# A brave new world of designer babies?

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# A BRAVE NEW WORLD OF DESIGNER BABIES?

By Sonia M. Suter<sup>†</sup>

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#### I. INTRODUCTION

With recent advances in genetics, the possibilities for reproductive uses are escalating. Prenatal testing and screening have become a routine part of pregnancy for most women in the United States, leaving the oncenarrow confines of genetics clinics for the broader world of general obstetrics. Couples undergoing in vitro fertilization may now have their embryos tested for genetic defects through preimplantation genetic diagnosis. Gene therapy is slowly offering the possibility of treating genetic and other diseases and may one day allow us to enhance or eliminate desirable and undesirable traits, respectively. Cloning, though not yet technologically feasible in humans, no longer seems merely the stuff of science fiction. As genetics has gained more prominence in the public discourse, inevitable concerns have been raised about the implications of reproductive advancements. The worries are often both forward and backward looking. Many worry about technologies we have never seen before: using gene therapy to enhance individuals, cloning those we find desirable, and creating chimeras of animals and humans. Others express concerns about returning to the attitudes and mistakes of our past. Indeed, many have condemned widely accepted (as well as some still theoretical) practices in reproductive genetics as a form of eugenics.

This Article explores the latter concerns—namely, that we are currently using, or will soon use, reproductive technologies in eugenic ways. I refer to these modern practices as "neoeugenics" to suggest that they share some key features with classic eugenics—e.g., the goal of increasing "good birth"—and that they differ because they occur primarily at the individual, rather than state, level. I make this distinction because the history of classic eugenics here and in other countries is reprehensible: people have been prohibited from certain unions, sterilized, and, in Nazi Germany, exterminated. "Eugenics," once a term suggesting scientific promise, public health improvements, and progress, now connotes injustice, abrogation of basic liberties, and poor science. To label a practice as eugenic is to deem it morally problematic at best and abusive and violating at worst. Modern geneticists, deeply cognizant of the troubled history of eugenics, have worked hard to distance their practices from those of the first half of the twentieth century.

Many articles describe certain reproductive technologies as eugenic or as a form of new eugenics to suggest they are of moral concern. Far too

<sup>1.</sup> See, e.g., Robert H. Bork, *The Challenges of Biology for Law*, 4 TEX. REV. L. & POL. 1, 3 (1999) ("If the possibility of cloning does not make the concept of offspring obsolete, the specter of eugenics once again looms."); Marsha Garrison, *Law Making for* 

often, commentators fail to elaborate on the widely shared assumption that eugenics is "bad." While many aspects of classic eugenics were indisputably horrific, this alone does not support the implication that eugenics is per se problematic. Without developing an understanding of what we mean by this term, the discourse regarding the propriety of current and future genetic technologies will be necessarily thin.

My goal is to give fuller substance to the term and to elaborate on the various aspects of eugenics so that we can more carefully evaluate current and future uses of reproductive technologies. Since many criticize these technologies as eugenic, I compare eugenics with neoeugenics to identify more precisely the features of neoeugenics reminiscent of and different from eugenics. What is it about today's technologies that raises fears about eugenics, and which aspects of these technologies deviate in important ways from eugenics? Recognizing these differences and similarities can help us isolate the areas of possible concern regarding neoeugenics. But, this is only the first step.

My next goal is to wrestle with the prevailing presumption that anything reminiscent of eugenics is per se problematic. Neoeugenics (and even eugenics), I shall argue, is not per se problematic. That is, many of the underlying goals are legitimate. This is not to say that neoeugenics is not problematic in practice; in fact, I shall point out various ways in which we should be deeply troubled by neoeugenics. The analysis, however, is highly contextual, depending both on social factors and individual circumstances. We may ultimately conclude that the context in which neoeugenics is now and will be practiced raises too many concerns. If that is so, the real issue is the social context that makes neoeugenics problematic. If practiced in the right context, neoeugenics need not be problematic. A contextual evaluation, however, suggests that social factors and individual circumstances, intent, and motivation often argue against neoeugenics.

In order to compare neoeugenics with eugenics, Part II addresses the first question: "What exactly is eugenics?" On the hundredth anniversary

Baby Making: An Interpretive Approach to the Determination of Legal Parentage, 113 HARV. L. REV. 835, 919 (2000) ("Use of donated preembryos also presents policy issues . . . . For example, a couple might use preembryo donation to engage in eugenic manipulation by choosing sperm and egg donors with traits they deem particularly desirable."); S. Rebecca Holmes-Farley & Michael A. Grodin, Law, Medicine and Socially Responsible Research, 24 AM. J.L. & MED. 153, 157 (1998) ("In addition, the feasibility of gene therapy and the prospect of human cloning raise anew the specter of eugenics . . . ."); Michael J. Malinowski & Maureen A. O'Rourke, A False Start? The Impact of Federal Policy on the Genotechnology Industry, 13 YALE J. ON REG. 163, 243-44 (1996) ("Ironically . . . the most readily available technologies—genetic diagnostic and screening capability—raise many of the most ominous ethical questions . . . , [including] eugenics.").

of the first sterilization law in this country, I begin with a brief history, highlighting how the movement was understood, who supported it and why, and what policies were implemented to achieve its goals. Part II also discusses various features of the eugenics programs, including the interference with reproductive autonomy, the underlying racism and discriminatory views, and the poor scientific basis for the practices. Of course, there are many features of eugenics that, at least with respect to intent, could be praised today: the mission to reduce disease in the population, the efforts to protect the public fisc, and the goal of reducing suffering. What makes "eugenics" such a complex term is that its practitioners were well-intentioned and it meant different things to different people.

Part III emphasizes the distinction between the eugenics era and modern reproductive genetics. I begin by noting the demise of some key features of the eugenics movement and then describe aspects of the twentyfirst century that protect against many dangers of the eugenics era. In particular, I show that developments within genetics, norms in genetic counseling, the development of the bioethics movement, and legal protections of reproductive rights distinguish the social milieu of current reproductive technologies from classic eugenics in important ways. Nevertheless, in Part IV, I argue that certain attitudes of the eugenics era remain today, including a resurgence of interest in heredity, race-based categorizations in genetics, a privileging of science, and a focus not only on individual beneficence but also on social welfare. I argue further that an individualized form of eugenics—neoeugenics—is emerging. Neoeugenics strives towards "good birth" at the individual, rather than state level. Current pressures drive many toward selection against genetic disease, and evolving technologies may only enhance the pressures toward voluntary "improvement" of the human species at the individual level. Part IV is merely descriptive, however, offering no normative assessment of these developments.

Part V examines whether prophylactic measures actually eliminate all the concerns associated with eugenics in the modern practice of reproductive genetics. If we evaluate neoeugenics through the lens of individual autonomy and reproductive rights as commonly understood, neoeugenics looks substantially different and much improved from classic American eugenics. Because this conception of autonomy tends to emphasize libertarian ideals, the restrictions on reproduction are the primary problem, and the absence of state coercion over reproduction constitutes an important distinction between neoeugenics and eugenics. I suggest, however, that we evaluate neoeugenics through the lens of relational autonomy. This perspective considers not only whether choices are made free of state and

medical coercion, but whether choices are made in ways that enrich the individual vis-à-vis his or her relationships with others—family, friends, and community. This perspective reveals that the problems with eugenics go beyond state coercion and include underlying prejudices, harms to the disadvantaged, social inequities, and commodification. When we evaluate neoeugenics through the lens of relational autonomy, we see that many of these concerns still exist. Yet, we also see that many are not unique to eugenics and neoeugenics but instead reflect broader concerns about existing discriminatory attitudes, inequities, or parental pressures that neoeugenics might exacerbate. In other words, the root of the problem is the social context in which eugenics and neoeugenics are practiced.

In this Article, my goal is first to emphasize that the concerns regarding eugenics and neoeugenics are more similar than we might think if we restrict ourselves to a liberal conception of autonomy. Second, I want to emphasize that neither eugenics nor neoeugenics can on its face be condemned, because evaluations and criticisms depend deeply on context and intent. As a result, an evaluation of neoeugenics may raise concerns to which we should be attentive, but it should not require broad scale dismissal of the entire enterprise.

#### II. THE RISE AND FALL OF THE EUGENICS MOVEMENT

It is not surprising that "eugenics" is a dirty word,<sup>2</sup> a proxy for all that can go wrong when genetics technology is misapplied. During the reign of eugenics<sup>3</sup> in the United States alone, over 60,000 people were involuntarily sterilized<sup>4</sup> under the authority of legislation in over thirty states.<sup>5</sup> Inspired by the success of the American eugenics program, Germany enacted a comprehensive sterilization law in 1933, which is estimated to

<sup>2.</sup> Owen D. Jones, Reproductive Autonomy and Evolutionary Biology: A Regulatory Framework for Trait-Selection Technologies, 19 Am. J.L. & MED. 187, 212 (1993); Daniel Wikler, Can We Learn From Eugenics?, 25 J. MED. ETHICS 183, 183 (1999) ("[T]he term 'eugenic' is now used primarily as an epithet.").

<sup>3.</sup> It is hard to pin down the precise span of the eugenics era. Most agree that it began around the 1870s, but there is no clear delineation as to when it ended. See, e.g., ALAN PETERSEN & ROBIN BUNTON, THE NEW GENETICS AND THE PUBLIC'S HEALTH 41 (2002) ("Eugenics was espoused and practiced from approximately 1870 to 1950."); ELOF AXEL CARLSON, UNFIT: A HISTORY OF A BAD IDEA 401 (2001) ("What can be called the American eugenics movement . . . had its origins about the 1870s . . . [and] lasted through the 1930s and then went into eclipse.").

<sup>4.</sup> Phillip Reilly, The Surgical Solution: A History of Involuntary Sterilization in the United States 2 (1991).

<sup>5.</sup> See infra text accompanying notes 108-109.

have led to the sterilization of 3,500,000 persons.<sup>6</sup> Nazi policy went a gruesome step further, resulting in the extermination of various "undesirables, including Jews and Gypsies."<sup>7</sup>

# A. The Origins of Eugenics

To understand the eugenics era, it is essential to understand what eugenics meant to scientists, policy makers, and the public. In 1883, Francis Galton, a scientist trained in medicine and mathematics, coined the term eugenics, which means good birth or well-born. Galton's investigation of the origins of natural ability revealed a disproportionate incidence of blood relatives among eminent men in various disciplines. This discovery led him to conclude that traits like character and talent were hereditary just like physical features. With his interest in heredity, Galton pondered whether the selective breeding of plants and animals could be applied to humans. Could not the race of men be similarly improved? . . . Could not the undesirables be got rid of and the desirables multiplied?

The scientific community embraced Galton's ideas in the early 1900s, in large part because they coincided with other important thoughts and developments in science. Darwin's theory of natural selection had been accepted<sup>13</sup> and for many was consistent with the notion that "biology was destiny." Darwin himself became a believer in eugenics. But most im-

<sup>6.</sup> Phillip R. Reilly, *Eugenics, Ethics, Sterilization Laws*, in 1 ENCYCLOPEDIA OF ETHICAL, LEGAL AND POLICY ISSUES IN BIOTECHNOLOGY 205, 210 (Thomas H. Murray & Maxwell J. Mehlman eds., 2000); *see infra* text accompanying note 102.

<sup>7.</sup> Lori B. Andrews et al., Genetics: Ethics, Law and Policy 60 (2d ed. 2006) [hereinafter Genetics].

<sup>8.</sup> Reilly, supra note 6, at 205; Wikler, supra note 2, at 184.

<sup>9.</sup> DANIEL J. KEVLES, IN THE NAME OF EUGENICS 7 (1985); Reilly, *supra* note 6, at 205; Wikler, *supra* note 2, at 184.

<sup>10.</sup> Francis Galton, Inquiries into Human Faculty and Its Development 24 (1883); Paul A. Lombardo, *Carrie Buck's Pedigree*, 138 J. Lab. Clin. Med. 278, 278 (2001) [hereinafter Lombardo, *Pedigree*]. The term fuses the Greek words for "good" and "birth." Reilly, *supra* note 6, at 204.

<sup>11.</sup> KEVLES, supra note 9, at 3.

<sup>12.</sup> *Id.* (citation omitted). Ultimately, Galton described eugenics as the "science of improving stock—not only by judicious mating, but whatever tends to give the more suitable races or strains of blood a better chance of prevailing over the less suitable than they otherwise would have." Wikler, *supra* note 2, at 184 (citing GALTON, *supra* note 10).

<sup>13.</sup> Wikler, *supra* note 2, at 184. Indeed, Galton claimed that the publication of the *Origin of Species* in 1859 had sparked his thinking in this area. KEVLES, *supra* note 9, at 8.

<sup>14.</sup> KEVLES, *supra* note 9, at 20. "Many eugenicists regarded disease as nature's way of weeding out the unfit." Martin S. Pernick, *Eugenics and Public Health in American History*, 87 Am. J. Pub. Health 1767, 1767 (1997). One speaker at the first major

portant, Mendel's laws of inheritance, which had attracted little attention when published in 1866, were rediscovered in 1900.<sup>16</sup> The emerging field of genetics was soon inextricably linked to the eugenics movement.<sup>17</sup>

Galton's theories of heritability led to research programs across the world. <sup>18</sup> In the United States, Charles Davenport, who would become the leader of American eugenics, <sup>19</sup> received funds to study evolution <sup>20</sup> and develop a eugenics research facility. In 1910, he created the infamous Eugenics Records Office at Cold Spring Harbor on Long Island, <sup>21</sup> which collected extensive family pedigrees to test theories of inheritance. <sup>22</sup> Davenport "provided eugenics with a cloak of scientific legitimacy that it wore for more than three decades."

