conditions be discussed for which tests are available, without respect to the prevalence of the condition or the relative risk of the pregnancy. Even if a variety of different conditions are col-

70. See Asch, supra note 30, at 90-91.
71. Id. at 87-88.
72. Id. at 88.
73. See id. at 87-92.
lapsed into logical categories, such as all the conditions that cause profound intellectual disabilities, the task would remain formidable. Obviously visits to the obstetrician (or family practitioner or nurse-midwife) need to address a host of issues concerning the pregnancy other than prenatal diagnosis so the time is limited to discuss these issues. Further, care providers do not consistently address these issues at all at the present time. One observational study of obstetricians and nurse-midwives in 1998 found that sixty percent of first prenatal visits addressed family history, sixty percent subsequently addressed maternal serum markers (“AFP”), and thirty-four percent discussed ultrasound in the second trimester. 74 For women of 35 years and older, ninety-eight percent were counseled about amniocentesis or CVS. Notably, the discussion of prenatal diagnosis for women less than 35 years took an average of 2.5 minutes while for women 35 and older, the discussion lasted an average of 6.9 minutes. 75 Of course, we also need to consider the time it would take to explain all of the results of testing. If thousands of tests are being conducted, dozens or even hundreds of results may be sufficiently abnormal to warrant discussion. 76

So from a practical standpoint, it is hard to imagine how expectations for a vastly expanded discussion about prenatal diagnosis could be accommodated. 77 Significantly lengthening the visits would require additional professional personnel, mechanisms to pay for the expanded services, and marked improvements in provider education to permit accurate patient counseling. These changes would necessitate a fundamental restructuring of prenatal services. If prenatal di-

75. Id.
76. The concepts of test sensitivity and specificity are important here but beyond the scope of this discussion. Suffice it to say that screening tests are designed to be highly sensitive but not necessarily specific. When a large population is screened, there is almost always a significant number of false positive test results for each true positive. In the case of maternal serum AFP screening for neural tube defects, for every one hundred women with an initially positive test result, only two will have an infant affected with a neural tube defect. See Aubrey Milunsky et al., Predictive Values, Relative Risks, and Overall Benefits of High and Low Maternal \(\alpha\)-Fetoprotein Screening in Singleton Pregnancies: New Epidemiologic Data, 161 AM. J. OBSTETRICS & GYNECOLOGY 291, 293 (1989).
77. An alternative approach to a comprehensive standard would be to simply perform all of the prenatal diagnostic tests for couples that choose prenatal diagnosis without offering education and separate choice about the different kinds of tests on the complete panel. This would save time on the front end of the testing sequence but would not eliminate the need to discuss the results of the tests at the other end. Such an approach would not uphold the ideal of informed consent and would pose some difficult dilemmas for couples who received more information than they really wanted. Of course there would be pressure from the professional community to limit the number of tests on the panel to a select number of relatively severe and relatively common conditions, but that temptation would have to be resisted if we wanted a truly comprehensive standard.
agnosis becomes an increasingly important medical service, these kinds of changes certainly are feasible. We might envision a whole new set of professional services to specifically address these needs, involving new professionals, new payment mechanisms, and new educational technologies. Until such time, a comprehensive standard could not be layered onto the current system of prenatal care.

A second concern with a comprehensive standard for information is that it does not permit an obvious distinction between what information is ethically desirable (presumably all) and what information might be mandatory. By mandatory here I mean that professionals could be held legally liable for damages if the information was not provided. Does a comprehensive standard mean that professionals could be successfully sued for any relevant information that they failed to provide to a couple upon the birth of an affected child? There are many rare conditions, mild conditions, and non-disease related conditions that are or will be amenable to prenatal diagnosis. It is one thing to claim that all these capabilities should be discussed with prospective parents, and quite another to assert that failure to do so should result in legally enforceable damages. Unless we are willing to say that a comprehensive standard is both ethically and legally mandatory, then a line-drawing exercise will be necessary to distinguish between omissions that merit sanction and those that do not.

A third concern with the comprehensive standard relates to the goals that such a standard seeks to gain. The concern is that line-drawing between different heritable or congenital conditions is hurtful to the community of those with disabilities. This sounds plausible, although we should not assume that those with disabilities, and those who have given birth to children with disabilities, are all in agreement with this point. In any case, the question is whether the promotion of a comprehensive standard ultimately will be less injurious to those with disabilities. Surely a social standard to encourage extensive discussion of these capabilities will promote actual use of the technology. A parallel effort can be made to reduce or eliminate discriminatory attitudes toward those with disabilities, but it seems highly likely nonetheless that prenatal diagnosis for an expanding list of conditions would become increasingly utilized. If so, then it also seems possible that disability will be seen less as an acceptable form of human diversity and more as an avoidable burden that people should choose to prevent. The basic point here is that a comprehensive standard for prenatal diagnostic information seems like a very poor strategy for promoting tolerance for disability.

These considerations leave our quest for professional standards for prenatal diagnosis on a broad middle ground. Some information is required in certain circumstances but all potential information need not nor cannot be provided. In my view, this requires some line-
drawing. That is, we, as a society, must make a determination of what kinds of information and tests should be offered for prenatal diagnosis and which need not be offered. If we accept this general premise, we must decide on a principle or set of principles by which such a line could be drawn. In my view, such a line should be drawn as a matter of professional standard, not as a matter of law or regulation. Further, as I will outline below, I believe the correct ethical analysis is provided by the wrongful birth torts. More specifically, the key question is whether the condition often results in tangible harms to the parents.

The concept of a general “line” in this context is consistent with recommendations of the majority of public bodies that have commented on this issue. Of course, there will be many arguments about where a line should be placed on a spectrum of disease severity and disease prevalence, but the basic concept of a line is familiar. A number of scholars and authoritative committees have raised concerns over the use of prenatal diagnosis for “mild” conditions or “trivial” indications. The President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research focused primarily on prenatal diagnosis for sex selection, stating:

The idea that it is morally permissible to terminate pregnancy simply on the ground that a fetus of that sex is unwanted may also rest on the very dubious notion that virtually any characteristic of an expected child is an appropriate object of appraisal and selection. Taken to an extreme, this attitude treats a child as an artifact and the reproductive process as a chance to design and produce human beings according to parental standards of excellence, which over time are transformed into collective standards. . . .[T]he Commission concludes that although individual physicians are free to follow the dictates of conscience, public policy should discourage the use of amniocentesis for sex selection.78

The Committee on Assessing Genetic Risks of the Institute of Medicine took a more concrete stand and recommended that:

prenatal diagnosis not be used for minor conditions or characteristics. In particular, the committee felt strongly that the use of fetal diagnosis for determination of fetal sex or use of abortion for the purpose of preferential selection of the sex of the fetus is a misuse of genetic services that is inappropriate and should be discouraged by health professionals. . . . The committee believes this issue warrants careful scrutiny over the next three to five years as the availability of genetic testing becomes more widespread, and espe-

cially as simpler, safer technologies for prenatal diagnosis are developed.79

The American Medical Association’s Council on Ethical and Judicial Affairs supports limitation of prenatal diagnostic services to more serious conditions. The council suggests: “Selection to avoid genetic disorders would not always be appropriate. . . . [S]election becomes more problematic as the effects of the disease become milder and as they become manifest later in life.”80 The Council states that a variety of factors influence whether prenatal selection for specific conditions would be ethically acceptable. The Council encouraged additional work on the appropriate uses of prenatal diagnosis stating: “[I]t is important to begin discussion of the issue now to ensure that appropriate ethical guidelines are in place when new applications become available.”81

Several scholars have taken similar positions. Thomas Murray concludes, “[i]n short, we should not offer to provide prenatally information about traits or afflictions that are not substantial burdens on parent and child. We certainly should not assist couples in a misguided quest for the child that embodies their ideal collection of traits, including gender.”82 Several authors have attempted to draw more lines to preclude specific uses of prenatal diagnosis. Stephen Post, Peter Whitehouse and Jeffrey Botkin argued against the use of prenatal diagnosis for familial Alzheimer disease.83 Carson Strong argued for no restrictions on prenatal diagnosis for disease related conditions.84 Strong’s analysis would support a clinician who refused services for diagnosing nondisease related characteristics.85 Dena Davis has written about the circumstance in which deaf parents consider using prenatal diagnosis to assure that their child also will be deaf.86 Davis concludes:

A decision, made before a child is even born, that confines her forever to a narrow group of people and a limited choice of careers, so violates the child’s right to an open future that no genetic counseling team should acquiesce in it. The very value of autonomy that

81. Id. at 641.
84. CARSON STRONG, ETHICS IN REPRODUCTIVE AND PERINATAL MEDICINE: A NEW FRAMEWORK 137-48 (1997).
85. Id. at 146.
grounds the ethics of genetic counseling should preclude assisting parents in a project that so dramatically narrows the autonomy of the child to be.\textsuperscript{87}

What are the competing considerations for developing a “line”? As we have seen, there is an expanding array of technical developments that permit an analysis of the embryo and fetus, potentially with less physical risk to the prospective mother. Since these tools are available and many couples wish to avoid the birth of a child with disabilities, there is an impetus to ensure that couples are aware of these options. To the extent that a child with a significant disability can have an adverse effect on the parents in terms of heartache, worry, time, effort, and money, the avoidance of these impacts promotes the welfare of the parents. We can say that failure to provide information about prenatal risks for a child with a significant disability is contrary to the interests of the parents. This concept is consistent with the basic rationale of the wrongful birth suits. However, this rationale weakens as the adverse impact on the parents weakens. The rationale virtually disappears for conditions that do not have a significantly adverse effect on the parents.\textsuperscript{88} This includes, arguably, non-health conditions, mild or treatable conditions, and conditions that do not affect children.

Some in the disability rights advocacy community argue that children with disabilities do not have adverse effects on parents and families.\textsuperscript{89} In my view, the advocates are correct that often, very often, the adverse effects are overstated. The literature does not support the notion that children with significant disabilities are a common trigger for divorce, or a source of chronic sorrow, or dysfunction in families. Such impacts occasionally occur, most often in couples with marginal coping skills to begin with, but they are not the norm. The literature tends to suggest that most families cope quite well with the demands of a disabled child and that the child is loved and supported as his or her own person and for what he or she brings to the family. I believe many or most of these parents would not consider the disabled child to have caused a negative impact on the family. So these issues are by no means straightforward. Yet, I think we can also say that successful coping with a significant disability requires an enormous investment of time, energy, money and lost opportunities. Even though a good outcome is often achieved, the path is difficult. Further, many parents who have had a child with, say, Tay Sachs disease or cystic fibrosis use prenatal diagnosis to prevent

\textsuperscript{87} Id. at 14.
\textsuperscript{89} See Asch, supra note 30, at 85.
the birth of a second affected child. So we certainly cannot conclude that all parents of disabled children view the experience as rewarding on the whole. The basic point here is that although families typically cope very well with the challenges of a disabled child, the experience is sufficiently demanding that many reasonable, sensitive people would choose to forgo that challenge. Further, the magnitude of that challenge can be used as a criterion for whether prenatal diagnostic information should be offered.

We might also question whether disabilities have adverse effects on the children themselves to the extent that prenatal diagnosis and pregnancy termination would be a preferred alternative for the child. In my view, criticisms of the wrongful life concept are valid, and it cannot be argued that prenatal diagnosis and pregnancy termination are justified on behalf of the child. While there may be rare exceptions to this general conclusion, it is valid for the great majority of conditions for which prenatal diagnosis is available.

Also in support of a duty to offer prenatal diagnostic information is the respect we hold for a certain protected sphere of decision-making around our reproductive lives. John Robertson argues that couples should be free to do what they want with their reproductive lives unless someone else is injured or risks injury on the process. 90 This makes sense, although agreement will break down on how we define injury and risk of injury in this context. Obviously, a big part of the abortion debate is whether “someone” of moral significance is being terminated. In any case, the basic point here is that we, as a society, may want to show somewhat more deference to reproductive decisions compared to other kinds of medical decisions.

In contrast, there are a number of important considerations that work to limit the provision of information. The basic fact that embryos are discarded through PGD and fetuses are terminated through other forms of prenatal diagnosis raises serious ethical concerns. For those who believe that prenatal life should be afforded full moral status, this whole enterprise is ethically unacceptable. For many others, embryos and fetuses do not have full moral status as persons but they have sufficient moral status to preclude destruction for trivial reasons. Society is likely to remain divided on the moral status question, but I believe there is sufficient consensus that public policy about prenatal diagnosis should not promote or condone discarding embryos or terminating fetuses for less than weighty reasons.

A more subtle set of considerations relate to the nature of the parent-child relationship. Parents have broad control over their chil-

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dren’s environment, including discipline, diet, religion and education. Fine-grained prenatal selections could extend this control to the biologic nature of children. To some extent, parents can alter the biology of children through surgery or medications, but these interventions are tightly regulated through the medical profession. Any such interventions would only be justified based on the welfare of the child. A surgeon would not perform plastic surgery on a child at the behest of a parent’s request unless the surgeon was convinced it was in the best interest of the child first and foremost. The immediate point is that society does exert some control over the parent-child relationship to limit the control parents have over many aspects of their children’s lives.

More to the point, however, is the question of whether the selection of children for desirable characteristics will improve the quality of children’s lives or of the parent-child relationship. Parents do try to influence and control the lives of their children to a significant extent, but, ultimately, children mature and move toward their own independent goals in life. This is always a complex and often difficult transition. Many people experience this transition first as a child and second as a parent. These are both central relationships in life. What will prenatal diagnosis and selection add to this relationship? To the extent that strong parent-child relationships are founded on a core of unconditional love, biologic selections may prove to be damaging to this central bond in life. This is a nebulous and hypothetical concern but sufficiently ominous to sustain a policy against broad-based prenatal diagnosis for non-health traits and mild conditions.

Finally, the impact of extensive prenatal diagnosis on those with disabilities must be considered. At the present time it is probably fair to say that social supports for those with disabilities have increased in recent decades despite the development of prenatal diagnostic technologies. This only means that there is no simple relationship between these social spheres. If prenatal diagnosis becomes a significant and important part of pregnancy management, then concerns over the impact of this technology on those with disabilities is entirely reasonable. If many prospective parents routinely seek their perfect child through extensive selections, then perhaps those parents who choose to forgo this technology will be seen as negligent. If social resources are devoted to selecting “the best” children, perhaps the disabled children who slip through the net will be the responsibility of their parents to muddle through as best they can. Or, darker still, perhaps withholding or withdrawing life-sustaining care often will be deemed appropriate for “defective” children who slip through the prenatal screen. Some will argue that any of these may come to pass in decades hence as long as we tolerate prenatal diagnosis at all.
But surely the risks are greater if we foster the extensive and detailed selection of children.

Each of these considerations deserves more attention than I can devote here. Nevertheless, we can return to the cases at the beginning and see how this discussion might guide us to a decision. In Case #1, Dr. Owen failed to provide Molly and Bert information about the increased risk of Down syndrome by virtue of Molly’s age. A child with Down syndrome was born. Do they have a legal and ethical claim against Dr. Owen, who chose not to inform them of the risk? In most jurisdictions a legal claim would have a strong foundation and, under my analysis, a strong claim for ethical criticism as well. This has become a familiar enough situation that relatively clear answers are available.

Case #2 is more problematic. The physician failed to take a full family history and a child was born with an increased risk of breast and ovarian cancer as an adult. To date, there is no clear standard that encourages obstetricians to take a family history of cancer since cancer is not immediately relevant to the health of the mother or fetus. No cases have been brought as of yet to explicitly raise this issue. Further, there is a general consensus that BRCA1/BRCA2 testing should not be offered in the context of prenatal diagnosis, nor are children generally offered genetic testing for adult onset conditions unless preventive measures are appropriate in childhood. The analysis above supports this general consensus. From my perspective, risk of an adult onset disease in a child does not cause a sufficient impact on the parents to warrant prenatal diagnosis as a standard of care.

Case #3 was developed as a situation in which prenatal diagnosis for a “trivial” and non-health related condition (perfect musical pitch) might seem plausible. Further, the error of the physician was providing false information, not the potentially more excusable error of omission in failing to inform about testing capabilities. There are no legal cases to address such a claim, nor can we expect one in the foreseeable future. From an ethical perspective, this analysis provides no support for the parent’s claim of injury. The notion that a healthy child embodies a harm to the family because he lacks an extraordinary talent is not sustainable. While perhaps we understand the parent’s sentiments in this situation, the use of this powerful technology for such a selection is contrary to a set of values that we must seek to protect. Prenatal diagnosis has appropriate uses, but our society must carefully articulate those uses before we lose too much in the name of progress.
A CHOICE OF EVILS IN PRENATAL TESTING

DAVID WASSERMAN*

INTRODUCTION

The aim of this paper is to examine the comparative strengths and weaknesses of two approaches to mitigating the offense given, and harm threatened, by prenatal testing for impairments: 1 limiting such testing to the most severe diseases and impairments, or imposing no medical limits at all. Although I favor the latter approach, I will argue that the alternatives present a choice between distinct evils.

To set the stage for this discussion, it is necessary to challenge the conventional picture of prenatal testing, its purposes, and its dangers. On this conventional view, prenatal testing serves the legitimate medical function of preventing severe diseases in future children, as well as the associated health threats to the parents and families of those children. Because of the small number of conditions that are currently detectable, such testing is largely used for the appropriate purpose of preventing such severe conditions as cystic fibrosis (CF), spina bifida, Duchenne’s Muscular Dystrophy (DMD), as well as Down syndrome and several other trisomies. There is one glaring exception: sex-selection, which is devoid of medical justifica-

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1. I will refer to prenatal testing for “impairments,” rather than “disabilities,” to reflect the now-conventional understanding of impairment as physical or mental abnormality, and disability as an interaction between such limitations and an individual’s environment. Clearly, a disability so understood is not the kind of condition that can be tested for prenatally, or genetically.

tion except for sex-linked diseases. Fortunately, however, there is little demand for prenatal sex selection in the United States, even for the relatively benign purpose of family balance; such testing is discouraged or condemned by professional organizations and, in some places, by law.3

But, according to this conventional view, a serious threat is just over the biotechnological horizon. “[T]he age of positive eugenics is almost upon us.”4 It will soon be possible to do prenatal genetic testing for minor disorders, and for minor risks of severe disorders; in the not so distant future, genetic tests will be available for positive traits as well, like intelligence. The medical community, particularly the obstetric establishment, views this prospect, with sanctimonious horror:

It may be too early to warn that we are at the edge of a slippery slope towards a new dimension of eugenics, but we must realise that new tools to fulfill the tempting wish to have not only healthy, but gifted children will soon be in our hands.5

This is not a wish, however tempting, that doctors should help their patients to fulfill, because terminating a pregnancy of a baby expected to be healthy is “counterintuitive to the Hippocratic ideas of health care.”6 To avoid this kind of professional abuse, “there is an urgent need to extend the current ban on prenatal paternity and gender testing to any parameter of prenatal genetic diagnosis that is not immediately related to severe disease in the prospective child.”7

A clue that there is something very wrong in this picture should come from the restriction to “severe disease.” It would be considered not only unnecessary but unethical and perverse for doctors to refuse to provide preventative or therapeutic services to their patients, or the public, for minor diseases (except in cases of extreme scarcity). Indeed, much of our current health care budget, and our public funding for research, prevention, and treatment, is directed towards arguably minor, or at least non-severe diseases. If prenatal testing serves the legitimate medical function of preventing diseases, why should it be wrong (if less urgent) to extend it to minor diseases? This restriction should make us question whether prenatal testing can be seen as a medical function at all, in the widely-accepted sense of a function serving to protect or restore the health of individual pa-

4. Henn, supra note 2, at 445.
5. Id. at 446.
6. Id.
7. Id. at 445.
tients. If it is not, however, we are not at the edge of a slippery slope, but already in an ethical limbo, facing unresolved questions about the basic legitimacy of a non-medical practice carried out by doctors and other health professionals.

I. DEMEDICALIZING PREGNATAL DIAGNOSIS

Prenatal diagnosis—whether through amniocentesis, chorionic villi/s sampling, or preimplantation genetic diagnosis; whether for Down, CF, female gender, or blue eyes—needs to be seen for what it is, or more importantly, what it is not. It is not a medical procedure—a procedure intended to protect or restore an individual’s health—unless it is undertaken to protect the mother’s health, or the health of the fetus or infant, through early intervention. It is, typically, a procedure to identify and destroy unwanted organisms. But to say that it is not a medical procedure is not to say that it is wrong, or even wrong for a doctor to perform. A pregnancy test for an unmarried adolescent, undertaken to procure an abortion at the earliest possible date (if the test is positive), is not a medical procedure either, unless it is intended to protect the health of the adolescent, which it rarely is (except in the expansive World Health Organization (WHO) sense of “health” in which avoiding the social burden of adolescent child-rearing is a matter of health). It is quite possible to regard abortion as justifiable, and to regard doctors as the appropriate agents to carry it out, while denying that it serves to protect or restore the health of individual patients. One can take a similar view of physician-assisted suicide—the fact that suicide is not health-protecting or restoring does not mean that doctors should not assist it.

What this does suggest, however, is that mainstream opponents of prenatal sex-selection cannot reject it on the grounds that it is not a bona-fide medical service. When groups such as the Institute of Medicine piously condemn genetic testing and abortion for sex-selection on the grounds that it is “a misuse of genetic services,” they need to explain why abortion for child- or disability-prevention is any less of an abuse, since neither typically serves to promote or protect the health of any individual human being. If doctors can legitimately perform non-healing functions in aborting the unwanted fetus carried by an adolescent girl, or in honoring the express desire of an elderly patient to avoid a lingering death, then why would they not perform a legitimate function by letting parents have the kind of children they want—male, brown-eyed, or unimpaired? The reason cannot be simply that facilitating such parental choice is not a medical

8. ASSESSING GENETIC RISKS, supra note 2, at 105.
The standard critique of sex selection conflates two distinctions: between pathological and normal human variations (or disease and non-disease states), and between medical and non-medical functions. Unlike many disability scholars and bioethicists, I believe there can be a plausible biological basis for the former distinction, between pathological and normal states; that the distinction need not reflect social, cultural, or moral values. But while this first distinction is needed to explain the second, which concerns the protection or restoration of health, the two distinctions are not identical. A doctor who prevents the existence of someone who will have certain pathological states—diseases or impairments—is not performing a medical function (although he may be performing a public-health function). The doctor who selects among in vitro embryos to find a compatible marrow-donor for an ailing child is performing a medical function for that child, but not for those embryos. If the rationale for the doctor’s services to enhance the couple’s freedom of choice or to save an ailing child (when no else else’s rights are violated), why should it matter if the conditions they “prevent,” unlike female sex or brown eyes, are abnormal, pathological, or inherently undesirable? There need not be anything wrong in a doctor’s performing a non-medical function; the job descriptions of professionals often change, and sometimes for the better.

II. TWO EVILS

The more credible concern about the expansion of prenatal testing is that doctors who assist their patients in aborting fetuses or discarding embryos, on the basis of sex or marrow-incompatibility, are doing something wrong, not because it is non-medical, but because it abets the degradation of the parental role and the commodification of children. The concern is that once parents who intend to have children can set conditions on the kind of children they will have, they slough off the commitment to loving and rearing whatever child they have and start down the slope towards designer babies; toward the corruption of child-making by a consumer mentality. This concern, however, grounds an objection to prenatal testing for disease and disability, as well as for sex and marrow-compatibility.

I do not want to dismiss this concern, because I think that the threat is real, if exaggerated. Moreover, I agree that autonomy has

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11. See, e.g., SCREENING AND COUNSELING, supra note 2, at 57-58.
enjoyed an unwarranted ascendancy as the “master value” in bioethics, and that its promotion must often yield to other concerns.\textsuperscript{12} But I will argue that the threat of insufficient commitment and commodification is not the only one raised by prenatal testing for disability, and that it may be the lesser of two evils. If such testing can be seen as the first step towards a noxious and destructive finickyness in the creation of children and families, it can also be seen as something very different and less novel. The phenomenology of selecting \textit{against} disability and selecting \textit{for} desired traits may be quite different, even if certain moral theories, such as standard act-utilitarianism, treat them as similar.\textsuperscript{13} Eliminating disabled fetuses or embryos may be seen as applying modern technology to the ancient imperative of discarding defective children, rather than to the (alleged) contemporary desire for “a perfect baby.”\textsuperscript{14}

The classical Greeks who left defective children on mountainsides were not nascent perfectionists; they were more likely to have been frightened, superstitious parents anxious to rid themselves of children with the marks of divine disapproval. Like modern parents who will not abort after the second trimester, ancient parents got rid of defective children with some scruples and constraints—they would not kill the children directly, but only facilitate their death from natural causes such as exposure.\textsuperscript{15} Beyond avoiding stigma and divine displeasure, their aspirations for their children may have been exceedingly modest.

The most effective way of countering the contemporary expression of those enduring fears and superstitions in the demand for prenatal disability testing may be to refuse to dignify such testing as a medical function; to treat it instead as a consumer service. The likelihood of serious impairment would be neither a necessary nor sufficient condition for that service. Permitting or requiring doctors to offer prospective parents the widest available menu of prenatal tests, including but not limited to tests for various impairments, might help to de-stigmatize disability. But such reproductive freedom would not be a “positive good,” or an unmixed blessing. A regime of unfettered parental choice would take the focus off disability only by further corrupting the process of child-making, encouraging a finicky

\textsuperscript{13} See, e.g., Julian Savulescu, \textit{Procreative Beneficence: Why We Should Select the Best Children}, 15 \textit{Bioethics} 413 (2001).
\textsuperscript{14} See Glenn McGee, \textit{The Perfect Baby} (2000).
\textsuperscript{15} For the classical Greek practice of exposing unwanted or defective children, see Sophocles, \textit{Oedipus Rex} (Roger D. Dawe ed., 1982). For a discussion of the classical Greek attitudes towards causation action and responsibility, see Arthur W.H. Adkins, \textit{Merit and Responsibility: A Study in Greek Values} (1975).
consumer mentality or a vulgar perfectionism on the part of prospective parents. Some would argue that this would be too high a price to pay for alleviating the stigma of disability; others would argue that it would fail, or backfire, increasing intolerance for disability.

III. TWO APPROACHES

There are two approaches to regulating prenatal testing that appear to parallel the two concerns about commodification and stigma. One approach would limit testing/responsibility/liability to a small subset of severe or widespread disabilities; the other would expand testing/responsibility/liability beyond disability to a full range of conditions that parents might seek to avoid, with the “burden of disability” merely one factor in the assessment of duties and damages. Dorothy Wertz and Jeff Botkin have offered very different versions of the former approach; I favor the latter approach and will defend it here, not as a means of promoting parental autonomy, which I regard as a suspect or overrated goal, but as a way of mitigating the harm and muting the expressive significance of prenatal testing for people with disabilities.

I will argue that these approaches should be seen as responsive to the two distinct concerns about prenatal testing I have sketched above: the growing sway of a consumer mentality toward procreation, and the continuing stigmatization of disabilities. Although both threats involve a degradation of the parental role, resistance to them may pull us in opposite directions. Disabilities may be less stigmatized in a reproductive regime in which neither they, nor any subset of them, have a special role in legitimizing abortion; consumerism may have less sway in a regime that permits testing only for the most severe disabilities. But the former takes the onus off disability by promoting a broader consumer mentality, while the latter discourages such a mentality by keeping the onus squarely on disability. Since it is neither feasible nor morally acceptable to prohibit all prenatal testing, we will be faced with a choice of evils.

To make the distinction between these two purposes is not to deny that some people with specific impairments, or their advocates, favor a narrowing approach that excludes their impairment, or even to deny that the dominant motivation for a narrowing approach may be to avoid the stigmatization of as many impairments as possible. But there is considerable force to the argument made by critics of line-

drawing that, if this is its purpose, it is self-defeating; that the focus and debate on the placement of the line will only serve to re-affirm the legitimacy of impairment in general as a basis for abortion. Those impairments placed on the near side of the line may enjoy little or no reduction in stigma, since their exclusion as grounds for abortion may be perceived as the result of balancing or compromise, not as the result of substantially changed beliefs about the burden they impose.

The tension between narrowing and widening approaches has a rough counterpart or analogue in debates about employee drug testing and airport profiling; between those who favor ever-greater refinement in the criteria for imposing an intrusive or demeaning procedure and those who favor its universalization. In the latter cases, the imposition of the same drug tests and security tests on everyone largely eliminates the insult to the preponderantly innocent members of suspect groups, at the cost of small inconvenience to everyone, great administrative burdens, and a more pervasive threat to civil liberties; in the case of prenatal testing, the costs of “universalization” are far less tangible: the corruption of parental attachment by a consumer mentality. As in prenatal testing, the costs of further refinement in drug testing are the greater stigmatization of those selected against by the more refined procedure, and the “penumbral” stigmatization of those who barely pass.

In the next Section, I will offer a critique of the most fully developed narrowing proposal. In the final Sections, I will take up two significant challenges to the alternative approach of consumer sovereignty: that it will increase, not reduce, the stigmatization of people with disabilities, and that it cannot accommodate wrongful life or wrongful birth actions under the rubric of medical malpractice or autonomy violation.

IV. PROPOSALS FOR RESTRICTING PRENATAL TESTING

Jeff Botkin and Dorothy Wertz have proposed quite different narrowing approaches, with very different kinds of restrictions on prenatal testing, both designed to maintain the medical legitimacy of the procedure. Botkin would permit testing only for conditions expected to impose serious burdens on parents and families, while Wertz would permit testing for any pathological condition for which the future child was at high risk, regardless of severity. Wertz’s approach

18. Botkin, Line Drawing, supra note 16; Wertz, supra note 16.
has the virtue of unprincipled consistency; it would permit testing and termination for any condition deemed pathological, however minor, from color-blindness to a missing toe. This permissive approach would be rejected by most defenders of current practice. I will have nothing further to say about it here, since I will be advocating the even more permissive alternative of eliminating the requirement that the condition tested for be pathological.

Botkin would drop the fiction that prenatal testing served any medical function for future children, but he argues that it does, or could serve, a legitimate medical function for actual parents and families—to protect them from harm arising from the birth and upkeep of children with severe impairments. While a notion of “family health” would be highly suspect, having the same pretextual quality as “maternal anxiety” as a medical justification for abortion in general, Botkin bases his standard on family welfare, not health. This commits him to a broader conception of the doctor’s professional role than many doctors and bioethicists would be willing to accept. But since I see no reason for restricting the doctor’s role to the protection and promotion of health, narrowly conceived, I have no criticism of Botkin on this ground.

