

## BOOK REVIEW

### **Prenatal Screening Policy in International Perspective: Lessons from Israel, Cyprus, Taiwan, China, and Singapore**

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*Heredity and Hope: The Case for Genetic Screening.* By Ruth Schwartz Cowan. Cambridge, MA: Harvard University Press, 2008. Pp. 304.

The word “eugenics” derives from the Greek words *eu* (εὖ) [beautiful] and *gen* (γέν) [relating to birth], or *eugenes*, which means “good in stock.”<sup>1</sup> In *Heredity and Hope*, historian Ruth Schwartz Cowan defends modern genetic testing—the new genetics, by distinguishing it from twentieth century eugenics—the old genetics. While we rightfully recoil from the old genetics, with its coercive methods and hateful motives, Cowan maintains that we should embrace the new genetics to enhance reproductive choice and promote the well-being of our offspring. In this Review I argue that the analogy between the old and new genetics can be less readily cast aside than Cowan appreciates.

In Part I, I discuss Cowan’s historical arguments and theoretical commitments. In Part II, I argue that Cowan overlooks a crucial moral similarity between the old genetics and new genetics: namely, whatever the differences between the means by which each is carried out, both are biological approaches to solve what are in large part social ills. Part III concludes with two ways in which the new genetics, no less than the old, might undermine social equality for people with disabilities. First, the new genetics threatens to express demeaning judgments about the lives of persons with disabilities. Second, a tendency to treat disabilities as predominantly genetic problems worthy of reproductive prevention could weaken our collective willingness to welcome into the world those whose abilities fail to meet the demands of modern society.

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1. RUTH SCHWARTZ COWAN, *HEREDITY AND HOPE: THE CASE FOR GENETIC SCREENING* 14 (2008) (citing FRANCIS GALTON, *INQUIRIES INTO HUMAN FACULTY AND ITS DEVELOPMENT* (1883)).

## I. THE HISTORY AND ETHICS OF GENETIC TESTING

In *Heredity and Hope* Ruth Schwartz Cowan brings a “historian’s tools”<sup>2</sup> to bear on the question of whether and under what conditions individuals and communities ought to encourage parental screening or offspring testing for genetic diseases and disabilities. Prompted in part by her own experiences of pregnancy, Cowan seeks to better understand the science and sociology of modern prenatal screening and provides fresh answers to some of the most vexing questions posed by our emerging powers of reproductive biotechnology: What does it mean to be a good parent? And how can we use genetic knowledge and scientific advances to improve society and lead worthy lives?<sup>3</sup> Cowan explains that simple carrier screening combined with pre-conception genetic counseling can be used to assess the risks of passing on a particular condition.<sup>4</sup> More sophisticated methods of prenatal diagnosis range from the non-invasive but less predictive—such as ultrasound imaging, performed between weeks sixteen and twenty of a normal pregnancy—to the more invasive and highly predictive—such as amniocentesis, performed at fifteen to sixteen weeks of gestation.<sup>5</sup>

Controversy marks each of these approaches, even carrier screening, which does not involve the destruction of prenatal life. Consider screening for untreatable and late-onset disorders, such as Duchenne’s Muscular Dystrophy or Huntington’s chorea.<sup>6</sup> Or consider susceptibility testing to reveal the statistical probability of a child developing, at some point over the course of his or her life, certain debilitating conditions, such as heart disease or mental illness.<sup>7</sup> For genetic diseases that do not manifest themselves until later in life, for those for which there is no available treatment, and for those for which testing offers no better than imprecise odds of acquisition, the desirability of genetic screening is less obvious.

Early in the first chapter of *Heredity and Hope*, Cowan uncovers the religiously inspired drive toward eugenics in Catholic countries such as France, Brazil, Argentina, and Mexico.<sup>8</sup> But eugenics gained popularity in the early-twentieth century not only across the globe but also across the political spectrum.<sup>9</sup> Cowan tells a fascinating story of eugenics in the former Soviet

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2. COWAN, *supra* note 1, at 9.

3. *See id.* at 1-2.

4. *See id.* at 10.

5. *See id.* at 74-77, 99, 107.

6. *See* Michael Parker & Anneke Lucassen, *Concern for Families and Individuals in Clinical Genetics*, 29 J. MED. ETHICS 70, 71-72 (2003).

7. *See id.* at 73.

8. *See* COWAN, *supra* note 1, at 22-25.

9. *See id.* at 27-28.