Many eugenicists too readily relied on Mendelian theory to explain complex traits.<sup>24</sup> Davenport claimed, for example, that "'nomadism,' 'shiftlessness,' and 'thalassophilia'—the love of the sea"—were based on single Mendelian characters.<sup>25</sup> Eugenicists paid little attention to the role of

American conference on eugenics described death as "the normal process of elimination in the social organism, and . . . in prolonging the lives of defectives we are tampering with the functioning of the social kidneys." *Id*.

- 15. KEVLES, *supra* note 9, at 20 (noting that Darwin remarked Galton had made "a convert of an opponent in one sense, for I have always maintained that excepting fools, men did not differ much in intellect, only in zeal and hard work. . . . [W]e now know, through the admirable labours of Mr. Galton, that genius . . . tends to be inherited.").
  - 16. Reilly, supra note 6, at 205; KEVLES, supra note 9, at 43.
- 17. Every member of the first editorial board of the journal *Genetics*, for example, supported the eugenics movement. In addition, textbooks in genetics and biology began to include sections on eugenics. Jon Beckwith, *Thinking of Biology: A Historical View of Social Responsibility in Genetics*, 43 BIOSCIENCE 327, 327-28 (1993); Wikler, *supra* note 2, at 184.
  - 18. Wikler, supra note 2, at 184.
- 19. Glenn McGee & David Magnus, *Eugenics, Ethics, in* 1 ENCYCLOPEDIA OF ETHICAL, LEGAL AND POLICY ISSUES IN BIOTECHNOLOGY 199, 204 (Thomas H. Murray & Maxwell J. Mehlman eds., 2000).
- 20. RUTH HUBBARD & ELIJAH WALD, EXPLODING THE GENE MYTH 18 (1993); KEVLES, *supra* note 9, at 45; Reilly, *supra* note 6, at 205.
  - 21. Reilly, supra note 6, at 205.
- 22. KEVLES, *supra* note 9, at 45; Reilly, *supra* note 6, at 43. This work led to Davenport's 1911 publication of HEREDITY IN RELATION TO EUGENICS, which was based on information about hundreds of families, often extending back three generations. KEVLES, *supra* note 9, at 46.
  - 23. Reilly, *supra* note 6, at 205.
- 24. For example, Davenport and Galton were strong proponents of Mendel's theories. Both were quick to conclude that a particular trait was heritable solely on the basis that it appeared with high frequency in a family pedigree. KEVLES, *supra* note 9, at 43.
  - 25. Id. at 48-49.

environment in the many complex traits they studied<sup>26</sup> and relied on unproven assumptions about race.<sup>27</sup> They conflated national and racial identity and believed that race determined behavior. Davenport, for example, described the Poles as "independent and self-reliant though clannish" and the Italians as prone to "crimes of personal violence." Like Galton, Davenport identified the white Protestant middle class as good stock.<sup>29</sup>

This combination of racist notions and sweeping claims about the heredity of complex and amorphous traits led many to answer Galton's initial question in the affirmative: The "race of men" could be improved; "undesirables" could "be got rid of and the desirables multiplied." This background reveals some key elements of the evolving eugenics movement in the early part of the twentieth century. First, it was in large part a comprehensive research program. Second, it was grounded in an overly simplistic, and often mistaken, understanding of heredity. Third, and perhaps most fundamental, its underlying goal was improvement of the human race by influencing heredity through patterns of breeding. As Galton once described, eugenics could "providently, quickly, and kindly" do "what Nature does blindly, slowly, and ruthlessly."

26. Davenport acknowledged that individuals were the products of "conditions *and* blood," but he viewed the "protoplasm" as crucial to "human fate." KEVLES, *supra* note 9, at 46. He wrote:

Pauperism is a result of complex causes. On one side it is mainly environmental in origin as, for instance, in the case when a sudden accident... leaves a widow or family of children without means of livelihood, or a prolonged disease of the wage earner exhausts savings. But it is easy to see that in these cases heredity also plays a part; for the effective worker will be able to save enough money to care for his family in case of accident; and the man of strong stock will not suffer from prolonged disease. Barring a few highly exceptional conditions poverty means relative inefficiency and this in turn usually means mental inferiority.

CHARLES BENEDICT DAVENPORT, HEREDITY IN RELATION TO EUGENICS 80 (1913), *cited* in Hubbard & Wald, *supra* note 20, at 14.

- 27. KEVLES, *supra* note 9, at 46-47.
- 28. *Id.* at 46-47.
- 29. Id. at 47.
- 30. *Id.* at 4; see supra text accompanying note 12.
- 31. *Cf.* ANGELA FRANKS, MARGARET SANGER'S EUGENIC LEGACY: THE CONTROL OF FEMALE FERTILITY 100 (2005) (describing one scientist who urged eugenics to broaden its narrow focus to allow for the role of environmental influences on human traits). *See generally* Carlson, *supra* note 3, at 337-45 (detailing the complexities of gene expression that went unrecognized throughout the eugenics era).
  - 32. KEVLES, supra note 9, at 12.

The underlying goals and scientific assumptions, however, reveal nothing about how these goals could be achieved. One strand of eugenics—positive eugenics—encouraged the "fit" to choose mates and procreate in accord with eugenic ideals.<sup>33</sup> The father of eugenics, Galton, promoted this strand. In his utopian world, informed people would make the "right" procreative decisions.<sup>34</sup> But it was not positive eugenics that "stirred the passions of the crowd."<sup>35</sup> Rather, it was negative eugenics—the attempts to discourage the "unfit" from procreating<sup>36</sup>—that led to particularly troubling policies in many countries, including the United States.

One method of achieving both positive and negative eugenic goals was through the popularization of eugenics ideas. Eugenics captured the public imagination; according to the Index of Periodical Literature, it was the second most popular topic in the print media in 1910.<sup>37</sup> Journalists widely described the now-infamous pedigrees of "white trash" families like the Jukes and the Kallikaks as evidence of the dangers of reproduction among the unfit.<sup>38</sup> In the 1920s, the American Eugenics Society further popularized eugenics with exhibits and "Fitter Family" competitions held "in the 'human stock' sections" at state fairs.<sup>39</sup> The state fairs were used to emphasize not only the positive benefits of heritable traits, like health and sound mind,<sup>40</sup> but also the social costs of poor inheritance<sup>41</sup> and the "menace of the moron."<sup>42</sup> One exhibit posed the question: "How long are we Americans to be so careful for the pedigree of our pigs and chickens and cattle—and then leave the *ancestry of our children* to chance or to 'blind' sentiment?"<sup>43</sup>

<sup>33.</sup> Robert J. Cynkar, Buck v. Bell: "Felt Necessities" v. Fundamental Values?, 81 COLUM. L. REV. 1418, 1428 (1981).

<sup>34.</sup> ALLEN BUCHANAN ET AL., FROM CHANCE TO CHOICE: GENETICS AND JUSTICE 42 (2000) ("Galton . . . wanted to secure voluntary acquiescence with eugenic guidelines by making eugenics a civil religion . . . .").

<sup>35.</sup> Cynkar, *supra* note 33, at 1428.

<sup>36.</sup> Id.

<sup>37.</sup> Reilly, *supra* note 6, at 205; Robert G. Resta, *The Twisted Helix: An Essay on Genetic Counselors, Eugenics, and Social Responsibility*, 1 J. GENETIC COUNSELING 227, 231 (1992) ("By the start of World War I, popular publications contained more articles on eugenics than on slums, tenements, and living standards combined.").

<sup>38.</sup> Reilly, supra note 6, at 205; Wikler, supra note 2, at 184.

<sup>39.</sup> KEVLES, supra note 9, at 61-62; Wikler, supra note 2, at 184.

<sup>40.</sup> KEVLES, supra note 9, at 62.

<sup>41.</sup> McGee & Magnus, supra note 19, at 200.

<sup>42.</sup> KEVLES, *supra* note 9, at 78-79; DIANE B. PAUL, CONTROLLING HUMAN HEREDITY: 1865 TO THE PRESENT, ch. 4 (1995) [hereinafter PAUL, HEREDITY]; McGee & Magnus, *supra* note 19, at 200.

<sup>43.</sup> KEVLES, *supra* note 9, at 62-63.

#### **B.** Government Involvement and Eugenics Laws

What had begun as a movement among scientists and intellectuals around the turn of the century<sup>44</sup> soon inspired political action to protect the public against the threat of poor genes. Both America and England were highly influential forces in the eugenics movement, but England demonstrated that the movement could be powerful even without restricting liberties in the way that the United States did. England's Parliament enacted only one eugenic statute—the Mental Deficiency Act—which gave a central authority the power to detain and segregate some "feebleminded" individuals, thereby indirectly interfering with their reproduction. Despite being "the source of much—indeed most—eugenic science and propaganda in the first forty years of the twentieth century," England never passed laws restricting marriage among the "feebleminded" nor compelled their sterilization. <sup>46</sup>

In the United States, in contrast, legislatures were prolific in enacting eugenics legislation.<sup>47</sup> By 1914, thirty American states had legal restrictions on marriage of the "feebleminded."<sup>48</sup> Anti-miscegenation laws both

<sup>44.</sup> McGee & Magnus, supra note 19, at 200.

<sup>45.</sup> Kevles, *supra* note 9, at 98-99. Control and segregation of the mentally deficient was seen as an effective solution to the hereditary threats this group posed to the larger public. As Winston Churchill, then Home Secretary in the Asquith government, explained, although the "feebleminded in Britain deserved 'all that could be done for them by a Christian and scientific civilization now that they were in the world,' they should, if possible, be 'segregated under proper conditions [so] that their curse died with them and was not transmitted to future generations." *Id.* at 98. This legislation, however, did not go as far as many eugenicists would have hoped; it did not result in the complete segregation of the "feebleminded and other degenerate types," allowing many such individuals to avoid institutionalization. *Id.* Moreover, the test of deficiency was "not heredity but social incapacity." *Id.* at 99.

<sup>46.</sup> Matt Ridley, Genome: The Autobiography of a Species in 23 Chapters 291 (1999).

<sup>47.</sup> Kevles attributes the different levels of legislative activity in England and the United States to jurisdictional differences: "[I]n Britain such matters fell to a national body, Parliament, whereas in America they were the province of the state legislatures, whose level of deliberation even today leaves a good deal to be desired." Kevles, *supra* note 9, at 100-01. More significant, perhaps, was the view in the early twentieth century America that public policy was best served "with the aid of scientific experts," of whom there were many in the area of eugenics eager to assist the government in social reform. *Id.* at 101.

<sup>48.</sup> KEVLES, *supra* note 9, at 99. The majority of such statutes voided marriages involving the idiots or insane, and the rest imposed restrictions on marriage among groups like the feebleminded or those with venereal disease. The justification for such laws was usually based on the inability of the mentally deficient to enter into contracts, but sometimes it was overtly eugenic. *Id*.

furthered and were justified by eugenics goals.<sup>49</sup> But it is the antiimmigration and involuntary sterilization legislation that most clearly marks the eugenics movement in the United States. With the support of other interest groups that lobbied for immigration restrictions at the end of the nineteenth century, eugenicists pushed to reduce the influx of the "genetically inferior."50 As the movement grew, its principles became central to the passage of the Immigration Restriction Act of 1924, which set quotas limiting the immigration of "biologically inferior" ethnic groups into the United States and favored the entrance of Northern Europeans.<sup>51</sup> Harry Laughlin, director of the Eugenics Record Office, served as eugenics expert to the House Committee on Immigration and Naturalization, where he and others presented testimony that certain races and ethnic groups, particularly those from southern and eastern Europe, were biologically inferior.<sup>52</sup> In the midst of post-World War I xenophobia, concerns about job loss, and racism, Congress eagerly adopted eugenics theories and passed the Immigration Act by an overwhelming majority. President Calvin Coolidge quickly signed the bill into law.<sup>53</sup>

Eugenicists believed that keeping "unfit" immigrants out of the United States, however, was insufficient to protect the "deteriorating germplasm." <sup>54</sup> In fact, they believed that negative eugenics required active government involvement to prevent degenerates within the United States from reproducing. The first sterilization law, enacted in Indiana in 1907, ad-

<sup>49.</sup> Id. at 100.

<sup>50.</sup> A general immigration statute from 1882, which had prevented "idiots, lunatics, convicts, and persons likely to become public charges" from entering the United States, was expanded in 1903 to restrict the immigration of known criminals, epileptics, those with infections or disease, polygamists, beggars, and anarchists. Cynkar, *supra* note 33, at 1432.

<sup>51. 22</sup> Stat. 214 (1882) (excluding idiots, lunatics, convicts, and persons likely to become public charges).

<sup>52.</sup> Among the claims was the assertion that "80-90% of Italian, Russian, Hungarian, and Jewish immigrants were feeble-minded." Resta, *supra* note 37, at 232.