I will not argue, however, that Botkin’s standard is untenable. He claims that the line he proposes will not only arrest the slide down the slippery slope toward “designer babies,” but mitigate the adverse impact of prenatal testing on people with disabilities. I do not know whether the implementation of his standard would reduce the adverse social and psychological impact on people with disabilities, though I am skeptical that it would. What I will claim is that the proposal to restrict offers of prenatal testing to conditions likely to have a substantial impact on family welfare is ambiguous and unworkable. Because the correlation between the medical severity of the conditions tested for and the psychological impact on families is much weaker and less susceptible to generalization than Botkin recognizes, it is not clear how he can develop a standard of care that would protect the welfare of families who had strong but idiosyncratic reactions to traits like female gender or webbed fingers. And to the extent that generalizations can be made about family welfare, they will license the offer of prenatal testing for traits such as female gender or webbed fingers in societies where the birth of children with those traits will be expected to have a significant impact on family welfare.

In the final Sections, I will take up two significant challenges to the alternative approach of consumer sovereignty: that it will increase, not reduce, the stigmatization of people with disabilities, and that it cannot accommodate wrongful life or wrongful birth actions under the rubric of medical malpractice or autonomy violation.

V. FETAL IMPAIRMENT AND PARENTAL WELFARE

Botkin’s “family welfare” standard is an unstable hybrid, because there is only a tenuous link between the medical severity of the fetal abnormality and the welfare of the family. As a medical notion, “severity” offers a workable if vague standard, at least if it is taken to involve only an ordinal comparison: most professionals and laypeople would rate Tay Sachs more severe than CF; CF more severe than color-blindness. But a standard based on “the impact of the medical condition on the family,” authorizing testing for “conditions that may significantly impair the legitimate interests of the parents [and other children]” 24 will either yield highly objectionable results in many cases or end up as little more than a variant of the parental-preference standard that Botkin rejects.

In an earlier article, Botkin proposes offering tests for conditions that would threaten harms to parents “of approximately the same magnitude as the harms of an unwanted pregnancy.” 25 His list includes diseases “often fatal in childhood,” chronic illnesses “requiring repeated hospitalization,” conditions that would not allow a child “to achieve independence in his or her adult years,” and conditions “of such severity that there are constant demands on the parents for time, effort, and financial resources.” 26 As Adrienne Asch has argued, these features—particularly the last two—have a much more contingent relationship than Botkin assumes to the specific medical conditions he cites as examples, such as Down and CF. Frequent, extended hospitalizations and life-long dependence may arise from deficient, discriminatory, and malleable social arrangements rather than from anything inherent in those medical conditions. Even if we accept, for the sake of argument, that these burdens are inherent in those conditions Botkin cites, it is not clear why these burdens should be regarded as worse than those of many conditions

24. Id. at 300.
25. Botkin, Fetal Privacy, supra note 16, at 36. Botkin arrives at this standard by arguing that it represents the same balancing of parental and family interests with fetal privacy and confidentiality that permits general abortions through the second trimester. Since I do not think fetuses have interests in privacy or confidentiality, I think Botkin’s derivation of this standard is mistaken, but this is not the place to make that argument.
26. Id. at 37-38.
he would exclude, such as Huntington’s. Many parents, I suspect, would not regard it as a greater harm to raise a child who required frequent hospitalization or continuing support than to raise a child with a fifty percent chance of premature death from the same degenerative condition that they or their spouse will soon die from. Although Botkin’s more recent paper talks about welfare rather than harm, the problem is the same: he neither supplies an account of harm or welfare that would draw the line where he wants it, nor offers evidence of a broad consensus on what counts as a significant harm or threat to welfare.

A growing body of research suggests that families with severely impaired children do not differ significantly in stresses and burdens from families with normal children. These findings weaken any presumption that family welfare will be damaged by the birth of an impaired child. Botkin might deny that evidence of the resilience and flourishing of families with severely impaired children would weigh against his current proposal. He insists that his standard now gauges family “impact,” not “burden,” so that only evidence of slight magnitude, not positive valence, would count against it. But he cannot maintain this value neutrality for even a single page. Just a paragraph above his declaration of neutrality, he asserts that “practitioners should provide information on conditions that may significantly impair the legitimate interests of the parents.” But talk of conditions that “impair” rather than “affect” is hardly more neutral than talk of “burden” rather than “impact.” Moreover, Botkin would have practitioners assess the “severity” of impact, a term which is hardly neutral. People ecstatically transformed by birth, marriage, or other blessed events would hardly describe the impact of those events as “severe.”

More important than Botkin’s inconsistency is the problem he would confront if he were consistent: the birth of any child, especially a first child, is such a transformative event that it may be difficult to claim that the birth of a child with a severe impairment will generally have a more substantial impact. Even if that claim can be established by definitional fiat—Botkin would offer testing only for conditions that typically involved extraordinary impacts, such as frequent hospitalization, intensive daily medical care, or life-long dependency—his proposal would also require offers of testing for genetically-

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31. Id. (emphasis added).
32. Id.
detectable athletic, musical, or intellectual prodigy. As Asch points out, the additional impact of child prodigies on their families may be at least as great as that of children with Down or CF.\textsuperscript{33}

Even if Botkin were able to support the generalizations he offers, and the lines he expects them to yield, he would have to face the problem of exceptions. Taking what is often regarded as a clear case, Botkin maintains that

\begin{quote}
[\textit{p}]hysicians should not be obligated to offer prenatal gender testing to all parents, even if we can find justification in isolated cases. In general terms, the impact of a child of the unwanted gender on the parents is not sufficiently severe to warrant offers of gender selection as the standard of care.\textsuperscript{34}
\end{quote}

It is hard to disagree with Botkin that an average American couple's preference for a boy, or a girl, or a "gender-balanced" family, does not implicate their family's welfare enough to warrant an offer of testing. But such a couple is unlikely to want testing specifically for that purpose. It is not clear what Botkin would propose in the case of a couple or family for whom the birth of a child of the unwanted gender might well have a severe impact: if, say, the prospective father or an older sibling had a history of sexual abuse toward girls. Presumably, Botkin would regard the doctor as obliged to offer prenatal gender testing to such parents, \textit{if she knew of these unusual circumstances}. But she would not know unless she asked or inquired.

Perhaps Botkin would respond that the doctor was not obliged to find out if there were circumstances that made particular fetal traits a threat to family welfare. But this would be a striking departure from normal medical practice. Doctors are obliged, for example, to ask if patients have (relatively rare) allergic response to common antibiotics. If, on the other hand, a doctor would be obliged to ask or inquire about circumstances that made even common fetal traits like female gender risky to family welfare, then it is not clear what role Botkin's "standard of care" would be left to play. The comparison to allergies suggests that the need for inquiry would be, if anything, greater in the case of prenatal testing, because threats to family welfare are harder to assess than reactions to antibiotics. If the doctor is protecting the parents' welfare rather than simply fulfilling their wishes, she must assess whether the birth of a child with a particular trait would in fact have (or be likely to have) a substantial impact on the family's welfare. She cannot make that assessment simply by asking the parents—they often do not know, and are likely to be wrong.

\textsuperscript{33} Asch, supra note 27, at 1653-56.
\textsuperscript{34} Botkin, \textit{Line Drawing}, supra note 16, at 301.
The point is not that physicians should decline to raise the prospect of testing, but that families’ actual responses to children with a variety of normal and abnormal traits are sufficiently varied to call almost any generalization into question. Botkin’s “standard of care” would require an inquiry into family strengths and vulnerabilities that would precede or accompany any offer of testing. But such an inquiry would eliminate the justification for a standard offer, or a routine multiplex test, because the doctor should offer whatever tests her inquiry indicates are warranted. Even if those tests in many cases were the very ones that would be on Botkin’s standard list, they would not enjoy the privileged status that his proposal confers on them.

There is a further problem with Botkin’s standard as it applies to social and cultural settings where his seemingly uncontroversial generalizations wouldn’t hold. It simply may be false in India, or in a number of Muslim countries, that “[i]n general terms, the impact of a child of the unwanted gender on the parents is not sufficiently severe to warrant offers of gender selection as the standard of care.” 35 The birth of a girl, or another girl, may mean impoverishment or stigmatization for the family. In other societies, the birth of a child with mild but visible deformities such as webbed fingers may have a similar impact on the family. Perhaps Botkin would contend that the parents would not have a “legitimate interest” in avoiding such consequences, even if they were innocent of the underlying prejudices. But it seems unreasonably harsh or demanding to claim that parents have no legitimate interest in avoiding poverty or ostracism based on the prejudices of the society in which they happen to live. Surely there is a case to be made at the policy level in these countries for limiting gender- and disability-testing, but doctors serving the welfare of their individual patients are hardly the appropriate instruments for that policy. Much like Erik Nord’s proposal to elicit social values as a basis for distributing scarce health-care resources, 36 Botkin’s standard appears defenseless against profoundly inegalitarian social values.

VI. IS UNRESTRICTED TESTING A BETTER ALTERNATIVE?

As I suggested earlier, I am willing to assume, for the sake of argument, a claim of Botkin’s that many disability critics reject: that line-drawing on the basis of parental or family welfare would reduce rather than exacerbate the adverse social and psychological effects of prenatal testing and selective abortion on existing people with disabilities. My argument has been that his proposal is unworkable as

35. Id.
36. See ERIK NORD, COST-VALUE ANALYSIS IN HEALTH CARE (1999).
the basis for a standard of care; that it will either yield a morally problematic failure to offer testing to families whose welfare is likely to be substantially affected by the birth of a child with certain “normal” traits or medically minor impairments, or else will undermine the justification for a standard offer, and instead require complex, individualized inquiries into family welfare.

The comparative virtue of the alternative approach—of offering any and all available testing—is that it would give no official or privileged role to impairments in the determination of whether to offer testing or abortion. I do not know whether such a regime would provide social and psychological benefit to existing people with disabilities. Botkin argues forcefully that it would not:

[I]t hardly seems beneficial to the welfare of the disabled community to advocate that all conditions be subject to prenatal diagnosis and selective termination. This would appear to be the fast lane to “perfectibilism” and intolerance for progressively less severe disabilities. If society condones and promotes prenatal diagnosis for the full spectrum of medical (and nonmedical) conditions, what message does that send? If we want to promote inclusiveness, understanding, and support for those with disabilities, requiring the extensive provision of prenatal diagnostic information and services would appear to be a poor strategy. My concern is that the attempt to eliminate the hurtful effects of line drawing in prenatal diagnosis will fuel a broader set of discriminatory attitudes in society that will be much more hurtful to those with disabilities in the long run.37

Forceful as this passage is, it conflates two distinct concerns: the social and psychological impact of a prenatal testing regime on people with disabilities, and the “kind of message it sends”—its expressive significance. I have argued that the stigmatization of impairments and the craving for perfection should not be seen as falling on some continuum of intolerance, but rather are quite distinct, at least in theory. There is no logical reason, and no psychological evidence I know of, that people who strive for perfection in themselves or their children are comparatively less tolerant of impairments than of imperfections or limitations that fall within the normal range for human beings. A relentless perfectionist can, quite consistently, be a universalist about impairment, finding all of us “impaired” when measured against his impossible ideal. A perfectionist may tend to minimize the differences between imperfections which are medically abnormal and normal.

I concede that I may be wrong about the psychology and social impact of perfectionism. Perhaps an unrestricted prenatal-testing re-

gime would in fact increase the stigmatization of impairments and discrimination against the people who bear them. Or perhaps it would make little or no difference, because most prospective parents would end up testing only for medically severe impairments in any case, in part because they shared in the stigmatization of those impairments, in part because those conditions were more readily tested for—not only because they have more detectable genetic links, but because the scientific development of prenatal tests reflects the popular stigmatization of the conditions tested for.

But this is not all that matters in gauging the expressive significance of a prenatal-testing regime. A testing policy that gave no special status to medical impairments, that did not treat them as providing even a presumptively stronger basis for termination than any other human trait or variation, would emphatically reject the exceptionalism about impairment that has dominated prenatal testing since its inception. It would “send the message,” to use Botkin’s phrase, that the prospect of impairment did not give parents a privileged or especially strong reason to abort; that impairments were just some among the indefinite number of variations that might be relevant to the decisions of prospective parents about whether to bring a child into the world.

VII. DUTY AND BREACH: THE DUTY TO INFORM AND THE FUTURE OF WRONGFUL BIRTH CLAIMS IN AN UNRESTRICTED PRENATAL TESTING REGIME

There is considerable uncertainty about the scope of the doctor’s duties to inform and test under an unrestricted testing regime. While this is not the place, and I am not the person, to suggest a protocol for assessing the preferences of prospective parents, several features seem clear. First, it would not require what Botkin calls “full disclosure”—the breathless recitation of every conceivable condition for which testing may be available. While some parents may want such disclosure, most will want far less, and some, none at all. The doctor should begin by asking the couple whether they want testing at all, or would rather take whatever nature yields. In the still-distant future when prenatal therapy is available, this may no longer

38. Julian Savulescu proposes a similar testing regime, in which “doctors are expected to disclose those facts which each individual patient would find relevant to her decision making” and in which any test she deemed relevant would be available “consistent with the fair allocation of limited health resources.” Julian Savulescu, Editorial, *Is There a Right Not to be Born? Reproductive Decision Making, Options, and the Right to Information*, 28 J. MED. ETHICS 65, 66 (2002). Savulescu favors parental autonomy because he believes that parents are the best judges of their own, and their children’s, well-being, and that we should aim to maximize well-being—a very different rationale than one based on respect for the dignity and equality of people with disabilities.

be an appropriate lead question, for the doctor may not be able to conscientiously take “no” for an answer. But for now, a blanket refusal to be tested should be conclusive, no matter how great the probability of a genetic abnormality, except perhaps in cases where the doctor has reason to suspect a substantial probability of a genetic or chromosomal condition that would, arguably, make the child’s life not worth living, his very birth a harm, for example, Tay Sachs, Lesch-Nyhan’s, Trisomies 13 or 18. (Of course, many couples would want to know why the doctor is asking, making the Gricean assumption that there must be some heightened risk to trigger the inquiry.) The doctor might present an overview of the range of normal and abnormal phenotypes, from female gender to Tay Sachs, perhaps with accompanying frequencies for sample conditions. It would then be up to the couple (or woman—but I will assume for simplicity’s sake that the doctor is addressing a couple) to decide whether they wanted to know more about particular conditions, or about the probabilities for those conditions, given their ages and family histories. And it would then be up to the couple to decide what tests, if any, to obtain. Some minimum probability for the tested condition might be required—but not a minimum varying with “severity” in any sense of that term.

The obvious question of who would pay could be addressed either by offering different health-insurance policies, with higher premiums for fuller coverage, or by adopting the usual co-pay mechanism. The former might be unreasonably difficult, since couples would have to decide on testing coverage well before they decided whether to have children. The latter might be fairer, and consistent with a general destigmatization policy if the charges for tests were based on their actual cost, not on some professional judgment of their medical appropriateness or urgency. Admittedly, those costs, as well as the very existence of the tests, might reflect professional judgments about priorities in genetic research and development. But the very fact that it was not the doctor, hospital, or insurer who was making those judgments would mute their expressive significance.

Under such a consumer-sovereignty/parental autonomy regime, standards for reasonable competence and adequacy in informing, testing, and reporting would evolve in practice, perhaps guided by model protocols or scripts by professional associations. The breach of a doctor’s duty to inform or perform with reasonable competence would be regarded as infringing the parents’ procreative autonomy. Claims for damages and offsets would be treated similarly for healthy and disabled children, since all are rewarding, expensive, and challenging, to varying degrees. An autonomy-based approach

40. The question would arise about whether one can suffer a loss of autonomy in being denied or misled about information that may be of dubious or exaggerated relevance—
would clearly favor uniform damages, punitive more than compensatory, reflecting the slight to the parents’ freedom and dignity rather than the impact on their budget or their emotions.

VIII. THE DEATH OF WRONGFUL LIFE CLAIMS?

The expressive significance of a refusal to limit wrongful birth suits to cases of impairment would be muted or lost if children were allowed to sue for wrongful life only on the basis of their impairments. One alternative would be to deny wrongful life suits altogether, or to limit them to conditions so severe that they arguably rendered life not worth living—including Tay Sachs, Lesch Nyhans, Trisomies 13 and 18, but little else. The other alternative, which I want to conclude by exploring, would be to extend the approach I have suggested for wrongful birth claims to wrongful life claims, so that they were not limited to impairment, but covered any significant and foreseeable harm the child suffered.

According to a line of argument that has enjoyed some recent currency, it is presumptively wrong to bring any child into the world, not just a severely disabled child. This argument rests on a claimed asymmetry between non-creation and creation: while it is not bad to fail to confer the goods of life, it is good to avoid the bads of life. Thus, the argument goes, because there is no bad in never existing, while there is good in avoiding the harms of existence, the good of existence is balanced or offset by the good of non-existence, so that the inevitable harms and sorrows of living make existence a net bad, and make creation a presumptive wrong.

I think this argument is profoundly mistaken. But it suggests an approach to wrongful life cases that does not treat the birth of a disabled child any differently in principle than the birth of a normal child. Those intentionally or negligently responsible for creating any child are presumptively responsible for the harms it suffers. In the case of parents, the care, nurturing, and material support they give

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42. For variations on this argument, see David Benatar, Why it is Better Never to Come into Existence, 34 Am. Phil. Q. 345 (1997); Seana Valentine Shiffrin, Wrongful Life, Procreative Responsibility, and the Significance of Harm, 5 Legal Theory 117 (1999).
their children would generally discharge any obligations arising from the infliction of these harms. In the case of third-parties like doctors, any responsibility/liability they have is superceded or nullified by their duty to the parents to provide assistance in bringing the child into existence. But when they breach their duty to the parents, either by failing to prevent pregnancy or by failing to disclose risk factors that would lead the parents to test and terminate, they are liable for the harms of the child's existence. As a practical matter, they become liable for the costs of raising the child and covering his medical expenses, costs that will obviously be greater with some impairments but will be considerable even for a normal child conceived through the doctor's negligence.

Many people would recoil at the idea that parents' duties to their children have a corrective or compensatory character—to redress the wrong doing by bringing them into existence. More broadly, this approach appears to involve much the same kind of suspect moral accounting as negative utilitarianism: only (non-comparative) bads are counted, with no offset for goods. (The actual accounting is not quite the same, because negative utilitarians look only at bads, while those who treat life-creation as a presumptive wrong either: (1) treat the good of existence as balanced or cancelled by the good of avoiding the bads of existence,43 or (2) contend that only the avoidance of bad, and not the attainment of good, can justify potentially harmful interventions without consent.)44

A more modest approach may be available to impose liability for the foreseeable harms suffered by a child, impaired or not, who would not be alive but for professional negligence. On a more plausible accounting, we count goods and bads, but only if they can be attributed to the agent. With this approach, the asymmetry is in the attribution: the bads in a child's life may be more readily attributable to the agent than the goods in that life.45 But why shouldn't a doctor whose negligent diagnosis averts an abortion that would otherwise have occurred get credit for the good as well as the bad of the impaired life that results? It is only in a “same number” case46—where the parents are committed to a fixed number of children—that the doctor could be said to be responsible in a but-for sense only for the bad, since the parents would have gone on to have a normal child had they aborted this time around. And making the doctor liable only in same-number cases would be highly problematic. The problem is not only epistemic; in knowing what in fact counts as a same number

43. Benatar, supra note 42.
44. Shiffrin, supra note 42.
46. The term comes from Derek Parfit, Reasons And Persons (1984).
case; it is conceptual, in determining what the criteria for such cases are. The problem is also moral, because the two most plausible criteria for distinguishing same (and different) number cases both place the doctor’s liability beyond his control—parental intentions with respect to the number of children they will have under different circumstances, which the doctor will not, and perhaps could or should not know; or the actual number of people who will ever exist in the world, an utterly contingent matter which no one can assess at the present time.

It is necessary to argue that there may be different states of mind required, or different causal connections, for the attribution of benefits and burdens, or even for particular benefits and burdens. Thus, it could be argued that only an individual with procreative intentions or “parental attachment”\textsuperscript{47} can claim credit for the good of, and goods in, a child’s existence, states of mind that a negligent physician will rarely possess. Or it could be argued that the adaptive processes that make life not only worthwhile, but incommensurably good for people with various disabilities, or that transform the attitudes of their parents from dread and despair to joy and enthusiasm, are, in effect, superceding causes, that block any attribution to the physician or other third parties for the benefits arising from those transformations. This approach would justify both of the lawsuits arising from J. Bopp’s hypothetical traffic accident:\textsuperscript{48} the negligent ob/gyn is responsible for the woman’s grief and burden, or at least the additional medical costs of raising an impaired child; the reckless driver is responsible for the traumatic loss of consortium between mother and child. The doctor receives no credit or offset for the transformation in the mother’s attitude that brought her joy and made her subsequent loss so traumatic; the driver receives no credit or offset for relieving the mother of her pre-transformation burden. The wrongful-life analogue would be a severely impaired child suing a negligent doctor for medical expenses while suing a third-party for attempted murder. The doctor would get no credit or offset in the adaptation that made the child’s life so valuable to him, and that arguably aggravated the harm threatened by his post-natal assailant; the assailant would get no credit or offset for attempting to remove his pre-adaptation burden.

CONCLUSION

I have argued, often in a somewhat oblique way, for the comparative virtues of an unrestricted regime of prenatal testing over a regime restricted by a criterion of “severity”—the severity of either the medical condition of the fetus, or the impact on the family. My primary argument has been a moral, not an empirical one—that an unrestricted regime will avoid or mute the expressive significance of prenatal selection for impairment: the “message” that the prospect of severe impairment provides a categorically better reason for refusing to bring a child into the world than the indefinite number of other potentially burdensome traits and conditions that a child may have. A testing regime that limited prenatal testing to severe impairments would obviously send that message, while a regime that limited such testing to conditions likely to have a severe impact on family welfare would either have similar expressive significance, in its reliance on presumptions about the impact of severe impairments, or else require a complex, individualized inquiry into family welfare that would render it impracticable.

I have conceded both that an unrestricted testing regime might not reduce the adverse social and psychological impact of prenatal testing on people with impairments, and that it might promote a noxious consumerism or perfectionism about the creation of children. Perhaps I underestimate the risks I concede, but my preference for incurring them has a moral basis as well—I think the further stigmatization of impairments, which an unrestricted regime would be directed against, would be a greater evil than the further commodification of children. But this moral conviction may rest in part on an empirical conviction, and perhaps a naive one—that the tendency to stigmatize physical and mental differences is deeply engrained and recalcitrant, whereas the tendency to treat children as commodities will be largely offset by the transformative effect of actually raising them.
DISABILITY EQUALITY AND PRENATAL TESTING:
CONTRADICTORY OR COMPATIBLE?

ADRIENNE ASCH*

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It takes considerable rhetorical agility to urge the public to support screening programs so as to prevent the conception of handicapped individuals while at the same time insisting that full respect be paid to such developmentally disabled adults as are already among us.1

Is it possible for the same society to espouse the goals of including people with disabilities as fully equal and participating members and simultaneously promoting the use of embryo selection and selective abortion to prevent the births of those who would live with disabilities? As currently practiced and justified, prenatal testing and embryo selection cannot comfortably coexist with society’s professed goals of promoting inclusion and equality for people with disabilities. Nonetheless, revamped clinical practice and social policy could permit informed reproductive choice and respect for current and future people with disabilities. In the first Section of this Article, I argue that the typical justifications offered by practitioners and researchers for prenatal testing are mistaken about the implications of disability.

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In the second Section, I explain why I discount the claim that people with disabilities have made great progress—notwithstanding the advent of prenatal testing. I conclude by proposing reforms to our current prenatal testing practices that would meet the challenges posed by many critics.

What has become known as the disability rights critique of prenatal testing has been formulated as follows:

(1) Continuing, persistent, and pervasive discrimination constitutes the major problem of having a disability for people themselves and for their families and communities. Rather than improving the medical or social situation of today’s or tomorrow’s disabled citizens, prenatal diagnosis reinforces the medical model that disability itself, not societal discrimination against people with disabilities, is the problem to be solved.

(2) In rejecting an otherwise desired child because they believe that the child’s disability will diminish their parental experience, parents suggest that they are unwilling to accept any significant departure from the parental dreams that a child’s characteristics might occasion.

(3) When prospective parents select against a fetus because of predicted disability, they are making an unfortunate, often misinformed decision that a disabled child will not fulfill what most people seek in child rearing, namely, “to give ourselves to a new being who starts out with the best we can give, and who will enrich us, gladden others, contribute to the world, and make us proud.”

In these several contentions can be discerned two broad claims: that prenatal genetic testing followed by selective abortion is morally problematic, and that it is driven by misinformation.2

In what follows, I discuss these claims as applied to social institutions beyond the family, arguing that researchers, professionals, and policymakers, who uncritically endorse testing followed by abortion, act from misinformation about disability, and express views that worsen the situation for all people who live with disabilities now and

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in the future.3

Bioethicists who sincerely promote the goals of inclusion and equality for people with disabilities assert that there is no contradic-
tion or tension between reforming such institutions as schools, workplaces, and the environment to include existing people with disabili-
ties, and seeking to prevent disability in the future through the prac-
tice of selective embryo implantation and pregnancy termination. Bonnie Steinbock, for example, writes:

Disability activists have a laudable goal: to change society so that it is welcoming and accepting of people with disabilities. However, there is no reason why society cannot both attempt to prevent dis-
ability and to provide for the needs of those who are disabled. As a matter of fact, the rise of prenatal screening has coincided with more progressive attitudes toward the inclusion of people with dis-
abilities, as evidenced in the United States by the passage of the Americans with Disabilities Act.4

I believe that Steinbock’s position is plausible for a different society than the one in which we now live, a society in which it is perceived to be as legitimate and respectable to have a disability as it is not to have one.

Rather than reiterate the basic outline of the critique of prenatal testing, I focus on Wikler’s and Steinbock’s belief that it is possible to respect and support existing and future people with disabilities and simultaneously to urge selection techniques to screen out children who would have disabling traits.5 I seek to examine the social context in which people choose to raise or not to raise children who would live with disabilities. My concern is to facilitate true reproductive choice for women by urging changes in the way prenatal testing oc-
curs and the rhetoric that surrounds it.6

3. I do not speak in this Article for other members of the Hastings Center Project on Prenatal Testing for Genetic Disability, or for any advocacy group associated with the dis-
ability rights movement.
5. Id.; REINDERS, supra note 1.
6. I, and nearly all others sharing a disability rights critique of prenatal testing, maintain an ardent pro-choice stance and assert that women should be free to make what-
ever decision they wish about maintaining a pregnancy or having an abortion. For the most recent elaborations of the disability rights critique, see Parens & Asch, Disability Rights Critique, supra note 2, at 40 nn.21-22 (referring to the work of others who share a pro-choice orientation to reproductive freedom and a disability rights critique of the routi-
ization of prenatal testing for disability); and see references contained in, Asch, Prenatal Diagnosis, supra note 2, at 1647, 1656 nn.8-17; Adrienne Asch, Why I Haven’t Changed My Mind about Prenatal Diagnosis: Reflections and Refinements, in PRENATAL TESTING, supra note 2, at 255 n.4.
I. WHAT IS DISABILITY “REALLY” LIKE, OR HOW MISINFORMED ARE PEOPLE ANYWAY?

Prenatal testing, and the more recent and less common embryo screening and selection, are justified by mistaken assumptions about the quality of life of people with disabilities, and are demeaning to existing people with disabilities. These assumptions are mistaken for several reasons:

1) They fail to recognize the extent to which the disadvantages associated with impairments result from discriminatory attitudes and practices rather than anything intrinsic to the impairment.
2) They place unwarranted emphasis on the size of one’s opportunity range rather than the possibility for meaningful choice and rewarding outcomes within that range.
3) They confuse the claim that having a capacity, skill, or experience is a good, with the claim that lacking a capacity, skill, or experience is inevitably bad. This confusion is due in part to the failure to distinguish the absence from the loss of a skill, capacity, or type of experience, and in part from the overly-narrow description of what is good or valuable.

A. Models of Disability

For the past quarter century of disability scholarship and theory in the United Kingdom and North America, a significant tension has existed between what is seen as a traditional “medical model” of disability and two newer approaches, termed the “minority group model” and the “social model” of disability.7 Theorists with a minority group or a social model argue forcefully that clinicians, policymakers, genetic researchers, and bioethicists err in ascribing the major difficulties of people with disabilities to their physical, cognitive, or emotional make-up. Instead, the theorists assert that the difficulties should be ascribed to the mismatch between the range of people actually in the world and the institutional practices, physical structures, modes of communication, and social attitudes that assume a much narrower range of human beings than exist.

The point is not that humans “construct conceptual worlds,” but that humans construct buildings. The opportunities which are lost to a disabled person are to be attributed not only to the species-atypicality of the person’s biology, but also to the architectural design of the buildings in which some of those opportunities reside.8

It is estimated that 19.7 percent9 of people in the United States have characteristics considered disabilities for purposes of public policy.10

Proponents of these social, or minority group, views hold that most of the disadvantages of having impairments are attributable not to the physical, cognitive, or emotional characteristics of individuals, but to the failure to account for everyone when designing physical, economic, and social institutions. According to the social and minority group models, people with nearly all prenatally detectable conditions—whether Down syndrome, spina bifida, Fragile X, Duchenne muscular dystrophy, sickle cell anemia, retinitis pigmentosa, or achondroplasia—can lead fulfilling lives notwithstanding the characteristics that distinguish them from the non-disabled.11

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10. As can be seen from note 9 and accompanying texts, who counts as a person with a disability, which conditions are considered “disabilities,” and whether conditions labeled “chronic illnesses,” “impairments,” “congenital malformations,” “genetic defects,” “deformities,” and “disorders” should be counted as disabilities are all extremely complex and beyond the scope of this Article. For recent discussions, see Barbara M. Altman, Disability Definitions, Models, Classification Schemes, and Applications, in HANDBOOK, supra note 7, at 97. I will refer to all health-related departures from species-typical functioning as disabilities, and I consider the three-pronged definition of disability contained in the Americans with Disabilities Act of 1990, 42 U.S.C. § 12102 (2000), as accurately describing the class of people with disabilities:

(2) The term “disability” means, with respect to an individual—

(A) a physical or mental impairment that substantially limits one or more of the major life activities of such individual;

(B) a record of such an impairment; or

(C) being regarded as having such an impairment.