Union, where “left-wing biologists found themselves trying to convince communist officials of the social value of eugenics . . . .”<sup>10</sup> Cowan illustrates the early origins of Nazi eugenics, which lay harrowingly close to home in the United States and Great Britain.<sup>11</sup>

From the turn of the century until World War II, the United States embarked on an ambitious program to produce a more genetically fit population.<sup>12</sup> America’s embrace of eugenics owed to the widespread perception that reproductive mechanisms promised more effective chances of social reform than compensatory, educational, or other institutional measures. Because “[a]cquired characters are not inherited,” *The Nation* magazine wrote in 1910, “the improved environment of one generation does not either raise or lower the inherent qualities of the next.”<sup>13</sup> That same year, New York biologist Charles Davenport established the Eugenics Records Office to keep genetic records of people in American hospitals, insane asylums, almshouses, and prisons.<sup>14</sup> In 1913, United States President Theodore Roosevelt wrote in a letter to Davenport,

Some day, we will realize that the prime duty, the inescapable duty, of the good citizen of the right type is to leave his or her blood behind him in the world; and that we have no business to permit the perpetuation of the citizens of the wrong type.<sup>15</sup>

Twenty-nine states would eventually pass legislation requiring sterilization of populations thought to have undesirable genetic qualities.<sup>16</sup> In 1927, the Supreme Court upheld the constitutionality of forced sterilization laws in *Buck v. Bell*.<sup>17</sup> A

10. *Id.* at 25.

11. *See id.* at 28-31.

12. For an in-depth review of primary sources detailing the history of the eugenics movement in the United States, see EDWIN BLACK, *WAR AGAINST THE WEAK: EUGENICS AND AMERICA’S CAMPAIGN TO CREATE A MASTER RACE* (2003); and DANIEL KEVLES, *IN THE NAME OF EUGENICS* (1985). Michael Sandel expertly condenses this history in his recent book, *The Case Against Perfection*, which is echoed by some of the facts presented here. MICHAEL SANDEL, *THE CASE AGAINST PERFECTION* (2007).

13. Editorial, *Eugenics and Social Reform*, *NATION*, Aug. 27, 1910, at 2C.

14. *See* STEPHEN TROMBLEY, *THE RIGHT TO REPRODUCE: A HISTORY OF COERCIVE STERILIZATION* 54-54 (1988).

15. BLACK, *supra* note 12, at 99 (quoting Letter from Theodore Roosevelt to Charles B. Davenport, Dir. of Biological Lab., Carnegie Dept. of Genetics and Eugenics Record Office (Jan. 3, 1913)). This passage has also been included in SANDEL, *supra* note 12, at 64-65.

16. BLACK, *supra* note 12, at 122; SANDEL, *supra* note 12, at 65-66.

17. 274 U.S. 200 (1927). Justice Oliver Wendell Holmes wrote for an eight justice majority: “It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind.” *Id.* at 207.

1929 report on the results of sterilizations undertaken in California<sup>18</sup> was widely cited by the Third Reich and informed the design of Germany's eugenic sterilization law.<sup>19</sup> And in 1935, the *Los Angeles Times* published an enthusiastic report of Nazi eugenics: "Here, perhaps, is an aspect of the new Germany that America, with the rest of the world, can little afford to criticize."<sup>20</sup>

After providing an authoritative history of medical genetics in Chapter Two, Cowan allays our misgivings about the new genetics in Chapters Three through Six, where she traces the history of carrier, prenatal, and infant screening programs for four hereditary diseases for which prenatal predictions are reliable and early detection is routine. These are Tay-Sachs disease and phenylketonuria (PKU), which are caused by enzyme deficiencies, and sickle-cell anemia and  $\beta$ -Thalassemia, which result from defects in the production of  $\beta$ -hemoglobin. In a series of richly textured narratives, Cowan recounts the fascinating tales of the scientists, clinicians, and counselors who developed gene mutation carrier screening programs for PKU, Tay Sachs, and  $\beta$ -Thalassemia to help people with high-risk genes bear healthy children.

By contrast to these success stories, her account of sickle cell screening for African-Americans in Chapter Five is disturbing. Cowan deftly describes a mismanaged program of defective screening and ineffective counseling that bears the mark of racial indifference or worse. While the sickle cell screening program falls squarely within Cowan's understanding of the new genetics, the failure of this program does not temper Cowan's endorsement of modern genetic testing—"without guilt, without ambivalence, and without apology"<sup>21</sup>—as scientifically and morally distinguishable from that which was objectionable about the old genetics.

