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## Aren't We all Eugenicists?: Commentary on Paul Lombardo's "Taking Eugenics Seriously"

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# FLORIDA STATE UNIVERSITY LAW REVIEW



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COMMENTARY ON PAUL LOMBARDO'S "TAKING EUGENICS  
SERIOUSLY"

*Mary B. Mahowald*

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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,”<sup>1</sup> 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.”<sup>2</sup> From the start, the flawed wording of this principle was evident: “men” was interpreted 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.”<sup>3</sup>

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.<sup>4</sup> Still, even if the claim were true, the decision would still illustrate eugenics, negatively defined as the effort to prevent the birth of “unfit” individuals.<sup>5</sup> For Holmes, coercive sterilization of a retarded woman was justified in order to ensure that her posterity would not be similarly affected.<sup>6</sup>

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1. *Buck v. Bell*, 274 U.S. 200, 207 (1927). Hereafter, I shall refer to this decision either 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.

4. *See* Paul A. Lombardo, *Three Generations, No Imbeciles: New Light on Buck v. Bell*, 60 N.Y.U. L. REV. 30, 52-53, 61 (1985).

5. Daniel J. Kevles cites the work of Francis Galton, Karl Pearson, and other eugenicists who “equated fitness with physique and mental ability, and assumed that it was centered 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 Galton’s approval, C.W. Saleeby proposed the distinction between negative and positive eugenics. *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 prolific breeding among the socially meritorious.” *Id.*

6. *Buck*, 274 U.S. at 207.

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.<sup>7</sup> 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.<sup>8</sup> 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 devaluing 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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7. Paul A. Lombardo, *Taking Eugenics Seriously: Three Generations of ??? are Enough?*, 30 FLA. ST. U. L. REV. 191, 208-09 (2002).

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.<sup>9</sup>

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."<sup>10</sup> The rationale that underlies testing and termination for this condition is similar to the rationale of the decision in *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.<sup>11</sup>

Ironically, in the years between Holmes's opinion in *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

9. Behavioral traits related to genetics include tendencies to alcoholism, obesity, sexual orientation, dyslexia, athleticism, and timidity. MARY BRIODY MAHOWALD, GENES, WOMEN, EQUALITY 246 (2000) (documenting these and other examples of behavioral traits attributed to genetics).

10. "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, *Prenatal Testing and Interventions*, in GENETICS IN THE CLINIC: CLINICAL, ETHICAL, AND SOCIAL IMPLICATIONS FOR PRIMARY CARE 59, 60 (Mary B. Mahowald et al. eds., 2001); Cynthia Powell, *The Current State of Prenatal Genetic Testing in the United States*, in PRENATAL TESTING AND DISABILITY RIGHTS 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 RAYNA RAPP, TESTING WOMEN, TESTING THE FETUS: THE SOCIAL IMPACT OF AMNIOCENTESIS IN AMERICA 295-96 (1999). Rapp also cites Down syndrome as the most common condition for which women seek prenatal testing. *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, *Prenatal Diagnosis of Genetic Disorders*, in PRINCIPLES AND PRACTICE OF MEDICAL THERAPY IN PREGNANCY 159, 162-66 (Gloria E. Sarto ed., Appleton & Lange 1992); Glenn Schemmer & Anthony Johnson, *Genetic Amniocentesis and Chorionic Villus Sampling*, 20 OBSTETRICS & GYNECOLOGY CLINICS N. AM. 497, 515-16 (1993).

11. See KEVLES, *supra* note 5, at 85 (discussing Saleeby's distinction between negative and positive eugenics).

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.<sup>12</sup> 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.<sup>13</sup>

Diane Paul has made it clear that the term “eugenics” can refer to very different kinds of behavior.<sup>14</sup> 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.<sup>15</sup> He thus suggests the need for line-drawing, by which we might distinguish between good and bad eugenics.<sup>16</sup> 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.

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12. See generally M.B. Mahowald et al., *Genetic Counseling: Clinical and Ethical Challenges*, 32 ANN. REV. GENETICS 547, 548-50 (1998) (discussing the origin, nature, and goals of genetic counseling).

13. See generally Lombardo, *supra* note 7.

14. See, for example, her excellent analysis of different meanings of eugenics and their implications in Diane B. Paul, *Eugenic Anxieties, Social Realities, and Political Choices*, in ARE GENES US? THE SOCIAL CONSEQUENCES OF THE NEW GENETICS 142, 143-45 (Carl F. Cranor ed., 1994).