<sup>53.</sup> KEVLES, *supra* note 9, at 96-97; McGee & Magnus, *supra* note 19, at 200; Reilly, *supra* note 6, at 205; Resta, *supra* note 37, at 231 (describing how Laughlin argued in favor of this legislation by suggesting that it was not only in the interests of American society but also in the interests of the restricted immigrants). As Vice-President, Calvin Coolidge had declared that "America must be kept American. Biological laws show . . . that Nordics deteriorate when mixed with other races. KEVLES, *supra* note 9, at 97.

<sup>54.</sup> EDWIN BLACK, WAR AGAINST THE WEAK: EUGENICS AND AMERICA'S CAM-PAIGN TO CREATE A MASTER RACE 58 (2003) (describing groups that were "identified as 'socially unfit' and targeted for 'elimination,'" whose extended families were considered "equally unfit because they supposedly carried the defective germ-plasm that might crop up in a future generation").

dressed those concerns.<sup>55</sup> Within six years, 14 states had enacted involuntary sterilization programs.<sup>56</sup> Their statutes authorized compulsory sterilization of habitual criminals and often of the insane, mentally ill, or idiots.<sup>57</sup> Sterilization, it was thought, would limit the inheritance of "feeble-mindedness" and reduce sexual licentiousness,<sup>58</sup> which eugenicists believed was linked to "feeble-mindedness."<sup>59</sup>

In spite of the many sterilization laws and estimates of a "feeble-minded menace" of three to four hundred thousand people, <sup>60</sup> by 1928, fewer than 9,000 people had been sterilized in the United States. <sup>61</sup> Sterilization laws were more symbolic than effective. They were also the subject of legal battles at various levels of government. In some states, legislatures opposed the laws; in others, executives refused to enforce them; in still others, governors vetoed them; <sup>62</sup> and finally, in some, courts overturned the statutes as unconstitutional under the Fourteenth or Eighth Amendments. <sup>63</sup> As the constitutional challenges proved effective and the influx of immigrants dropped, the eugenics movement temporarily lost steam, and

<sup>55.</sup> KEVLES, *supra* note 9, at 100; Reilly, *supra* note 6, at 206. The first sterilization bill was introduced in 1897 to the Michigan legislature, but it did not come to a floor vote. *Id.* Pennsylvania's legislature went a step further in 1905 when it passed a bill authorizing involuntary legislation, but that bill was vetoed by the governor. *Id.* 

<sup>56.</sup> Reilly, *supra* note 6, at 207. By 1917, involuntary sterilization laws existed in fifteen states and in all regions except the South. KEVLES, *supra* note 9, at 100.

<sup>57.</sup> KEVLES, *supra* note 9, at 100. Iowa's statute was the most far reaching, requiring sterilization of individuals with such behaviors and conditions as "drug addiction, sexual offenses, and epilepsy." *Id.* 

<sup>58.</sup> *Id.* at 107-08. Of course, these views seemed to equate sterilization with castration. In fact, sterilization did not reduce sexual drive in men or women. *Id.* at 108; Reilly, *supra* note 6, at 206.

<sup>59.</sup> This link was hopelessly circular: "Immoral behavior was taken ipso facto as evidence of feeblemindedness, which in turn was claimed to produce immoral behavior." KEVLES, *supra* note 9, at 107.

<sup>60.</sup> Id. at 106-07.

<sup>61.</sup> Id. at 106.

<sup>62.</sup> *Id.* at 109. When vetoing the Pennsylvania sterilization bill, Governor Pennypacker remarked: "It is plain that the safest and most effective method of preventing procreation would be to cut off the heads of the inmates." *Id.* 

<sup>63.</sup> KEVLES, *supra* note 9, at 109; Reilly, *supra* note 6, at 207. By World War I, courts had found sterilization statutes unconstitutional in seven states. KEVLES, *supra* note 9, at 110. In New York, the constitutional challenge of its sterilization law revealed some disagreements among the eugenics experts regarding the best strategy to reduce retardation. Davenport testified that he favored segregation over sterilization, and another prominent eugenicist argued that sterilization should be voluntary. Reilly, *supra* note 6, at 207.

very little involuntary sterilization legislation was enacted around and during World War I.<sup>64</sup>

The hiatus was short-lived, however. The 1920s saw a stronger and more powerful eugenics movement. Prominent eugenicists were members of prestigious intellectual institutions, wealthy donors founded more eugenics organizations, and local eugenics organizations proliferated. Most important, however, were Harry Laughlin's efforts to revitalize sterilization laws. He not only published the highly influential *Eugenical Sterilization in the United States*, which demonstrated the societal benefits of the eugenics strategy, but he also drafted a model sterilization law to overcome the constitutional objections that had stymied previous sterilization laws. Finally, legislatures revisited the question of eugenic sterilization and enacted new laws, even in states where governors had vetoed prior attempts. Seventeen states had sterilization laws by 1926 and, in a few states, directors of state institutions allowed involuntary sterilizations for eugenics purposes even without statutory authority.

## C. Constitutional Challenge to Eugenics: Buck v. Bell

The constitutionality of eugenics sterilization was still at issue, however, even after the Michigan Supreme Court upheld a sterilization law against constitutional challenges in 1925.<sup>69</sup> Determined proponents of eugenics sterilization initiated a lawsuit in Virginia, *Buck v. Bell*, to test the constitutionality of Virginia's sterilization law, which had been carefully drafted to avoid many of the legal pitfalls of prior legislation.<sup>70</sup> The litiga-

- 64. KEVLES, supra note 9, at 110; Reilly, supra note 6, at 207.
- 65. Reilly, supra note 6, at 207.
- 66. The work became a "prized reference text among sterilization activists." Lombardo, *Pedigree*, *supra* note 10, at 279. Indeed, it was so highly respected in Nazi Germany that the University of Heidelberg awarded Laughlin an honorary degree in 1934. Reilly, *supra* note 6, at 207.
  - 67. Reilly, *supra* note 6, at 206-07.
  - 68. Id. at 208.
- 69. Smith v. Wayne, 231 Mich. 409, 415-16 (1925) (finding that the statute was "justified by the findings of biological science" and was a "proper and reasonable exercise of the police power of the state"); Reilly, *supra* note 6, at 207-08.
- 70. Dr. Priddy, the superintendent of the Virginia Colony for Epileptics and Feebleminded, relied on Laughlin's 1914 Model Sterilization Act in proposing the legislation that was enacted in Virginia. Lombardo, *Pedigree*, *supra* note 10, at 279. This legislation was one of several statutes that Dr. Priddy initiated in his efforts to rid society of the "blight of mankind" caused by the growing number of "feebleminded." Among the early statutes was one that allowed the superintendent of the Colony to provide "moral, medical and surgical treatment as [he] may deem proper," which he used to justify the sterilization of more than two dozen women. One patient brought an action for damages associated with her involuntary sterilization. Although Dr. Priddy received a jury verdict in

tion and reasoning of the courts in this infamous case vividly illustrate how deeply eugenic ideals had penetrated American culture.

Carrie Buck was chosen for the first sterilization under the new Virginia law because she was considered a classic example of a sexually immoral and mentally deficient individual accounted for by "hereditary qualities." Her putative life of "immorality, prostitution, and untruthfulness" and illegitimate pregnancy led her foster parents to institutionalize her at the Virginia Colony for Epileptics and Feebleminded. Not only was she deemed "socially inadequate' and 'the probable potential parent of socially inadequate offspring," but an IQ test also placed her at the intellectual level of a nine-year-old. In addition, her mother, who was also institutionalized, was considered equally morally deficient as was Carrie's illegitimate daughter of less than a year, who "showed backwardness."

When Carrie's guardian challenged the petition to sterilize Carrie, numerous eugenics experts and others testified in support of the heritability of Carrie Buck's "feeblemindedness." Laughlin testified in writing that Carrie's "family history . . . demonstrates the hereditary nature of the feeble-mindedness and moral delinquency described in Carrie Buck." With

his favor, after claiming the defense of therapeutic prerogative, the case highlighted "the importance of complying with every technical requirement of law," and likely inspired him to pursue legislation that specifically granted the power to perform involuntary sterilizations for eugenic purposes. Paul A. Lombardo, *Three Generations*, *No Imbeciles: New Light on Buck v. Bell, 60 N.Y.U. L. Rev. 30, 36-45 (1985) [hereinafter Lombardo, Three Generations].* 

- 71. Lombardo, Pedigree, supra note 10, at 280.
- 72. *Id*.
- 73. *Id.* (quoting Virginia Colony officials).
- 74. Carrie's mother had several illegitimate children, each with a different father; had a history of syphilis; and was thought to be a prostitute. *Id.* at 279-80.
- 75. KEVLES, *supra* note 9, at 110; Reilly, *supra* note 6, at 208; Cynkar, *supra* note 33, at 1418; Lombardo, *Pedigree*, *supra* note 10, at 278-80. Carrie's child, Vivian, was given a mental test at just six months and diagnosed by a sociologist and field worker from the Eugenics Record Office as "below the average." *Id.* Not surprisingly, psychologists criticized these field workers' amateur diagnoses of mental abilities as being based on improper testing simply to support their eugenic theories. *Id.* At one point, "the secretary of the local Red Cross pointed out to Dr. Priddy that Carrie's daughter had never undergone a psychiatric examination and that there was no evidence" she was in fact "feebleminded." Cynkar, *supra* note 33, at 1438.
- 76. One teacher spoke of Carrie's flirtatious behavior; a nurse described Carrie's infant daughter as having "a look about [her] that is not quite normal"; and other witnesses described Carrie and other members of her family as "peculiar." Lombardo, *Pedigree*, *supra* note 10, at 280.
- 77. Cynkar, *supra* note 33, at 1439. In fact, the pedigree was drawn from rather vague and scanty descriptions of Carrie and her family members. Moreover, Laughlin never

so much evidence supporting that Carrie would be a "potential source of [an] incalculable number" of "feeble-minded" descendants, the Circuit Court upheld the sterilization order, and the Virginia Supreme Court affirmed. The case ultimately reached the United States Supreme Court. Readily accepting the lower court's findings that Carrie Buck was "the probable potential parent of socially inadequate offspring," Justice Holmes infamously declared that "three generations of imbeciles are enough." In a remarkably short five-paragraph opinion, he held that the sterilization statute did not violate Carrie Buck's rights of due process and equal protection under the Fourteenth Amendment and upheld the lower court rulings. 81

Justice Holmes concluded that the procedural rights of patients under the statute "are most carefully considered." As to the substantive due

actually examined Carrie. *Id.* Nevertheless, the illegitimacy in Carrie's family was damning given that many eugenicists found a high correlation between illegitimacy and "feeblemindedness." Lombardo, *Pedigree*, *supra* note 10, at 280.

- 78. Cynkar, *supra* note 33, at 1439-40.
- 79. Buck v. Bell, 274 U.S. 200, 207 (1927).
- 80. Id.
- 81. Carrie Buck's attorney, I.P. Whitehead, raised a substantive due process claim, arguing that the statute violated her "constitutional right of 'bodily integrity" and that it deprived her of life without due process of law—which the Fourteenth Amendment protected by prohibiting "deprivation not only of life, but of whatever God has given to everyone with life." His equal protection argument rested on the fact that only the "feebleminded" individuals who were institutionalized were subject to involuntary sterilization, and that the state had no good justification for singling out this group, particularly since their segregation in institutions already achieved the objectives of preventing their procreation. Cynkar, *supra* note 33, at 1447.
- 82. Justice Holmes noted that the statute required (1) a petition to the "special board of directors of his hospital or colony, stating the facts and the grounds for [sterilization], verified by affidavit," (2) that the inmate, and his guardian be served notice "of the petition and of the time and place of the hearing in the institution, . . . and if there is no guardian the superintendent is to apply to the Circuit Court of the County to appoint one," (3) "that the inmate may attend the hearings if desired by him or his guardian," (4) that the evidence for the sterilization "be reduced to writing," (5) that any party may appeal to the Circuit Court of the County "after the board has made its order for or against the operation," and (6) that any party may apply to "the Supreme Court of Appeals, which, if it grants the appeal, is to hear the case upon the record of the trial in the Circuit Court and may enter such order as it thinks the Circuit Court should have entered." Buck, 274 U.S. at 206. He failed to note the procedural protections that are missing, such as the inmate's "right to an attorney and the right to subpoena and cross-examine witnesses, including experts who would be paid by the state to testify on behalf of the inmate." LORI B. AN-DREWS ET AL., TEACHER'S MANUAL TO ACCOMPANY GENETICS: ETHICS, LAW, AND POL-ICY 8 (2d ed. 2006). And of course, as Paul Lombardo has shown, the procedural protections in place did little to protect those like Carrie Buck, when there was "no true advo-

process claim, he declared that compulsory sterilization was no worse than drafting good men for war or compulsory vaccination to protect the public. Better, he concluded, to "prevent those who are manifestly unfit from continuing their kind" than to wait "to execute degenerate offspring for crime, or to let them starve for their imbecility." Finally, he summarily dispensed with the equal protection claim, concluding that the statute actually promoted equality by enabling "those who otherwise must be kept confined to be returned to the world." In short, Holmes was thoroughly persuaded by eugenic claims that "sterilization was the most humane way to deal with the feebleminded."