Cowan defends the new genetics by dislodging contemporary reproductive practices from their pejorative connection to Nazi eugenics.<sup>22</sup> Cowan condemns coercive and discriminatory practices like sex segregation, anti-miscegenation laws, anti-immigration policies, forced sterilization, and genocide, which were built upon a flawed "genetics of probability and statistics in large populations."<sup>23</sup> The old genetics adopted a collectivist approach to human betterment, in which the desirability of the targeted traits corresponded to some *Wunschbild*, or "ideal

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18. E.S. GOSNEY & PAUL POPENOE, *STERILIZATION FOR HUMAN BETTERMENT: A SUMMARY OF RESULTS OF 6,000 OPERATIONS IN CALIFORNIA, 1909-1929* (1929).

19. PHILIP REILLY, *THE SURGICAL SOLUTION: A HISTORY OF INVOLUNTARY STERILIZATION IN THE UNITED STATES* 106 (1991).

20. K. Burchardi, *Why Hitler Says: "Sterilize the Unfit!,"* L.A. TIMES, Aug. 11, 1935, at F9; see SANDEL, *supra* note 12, at 67.

21. COWAN, *supra* note 1, at 227.

22. *See id.* at 40, 113-14.

23. *Id.* at 234.

type,” for the model human form as determined by national character.<sup>24</sup> Collectivist thinking about eugenics was exemplified in a 1914 report to the American Breeders Association<sup>25</sup> delivered by then-director of Eugenics Records Office Harry Laughlin, to whom Cowan attributes the strategy for the 1924 immigration quotas.<sup>26</sup> Laughlin argued: “Society must look upon germ-plasm as belonging to society and not solely to the individual who carries it.”<sup>27</sup> However objectionable we find the collectivist coercion of the old genetics, Cowan warns us not to commit the “genealogical fallacy” of holding the new genetics responsible for the sins of the old.<sup>28</sup>

In Chapters Five and Six, Cowan attempts to expose as “historically fallacious” the popular argument that the old and new genetics are morally equivalent.<sup>29</sup> Cowan argues that, whereas the goal of the old genetics was to prevent carriers of genetic mutations from reproducing, the new genetics seeks to enhance procreative freedom and offspring well-being. Cowan endorses a program of genetic screening that involves neither threat nor force, and instead privileges clinical biology, parental choice, and prevention of disease. Cowan follows legal scholars such as John Robertson in endorsing parents’ procreative freedom to use genetic testing and prenatal interventions “to control the use of one’s reproductive capacity.”<sup>30</sup> Decisions about whether and what type of children to have considerably influence a parent’s sense of identity, and these choices also give rise to a host of ensuing benefits and burdens. Even if prospective parents feel pressure to exercise their procreative freedom in ways that conform to reproductive norms, “eugenics is about state control of reproduction,” Cowan emphasizes, “not about internalized standards of normality.”<sup>31</sup> Procreative freedom is also connected to offspring welfare. “Parents tend to pay closer attention to the well-being of their offspring,” philosopher Nicholas Agar explains, “than does the state pursuing some broad program of human stock improvement.”<sup>32</sup>

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24. See *id.* at 28-37, 235-36; cf. DESMOND KING, *IN THE NAME OF LIBERALISM: ILLIBERAL SOCIAL POLICY IN THE USA AND BRITAIN* 52 (1999).

25. JONATHAN PETER SPIRO, *DEFENDING THE MASTER RACE: CONSERVATION, EUGENICS, AND THE LEGACY OF MADISON GRANT* 236 (2008).

26. See COWAN, *supra* note 1, at 21.

27. SPIRO, *supra* note 25, at 236 (quoting Harry H. Laughlin).

28. See COWAN, *supra* note 1, at 67.

29. COWAN, *supra* note 1, at 234.

30. JOHN A. ROBERTSON, *CHILDREN OF CHOICE: FREEDOM AND THE NEW REPRODUCTIVE TECHNOLOGIES* 16 (1994).

31. Ruth Schwartz Cowan, *Moving up the Slippery Slope: Mandated Genetic Screening on Cyprus*, 151C AM. J. MED. GENETICS 95, 95 n.1 (2009).