11. Hans Reinders differentiates people with “disabilities” such as Down syndrome from people with “illnesses,” such as cystic fibrosis and Duchenne muscular dystrophy, applying his social analysis to the former group but claiming (without evidence) that people with these chronic illnesses have diminished lives because of their medical problems, and not because of social arrangements. See REINDERS, supra note 1, and many other adherents of the disability critique of prenatal testing and selection, include people with all characteristics that are not lethal in the first months or years of life. See Adrienne Asch, Why I Haven’t Changed My Mind about Prenatal Diagnosis: Reflections and Refinements, PRENATAL TESTING, supra note 2, at 234 [hereinafter Asch, Reflections] (quoting other phi-
disability might mean shorter-than-average life expectancies; might entail living with weakness, pain, or fatigue; might require more time than is typical for medical visits or hospital stays; might preclude seeing, hearing, or speaking; might require moving with wheelchairs, crutches, or braces; or might prevent some people from reading, writing, or participating in activities using numbers. Notwithstanding these departures from the species-typical, the social and minority group models contend that virtually everyone with a disability can participate in many everyday activities, experience relationships, discover the world beyond themselves, and contribute to familial, social, political, and economic life.

Many in the field of bioethics such as Steinbock, Singer, Baily, Buchanan, and others who reject the disability rights critique of prenatal testing, acknowledge that a share of the problems of people with disabilities stem from life in a society that has still not made all the changes that would permit them to travel, communicate, learn, work, and play easily alongside their non-disabled peers. Yet they argue that it is better not to have a disability than to have one, and that it is preferable to select against the embryo or fetus with a disabling trait. “The fact that a disability can be under unusual circumstances advantageous is consistent with its being ordinarily a disadvantage. . . . [D]isabilities are not generally advantageous, not something to be hoped for; indeed, they are to be avoided, if possible. They are not merely neutral forms of variation.”

Peter Singer, another eminent bioethicist, says:

[O]n the one hand we are naturally sympathetic to the claims of a disability rights movement that models itself on movements defending the rights of women and ethnic minorities, and, on the other hand, we all accept that to have a disability is to be worse off than to be without the disability.

. . . There are many things that people who are paralyzed below the waist could not do in any society, no matter how constructed. They cannot visit untracked wilderness, go ice skating, or play football. And many other things that they can do, they can do only with difficulty, and with more time than it would take those who have the use of their legs.

. . . The decision to abort a fetus that has, say, Down syndrome, is . . . a decision that says: “Since I will only have two children, I . . .

losophers with the sorts of illnesses Reinders excludes from his analysis, but who share much of my view). See also Diane Beeson & Troy Duster, African American Perspectives on Genetic Testing, in THE DOUBLE-EDGED HELIX: SOCIAL IMPLICATIONS OF GENETICS IN A DIVERSE SOCIETY 151 (Joseph S. Alper et al. eds., 2002) (discussing individuals and family members affected by cystic fibrosis and sickle cell anemia).

12. Steinbock, supra note 4, at 113.
want them to have the best possible prospects for a full and rich life. And if, at the outset, those prospects are seriously clouded, I would rather start again.\textsuperscript{13}

In the same vein, Mary Ann Baily writes:

The background to my decision is . . . my belief that, all other things equal, disability (specifically, a disability for which I would consider an abortion) would make life more difficult for my child, my family, and me. This is not the same thing as saying it would be an overwhelming burden or would make a fulfilling life impossible. . . . It means only that if I have a choice, I would prefer to avoid them [the difficulties], for all of our sakes.\textsuperscript{14}

In their recent book on the ethical issues posed by the new developments in genetics, four bioethicists write: “Shouldn’t parents seek the best—even through genetics—for their offspring? Don’t we expect them to?”\textsuperscript{15} During the deliberations that resulted in the book of essays collected in \textit{Prenatal Testing and Disability Rights}, we found that the question of just how bad or different it was to have a disability loomed as the most contentious and divisive topic of all those we examined. If people with and without disabilities expect to use medicine to maintain or restore health and functioning after a heart attack, broken leg, or a back problem, it is because people value the capacities to move, to carry objects, and so forth. If the average lifespan in the United States is upwards of seventy years, and people with cystic fibrosis or muscular dystrophy commonly die before reaching age forty, it seems cruel and tragic to bring such a child into the world if testing and abortion could ensure that children would be free of the genes for those conditions. Any prospective parent would prefer for a child to live out the typical lifespan rather than know that a child would die before the age of eighteen. Similarly, prospective parents who take hearing, seeing, and walking for granted, and as integral to all of life’s rewarding pursuits, are likely to fear that a child who cannot do one of these things will have enormous difficulty in constructing any, much less many, alternative plans of life.\textsuperscript{16} Intellectual disability is especially disconcerting to many in today’s society,


\textsuperscript{14} Mary Ann Baily, \textit{Why I had Amniocentesis}, in \textit{Prenatal Testing}, supra note 2, at 64, 67.

\textsuperscript{15} Allen Buchanan et al., \textit{From Chance to Choice: Genetics and Justice} 156 (2000).

\textsuperscript{16} I use this notion of plans of life because one of the reasons suggested for giving health and health care great social legitimacy is that they are seen as foundational to constructing virtually any satisfying life plan. In the book \textit{From Chance to Choice}, the authors argue that advances in genetics should be used to give control over the health of future children to parents, so that their children may take best advantage of all the opportunities available to them in a complex society. \textit{Id.} at 156-202.
based in written communication and relying ever more on people’s facility with words, numbers, and complex ideas. One student of genetics comments that “[m]ental retardation is less desirable than normal mental function, in part because retardation drastically contracts the range of worthwhile lives a person might be able to lead.”

The question keeps emerging: Just how much of the difficulty posed by disability is “socially constructed?” Could there be a social and natural world in which it would be as easy and enjoyable to live with disability as it is to live without a disability? Does the answer depend upon the particular condition under discussion—for example, should cystic fibrosis be distinguished from deafness (the former affecting needs for medical care and life expectancy, the latter affecting neither)? How much of what is negative about impairment or disability is “intrinsic” to the condition and would remain even in a society more inclusive of disability than the United States in the twenty-first century? If people prize health, and assume species-typical seeing, hearing, walking, speaking, and learning as foundational, is it not undesirable to have a condition that reduces one’s general health or that limits or denies such functions as speech, hearing, cognition, or sight?

B. Disability and the Normal Opportunity Range

People without any disabilities naturally assume that the typical complement of human capabilities is desirable, and perhaps critical, for most plans of life. Health care is given high priority when people rank important social goods because health and species-typical functioning are taken to be essential for having a good life.


18. It is important to note that prenatally diagnosable conditions include some that will manifest themselves at different ages in life. Cystic fibrosis and Down syndrome can be determined virtually immediately; muscular dystrophy, retinitis pigmentosa, and other conditions may not manifest themselves until childhood or adolescence; polycystic kidney disease or Huntington’s disease may not appear until mid-adulthood. Although some commentators on prenatal testing have different views on the merits of testing depending upon the age of onset of the condition, I discuss the social practice of prenatal testing without regard to the life stage at which the condition expresses itself, for reasons discussed in the last section of this Article. It is also important to note that at times there is reason to distinguish between conditions that affect health—how sick one is, how often one must see doctors for acute distress or flare-ups of chronic conditions—from conditions often termed disabilities, such as deafness, blindness, and intellectual disabilities that have no medical component associated with them. Ron Amundson, *Disability, Handicap, and the Environment*, 23 J. Soc. Phil. 105 (1992) (discussing the difference between the terms “disability” and “health”). Given that a condition can be detected prenatally and that social practices encourage such testing, for the purposes of this Article it does not matter whether the condition is typically thought of as an illness, disorder, chronic condition, or disability.

19. What makes for a “good life” is a question that has lent itself to a rich body of philosophical literature that cannot be adequately summarized or resolved in this Article. I mention it to point out that evaluating the importance of health, or of any human capacity,
there are variations on what “good lives” contain, many people in the United States would probably say that they would like their children’s lives to include several of the following opportunities: to appreciate beauty; learn about the world; master some skills; make contributions to others; participate in satisfying relationships; live without physical or psychological pain; be safe from physical harm; develop their own interests; find satisfying work; take care of themselves; be interested in other people’s welfare; and make decisions about their lives for themselves without pressure from others. This list is not meant to be exhaustive, and it is not intended to suggest that each life must contain all of these characteristics to be satisfactory to the person living it.20

Bonnie Steinbock quotes a 1989 article in which I wrote:

The inability to move without mechanical aid, to see, to hear, or to learn is not inherently neutral. Disability itself limits some options. Listening to the radio for someone who is deaf, looking at paintings for someone who is blind, walking upstairs for someone who is quadriplegic, or reading abstract articles for someone who is intellectually disabled are precluded by impairment alone. . . . It can be done with reference to the kinds of lives people hope to lead for themselves, hope to offer their children, and seek to promote in the society. Norman Daniels’ work on justice in health care argues that health care is crucial for giving people access to the range of opportunity in a society, because he sees it as impossible for people with less-than-species-typical health and functioning to be able to avail themselves of the normal opportunity range in the society. See NORMAN DANIELS, JUST HEALTH CARE: STUDIES IN PHILOSOPHY AND HEALTH POLICY (1985). For applications in the prenatal testing context, see BUCHANAN ET AL., supra note 15. There, the authors do not explicitly set out a list of the components of a good life, arguing that a liberal and pluralistic society such as the United States must permit many very divergent life plans. However, they do state that:

The core notion of eugenics, that people’s lives will probably go better if they have genes conducive to health and other advantageous traits, has lost little of its appeal. Eugenics, in this very limited sense, shines a beacon even as it casts a shadow. Granted, when our society last undertook to improve our genes, the result was mayhem. The task for humanity now is to accomplish what eluded the eugenicists entirely, to square the pursuit of genetic health and enhancement with the requirements of justice.

Id. at 56-57.

20. I make no sweeping claims for the list I give; instead I am influenced by such philosophical writing on quality of life as that found in ETHICS OF CONSUMPTION: THE GOOD LIFE, JUSTICE, AND GLOBAL STEWARDSHIP (David A. Crocker & Toby Linden eds., 1998). The list I give bears some resemblance to ideas found in Martha Nussbaum’s essay, The Good As Discipline, the Good As Freedom, in ETHICS OF CONSUMPTION, supra, at 312, 318-20, but note that Nussbaum insists that in order to have such a good life, persons must possess all these capabilities. “The ‘capabilities approach,’ as I conceive it, claims that a life that lacks any one of these capabilities, no matter what else it has, will fall short of being a good human life.” Id. at 320.

For discussions of “the good life” as applied to philosophical issues of disability, see David Wasserman, Distributive Justice, in DISABILITY, DIFFERENCE, DISCRIMINATION: PERSPECTIVES ON JUSTICE IN BIOETHICS AND PUBLIC POLICY 147, 155-200 (Anita Silvers et al. eds., 1988); and David Wasserman, Philosophical Issues in the Definition and Social Response to Disability, in HANDBOOK, supra note 7, at 229-34.
It is possible to acknowledge that disabilities may preclude some activities that many people find worthwhile—appreciating sunsets, relishing bird songs, experiencing the interaction of body and nature in a hike through the woods. But I now would put my convictions somewhat differently from the words Steinbock quotes. Having capacities is good, but I am not sure that any capacity is an “intrinsic” good. If typical capacities and health achieve value because they enable people to participate in facets of life, it is crucial to note how much of life is open, in today’s society, to people with disabilities. Brief acquaintance with people who have disabilities and who work, play, study, love, and enjoy the world should demonstrate that very few conditions preclude participating in the basic activities of life, even if some conditions limit some classes of them, or methods of engaging in them.

As a person who is blind, I cannot see a baby’s smile, the antics of a friend’s dog, or the paintings of Picasso. I am quite confident that I would get pleasure and satisfaction from such experiences. Nevertheless, if people who are blind cannot enjoy one class of aesthetic experiences, many others are available (weaving, sculpture, music, ocean breezes, etc.). When it is noted that people who are deaf create poetry and theater in American Sign Language, that people with mobility impairments become involved in adapted or typical athletics, that persons with autism or Down syndrome increasingly articulate their own views of their needs and experiences, it is evident that realms of activity often thought unimaginable for people with disabilities are components of many of their lives.

C. Having and Lacking Capacities

The reader without a disabling condition may be thinking: “My life would lose pleasure if I suddenly lost my sense of hearing or sight or could no longer lift weights because of a back problem!” I respond by acknowledging that losing capacities one has is a sad or disappointing event, just as losing other things can be sad and disappointing. If I lose loved ones through death, or face the fact that a once beloved person is no longer important in my life, I grieve deeply. If I misplace a treasured letter, I can mourn its loss, but no one can say that I am entitled to own treasured letters or to possess the relationships that produced such letters. If you take my VCR out of my house without my permission, you have removed something from me that I

21. Steinbock, supra note 4, at 115 (quoting Asch, Reproductive Technology, supra note 2, at 73).
am happy to own and use. I will probably be angry at the loss, the violation of my home, the disrespect shown by taking something from me without my permission, and the unexpected change in my circumstances. If I become paralyzed in a car accident, I can be angry at reckless driving, regret the changed method of navigating in the world—I can even note its inconveniences or remember the pleasures of strolling or striding—but I am not owed the ability to stroll or stride, any more than I am owed a VCR. Thus, we should distinguish our thinking about the importance of having capacities from the distress of losing parts of life we prize, and distinguish our concerns for particular capacities from our concerns about losses, changes, or human carelessness or cruelty.

Contrary to the common belief that people born without certain capacities cannot understand how losing them is intolerable because such people never knew the joys of full health or full mobility, I contend that disabled individuals are well aware of what they do not have. They are told all their lives what they are missing, sometimes merely as a description, often in tones of pity and condescension. They are surrounded by people enjoying paintings they don’t see, music they don’t hear, or sports they don’t play. It is utterly ludicrous to think that anyone born with a disability who is not full of sorrow and rage at her condition is simply denying the glories of the world she doesn’t know.

Not only must we distinguish valuing health and function from fearing loss, we must also distinguish valuing capacity from valuing the idea of choice. Walking, learning, or seeing permit choices among the range of activities that will be somewhat more constrained if someone does not have a capacity, or has less of it than is customary. Those who insist that a good life requires the full complement of species-typical capabilities are driven by a passion for unrestricted choice and oppose any hindrance to that choice. What is prized is not the sensation of walking itself but how walking enables people to take part in certain activities that might be difficult or impossible otherwise.

No person in the world is likely to be interested in all of the physical, intellectual, and aesthetic experiences the world affords. Even the voracious reader will not delve into every book written in every language or even in her native tongue. No devotee of classical music will have the time to study every available work composed since the twelfth century. The serious athlete is unlikely to become proficient at every known sport or game played in her country, much less to discover the pleasures of games enjoyed on other continents. No proponent of the opportunity range or the “open future” expects anyone
to take advantage of all that the world offers.\textsuperscript{22} The people who prize the idea of the open future argue that people should have no barriers to their own exercise of choice, self-discovery, and self-realization. The paramount value is that people explore each possible opportunity, but that nothing should get in the way of their own freedom to choose which opportunities to pursue.

If having a capacity is good, is not having a particular ability bad, negative, or “dis-valuable”?\textsuperscript{23} My answer is that having a capacity can be good, but the absence of capacity is simply an absence; it need not be seen as negative, “dis-valuable” to be blind any more than it is negative or “dis-valuable” to be shorter than some people, or to be mystified by higher mathematics. In these reflections on valuing capacity, I generally concur with Anita Silvers, who writes:

\begin{quote}
[If disadvantage is tightly tied to impairment, its source does not seem to lie in the loss of something of intrinsic value. This is not to deny that seeing well, hearing well, and moving well possess intrinsic value and are crucial components of more complex activities having intrinsic value. Rather, it is to notice that, although the experience of engaging in these activities can be (but is not always) intrinsically good, not engaging in them is not intrinsically bad.\textsuperscript{24}]
\end{quote}

If disability is a simple human variation, why do we try to promote good prenatal care in women, or to promote health in the population? There is nothing to lament about capacities to hear, speak, move, or think. The difference between selecting out fetuses and protecting them (by promoting prenatal care for women) is just that. We protect the possibility for capacity when we promote fetal health, but we refuse to acknowledge or permit the growth of people who will not have such capacity when we select against fetuses as potential people with disabling traits. Similarly, there is nothing wrong with possessing skills or aptitudes for athletics, physics, or carpentry; but the society has not yet said that only people who possess such aptitudes are welcomed. The absence of a capacity is not necessarily “bad”; the opposite of having a capacity is not having it; having it and not having it can be equally legitimate ways of living a life.


\textsuperscript{23} Parens & Asch, \textit{Disability Rights Critique}, supra note 2, at 23-26 (suggesting that disabling traits are “dis-valuable”). As a co-author of this article summarizing deliberations of a large project group, I was committed to reporting these ideas, but speaking for myself, I do not subscribe to this characterization of disability. There may be undesirable features to life with disabilities, but such features are intimately connected to the way in which disability is perceived, as will be discussed in the next Section of this Article.

\textsuperscript{24} Anita Silvers, \textit{Formal Justice}, in \textit{DISABILITY, DIFFERENCE, DISCRIMINATION}, supra note 20, at 90-91. But note that Silvers and I differ on whether the capacities are intrinsically good. \textit{See id.}
Those who maintain that disability forecloses opportunity, and that any foreclosed opportunity diminishes life, focus too narrowly on the activity and do not see it as a means to an end, e.g., visual instead of aesthetic pleasure; walking instead of mobilizing or exploring; talking instead of communicating. These assumptions are demeaning to people with disabilities because they exaggerate their hardships and deprivation; obscure the injustice and discrimination they face; and dismiss or discount their own testimony of living rich and rewarding lives.25

Thus far, I have argued that even if species-typical health and function appear to be prerequisites for constructing life plans, people with disabilities can participate in a very large range of activities. Many people with disabling traits manage to have rewarding lives in today’s United States, making use of advances in medical treatment, assistive technology, and the social changes that ease participation in travel, school, and work.

II. THE LIMITS OF PROGRESS

Defenders of the practices of prenatal testing and embryo selection deny that these practices are incompatible with greater inclusion and participation of those with disabilities. In this Section, I rebut their claims. They claim that while prenatal testing for disability is becoming more widespread and routine, existing people with disabilities are making dramatic strides towards social and economic equality. I argue that the appearance of progress is illusory, or at least grossly exaggerated.

Gaps remain between people with and without disabilities in terms of education, employment, income, social life, and civic participation.26 According to the traditional medical model of disability, those gaps are inextricably tied to the conditions themselves. With the advent of the minority group and social models, it has become possible to disentangle how factors in the built environment, modes of information dissemination, and laws and practices governing political participation, work, and education excluded, segregated, or limited the lives of people with disabilities. The richness of these latter models of disability is the legislation they helped to create, embodying a national commitment to equal opportunity in education.27

public services,28 employment, transportation, and places of public accommodation.29

Those who support vigorous efforts to reduce disabling conditions by preventing the births of people who will have them observe these legal gains and the increased presence of people with disabilities in schools and public places to demonstrate that there is no tension between prenatal selection and including those disabled people already in the population.30 Under their view, it is possible to disvalue the disabling trait, and nonetheless to respect as social and moral equals people who exhibit these disliked traits. Prevailing social attitudes toward people with disabilities, and data about the effects of legal changes on employment, lead me to be anything but sanguine.

A. The Persistence of Negative Attitudes Toward People With Disabilities

In passing the Americans with Disabilities Act in 1990 (ADA),31 Congress recognized that millions of the nation’s population continued to be treated differently and pejoratively by the non-disabled majority:

[I]ndividuals with disabilities are a discrete and insular minority who have been . . . subjected to a history of purposeful unequal treatment, and relegated to a position of political powerlessness in our society . . . resulting from . . . assumptions not truly indicative of the . . . ability of such individuals to participate in, and contribute to, society[.]32

In enacting the ADA and its predecessors (Title V of the Rehabilitation Act of 1973,33 and the Architectural Barriers Act of 1968),34 the federal government recognized the need for the law to redress these systemic problems. Nothing in the nation’s practices toward its millions of disabled inhabitants demonstrated success in devaluing disabling traits without also relegating the people with those traits to a status as economic and social inferiors.

Writing from a social constructionist perspective, David Wasserman contends that, “the disadvantages associated with impairments have their source in pervasive attitudes of contempt and

30. See BUCHANAN ET AL., supra note 15; Steinbock, supra note 4.
disrespect. Unlike people with obsolete skills, but like people of color, people with disabilities are not regarded as moral equals by the larger society, and the disadvantages they face reflect their devaluation. Ron Amundson explains the devaluation as follows:

Rehabilitation literature is full of examples of how able bodied people think of disabled people not as having specific disabilities, but as being generally incompetent. This social image reinforces the illusion that global disadvantages and handicaps flow from nature itself. In turn, the prejudice of the blind person’s global incapacitation provides an excuse to reject the demands of blind people for the kinds of environmental modifications which would increase their access to goals. Like the myths which burden women and ethnic minorities, the myth of the globally incapacitated disabled person is self-supporting.

Outlawing discrimination in public programs, employment, and places of public accommodation has not markedly altered how social science, medicine, and bioethics discuss disability when it comes to making childbearing decisions. Joan Retsinas further describes this devaluation:

Attitudes toward congenital disability per se have not changed markedly. Both premodern as well as contemporary societies have regarded disability as undesirable and to be avoided. Not only have parents recognized the birth of a disabled child as a potentially divisive, destructive force in the family unit, but the larger society has seen disability as unfortunate.

... Our society still does not countenance the elimination of diseased/disabled people; but it does urge the termination of diseased/disabled fetuses. The urging is not explicit, but implicit.

Natalie Angier puzzles about the seeming contradictions in contemporary dealings with the nation’s disabled population: “[T]he dominant culture appears to be moving in two contradictory directions: more accommodating of disabilities in adults, but less tolerant of imperfections in children.” Surely it is logically possible to appreciate the species-typical without demeaning those who depart from it, but the historic record and contemporary practices have not displayed such logic. Describing children with disabilities as children with “special needs,” using the euphemism of “special needs adoption” when referring to placing children with disabilities in homes,

35. Wasserman, Distributive Justice, supra note 20, at 175.
36. Amundson, supra note 8, at 114.
and maintaining a system of “special education” reveal that people with disabling conditions are “others,” not part of the total community. Were youth with disabling traits truly viewed as deserving of consideration when designing schools, daycare centers, and after-school programs, the programs would be created with the expectation that children differed from one another in many ways, and budget, staffing, and institutions would reflect the true diversity of the nation’s youth.

B. Translating Law Into Practice

In the late 1980s, disability policy historian Edward Berkowitz noted that: “The nation concentrates too much of its money on granting tickets out of the labor force and gives too little attention to the demands of the handicapped for tickets into the labor force.” 39 Writing about the ADA ten years after its passage, economist Richard Burkhauser takes a hard look at the strengths of the law and at what it has and has not accomplished to improve the status of people with disabilities:

The ADA is a testimonial to the ability of the disability rights movement to affect policy and to the political power of the idea that people with disabilities can and should work.

. . .

. . . [M]ost people outside the disability rights movement classify people with disabilities as “not expected to work.” This is true of the general population and more disappointingly it is true of the social science and public policy community.

. . .

. . . If they [referring to children but arguably applicable to everyone with a disability] are not expected to work, there is no reason to invest either in infrastructure or in broader social programs to turn sows’ ears into silk purses.

. . .

. . . I am now convinced that not only are the majority of people able to work following the onset of a disability but that they, in fact, are already doing so. Hence, public policies that focus on encouraging work following the onset of disability are not based on daydreams or good wishes. 40

Another observer of the impact of the law on social inclusion and economic participation laments how much remains to be accomplished toward the law’s lofty aspirations:

39. Amundson, supra note 8, at 115.
It is clear that Congress regarded the deprivation and disadvantage of people with disabilities as giving moral urgency to the antidiscrimination mandate of the ADA. The statute is prefaced by the finding that people with disabilities are, as a group, among the least advantaged members of society (Section 2(a)(6)).

. . . [T]he primary beneficiaries of the ADA are the “disability elite”—those individuals with disabilities who possess indisputable competence, which they are prevented from displaying by structural or attitudinal barriers . . . . This, however, is the “trickle-down” pattern we have come to expect from the enforcement of laws against race and gender discrimination; it does not offer the same reproach to a statute designed to eliminate discrimination as it would to a statute designed to improve the material condition of the worst-off or least advantaged.41

Unfortunately, the public consciousness of disability and the inclusion of adults who have disabilities appear more superficial than genuine. A decade after the passage of the ADA, and nearly thirty years after enactment of the Title V employment provisions of the Rehabilitation Act, people with disabilities are not succeeding in gaining access to work, and courts are frequently ruling against them when they bring cases of employment discrimination.42 If society truly believed that people with disabilities could contribute to the nation’s economy, the unemployment rate would be calculated to show that millions of the nation’s disabled population of working age were not in the labor force. Considering that people with disabilities are estimated to be about twenty percent of the nation,43 industry’s failure to pursue their labor and business with accessible product design and representative advertising is astonishing, and actually detrimental to the society as a whole.

Despite the symbolic and tangible changes attributable to laws like the Americans with Disabilities Act, the nation’s disabled population is still less educated, less employed, less involved in civic life, less represented in the political process, and less influential on the design of products than their numbers warrant. Thus, we do not have the inclusive society envisioned by Gliedman and Roth in their 1980

42. See Survey, supra note 26; Burkhauser, supra note 40; Ruth Colker, Winning and Losing under the Americans with Disabilities Act, 62 OHIO ST. L.J. 239 (2001); see also Chevron U.S.A., Inc., v. Echazabal, 536 U.S. 73, 74 (2002) (affirming EEOC regulation allowing an employer to screen out a potential worker with a disability if the job is a threat to his health or safety); Bd. of Trs. v. Garrett, 531 U.S. 356 (2001) (holding state immunity bars Title 1 ADA claims for money damages by individuals against a nonconsenting state or its agencies in federal court).
43. McNutt, supra note 9, at 1.
groundbreaking work on disability that laid out a minority group analysis and showed that children and adults with disabilities were expected to play no valued social role whatsoever.\textsuperscript{44} It is in this discriminatory society in which researchers develop tests to discover disabling traits in embryos and fetuses; clinicians urge prospective parents to use these tests; government bodies endorse population screening for certain conditions, such as cystic fibrosis,\textsuperscript{45} and support the use of funds from public and private health insurance to pay for such tests.

III. THE “MESSAGE” OF SELECTING FUTURE CITIZENS

In the preceding sections of this Article, I have discussed the contention that embryo selection and prenatal testing stem from society’s misinformation about life with disability. Life with nearly all disability potentially contains rewarding personal relationships, stimulation and discovery, self-development, and contributions to others. Although not every difficulty of living with a disabling condition or health problem stems from society’s failure to include its disabled citizens, a very large number can be traced to discriminatory attitudes and the social distance and segregated or restricted opportunities created by the non-disabled majority. I now take up the claim that the societal promotion of the selection techniques is morally problematic. I would argue that at least some of the rhetoric that endorses selecting children’s characteristics conveys bias and disrespect for people with disabilities, and not merely information about the effects of a disabling trait.

Detractors of the disability critique have labeled one of its major components the “expressivist argument.”\textsuperscript{46} Although I am not comfortable with the term and think that the concerns about parental attitudes toward all children are as important as the concerns about disability, I continue to support a version of this argument. Before discussing the social practices that give rise to my belief that the genetics and medical professionals are giving an offensive message, let me state that I am concerned with what professionals do by way of promoting testing; I am not making any claims that prospective parents’ familial goals and reproductive decisions should be evaluated by outsiders, or can be understood as communications to outsiders.

Elsewhere I used the following words to characterize possible re-

\begin{footnotesize}
\begin{enumerate}
\item\textsuperscript{44} Gliedman & Roth, supra note 7, at 31-42.
\item\textsuperscript{46} See Buchanan et al., supra note 15.
\end{enumerate}
\end{footnotesize}
actions of the disability rights movement to the current practices of prenatal selection:

People with just the disabilities that can now be diagnosed have struggled against an inhospitable, often unwelcoming, discriminatory, and cruel society to fashion lives of richness, of social relationships, [and] of economic productivity. For people with disabilities to work each day against the societally imposed hardships can be exhausting; learning that the world one lives in considers it better to “solve” problems of disability by prenatal detection and abortion, rather than by expending those resources in improving society so that everyone—including those people who have disabilities—could participate more easily, is demoralizing. It invalidates the effort to lead a life in an inhospitable world.47

In evaluating whether certain actions or practices send messages, James Lindemann Nelson contrasts flying the Confederate flag over the South Carolina Statehouse (which he argues sends a possibly negative and offensive message to African-Americans) with the uses of prenatal testing made by prospective parents, which he believes contain no clear communication and need not offend anyone.48 Like Nelson, I agree that the parental actions are not intended and should not be viewed as communicative. Nelson, however, goes on, “[b]ut rather than individual choices, consider the general social practice of developing and disseminating more and more tests for more and more conditions: Does that practice not express a clearer and plainly objectionable meaning . . . ?”49

Nelson concedes that prenatal testing “take[s] place against a very disturbing historical backdrop concerning the place to which people with disabilities have been assigned in American society.”50 He concludes that the social endorsement of testing and abortion is much less settled and clear in what it intends or conveys than displays of the Confederate flag at the state capital.51 Perhaps he feels that if the societal motive for screening to prevent the births of children with disabilities was analogous to historical and contemporary American racism, there would be reason for disability advocates to limit women’s reproductive freedom and to ban the use of the technology. In this he forgets that the critique of testing and selective abortion is intended to change professional practice and rhetoric and to give more comprehensive information about disability to prospective par-

47. Asch, Reflections, supra note 11, at 240.
49. Id. at 207-08.
50. Id. at 209.
51. Id. at 210.
ents. Critics have never intended to curtail women’s decision-making about their reproductive lives.