Buck v. Bell marks the pinnacle of legal legitimacy of compulsory sterilization and also represents much of what was wrong with eugenics, including the underlying racism and class biases, <sup>88</sup> reinforcement of social inequities, <sup>89</sup> and threats against democracy. <sup>90</sup> Although the movement enjoyed widespread support from various camps until the Second World War, there were notable critics <sup>91</sup> who voiced these concerns and others. A few religious leaders, especially those of the Catholic Church, objected

cate for the victim and no unbiased decision-maker." *Id.* (referring to Lombardo, *Three Generations*, *supra* note 70, at 50-55).

- 83. Buck, 274 U.S. at 207.
- 84. Id.
- 85. He did so almost snidely, remarking that such claims are the "usual last resort of constitutional arguments to point out shortcomings of this sort." *Id.* at 208.
  - 86. Id.
- 87. Cynkar, *supra* note 33, at 1450. Justice Holmes explicitly accepted the lower court's finding that sterilization was not detrimental to Carrie Buck's health and would actually promote her and society's welfare. *Buck*, 274 U.S. at 207.
- 88. KEVLES, *supra* note 9, at 121; PAUL, *supra* note 42, at 11; Garland E. Allen, *Is a New Eugenics Afoot?*, 294 SCI. 59, 61 (2001) (noting that one critic, for example, "claimed that eugenics was racism disguised as science"); Jennifer Geetter, *Coding for Change: The Power of the Human Genome to Transform the American Health Insurance System*, 28 AM. J.L. & MED. 1, 20 (2002).
- 89. MARK H. HALLER, EUGENICS 89 (1984) (stating that one of the main critics on these grounds "feared the belief in innate class differences, since such a belief often excused inequalities between the classes and thwarted efforts to extend protection and opportunities to individuals in the poorer classes"); KEVLES, *supra* note 9, at 121 ("In the impassioned view of many dissidents, to rank the merits of the national germ plasm of the future ahead of the human needs of the socially disadvantaged in the present seemed morally outrageous.").
- 90. KEVLES, *supra* note 9, at 120 ("Various critics pointed to the mainline eugenic movement's distrust of democracy, to its claims that men were not created equal even in political right, to its threat to establish some sort of caste system of government.").
- 91. PAUL, HEREDITY *supra* note 42, at 11-12 (noting, however, that some of the "harsh critics of the eugenics movement often shared some of its assumptions").

that eugenics threatened human dignity by commodifying and restricting reproduction. 92

The most common criticism was eugenics' reliance on erroneous and oversimplified scientific notions and careless, often false, characterizations of individuals based on class, education, and status. <sup>93</sup> Carrie Buck, for example, the "ideal" candidate for eugenic sterilization, was in fact neither an imbecile nor immoral, as Paul Lombardo has shown. Her attorney could easily have countered the state's evidence of her "feeblemindedness," had he chosen to be a true advocate for her. <sup>94</sup> Carrie's school re-

<sup>92.</sup> See HARRY BRUINIUS, BETTER FOR ALL THE WORLD: THE SECRET HISTORY OF FORCED STERILIZATION AND AMERICA'S QUEST FOR RACIAL PURITY 230 (2006) ("[Catholics] insisted on the essential spiritual dignity of every human individual. [T]he physical attributes of mankind . . . were still subject to an immutable 'natural law' governed by the laws of God . . . Marriage and bringing forth children were considered sacred rights or even duties . . . ."); Kevles, supra note 9, at 119 ("The Church stressed the role of love and religious ethics, rather than parental perfection of physique and intelligence, in producing offspring with eugenic qualities."); Christine Rosen, Preaching Eugenics: Religious Leaders and the American Eugenics Movement 140 (2004) ("Catholic interpretation of natural law . . . stresses the dignity of the individual.").

<sup>93.</sup> See KEVLES, supra note 9, at 121-22 (noting that "for most scientists, much of what passed as eugenic research was slipshod in method, evidence, and reasoning" and a form of biological reductionism); NANCY ORDOVER, AMERICAN EUGENICS: RACE, QUEER ANATOMY AND THE SCIENCE OF NATIONALISM 230 n.103 (2003) (describing one who defected from the American Eugenics Society because of Laughlin's dismally "skewed statistics"); Allen, supra note 88, at 64 (noting the criticisms regarding poor data collection and "the failure of eugenicists to define traits like feeblemindedness or criminality"); Geetter, supra note 88, at 19-21 (2002) (noting critics' concerns that eugenics privileged heredity over environment, and their belief that "society largely made people bad, rather than heredity"). Nevertheless, "[n]early all geneticists of the 1920s and 1930s—including those traditionally characterized as opponents of eugenics—took for granted that the "feebleminded" should be prevented from breeding." DIANE B. PAUL, Did Eugenics Rest on an Elementary Mistake?, in THE POLITICS OF HEREDITY 127 (1998) [hereinafter PAUL, POLITICS]. It was not until the late 1920s or 1930s that the scientific criticisms really began to mount. ANGELIQUE RICHARDSON, LOVE AND EUGENICS IN THE LATE NINETEENTH CENTURY: RATIONAL REPRODUCTION AND THE NEW WOMAN 222-23 (2003); Allen, supra note 88, at 59.

<sup>94.</sup> Carrie's attorney was "an ineffective and unenthusiastic defender of his client's interests." Elliott A. Brown, *Case Histories, Interest Group Litigation, and Mr. Justice Holmes: Some Unexplored Questions on Psycho-Political Behavior*, 24 EMORY L.J. 1037, 1049-50 (1975). He challenged the State's attempt to use surgical sterilization, but conceded that "the State has the right to segregate the feebleminded and thereby deprive them of the 'power to procreate.'" Cynkar, *supra* note 33, at 1448. He failed to challenge the alleged social utility of limiting the procreation of the "feebleminded," the power of the state to pursue eugenic goals, and the underlying "scientific' theories." *Id.* Moreover, he failed to bring forward any witnesses to challenge the assertions regarding Carrie Buck, which ultimately proved false. Lombardo, *Three Generations, supra* note 70, at 51.

cords indicated that she was a normal child promoted to sixth grade in five years, and a teacher commented that she was "very good—deportment and lessons." Later in life, she was an avid reader who "regularly displayed intelligence and kindness that belied the 'feeblemindedness' and 'immorality' that was used as an excuse to sterilize her." Moreover, her illegitimate pregnancy, which resulted in her institutionalization and "evidenced" her moral impropriety and "feeblemindedness," was probably the result of rape by her foster mother's nephew. <sup>97</sup>

Although *Buck v. Bell* was based on shoddy science, shoddy advocacy, and a shoddy investigation into the true state of Carrie Buck's life and health, it was a milestone for eugenics policymaking, laying to rest any constitutional concerns surrounding sterilization statutes. By 1931, four years after *Buck* was decided, 28 states had eugenic sterilization laws, which they then implemented vigorously. For over a decade, the nation sterilized roughly 2,500 to 3,000 individuals a year. America had reached the pinnacle of its eugenics efforts.

## D. World War II and the Decline of Eugenics

Inspired by the dominance of American eugenicists in their legislative and research efforts, other countries soon followed suit. Germany's program of "Racial Hygiene" and sterilization ultimately dwarfed the eugenic efforts of the United States and others. In 1933, Germany enacted a comprehensive eugenic sterilization act, which created a system of Hereditary Health Courts with authority to sterilize the unfit. The act originally targeted those with a "great probability" of passing on "feeblemindedness," mental illness, and various disabilities and diseases. Eventually, the law included non-Germans and many others on the "weakest of pre-

In fact, Lombardo has suggested that the behavior of Carrie's attorney "suggests a deliberate decision not to defend Carrie." *Id.* 

97. Id. at 52-54, 60-61.

<sup>95.</sup> Lombardo, Three Generations, supra note 70, at 52.

<sup>96.</sup> Id. at 61.

<sup>98.</sup> One year the total reached nearly 4,000; and as late as 1940, a reported 2,800 sterilizations took place. Reilly, *supra* note 6, at 208.

<sup>99.</sup> BLACK, *supra* note 54, at 258, 262-77 (2003). Many European countries—including Germany, Norway, Sweden, and Finland—enacted sterilization laws. Reilly, *supra* note 6, at 210.

<sup>100.</sup> Germany, like many other countries, did not start immediately with sterilization but first employed other eugenics efforts, such as legislating against sexual relations between Aryans and Jews; creating marriage advice clinics; and instituting the positive-eugenics Lebensborn programs, which encouraged ideal Aryans to procreate by providing extra public benefits. Reilly, *supra* note 6, at 210; Wikler, *supra* note 2, at 185-86.

<sup>101.</sup> Reilly, supra note 6, at 210.

tenses," including being half-Jewish. It is estimated that the Nazi programs sterilized 3.5 million individuals. In 1939, the Third Reich went far beyond sterilization, implementing euthanasia to eliminate the mentally diseased, the disabled, and the Jews. Roughly 70,000 patients were selected for euthanasia, including tens of thousands of "Aryans," most of whom were young children. Ultimately, the Germans would expand their eugenics program into the Holocaust, which took the lives of roughly 11 million individuals.

The World War II era reflects both the extremes of eugenics and the beginning of its end. When Germany lost the war, its eugenics efforts necessarily stopped. Around that time, eugenics also fell out of fashion in the United States. Most believe that its demise was primarily due to "universal revulsion" of the Nazi version of eugenics. <sup>105</sup> Some argue instead that it

103. KEVLES, supra note 9, at 118; Wikler, supra note 2, at 185. It is humbling to note that in England and the United States, the eugenics community seriously debated and considered euthanasia. Although ultimately unsuccessful, some lawmakers proposed legislation giving physicians the authority to euthanize mentally retarded and permanently diseased individuals. Euthanasia was considered by Laughlin and others at the Eugenics Section of the American Breeders Association as the eighth of nine eugenic options. As one eugenicist wrote, "[h]eredity is the fundamental cause of human wretchedness. The surest, the simplest, the kindest, and most humane means for preventing reproduction among those whom we deem unworthy of this high privilege [reproduction], is a gentle, painless death." Cynkar, supra note 33, at 1429. Davenport himself argued in defense of a physician who publicized his euthanasia of infants with birth defects, writing, "If the progress of surgery is to be used to the detriment of the race . . . [i]t may conceivably destroy the race. Shortsighted they who would unduly restrict the operation of what is one of Nature's greatest racial blessings—death." BLACK, supra note 54, at 247-56 (quoting W. DUNCAN MCKIM, HEREDITY AND HUMAN PROGRESS 120 (1900)). Propaganda in favor of eugenic euthanasia resulted in a successful film called THE BLACK STORK, in which a woman who is counseled against having children for eugenic reasons gives birth to a defective child who is allowed to die and ends up in the welcoming arms of Jesus Christ. Id. at 257-58; see also MARIN S. PERNICK, THE BLACK STORK: EUGENICS AND THE DEATH OF "DEFECTIVE" BABIES IN AMERICAN MEDICINE AND MOTION PIC-TURES SINCE 1915 (1996).

104. MICHAEL BERENBAUM, *The Uniqueness and Universality of the Holocaust, in A Mosaic of Victims: Non-Jews Persecuted and Murdered by the Nazis 20 (Michael Berenbaum ed., 1990) (describing the Holocaust as "the systematic murder of eleven million people, six million of whom were Jews . . . and five million of whom were non-Jews").* 

105. KEVLES, *supra* note 9, at 251 ("[The] Holocaust had all but buried the eugenic ideal. After the Second World War, 'eugenics' became a word to be hedged with caveats in Britain and virtually a dirty word in the United States, where it had long been identified with racism."); Beckwith, *supra* note 17, at 329. In 1954, the *Annals of Eugenics* was

<sup>102.</sup> Within a year of the law's enactment, the courts approved two-thirds of the 84,500 petitions for sterilization. By the next year, the number sterilized nearly tripled. Id

was due to a shortage of nurses and surgeons available to perform the sterilizations. <sup>106</sup> In addition, the maturation of genetics revealed that eugenic explanations of complex traits were "at best quaint and at worst dangerous." <sup>107</sup> Nonetheless, eugenics programs did not completely die for several decades—eugenic sterilizations continued until the 1970s and perhaps early 1980s. <sup>108</sup> Even now, only a handful of states have repealed their eugenics sterilization laws, although the programs are inactive in those states that still retain such legislation. In Europe, countries no longer provide legal authority for involuntary sterilizations and some countries actively prohibit them. <sup>109</sup> Today, in the United States and Europe, at least, most would argue that classic eugenics has come to an end. <sup>110</sup>

#### III. PROPHYLAXIS AGAINST CLASSIC EUGENICS

While most argue that the classic eugenics movement met its demise in the mid-1930s and '40s or later, <sup>111</sup> some suggest that eugenics never died, but merely transformed itself. <sup>112</sup> If some form of eugenics exists or is

renamed the *Annals of Human Genetics*, reflecting the attempts among geneticists to distance the science of genetics from eugenics. KEVLES, *supra* note 9, at 251-52.