32. Nicholas Agar, *Liberal Eugenics*, 12 PUB. AFF. Q. 137, 142 (1998).

## II. AN ANALOGY BETWEEN NEW AND OLD

The moral distinction Cowan tries to draw between the old genetics and the new genetics is important but incomplete. Cowan recognizes that the old genetics was not always carried out through coercion by the state. Some practices belonging to the old genetics she recounts in the United States were both voluntary and private. In the early decades of the twentieth century, “Better Baby”<sup>33</sup> and “Fitter Families”<sup>34</sup> contests awarded trophies at state fairs across the country for families with the finest genetic histories. Cowan notes that many universities and even high schools offered courses instructing students how to make wise reproductive decisions.<sup>35</sup> And she makes clear that supporters of Margaret Sanger’s birth control clinic sought to discourage childrearing among those deemed unfit.<sup>36</sup> What Cowan fails to appreciate is the important normative connection between these examples of what she labels the “old genetics” and varied incarnations of the “new genetics” operating around the world today, especially in southeast Asia.

Just as the old genetics was not always coercive or state-sponsored, the new genetics is not always free of state sponsorship or coercion. Cowan acknowledges this fact but nonetheless fails to incorporate its significance into her analysis. In parts of Asia, the Middle East, and the Mediterranean, laws aimed at the propagation of healthy people are enforced to this day.<sup>37</sup> In Israel, a 1986 ordinance provides federal funding for voluntary genetic testing of all citizens to determine carrier status of Tay-Sachs disease among Jews of Eastern European descent.<sup>38</sup> In Cyprus, the 1972 Thalassaemia Program makes screening of all high school students compulsory for the hereditary blood disease  $\beta$ -Thalassaemia; the state then pays for voluntary prenatal screening of and abortion

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33. See ANNETTE K. VANCE DOREY, *BETTER BABY CONTESTS: THE SCIENTIFIC QUEST FOR PERFECT CHILDHOOD HEALTH IN THE EARLY TWENTIETH CENTURY* (1999).

34. See Steven Selden, *Transforming Better Babies into Fitter Families: Archival Resources and the History of the American Eugenics Movement, 1908–1930*, 149 *PROC. AM. PHIL. SOC’Y* 199, 210-11 (2005) (citing KAN. BUREAU OF CHILD RESEARCH, *FITTER FAMILIES FOR FUTURE FIRESIDES: A REPORT OF THE EUGENICS DEPARTMENT OF THE KANSAS FREE FAIR, 1920-1924* (1924)); see also KEVLES, *supra* note 12, at 61-62 (detailing the history of the Fitter Families competitions, which began in Topeka in 1920); SANDEL, *supra* note 12, at 65 (noting that families underwent medical, psychological, and intelligence testing to determine winners).

35. See COWAN, *supra* note 1, at 20; see also SANDEL, *supra* note 12, at 65.

36. See COWAN, *supra* note 1, at 172.

37. See *id.*, at chs. 4, 5.

38. See Etty Broide et al., *Screening for Carriers of Tay-Sachs Disease in the Ultra-Orthodox Ashkenazi Jewish Community in Israel*, 47 *AM. J. MED. GENETICS* 213, 215 (1993); see also COWAN, *supra* note 1, at 133-39 (describing the history of Tay-Sachs screening in the United States).

services for all affected persons.<sup>39</sup> In Taiwan, the Genetic Health Law has mandated prenatal screening since 1985; physicians must recommend sterilization if it is “considered necessary” to address an incurable “genetic, infectious, or psychiatric disease,” and they must also advise abortion when it is “considered necessary” for an “abnormal fetus.”<sup>40</sup> And in China, the 1994 Law on Maternal and Infant Health Care stipulates as a condition of marriage that couples must undergo genetic screening. If either partner is diagnosed with certain genetic diseases, the couple is not permitted to marry without undergoing sterilization or long-term contraceptive measures.<sup>41</sup>

If genetic screening for disease and disability seems disquieting only insofar as it deprives parents of free choice, consider Singapore’s voluntary program of new genetics. Michael Sandel provides a vivid account of the Prime Minister’s Policy Statement of 1983, which encouraged childbearing among the well-educated classes by providing for state-subsidized “love boat” cruises for unmarried individuals with university degrees, incentives for childbearing among college-educated women, “courtship classes” in universities, and an official dating service.<sup>42</sup> Singapore’s eugenics program also discouraged reproduction by members of society perceived as possessing undesirable hereditary traits. Sandel notes that “low-income women who lacked a high school degree were offered \$4,000 as a down payment on a low-cost apartment—provided they were willing to be sterilized.”<sup>43</sup>