A. Clinical Practice

Clinicians providing medical services and prenatal counseling to pregnant women (whether obstetricians, nurse practitioners, midwives, or genetic counselors) obviously play crucial roles in communicating whether prenatal testing should be undertaken, what the tests reveal, and what they can mean for the health of the potential child and the life of the family. Despite the professional commitment to non-directiveness in genetic counseling, it is clear that many professionals do not practice in a way that legitimates the choice to maintain a pregnancy of a fetus affected by a disabling trait.\footnote{Parens & Asch, Disability Rights Critique, supra note 2, at 5-8.} Counselor education contains little opportunity for contact with disabled children or adults in non-medical settings where clinicians could observe how people with disabilities manage day-to-day life.\footnote{For a discussion of genetic counseling, see Barbara Bowles Biesecker & Lori Hamby, What Difference the Disability Community Arguments Should Make for the Delivery of Prenatal Genetic Information, in Prenatal Testing, supra note 2, at 340-57; and Parens & Asch, Disability Rights Critique, supra note 2.} An especially troubling example is the finding by Lippman and Wilfond that pediatric and prenatal genetic counseling gave radically different information about the same conditions to families.\footnote{Abby Lippman & Benjamin S. Wilfond, Twice-Told Tales: Stories about Genetic Disorders, 51 AM. J. HUM. GENETICS 936, 936-37 (1992).} In situations where parents were raising infants and young children with Down syndrome and cystic fibrosis, counselors stressed ways in which lives of the affected children would resemble those of non-disabled peers, focusing on capacities for education, stimulation, play, and relationships. By contrast, the stories given to prospective parents if the diagnosis was made prenatally concentrated on medical complications and differences from the lives of non-disabled children.\footnote{Id.} Such differences in information run afoul of non-directiveness.

It is hard to read the very different descriptions contained in Lippman and Wilfond’s report of the prenatal and post-birth accounts of Down syndrome and cystic fibrosis as anything other than:

If you can avoid this bad thing, you should; if you weren’t lucky enough to avoid it, we don’t want to tell you how really awful it is going to be. We fear you won’t be able to stand it, so we will let you find out for yourself. We don’t have to give you news we think won’t help you feel good about your child.

If prospective parents are ever to have the opportunity to make thoughtful decisions about whether they are prepared to raise a child
with a prenatally detectable disability, they need to know as much as counselors can tell them about the overall experience of children and families living with the diagnosed condition. Omitting the ways in which a child with cystic fibrosis or Down syndrome can participate in the life of family, school, and community underscores disability as a negative factor, especially if the information parents are given about what children with either condition cannot do focuses on the needs for medical follow-up or on shortened life expectancy. Similarly, the parent learning that her or his newborn daughter or son can expect to go to school, get a job, and enjoy loving relationships with others should not be kept in ignorance regarding the need for medication, therapy, or hospitalization that may be part of her or his child's life. The premise of counseling, or of educating people about their own and their children's possible futures, is that anyone contemplating raising a child or actually involved in parenting will profit from learning about what could be in store. If professionals in one instance accentuate the negative, and in another instance accentuate the positive, they show disrespect for the intelligence and sincerity of the people who rely upon them for information and assistance. Counselees in each situation deserve to learn as much as they can from knowledgeable professionals; and professionals betray the people they serve by slanting the information in the direction of a particular result. If counselors, midwives, and obstetricians are truly committed to patient decision-making and to informed reproductive choice, they should be providing enough information about life with a disabling condition so that prospective parents can imagine the ways in which life can be worthwhile as well as those in which it can be difficult. Similarly, the parent of a toddler whose health is going to be affected by the need for medications, home-based therapy, early educational services, or hospital stays should be able to take account of those factors when deciding where to live and what job to seek. The stated neutrality and non-directiveness of genetic counselors is very much open to question if further research determines that these differences in prenatal and pediatric counseling are the norm.

B. Rationales for Test Development

Remember that scientists persuaded Congress to budget three billion dollars over fifteen years to map and sequence the human genome, promising that the new knowledge would lead to treatments and cures for disease and disability. "In 1988, Congress appropriated funds . . . to begin planning the Human Genome Project. Planners set a 15-year time frame, estimated that the price tag would be $3 bil-
lion, and laid out formal goals to get the job done. Francis Collins explains the project’s purposes this way:

Scientists wanted to map the human genetic terrain, knowing it would lead them to previously unimaginable insights, and from there to the common good. That good would include a new understanding of genetic contributions to human disease and the development of rational strategies for minimizing or preventing disease phenotypes altogether.

Although the goal is said to be cure or treatment, to date researchers have developed very few therapies that would help anyone now living with a genetic condition. Instead of developing therapies or treatments for most of the genetic conditions for which the specific gene is known, researchers developed prenatal tests and embryo selection techniques that inform prospective parents about future children, but do nothing for anyone now living with a genetic condition. Some prospective parents will seek out information yielded by the tests even if they intend to continue a pregnancy regardless of the finding, but generally, the purpose of screening embryos or testing fetuses is for women (and their partners) to decide whether to carry a particular fetus to term. Several scholars who have reflected on the phenomenon of prenatal testing acknowledge that the resources are allocated to testing and counseling on the assumption that most people who learn that an embryo or fetus carries a disabling trait will not proceed with implantation or pregnancy. Promoting informed reproductive choice may be the stated goal of test developers, but the generally expected and desired result of a disability diagnosis is the termination of that particular pregnancy in hopes that the next one will yield an embryo or fetus free of a detectable disabling trait.

Consider that as yet there are tests for only some of the many single-gene traits. Geneticists have not sought funding to develop the prenatal test for hair or eye color, for example, because these traits have relatively little social consequence. There is nothing negative ascribed to having blue eyes or brown, blond hair or black. Developers of tests for embryos and fetuses believe that prospective parents will (or should) wish to avoid the births of children who will have disabling conditions because the perceived difficulties of their lives

57. Id.
58. A notable exception was reported by Gina Kolata as follows: “The achievement, announced yesterday in France, comes after a decade of widely heralded promise followed by dashed hopes for the revolutionary treatment.” Gina Kolata, Scientists Report the First Success of Gene Therapy, N.Y. TIMES, Apr. 28, 2000, at A1.
59. See, e.g., Arthur L. Beaudet, Carrier Screening for Cystic Fibrosis, 47 AM. J. HUM. GENETICS 603 (1990) (discussing the benefits and harms associated with the implementation of cystic fibrosis carrier testing to reduce the burden of cystic fibrosis on society).
are likely to outweigh benefits to the child, the family, and the society. The tests do nothing to promote the health of the developing fetus or the health of the pregnant woman. Rather, they are offered so that people may decide against becoming a parent of a child with a particular characteristic that clinicians and policy makers understand to be detrimental to a satisfying life for the child or the family, or that may require outlays of societal resources. Andrews and Hibbert describe the attitude toward disability found in law, science, and medicine as follows:

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.

... In large measure, the history of eugenics is a history of brutality against the disabled... 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.60

The authors go on to speculate that: “Once genetic disease is no longer seen as a random characteristic, this may reduce our communal commitment to people with genetic disabilities.”61 When commentators talk about the social costs of providing medical care, education, or supportive services for children and adults with disabilities, they neglect to point out that non-disabled children and adults require societal investment; that the costs of creating an accessible society must be borne simply to assist the vast majority of people with non-diagnosable, non-genetic conditions that arise during a life; and that people with disabilities can contribute to the economy and to their families by virtue of the characteristics they have in addition to their impairments.62

C. Line-Drawing

If prenatal testing and embryo selection are not intended to give messages about which types of children the society will accept and welcome, proposals for “drawing lines” about the types of tests to be offered or withheld must be carefully examined and, in my view, rejected. Many clinicians and bioethicists fear that the consumerism of

61. Id. at 321.
assisted reproduction, the anxieties of people who delay parenting and expect to have only one or two children, and the pressures parents feel to give their children “the best” start in life all contribute to a desire for “‘designer’ children.” To counter these tendencies, some are urging that researchers decline to develop, and clinicians decline to provide, tests that inform people about what professionals perceive to be traits that do not pose serious harms to the child or the family.

Jeffrey Botkin and Thomas Murray argue that some information and choice is inimical to what good parents should consider and to what a caring society should accept. Botkin distinguishes traits for which tests should and should not be offered by appealing to a notion of parental harm caused by raising children with some diagnosable conditions, saying that they should be able to get information “designed to prevent harms to parents that are approximately the same magnitude as the harms of an unwanted pregnancy.” On his parental harm criterion, prenatal diagnosis should not be offered for late-onset conditions, such as Huntington’s disease or breast or colon cancers; nor would they be made available for traits he would describe as not seriously threatening the interests parents should have in raising children.

Murray, too, opposes what he describes as the desire for perfectabilism, that would lead parents to seek diagnoses of “trivial” conditions. I read Murray as believing that the conditions for which tests have been available are of sufficient gravity that prospective parents should get to decide whether or not they can imagine living with and adequately nurturing a child with the disability. Although he does not wish to ignore the concerns of people with a disability critique of prenatal selection practices, he appears to be able to imagine that professionals should draw the line as to which conditions parents should consider when making decisions about their families, and which they should not. When professionals develop tests and offer them to parents, then, Murray and Botkin would both argue for creating a list of the serious conditions that parents should think about, and of refusing to give prospective parents the chance to decide for themselves which characteristics of future children might be of significance to them. Murray and Botkin share some of the disability critique of current practice; they recognize that at least some disabling traits in some families do not preclude rewarding lives for individuals and families; and they disagree that prospective parents

64. Murray, supra note 63; Botkin, supra note 63.
65. Botkin, supra note 63, at 36.
67. Id.
should retain an openness to the many characteristics that every child will display.

Sadly, I believe that the very desires that would have Murray and Botkin limit diagnoses to only some, but not all, characteristics that might be determined prenatally, turns the professional assistance to reproductive autonomy into the very “message” about the badness of disability that alarms critics of the current practices. Why should parents be told by test designers: “We think that cystic fibrosis, or muscular dystrophy, or deafness, or Down syndrome should make parents think at least twice before contemplating childraising; but other conditions are too trivial for parents to object.” If prenatal selection is not intended to harm existing people with the conditions that can now be diagnosed and instead is designed to give value-free information to prospective parents, creating an official list of conditions that parents should worry about will have an undesirable effect on the societal acceptance and self-esteem of those with the listed conditions. Why should it be acceptable to avoid some characteristics and not others? How can the society make lists of acceptable and unacceptable tests and still maintain that only disabling traits, and not people who live with those traits, are to be avoided? If it is legitimate to be a person with a disability, or to parent a child with such a disabling condition, should the society make a list of “serious” and “trivial” characteristics?

Endorsing testing and selecting against some traits, and refusing to let people select against other traits, will surely exacerbate the discrimination and stigmatization of future children with the listed conditions. I, and many others with a disability critique of the existing practices, find this suggestion of line-drawing clear evidence that the current arrangement and any future line-drawing reforms are much too close for comfort to running the Confederate flag up the flagpole. The flying Confederate flag tells people historically victimized by racist discrimination that racism and the history of racism is and was acceptable; enumerating a set of testable genetic diseases tells people who currently have those conditions that it would be better if prospective parents went to considerable lengths to prevent the births of children with those conditions. Consequently, I can only urge people who support reproductive choice and also support disability inclusion and equality to oppose line-drawing efforts. It must become as acceptable to test for tone deafness or color blindness (if tests are ever developed) as it now is to test for certain forms of deafness and blindness. Undoubtedly, more prospective parents will terminate for the latter conditions than the former, but at least the decisions will be those of the people ultimately raising children, and not society, in the form of its insurance carriers and clinicians as gatekeepers.
A word should be said about line-drawing in the context of the nation’s continuing struggle over women’s rights to abortion. So long as the courts uphold women’s freedom to end pregnancies for any reason during the first twenty-four weeks of gestation, most people who seek to use diagnostic techniques to make termination decisions will get the information about the fetus within the time limit for legal abortion. But suppose the courts were to ban abortions after the first trimester, or after twenty weeks of pregnancy, leaving an exception for abortions sought after receipt of prenatal diagnostic test results? Martha Field argues that any abortion exceptions based on disability would send just the sort of devaluing message proponents of testing claim is absent from the current enterprise.

An argument based upon discrimination against the handicapped does not dictate whether there will be any abortion right or how long any such right will last. It only maintains that the same rules must be adopted without regard to whether the child-to-be is projected to have a disability. Under this view, states could not prohibit third-trimester abortion while making an exception for disability. Nor could they make any exception for disability if they were able to and did prohibit abortion generally.68

At the outset of this Article, I indicated that I would focus on the question of whether society could simultaneously promote social and moral equality for people with disabilities in the world and nonetheless work to urge people not to reproduce children who would have disabling conditions. I believe that it will be very difficult for most families to consider bringing children with diagnosable disabilities into the world if they know that the society believes that their births should have been prevented. When I wrote about prenatal diagnosis in 1989, I described prospective mothers (and I would say all prospective parents) as hoping “to give ourselves to a new being who starts out with the best we can give, and who will enrich us, gladden others, contribute to the world, and make us proud.”69 Writing about “maternal practice,” (but it can apply to fathers as well), Sara Ruddick suggests that the third basic component of maternal (or parental) work is to nurture the growing child so that she or he will be an acceptable member of the larger society.70 Raising children is work, whether or not the child has a characteristic termed a disabling trait. Virtually every parent worries about whether his son’s moodiness or her daughter’s adventurousness will cause problems down the line. Will children find friends, love, work, community? Will others appreciate them—warts and all? Will children grow to find a place for

69. Asch, Reproductive Technology, supra note 2, at 86.
themselves that they will take pride in, will comfortably rest in?

If these are the anxieties of all parents raising all children, those anxieties can only be heightened if parents know and love a child whose disabling characteristics meet with aversion, social embarrassment, discrimination, and exclusion. Only when policies, laws, medical professionals, schools, and media communicate that it is respectable and legitimate to live with a disability, and only when day-to-day reality approximates the aspirations that gave rise to the Americans with Disabilities Act, will it be possible to imagine that the social problems of disability will not compound any biological limitations. Ever-increasing prenatal testing and vigorous enforcement of existing anti-discrimination laws might continue to develop along their separate tracks, because geneticists and doctors work in arenas quite different from the advocates for greater social services, increased access to education, and employment for the nation’s disabled population. Yet I persist in believing that as part of the goal of creating such a welcoming society, we must persuade professionals to change what they tell prospective parents about life with disability; convince those parents to learn about how children and adults in today’s world survive and thrive; and then endorse the choices people make about their reproductive and family lives.

Daniel Wikler’s words opened this Article with what readers may have interpreted as irony or skepticism. I believe Wikler is committed to the project of supporting full inclusion of disabled people, but believes that prospective parents should refrain from producing children whose genetic endowments compromise their life choices.71 I fear that the current climate in which prenatal testing takes place displays neither the rhetorical agility nor the social commitment to equality that I desire. If we are ever to make it as least as acceptable to bear and raise a disabled child as a non-disabled one, we must simultaneously commit ourselves to both social reforms that include all people, whatever their characteristics, and to accepting consumerism in the reproductive marketplace. Creating such a climate will take at least as much rhetorical agility as Wikler thinks he has displayed.72

71. R EINDERS, supra note 1; E-mail from Daniel Wikler, Professor of Ethics and Population Health, Harvard School of Public Health, to author (Sept. 10, 2002, 23:03 CST) (on file with author). See infra note 72 for the content of this e-mail.

72. In an e-mail, Daniel Wikler confirmed that he believes it is possible to support screening programs to prevent the conception of handicapped individuals, while insisting that full respect be paid to developmentally disabled adults:

You’re right. I do think it’s possible but also that it’s difficult, i.e., that there is a tension. The ingredients of my view are:

1. In at least some cases the individual would have had greater opportunity for well-being, all things considered, without the disability.
2. Thus if we have a choice between a population in which many have this disability and one in which few do, then all things considered more people will have a better chance of having greater well-being. This consideration belongs on the balance scale, though it is not determinative.

3. There is a bit of tension in holding these two thoughts in one’s head simultaneously: [that] this person’s disability is likely (though not certain) to decrease this person’s likelihood of attaining high levels of well-being; AND that this worth of this person is the same as everyone else’s, the disability notwithstanding.

4. One source of tension comes from the fact that so many people with the disability do just fine.

5. Another source is that in some cases (for some “disabilities,” it may be most or even all), the reason that the trait detracts from expected likelihood of well-being is that society is unjust (stigmatizing or unjustly unaccommodating).

6. A third source is that in the case of disabilities stemming from a person’s genes, or acquired early in life, the person’s identity and sense of community may be powerfully affected by having the disability, so that targeting the disability may be understood as denigrating that personal or social identity.

7. A fourth source is the historical record, in which supposedly humanitarian efforts to improve the well-being of future generations have in fact been unjust, violent, and indefensible efforts to rid societies of stigmatized people and groups who in most cases were highly vulnerable. We have to be on guard against this, even when we think our motives are above reproach.

Given 4, 5, 6, and 7, I don’t think there is a cost-free way out of the dilemma, and I’m certainly prepared to consider an argument that in some cases the dilemma should be resolved in favor of calling off the effort to prevent the disability from affecting future generations. However, in many cases my view is that the balance scale tilts in the opposite direction, because of 1 and 2. The important thing, in my view, is to grant that both sides of the balance scale have weight; and then to try to do a conscientious job of weighing.

Wikler, supra note 71.
THE IDEOLOGICAL CONTEXT OF THE DISABILITY RIGHTS CRITIQUE: WHERE MODERNITY AND TRADITION MEET

JANET DOLGIN*

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Erik Parens and Adrienne Asch have summarized the disability rights critique of prenatal testing in two broad claims: “that prenatal genetic testing followed by selective abortion is morally problematic, and that it is driven by misinformation.” These claims, though consonant with assertions of many pro-life groups, are intended to serve different ends. Parens and Asch explain that most authors associated with the disability rights critique are feminists who support a woman’s right to abortion. In contrast, pro-life adherents predicate differences between women and men on inexorable natural truths and define their position about abortion as an inevitable correlate of

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1. The term “critique” as used in this Article refers to the disability rights critique of prenatal testing, embryo selection and selective abortion. This Article discusses the work of Professor Adrienne Asch and others who have contributed to the development of the disability rights critique of prenatal genetic testing, embryo selection and selective abortion. The Article focuses on the work of Adrienne Asch because she participated in the Symposium from which this issue of the Law Review developed. See Adrienne Asch, Disability Equality and Prenatal Testing: Contradictory or Compatible?, 30 Fla. St. U. L. Rev. 315 (2003). Often, the Article speaks broadly about the work of the disability rights critique. Limitations of space preclude detailed discussion of differences among those associated with the work of the critique. Such differences do exist.

2. Erik Parens & Adrienne Asch, The Disability Rights Critique of Prenatal Genetic Testing: Reflections and Recommendations, in PRENATAL TESTING AND DISABILITY RIGHTS 3, 13 (Erik Parens & Adrienne Asch eds., 2000). Parens and Asch further describe the critique through three broad assertions: first, that discrimination is the central problem for disabled people and for their families; second, that those who abort a “desired child” because of a disability diagnosed through prenatal testing “suggest that they are unwilling to accept any significant departure from the parental dreams that a child’s characteristics might occasion”; and third, that selective abortion constitutes an “unfortunate, often misinformed decision that a disabled child will not fulfill what most people seek in child rearing.” Id. at 12-13.

3. Id. at 12 (naming Adrienne Asch, Martha Saxton, Anne Finger, and Deborah Kaplan).
a world in which women and men enjoy different statuses and perform different roles. Yet, pro-life activists would seem further to echo adherents of the disability rights critique in categorizing abortion of “damaged’ embryos” as the “most offensive” of all abortions. Again, however, these concrete similarities are belied by each group’s encompassing goals. Adherents of the critique do not argue that selective abortion is problematic because abortion is problematic. Moreover, the “misinformation” to which Parens and Asch refer does not refer expressly to the ontological status of the fetus. Rather, they refer to misinformation about “what life with disability is like for children with disabilities and their families.” To adherents of the critique, its basic propositions are not concerned centrally with abortion. Rather these propositions concern attitudes toward disability and “toward children, parenthood, and ultimately ourselves.”

The critique’s platform and analysis situate its adherents in the middle of a much wider discourse within American society about the scope and meaning of family. That discourse incorporates a series of related debates about reproduction (including abortion) and about the shifting contours of the relationship between parents and children.

The work of those associated with the disability rights critique—which seems often to belie social expectations about visions of family from the “left” and visions of family from the “right”—provides an unusual context within which to explore the dimensions of a broad

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4. See Kristin Luker, Abortion and the Politics of Motherhood 201 (1984). Luker explains that “abortion has become a symbolic marker between those who wish to maintain this division of labor [based on gender] and those who wish to challenge it.” Id. This claim is representative, not comprehensive. It does not apply to all of those who oppose abortion. See, e.g., Ruth Colker, Feminism, Theology, and Abortion: Toward Love, Compassion, and Wisdom, 77 Cal. L. Rev. 1011, 1074 (1989) (suggesting that we “give more credence both to arguments about how women’s well-being is affected by abortion legislation and to arguments about how our valuation of life is affected by abortion policy” and attempting to “understand more fully the arguments of both the pro-choice and pro-life advocates”).

5. Luker, supra note 4, at 207. Luker reports that for pro-life activists to defend “damaged’ embryos” is particularly praiseworthy because it is to defend “the weakest of the weak, and most pro-life people we interviewed were least prepared to compromise on this category of abortion.” Id. at 207-08.

6. Marsha Saxton speaks about a disability activist who identified fetuses as “our people.” Marsha Saxton, Disability Rights and Selective Abortion, in Abortion Wars: A Half Century of Struggle, 1950-2000, at 374, 383 (Rickie Solinger ed., 1998). Saxton comments: Are those in the disability rights movement who question or resist selective abortion trying to save the “endangered species” of disabled fetuses? When this metaphor first surfaced, I was shocked to think of disabled people as the target of intentional elimination, shocked to realize that I identified with the fetus as one of my “species” that I must try to protect.

Id.

7. Parens & Asch, supra note 2, at 20.
8. Id. at 19.
ideology⁹ of personhood in terms of which Americans contemplate the shifting contours of family and of relationships between individuals and community more broadly. Those who have developed the critique oppose embryo selection and selective abortion while working to safeguard the right to abortion in general.¹⁰ They remain committed to autonomous individuality and choice, and they work to delineate the meaning of community. However, for those who favor a pro-choice position, these propositions present hard questions. Moreover, as Adrienne Asch has suggested, the questions are not easily entertained by law or the political process.¹¹

This Article explores the ideological implications of sustaining a pro-choice position with regard to abortion generally alongside a position that frowns on abortion for the specific purpose of selecting against an embryo or fetus identified as carrying disabling traits. The exploration aims to contextualize each position within a broader social debate about the parameters of family life. It begins by presuming that the specific debate about prenatal testing and abortion may prove valuable to a society increasingly anxious to re-construct the domestic arena and largely relegated to the institutions and language of the law for advancing that agenda.

Part I of this Article considers the limitations of contemporary legal and political processes in exploring the implications of prenatal genetic testing. Part II outlines the parameters of a debate related to the central concerns of the disability rights critique—a debate about family, generally, and about abortion, in particular—and considers the law’s role in that debate. Finally, Part III suggests that the factors that make it difficult to effect the agenda of the disability rights critique through legal channels are the same factors that establish the critique’s unusual significance for those concerned to understand the socio-cultural parameters of the debate about abortion and the

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⁹ The term “ideology” and the related term “ideological” are not used in this Article to refer to a system of political beliefs but rather to refer to the pervasive, often articulated, forms in terms of which people understand what it means to be a person. Janet L. Dolgin & JoAnn Magdoff, The Invisible Event, in SYMBOLIC ANTHROPOLOGY 351, 363 n.7 (Janet L. Dolgin et al. eds., 1977). This definition is similar to that of the French anthropologist Louis Dumont who wrote:

Our definition of ideology thus rests on a distinction that is not a distinction of matter but one of point of view. We do not take as ideological what is left out when everything true, rational, or scientific has been preempted. We take everything that is socially thought, believed, acted upon, on the assumption that it is a living whole, the interrelatedness and interdependence of whose parts would be blocked out by the a priori introduction of our current dichotomies.


¹⁰ Marsha Saxton suggests that “the reproductive rights movement emphasizes the right to have an abortion; the disability rights movement, the right not to have an abortion.” Saxton, supra note 6, at 375.

¹¹ See discussion infra Part I.
related, more widespread social debate about family.

I. BEYOND THE LAW: THE ABORTION DEBATE AND DISABILITY RIGHTS

Almost two decades ago Adrienne Asch wrote that the debate about abortion would be furthered were it more widely conducted outside the universe of “politics and the courts.” Asch is not a lawyer or a law professor. It is thus unsurprising that her work, though read by lawyers and legal academics among others, is not for the most part aimed at transforming the law’s responses to abortion, prenatal embryo selection or other matters. Yet, her express preference for considering abortion outside contexts defined by courts of law or by the political process is more than a simple statement of professional affiliation.

Asch’s preference was predicated on her sense that “rational discussion” about abortion and related matters is more likely to be facilitated in non-legal, non-political contexts. Law and politics, she implies, do not encourage people to listen carefully to the others’ positions and thus do not encourage people to re-consider, and perhaps amend, the nuances of their own positions. In contrast, judicial and political contexts stress practical results and foster a vision in which one either wins or one loses. Neither the courts nor the political process have the luxury of facilitating the sort of intellectual debate which, effected in good faith, may carry its own rewards in facilitating clarification and enlightenment.

Even more, the law is not, at present, likely to provide a felicitous arena for effecting the central goals of the disability rights critique. In struggling to resolve disputes about abortion and about family relationships more broadly, the law has relied on two competing assumptions. The disability rights critique elides the first and rejects

12. Adrienne Asch, Abortion in Context, WOMEN'S REV. BOOKS, Nov. 1985, at 12 (reviewing ABORTION: UNDERSTANDING DIFFERENCES (Sidney Callahan & Daniel Callahan eds., 1984)).

13. Having said this, it must be noted that Asch has published in law reviews and has sometimes argued, much as any legal scholar might, for particular legal responses and against others. See, e.g., Adrienne Asch, Critical Race Theory, Feminism, and Disability: Reflections on Social Justice and Personal Identity, 62 OHIO ST. L.J. 391, 423 (2001) (arguing for an interpretation of the Americans with Disabilities Act (ADA), 42 U.S.C. §§ 12101-12213 (1994), that provides greater “equality, more inclusivity, and greater appreciation of the complexity of humanity in all its variability”). More specifically, Asch argues that more people should be allowed to file claims under the ADA even if their claims are later rejected by courts. Id. at 405.

14. In the American setting, as de Tocqueville realized over a century and a half ago, there often is only a thin space between political concerns and judicial responses. De Tocqueville opined: “There is hardly a political question in the United States which does not sooner or later turn into a judicial one.” 1 ALEXIS DE TOCQUEVILLE, DEMOCRACY IN AMERICA 248 (J.P. Mayer et al. eds., 1966) (1855).

the second. First, and most widely, the law has presumed the autonomous individuality of family members, especially in contexts that do not implicate the scope of the parent-child relationship. In increasingly since the middle of the twentieth century, American law has safeguarded the right of adults within families to negotiate their own realities and effect their own choices. The disability rights critique aims to temper, though not to preclude, choice. Second, especially in the context of contentions about abortion, the law has modulated its commitment to preserving the choices of autonomous individuals by limiting the right to abortion in light of the ontological status of the fetus. So, for instance, in Webster v. Reproductive Health Services, the Supreme Court found that Missouri’s abortion law did not violate the right delineated in Roe in its express assertion that “[t]he life of each human being begins at conception.” Adherents of the disability rights critique generally reject contentions of this sort.

In general, those who have developed the disability rights critique are more concerned with the implications of prenatal genetic testing for the society as a whole than with individual decision-making. Adrienne Asch, for instance, does not oppose the right of a prospective parent to undergo prenatal testing and to abort a fetus. In fact, she would prefer that someone, convinced that he or she would be unable adequately to raise a disabled child, abort a disabled fetus than give birth to a child about whom the parent might remain ambivalent and whose needs the parent might not be able or ready to meet. Asch would thus favor responses that generally lie beyond the law’s capacity to design.

Asch’s preference—or more actually, perhaps, her plea—that the social debate about abortion (and, by implication, disability rights and prenatal testing) be entertained, at least some of the time, outside legal and political settings would seem to reflect other more subtle concerns. These concerns are worth exploring. The exploration holds implications for the larger ideological context within which legal and political responses to abortion and disability rights are being constructed and transformed.

In the two decades since Asch expressed a preference for discussing the implications of abortion outside legal and political contexts,
the disability rights critique has focused its agenda and concerns around a series of issues involving reproduction and the avoidance of reproduction that American society has largely left to the law and the political process to frame and to resolve. In considering these issues, the law has constructed a morality of choice that values autonomous individuality at the expense of community. Secondarily it has relied, in a few limited contexts, on a “traditional” morality that presumes communities defined through inequality and hierarchy (as in the relationship between parents and children). The law has not, however, produced a coherent morality of “modernity” that aims to safeguard community and autonomy.

Asch’s preference for furthering the debate about abortion outside legal and political contexts may encourage innovative responses, not constrained by familiar legal presumptions about personhood and community. The remainder of this Article examines responses—many legal, some not—to abortion and disability rights in order better to understand the ideological context within which law and society respond to the related concerns in American society about families, abortion and prenatal testing.

II. Matters of Morals / Matters of Law

A. The Ideological Context of Debate

Questions about abortion and prenatal testing are encompassed within a broader debate in contemporary American society about the scope and parameters of family (and of personhood and community). That debate has garnered widespread attention since the second half of the twentieth century. This Part of the Article delineates the contours of that debate, suggests that the debate has largely been left to the law because of the erosion of alternative institutional arbiters, and briefly indicates the tenor of the law’s response. That response suggests the need, as Asch intuited more than twenty years ago, for alternative arenas encouraging discourse about families, disabilities, and personhood.

22. There are, of course, other contexts within which discourse about society’s treatment of disabled people is furthered. For the most part, the discourse has been channeled by appeal to the legal and political processes. Among the most important successes of that appeal to law and politics was the promulgation of the Americans with Disabilities Act of 1990, 42 U.S.C. §§ 12101-12213 (2000).