- 106. Reilly, *supra* note 6, at 210.
- 107. *Id.* at 211.
- 108. In the 1950s, Georgia, North Carolina, and Virginia performed one-half to three-quarters of the nation's involuntary sterilizations. In 1958 alone, these three states performed nearly 600 such surgeries. In the early 1970s, North Carolina performed more than twenty sterilizations under its eugenics statute. Reilly, *supra* note 6, at 211 ("Although one cannot point to a moment in which state-sanctioned eugenical sterilization in the United States ended, a satisfactory date is 1983 when a class-action lawsuit brought by women in Virginia who had been sterilized without their consent while in state facilities was settled.").
  - 109. Id. at 212.
- 110. Existing programs and legislation in some Asian countries could be described as eugenic. For example, China's Maternal and Infant Health Care Law enacted in 1994 requires medical counseling for the marriage of people with relatives who have such conditions as mental retardation, epilepsy, and mental illness. In addition, some of the language suggests that sterilization or long-term contraception is required for individuals to marry if they are at risk of having children with those conditions. Reilly, *supra* note 6, at 213; *see China's 'Eugenics' Law Still Disturbing Despite Relabelling*, NATURE, Aug. 20, 1998, at 707; Dennis Normile, *Geneticists Debate Eugenics and China's Infant Health Law*, 281 Sci. 1118 (1998); Jack Kim, *North Korea Tied to Baby Deaths*, WASH. TIMES, Mar. 23, 2006, at 14 (describing the lack of people with physical disabilities in North Korea because "they are killed almost as soon as they are born").
- 111. Lene Koch, The Meaning of Eugenics: Reflections on the Government of Genetic Knowledge in the Past and the Present, 17 SCI. IN CONTEXT 315, 317 (2004).
- 112. See, e.g., Wendy Kline, Building a Better Race: Gender, Sexuality and Eugenics From the Turn of the Century to the Baby Boom (2001) (arguing that

possible today, one thing is clear—it is not precisely the same kind of eugenics as that of the twentieth century. Many of the features that marked "classic" eugenics are now absent in the United States. "Fitter family" competitions no longer exist; individuals are no longer diagnosed as "feebleminded" or segregated and institutionalized on that basis; the Immigration Restriction Act of 1924 and anti-miscegenation laws were repealed;<sup>113</sup> the Eugenics Records Office, home of many of the eugenic theories and policy work, officially closed in 1939; 114 and, most importantly, statewide programs of involuntary sterilization and "euthanasia" of the unfit no longer exist. Indeed, in some states, governors have formally apologized to the victims of eugenics. 115 Moreover, developments within the field of genetics and genetic counseling, bioethical norms, and modern legal protections of reproductive rights act as a prophylaxis against some of the most troubling features of classical eugenics. These developments would have likely protected the Carrie Bucks of the past from the law's indifference to their reproductive rights, the medical profession's indifference to their ability to make informed and personal medical decisions, and the scientific community's indifference to their true intellectual and medical status.

As human genetics evolved into a legitimate discipline, geneticists began to distance themselves from the wildly over-simplistic, racially biased, and sweeping claims that marked the eugenics movement. Advancements in genetics ultimately debunked the "science" of classic eugenics by revealing the complexities of inheritance and the multifactorial components of traits and even disease. The science of the eugenics era was

eugenicists shifted their tactics from a focus on heredity to a focus on the home environment of children and, with this shift in focus, embarked on a form of "positive" eugenics where the fit were encouraged to procreate, contributing to the baby boom of the 1950s).

<sup>113.</sup> Jones, *supra* note 2, at 215 n.140 (Immigration Act of 1924, ch. 190, 43 Stat. 153 (repealed 1952)); Resta, *supra* note 37, at 231 (describing repeal of antimiscegenation laws in the 1960s).

<sup>114.</sup> Resta, *supra* note 37, at 233.

<sup>115.</sup> See Michael G. Silver, Eugenics and Compulsory Sterilization Laws: Providing Redress for the Victims of a Shameful Era in United States History, 72 GEO. WASH. L. REV. 862, 886-88 (describing the apologies of governors in Virginia, North Carolina, Oregon, South Carolina, and California).

<sup>116.</sup> But see KEVLES, supra note 9, at 259-68 (describing lingering attitudes in favor of positive eugenics among some scientists); Resta, supra note 37, at 232-33 (noting that the geneticists rejected eugenics "slowly and not as completely as some authors have suggested").

<sup>117.</sup> Evidence suggests that some of the pedigrees of dysgenic families, intended to prove the eugenic theories about the inheritance of unfit traits, were manipulated consciously and unconsciously. Resta, *supra* note 37, at 230.

shoddy and careless, and many of its strongest proponents were non-scientists with only a slim grasp of genetics. As Troy Duster writes, "[t]hose on the fringe of genetics and biology commonly preached the gospel of eugenics, magically converting spurious correlations into causation, and subsequently into social policy." Even the scientists were careless and inaccurate in collecting and interpreting data and in reaching conclusions, often reducing complicated patterns of inheritance into simple Mendelian patterns. <sup>119</sup>

Carrie Buck's case is a prime example. Treating her merely as a pawn in his social agenda, Laughlin tried to "construct a 'precise' psychological and genealogical analysis of Carrie Buck that would stand up in a court of law" without bothering to examine her or to collect careful data about her or her family. While diagnoses are still not always perfect, it would be rare to find physicians making such reckless diagnoses today. In part, this is because modern genetic claims, though surely to be revised as we learn more in the future, are based on more accurate clinical evaluations and molecular analysis. In short, genetics is not only more advanced today—it is more careful and rigorous than the "science" of eugenics. 121

As genetics grew more sophisticated, the focus turned away from social reform to biochemical understandings and prevention of genetic disease. Whereas eugenics was in many ways separate from medicine, 123

- 118. Troy Duster, Backdoor to Eugenics xii (2003).
- 119. See supra text accompanying notes 24-29.
- 120. Cynkar, supra note 33, at 1439; see supra note 75.
- 121. DUSTER, *supra* note 118, at xii. Duster writes:

  [T]he old eugenics movement was not based upon any demonstrable successful intervention by medicine or science into human genetic affairs. The current technology is both eminently successful in its predictive power, and potent in extending its impact to such concerns as the prenatal detection of human birth defects, and the application of growth hormones from gene-splicing techniques with recombinant DNA...

  [T]he new genetics technology is more immediate in its promise: the mitigation of problems (birth defects, mental illness, nutritional deficiency) not the creation or sustenance of discredited claims of racial superiority or purity.

Id.

122. KEVLES, *supra* note 9, at 251-53; Seymour Kessler, *The Psychological Paradigm Shift in Genetic Counseling*, 27 Soc. Bio. 167, 168 (1980).

123. The pioneer genetic counselors tended to be non-medical geneticists or non-practicing physicians, who brought about legislation to require sterilization of some mentally handicapped people. They focused on societal, rather than individual, concerns. Kessler, *supra* note 122, at 168; *see also* Dorothy Wertz, *Eugenics and Genetics*, GENE-LETTER, Feb. 1999, *available at* http://www.genesage.com/professionals/gene letter/archives/eugenicsdefinitions.html. Wertz writes:

the new human genetics found a legitimate home within medicine by the middle of the twentieth century. 124 The science of heredity was no longer primarily a tool for social and legislative reform, indifferent to the plight of individuals like Carrie Buck; it was now a tool within medicine used for individuals' benefit. As human genetics entered the medical community, a new field of "genetic counseling" emerged. 125 In its infancy, genetic counseling was described as "genetic hygiene" or even "eugenic," but its "new, improved" eugenics philosophy emphasized "individual idealism regarding future generations," with some genetic counselors withdrawing their support from the eugenics movement altogether. 128 Others did "not oppose eugenics, per se," but opposed the particular methods of "traditional eugenicists." To distance themselves from the "more pretentious eugenic suggestions," and many of these early genetic counselors strongly objected to compulsory sterilization and urged voluntary compliance from affected individuals. In addition, they tried to provide "informed, sympathetic counseling" for people with genetic risks who faced reproductive decisions. 131

For some time, genetic counselors were often explicitly directive, which is to say they were prescriptive about patients' medical options. <sup>132</sup> In the new medical setting, many features of the doctor-patient relationship temporarily became a part of genetic counseling. The genetic coun-

The leaders of eugenic thought in the 19th and 20th centuries were a mixed lot, including socialists and conservatives, philosophers (John Stuart Mill and Bertrand Russell), feminists, birth control crusaders (Margaret Sanger), psychologists, behavioral scientists, politicians, and even playwright George Bernard Shaw. Few were physicians or geneticists, who were mostly concerned with their patients or their research, rather than with improving society.

Id. See also Anne Kerr & Tom Shakespeare, Genetic Politics: From Eugenics to Genome 11 (2002) (describing "a general disinterest in eugenics amongst the medical profession"); Kevles, *supra* note 9, at 332 n.36 ("Predominantly laymen, eugenic activists were usually so much more concerned with propaganda than with knowledge that even pro-eugenic scientists found the situation an embarrassment.").

- 124. KEVLES, supra note 9, at 253.
- 125. Ian H. Porter, *Evolution of Genetic Counseling in America*, in GENETIC COUNSELING 26 (Herbert A. Lubs & Felix de la Cruz eds., 1977); Sheldon C. Reed, *A Short History of Genetic Counseling*, 21 Soc. Bio. 332, 334-35 (1974).
  - 126. KEVLES, supra note 9, at 253.
  - 127. Koch, *supra* note 111, at 317.
  - 128. Kessler, *supra* note 122, at 168.
  - 129. Resta, supra note 37, at 233.
  - 130. Porter, *supra* note 125, at 24.
  - 131. *Id.* at 23-24.
  - 132. Koch, *supra* note 111, at 317.

selor was seen as educator and advisor, and the counselees were expected to comply with the counselor's recommendations. With the growing sense of "individual idealism," however, genetic counselors adopted a non-directive style 134 in which the counselor (usually a physician) did not have ultimate control over the client. Non-directiveness markedly contrasts with the norms of eugenicists, who were directive, controlling, and completely indifferent to the choices of young women like Carrie Buck. Under non-directiveness, the medical professional is expected to remain neutral as to an individual's ultimate decisions, because genetic counselors strongly believe such decisions are for the patient and no one else to make.

The commitment to non-directiveness grew as more non-physician genetic counselors entered the profession. Genetic counselors realized that preventive goals were no longer realistic. Moreover, they recognized that genetic information could evoke strong emotional responses and have potential long-term effects on the individual and family. Social and cultural changes were perhaps equally important. Our culture was becoming increasingly uncomfortable making moral judgments about others, adopting a "language of therapy" to respond to issues that once would have been included in moral discourse. Thus, the psychological-paradigm for genetic counselors mirrored cultural changes, emphasizing the need to help patients reach decisions in a non-judgmental, supportive manner—again, in sharp contrast to eugenics.

<sup>133.</sup> Kessler, *supra* note 122, at 168.

<sup>134.</sup> *Id*.

<sup>135.</sup> One key difference between the counselor-counselee and the typical physician-patient relationship was that the counselee was usually not a "patient." That is, she did not require treatment or therapy but rather education about her reproductive options. *Id.* at 169. Conflicting perspectives regarding the professional's role created a tension that somewhat remains even today as to how directive genetic counselors should be. The tension is greatest among geneticists who were trained under the more traditional medical model. A commentator explains: "One traditional principle of genetic counseling is the neutrality of the counselor in decisions about reproduction. This is unusual in medical practice, and is a difficult attitude for many physicians to adopt . . . ." Porter, *supra* note 125, at 24-25.

<sup>136.</sup> These attitudes lasted until at least the late 1930s. CARLSON, *supra* note 3, at 202-15 (describing the debate among physicians regarding compulsory sterilization, which focused on societal effects with no discussion of patient choice except to describe cases where the patient him or herself urgently wanted the procedure).

<sup>137.</sup> Kessler, *supra* note 122, at 169-70.

<sup>138.</sup> I thank Professor Carl Schneider of the University of Michigan Law School for these insights.

The bioethics movement has been an additional antidote to eugenics. The movement, which emerged in the early 1970s, <sup>139</sup> reflects an "unqualified" commitment to individual rights and autonomy. <sup>140</sup> In both theoretical and practical ways, it has altered the relationship between doctor and patient, emphasizing the central role of the patient in medical decision making and rejecting the stark paternalism of the eugenics era. Indeed, this deep commitment to patient autonomy has been a driving force behind the principle of non-directiveness among genetic counselors and the efforts not to force or direct reproductive decision making. <sup>141</sup>

A related development in the law and bioethics, which perhaps offers the greatest protections against some of the eugenic measures of the twentieth century, is the recognition of individual interests in procreative autonomy. Roe v. Wade<sup>142</sup> and Planned Parenthood of Southeastern Pennsylvania v. Casey, while failing to overturn the holding of Buck v. Bell, 144 reflect a very different attitude toward reproductive interests. Jus-

<sup>139.</sup> DAVID J. ROTHMAN, STRANGERS AT THE BEDSIDE 193 (1991). Within only a few years, the movement had gained "a vitality and a standing that were in every way remarkable." *Id.* at 241.

<sup>140.</sup> So great is this focus, that some have criticized the movement for overvaluing individualism at the expense of other social values. *Id.* at 243.

<sup>141.</sup> The growing number of genetic associates is an additional force behind the norm of non-directiveness. This group of professionals tends to consist mostly of welleducated, bright women, who are committed to patient autonomy and individual rights and who are not trained within the traditional medical model. In fact, many find that model offensive and degrading to the client. They therefore work hard to resist the paternalism and directiveness of traditional medicine. Genetic associates have played a significant role in reinforcing non-directiveness for additional reasons. Because their profession is relatively new, genetic counselors have had to make a place for themselves in the hierarchical medical world. In some situations, genetic associates have felt physicians curtail their opportunity to practice the counseling for which they have been trained. CHARLES L. BOSK, ALL GOD'S MISTAKES: GENETIC COUNSELING IN A PEDIATRIC HOSPI-TAL 24 (1992) (describing a genetic associate's frustration with her limited opportunities to provide genetic counseling). This conflict allies many genetic associates with patients in a struggle to overcome the physician's attachment to control over medical decision making. Consequently, it may have heightened genetic counselors' dedication to nondirectiveness.