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.<sup>17</sup> 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.”<sup>18</sup> 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.”<sup>19</sup> 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,

what people object to in eugenics is not the goal, such as improving

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17. This critique, also called “[t]he 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 *PRENATAL TESTING AND DISABILITY RIGHTS*, *supra* note 10, at 12-13.

18. THE COMPACT OXFORD ENGLISH DICTIONARY 536 (1993).

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.”<sup>20</sup>

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.<sup>21</sup> 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.<sup>22</sup>

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. Be-

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20. Paul, *supra* note 14, at 145.

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;<sup>23</sup> 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.<sup>24</sup>

Prenatal testing and selective abortion are at neither end of the spectrum between good and bad eugenics. By broad social agreement, the *Buck v. Bell* decision belongs closer to the bad end.<sup>25</sup> 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:

NAZI GENOCIDE	HEALTH-PROMOTING BEHAVIOR DURING PREGNANCY
Coercive intervention by state or government	Autonomous decisions by potential parents
Directed to born persons as a group	Directed to potential children as individuals
Terminating their lives	Supporting their lives
To avoid a specific trait or traits	To promote health or other conditions
Judged by state to be undesirable	Judged by potential parents to be desirable

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.

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.

25. As Paul Lombardo observes, “[m]any of the commentaries on *Buck* describe the case as an aberration traceable to the ‘eugenics craze’ of the Progressive Era.” Lombardo, *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.<sup>26</sup> 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.<sup>27</sup> 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 wholistically, 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.<sup>28</sup> 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.<sup>29</sup>

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

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28. See MARY BRIODY MAHOWALD, *WOMEN AND CHILDREN IN HEALTH CARE: AN UNEQUAL MAJORITY* 93-97 (1993) (discussing the meaning of a "right," distinctions between legal and moral, positive and negative, absolute and relative rights, and differences between the right to have a child and the right to reproduce).

29. Lombardo, *supra* note 4, at 57-63.

which the critique is associated.<sup>30</sup> According to Erik Parens and Adrienne Asch, the critique involves three main claims.<sup>31</sup> 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.<sup>32</sup>

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.<sup>33</sup> (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

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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).

31. Parens & Asch, *supra* note 17, at 12-13.

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.<sup>34</sup> 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.”<sup>35</sup> 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.”<sup>36</sup> 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.

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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*.<sup>37</sup> 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.<sup>38</sup> 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.<sup>39</sup> This incidence is lower than it was prior to the advent of prenatal testing and the

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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).

38. See *Buck v. Bell*, 274 U.S. 200 (1927).

39. RICKI LEWIS, *HUMAN GENETICS: CONCEPTS AND APPLICATIONS* 212 (2d ed. 1997).

availability of selective abortion. However, because the lifespan of affected individuals has improved considerably during the past few decades,<sup>40</sup> 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.<sup>41</sup> 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.<sup>42</sup> 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.<sup>43</sup> 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.<sup>44</sup>

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.<sup>45</sup> 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

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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).<sup>46</sup> 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.”<sup>47</sup> Some parents claim they are easier to raise than their unaffected offspring.<sup>48</sup> 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

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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.

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.

48. See generally P. Gunn & P. Berry, *The Temperament of Down's Syndrome Toddlers and Their Siblings*, 26 J. CHILD PSYCHOL. & PSYCHIATRY 973 (1985); Brian E. Vaughn et al., *Short-Term Longitudinal Study of Maternal Ratings of Temperament in Samples of Children with Down Syndrome and Children Who Are Developing Normally*, 98 AM. J. MENTAL RETARDATION 607 (1994).



land.<sup>49</sup> 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.<sup>50</sup>

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.<sup>51</sup> To the extent that this is so, prenatal testing and termination of affected fetuses cannot be considered

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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.”<sup>52</sup> 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 *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 *expected* to undergo prenatal testing because of the supposedly high risk of a chromosomal anomaly, especially Down syndrome.<sup>53</sup> To a lesser degree women are expected and encouraged

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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, *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.” *Id.*

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, *Why I Had Amniocentesis*, in PRENATAL TESTING AND DISABILITY RIGHTS, *supra* note 10, at 64-71; RAPP, *supra* note 10, at 3-5. However, whether prenatal testing is truly or

to terminate the pregnancy if the fetus is affected.<sup>54</sup> 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.”<sup>55</sup> 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.

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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. ROUNDTABLE 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.