Singapore’s sterilization payments and love boat cruises were state-sponsored and “collectivist” in character, Sandel observes, but they were not coercive, at least not in the conventional sense of forcing people, under threat of punishment, to breed or be made sterile.<sup>44</sup> If the Singapore case gives reason for unease, this suggests that doing away with bad science, racist intentions, and

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39. See COWAN, *supra* note 1, at 208-12; Panayiotis Ioannou, *Thalassemia Prevention in Cyprus. Past, Present and Future*, in *THE ETHICS OF GENETIC SCREENING* 55, 62-63 (Ruth Chadwick et al., eds., 1999).

40. Bureau of Health Promotion, Dep’t of Health, ROC (Taiwan). Genetic Health Law (effective Jan. 1, 1985), available at <http://www.bhp.doh.gov.tw/bhpnet/portal/LawShow.aspx?No=200712250017>; see also ROC, Public Health: Health Promotion Programs—Maternal and Child Health Care (2002), <http://www.gio.gov.tw/taiwan-website/5-gp/yearbook/2002/chpt15-3.htm>.

41. Muying Baojian Fa [Law on Maternal and Infant Health] (promulgated by Standing Comm. Nat’l People’s Cong., Oct. 27, 1994, effective June 1, 1995), 1994 FA GUI HUI BIAN 158, translation available at [http://www.npc.gov.cn/englishnpc/Law/2007-12/12/content\\_1383796.htm](http://www.npc.gov.cn/englishnpc/Law/2007-12/12/content_1383796.htm); see also James M. Reichman, Mayer Brezis & Avraham Steinberg, *China’s Eugenics Law on Maternal and Infant Health Care*, 125 *ANNALS INTERNAL MED.* 425, 426 (1996).

42. SANDEL, *supra* note 12, at 69.

43. *Id.* (citations omitted).

44. *Id.* at 70.

coercive practices might not make a sociotechnical system of genetic control as admirable or innocuous as Cowan would have us believe.

The core of Cowan's argument is that the new genetics is "anti-eugenic" and "pro-natalist."<sup>45</sup> Modern genetic screening facilitates reproduction among those with recessive gene mutations, she claims, by enabling individuals to find partners without such recessive mutations and by "allow[ing] people who are genetically 'at-risk' to have as many children as they want."<sup>46</sup> This argument works well for Cowan's four case studies of Tay-Sachs, PKU,  $\beta$ -Thalassemia, and sickle-cell anemia. But it does not apply to prenatal screening for Down syndrome, which among all genetic anomalies, is the condition for which fetuses are tested and aborted at the highest rate.<sup>47</sup> Cowan notes that the conception of children with Down syndrome cannot be prevented through carrier screening since the condition can, to date, be detected only through prenatal diagnosis and reliably prevented before birth only through abortion.<sup>48</sup> But she fails to acknowledge the accompanying fact that for Down syndrome, the new genetics cannot be pro-natalist in the way that screening programs for Tay-Sachs and PKU have been. Cowan's claim that "[t]he technologies of genetic screening reduce, rather than increase, the likelihood of selective abortion"<sup>49</sup> is simply wrong when applied to testing for Down syndrome.

### III. A CHALLENGE TO THE NEW GENETICS

There are two additional reasons to worry about the new genetics. Both flow from the fact that the new genetics shares with the old genetics the goal of applying scientific knowledge of hereditary processes to the practice of human reproduction for the purpose of creating people of a particular type, even if only to avoid bringing into the world children with certain disabilities. The first reason is that the new genetics threatens "expressive" harm toward those whose genetic traits are targeted for elimination through reproductive measures.<sup>50</sup> On this account, parental screening, genetic testing, and selective abortion on the basis of disability can express harmful and demeaning judgments about the lives of

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45. COWAN, *supra* note 1, at 95 ("The first provider of prenatal diagnosis was a physician who wanted to help the carrier of a genetic disease *have* a baby; the first patient was a woman who, absent the test, would have probably terminated her pregnancy.").

46. *Id.* at 116.

47. See Caroline Mansfield, Suellen Hopfer & Theresa M. Marteau, *Termination Rates After Prenatal Diagnosis of Down Syndrome, Spinal Bifida, Anencephaly, and Turner and Klinefelter Syndromes: A Systematic Literature Review*, 19 *PRENATAL DIAGNOSIS* 808, 810 (1999) (reporting U.K. abortion rates of 92% following a prenatal diagnosis of Down syndrome).