<sup>142. 410</sup> U.S. 113 (1973).

<sup>143. 505</sup> U.S. 833 (1992).

<sup>144.</sup> In fact, *Roe* cites *Buck* as authority for the notion that reproductive rights are not unlimited, as follows:

<sup>[</sup>I]t is not clear to us that the claim asserted by some amici that one has an unlimited right to do with one's body as one pleases bears a close relationship to the right of privacy previously articulated in the Court's decisions. The Court has refused to recognize an unlimited right of this

tice Holmes, in *Buck v. Bell*, claimed to be concerned with due process protections with respect to procreation, but he was ultimately only concerned with procedural due process. <sup>145</sup> In contrast, *Roe* and *Casey* rely on theories of substantive due process that align procreative decision making with other decisions "central to personal dignity and autonomy, [and] central to the liberty protected by the Fourteenth Amendment," <sup>146</sup> such as decisions relating to child rearing and marriage. These rights have been internalized within a substantial portion of our culture and strongly reinforce non-directive norms and the notion that reproductive decisions are the individual's to make without interference from medical or other authority. <sup>147</sup>

#### IV. TOWARD NEOEUGENICS

With these developments in science, bioethics, and the law, it would seem that we are safely removed from the norms and attitudes of the eugenics movement. Yet, some claim that prenatal genetic testing and future genetic technologies are a "backdoor to eugenics," achieving the same goals of "good birth" (albeit at the individual, rather than state, level). In Sections IV.A and IV.B below, I argue that contemporary attitudes, combined with current and evolving technologies, drive us towards Galton's utopia: a new form of eugenics, or "neoeugenics"—a voluntary "improvement" of the human species at the individual level. Galton never supported compulsory sterilization; he believed that an educated and enlightened public would make the "right"—i.e., eugenic—reproductive decisions. As we shall see, the underlying goal of eugenics—improving

kind in the past. Jacobson v. Massachusetts, 197 U.S. 11 (1905) (vaccination); Buck, 274 U.S. 200 (1927) (sterilization).

Roe, 410 U.S. at 153-54.

145. *See supra* text accompanying notes 79-87 (describing how Justice Holmes gave substantive due process short shrift).

146. Casey, 505 U.S. at 851.

147. Most genetic counselors are advocates of their counselees' "right to choose and decide about [their] reproductive destin[ies]." Kessler, *supra* note 122, at 169.

148. DUSTER, *supra* note 118, at 114-15; *see also* Angus Clarke, *Is Non-Directive Genetic Counselling Possible?*, 338 LANCET 998, 1000 (1991) (contending that "an offer of prenatal diagnosis implies a recommendation to accept that offer, which in turn entails a tacit recommendation to terminate a pregnancy if it is found to show any abnormality"); Resta, *supra* note 37, at 240.

149. See supra text accompanying notes 32-34. Just under 40 years ago, Robert Sinsheimer, a molecular biologist at the California Institute of Technology, "argued that freedom of choice would vindicate the new genetics, and set it apart from the discredited eugenics of old." Michael J. Sandel, *The Case Against Perfection*, ATLANTIC MONTHLY, Apr. 2004, at 62. The "new eugenics would be voluntary rather than coerced, and also

reproduction—can exist with or without state mandate. In Section IV.C, I then compare old and new eugenics and argue that the differences between some attitudes of the eugenics era and our contemporary culture are not as dramatic as people often describe.

My claims in Part IV are largely descriptive. Given that legal, medical, and cultural developments have greatly enhanced autonomy with respect to reproductive decisions, our concerns regarding eugenics are arguably over. In Part V, I contend that these protective norms are grounded in a Kantian, libertarian conception of autonomy, which serves as a powerful weapon against government and medical tyranny. Nevertheless, these developments may be inadequate to deal with other problematic aspects of eugenics and neoeugenics. Thus, Part V also offers a contextual and relational conception of autonomy through which to evaluate whether we have really eradicated all of the concerns surrounding eugenics. It concludes that motivations, intentions, and responses to eugenic efforts are central to evaluating the moral propriety of eugenics. The mere fact that something appears eugenic-like cannot alone be grounds for condemnation. Instead, certain cultural and individual norms and attitudes are what make some reproductive practices problematic.

# A. Prenatal Testing and Current Genetic Reproductive Technologies

Since the mid-1970s, families have been able to use prenatal testing to select against various genetic and chromosomal diseases and other birth defects. Numerous pressures have made diagnostic tests like amniocentesis and chorionic villus testing, as well as ever-improving prenatal screening tests, <sup>150</sup> a routine part of pregnancy. <sup>151</sup> Although decisions to undergo prenatal testing are voluntary, "they still take place within a normative context favoring prophylaxis . . ." <sup>152</sup> Perhaps the greatest social pressure is

more humane. Rather than segregating and eliminating the unfit, it would improve them." *Id.* at 50.

<sup>150.</sup> See, e.g., Rob Stein, Down Syndrome Now Detectable in 1st Trimester, WASH. POST, Nov. 10, 2005, at A1 (describing the results of a study of more than 38,000 women who underwent a new, first-trimester, prenatal screening test for Down syndrome, which allows "women to decide sooner whether to undergo the riskier follow-up testing needed to confirm the diagnosis").

<sup>151.</sup> See Sonia M. Suter, The Routinization of Prenatal Testing, 28 AM. J.L. & MED. 233, 235 (2002) [hereinafter Suter, Routinization]. The American College of Obstetricians and Gynecologists recently issued new practice guidelines advising that "[a]ll pregnant women, regardless of their age, should be offered screening for Down syndrome in their first trimester." Thomas H. Maugh II, Down Syndrome Screening Advised for All Pregnancies, L.A. TIMES, Dec. 31, 2006, at A19.

<sup>152.</sup> Koch, supra note 111, at 324.

the view that one should undergo prenatal testing and screening because it is in the best interests of one's future child.<sup>153</sup> This view is prevalent because testing is presented as "treatment" or "doing what's best," when of course such treatment merely "prevents disease" by preventing the existence of someone with the disease.<sup>154</sup> Thus, some undergo testing because of a mistaken belief that it offers the possibility of true treatment.<sup>155</sup> Others think that good parenting requires one to prevent future suffering in a child with a genetic condition by terminating the pregnancy.<sup>156</sup> Some pa-

155. Suter, *Routinization*, *supra* note 151, at 247. That article notes:

Some pregnancy books present information about amniocentesis in a manner that suggests it protects the fetus. *Your Pregnancy Week by Week* discusses amniocentesis in a section of the chapter entitled "How Your Actions Affect Your Baby's Development." This same section heading is used in other chapters to discuss the harmful effects of smoking and alcohol consumption. In describing amniocentesis under such a heading, the book suggests that prenatal testing "constitutes maternal *good* behavior." *What to Expect When You're Expecting* places a boxed insert entitled "Reducing the Risk in Any Pregnancy," which includes advice on such things as smoking, alcohol and weight gain, in the middle of its discussion of amniocentesis.

*Id.* (citing Helena Michie & Naomi R. Cahn, Confinements: Fertility and Infertility in Contemporary Culture 84 (1997) (describing this approach as creating the "completely unsupported inference . . . that genetic disorders can be prevented by behavioral changes.")).

156. See Michael J. Malinowski, Coming Into Being: Law, Ethics, and the Practice of Prenatal Genetic Screening, 45 HASTINGS L.J. 1435, 1472-74 (1994) (describing a couple's decision to terminate a pregnancy because they "could [not] watch a child suffer through life"); Suter, Routinization, supra note 151, at 247-48. Perhaps equally important is the parents' desire to prevent the suffering they themselves might experience in watching a child endure a serious disability.

<sup>153.</sup> Whether the goal is to remove a genetic defect or enhance a male child's ultimate height from 5'3" to 6'3", the parents are usually motivated by what will be in the best interests of the child. Robert Wachbroit, *What is Wrong with Eugenics?*, *in* ETHICAL ISSUES IN SCIENTIFIC RESEARCH: AN ANTHOLOGY 331 (Edward Erwin et al. eds., 1994) ("[A]ny property that is a plausible candidate for eugenics is one that prospective parents reasonably believe confers an advantage to the child. Any advocacy of eugenics will start with that thought.").

<sup>154.</sup> Suter, *Routinization*, *supra* note 151, at 247-48 (discussing that patients and popular pregnancy books often cast prenatal testing as "doing what's best" for the fetus or future child rather than as an effort to "select the best child"); Elizabeth Weil, *A Wrongful Birth*, N.Y. TIMES MAG., Mar. 12, 2006, at 51 ("[Prenatal testing] is not a medical procedure to promote the health of the fetus. It is a procedure to give prospective parents information to decide whether or not to eliminate a possible future life." (quoting Professor Adrienne Asch)).

tients and physicians believe parents have an obligation to prevent the birth of children with even minor birth defects. 157

In addition, the economic, psychological, and social difficulties of caring for a child with multiple or serious birth defects or diseases may lead families to pursue prenatal testing to select against unhealthy children. For some, a largely unspoken motivation is discomfort with disabilities and imperfections. In addition, social norms that view the "gathering of

157. See Andrea Kalfoglou et al., Washington, DC: Genetics and Public Policy Center, Reproductive Genetic Testing: What America Thinks 14 (2004) (discussing public opinion surveys, which found that 51.5% of respondents agreed or strongly agreed that "parents ought to do everything technologically possible to prevent their child from suffering including using reproductive genetic technologies"). As an example:

When a television anchorwoman with ectrodactyly—a mild genetic condition that fused the bones of her hands—chose to continue a pregnancy with a fetus that inherited the condition, many accused her of being immoral or irresponsible. Even healthcare professionals sometimes blame women for the birth of a child with a genetic condition, particularly if the woman refused testing.

Suter, *Routinization*, *supra* note 151, at 248 (citing Lori B. Andrews, *Prenatal Screening and the Culture of Motherhood*, 47 HASTINGS L.J. 967, 981-82 (1996) [hereinafter Andrews, *Prenatal Screening*]).

158. But see Weil, supra note 154, at 52-53 (describing studies that "have shown that the raising of children with impairments is on the whole a lot less difficult and a lot less different from raising so-called normal kids than we imagine it will be"); id. at 53 ("Families with severely impaired children do not differ significantly in stresses and burdens from families with normal children . . . . A child prodigy can have just as much impact on a family as a child with cystic fibrosis or Down." (quoting Professor David Wasserman)). However, in response to Weil's article, several readers wrote to express their disagreement with the idea that the stress of raising severely disabled children is comparable to that of raising normal children, asserting that families with severely disabled children do face greater difficulties and burdens. One letter read:

Parents of children with severe disabilities must provide round-theclock supervision and care. Then there's the enormous cost of specialized medical equipment and supplies, and the heartache of constant medical crises and setbacks. Parents of severely impaired children also worry about who will care for their children after they're gone, and few have malpractice-settlement trust funds to rely on.

Julia E.S. Spencer, Letter to the Editor, *A Wrongful Birth?*, N.Y. TIMES MAG., Mar. 26, 2006, at 8. "Regardless of how many studies have been conducted, only the parents of a special-needs child can truly understand the difficulties and heartbreak of being in such a situation." *Id.* 

159. Allen, *supra* note 88, at 61; Malinowski, *supra* note 156, at 1453; Suter, *Routinization*, *supra* note 151, at 249-50.

information as a sign of responsible behavior and good decision making" also push many towards prenatal testing. 160

Not surprisingly, the medical profession, which is strongly motivated by the "moral imperative to know," laso enthusiastically supports prenatal testing and screening. Genetic counselors believe families can benefit from this technology: those with normal results can be reassured and those with abnormal results can make decisions about whether or not to continue the pregnancy in light of their own values. Most health-care professionals think that being informed and prepared is always better for families that have children with disabilities. Others favor prenatal testing because of their "bias toward termination" when abnormalities are found and their belief that such terminations benefit the families and society.

<sup>160.</sup> KALFOGLOU ET AL., *supra* note 157, at 13-14 (describing survey results showing that the most important benefit people found for genetic testing was "the ability to plan and prepare for the challenges of having a special need child," with study participants asserting that "[t]he information is . . . just a powerful thing to have"); Suter, *Routinization*, *supra* note 151, at 246.

<sup>161.</sup> Gwen Anderson, *Nondirectiveness in Prenatal Genetics: Patients Read Between the Lines*, 6 NURSING ETHICS 126, 129-30 (1999) ("In genetics, clinicians and researchers believe that knowledge and genetic science are moral goods.").

<sup>162.</sup> Suter, *Routinization*, *supra* note 151, at 245 (describing the view that couples can use the information to prepare for the arrival of a child with a disability even if they ultimately choose not to terminate the pregnancy).