23. Despite the apparent need for alternative institutional arbiters of moral questions, almost none are available in the contemporary American context outside small, generally marginal, and often isolated religious communities.
B. The Ideological Context: The Debate About Family

The roots of the contemporary debates about abortion and family life lie in the history of the American family. The so-called “traditional” family appeared at the end of the eighteenth and start of the nineteenth centuries in response to the needs and pressures of the Industrial Revolution. This family replaced the larger colonial family that functioned as an interconnected part of local communities.24

By the nineteenth century, American society envisioned the ideal family as contrasting in almost every regard with the marketplace.25 In the marketplace, putatively equal autonomous individuals were expected, in theory though far less often in fact, to negotiate the terms of their own bargains. In contrast, the family was understood as a hierarchical whole, defined through love rather than through money.26 Moreover, within families roles depended on gender. The home was associated with women and children and the marketplace with men. Society envisioned the nineteenth century home as a haven from within which to escape the harsh tensions of the marketplace. At home, wives and mothers were expected to provide caring sanctuary to their working husbands and treasured children.27 Thus throughout the nineteenth and first half of the twentieth centuries, the home was differentiated from the marketplace as an arena that valued status more than achievement, hierarchy more than equality, and the social whole more than individual autonomy. State law regu-

25. As John Demos explained, colonial families were “continuous” with the larger social world both socially and economically. JOHN DEMOS, PAST, PRESENT AND PERSONAL: THE FAMILY AND THE LIFE COURSE IN AMERICAN HISTORY 28 (1986).
26. See GROSSBERG, supra note 24, at 6-7 (attributing development of nineteenth-century family to combination of laissez faire ideology of marketplace and egalitarian ideology of the new Republic).
27. David Schneider, an anthropologist who studied the American family just before it began openly to shed traditional forms, posited the contrast between home and work to sit at the center of the ideology that defined traditional American families. DAVID M. SCHNEIDER, AMERICAN KINSHIP: A CULTURAL ACCOUNT 45-49 (1968). Schneider wrote:
   The set of features which distinguishes home and work is one expression of the general paradigm for how kinship relations should be conducted and to what end. These features form a closely interconnected cluster.
   The contrast between love and money in American culture summarizes this cluster of distinctive features.
   . . .
   . . . [T]he opposition between money and love is not simply that money is material and love is not. Money is material, but love is spiritual. The spiritual quality of love is closely linked with the fact that in love it is personal considerations which are the crucial ones.
   Id. at 48-49.
28. DEMOS, supra note 25, at 31 (describing traditional family as refuge and loving “fortification”).
lated this “traditional” family through rules that contrasted with the rules that regulated life in the marketplace.

During this period, family life did change, but it was not for a century and a half that the “traditional” family began *visibly* to collapse. Before the late twentieth century, the family underwent a comparatively subtle process of transition. That process, much as the more revolutionary process of change in family life that commenced in the second half of the twentieth century, was reflected in legal changes.29 These legal changes suggested, at first tentatively, a new social readiness—not broadly acknowledged for another century and a half—to define family members in certain contexts for certain purposes through Enlightenment values,30 especially equality and liberty.

For over a century, however, society continued to portray the family generally as a social unit that ideally reflected community rather than individuality and fixed roles rather than bargain and choice. Only in the second half of the twentieth century did society and the law openly acknowledge and reinforce a vision of family broadly predicated on Enlightenment values, including especially equality and liberty (framed as autonomy). Family members, especially adults, began increasingly to view themselves as autonomous individuals free to negotiate the terms of their familial relationships.

That shift is reflected in a wide set of demographic changes, including increases in the incidence of divorce, nonmarital cohabitation, and nonmarital parentage.31 These changes in turn are reflected in far-reaching legal changes including, for instance, the Supreme Court’s delineation of a constitutional right to privacy in familial settings,32 the acceptance of prenuptial agreements33 and of cohabitation

29. *See infra* note 30 and accompanying text.
30. In both the nineteenth and twentieth centuries, changes in family law reflected, far more than they effected, social changes. So, for instance, the promulgation of laws referred to generally as Married Women’s Property Acts, in the mid-nineteenth century freed married women from some part of the legal limitations regarding property ownership that marriage once brought to them. LESLIE J. HARRIS & LEE E. TETELBAUM, FAMILY LAW 13 (2d ed. 2000). These statutes were generally uncontroversial when they were adapted by state legislatures. *Id.*
33. *See, e.g.,* Posner v. Posner, 253 So. 2d 381, 383 (Fla. 1970) (finding that public policy supports enforcement of prenuptial agreements); Scherer v. Scherer, 292 S.E.2d 662, 666 (Ga. 1982) (relying expressly on contract law to enforce a prenuptial agreement); O-
agreements, and the so-called “no fault” divorce revolution. After the 1960s, these changes occurred quickly and dramatically and resulted in widespread legal debate in courts, in legislatures, and in law schools, about the meaning of family and the implications of family life.

C. The Erosion of Institutional Arbiters

In an earlier time, questions about the moral and practical scope of family life were considered by a wide variety of institutional arbiters. But in the late twentieth century, those institutional settings collapsed or became far less central to or interested in defining the parameters of the domestic sphere. In part, this is a product of the same economic, political and social forces that re-defined the family.

Churches, schools, and voluntary communal groups were among the central institutions that traditionally directed discourse about the contours of family life in the United States. After World War II, each became significantly less important as an arbiter of moral matters within society generally. Churches, identified by de Tocqueville in the nineteenth century as central to the construction and significance of American mores, began clearly to wither in significance in the second half of the twentieth century. Church attendance declined and even those who continued to attend churches became less committed to particular denominations and church communities. Similarly, the influence of schools in delineating the proper scope of family life...
ily relationships declined dramatically after World War II. In fact, parents and the government have seemed similarly uninterested in schools generally, at least compared with other periods and other countries. Moreover, a large number of voluntary communal groups, regarded by de Tocqueville as essential to the preservation of the American moral order, have ceased to exist or continue to exist but without active members. These shifts have left Americans, faced with disputes about the parameters of family life, more inclined to turn to the law for resolutions.

Yet, as Asch intuited almost two decades ago, the law’s responses to disputes about family matters are often limited in form and scope. In particular, at least since the 1970s, the law, in responding to disputes involving family and other communal relationships and identities, has generally been committed to autonomous individuality and to the protection and elaboration of individual rights. Thus the law has been increasingly ready to sacrifice the demands of community to those of individual autonomy. In the last several decades, the law’s commitment to individuality has inevitably shaped debate in the United States about a related set of matters, including, for instance, families, reproduction, the avoidance of reproduction, and privacy—including reproductive privacy.

And so, in fact, despite Asch’s reasonable preference for furthering debate outside, as well presumably as inside, legal and political contexts, the tone and dimensions of debate in the United States about both abortion and family life have been largely forged in courts of law and in political responses to those courts’ presumptions and pronouncements. The law has provided a fulcrum for vociferous, often antagonistic, debate about abortion. However, the shape of the public debate about abortion has been limited and its most important implications have largely been disguised as opposing groups have sought to gain the law’s assistance in effecting concrete agendas, often at the

39. The role of schools in directing moral discourse generally has declined dramatically since World War II. Neil Postman has noted, for instance, that in the early decades of the Republic it was assumed that an educator’s job included teaching about the “American creed” and the values it was presumed to reflect. Neil Postman, The Disappearance of Childhood 140, 150-52 (1982).

40. Robert Putnam notes a startling decline in the number of parents who have participated in Parent Teacher Associations (PTAs) after the 1950s. Putnam, supra note 38, at 55-57. He reports that about a quarter million families a year dropped out of PTAs for two and a half decades after 1960. Id. at 56.

41. See Stephanie Coontz, The Way We Really Are 143 (1997) (noting that in the U.S., funding education is not a national priority as it is in many other countries).

42. See de Tocqueville, supra note 14, at 485-88.

43. Putnam, supra note 38.

44. Many legal scholars have commented in recent decades on the focus that American law places on what Mary Ann Glendon refers to as “rights discourse” (or “rights talk”). Mary Ann Glendon, Rights Talk: The Impoverishment of Political Discourse 7 (1991).
expense of furthering what Asch calls “rational discussion.”45 In this regard, the disability rights critique could provide a useful perspective on abortion and relationships within family settings generally. This is so, insofar as the critique combines a focus on communal responsibility with an interest in safeguarding individuals’ rights and therein reflects aspects of both pro-choice and pro-life positions in the abortion debate.

D. A Discourse About Abortion Alongside the “Debate About Abortion”46

In significant part, the struggle in the United States about abortion has been played out through appeals to legal institutions, including courts and legislatures. The history of that struggle suggests the limits of the law as a moral arbiter. This Part sketches the ideological contours of the debate about abortion as one component of the wider debate about family. It further suggests that the law’s intense involvement in shaping abortion rights and other family relationships, especially in the last half century, has shaped discourse in light of the law’s capacity to contemplate disputes and to preclude or resolve them. This Part is thus intended to serve as background to the next Part, which considers the place of the disability rights critique in broadening social discourse about abortion and about family relationships.

Since the middle of the twentieth century, American society and law, long committed to autonomous individuality in the marketplace, have become increasingly committed to valuing and safeguarding autonomous individuality in family settings.47 The law’s increasing readiness to resolve family disputes through principles of constitutional law has reinforced this commitment.48 The Supreme Court rarely entertained family matters before the second half of the twentieth century.49 Since that time, shifts in constitutional jurisprudence have facilitated family litigants’ invocation of Fourteenth Amendment due process and equal protection rights.50 This jurisprudence

46. I am now working on an essay (Embryos as Symbols: A New Debate in an Old Guise) that focuses more extensively on the issues considered in this Part that cannot be addressed here in light of present space limitations.
47. See supra Part II.B (characterizing shifts in social and legal understanding of family life in last half of twentieth century).
48. See generally Dolgin, supra note 36 (describing frequency with which Americans turn to law, and especially to constitutional law, to resolve moral disputes).
presumes individual rights, and has consequently resulted in a set of constitutional protections for *individuals* within families. So, for the most part, at present, constitutional law protects the autonomous individual and a concomitant right to choice, of family members, and especially of adults within families. For the most part, constitutional law has not provided for a comparably coherent response to defining and protecting relationships that do not presume autonomous individuality. So, for instance, the Supreme Court has been far less successful at defining and safeguarding family relationships between parents and children than at safeguarding the autonomous individuality of adults within family settings.

The limited right to abortion, defined in *Roe*, and re-assessed, but in some part preserved, in *Casey*, depends on a jurisprudence that presumes autonomous individuality. That jurisprudence is unproblematic unless the status of the fetus is invoked and balanced against the “status” of the woman. The pregnant woman, defined in *Roe* as free to effect some, though not all, choices about abortion, can be understood within the same ideological framework that encouraged the Court, eight years earlier in *Eisenstadt v. Baird* to

51. See, e.g., Planned Parenthood v. Casey, 505 U.S. 833 (1992). The Court in *Casey* reaffirmed the basic right of a pregnant woman to abortion, noting expressly that the decision followed in significant part from the Court’s concern with protecting “individual liberty” and its commitment to stare decisis. *Id.* at 857. The Court wrote:

An entire generation has come of age free to assume *Roe’s* concept of liberty in defining the capacity of women to act in society, and to make reproductive decisions; no erosion of principle going to liberty or personal autonomy has left *Roe’s* central holding a doctrinal remnant; *Roe* portends no developments at odds with other precedent for the analysis of personal liberty. *Id.* at 860-61.


53. This jurisprudence reflects the absence of social consensus with regard to the meaning of childhood and the scope of the parent-child relationship. The confused state of the Court’s reasoning about children-in-families is illustrated by its 2000 decision in *Troxel*. *Id.* See also, Dolgin, *supra* note 36, at 369-92 (analyzing limitations of the Court’s decision in *Troxel*).


55. See *Casey*, 505 U.S. at 833. In *Casey*, the Court re-structured *Roe’s* delineation of the moral implications of the biological dimensions of pregnancy. In particular, *Casey* abandoned the trimester framework erected in *Roe*. See id. at 872-73. That conclusion, clearly responsive to claims about the status of the fetus, facilitated the Court’s upholding of a set of state regulations that seem clearly to interfere with a woman’s right to abortion. The Pennsylvania Abortion Control Act of 1982, at issue in *Casey*, required, among other things, that a woman seeking an abortion be given certain information before the abortion and wait at least twenty-four hours before having the procedure performed; required a minor seeking an abortion to get parental consent from at least one parent or go before a judge for permission, among other things; and required a married woman seeking an abortion to notify her husband. *Id.* at 844. In *Casey*, the Court upheld the first two regulations and declared the third unconstitutional. *Id.* at 887-98.

56. See infra notes 62, 70 and accompanying text.

couraged the Court, eight years earlier in *Eisenstadt v. Baird*, to view adults’ sexual relationships as subject to individual choice rather than to traditional, fixed understandings of sexuality, marriage and reproduction. Thus, in some part, the Supreme Court’s responses to the debate about abortion parallel responses to the wider debate within American society about the right of family members to construct the terms of their relationships.

There is, however, an alternative perspective within the debate about abortion that the Court and the legal system more broadly have been willing to entertain. This perspective brings a counterweight to the presumed importance of choice and individuality. While those favoring a right to abortion have consistently stressed the right to individuality and to equality of women within the domestic sphere, opponents of abortion, generally identified as adherents of tradition in family matters, have stressed the ontological status of the fetus as a moral being—a person, in effect.

Insofar as pro-life voices have framed the political struggle about abortion in terms of the ontological status of the fetus, they have created a basis for decision-making, not predicated on the valuation of autonomous individuality. This framework, which has proved moderately effective as a strategic matter, has also served to disguise, and thus to further, a more encompassing agenda. The larger agenda implicates not only the status of embryos and fetuses but the meaning of personhood and the scope of family relationships. Thus, it implicates the locus of power within familial, and other communal, settings.

For abortion opponents, assertions about the fetus-as-child have provided the sort of strategic tool that has largely been lacking in other contexts involving legal responses to adults’ expanded choices, especially about reproductive matters, within family contexts. In the

58. 405 U.S. 438 (1972) (defining constitutional right of an *individual*, whether married or not, to use contraception).

59. Clearly, traditional understandings of these matters are themselves subject to change. The essential difference between traditional understandings and modern understandings is not the presence or absence of change, but is located in a comparison between fixed statuses and attendant roles on the one hand and autonomous choice on the other. See JANET L. DOLGIN, DEFINING THE FAMILY: LAW, TECHNOLOGY, AND REPRODUCTION IN AN UNEASY AGE 14-15 (1997) (contrasting traditional and modern ideologies of family).

60. David J. Langum, A Personal Voyage of Exploration through the Literature of Abortion History, 25 LAW & SOC. INQUIRY 693, 702-03 (2000) (generally opposing abortion on grounds that “abortion is the killing of a life form” but recognizing the presence of responsible argument among those favoring right to abortion).

61. See, e.g., LUKER, supra note 4, at 192-215 (comparing responses of activists on both sides of debate about abortion). Luker correlated value judgments among a group of women activists about the status of the fetus on the one hand and about the scope of family life on the other, and concluded that the abortion debate provides a forum for contemplating a wider set of issues, including the parameters and meaning of motherhood. *Id.*
struggle over abortion, the centrality of claims about the status of the fetus in arguments presented by abortion opponents has proved powerful, though not determinative, in advancing a pro-life agenda. It has even resulted in those who support a right to abortion hesitating, at least in public contexts, to explore questions about the ontology of fetal development. The centrality of legal responses in the debate about abortion has compelled those involved on all sides to sacrifice expansive discourse in the hope of legal victory. In consequence, a wider and more far-reaching social debate within society about the implications of abortion has largely been foreclosed in public settings.

This suggests the potential importance of the disability rights critique to the wider debate about abortion and of Asch’s early intuition that questions about abortion might best be furthered outside legal and political settings. In short, the work of those within the disability rights movement, who favor protecting a woman’s right to abortion but who disfavor abortion for purposes of precluding the birth of a disabled child, challenges society to engage actively in a wider debate about abortion and the implications of abortion discourse for the meaning of personhood and the scope of family.

III. THE DISABILITY RIGHTS CRITIQUE, THE DEBATE ABOUT ABORTION, AND THE MEANING OF FAMILY

The disability rights critique belies expectations about differences in the ethos and world view of those who favor a legal right to abortion and of those who oppose that right. Firmly committed to Enlightenment values and an ideology that prizes choice and

62. After Roe, pro-life advocates worked, for instance, to amend the Constitution to provide that life begins "from the moment of conception." KATHLEEN M. SULLIVAN & GERALD GUNTHER, CONSTITUTIONAL LAW 531 (14th ed. 2001) (considering changes in two decades after Roe). By the late 1980s many commentators presumed that the Court was ready to overrule Roe. Id. However, in Planned Parenthood v. Casey, 505 U.S. 833 (1992), the Court upheld (while modifying the limits of) the basic right to abortion defined in Roe. After Roe, pro-life groups worked assiduously to focus the debate about abortion around a set of presumed biological truths. Ronald Dworkin, The Concept of Unenumerated Rights, 59 U. CHI. L. REV. 381, 404 (1992) (noting claims about biological status of fetus). Abortion opponents portray fetuses as babies, stressing, for instance, that after conception an embryo has a "biological blueprint for a new individual." Reva Siegel, Reasoning from the Body, 44 STAN. L. REV. 261, 325-26 (1992) (quoting Ray Kerrison, Backdrop to Bush's Court Selection: Pictures Show What Abortion is About, N.Y. POST, July 25, 1990, at 2). Proponents of the right to abortion deny that conception, or any other biological milestone during gestation, endows the fetus with moral standing. See, e.g., C.R. AUSTIN, HUMAN EMBRYOS: THE DEBATE ON ASSISTED REPRODUCTION 22-31 (1989) (showing difficulty of settling on any moment in biological development as conclusive of the status of personhood).

63. See, e.g., Saxton, supra note 6, at 390 (noting "taboo placed on discussions of the fetus among feminists).

64. See, e.g., Adrienne Asch & Gail Geller, Feminism, Bioethics and Genetics, in FEMINISM AND BIOETHICS: BEYOND REPRODUCTION 318 (Susan Wolf ed., 1996); Saxton, supra note 6, at 374.

65. Luker, supra note 4, at 194-215.
autonomous individuality, those who have constructed the critique are concerned as well with elaborating an understanding of relationships and community that may sometimes preclude or limit choice.\(^{66}\) Thus the critique reflects modernity’s commitment to individuality and choice, but it modifies that commitment for the sake of safeguarding a community\(^{67}\) of disabled people.

The critique presumes autonomy but prizes community. It values choice but is cognizant of the risk of sacrificing communal responsibility to individual preference. Many of those associated with the critique identify as feminists and/or leftists.\(^{68}\) Yet some of their central positions, especially if viewed outside the critique’s larger ideological frame, seem more consonant with a pro-life than a pro-choice platform. The readiness of the critique’s adherents to cross starkly defined lines of social and legal debate makes it difficult for them to depend on extant legal responses in advancing the critique’s agenda. At the same time, however, the critique, precisely because it merges (and values) a number of arguments and assertions more generally viewed as ideological antagonists in the debates about abortion and family life, suggests a new framework within which to contemplate and analyze abortion, personhood and communal (including familial) relationships.

### A. The Disability Rights Critique and the Law

In significant part, the critique’s agenda is not represented in the language of the law or directed at law-makers.\(^{69}\) American law, reflecting disharmony about abortion within society, has variously provided for those anxious to safeguard a right to abortion and for those who oppose abortion. Sometimes courts have institutionalized aspects of each position.\(^{70}\) But the law has generally done that without mediating the ideological concerns of those who value autonomous

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67. See infra notes 80, 81 and accompanying text (for consideration of that community’s construction).
68. See, e.g., Adrienne Asch & Michelle Fine, Shared Dreams: A Left Perspective on Disability Rights and Reproductive Rights, in WOMEN WITH DISABILITIES 297 (Michelle Fine & Adrienne Asch eds., 1988); Parens & Asch, supra note 2, at 12.
69. Many of the law’s limitations in facilitating social debate about abortion (which Asch recognized almost twenty years ago) apply as well to debate about prenatal testing, embryo selection, and selective abortion. See Asch, supra note 12.
70. So, for instance, in Planned Parenthood v. Casey, the Supreme Court upheld the Fourteenth Amendment due process right to abortion delineated in Roe. 505 U.S. 833, 846-53 (1992). The Court’s plurality announced, however, that "a woman’s liberty is not so unlimited . . . that from the outset the State cannot show its concern for the life of the unborn, and at a later point in fetal development the State’s interest in life has sufficient force so that the right of the woman to terminate the pregnancy can be restricted."

*Id.* at 869.
choice and of those who value limitations on choice. The law’s responses to abortion have not stilled controversy. Instead, they have hardened lines of debate and have sharpened a sense that disagreements about abortion constitute a battleground on which the voices of modernity oppose those of tradition.

In this context, appeals to the law by those concerned with regulating abortion almost always rely either on the language of choice and individual autonomy or on language committed to the personhood of the fetus. Thus, often, pro-choice and pro-life adherents speak past each other. Partly for strategic reasons, those appealing to the law to provide for or to prohibit abortion have generally not forged alternative, more nuanced approaches. The law’s responses, in turn, have encouraged ever sharpened dispute and have strengthened perceptions of the debate about abortion—and about the larger set of family issues that the debate about abortion symbolizes—as essentially impervious to mediation.

The work of the critique’s advocates offers an alternative frame for discourse. The critique has situated itself adjacent to, rather than inside, the law’s debate about abortion—in part because the law’s responses to abortion provide no place for the critique’s vision. The law has furthered the ends of those committed to pro-choice positions by constitutionalizing a right to choice in reproductive matters. The critique’s willingness to limit choices about abortion precludes comfortable alliance with some pro-choice rhetoric and with the legal framework reflecting that rhetoric. On the other hand, the law has furthered the ends of those committed to pro-life positions by focusing on the ontological status of the fetus. The willingness of the critique’s adherents to provide generally for abortion precludes alliance with most pro-life programs and with the legal framework that supports those programs.

In fact, those associated with the disability rights critique do not generally aim to curtail women’s legal choices about abortion. Rather, they aim to reshape the ground on which those choices are entertained by individuals and by society. They urge, for instance, that physicians, other health care workers, and genetic counselors advising women and couples about the implications of prenatal testing be encouraged to think about prenatal testing and selective abortion more expansively than is generally the case.71 The hope is that, as a result, such counselors will more often refrain from presuming,

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71. See, e.g., Saxton, supra note 6, at 381-90 (reframing implications of prenatal screening and selective abortion).
and thus unthinkingly communicating, the belief that any fetus identified as disabled should be aborted.72

The work of the disability rights critique suggests that opposing positions in the debate about abortion (and family matters more widely) may be more open to mediation than is generally presumed. In working to construct a program that values the notion of autonomy, generally prized by those identified as pro-choice, and that values limitations on choice, generally prized by those identified as pro-life, the critique offers new options for discourse, and ultimately for shared understanding. Moreover, the critique promises to enrich debate by suggesting the ideological commonality of the debate’s antagonists. At base, neither set of voices in the debate about abortion rejects the significance of choice and neither rejects the significance of community. Both interests are foundational to virtually all contemporary discourse about abortion and about the parameters of the domestic arena. Indeed, taken together, the pro-choice and pro-life positions in the debate about abortion reflect the parameters of the ideological framework within which Americans broadly understand personhood.

B. The Disability Rights Critique and American Ideology

In short, the critique’s central propositions73 as well as its broader agenda suggest that pro-choice and pro-life positions can be envisioned as ideological points within a broader debate rather than as absolute, unbridgeable ideological opposites. In aiming to protect individual autonomy while focusing on the construction of community, the critique suggests areas of compatibility and shared concern.74 These include concern for safeguarding choice, a concern often elided by pro-life adherents, self-consciously aligned with tradition; and concern for responsible community that sometimes trumps choice and individuality, a concern often elided by pro-choice adherents, self-consciously aligned with modernity and firmly committed to autonomous choice.

Adrienne Asch and Michelle Fine have summarized the broad goals of the disability rights movement to include “a commitment to

72. See Adrienne Asch, Why I Haven’t Changed My Mind About Prenatal Diagnosis, in PRENATAL TESTING AND DISABILITY RIGHTS 234 (Erik Parens & Adrienne Asch eds., 2000) (noting messages communicated in settings involving prenatal testing and subsequent abortion); Asch & Fine, supra note 68, at 297. Asch and Fine assert that “[g]enetic counselors, physicians, and all others involved with assisting women during amniocentesis should gain and provide far more and very different information about life with disabilities than is customarily available.” Id. at 302.

73. Parens & Asch, supra note 2, at 12-13 (summarizing three central propositions of disability rights critique of prenatal diagnosis and selective abortion).

74. See, e.g., Asch & Fine, supra note 68, at 304.
self-determination and a shared sense of community, recognizing that the one is meaningless without a sense of the other. More specifically, in valuing a woman's right to abortion, the critique presumes the importance of choice in the initial decision to have or to preclude having children. In disfavoring the abortion of a particular (disabled) child, the critique values restrictions on choice with regard to the constitution of one's children.

In this regard, the critique's encompassing agenda commits its adherents communal solidarity even if that necessitates limitations on choice. Those within the disability rights movement have implicitly embarked on an ideological journey committed to shaping and securing a construct of community. Others' models of community provide tentative guideposts. Some adherents of the critique have invoked models of community identified through reference to race or gender. Others have sketched models of community through reference to the "social experience" of disability. None of the proposed frameworks adequately defines the disability community but each indicates the significance of the project.

75. Id. For Asch and Fine, effecting this goal would serve as well to constitute a "just and inclusive society." Id.
76. This pattern, providing for toleration of diverse choices in the creation of family relationships but less room for choice in the constitution of family relationships, is reflected in the decisions of a few judges who have struggled to preserve the notion that adults within families should be free to negotiate the terms of their own relationships, but that choice should be limited with regard to children and the parent-child relationship. See, e.g., Janet L. Dolgin, A Rendezvous in the Marketplace? Transformations in Family Law in the United States, in Regulating Morality: A Comparison of the Role of the State in Mastering the Mores in the Netherlands and the United States 193, 204 (Hans Krabbendam & Hans-Martien ten Napel eds., 2000).
77. Carol J. Gill, The Social Experience of Disability, in Handbook of Disability Studies 365, 365 (Gary L. Albrecht et al. eds., 2001) (noting the experience of disability "may seem at first no different from the social stereotyping of other marginalized groups").
78. See, e.g., Saxton, supra note 6, at 374; Joanna K. Weinberg, Autonomy as a Different Voice: Women, Disabilities, and Decisions, in Women with Disabilities, supra note 68, at 269, 269-71 (noting "similar patterns" in histories of women's movement and disability rights movement).
80. During the second half of the twentieth century, many groups, anxious to redress social wrongs directed at their members, modeled their strategies on those developed in the context of the civil rights movement. This has proved problematic to African-Americans as well as to these groups. None share the particular history and experiences of African-Americans. Moreover, the conflation of the history and experience of non-Black minority groups with the history and experience of African-Americans has served to mask the centrality of racism in much of American history.

A framework modeled to reflect the social experience of disability is also of limited value in constructing the sort of community to which the critique's adherents aspire. Among other things, as sketched by Carol Gill, this experience includes at its center a "persistent and disquieting sense of mistaken identity." Gill, supra note 77, at 353. Committing the disability rights movement, writ large, to this identity may provide a basis for shared identity among some people with disabilities but is likely to limit, rather than to expand, the possibility of establishing communal relationships between disabled and non-disabled peo-
Asch suggests a different model for community in asserting that a society anxious to avoid the births of children with disabilities is a society unprepared to provide for the needs of existing people with disabilities. Her apperception suggests the need to define and strengthen communities that include disabled people along with people not so identified. This community, envisioned with reference to its most felicitous potential, would reach beyond the social experience of disability and past various histories of social discrimination to convince “outsiders” that they are also “insiders” (and “insiders” that they may become, and can certainly profit from identifying with, “outsiders”). The disability rights movement may be especially well situated to construct a community able to temper autonomy with respect for responsible personhood. That is so, insofar as no one is immune from disability and no parent or potential parent is guaranteed to bear or to raise children free from disabilities and illness.

IV. CONCLUSION

In the American setting, the illusion of unending choice has become increasingly compelling since the early years of the Industrial Revolution, first in the marketplace, and, a century and a half later, in the home. The discourse engendered by the disability rights critique may fail to persuade significant numbers of prospective parents, especially those favoring a right to abortion, to forego selective abortion and embryo selection. Yet, the discourse stimulated by the disability rights critique may prove valuable in providing a new lens through which to consider the ideological constructs that shape understandings of personhood and of relationships between people within American society. And so, even if the work of the critique does not widely alter responses of society or the law to genetic testing, selective abortion, and pre-implantation embryo selection, discourse engendered by the critique may encourage prospective parents to understand that the choice to undergo prenatal genetic testing and the choices that follow such testing are morally complicated. These are choices that implicate the scope and meaning of the parent-child relationship, as well as understandings of the “Other” (and thus inevitably of the Self) within society.

ple. For the disability rights movement, that is essential. And for the rest of society, it promises a model for “modern” communities that could prove extremely valuable.

81. Telephone conversation with Adrienne Asch, Henry R. Luce Professor of Biology, Ethics, and the Politics of Reproduction, Wellesley College (June 12, 2002). See also supra note 72.
GENETIC DISCRIMINATION IN
A TIME OF FALSE HOPES

JOHN V. JACOBI*

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Law anticipated genetic discrimination in insurance. Legislators in the 1990s accepted genetic equity as a valuable, if abstract, concept largely removed from the realities of insurance underwriting or coverage decisions. Things may become complex quickly, however, when genetic discrimination laws face reality. Difficulties suggest themselves when one attempts to define “discrimination” in practice and then to match statutory language to the practical problem of limiting its effect. Enforcing genetic prohibitions raises perplexing regulatory problems, as forms of health finance morph more rapidly than regulators can anticipate.

The enterprise is vital notwithstanding the difficulties. Denial of coverage or care on the basis of genetics violates the principles of social solidarity that are, or should be, at the core of health insurance law. State and federal lawmakers enacted laws limiting or forbidding genetic discrimination in health coverage during the 1990s, a period of both broad economic growth and very stable health care costs. More recently, the economy has faltered and health care cost inflation has revived with a vengeance. Renewed health care cost inflation appears to be consistent with the nearly Malthusian tendency with which technological advances in health care and the increasing demands of an aging population drive the expense of health services

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ever higher. ¹ A tight economy and increasing costs will create the perception of scarcity and further the pressure to ration care. In such times, the movement to genetic equity in insurance takes on a new character. In good times, the movement seemed a piece of incremental reform, marginally expanding insurance access. Under cost-containment scrutiny, however, it takes on a different cast. In these more restrained times, advocates of genetic equity in health insurance must firmly establish their position in anticipation of renewed attention to rationing.