48. See COWAN, *supra* note 1, at 84-87, 104-05.

49. *Id.* at 240.

50. See Jaime King, *Predicting Probability: Regulating the Future of Preimplantation Screening*, 8 *YALE J. HEALTH POL'Y L. & ETHICS* 285, 317 (2008).

people with disabilities.<sup>51</sup> Some disability activists argue that selecting against disability sends a message that people with disabilities “are ‘too flawed’ in [their] very DNA to exist,”<sup>52</sup> and thus are “viewed as unfit to be alive, as second-class humans, at best, or as unnecessary persons who would not have been born if only someone had gotten to them in time.”<sup>53</sup>

Is there good reason to think that preventing the birth of people with disabilities sends a disparaging message to people living with disabilities, who can observe their diminishing numbers?<sup>54</sup> Critics of this claim argue that choosing to prevent the birth of certain types of offspring does not express negative attitudes about the moral worth of people with those traits. The message that genetic screening sends, Cowan argues, turns exclusively on the reasons for which it is sought. Prospective parents who choose to terminate a pregnancy on the basis of fetal disability need not believe that people with disabilities are defective or inferior.<sup>55</sup> Indeed, most probably believe simply that a child with a disability is less likely to enjoy the full range of activities and opportunities available to children without disabilities.<sup>56</sup> Parents who wish to avoid giving birth to a child with a disability likely feel this way not because they negatively value people with disabilities, but instead because they positively value the autonomy that disabilities circumscribe.<sup>57</sup>

This reply misfires. While the idea that noble intentions determine the meaning of prenatal screening might be appealing, the social meanings of prenatal screening are a function of context, not intent.<sup>58</sup> Prenatal testing takes

51. See Erik Parens & Adrienne Asch, *The Disability Rights Critique of Prenatal Genetic Testing: Reflections and Recommendations*, in *PRENATAL TESTING AND DISABILITY RIGHTS* 3, 13 (Erik Parens & Adrienne Asch eds., 2000).

52. Marsha Saxton, *Disability Rights and Selective Abortion*, in *ABORTION WARS: A HALF CENTURY OF STRUGGLE, 1950-2000*, at 374, 391 (Rickie Solinger ed., 1998).

53. ROBERT H. BLANK, *REGULATING REPRODUCTION* 91 (1990).

54. See generally Rayna Rapp, *Moral Pioneers: Women, Men and Fetuses on a Frontier of Reproductive Technology*, in *EMBRYOS, ETHICS, AND WOMEN’S RIGHTS: EXPLORING THE NEW REPRODUCTIVE TECHNOLOGIES* 101 (Elaine Hoffman Baruch, Amadeo F. D’Adamo Jr., & Joni Seager eds., 1988).

55. See Allen Buchanan, *Choosing Who Will Be Disabled: Genetic Intervention and the Morality of Inclusion*, 13 *SOC. PHIL. & POL.* 18, 31 (1996) (suggesting that women who choose to abort on the basis of disability might “simply wish to be spared avoidable and serious strains on one’s marriage or on one’s family”).

56. See Robert L. Shinn, *Foetal Diagnosis and Selective Abortion: An Ethical Exploration*, in *GENETICS AND THE QUALITY OF LIFE* 74, 78-79 (Charles Birch & Paul Abrecht eds., 1975).

57. See ALLEN BUCHANAN ET AL., *FROM CHANCE TO CHOICE: GENETICS AND JUSTICE* 283-84 (2000).

58. See Rayna Rapp, *Refusing Prenatal Diagnosis: The Meanings of Bioscience in a Multicultural World*, 23 *SCI. TECH. & HUM. VALUES* 45, 45 (1998) (analyzing the social impact and

place against a cultural background in which people with disabilities have been “subjected to a history of purposeful unequal treatment, and relegated to a position of political powerlessness in our society.”<sup>59</sup> Although the Supreme Court has declined to treat disability as a suspect class under the Equal Protection Clause,<sup>60</sup> the Court has recognized that people with disabilities in America have been systematically “shunted aside, hidden, and ignored.”<sup>61</sup> The meaning of a practice that seeks to prevent the existence of people with disabilities should be considered against this history of disability-based discrimination, segregation, forced institutionalization, infanticide, and compulsory sterilization.<sup>62</sup> Disability-selective abortion may be chosen for benign reasons, but when that decision is understood in light of a community’s shared meanings, it may nevertheless transmit a message that people with disabilities are “less worthy of toleration or respect than of aversion and surgical repair.”<sup>63</sup> Even if prospective parents do not intend to express hurtful ideas, it may be reasonable to expect people with disabilities to receive these messages and be pained by them.