<sup>163.</sup> *Cf.* DOROTHY C. WERTZ, JOHN C. FLETCHER & KÅRE BERG, WHO HUMAN GENETICS PROGRAMME, REVIEW OF ETHICAL ISSUES IN MEDICAL GENETICS 62 (2003) (setting forth policy recommendations by health care professionals, including that "[p]renatal diagnosis can be used to prepare for the birth of a child with a disability instead of making a decision about abortion").

<sup>164.</sup> Weil, *supra* note 154, at 53 (describing the ways in which medical professionals systemically and subtly express this bias, from their manner of and systems for delivering bad news to the way they describe the prognosis and options to families).

<sup>165.</sup> Numerous studies have collected data on the societal and cost benefits of screening and mandatory offer of screening. See, e.g., Nancy Anne Press & Carole H. Browner, Collective Silences, Collective Fictions: How Prenatal Diagnostic Testing Became Part of Routine Prenatal Care, in Women and Prenatal Testing: Facing the Challenges of Genetic Technology 202 (Karen H. Rothenberg & Elizabeth J. Thomson eds., 1994) (citations omitted) (noting that "the Department of Health and Human Services recently made it a goal . . . to 'increase to at least 90 percent [from 65%] the proportion of women . . . who are offered screening and counseling on prenatal detection of fetal abnormalities."); Tryfon Beazoglou et al., Economic Evaluation of Prenatal Screening for Down Syndrome in the U.S.A., 12 Prenatal Diagnosis 1241,1245 (1998) (estimating that "a universal triple test could prevent the birth of 1136 babies with Down syndrome . . . , while allowing 2057 live births with Down syndrome. The total financial savings per year are \$140 million"); Jo-Ann Johnson et al., Prenatal Genetic Screening for Down Syndrome and Open Neural Tube Defects Using Maternal Serum Marker Screening, 21 J. Soc'y Obstetricians & Gynaecologists Can. 887, 889 (1999) (noting that the added

Just as eugenicists often spoke in the same breath about the social and individual benefits of eugenics, physicians often justify genetic testing in the same manner.

The professional attitudes in favor of prenatal testing are often communicated to patients, directly or indirectly, which can lead to powerful pressure to undergo such testing. Generally, genetic counselors try to hide any biases they might have in favor of or against prenatal testing, given their commitment to non-directiveness. 166 Medical geneticists, however, are more directive and non-geneticist physicians even more so. 167 In addition, legal pressures create incentives for health-care providers to push or encourage prenatal testing. For example, if a patient has undergone prenatal testing or screening, the provider is better shielded from wrongful birth claims. 168 Indeed, one study has shown that in response to a legal mandate requiring that a prenatal screening test be offered, medical professionals provided limited, directive counseling, suggesting they were "more interested in *persuading* ... than *informing* patients."<sup>169</sup> As prenatal testing becomes more routine and moves out of genetics clinics into obstetricians' offices, more directive and less frequent counseling may lead more patients to experience discussions with physicians as recommendations or

costs of prenatal screening are "likely to be offset by . . . a higher detection rate of [Down Syndrome] and [spina bifida], a lower false-positive rate and, . . . a decrease in the overall number of amniocenteses performed.").

166. ROBIN BUNTON, NEW GENETICS AND NEW PUBLIC HEALTH 139 (2001) (noting that "adherence to a nonprescriptive (often referred to as 'nondirective') approach is perhaps the most defining feature of genetic counseling" and "stems from a firm belief that genetic counseling should—insofar as is possible—be devoid of any eugenic motivation" (citing ANN PLATT WALKER, A GUIDE TO GENETIC COUNSELING 8 (1998))).

167. See generally Deborah F. Pencarinha, Ethical Issues in Genetic Counseling: A Comparison of M.S. Counselor and Medical Geneticist Perspectives, 1 J. GEN. COUNSELING 19 (1992); Suter, Routinization, supra note 151, at 245. For example, approximately 30% of genetics professionals in the United States would provide negative slanted counseling for some serious genetic conditions. DOROTHY C. WERTZ & JOHN C. FLETCHER, GENETICS AND ETHICS IN GLOBAL PERSPECTIVE 373 (2004) (49 percent of genetics professionals in the United States would give negatively slanted counseling for anencephaly, and 37 percent would give negatively slanted information for Trisomy 13); Dorothy C. Wertz, Eugenics Is Alive and Well: A Survey of Genetic Professionals Around the World, 11 SCI. CONTEXT 499 (1998) (28 percent of genetics professionals in the United States and 42 percent of U.S. primary care physicians would give negatively slanted counseling for open spina bifida).

168. Suter, Routinization, supra note 151, at 251; Weil, supra note 154, at 52.

169. Press & Browner, *supra* note 165, at 201. The study showed that in California, where the offer of such screening was mandated, the acceptance rates for the screening test were 85% as compared with the national average of 65%. *Id.* at 216 n.10.

requirements that they *should* have genetic testing, <sup>170</sup> and sometimes that they should terminate if an abnormality is detected. <sup>171</sup>

Although not everyone undergoes prenatal testing, the use of this technology to select against disease has become part of the culture of pregnancy, accepted by most and expected by many. Nevertheless, current technologies are not cost free (physically, emotionally, or economically). The two most common forms of diagnostic testing, amniocentesis and chorionic villus sampling (CVS), are invasive procedures that pose a small but real risk of pregnancy complications, including miscarriage. The risk associated with amniocentesis is lower than with CVS, but the former has the downside of being performed in the second trimester, whereas CVS can be done in the first trimester. Thus, if an abnormality is found via amniocentesis and the patient wants to terminate, the procedure will be more physically and emotionally difficult than it would have been if done during the first trimester. In addition, amniocentesis and CVS are not inexpensive, although insurance generally provides coverage if the tests are medically indicated. Finally, the options available if abnormalities

<sup>170.</sup> Suter, Routinization, supra note 151, at 242-46.

<sup>171.</sup> Andrews, *Prenatal Screening*, *supra* note 157, at 990 n.117 (1996) (noting that even when defects are not severe, many physicians pressure women to terminate affected pregnancies).

<sup>172.</sup> Suter, Routinization, supra note 151, at 242-46.

<sup>173.</sup> Richard L. Berkowitz et al., *Challenging the Strategy of Maternal Age-Based Prenatal Genetic Counseling*, 295 JAMA 1446, 1446 (2006). In a low risk population with a background pregnancy loss of around 2%, a second trimester amniocentesis will increase this risk by another 1%. This difference did not reach statistical significance, but the increase in spontaneous miscarriages following second trimester amniocentesis compared with controls (no amniocentesis) did (2.1% versus 1.3%). Compared with second trimester amniocentesis, transcervical CVS carries a significantly higher risk of pregnancy loss (14.5% versus 11%) and spontaneous miscarriage (12.9% versus 9.4%). Zarko Alfirevic et al., *Amniocentesis and Chorionic Villus Sampling for Prenatal Diagnosis*, Vol. Cochrane Database Systematic Revs (2003) (CD003252).

<sup>174.</sup> For several reasons, terminations in the second trimester are generally more emotionally taxing. Women usually have felt fetal movement, enhancing the bonding with the fetus. In addition, most people will be aware of the woman's pregnancy by that stage, making the decision to terminate more complicated because the end of the pregnancy will be more public. And, of course, the termination procedure is more physically demanding later in the pregnancy. Suter, *Routinization*, *supra* note 151, at 258 n.155.

<sup>175.</sup> The full cost of invasive testing for chromosomal disorders is approximately \$1300. Ryan Harris et al., Cost Utility of Prenatal Diagnosis and the Risk-Based Threshold, 363 LANCET 497 (2004); see also Miriam Kuppermann et al., Procedure-Related Miscarriages and Down Syndrome—Affected Births: Implications for Prenatal Testing Based on Women's Preferences, 96 OBSTETRICS & GYNECOLOGY 511 (2000). Kupperman writes:

are found are still woefully inadequate. Treatment or amelioration of genetic conditions is rarely if ever possible. While many ultimately choose termination, others have no such option for religious, moral, or personal reasons. Thus, although many people do use prenatal testing or screening to decide whether or not to continue pregnancies, the costs associated with these tests limit how many ultimately use them to select against disease.

## B. Advancing Technologies: Towards "Designer Babies"

As assisted reproductive technologies develop, they will overcome many of the barriers that currently prevent some people from choosing to select against disease. They may even move many towards selection of "fitter" or "improved" children, a form of positive neoeugenics. Several new technologies will aid this progression of neoeugenics.

One technique, which is still in the experimental stage, is to analyze fetal cells that have been isolated from maternal blood. This form of prenatal testing eliminates the risks of complications associated with amniocentesis and CVS and may therefore make prenatal testing more desirable to some. <sup>176</sup> It does not, however, overcome the difficult reality that most prenatally diagnosed diseases cannot be treated, but only prevented through pregnancy termination.

Another option available to couples who want to select against disease, but do not want to terminate a pregnancy, is preimplantation genetic diagnosis (PGD) of embryos created through in vitro fertilization (IVF). This technique involves prenatal diagnosis of fertilized embryos, which can be implanted in the woman's uterus.<sup>177</sup> Unfortunately, PGD shares many of

For several decades, prenatal diagnoses of chromosomal disorders, including amniocentesis and later chorionic villus sampling (CVS), have been reserved for women aged 35 years or older at delivery. With the emergence of expanded maternal serum and ultrasonography screening programs, that age- and risk-based cutoff has become entrenched further. Insurance coverage for invasive testing has become more available to younger women, but only to the extent that they have been found via serum or ultrasonographic screening to be at least as high a risk as an unscreened 35 year old.

Id.

176. Lori B. Andrews, Future Perfect: Confronting Decisions About Genetics 59 (2001).

177. Jeffrey R. Botkin, *Ethical Issues and Practical Problems in Preimplantation Genetic Diagnosis*, 26 J.L. Med. & Ethics 17, 17 (1998); *see also* Susannah Baruch et al., Preimplantation Genetic Diagnosis: A Discussion of Challenges, Concerns, and Preliminary Policy Options Related to the Genetic Testing of Human Embryos 3-4, *available at* http://www.dnapolicy.org/images/ reportpdfs/PGDDiscussionChallengesConcerns.pdf (presenting an overview of preimplantation genetic diagnosis).

the problems associated with IVF. First, it is fairly expensive and not always covered by insurance. Second, because the success rate of impregnation is lower than most would like, harvesting eggs from the woman—a procedure not without burdens—may have to be done multiple times. As a result, some are skeptical as to how high the demand for this technology will be in the near future. Researchers are developing techniques to reduce cost and eliminate some of the physical hardships currently associated with IVF and PGD. Although PGD overcomes some of the emotional complications associated with prenatal testing and termi-

178. BARUCH ET AL., *supra* note 177, at 22 ("PGD is expensive. It requires IVF, which costs on average \$10,000-\$12,000. The addition of PGD can add \$2,500-\$4,000, bringing the total cost to approximately \$12,500-\$16,000. Insurers may not cover PGD at all, or may pay only for the genetic testing, leaving prospective parents to pay for the IVF."); *id.* at 6 ("If there is to be widespread insurance reimbursement of PGD, those who underwrite coverage—mainly employers and insurance companies—must view it as cost effective. Otherwise, the cost of PGD will be paid out-of-pocket by patients."); Botkin, *supra* note 177, at 18 (noting that "insurance carriers or government funding agencies" are unlikely to cover these costs "given the nonessential nature of this intervention, the cheaper alternatives, and the controversial nature of prenatal diagnosis in general").

179. Botkin, *supra* note 177, at 17-18.

180. *Id.* at 18 (noting that older women are unlikely to choose this procedure when the "efficiency of IVF declines significantly with age" and there are much cheaper and more reliable methods, and questioning generally whether "many couples will believe that the added benefits of PGD technology will justify its costs and other burdens"); *see also* Andrea L. Kalfoglou, *PGD Patients' and Providers' Attitudes to the Use and Regulation of Preimplantation Genetic Diagnosis*, 11 REPRODUCTIVE BIOMEDICINE ONLINE 486, 487 (2005). Kalfoglou writes:

Disadvantages [of IVF] included failure to conceive using IVF, risks for the mother and resulting child, the physical burdens and side effects of IVF cost, and the 'dilemma of what to do with spare embryos.' Two studies found that 'unreliability of the genetic test results' or 'unsuccessful genetic analysis' were also a concern for potential consumers. While [some studies] found that low success rates, cost, and risk of misdiagnosis were identified as disadvantages by PGD users, [other studies] found these were not major concerns.

*Id.* (citations omitted). *But see* BARUCH ET AL., *supra* note 177, at 5 ("For the moment, one would expect very few people who otherwise have no problems achieving a healthy pregnancy to utilize PGD. Nonetheless, that could change as IVF techniques improve and the number of genetic tests that can be employed successfully in PGD increases.").