This Article posits that overt rationing is inevitable. It argues that the genetic antidiscrimination movement, along with others pursuing health coverage equity, must consolidate its position in anticipation of retrenchment. Genetic equity should be regarded not as an exceptional goal, but as an aim consistent with a broader movement toward equitable access to health care in a time of scarcity.

Part I of this Article describes genetic discrimination as it pertains to health coverage. Part II examines the statutory response to genetic discrimination. It first considers but then rejects the possibility that genetic discrimination in health coverage can be remedied by the Americans with Disabilities Act (“ADA”). ² It then examines specific genetic discrimination laws adopted in many states in recent years. Part III examines the difficulties that will arise in enforcing statutory prohibitions. It concludes that some of the enforcement difficulties may be avoided by clearer statutory drafting, while others are inherent in the modern forms of health finance. Part IV looks to the future—it recognizes that genetic discrimination laws cobbled onto existing insurance institutions may cause instability in insurance markets and that serving the goals of equitable access to health care requires broader systems change. It forecasts increasing cost pressures on health care delivery, and suggests that such pressures will lead inevitably to some form of rationing. It concludes that well-established antidiscrimination principles are essential for the integrity of any rationing response to scarcity.

It may be important at the outset to be clear on why an examination of genetic discrimination in health insurance is and is not important. There is very little evidence that insurers have used genetic makeup in any substantial way to assist in either underwriting or coverage decisions. Insurers may do so; however, should they be permitted? Are scientific advances likely to render prognostic testing feasible and economic? Such practices would be the appropriate sub-


ject of prohibitory legislation. More significantly, however, the wide adoption of genetic discrimination statutes in advance of need suggests a broad social rejection of the propriety of considering such information. The justification for genetic discrimination legislation and, generally, the relationship between these statutes and insurance are of great interest to those concerned with financing care for historically expensive populations, such as the chronically ill. These statutes suggest that support for the putative American tradition of matching the price of health insurance to anticipated risk by market methods is fading. The resurgence of health cost inflation, however, suggests that emerging principles of health insurance access equity will run squarely into a cost-conscious attempt to restrict funding for care.

I. THE PROBLEM OF GENETIC DISCRIMINATION IN HEALTH COVERAGE

“Genetic discrimination” is a topic that has attracted substantial scholarly interest in general and in the insurance context in particular. The use of genetic information for insurance purposes is controversial, notwithstanding several circumstances suggesting that genetic information is of little practical importance to insurers and un-

3. An early definition of “genetic discrimination” was “the denial of rights, privileges or opportunities on the basis of information obtained from genetically-based diagnostic and prognostic tests.” Lawrence Gostin, Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests By Employers and Insurers, 17 AM. J.L. & MED. 109, 110 (1991). That definition is underinclusive, as information providing the opportunity for disparate treatment can be obtained through means other than tests. Family history and manifestation of illness related to genetic conditions are other avenues for discovering genetic information that could be used to discriminate. See Lawrence O. Gostin & James G. Hodge, Jr., Genetic Privacy and the Law: An End to Genetics Exceptionalism, 40 JURIMETRICS J. 21, 51 (1999); see also Phillip B. Reilly, Genetic Discrimination, in GENETIC TESTING AND THE USE OF INFORMATION 106, 107 (Clarisa Long ed., 1999) (describing history of use of term); Jennifer S. Geetter, Coding for Change: The Power of the Human Genome to Transform the American Health Insurance System, 28 AM. J.L. & MED. 1, 2 (2002) (claiming “genetic discrimination” eludes definition).


derwriters. First, the genetic code as our “book of life,” through which actuaries may thumb to ascertain our future health history, is a seriously strained metaphor. The relationship between our genetic makeup and our health is complex. Very few diseases have clear relationships with a single genetic characteristic. Most diseases have complex causes, some genetic and some environmental. Genetic testing is, therefore, in most cases a very imperfect means of projecting future illness. Second, genetic treatments have not materialized at a rate that creates a major impact on health care costs, suggesting that insurers will be unlikely to undertake aggressive steps to limit access to this category of care. Third, most Americans with health insurance coverage are not in plans that medically underwrite. Instead, they are covered by Medicare, Medicaid, or large employment-based groups that determine coverage on the basis of group membership or categorical status and not on the basis of medical condition.

Nevertheless, genetic discrimination is both controversial and important. It is controversial because the suggestion that people will be denied coverage or care on the basis of their genetic makeup is viewed as quintessentially unjust. To the extent that advantage should follow desert, genetic discrimination is disfavored for disadvantaging people on the basis of characteristics irrevocably set at the moment of conception. In addition, use or abuse of genetic information threatens to reveal intimate physical information. As is true with any intimate information, its disclosure may be embarrassing. Perhaps more significantly, this intimate genetic information is often unwelcome even to the subject—many of us do not want to know the future. The major emphasis of the genetic discrimination discussion, however, is on the use to which genetic information is put. It may be used to treat people disparately in employment, social relationships, and access to services.

Some instances of alleged disparate treatment have been the sub-

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6. See Elizabeth Pennisi, Finally, the Book of Life and Instructions for Navigating It, 288 SCIENCE 2304, 2305 (2000); see also NICHOLAS WADE, LIFE SCRIPT 19 (2001).
7. See LORI B. ANDREWS, FUTURE PERFECT: CONFRONTING DECISIONS ABOUT GENETICS, 148-49 (2001); Greely, supra note 4, at 1486-87; Suter, supra note 4, at 688-89.
8. Greely, supra note 4, at 1486-87.
9. Id. at 1488.
10. See Diver & Cohen, supra note 4, at 1440-41.
11. See Rothstein & Hoffman, supra note 5, at 852-53.
ject of enforcement activity. Generally applicable genetic discrimination statutes address disparate treatment on the basis of genetic makeup. These statutes employ two strategies for combating such discrimination. The first is to maintain confidentiality with respect to genetic information through privacy rules. This forestalls the opportunity for disparate treatment by holding close the data on the basis of which type of discrimination might occur. The second is to prohibit or regulate the use of genetic information when testing is permitted or information is otherwise disclosed. This strategy enforces the legislature’s judgment of the acceptable and unacceptable circumstances in which genetic condition may be taken into account, for example, in employment or public accommodations decisions.

In the health insurance context, “genetic discrimination” can thus be a remarkably plastic term and requires separate analysis. “Discrimination” in insurance law is often not a term of approbation, but rather refers to a common task of actuaries: the assortment of risks according to their likely realization and cost. Such assortment has been grist for the mill for insurers and actuaries, as they attempt to match the price of coverage against its likely cost and to charge applicants for coverage according to their (hopefully relevant) individual characteristics. Under some circumstances, insurance law requires such discrimination, forcing firms to charge premiums for coverage of risks in relation to the expected cost of such coverage.

In recent years, discrimination in insurance (genetic discrimination in particular) has come to be used to describe circumstances in

13. EEOC v. Burlington N. & Santa Fe Ry. Co., No. 02-C-0456 (E.D. Wis. May 8, 2002). A $2.2 million dollar settlement was awarded to thirty-six individuals who were subjected to genetic testing by their employer after developing Carpal Tunnel Syndrome.

14. In Ohio:

No health insurance corporation, in processing an application for coverage for health care services under an individual or group health insuring corporation policy, contract, or agreement or in determining insurability under such a policy, contract, or agreement, shall do any of the following:

(1) Require an individual seeking coverage to submit to genetic testing or screening
(2) Take into consideration the results of genetic screening or testing
(3) Make any inquiry to determine the results of genetic screening or testing
(4) Make a decision adverse to the applicant based on entries in medical records or other reports of genetic screening or testing

OHIO REV. CODE ANN. § 1751.64(B) (West 2001).

In New Mexico: “Discrimination by an insurer against a person or member of the person’s family on the basis of genetic analysis, genetic information or genetic propensity is prohibited.” N.M. STAT. ANN. § 24-21-4(A) (Michie 2001).

15. Diver & Cohen, supra note 4, at 1444-45.

16. COLO. REV. STAT. ANN. Ch. 10-3-1104.7(1)(c) (2002); N.J. STAT. ANN. Ch. 10:5-5 (2001).

17. OHIO REV. CODE ANN. Ch. 1751.64 (2002); MD. CODE ANN., INS. § 27-909(c)(1) (2001).

18. See infra text accompanying notes 59-60.
which insurers use applicants’ or insureds’ characteristics to treat them differentially, in a manner disapproved of by legislatures. Genetic discrimination in health coverage usually refers to one of two different genetic sorting techniques. The first, which might be called discrimination in underwriting, occurs when a health insurer\(^{19}\) uses genetic characteristics to determine whether to provide coverage to a person. The second, which might be called discrimination in coverage, occurs when a health insurer makes decisions on the basis of genetic characteristics to pay for particular treatment.

Genetic discrimination statutes regulate both the disclosure and use of genetic information in the insurance relationship.\(^{20}\) They seek to assure that an individual’s genetic information will not leak out of the insurance process to taint his or her other public and private relationships. In addition, these statutes directly shape the insurance relationship by setting out whether and when genetic information may be employed by insurers. These latter statutory ends, governing the use of genetic information by insurers, reach both the irrational and the rational use of genetic information. While the roots of genetic discrimination laws are in the history of irrational genetic information, such as the use of carrier status for sickle cell anemia as a predictor of primary disease expression, current laws clearly prohibit the use of genetic information under circumstances when its use would undoubtedly be entirely rational.\(^{21}\) The next Section examines the varied laws governing genetic discrimination in health insurance.

II. THE LAW’S RESPONSE TO GENETIC DISCRIMINATION IN HEALTH INSURANCE

A. Federal Law

1. The Murky Role of the ADA

The ADA recites a congressional finding that America should assure people with disabilities “equality of opportunity, full participation, independent living, and economic self-sufficiency”\(^{22}\) and a statutory purpose of “the elimination of discrimination against individuals with disabilities.”\(^{23}\) President George H. Bush spoke expansively at the Act’s signing, predicting that the ADA would advance the day

\(^{19}\) “Health insurer” here broadly includes private insurance companies, employment-based health and welfare plans, or other entities administering plans responsible for paying health-related costs incurred by members, whether or not they are “insurers” for purposes of state insurance law.

\(^{20}\) Diver & Cohen, supra note 4, at 1443-44; Suter, supra note 4, at 691-92.

\(^{21}\) See Abraham, supra note 5, at 127; Greely, supra note 4, at 1500; John V. Jacobi, The Ends of Health Insurance, 30 U.C. DAVIS L. REV. 311, 332-33 (1997).


\(^{23}\) Id. § 12101(b)(1).
“when no Americans will ever again be deprived of their basic guar-
antee of life, liberty, and the pursuit of happiness.” The United
States Equal Employment Opportunity Commission and others opined that the ADA is sufficiently broad to reach and prohibit ge-
netic discrimination in health insurance. For two reasons, however,
it is now increasingly clear that the ADA will not be so interpreted.

First, the ADA protects against disability discrimination only
those with an “impairment that substantially limits . . . major life ac-
tivities,” those with a “record of such an impairment,” and those
“regarded as having such an impairment.” The Supreme Court has
found that the ADA’s definitions set a “demanding standard” for dis-
ability. The individual’s condition must be such that it “prevents or
severely restricts the individual from doing activities that are of cen-
tral importance to most people’s lives.” In addition, the condition
must presently cause a substantial limitation; it is not sufficient that
the condition did in the past, or may in the future, limit an individ-
al’s actions.

An individual with an unexpressed genetic trait has a greater or
lesser probability of developing an illness, depending on the rela-
tionship between the genetic trait and the disease. It is unlikely, how-
ever, that he or she presently experiences any limitations on daily ac-
tivities. In addition, it is unlikely that he or she would be able to es-
tablish that the insurer “regarded [him or her] as” disabled. 36 This “regarded as” prong of the ADA is met only if “a covered entity mistakenly believes that a person has a physical impairment that substantially limits one or more major life activities, or ... mistakenly believes that an actual, nonlimiting impairment substantially limits one or more major life activities.” 37 In the absence of the covered entity’s erroneous belief in a current impairment substantially limiting major life activities, a person may not state a claim of disability under the “regarded as” prong. Because a person with an unexpressed genetic condition is unlikely to be regarded as “disabled,” then he or she may not state a claim under the ADA.

The second barrier to an ADA action to remedy genetic discrimination in insurance is the statute’s insurance “safe harbor” provision. Congress did not leave the relationship between insurance practices and disability to be interpreted according to the ADA’s general provisions, but spoke to coverage issues directly in § 501(c). 38 This section permits insurers and employers providing either insured or self-insured plans to engage in traditional risk classification practices so long as such practices are not a “subterfuge” for unlawful discrimination. 39 Depending on the definition of “subterfuge,” § 501(c) can be a permissive safe harbor for covered entities or a substantial protection for people with disabilities. As with the application of the term “disability” to individuals with unexpressed genetic traits, the EEOC weighed in early on with an interpretation that has met with little respect in the courts.

The EEOC issued compliance guidance in 1993 in which it interpreted § 501(c) as requiring that risk classification for health benefits purposes be “justified by the risks or costs” associated with cover-

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37. Sutton, 527 U.S. at 489.
39. Section 501(c) permits an insurance company or seller of “bona fide” coverage subject to state law and sponsors of “bona fide” health coverage subject to state law to underwrite, classify, and administer risks in conformity with state law. 42 U.S.C. § 12201(c)(1)(2). It also permits any person to sponsor or administer a plan of health coverage not subject to state law so long as the plan is “bona fide.” 42 U.S.C. § 12201(c)(3). In this context, “bona fide” merely means that the plan “exists and pays benefits.” Fitts v. Fed. Nat’l Mortgage Ass’n, 236 F.3d 1, 4 (D.C. Cir. 2001) (quoting Pub. Employee Ret. Sys. of Ohio v. Betts, 492 U.S. 158, 166 (1989)). “No covered entity, notwithstanding the permissive language of § 201(c) generally, may use a benefits plan as a ‘subterfuge’ to evade the employment and public accommodations provisions of the ADA.” 42 U.S.C. § 12201(c). As is discussed in the text, the meaning of “subterfuge” in this context has been controversial.
A principal means by which the EEOC suggested a covered entity could justify differential treatment of risks, such as the capping of coverage for one condition but not another, is by producing “legitimate actuarial data” to prove that all actuarially similar conditions are treated in the same manner. This principle of actuarial equivalence was accepted early on by some courts, although it has been rejected more recently by the circuit courts that have considered the issue.

The contrary (and now prevailing) interpretation of § 501(c) rejects the requirement of actuarial equivalence. Instead, it reads “subterfuge” as consistent with the use of the term in the Age Discrimination in Employment Act (“ADEA”). The clear modern trend is to interpret “subterfuge” as “a scheme, plan, stratagem, or artifice of evasion.” Interpreting the ADEA, the Supreme Court has rejected both the legislative history and EEOC guidance suggesting a different meaning of subterfuge and has instead adhered to a “dictionary” interpretation of a specific intent to evade the non-discrimination requirements of the statute. Courts have rejected similar reliance on legislative history and EEOC guidance for an interpretation of the ADA and have required plaintiffs asserting subterfuge to demonstrate more than mere absence of actuarial equity and instead to demonstrate a conscious plan to discriminate.

Under the now-prevailing view of the law, therefore, an individual seeking to employ the ADA to remedy an instance of alleged genetic discrimination in health coverage would face two barriers. If she has suffered discrimination on the basis of unexpressed genetic traits, an ADA claim would likely fail for lack of standing—an unexpressed genetic trait is unlikely to be considered disabling. Should an individual cross that barrier by, for example, establishing that the unexpressed genetic trait substantially interferes with her reproductive

47. Leonard F., 199 F.3d at 104-06.
activities,48 she would be faced with the burden of establishing that
the coverage decision is not protected by the insurance safe harbor.
Most critically, she would have to demonstrate that the coverage was
guided not “merely” by business judgment, but rather was motivated
by discriminatory animus and a desire to harm the individual be-
cause of her genetic condition.49

2. HIPAA’s Specific but Limited Protections

The general disability discrimination provisions of the ADA do
not, then, reach genetic discrimination. Bills establishing general ge-
genetic discrimination prohibitions have been proposed,50 but none has
been adopted to date. Congress did address an aspect of genetic dis-


Williams, 534 U.S. 184, 195 (2002).

49. See Betts, 492 U.S. at 168-75 (describing the difference between the (rejected)
business justification rule under the ADEA and the subjective animus rule affirmed by the
Court).

(prohibiting health insurers from using genetic information to impose enrollment restric-
tions or adjust group premiums, making it unlawful for an employer to discriminate based
on genetic information, and requiring genetic information to be treated as part of a confi-
dential medical record); Genetic Nondiscrimination in Health Insurance and Employment
Act of 2001, H.R. 602, 107th Cong. (2001) (making it unlawful to discriminate because of
genetic information in employment and prohibiting health plans from discriminating in
enrollment, eligibility contribution rates, or premiums based on genetic information);
Genetic Nondiscrimination in Health Insurance and Employment Act of 2001, S. 318,
107th Cong. (2001) (making it unlawful for an employer to discriminate because of pro-
tected genetic information; an employer can request, require, collect, or purchase informa-
tion if used for monitoring of biologic effects of workplace toxic substances; also, a group
health plan or a health insurance issuer cannot discriminate in enrollment in health ins-
urance based on genetic information).

42 U.S.C. §§ 300gg to 300gg-41); see generally Coleen E. Medill, HIPAA and its Related
Legislation: A New Role for ERISA in the Regulation of Private Health Care Plans, 65

(2000)); see Diver & Cohen, supra note 4, at 1449-50; Rothstein & Hoffman, supra note 5,
at 869.

(2000)).
This protection, unlike that of the ADA, clearly applies to genetic conditions and has some concrete, if limited, value in preventing genetic discrimination. For group coverage, it limits the use of genetic information by imposing periods of exclusion from coverage and determining group eligibility. It provides for “continuation coverage” and guaranteed renewal from sellers of individual coverage for individuals with a sufficiently long history of continuous coverage, and prohibits insurers from citing genetic conditions to avoid those requirements. Plans are free, however, to decline to cover particular treatments or to impose “limitations or restrictions on the amount, level, extent, or nature of the benefits or coverage” as they see fit. In addition, the term “genetic information” is not a defined term, and the extent of the protection offered from genetic discrimination is therefore uncertain.

B. State Laws: Evolution and Limits

Federal law provides only very limited protection from genetic discrimination in health coverage. The ADA is likely to be totally ineffective in this area, and HIPAA provides only limited benefits. State genetic discrimination legislation has expanded into this near-vacuum. Insurance has long been regulated in the first instance by the states, a tradition formalized with the 1948 passage of the McCarran-Ferguson Act. State law regulating health insurance has shifted over time, moving from limited regulation to protect free markets for health insurance to more intrusive regulation imposing restrictions on insurance practices for the purpose of advancing social goals.

Selecting among and accurately quantifying risk is a core task for insurance companies. Firms seek to assess risk more precisely than their competitors and (where prices may easily be varied) match the premium closely to the expected cost of coverage or (where prices are less easily varied) choose to offer coverage to better risks and to de-
cline coverage to poorer risks. 58 State regulation of insurance historically concerned itself with monitoring the solvency of insurance companies and protecting insureds from outright fraud and misrepresentation. To the extent state regulators concerned themselves with the mechanics of underwriting, they were concerned primarily with an abuse quite different from genetic discrimination. Regulators were concerned with favoritism shown to sophisticated purchasers, by which favored customers paid less than the expected cost of coverage while unsophisticated customers made up for the difference by paying above their actuarially “true” premium.

To combat this perceived flaw in the insurance market, states adopted unfair trade practices acts; these acts came to be interpreted as requiring insurers to segment insured populations by their level of actuarial risk in order to prevent the forced (or at least unknowing) subsidization of one group of insureds by another and instead to mandate “fair discrimination.” 59 The principle that rating differentials must be actuarially justified spawned the first state prohibitions of genetic discrimination. These laws barred insurers from considering recessive genetic traits such as that for sickle cell anemia or Tay-Sachs when making rating or underwriting decisions. 60 These statutes merely enforced the general rule requiring actuarial justification, as the presence of the trait in and of itself bears no relationship with an individual’s health risk. 61

The next phase of state genetic discrimination legislation swept more broadly and varied from the actuarial validity principle. In the 1990s, states began to adopt genetic discrimination statutes that barred insurers from considering genetic information that bore some relationship to the subject’s future health. These newer statutes barred insurers from taking into account genetic evidence that an individual might be more likely to experience an illness than a person without the genetic trait. These statutes barred the use of specifically identified genetic tests or the information gained from others’ use of

58. See KENNETH ABRAHAM, DISTRIBUTING RISK 67-68 (1986); SYLVIA A. LAW, BLUE CROSS: WHAT WENT WRONG? 75-77 (2d ed. 1976).
59. Jacobi, supra note 21, at 321-22; Leah Wortham, Insurance Classification: Too Important to be Left to the Actuaries, 19 U. Mich. J.L. Reform 349, 381-86 (1986). States occasionally created exceptions to this “fair discrimination” requirement. For example, race is an actuarially valid factor in predicting life expectancy, but its use in pricing life insurance is nevertheless widely prohibited by state law. ABRAHAM, supra note 58, at 76.
60. See Jacobi, supra note 21, at 331.
61. See, e.g., MD. CODE ANN., INS. § 27-208 (West 2001) (barring insurance decisions based on “sickle-cell trait, thalassemia-minor trait, hemoglobin C trait, Tay-Sachs trait, or genetic trait that is harmless in itself”) (emphasis added). It is conceivable that there would be an actuarial justification for the use of such information in connection with health insurance that included dependent coverage, as the health of offspring could be affected. See Greely, supra note 4, at 1489.
these tests by insurers. These statutes part ways with the earlier model based on unfair trade practices acts: they bar the use of genetic information even if it is clearly relevant to assessing risk.

These new statutes demonstrate a legislative determination to shift the meaning of non-discrimination from a principle requiring equal treatment absent an actuarial showing of difference to one requiring equal treatment notwithstanding actuarial difference. More recent statutes adhere to the principle that it is inappropriate to charge individuals with the actuarial cost of their inherited traits and extend the protection even further. The protection is extended by barring the use of genetic information whatever its source. The prohibition, then, extends beyond the use of laboratory test results, and encompasses information on “genetic characteristics” from any source and of any type. The evolution of these state statutes demonstrates an uneven and incomplete but discernable progression from state policy protecting individuals from irrational discrimination in insurance practices to one protecting individuals from the rational but disfavored practice of actuaries’ taking into account genetic information in setting the availability, terms and conditions of coverage.

III. EQUALIZING COVERAGE: SHORT TERM CONCERNS

Genetic discrimination laws effect a social judgment that an individual’s access to health coverage should not depend on the results of a genetic lottery. Legislators employ “addition by subtraction” to accomplish this goal. They subtract the factor of genetic condition from those permissibly considered in insurance decisions in order to add coverage to people who may otherwise be excluded. Long-term concerns with this equalitarian strategy are examined in Part IV. However, in this Part, more immediate concerns are examined: Assuming the wisdom of and continuing political viability of the genetic anti-discrimination movement, what implementation concerns must be addressed?

The first such concern is for drafting clarity. In many instances, genetic discrimination legislation fails to serve its apparently-intended goals due to correctable incompleteness of the protections offered. The second concern is less readily remedied. The enforcement of genetic discrimination prohibitions is premised on a trans-

62. See, e.g., COLO. REV. STAT. ANN. § 10-3-1104.7 (2002) (prohibiting the use of genetic test results for health insurance underwriting or rating purposes); MINN. STAT. § 72A.139 (2001).


64. See CAL. INS. CODE § 10123.3 (West 2002); HAW. REV. STAT. § 431:10A-118 (2001); NEB. REV. STAT. § 44-7, 100 (2001); N.J. STAT. ANN. § 17B:30-12(e) (West 2002).
parency of methods that no longer characterizes the relevant aspects of the insurance business. The prohibition of overt discrimination is no longer sufficient (if it ever was). The managed care transformation of insurance practices forces attention to less visible practices controlled not by simple directives and commands, but by subtle nudges and incentives. Strategies for addressing both concerns are described in this Part.

A. Ambiguities in the Law: Speaking Clearly

Laws prohibiting genetic discrimination in health care are both largely untested and widely varied. They are largely untested for several reasons. First, few diseases have been identified definitively with particular genetic conditions. Diseases believed to be associated with genetic traits have not, as of yet, been connected by researchers to specific traits. Many diseases that have been linked to genetic components are related to more than one genetic anomaly, as well as environmental factors. The complex relationship between genetic information and disease confounds attempts to predict future illness solely, or primarily, on the basis of genetic information. The uncertainty of the value of genetic information under such circumstances renders it insufficiently valuable in the risk assessment process to justify an insurer’s brooking the possible political and public disapproval associated with genetic underwriting. It is likely, however, that advances in genetics will produce information sufficiently predictive of future illness to render genetic underwriting economically plausible.

When insurers find genetic information economically interesting, the differences among the state statutes will begin to matter. As is described more fully above, statutes prohibiting or regulating the use of genetic information by insurers fall into three general categories: those barring the use of genetic information irrelevant to the assessment of risk; those barring the use of information derived from specifically identified laboratory tests; and those barring the use of broadly defined “genetic information.” The first species of discrimination is irrational, and the enforcement of insurance practices should be grist for the mill for state insurance departments. The second and third, however, forbid rational insurer activity by imposing

65. See Greely, supra note 4, at 1493.
66. Id. at 1484-86; Rothstein & Hoffman, supra note 5, at 855-56.
67. Diver & Cohen, supra note 4, at 1454-55.
68. See ABRAHAM, supra note 58, at 67-68.
70. See supra Part II.B.
rules forbidding the use of information relevant to the assessment of risk.

Assuming advancements in science are sufficient to make the game worth the candle, insurers will have an interest in probing the statutes’ ambiguities. The lesson of the ADA suggests that ambiguous language will be interpreted to narrow, not broaden, the statutory protections. As the ADA has been interpreted under the shadow of resistance to the cost of accommodation, so would genetic discrimination statutes be interpreted under the shadow of the rising cost of health coverage. Ambiguous language in the ADA regarding the disability status of people suffering disparate treatment for disabling conditions subject to correction has been interpreted to sharply narrow the ADA’s reach, notwithstanding substantial legislative history and EEOC interpretative guidance to the contrary. Similarly, ambiguous language in the ADA regarding insurance underwriting practices affecting people with disabilities has been read to support pre-ADA risk segmentation practices, notwithstanding substantial legislative history and EEOC interpretative guidance to the contrary. In both cases, the language of the statute contained genuine ambiguity. In both cases the interpretation favoring a narrow construction, less costly to those required to comply with the statute, was favored.

The second wave of genetic discrimination statutes tends to contain few serious ambiguities, but the statutes’ very specificity sharply limits their reach. They tend to prohibit only the use of specifically described laboratory tests for genetic traits. Laboratory tests not specifically prohibited by the statutes may therefore be permissible, as would any method of determining genetic traits not reliant on laboratory tests—for example, inquiring into family history of illness. The third wave of statutes corrects this flaw (if it is a flaw) by more broadly prohibiting the use of “genetic characteristics” (however discovered) in underwriting or pricing health insurance.

71. Self-interested insurers will begin to use genetic information when the tests are cost effective, scientifically accurate, predictively powerful, and lawful. See T.H. Cushing, Should There Be Genetic Testing in Insurance Risk Classification?, 60 DEF. COUNS. J. 249, 252 (1993); Jacobi, supra note 21, at 327-31.


73. See supra text accompanying notes 45-48 (discussing the trend toward reading the ADA’s “safe harbor” provision as permitting traditional actuarial methods).


75. See Geeteter, supra note 3, at 52; Greely, supra note 4, at 1495-96; Suter, supra note 4, at 702.

76. See CAL. INS. CODE § 10140(b) (West 2002); HAW. REV. STAT. ANN. § 431:10A-118(b) (Michie 2002); NEB. REV. STAT. ANN. § 44-749 (2002); N.J. STAT. ANN. § 10:5-5
These broader statutes avoid the over-specificity concerns of those of the second wave, but they will raise new interpretation concerns as courts attempt to determine what information is “genetic” and therefore excluded from insurers’ use.\textsuperscript{77}

As genetic testing becomes an issue more practical than academic, the questions asked about genetic testing legislation will become more pointed. The lessons to be drawn from the ADA’s fate suggest that statutory ambiguity is the enemy of consumer protection. Legislatures, therefore, would be wise to consider how well their current law matches the goals they set for it. The reasons for passage of legislation barring or regulating the use of genetic information for health coverage purposes can be reduced to two. First, limitations on the use of genetic information may encourage people who would benefit from genetic testing to avail themselves of that technology. Absent such protection, they may be concerned that the results of genetic testing could impair their ability to obtain or retain health coverage. At sufficient levels, such concern could interfere with the scientific and therapeutic benefits of genetic testing.\textsuperscript{78}

The second reason for passage of genetic discrimination legislation is the belief that such legislation makes health coverage more readily available. Having health coverage is a very good predictor of access to health care;\textsuperscript{79} access to health care is a primary good, one that all rational people find desirable;\textsuperscript{80} and the natural lottery of genetic endowment is an inappropriate basis on which to allocate such an important good.\textsuperscript{81} Genetic discrimination legislation serves this goal by taking genetic information out of the allocative formula.

\footnotesize{(West 2001); N.M. STAT. ANN. § 24-21-4 (Michie 2002); V A. CODE ANN. §§ 38.2-508.4 (Michie 2001); see also Mulholland & Jaeger, supra note 74, at 320; Suter, supra note 4, at 702-03.}

Pending federal legislation appears to fit into the broader version of genetic discrimination statutes, although none has yet passed. See S. 318, 107th Cong. (2001); H.R. 602, 107th Cong. (2001).

\textsuperscript{77}. See Suter, supra note 4, at 702-04.

\textsuperscript{78}. Id. at 707-08.

\textsuperscript{79}. The Institute of Medicine’s Committee on the Consequences of Uninsurance recently released its findings. It concluded: “In summary, uninsured adults receive health care services that are less adequate and appropriate than those received by patients who have either public or private health insurance, and they have poorer clinical outcomes and poorer overall health than do adults with private health insurance.” INST. OF MED., COMM. ON THE CONSEQUENCES OF UNINSURANCE, CARE WITHOUT COVERAGE: TOO LITTLE, TOO LATE 87 (2002); see also Diane Rowland et al., Uninsured in America: The Causes and Consequences, in THE FUTURE OF THE U.S. HEALTHCARE SYSTEM: WHO WILL CARE FOR THE POOR AND UNINSURED? 25, 38 (Stuart H. Altman et al. eds., 1998) (“The research on differences in care patterns for uninsured versus insured individuals increasingly reveals that the uninsured are more likely to incur adverse health outcomes.”).