A second reason to worry about genetic testing is that disability-selective abortion might encourage an unwillingness to accommodate, care for, or find ways to improve the lives of those whose abilities fail to meet the demands of modern society.<sup>64</sup> Consider that when the earliest prenatal diagnostic techniques

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contextually-bound cultural meanings “of prenatal diagnosis, a cluster of technologies used for assessing the chromosomal and genetic normalcy of fetuses in utero . . . all backed up by abortion technology, for those who receive bad news about the health of their fetuses and choose to end specific pregnancies”).

59. Americans with Disabilities Act of 1990, Pub. L. No. 101-336, § 2, 104 Stat. 327, 329 (1990) (codified as amended at 42 U.S.C. § 12101(a)(7) (2000) (deleted by amendment in 2008)).

60. *City of Cleburne v. Cleburne Living Ctr., Inc.*, 473 U.S. 432 (1985) (denying constitutional status as a quasi-suspect or suspect class to the disabled, but applying rational basis review to strike down a municipal zoning ordinance under which the city refused to grant a permit to build a group home for the mentally retarded); see also Michael Ashley Stein, *Same Struggle, Different Difference: ADA Accommodations as Antidiscrimination*, 153 U. PA. L. REV. 579, 612-15 (2004). Stein notes that “[c]anonical scholarship . . . distinguishes the treatment of people with disabilities from that of other protected groups because it conceives of and discusses disability as a biologically compelled reality, rather than as a contingent social construct.” *Id.* at 612.

61. *Alexander v. Choate*, 469 U.S. 287, 296 (1985).

62. See JOSEPH P. SHAPIRO, *NO PITTY: PEOPLE WITH DISABILITIES FORGING A NEW CIVIL RIGHTS MOVEMENT* 12-40 (1993).

63. See Dov Fox, *Safety, Efficacy, and Authenticity: The Gap Between Ethics and Law in FDA Decisionmaking*, 2005 MICH. ST. L. REV. 1135, 1149 (making a similar argument with regard to the larger social consequences of cosmetic operations used to alter non-Anglo-Saxon-identified racial and ethnic features).

64. See Wendy F. Hensel, *The Disabling Impact of Wrongful Birth and Wrongful Life Actions*, 40 HARV. C.R.-C.L. L. REV. 141, 180 (“[S]ociety’s compassion towards the mother of a child with disabilities will diminish if she ‘easily’ could have prevented the hardships resulting from her

were introduced in the 1970s, abortion was thought to be a temporary approach that would soon be replaced by therapeutic measures for fetal disease.<sup>65</sup> However, there are few treatments for genetic disabilities today, and the search for such therapies has slowed considerably.<sup>66</sup> If reproductive fixes replace therapeutic approaches to genetic conditions, the new genetics could enervate our collective will to confront the challenge of disabilities.<sup>67</sup>

A straightforward objection to this argument is that that society can seek to prevent disabilities before birth and, at the same time, provide for the needs of those born with disabilities.<sup>68</sup> I do not disagree that *ex ante* and *ex post* approaches can be coherently pursued in tandem, at least as a matter of moral logic. However, these approaches are seriously at odds as a matter of moral psychology. The “why not both?” objection neglects the influence of prevailing norms on social attitudes and the way that changes in social practice can bring about changes in the ways we understand ourselves and the ways we choose to solve the challenges we face.<sup>69</sup> Selective abortion reinforces the view that

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child’s condition.”).

65. See Theodore Friedmann, *Opinion: The Human Genome Project—Some Implications of Extensive “Reverse Genetic” Medicine*, 46 AM. J. HUM. GENETICS 407, 412 (1990); Abby Lippman, *The Genetic Construction of Prenatal Testing: Choice, Consent, or Conformity for Women?*, in WOMEN AND PRENATAL TESTING: FACING THE CHALLENGES OF GENETIC TECHNOLOGY 9, 26 (Karen H. Rothenberg & Elizabeth J. Thomson eds., 1994).

