INTRODUCTION

GENES AND DISABILITY: QUESTIONS AT THE CROSSROADS

MARY CROSSLEY* & LOIS SHEPHERD**

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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* Florida Bar Health Law Section Professor of Law, Florida State University College of Law.

** Associate Professor, Florida State University College of Law. The authors would like to thank Román Ortega-Cowan and the *Law Review* editorial staff for their valuable assistance in hosting the symposium and for their commitment to the production of this issue.

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).

2. *See* Adrienne Asch, *Disability Equality and Prenatal Testing: Contradictory or Compatible?*, 30 FLA. ST. U. L. REV. 315, 339-42 (2003). "[C]reating 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." *Id.* at 339.

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).

5. *See* Suzanne Holland, *Selecting Against Difference: Assisted Reproduction, Disability and Regulation*, 30 FLA. ST. U. L. REV. 401, 402-03 (2003).

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,[6] are complex issues that receive thoughtful analysis in a number of the articles in this issue.[7]

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."[8] 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.[9] 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.[10] 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.[11] While the broader debates over

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6. *See* Jeffrey R. Botkin, *Prenatal Diagnosis and the Selection of Children*, 30 FLA. ST. U. L. REV. 265, 287-92 (2003) (proposing a standard of the welfare of the parents).

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).

8. Larry I. Palmer, *Genetic Health and Eugenics Precedents: A Voice of Caution*, 30 FLA. ST. U. L. REV. 237, 237 (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 "valu[ing] 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.[12] 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*[13] 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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ment to use, prenatal genetic tests); Mahowald, *supra* note 9, at 224 (acknowledging the coercive effect of "economic costs and social pressures").

12. *See* Jacobi, *supra* note 7.

13. 274 U.S. 200 (1927).

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 inhospitability 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

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14. *See* Eric Rakowski, *Who Should Pay for Bad Genes?*, 90 CAL. L. REV. 1345 (2002).

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.*

16. Wood v. Univ. of Utah Med. Ctr., No. 20000827, 2002 WL 31895671 (Utah Dec. 31, 2002).

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?*,[17] Paul Lombardo, a law professor and historian who has studied extensively the history behind the Supreme Court's notorious decision in *Buck v. Bell,*[18] 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.[19] 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[20]—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.[21] 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,"*[22] 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

17. Lombardo, *supra* note 1.
18. 274 U.S. 200 (1927).
19. Lombardo, *supra* note 1, at 192-202.
20. *Id.* at 205.
21. *Id.* at 213.
22. Mahowald, *supra* note 9.

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."[23] 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.[24]

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*,[25] Palmer looks to the "eugenic precedents" of the Nazi Doctors' trial at Nuremburg 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.[26] 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.[27] 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*[28] adopts a

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23. *Id.* at 223-24.
24. *Id.* at 233-34.
25. Palmer, *supra* note 8.
26. *Id.* at 242.
27. *Id.* at 243.
28. Botkin, *supra* note 6.

medical professional's perspective and poses the question: "What tests should an ethical practitioner provide?"[29] 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.[30] 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*,[31] 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.[32] 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."[33]

In *Disability Equality and Prenatal Testing: Contradictory or Compatible?*,[34] 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[35] 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.[36]

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.[37] 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."[38] 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.[39] People can lead fulfilling lives without the full panoply of species-typical capacities.[40] 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."[41] 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*,[42] 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-

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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"[43] 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,"[44] 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)[45] 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 history[51] and should health insurance system has been incrementally been moving.[52]

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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.*