\textsuperscript{80}. See Geetter, supra note 3, at 65-66; Suter, supra note 4, at 706-07.

\textsuperscript{81}. See Geetter, supra note 3, at 65-66; Suter, supra note 4, at 706-07.
Legislation serving the first goal is directed at the use of genetic information derived from genetic "tests," for the evil to be avoided is not the differential treatment of people based on their genetic heritage, but use of information derived from laboratory tests—tests otherwise useful for scientific or therapeutic purposes. Some genetic discrimination laws directed to this goal suffer from excessive specificity, limiting coverage to specifically enumerated tests. Technology is advancing, and a wide variety of tests are used to ascertain different genetic conditions. Statutes intended to provide comfort that testing undertaken for research or therapeutic purposes cannot be used for insurance purposes must more broadly catalogue currently available technology and anticipate future developments. One means of doing so is to define the tests functionally, so as to capture laboratory tests analyzing human genetic material and proteins for the purpose of identifying inherited or genetic characteristics.

As is described above, however, many recent genetic discrimination statutes are focused on the broader goal of preventing insurers from differentially treating individuals in underwriting and coverage decisions. States seek through these laws to interfere in the insurance marketplace to limit the use of relevant risk-predicting information related to genetic makeup. Unlike laws focused on laboratory tests, these more recent laws are premised on the notion that it is fundamentally unfair to differentially treat individuals for coverage purposes on the basis of immutable characteristics. It is natural, then, that these laws would bar insurers from considering genetic information beyond that revealed by laboratory tests, and extending to family history and health history.

These statutes raise a set of interpretive concerns which are different from those raised by statutes limited to the results of laboratory tests. Fundamentally, laws banning consideration of information on genetic factors derived from any source are in substantial tension with general principles of risk assessment that continue to animate

82. See, e.g., CAL. INS. CODE § 10147(e) (West 2002); MD. CODE ANN. INS. § 27-909(a)(5) (2002); MINN. STAT. ANN. § 72A.139.2(b) (West 2002); see also Greely, supra note 4, at 1494-96.

83. See THE N.Y. TASK FORCE ON LIFE AND THE LAW, GENETIC TESTING AND SCREENING IN THE AGE OF GENOMIC MEDICINE 31-40 (2000); Greely, supra note 4, at 1494-96.

84. See Greely, supra note 4, at 1495 (describing MICH. COMP. LAWS. ANN. § 550.1401 (West 2000), as an example of a law broadly defining genetic testing).

85. See Gostin & Hodge, supra note 3, at 51-52; Greely, supra note 4, at 1494-95.

86. See Geetter, supra note 3, at 65; Suter, supra note 4, at 706-07.

87. S.C. CODE ANN. § 38-93-10(2) (Law. Co-op. 2001). (defining genetic information as "information about genes, gene products, or genetic characteristics derived from an individual or a family member of the individual"); see also N.J. STAT. ANN. § 10:5-5(oo) (West 2002) (defining genetic information as "information about genes, gene products or inherited characteristics that may derive from an individual or family member").
the business of health insurance. But short of that substantial concern, these statutes raise definitional issues that can be resolved with careful drafting. Here, too, prudence suggests that legislatures consider precisely what circumstances beyond the results of laboratory tests are beyond the scope of consideration by insurers. One can infer at least probabilistic information about an individual’s genetic makeup from many sources, including the results of genetic tests of the individual’s relatives, the health history of the individual’s relatives, results of the individual’s own genetic tests, and the individual’s own health history. Legislators can control the interpretation of genetic discrimination statutes if they clearly define what conditions may and may not be considered in the underwriting and coverage process.

B. Avoiding the Effect of Clear Laws: Covert Discrimination

The preceding Section cautions that the fate of the ADA suggests that vague consumer protection statutes will be eviscerated by courts. It further points out aspects of current genetic discrimination law that contain ambiguity, and suggests clarification. This Section assumes, first, that a jurisdiction has adopted genetic discrimination legislation of the third, or broadest, type as described in Part III.A. This type bars insurers from considering genetic information from any source in underwriting or coverage decisions. Second, it assumes that the legislation has been drafted to avoid the textual ambiguities discussed above. Clarity in legislative drafting, while important, is insufficient to implement public policy; the laws must be enforced.

Some enforcement is easy. Overt violations of core provisions of genetic discrimination laws can be detected and corrected by regulators. For example, regulators can combat the solicitation of prohibited information in insurance applications and contracts by requiring firms to file those forms for review prior to use. Similarly, regulators can respond when informed that an insurer, using prohibited genetic criteria, is refusing to approve a treatment otherwise within the range of covered services. Much more troubling and difficult to regulate is covert cheating in either underwriting or coverage decisions. History suggests that such covert cheating will occur in con-

88. See infra Part IV.A.
89. See Greely, supra note 4, at 1496-97.
90. For purposes of the discussion in this section, the legislation could be state or federal. The importance of the distinction between state and federal enactment of genetic-discrimination legislation is addressed below in Part IV.A.
91. See supra text accompanying notes 64-65.
92. See infra Part III.A.
nection with genetic discrimination laws, and that it will be difficult to control.

Insurers, interested in maintaining a competitive edge in risk assessment,94 will have an interest in cheating at the enrollment stage to the extent they believe that the prohibited genetic information is relevant to the underwriting process. History suggests that some insurers subject to laws limiting their ability to use relevant risk data will seek to avoid the effects of the laws to avoid enrolling high-risk members. Both Medicare and Medicaid permit program beneficiaries to enroll in private managed care plans under some circumstances.95 Both programs bar participating managed care plans from considering the health, experience, or other risk factors when enrolling program beneficiaries in their plans.96 There is some evidence that Medicare HMOs, and better evidence that Medicaid HMOs, have screened applicants surreptitiously to favor low-risk beneficiaries.97

Enforcement of laws prohibiting insurers from considering risk information faces difficulties as it attempts to cabin activity which is quite fundamental to the history and economics of the business of insurance. Two paths may be taken. In the first, civil and criminal sanctions are levied against insurers who are discovered to have violated the laws, with the aim of specifically and generally deterring similar conduct in the future.98 The second path seeks methods to serve the goal of access for high-risk individuals while accommodating the income maximization impulses of the insurers. One such method would bar differential treatment of applicants on the basis of risk factors, but would recognize insurers' higher costs. This recognition may come through adjusting premiums on the basis of risk. This is an appropriate strategy in a program such as Medicare, with a single payer.99 In the alternative, in a program in which community rating or other risk-leveling methods have been applied to markets with multiple purchasers, a reinsurance method may be adopted to compensate insurers with aggregate risk experience over a set

94. See supra text accompanying notes 59-60.
96. See id. § 1395w-21(g) (specifying Medicare requirements); id. § 1396b(m)(2)(A)(v) (specifying Medicaid requirements).
98. See Davies & Jost, supra note 97, at 387-88, 394-404.
threshold. This latter method “suppresses the incentive to engage in risk selection in various indirect and surreptitious ways” by assuring some substantial recognition of the income loss otherwise resulting from the loss of risk assessment methods.

Disparate treatment in plan enrollment is only half of the problem addressed in genetic discrimination legislation. The other major problem is discrimination in coverage—disparate treatment in deciding which treatments will receive funding. Coverage discrimination occurs when insurers fail to approve funding for treatments that rely on genetic technology to treat genetic conditions or fail to approve conventional treatments for genetic conditions in circumstances in which treatment would otherwise be covered. Coverage discrimination occurs, and can be expected to occur in genetic circumstances for two reasons. First and most obviously, cost pressures and the resulting cost containment methods pioneered by managed care organizations increase the chances that care formally included in the contractual terms of the insurance plan will be improperly denied.

Insurers may also engage in coverage discrimination as an alternative method of engaging in underwriting discrimination. Suppose a firm wishes to exclude individuals with presumably expensive genetic conditions from its plan. Suppose further that the discrimination law clearly stated that genetic conditions could not be considered in the application or underwriting process and that the clear provisions of the law were efficiently enforced. The firm may be unable—without being caught—to prevent the individual from enrolling in the insurance plan. Under such circumstances, an insurer may choose to achieve indirectly what is denied directly by providing services to the reluctantly-enrolled member in a way that discourages the member from remaining a plan member.


101. Id.


103. OHIO REV. CODE ANN. § 1751.64(B) (West 2001):

No health insuring corporation . . . shall do any of the following:
(2) Take into consideration the results of genetic testing . . .
(4) Make a decision adverse to the applicant based on entries in medical record, or other reports of genetic screening or testing . . .
(D) No health insuring corporation shall cancel or refuse to issue or renew coverage for health care services based on the results of genetic screening or testing.

New Mexico law states that “discrimination by an insurer against a person or member of the person’s family on the basis of genetic analysis, genetic information or genetic propensity is prohibited.” N.M. STAT. ANN. § 24-21-4(A) (Michie 2001).

104. See infra Part IV.B.
There are several subtle ways for plans to discourage a member of a disfavored class of individuals with potentially expensive genetic conditions. They can strive for excellence in services of little interest to the disfavored class, while settling for mediocrity in areas of particular interest to that class. They can add extra services of interest to the unaffected population and hew to the basics in areas of interest to the more expensive group. They can move more slowly and less efficiently with approvals and pre-certifications for disfavored services, and target medical necessity utilization review to services of particular interest to people with genetic conditions.105

Clearly these actions would violate genetic discrimination laws if intentionally undertaken to drive away people with genetic conditions—and perhaps even if such disparate treatment were not crafted for such a purpose. Further, they may be unwise from even a coldly-calculating business proposition in light of the spillover effects bad services to one class of insureds may have on the firm’s reputation with preferred classes of customers.106 But this harmful behavior may be economic in some circumstances and used as a method to drive away people who are perceived as bad risks.107 The potential for such behavior is taken sufficiently seriously to generate proposals to counter its effect.

Covert forms of discrimination are, of course, more difficult than overt forms to detect and remedy. In health insurance, there are at least two senses in which discrimination could be said to be covert. Covert discrimination could arise when an insurer decides to discriminate and, in order to avoid detection, hides the decision and disguises the result. The more common sense form of covert discrimination could arise in the health insurance arena through the natural action of a structure designed to limit utilization and subject that structure to a patchwork of only partially successful controls. The structure of modern health insurance is based on managed care. It is well understood that managed care plans control costs in part by cre-

105. See KRONICK & DE BEYER, supra note 97, at 14-17 (discussing subtle methods by which managed care organizations might disfavor people with chronic illnesses in delivering services); Jacobi, supra note 21, at 395-96; Newhouse et al., supra note 99, at 27-28.

106. See KRONICK & DE BEYER, supra note 97, at 211.

107. The stakes for risk selection are high. The most expensive ten percent of the population accounts for about seventy percent of health care expenditures in any year. A plan that avoids these high-risk individuals—or at least one that avoids more of them than its competitors—experiences a substantial economic advantage. See Lynn Etheredge et al., What is Driving Health Systems Change?, HEALTH AFF., Dec. 1996, at 93, 96; see also Richard Kronick et al., Diagnostic Risk Adjustment for Medicaid: The Disability Payment System, HEALTH CARE FINANCING REV., Spring 1996, at 7-9 (explaining that a Medicaid HMO enrolling members from the least expensive fifth of program participants would earn substantial profits, while an HMO enrolling members from the most expensive fifth of the program would suffer substantial losses).
ating incentives for health care providers to reduce utilization.¹⁰⁸

There is extensive literature on patient protection in managed care, and it will not be canvassed here.¹⁰⁹ Suffice it to say that protecting individuals from genetic discrimination in the form of covert, improper coverage denials can be seen as within the broader enterprise of protecting individuals from covert denials of coverage by managed care organizations in general. Formal governmental enforcement has an important role in this enterprise, as regulators review insurance plans for compliance with structural regulations calculated to minimize the opportunity and incentive to stint on care.¹¹⁰

One important form of such regulatory oversight is the close review of the contracts governing the relationship between insurers and consumers. This traditional form of regulation takes on added significance as cost-containment pressures drive insurers to aggressively control utilization.¹¹¹ It is inescapable, however, that, in a health insurance system driven by market and not regulatory theory, consumer-driven checks against inappropriate denials of coverage are a more significant check.¹¹²

One consumer-driven corrective to stinting is formal or informal litigation. Consumers suffering improper denial of coverage can sue in the traditional sense, either under state contract law¹¹³ or section 502 of the Employee Retirement Income Security Act (“ERISA”).¹¹⁴ Much less formally, plan members can invoke internal grievance procedures to resolve coverage disagreements.¹¹⁵ An intermediate form of dispute resolution permits a plan member to appeal a denial of coverage to independent, outside reviewers. This independent review usually submits disputes to professionals unconnected to the plan


¹¹¹. See Trubek, supra note 108, at 141-43.

¹¹². See id. at 138-41.

¹¹³. State law remedies are unavailable to the vast majority of those with private insurance as a result of ERISA preemption. See infra Part IV.A.


and certified by state insurance officials.\footnote{See id.} This mechanism is sure to gain additional significance as a result of the Supreme Court’s recent finding that state laws mandating plans to cooperate in independent utilization review are not preempted by ERISA.\footnote{Rush Prudential HMO, Inc., v. Moran, 536 U.S. 355, 340 (2002).} One shortcoming of these adversarial mechanisms is that they require a “trigger event.” That is, patients are likely to invoke them when they have been denied coverage of a discrete treatment but are unlikely to invoke them when they have suffered the more diffuse harm of coverage for a lesser quality of care.\footnote{Jacobi, \textit{supra} note 108, at 757-59.} Another shortcoming is that patients are unable to invoke them if they are unaware that they have been denied coverage. They are more likely to be unaware of such denials as insurers shift utilization decisions to physicians and as physicians therefore become less likely to notify patients of costly alternatives.\footnote{Id. at 759-62.}

Other consumer protection devices must be available to consumers to counter insurers’ stinting tendencies. A cluster of such devices accept market discipline as an alternative to direct government oversight and seek to supplement the tools available to consumers in their efforts to navigate health insurance markets. In market systems, quality is controlled by the cumulative conduct of individual purchasers, who reward producers willing to provide desired services at a reasonable price. Such market-driven quality assurance mechanisms are effective only to the extent that consumers have sufficient information to judge the quality of services offered by market participants.\footnote{Id. at 766.} Some regulatory tools seek to take advantage of the natural tendency of markets to reward quality by empowering consumers. This form of regulation is directed at improving the balance of information access between plans and consumers in order to enhance the ability of consumers to evaluate the quality of plans. The goal of such regulations is to reduce information deficits so that consumers can reward with patronage the plans that deliver what all plans promise: high-quality care.\footnote{See Jacobi, \textit{supra} note 108, at 762-64; Trubek, \textit{supra} note 108, at 136-38.}

The publication of evaluative data on health plans serves the goal of leveling the playing field between consumers and plans. Public entities and private organizations such as the National Committee for Quality Assurance gather, analyze, organize, and publish data describing the structure and performance of plans.\footnote{Jacobi, \textit{supra} note 108, at 770-73; Trubek, \textit{supra} note 108, at 136-38.}
In the context of genetic discrimination, such evaluative systems can serve two goals. First, they can facilitate determination of which plans are engaged in stinting activity by evaluating consumer surveys, structural measures, and health outcomes for particular forms of treatment. Consumers concerned about the manifestations of genetic discrimination can thereby obtain a window into the behavior of various plans and choose accordingly. Second, they permit regulators to monitor plan activity for early warning signs of stinting. Even if the population of consumers concerned about a form of genetic discrimination is too small to have a powerful market impact, regulators could discern improper behavior by evaluating the data and audit the plan’s practices to determine if there has been a violation of the law.

In the event, then, that genetic science develops sufficiently in its diagnostic and therapeutic capabilities to render genetic discrimination a more significant problem than it now is, current genetic discrimination statutes form a basis for the regulation of insurance to limit the effects of such discrimination in underwriting and coverage decisions. The statutes must be clarified, however, to make crystal clear the conduct that is prohibited; absent such clarity, genetic discrimination statutes are likely to face the fate of the ADA: gradual diminution in effect due to courts’ constantly erring on the side of regulated entities and against the interests of consumers. In addition, regulators must apply to this form of improper insurance practice the array of consumer protection devices, now in their infancy, developed to protect consumers from the dark shunning and stinting tendencies of managed care organizations. These two steps are necessary to assure the immediate ability of genetic discrimination statutes to have an effect in the insurance market. The next Section explores the broader issues in insurance law and policy raised by genetic discrimination statutes.

IV. THE FUTURE OF GENETIC DISCRIMINATION

The previous Part described implementation concerns that will arise if and when genetic science advances sufficiently to render genetic discrimination in health insurance a substantial public policy concern. That Part assumed, in addition to advances in science, that a general agreement in genetic discrimination laws is intended to serve at least two goals: first, assuring individuals that the advantages of genetic testing for diagnostic and research purposes would not be outweighed by the disadvantages attendant on the revelation of genetic information to insurers and others; and second, ensuring that the “genetic lottery” is not used as a basis for differential treat-

123. See Jacobi, supra note 108, at 767-68.
ment in health insurance underwriting or coverage decisions. This Part also adopts those assumptions and, in addition, assumes that the technical drafting and enforcement concerns raised in the previous Part have been resolved. It addresses the public policy concerns that would arise were genetic discrimination laws to have important application (because genetic discrimination had become economically advantageous to insurers) and effective structure (because drafting and enforcement concerns had been resolved). This Part addresses two such concerns, one related to the stability of the insurance market and the other related to allocative equities arising during times of growing scarcity in health care resources.

A. Adverse Selection and Exceptionalism

1. Regulating Around Adverse Selection

Genetic discrimination statutes create—are intended to create—information asymmetries between individuals and insurers, as individuals learn more about their future risk and insurers are prohibited from sharing in that knowledge. It is unclear at this point how valuable such information will be for insurance purposes, as it is uncertain how close the connection is between simple genetic variation and most illnesses. To the extent genetic tests develop strong predictive capability, their results may be valuable to individuals as they decide whether or not to invest in health insurance. If applicants for coverage have access to prognostic information and insurers do not, adverse selection may come into play, with high-risk individuals opting for coverage and low-risk individuals opting out. An extreme version of this scenario has been described as follows:

Customary protections against adverse selection—individual underwriting, combined with preexisting conditions[,] exclusions, deductibles, and coinsurance provisions—will prove less and less effective as a means of sorting applicants into actuarially sound risk

124. One other practical concern for genetic discrimination laws should be mentioned for the sake of completeness. ERISA has the well-understood effect of fracturing health insurance regulation. States have the primary responsibility of regulating insurance, but they are inhibited from regulating some aspects of employment-based health insurance, and ERISA itself does not fill in the regulatory gaps in any satisfactory way. See Karen A. Jordan, Coverage Denials in ERISA Plans: Assessing the Federal Legislative Solution, 65 Mo. L. Rev. 405 (2000); Larry J. Pittman, ERISA’s Preemption Clause: Progress Towards a More Equitable Preemption of State Laws, 34 IND. L. REV. 207 (2001); Edward A. Zelinsky, Travelers, Reasoned Textualism, and the New Jurisprudence of ERISA Preemption, 21 CARDOZO L. REV. 807 (1999). The Supreme Court has shifted from a practice of strictly construing ERISA preemption while imploring Congress to correct a clearly unintended effect of the legislation to one of more narrowly construing ERISA preemption to permit states greater regulatory authority over employment-based insurance plans. See Rush Prudential HMO, Inc. v. Moran, 536 U.S. 355 (2002); N.Y. State Conference of Blue Cross & Blue Shield Plans v. Travelers Ins. Co., 514 U.S. 645 (1995).

125. See Greely, supra note 4, at 1498.
classifications. Cross-subsidization between low-risk insureds and high-risk insureds will intensify. Unable to sort high-risks into high-premium risk classifications, insurers will respond by increasing premiums or restricting coverage across the board. Higher premiums will begin to drive many low-income, high-risk insureds and many lower-risk insureds of all income groups from the market.126

The problems posed by adverse selection may be of more technical than practical interest for several reasons. First, most people with private health coverage obtain it as an incident of employment, a context in which there historically has been limited individual experience rating, and where lower-risk members and potential members have had incentives to purchase coverage (where they explicitly share in the cost of coverage) that may overcome cost-based disincentives derived from their knowledge of their low-risk status.127 Second, the distribution of genetic risk may be quite complex, frustrating attempts to sort most individuals into valid categories based on genetic risk. Insurers faced with expanding knowledge of genetic traits that have an effect on health only in complex combination with other genetic traits or with environmental conditions may not gain information appropriate to the risk categorization of applicants. If, for example, many applicants have a mixture of genetic indications of a low probability of many different illnesses, actuaries may be faced with a situation in which “the cost of refining classifications is not worth the competitive benefit derived,”128 and the genetic information may become background noise in the underwriting process. Third, low-risk individuals often decide to purchase health coverage even if the premium exceeds that reflecting their actuarial risk. That is, they may be sufficiently risk-averse to purchase “overpriced” coverage rather than risking the prospect of being uninsured in the event of a significant illness not related to genetics—for example, traumatic injury or illness caused by infectious disease.129

It may be, on the other hand, that genetic information will come to provide sufficiently significant information about risk to cause considerable dislocations attributable to adverse selection in insurance markets. Regulation is not helpless to combat such effects. Genetic equity principles can be sustained notwithstanding the emergence of significant adverse selection problems, through the adoption of several available corrective modifications to the insurance market. Some of these steps would be modest in nature, and some would require more radical change.

126. Diver & Cohen, supra note 4, at 1456 (citations omitted).
127. Id.
128. ABRAHAM, supra note 58, at 68.
129. See Jacobi, supra note 21, at 389; Korobkin, supra note 109, at 823-24.
Many states adopted reforms in the 1990s limiting the ability of health insurers to engage in risk selection. These statutes, aimed at individual and small group markets (the last bastions of the market permitting insurer risk selection), imposed explicit limits on the extent to which insurers could vary premiums on the basis of predicted risk and required insurers to offer coverage and to renew coverage once accepted. Legislators anticipated that these limits to risk selection would produce some adverse selection, and they therefore included in the reforms corrective measures. To encourage people to obtain coverage before the need for treatment arises, they permitted insurers to impose preexisting illness exclusions. The reforms barred insurers from using price differentials as a risk selection mechanism, and states anticipated that insurers may use plan design as a proxy, discouraging the enrollment of high-risk individuals by offering coverage deficient in services vital to people with chronic illnesses. To counter this effect, states mandated uniform standard coverage packages and instituted a variety of reinsurance mechanisms which equalize the burden of covering high-risk subscribers.

Although the record is ambiguous, these steps seem to have been, in some measure, successful in permitting states to shift individual and small group insurance markets to a more egalitarian footing, while avoiding extreme adverse selection; and similar mechanisms could likewise correct existing adverse selection problems caused by genetic discrimination laws. The stakes could be quite high. Absent regulatory correction, the adverse selection caused by substantial asymmetries of information between applicants and insurers could greatly impair the operation of insurance markets. Even if successful, the corrective measures will require substantial regulatory oversight of insurance markets. The dislocations caused by implementing meaningful genetic discrimination laws evokes an important question: why exclude genetic information and not other information predictive of future health status? The next Section briefly examines

130. See Hall, supra note 100, at 691-94; Jacobi, supra note 21, at 370-73.
131. See Del. Code Ann. tit. 18, § 7201 (2001); N.J. Stat. Ann. § 17B:18-64 (West 2002). Federal law limits the ability of insurers to impose periods of preexisting illness exclusions, but only when an insured has been continually covered by insurance for twelve months. 29 U.S.C. § 1182 (2000). This provision of federal law is entirely consistent with the goal of encouraging individuals to obtain coverage before needing treatment but limits excessive or repeated periods of exclusion beyond those considered necessary by Congress. See Jacobi, supra note 21, at 376-77.
132. See Korobkin, supra note 109, at 824-25.
133. See id. at 827.
135. See Hall, supra note 100, at 725-26.
136. See Diver & Cohen, supra note 4, at 1457-58.
137. See Abraham, supra note 5, at 127.
the genetic exceptionalism debate.

2. Exceptionalism, Incrementalism, and Social Pooling

American insurance law has permitted or even encouraged insurers to consider the risk profile of an individual or group applying for health coverage, although recent incremental changes in insurance law suggest a trend toward social pooling. Genetic discrimination laws forbid consideration of one form of relevant risk data. As was true with the (at times) exceptional treatment of HIV information, the justification for the exceptional treatment of genetic information for purposes including underwriting and coverage decisions has been questioned. Should genetic information be treated differently than other health status information?

Genetic discrimination legislation’s two goals—encouragement of genetic testing for diagnostic and research purposes and protection of individuals from unfair coverage and treatment—suggest different answers to this question. To the extent that the goal of genetic discrimination laws is “only” to remove inhibitions to participation in genetic testing, exceptionalism arguments have some force. Unlike other health information, it is argued, genetic characteristics are immutable and invariably forecast future health conditions. Genetic information, then, may loom uniquely large in the minds of people contemplating participation in genetic testing, and the social value of genetic testing is sufficiently high to support unique protections from others’ use of resulting genetic information. There is some force to these arguments. However, as understanding emerges of both the complexity of the genetic causes of disease and the complexity of the relationship between genetics and environment for most diseases, this justification weakens.

More comprehensive genetic discrimination laws are clearly motivated by the second goal: genetic equity in coverage. The trend toward these broader laws suggests a rejection of insurance underwrit-

138. See generally Jacobi, supra note 21, at 314-18.
139. See Abraham, supra note 5, at 127.
141. For a more complete discussion of the genetic exceptionalism debate, one that encompasses primarily the issue of informational privacy but also the use of genetic information, see, for example, Gostin & Hodge, supra note 3, at 21; Lazzarini, supra note 4, at 149; Ross, supra note 4, at 141; Suter, supra note 4, at 669.
142. See supra text accompanying notes 79-82.
143. See Gostin & Hodge, supra note 3, at 34-35; Ross, supra note 4, at 142-43; Suter, supra note 4, at 710-15.
144. See Greely, supra note 4, at 1485-87.
145. See Gostin & Hodge, supra note 3, at 31-32; Ross, supra note 4, at 142-43; Suter, supra note 4, at 710-15.
146. See supra text accompanying notes 81-82.
ing and coverage decisions that differentiate on the basis of inherited traits, conditions clearly beyond the control of the individual. By passing broader genetic discrimination laws, legislators suggest that it is unfair to subject individuals to disadvantage in insurance purchase or use on the basis of inherited characteristics.  

Taken in isolation, this view has considerable appeal. Viewed in the context of an insurance system traditionally governed by differential risk assessment, however, two observations should be made. First, as is discussed above, genetic discrimination laws may necessitate substantial regulatory intervention to limit adverse selection.  

In addition, however, there is the broader equity concern. While individuals with unfavorable genetic characteristics do not “deserve” resulting disadvantage in insurance access, it is not clear that they have any greater claim to remedial action than do individuals disadvantaged by reason of previous traumatic injury or infectious disease. No person who has or acquires characteristics, without her own fault, marking her as a high risk for future health utilization “deserves” lesser access to health coverage.

If, as it appears, genetic information is not sufficiently exceptional to separate it from other information useful in the process of risk selection, genetic discrimination laws can be justified only as part of a larger incremental reform movement in health insurance. If the future of the American health insurance system is a model in which insurers rely on risk selection where such business methods are economically valuable, then selecting genetic conditions as an exception to the rule is difficult to justify. There is thin but suggestive evidence, however, that the American health insurance system is moving incrementally toward a system in which access to coverage is not tied to risk and in which the guiding principle is not individual assessment but social pooling to improve access to coverage and care.

Federal and state law has shifted in recent years to limit risk segmentation in insurance markets. As is described above, many states have adopted reforms limiting the ability of health insurers to engage in risk selection in individual and small group markets. In addition, HIPAA, passed in 1996, imposed federal restrictions on insurers’ ability to impose risk-related restrictions on coverage in some circumstances. The swift acceptance of genetic discrimination

147. See Geetter, supra note 3, at 65-66.
148. See supra Part IV.A.1.
149. See Abraham, supra note 5, at 127 (“[T]he puzzle is why the law should prohibit health insurers from using genetic information that is the product of the natural lottery—while permitting them to use information that reflects other features of this lottery.”).
150. See supra Part IV.A.1.
151. See supra text accompanying notes 51-53.
152. See Jacobi, supra note 21, at 376-79.
laws, seen against this background, suggests that the law’s protections represent not merely a case of special pleading, but rather, they are part of a larger trend of incremental insurance reform.

Splashy, systemic reform of the American health insurance market has famously failed.\textsuperscript{153} The failure of large-scale reform, however, was more a product of American skepticism of large government than a lack of public interest in making health coverage available on a more egalitarian footing.\textsuperscript{154} An argument can be made that incremental reform is currently proceeding (slowly and unevenly) on two fronts in the direction of assuring access to health coverage, regardless of health status and ability to pay.