66. See Patricia E. Bauer, *If the Test Says Down Syndrome*, WASH. POST, Nov. 16, 2007, at A33 (“The diagnostics carry the unspoken message that people with Down syndrome are ‘bad outcomes,’ people whose lives are not worth living. Yet there hasn’t been a comprehensive effort to collect data on the outcomes of adults with the condition, nor have there been well-funded efforts to develop treatments for them.”).

67. See LORI B. ANDREWS, *FUTURE PERFECT: CONFRONTING DECISIONS ABOUT GENETICS* 101 (2001) (“Once prenatal diagnosis and testing are made available for a particular disorder, there may be a tendency to discontinue funding for research to help combat the medical problems for existing people with that disorder and to discontinue social services for such individuals.”); BARBARA KATZ ROTHMAN, *TENTATIVE PREGNANCY: PRENATAL DIAGNOSIS AND THE FUTURE OF MOTHERHOOD* 9 (1986) (arguing that the rise of prenatal genetic testing transforms disability from a social problem into an individual problem).

68. See Bonnie Steinbock, *Preimplantation Genetic Diagnosis and Embryo Selection*, in A COMPANION TO GENETHICS 175, 182 (Justine Burley & John Harris eds., 2002) (arguing that the rise of prenatal screening has “coincided with more progressive attitudes toward the inclusion of people with disabilities, as evidenced in the United States by the passage of the Americans with Disabilities Act”).

69. See Dov Fox, *Silver Spoons and Golden Genes: Genetic Engineering and the Egalitarian Ethos*, 33 AM. J.L. & MED. 568, 611 (2007) (“Even with disability rights legislation on the books, if poverty or poor school performance become genetic problems to be cured by technology, rather than social problems worthy of political remedy, then conditions that were once addressed through education or economic intervention will be managed instead by producing people who better fit the

individual impairment alone explains why disability disadvantages.<sup>70</sup> Only in unaccommodating infrastructures does an impairment of normal psychological or physiological functioning burden the capacity to achieve a basic activity such as moving about freely. The biological view of disability overlooks and inadequately addresses the important social component of what makes impairments disabling.<sup>71</sup>

## CONCLUSION

While Cowan's unqualified celebration of the new genetics will not convince its critics, *Heredity and Hope* offers a provocative reply to those disability advocates, reproductive feminists, and antiabortionists who would compare modern, prenatal genetic screening to Nazi eugenics. This perspective comes at a critical moment. Cowan's historical analysis of Tay-Sachs, PKU, and  $\beta$ -Thalassemia provides the strongest case yet for the December 2007 recommendation by the American College of Obstetricians and Gynecologists that hospitals and physicians should be required to expand their offer of prenatal testing for a range of conditions to pregnant women of all ages.<sup>72</sup> Cowan is right that the founders of medical genetics "viewed their basic project as the relief of human suffering, not improvement of the race."<sup>73</sup> But this argument about intentions misses the point. If we come to believe that the fitting way to deal with disabilities is to keep the people who would have them from ever coming into existence, there is a serious risk we will lose our commitment to reform society in ways that meaningfully include people with disabilities.

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social roles we choose to reward.").

70. See Martha Saxton, *Prenatal Screening and Discriminatory Attitudes About Disability*, in EMBRYOS, ETHICS, AND WOMEN'S RIGHTS: EXPLORING THE NEW REPRODUCTIVE TECHNOLOGIES, *supra* note 54, at 217, 221-22 ("[T]he disability can produce considerable inconvenience . . . . But it is the discriminatory attitudes and thoughtless behavior that make life difficult.").

71. See Christopher Newell, *The Social Nature of Disability, Disease and Genetics: A Response to Gillam, Persson, Holtug, Draper and Chadwick*, 25 J. MED. ETHICS 172, 173 (1999) ("I suggest a social constructivist account, but this does not deny a physiological component . . . . Genetic conditions occur in a social context, and their meaning and impact are inherently social.").

72. ACOG Practice Bulletin No. 88: *Invasive Prenatal Testing for Aneuploidy*, 110 OBSTETRICS & GYNECOLOGY 1459 (2007); see also Press Release, Am. Coll. of Obstetricians & Gynecologists, New Recommendations for Down Syndrome: Screening Should Be Offered to All Pregnant Women (Jan. 2, 2007), [http://www.acog.org/from\\_home/publications/press\\_releases/nr01-02-07-1.cfm](http://www.acog.org/from_home/publications/press_releases/nr01-02-07-1.cfm).

73. COWAN, *supra* note 1, at 236.