The first front is discussed above; it comprises laws moving away from risk segmentation and toward community rating and social pooling. This evolutionary movement increases the social cost of coverage, in part, due to the cost of increased regulation and, in part, due to the increased risk profile of those covered.\textsuperscript{155}

The second front for incremental reform concerns payment for coverage. Independent of the cost of insurance reform, the cost of health care coverage is rising rapidly.\textsuperscript{156} At the same time, long-term trends suggest that employment-based coverage is weakening, with less coverage and higher cost-sharing, particularly for low-income workers.\textsuperscript{157} Over time, the public sector has come to play a larger role, with nearly one-half of care now financed by public programs.\textsuperscript{158} As low-income workers and their families found limited access to decent employment-based health coverage,\textsuperscript{159} the government has

\begin{itemize}
  \item \textsuperscript{153} See generally Theda Skocpol, Boomerang: Clinton’s Health Security Effort and the Turn Against Government in U.S. Politics (1996).
  \item \textsuperscript{154} See Suter, supra note 4, at 724-25.
  \item \textsuperscript{155} See Geetter, supra note 3, at 70-74; Hall, supra note 100, at 695-97.
  \item \textsuperscript{156} See Altman & Levitt, supra note 1, at 84; Milt Freudenheim, Health Insurers Are Seeking 20% Rate Rise, N.Y. TIMES, June 5, 2002, at C2.
  \item \textsuperscript{157} See Henry S. Faber & Helen Levy, Recent Trends in Employer-Sponsored Health Insurance Coverage: Are Bad Jobs Getting Worse?, 19 J. HEALTH ECON. 93, 102 (2000); John Holahan & Johnny Kim, Why Does the Number of Uninsured Americans Continue to Grow?, HEALTH AFF., July-Aug. 2000, at 188, 194-95.
\end{itemize}
picked up the slack. Medicaid programs expanded, and programs covering low-income children and adults who are not eligible for Medicaid have been created. This trend slowed or even reversed briefly in the late 1990s, at the height of economic expansion. This pause is clearly temporary, as the end of extraordinarily good economic times and increased health care cost inflation once again threaten the employment-based insurance system. As a recent analysis concluded,

> [u]ltimately, the combination of higher growth in health care costs, through its effect on premiums, and a slowing economy threaten a major increase in the number of people who are uninsured. Evidence is already appearing that small employers are dropping coverage in response to sharp premium increases. When employers shield workers less from premium increases, rates of employee take-up will continue to fall.

Putting these trends together, it can be predicted that private insurance coverage will continue to erode and that government will be called upon to finance coverage for an increasingly large percentage of the population. Further, the public program expansions in recent years have often been structured so as to permit government to simply purchase coverage from private insurers. Government gains comfort as a purchaser of coverage if the market from which it selects coverage is structured according to policies consistent with broad coverage of individuals of all risk categories; government (as a purchaser of coverage) is not served by insurance markets designed to limit coverage to those most in need of access to health care.

The pieces of this incrementalist reform agenda, then, include both a shift in regulatory structure toward social pooling and away from individual risk selection and an increasing commitment of public funds to finance the purchase of coverage for those priced out of the market. As has been stated, the evidence that insurance markets are moving in the right direction is thin but suggestive. The evidence that government will continue the trend of financing a greater portion of health care is no more certain. The next Section assumes,

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163. See id.
164. Full discussion of the reluctance of Americans to accept public responsibility for health coverage is beyond the scope of this Article. American opinion on the broad public finance of health care continues to span the spectrum from that regarding health care as a
somewhat hopefully, that some version of incremental reform is adopted and that broad coverage is available to all, independent of their ability to pay or the market’s evaluation of their risk status. It raises questions regarding the effects of scarcity in health services on access to services for people with genetic conditions.

B. Scarcity and Equity

Genetic discrimination laws were enacted before substantial need arose and reflected, in part, a social consensus that people with genetic conditions suggestive of future health risk should not be disparately treated in health insurance underwriting and coverage decisions. The discussion above describes appropriate steps for crafting and enforcing genetic discrimination laws in order to achieve that goal and suggests effects that these laws may have on health insurance markets in the future. The previous Section argues that genetic discrimination legislation’s effect on health insurance markets is consistent with a trend of incremental reform of America’s health insurance market toward an ethos of social pooling, in which marketplace tendencies to exclude those most in need of health coverage would be subverted in the service of broader access to care.

The previous discussion somewhat artificially excluded consideration of health care cost inflation in gauging the strength of the social commitment to genetic equity. This Section briefly sketches out the cost containment and rationing pressures that are likely to arise in the near future and concludes that explicit genetic discrimination should be firmly in place before those pressures become strong. It is not unlikely that strong pressures to ration care will coincide with the time when genetic science has advanced sufficiently to test social resolve in favor of genetic equity. When the pressure to ration medically useful care becomes strong, abstract concepts of equity may face critical reevaluation.

The pressure to ration, of course, derives from health care cost in-
flation. After a brief hiatus, health care cost inflation has returned with a vengeance.\textsuperscript{165} Two prominent health finance analysts have demonstrated that health care inflation well above the rate of background inflation has been the norm for the past four decades, with brief periods of low inflation, and notwithstanding a wide variety of strategies to corral health care costs:

[N]either regulation, voluntary action by the health care industry, nor managed care and market competition have had a lasting effect on our nation’s health care costs. Some might argue that we were not serious or comprehensive enough about any one of these approaches for them to have had a lasting impact. On the other hand, it could be argued that the point is academic; we were as serious as public and political support for any one approach would allow.\textsuperscript{166}

The authors suggest that the cost-containment efforts are doomed to fail until the need for rationing is faced; in the alternative, they suggest that the cost history is traceable to “the American people’s uncontainable desire for the latest and best health care,” which will not lessen and which dooms us to an ever-rising spiral of cost.\textsuperscript{167}

Henry Aaron argues that the resurgence of health care cost inflation is to be expected and is consistent with decades-old trends. He suggests, in fact, that the factors leading to inflation are intensifying.\textsuperscript{168} The factors that will only increase in salience over time are technological innovation in health care (particularly pharmaceuticals) and an aging population; the one-time factor is the bounce-back from spent managed care cost-containment efforts.\textsuperscript{169} As Americans’ appetite for innovative treatments is only exceeded by the interest of entrepreneurial health care firms and professionals, the technological inflation driver is sure to continue in force. Similarly, the population is aging—a good thing, given the alternative—and therefore requires more and more intense services.

In the short run, Americans are likely to react to health inflation as we always have: “try small things that work at the margin, complain a lot, but ultimately pay the bill.”\textsuperscript{170} The time is imminent, however, when decisions will have to be made to deny insured people coverage for services that are “genuinely beneficial or that patients

\textsuperscript{165} See Freudenheim, \textit{supra} note 156; Christopher Oster, \textit{At a Premium: Insurance Costs Loom as a Cloud Over the Economy}, WALL ST. J., Apr. 11, 2002, at A1.

\textsuperscript{166} Altman & Levitt, \textit{supra} note 1, at W83.

\textsuperscript{167} Id.


\textsuperscript{169} Id. at 86.

\textsuperscript{170} Altman & Levitt, \textit{supra} note 1, at W84.
and their physicians [think] are beneficial."171 That is, care will have
to be rationed. Unlike other industrialized nations, America has no
political process through which hard decisions on the funding of
health treatments can be openly discussed,172 although we have ex-
perimented with such a process in a clumsy and experimental way.173
We have relied in surprisingly large part on the talismanic signifi-
cance of statutory and contractual limits of coverage to that which is
medically necessary, a term that lacks a cost-effectiveness component
and, in any event, is sufficiently vague as to provide little practical
guidance.174 Even very desirable goods must compete in some sense
with others. As health care costs increase, so will conflicts. For some
goods and services, this eventuality would merely lead to individual
choices to refuse one good or service for another. In the case of health
care, however, with its high and uncertain costs, the history of insur-
ance, and the “non-elective” nature of many consumption choices,
some form of rationing is inevitable.

It is beyond the scope of this Article to predict what processes and
with what resulting procedures Americans will construct their ra-
tioning system. Instead, I simply point out that any such system is
likely to threaten care for people with genetic conditions. They face
the threat likely to be faced by all with new or unusual health needs—the disfavored position in a game of musical chairs. In the
game of musical chairs, players circle a ring of chairs and sit down
when the music stops. One person cannot do so; others have already
taken all available chairs, and the player left standing is “out,” due to
her inability to gain a seat. If expensive and effective genetic treat-
ments emerge, they will be new and unfamiliar. If we come to accept
limits on spending for medically necessary care, the risk is high that
those who would benefit from unfamiliar, new and expensive treat-
ments will be left standing, as others, beneficiaries of older, more
familiar treatments, occupy all of the chairs. In other words, the fail-
ure to thoughtfully plan for scarcity places at risk the more vulner-
able members of society—the poor, the disabled, and, in these cir-
cumstances, those who claim the benefit of expensive new treat-
ments. Forethought is therefore essential.

But how? Some taxonomy of “medically necessary” treatments
must be derived in order to assort care between those types that will
draw resources and those that will not. If history is any guide, there

171. Aaron, supra note 168, at W86.
172. See id. at 85-86.
173. See Michael J. Astrue, Pseudoscience and the Law: The Case of the Oregon Medi-
cal Rationing Experiment, 9 ISSUES LAW & MED. 375 (1994); Note, The Oregon Health Care
174. See generally William M. Sage, Physicians As Advocates, 35 HOUS. L. REV. 1529
(1999).
will be a tendency to favor established treatments over the new and
treatments valued by the majority rather than those favored by the
minority. Here, the egalitarian underpinnings of both disability law
and genetic discrimination law must be called upon to make the case
that it is illegitimate to make choices against coverage on the basis of
the disability status of the expected recipient or on the basis of the
genetic condition of the expected recipient. Disability-neutral and
genetic-neutral methods of utilization management are called for.

One much-discussed approach to dealing with scarcity was re-
cently developed by Daniel Callahan. Callahan suggests a means
to approach scarcity:

[I]t is a fundamental mistake to generalize from the success of the
past to assume like gains in the future. As George Washington
once noted, “It would be . . . unreasonable to suppose that because
a man has rolled a snowball till it acquired the size of a horse that
he might do so till it was as large as a house.” Success there will
surely be, and medical progress as well. But (a) the future is
unlikely to hold great gains such as there were in the past, that is,
medical gains that have a decisive population health benefit; (b) fu-
ture advances will be proportionately far more expensive to find
and to implement than those of the past; and (c) future advances
will be considerably more likely to be ambiguous, perhaps even
contradictory, in their human benefit.

Callahan’s solution is to substitute a vision of “sustainable medicine”
for our current bias in favor of all beneficial medicine. It is a vision of
medicine with limits, and it requires that we accept fundamental
limits on our ability to rely on medicine to extend our lives indefi-
nitely. In some aspects, Callahan’s vision comports easily with the
egalitarian vision of genetic discrimination. In others, it raises the
sorcerer of majoritarian bias that has historically threatened people
with disabilities and now threatens people with genetic conditions.
Callahan states as a goal of sustainable medicine “a decent level of
physical and mental competence” and endorses “finite and steady-
state health goals and . . . limited aspirations for progress and tech-
nological innovation.”

Callahan’s vision stands, in one sense, for what is inevitable: the
creation of a methodology for reducing our thirst for ever more ex-
pensive and only marginally beneficial (if that) technological devel-
lopments. It also presents a vision that can be construed as dangerous
to those who are “different,” including people with disabilities and

175. DANIEL CALLAHAN, FALSE HOPES (1998).
176. Id. at 48.
177. Id. at 35 (defining a component of sustainable medicine as involving equitable
distribution and equal opportunity for benefit).
178. Id.
people with genetic conditions. If “we” embrace a vision with limited aspirations, are we anticipating a game of musical chairs, in which either established treatments or treatments for the majority (or both) are appropriate, but new treatments or treatments for people with disabilities or genetic conditions are not? The push to rationing is coming, and the danger is clear. The struggle for disability rights shows that egalitarian notions are more easily embraced in the abstract than when practical costs are apparent. At each step of the way, as disability and genetic discrimination in health insurance is encountered, egalitarian positions, rooted in the disability rights history, must be advanced. A norm of social pooling without regard for disability or genetic condition must be reinforced. The stakes are high now, but the future brings greater dangers as false hopes for endless medical progress are confronted.

CONCLUSION

Genetic discrimination laws, adopting a notion of genetic equity in underwriting and coverage decisions, have broad support. That support is suspect, however, for two reasons. First, the laws were enacted at a time when genetic discrimination was a largely abstract notion, with genetic diagnostic and treatment methods in their infancy. Second, they were adopted, in large part, during times of plenty, with relatively low health care cost inflation and high employment supported by a robust economy. The laws are varied and sometimes vague. The hard lessons learned from the dismemberment of the ADA by courts seizing on statutory ambiguities to limit individual rights suggest that genetic statutes be clarified in advance of the time when genetics makes their protected vitally important, and that enforcement mechanisms be clearly set out.

Genetic discrimination laws are important both in their own right and as bellwethers for a movement of incremental reform of insurance law. These reforms, of which genetic discrimination laws are a part, move a system, perversely making access to health coverage more readily available the less a person needs it, to one operating on a more egalitarian footing. These reforms will confront a tradition of health insurance law surprisingly hostile to social pooling mechanisms, and care must be taken to avoid adverse selection and other transitional market faults.

The laws will face their sternest tests and will be most vital to protect access to health coverage as health care cost inflation surges. The inevitable real increases in health care costs will increasingly strain reasonable limits on society’s ability to pay. Rationing in some form will be inevitable. People with expensive genetic conditions or who will benefit from as-yet undiscovered genetic treatments will
face the same problem in a rationing regime as will others with new, unfamiliar, or disfavored health needs. They will face a game of musical chairs in which individuals with “traditional” illness and health care needs will believe they are entitled to sit when the music stops. The equitable principles underlying genetic discrimination laws must be well-entrenched before this game is played, in order to ensure that difficult choices will be made in an equitable manner.
SELECTING AGAINST DIFFERENCE: ASSISTED REPRODUCTION, DISABILITY AND REGULATION

Suzanne Holland*

I. THE "PROBLEM" AT HAND

In 1993, Martha Field suggested a standard for parental discretion in cases of abortion and in cases concerning what she referred to as “handicapped” newborns. She argued against parental discretion to control the fate of a handicapped newborn when that fate involves ending the newborn’s life. Similarly, on the grounds of equal protection from discrimination, Field insisted “that whatever the moment at which a right to life begins for children who do not have handicap, the same stage of development defines the right to life of children who do have handicap . . . [and that] [t]his antidiscrimination approach applies not only after birth, but even before.” In other words, on the basis of equal protection from discrimination, we ought not kill newborns with handicaps; nor should we deprive them of the right to be born, whenever that right obtains to other fetuses.

Professor Field’s provocative analysis opens a window into a question that we have more reason to be concerned about than we did nine years ago when her article appeared: the issue of prenatal testing for genetic selection and identification. What of the pre-implantation embryo that is found to be “defective”? What constitutes an identifiable “defect” in the realm of prenatal diagnosis that could subsequently result in a handicapped newborn? The answer is rather straightforward in one sense: some chromosomal mutations are readily identifiable and are clearly linked to genetic conditions such as trisomy, hemophilia, Cystic Fibrosis, Tay-Sachs disease, Huntington’s disease, and others. Some forms of deafness, blindness, intersexuality, and other conditions less readily identifiable by the

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1. Martha A. Field, Killing “the Handicapped”—Before and After Birth, 16 Harv. Women’s L.J. 79 (1993). Recognizing that disability is a preferred term for persons with impairments, Field uses the term “handicapped” in part because it is the case that “in the newborn context the more degrading term is the norm.” Id. at 79 n.1.

2. Id. at 132.
term “disease” are also genetically linked. Prenatal genetic testing for single gene traits makes it possible to abort “defective” fetuses, but today, technology has the potential to increase the options for eugenic selection by parents. Termination of pregnancy is not the sole option. It is also possible, prenatally, to select out for certain undesirable traits and conditions, even as it will be increasingly possible to perform types of genetic engineering that would alter the genetic composition of the pre-implantation embryo, or the fetus.

Although it may border on stating the obvious, I want to suggest that eugenic practices are widespread in our culture. Earlier this year, for example, we had the news that prenatal genetic diagnosis (PGD) was used to select an embryo without the gene for early onset Alzheimer’s, resulting in a disease-free baby born to a woman who has a gene for a specific form of Alzheimer’s, thus sparing the baby the fate of the mother. Similarly, Britain’s Human Fertilisation and Embryology Authority (HFEA) found itself considering whether to allow parental use of PGD in order to select out a pre-implantation embryo free of thalassaemia, a rare genetic blood disorder fatal in children. I will not elaborate upon the ethical issues accompanying each of these cases, but it is important to be clear that each time we make use of genetic technologies to accomplish desired genetic ends, we are practicing eugenics, for good or for ill. We have already heard much about such issues in this conference, but my aim in these remarks is to pose some questions and challenges to the regulatory framework surrounding the primary site of eugenic practices, the assisted reproduction industry. I do so not from the perspective of the law, since that is not my discipline, but from the perspective of ethics.

In the interest of disclosure, I feel I should say that, on one hand, I do not think of myself as having any first-hand experience with disability, and so I feel that my remarks lack the kind of authenticity of one who has lived with impairment on an intimate and daily level. And on the other hand, there is something distinctive about my otherwise quite privileged life that does guide much of my thinking on this issue of genetics and disability, and that is that I live my life as a homosexual person in a deeply heteronormative culture. The life that is open to me to live is therefore constrained in some very real ways by virtue of the fact that I have what I think can be rightly called something of a social handicap, though it is certainly not a disability in any legal sense.

Not surprisingly then, I am particularly interested in some of the murkier cases of eugenic intervention—by murky I mean the so-called behavioral conditions that are found to have genetic linkages, such as intelligence, alcoholism, aggression, homosexuality, and so on. Persons having these traits are not generally considered to be disabled and do not fall under the protection of the Americans with Disabilities Act. However, such persons might reasonably be viewed as having impairments that affect one’s emotional and social life perhaps more than one’s physical well being; although the latter can certainly be affected as well. Being a homosexual male in a heterosexual male culture, for example, often imperils one’s bodily integrity and safety. Here is an instance where the social construction of disability appears brightlined: the “problem” with being homosexual is not the fact of one’s basic sexual orientation; it is the problem of a previously established social norm against which the homosexual appears to be abnormal, or otherwise defective. The problem is similar for differently-abled persons, as well: society construes their difference to mean less than normal, less than desirable. That difference matters is a sign of its social construction, as Adrienne Asch has long pointed out.

Thus, I proceed to a brief overview of the assisted reproductive technologies (ARTs) sector. Following this, I look at the issue of human flourishing—what is required for a good life in the Aristotelian sense. With this view in mind, I next consider the problems and possibilities of genetic intervention in assisted reproduction, and examine some of the issues of regulation brought about by ARTs and eugenics.

II. THE ASSISTED REPRODUCTION TECHNOLOGIES INDUSTRY (ARTs)

The assisted reproduction services sector is one of the fastest


7. In using the term “regulation” throughout this Article, I do not necessarily mean legal regulation, although I do not rule it out. I do favor, however, robust and binding guidelines, or Codes of Ethics, that specify the ethical content of eugenic intervention in prenatal testing and genetic selection in the ARTs sector.

8. Mary Mahowald prefers the acronym MART (Medically Assisted Reproductive Technologies) instead of ARTs because MART indicates the use of technologies that depend on medical assistance, versus some forms of ARTs, as Mahowald notes, that “can be accomplished without medical assistance.” Mary B. Mahowald, Medically Assisted Reproductive Technology: Variables, Verities, and Rules of Thumb, 6 Assisted Reprod. Revs. 175, 175 (1991). In this Article I am exclusively using ARTs in the former sense.
growing industries related to advances in genetics. Over the last ten years, the industry has grown so voraciously that estimates of its growth are represented by some 300-plus clinics, for a combined value exceeding two billion dollars per year.\(^9\) None of this is regulated by the federal government, although some piecemeal state regulations do exist.\(^{10}\) What began as a rather benign effort twenty-plus years ago to help infertile couples conceive has today become a vast industry offering a dizzying array of services to make conception not simply possible, but highly selective. In a society that prizes freedom of choice, it is hard to see, prima facie, what could be wrong with such a scenario.

The question arises, however, whether freedom of choice ought to be unbounded. That is to say, should the fertility industry remain an unregulated oasis of genetic choice for anyone who can afford its offerings, or should we seek somehow to draw boundaries around the eugenic selections it makes possible, and if so, on what basis? And whose values will determine those boundaries? Of course we will get a very different answer to the question if we proceed from the vantage point of those with handicap or disability.

I propose, against Robertson and others,\(^{11}\) that reproduction is a bounded right. Because it is both personal and social, it has corresponding social obligations.\(^{12}\) One of those obligations, the one I wish to examine here, is to vulnerable populations. By this I mean to suggest that among the ethical imperatives of society is support of and advocacy for its most vulnerable members. Such an obligation must begin by listening to these members of society and acknowledging their epistemological privilege—that such persons have a valuable standpoint on knowledge gathered by virtue of their lived experiences, and that they ought to be involved in the decisions and policies that most affect their lives, as Field has suggested.\(^{13}\) This social obligation, I believe, extends to regulatory guidelines for the allowable uses of assisted reproduction with respect to vulnerable population groups. Those who have reason to fear that, had the technology been possible earlier, they might not have been born, or might not have

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\(^{13}\) Field, *supra* note 1, at 115-24.
been selected with the particular genetic configuration that they now possess—these are the persons whose epistemological standpoint must be sought. These are the persons who must be given voice in any discussion of industry regulations or guidelines. Justice demands this of us.

Indeed, the case can be made that the increasing reliance on reproductive technologies to select genetically desirable children on the part of those who can afford those technologies raises several justice questions. One such question is that of fairness in distribution of benefits and burdens of these unregulated technologies. Another question has been raised by Professor Field—that of justice as equal protection and freedom from discrimination for handicapped newborns. Similarly, Dorothy Roberts raises issues of racial justice in critiquing the reliance on reproductive technologies to strengthen the genetic ties of the white dominant culture. I wish to bring a focus on justice into deliberations on the fertility industry, vis-à-vis the role it plays in eugenic selection for the elimination of disability and difference. It is a matter of justice to suggest that human beings ought not to be constrained unduly, but allowed to reach their full capacities, as Martha Nussbaum tells us.

III. HUMAN FLOURISHING, DISABILITY AND REGULATION

In Women and Human Development, Nussbaum outlines what she calls “central human functional capabilities,” by which she means to suggest that there are basic capacities common to all human beings across all cultures. Nussbaum argues that a good society is one that supports a minimal threshold by which its citizens can realize ten central capabilities. She does not consider whether her claim of basic capacities inherent in being human also holds for disabled citizens in society (other than economically and gender disadvantaged persons), but I think it might be useful to open the issue here, and to try and extend the capabilities to our topic.

I will not enumerate all ten capabilities, though I wish to elaborate upon a few that seem to me to be fruitful for my exploration. Nussbaum claims that among the central human functional capacities are these six: life, bodily health, bodily integrity, practical reason, affiliation, and control over one’s environment, both political and

14. I do not propose to answer all of these questions, or to advance any theory of justice pertaining to disability rights, although this is surely a paper in need of an author.
15. *Field, supra* note 1, at 96-105.
17. *See MARTHA C. NUSSBAUM, WOMEN AND HUMAN DEVELOPMENT 75-80 (2000).*
18. *Id. at 78.*
19. *Id. at 75.*
To parse these more fully, Nussbaum offers the following content: “Life,” she describes as, “[b]eing able to live to the end of a human life of normal length; not dying prematurely, or before one’s life is so reduced as to be not worth living.” “Bodily Health,” she defines as, “[b]eing able to have good health, including reproductive health; to be adequately nourished; to have adequate shelter.” “Practical Reason” means, among other things, the ability “to form a conception of the good and to engage in critical reflection about the planning of one’s life.” Finally, “Control over One’s Environment” specifies both political and material content, though it is the material content that interests me here. Nussbaum writes that material control over one’s environment means “[b]eing able to hold property . . . in terms of real opportunity; and having property rights on an equal basis with others; having the right to seek employment on an equal basis with others.” When Field suggests, for example, that the right to live in community is a fundamental right for human flourishing of some persons with disabilities, this would seem to cohere with Nussbaum’s capacity for control over one’s environment.

It seems to me that the content specified by Nussbaum’s capabilities list is relevant to the issue of genetics, disability, and government regulation. I imagine we would like to insist that all persons living with disabilities deserve access to, for example, “Life” as Nussbaum defines it: “Being able to live to the end of a human life of normal length; not dying prematurely, or before one’s life is so reduced as to be not worth living.” While it is implicit that this means government must provide basic necessities to secure the fulfillment of life as defined, for our purposes we might want to make it explicit that it devote enough monies that such a capacity can be attained for every baby born in this country. Perhaps we should prioritize funding and research dollars for these kinds of public health concerns, rather than approving of more research dollars for genetic selection and enhancements. To secure life and bodily health, as Nussbaum defines them, means that many more resources would be needed for public health care, particularly for the prenatal care for all mothers-to-be. More would also be needed in terms of funding for disabilities so that disabled persons can be assured of living to the end of a hu-
man life of normal length. Of course this is just a start, and this list is necessarily partial.

Nussbaum’s theory of capabilities, with its emphasis on full personhood and human flourishing could provide a moral grounding for genetic interventions in assisted reproduction. Focusing on the obligation of society to assist its members in realizing their capacities for flourishing, it would seem reasonable to discourage any practice of selecting out undesirable behavioral traits. Similarly, we also ought to discourage prenatal selection of embryos by parents-to-be who believe that the life of the future child will be perhaps more socially difficult. Nussbaum argues persuasively that persons living under disabling conditions in developing countries, for example, can attain to most of the capacities with sufficient social resources. By extension, children whose chromosomal configurations seem less than optimal (when viewed in the petri dish) ought to be allowed to reach their full capacities, however inconvenient for society. In relation to our topic, the capabilities theory is most helpful, I think, in providing us a set of standards by which society can measure itself as a welcoming society for people who are differently abled, or stigmatized with social handicaps. After all, what is so objectionable about providing persons with the resources to flourish, given the lives that are theirs to lead?

In short, I think that Nussbaum’s capabilities do provide a way to begin to reframe our thinking about ARTs and genetic intervention. Certainly, they highlight for us the crassness of a society that seeks the genetic quick fix, rather than the cultivation of adequate social resources that might foster the embrace and appreciation of all persons with differences, and all differences in persons.

IV. PROBLEMS AND POSSIBILITIES

I have hinted at some of the problems of the assisted reproduction industry and its relationship with genetic selection. Specifically, I locate four problems to which one solution is regulation. First, a personal problem. I have already alluded to a fear that I share with many disabled persons—the fear of elimination. Such a fear is both irrational in my case (we cannot select out the gene or genes for homosexuality because we do not know them, and if we did, it may raise more issues than it could “solve”), and such a fear is also partly rational: homosexuals everywhere face outright bigotry. The data

29. NUSBAUM, supra note 17, at 78-80.
30. See supra note 7.
Jeffrey Botkin cites in his talk, for example, indicate the presence of a rational basis for fear of elimination since twenty-seven percent of college-age students surveyed would terminate a homosexual pregnancy if they had knowledge of one. However, since sexuality itself is infinitely complex and appears to be the mysterious result of environmental and biological factors, along with free will, my fear is a slippery slope concern that does not itself constitute an argument. As with most slippery slope concerns, it constitutes a warning.

But second, I have a concern that the popularization of reproductive technologies through internet sites, magazines, advertisements and marketing encourages and magnifies “genetic ties,” to use Dorothy Roberts’s term—to the exclusion of other forms of family and relationship. In this sense, it fosters a culture of genetic determinism that is as dangerous as it is based on false assumptions about the significance of genes to human flourishing. It is dangerous precisely to the extent that it focuses our attention away from social solutions to solvable problems, and portrays false hopes of biological solutions to social issues. Violence, for instance, is surely more of a social problem than a biological one and even if it were proven to be genetically correlated, we could not “eliminate” the condition in eliminating some of the genes. (After all, we are not even able to eliminate breast cancer by genetic intervention, though we know of two of the genes for inherited breast cancer—BRCA1 and BRCA2).

Third, I believe that ARTs encourage the commodification of entities that are intimately connected to our sense of personhood, such as eggs and embryos, for example. Indeed, ARTs make possible, in both a literal and metaphorical sense, the commodification of reproduction. The rhetoric of commodification is carefully circumscribed in the assisted reproduction industry, so that no one would ever ask, “how much did your baby cost?” But, buying a pregnancy is actually what occurs in the unregulated marketplace of reproductive technologies. The question I pose sounds crass to the ears, but for those of us who are concerned with the reaches of new genetic technologies and their eugenic implications, the question of “how much did your baby cost?” might come to lose its crass edge as, increasingly, people who can afford to do so elect to give their progeny all of the advantages that genetics can provide via assisted reproduction.

My final problem with ARTs is that they are wholly unregulated, a point to which I and others in this symposium have already al-

32. Roberts, supra note 16, at 212.
33. For a fuller discussion on this point, see Suzanne Holland, Contested Commodities at Both Ends of Life: Buying and Selling Gametes, Embryos, and Body Tissues, 11 KENNEDY INST. ETHICS J. 263 (2001).
cluded. They are almost entirely for profit, and extremely expensive. Thus, as currently constituted, the ARTs industry represents a challenge to the principle of justice in the following respects. Rather than promoting equality and nondiscrimination, a principle Martha Field urges on us, ARTs encourage a culture of discrimination and selectivity; rather than being broadly accessible, they are only available to the elite. This poses a challenge to justice as fairness.

A capabilities approach, as I have argued, can provide a clear set of basepoints against which to measure the success or failures of any society with respect to fostering that Aristotelian notion of human flourishing. Moving toward a regulatory framework that might encompass some of my earlier suggestions would help bring ARTs into accord with the telos of society as promoting human flourishing, and foster the conditions by which each member can realize his or her capabilities. This telos, grounded in respect for and commitment to human personhood, is what anchors my suggestion for regulations on the kinds of choices available to those seeking medically assisted reproduction. For example, just as in this country we have actively discouraged embryo selection on the basis of sex, so we ought openly to discourage embryo selection for all behavioral traits thought to put one at a social disadvantage.

V. CONCLUSION

I have proposed that assisted reproductive services be subject to regulation for at least three reasons: (1) they are, in effect, dealing with the commodification of human entities; (2) they facilitate selecting out who gets to live a human life; and (3) they have a rhetorical association with the history of eugenics that is perpetuated by increasing the options offered to couples for eugenic uses of genetic technologies, specifically those options that encourage selecting out undesirable behavioral traits and enhancing “desirable” ones. Because commitments to human personhood for society as a whole can be undermined by the increasing reliance on genetic technologies that make eugenic selection more acceptable, I believe that the burden of proof for making eugenic choices in fertility clinics falls on those who wish to use them, rather than on those who argue against them.

Oversight and regulation will not be an easy task, and I am aware that the suggestion will be irksome to my libertarian critics. It is,

34. Field, supra note 1, at 96-105.
35. In 2001, The American Society of Reproductive Medicine became the focus of controversy for what appeared to be conflicting policies on the ethics of using sex selection by its member practitioners. For a detailed report of this conflict, see Steinbock, supra note 12, at 24-25.
however, a matter for public debate and discussion, and one that we would do well to begin before prenatal genetic selection takes us far down an uncharted path where it may be difficult to use a moral compass to find a clear way through.