181. See THE ETHICS OF INHERITABLE GENETIC MODIFICATION: A DIVIDING LINE (John E. J. Rasko et al. eds., 2006) ("PIGD is not a simple procedure; it involves hormonal stimulation to retrieve multiple eggs . . . "). Researchers are working on new techniques to facilitate the process. See Hospital Is First to Adopt Cheaper IVF, TIMES (London), Jan. 9, 2007, at 4 (reporting on a UK hospital which has received permission to adopt in vitro maturation, a "safer method of [IVF] that it claims could save couples up to £1,700").

nation, those who believe that life begins at conception may still be troubled by the prospect of embryo destruction if the embryo is found to carry disease genes. <sup>182</sup>

A third technological advance that will push us further toward neoeugenics is the ever-increasing identification of genes and our understanding of how they work. Is In time, we are likely to learn about genes associated with (if not determinative of) various traits and behaviors. Not only will we have knowledge about the genetics of more diseases and traits, but our capacity to genetically analyze biological samples (whether from amniotic fluid, maternal serum, or IVF embryos) will exponentially increase. The technological imperative to learn as much as possible about our future children with respect to disease, and possibly traits, may similarly increase. In the not too distant future, DNA chips and next-generation technologies will allow for the analysis of thousands of genetic variants, in contrast to the more limited analysis of a handful of disease genes today. These technologies will inevitably reduce the cost and increase the efficiency of testing, making prenatal diagnosis even more desirable and broader in its scope.

<sup>182.</sup> PGD almost always involves excess embryos, and "embryos that have been found to carry genetic mutations linked to diseases or disabilities are less likely to be candidates for donation." Some people view this as morally or ethically problematic but nevertheless think it may be defensible in some limited situations and that PGD should be strictly regulated and limited in order to minimize the creation and destruction of embryos. Still others believe the creation and potential destruction of embryos is categorically unacceptable and thus are opposed to PGD and IVF under all circumstances. BARUCH ET AL., *supra* note 177, at 5.

<sup>183.</sup> Weil, *supra* note 154, at 50 ("[T]he number of prenatal genetic tests is increasing exponentially—it jumped from 100 to 1,000 between 1993 and 2003.").

<sup>184.</sup> See Suter, Routinization, supra note 151, at 249 (describing the way in which identification of new disease genes leads to increased interest in this information and need for reassurance).

<sup>185.</sup> George M. Church, *Genomes for All*, SCI. AM., Jan., 2006, at 40-41, 47 (describing "next-generation technologies that make reading DNA fast, cheap and widely accessible," and which are "coming in less than a decade"); Michael J. Malinowski, *Law, Policy, and Market Implications of Genetic Profiling in Drug Development*, 2 HOUS. J. HEALTH L. & POL'Y 31, 40-43 (2002) ("DNA chips can be used to test the samples of individuals for the presence of thousands of identified genetic variations and, alternatively, to screen hundreds of thousands of individuals with a shared phenotype characteristic to isolate and identify shared genetic expressions.").

Fourth, gene therapy, or transfer, <sup>186</sup> may also create pressures toward neoeugenics. In spite of their initial optimism, scientists have been disappointed at how little gene transfer has progressed since the 1990s. <sup>187</sup> In addition, the procedure is not without risks. <sup>188</sup> Despite these difficulties,

186. Larry R. Churchill et al., *Genetic Research as Therapy: Implications of "Gene Therapy" for Informed Consent*, 26 J.L. MED. ETHICS 38, 42, 45 (1998) (suggesting that federal agencies "delete the terms gene therapy . . . and any language that would imply that a gene therapy already exists from the informed consent process" because, "[a]t present, gene transfer research amplifies the . . . existing confusions between research and therapy and intensifies extant problems of informed consent"). Churchill also writes:

[The] tendency of policy-makers to see entry into gene transfer research protocols as a viable avenue of treatment further diminishes the possibility for a robust exercise of informed consent in the research context. Such thinking indicates to the potential research subject that clear therapeutic benefits can be obtained in gene transfer research, when the actual likelihood of individual benefit for the subject is often minimal or non-existent.

Id. at 42-43.

187. Despite the public's enthusiasm for and belief in the success of gene therapy, Churchill et al., *supra* note 186, at 43-44, the "FDA has not yet approved any human gene therapy product for sale." U.S. Food and Drug Administration Center for Biologics Evaluation and Research, Cellular & Gene Therapy, http://www.fda.gov/cber/gene.htm (last visited Feb. 6, 2007). Even the one putative success cannot be described as such without qualification:

Because the gene therapy was superimposed, for appropriate reasons of safety, on the new but standard . . . treatment [with a synthetic enzyme that the participants were missing], it has been very difficult to determine precisely how much of either the scientific or the clinical success was due to [the synthetic enzyme], the gene-corrected cells, or to some combination of the two.

Churchill et al., supra note 186, at 44. Another observer writes:

A central challenge . . . is perfecting methods for delivering therapeutic genes to cells. Often genes introduced into patients do not reach enough of the appropriate cells or, for reasons that are not always clear, function poorly or shut off after a time. Under those conditions, a gene that could potentially be helpful would have little chance of affecting a disease process.

Theodore Friedmann, *Overcoming the Obstacles to Gene Therapy*, SCI. AM., June 1997, at 96. Gene therapy faces a number of technical hurdles, from getting the DNA into the patient to the appropriate site, to making sure the therapeutic genes function properly and continue functioning for the time necessary to achieve the desired therapeutic effect. GENETICS, *supra* note 7, at 483-84.

188. In the most famous tragic outcome of gene-transfer research, eighteen-year-old Jesse Gelsinger died after participating in a study to determine whether gene transfer would produce the enzyme that individuals lack who have ornithine transcarbamylase deficiency, an x-linked, dominant, single-gene disorder, which prevents the metabolization of ammonia. Jesse was participating in a "Phase I" trial intended to determine the "maximum tolerated dose" of the treatment; he received the highest dose in the trial.

one can easily imagine that in the future (perhaps more remote than researchers would like to believe), we will be able to use gene transfer to treat some genetic diseases. When and if that becomes possible, it is easy to imagine that the desire to select against and *treat* genetic disease will be great. At this point, eugenics—creating the "well-born"—would become intertwined with true disease treatment. 190

Gene transfer may also open the door to positive eugenics, where the focus would be on *improving* births rather than preventing undesirable births. Theoretically, the technology will be used to *enhance* certain desirable qualities—not merely to treat disease. At the extreme, the distinction between treatment and enhancement seems clear. The former aims to eradicate disease, such as to provide a gene to prevent a child from inheriting a form of immune deficiency, <sup>191</sup> whereas the latter aims to improve what is "normal," such as using gene transfer to help a child of average height

Within twelve hours, he started experiencing adverse reactions, which culminated in a clotting disorder, coma, kidney failure, and eventually death. See Sheryl G. Stolberg, The Biotech Death of Jesse Gelsinger, N.Y. TIMES MAG., Nov. 28, 1999, at 137. "[A]fter his death, reports surfaced of other adverse events, including several deaths, that had not been disclosed to reviewers, experimental subjects, or the public." GENETICS, supra note 7, at 482. More recently, three children with "severe combined immunodeficiency disease, or SCID, a potentially fatal genetic disorder that leaves its victims susceptible to life-threatening infections," participated in gene-transfer research and developed leukemia; sadly, one of those children died. Seventeen children had been "treated," and "virtually all [had] shown major improvement if not a cure." Thomas H. Maugh II, Gene Therapy Experiments Put on Hold, L.A. TIMES, Mar. 4, 2005, at A16. The leukemias were attributed to "insertional mutagenesis," the creation of a mutation caused by a retrovirus—which was used to transfer the gene—inserting into a working gene, in this case an oncogene, which if mutated can cause leukemia. Matthew P. McCormack & Terence H. Rabbitts, Activation of the T-Cell Oncogene LMO2 after Gene Therapy for X-Linked Severe Combined Immunodeficiency, 350 N. Eng. J. Med. 913 (2004).

189. It will be problematic, if not impossible, to use gene therapy to treat certain genetic conditions. So far scientists have focused on using the technique to transfer working genes to individuals with recessive genetic conditions caused by the failure of their genes to produce necessary enzymes. Using gene transfer to help a body produce a missing enzyme is complicated enough, but far simpler than using it to overcome the health effects of dominant mutations or chromosomal abnormalities. In addition, some conditions are caused by the harmful effects of mutations (whether recessive or dominant) early in development, and therefore are not likely to be treated by somatic cell gene transfer. *See* Friedmann, *supra* note 187, at 101 (discussing the need to carry out gene therapy very early in life before the immune system is fully competent to prevent an inactivating immune reaction).

190. This form of neoeugenics would likely be the least morally problematic (assuming of course safety issues were overcome) because it would be "true" treatment of disease. *See infra* text accompanying note 285.

191. See Maugh II, supra note 187, at A16.

become taller.<sup>192</sup> Genetic enhancement, and gene therapy, for that matter, can theoretically occur at the somatic cell level (where the genetic alteration would occur in non-reproductive cells and therefore would not be inherited by future progeny) or at the germline level (where the genetic alterations would occur in the reproductive cells so that future generations could inherit the alterations).<sup>193</sup> Germline level enhancement is more relevant to the focus of this Article since it is a technology that can "improve" future generations. In some ways, it represents the greatest extreme of trying to create the "well born."

# C. Cultural Norms and Acceptance of Non-Therapeutic Reproductive Technologies

In spite of the public's unease with some of these technologies, <sup>194</sup> there is good reason to believe that, if genetic enhancement becomes technologically feasible and safe, many (though surely not all) would choose it for their children. In a culture where parents seek advantages for their children in schooling, diet, exercise, extracurricular activities, and the like, it is hard to imagine that cultural pressures would not be great to pursue the same for their children with respect to enhanced traits. <sup>195</sup> As has been

#### 195. It has been observed that:

[There] is enormous public interest in enhancing appearance and performance: television shows feature "extreme makeovers" and other types of cosmetic surgery; the market for dietary supplements, many of which are touted for their "enhancement" effects, is huge; and parents in record numbers are enrolling their children in tutoring and other educational enhancement programs in an effort to give them academic advantages. As the President's Council on Bioethics observes . . . "We have every reason to expect exponential increases in biotechnologies and, therefore, in their potential uses in all aspects of human life."

GENETICS, *supra* note 7, at 566. Although genetic enhancement "may indeed be very far down the road," for technological reasons, "the potential demand may be so great that private companies may soon begin making a substantial commitment toward enhancement research and development." *Id.* at 439-40; *see also* GREGORY STOCK, REDESIGNING

<sup>192.</sup> Of course, distinguishing between treatment and enhancement at the margins becomes problematic.

<sup>193.</sup> SUSANNAH BARUCH ET AL., HUMAN GERMLINE GENETIC MODIFICATION: ISSUES AND OPTIONS FOR POLICYMAKERS 13 (2005), available at http://www.dnapolicy.org/images/reportpdfs/HumanGermlineGeneticMod. pdf ("If and when it occurs, germline genetic modification would involve introducing a new genetic sequence into a person's germline cells that could be passed to future generations."). See generally id. at 13-24 (providing an overview of the ethical and safety concerns involved, as well as presenting various policy options).

<sup>194.</sup> See KALFOGLOU ET AL., supra note 157, at 16-17 ("All data indicate that most Americans disapprove of the use of hypothetical reproductive genetic testing to select socially desirable traits such as intelligence, strength, or hair and eye color.").

demonstrated in the competitive world of sports, once one individual uses a technique or drug that enhances performance, the pressure on other competitors to do the same is enormous. Of course, parenting is not a competitive sport and the pressures to win may not be so great. But when major life opportunities depend so strongly on abilities (admission to good schools being the prime example), it is hard to imagine that many parents wouldn't feel subtle, or perhaps not so subtle, pressures to seek such advantages for their children. In fact, public opinion polls suggest that there may be substantial demand for genetic enhancement. Forty to forty-five percent of the American public polled in 1986 and 1992 approved of gene therapy to enhance physical and intellectual traits.

All of these technologies will likely push us further toward treatment of or selection against not just serious diseases, but also more trivial diseases and even traits. If we discover that some genes are associated with lesser conditions or traits we want to improve, and the genes are detectable through genetic testing, then a measurable biological factor will be associated with the conditions or traits. The ability to test for these conditions, or to improve them, may contribute to a technologically created

HUMANS: OUR INEVITABLE GENETIC FUTURE 5 (2002) ("The coming possibilities [of genetic enhancement] will be the inadvertent spinoff of mainstream research that virtually everyone supports . . . . [O]nce a relatively inexpensive technology becomes feasible in thousands of laboratories around the world and a sizable fraction of the population sees it as beneficial, it *will* be used.").

196. One physician's experiment surveyed nearly 200 athletes between 16 years old and mid-30s: "He asks each: 'I have a magic pill that would ensure you win every single competition, but you will die in five years. Will you take it?' More than 50 percent respond yes." Rick Maese, *Gene Therapy's Impact on Sports Worries Experts: It Could Be Used to Create Bigger, Stronger, Faster Super-Athletes*, ORLANDO SENTINEL, May 22, 2005, at A1.

197. Rick Weiss, Gene Enhancements' Thorny Ethical Traits: Rapid-Fire Discoveries Force Examination of Consequences, WASH. POST, Oct. 12, 1997, at A1; cf. KAL-FOGLOU ET AL., supra note 157, at 11, fig.3.1 (showing nearly thirty percent approval for use of reproductive genetic testing for intelligence/strength). However:

[t]hose polls also suggested . . . that the science had gotten ahead of the public understanding about the possible consequences of a free market in genes. Few people realize, for example, that although gene therapy holds promise against inherited diseases and cancer, none of the approximately 2,000 patients treated so far has been cured by the still experimental technique. Meanwhile, the procedure—which generally uses special viruses to inject new genes into people's cells—has the potential to cause cancer or other problems.

Weiss, *supra* at A1.

198. It is likely that, at most, we will find an association between genes and traits, i.e., increased probabilities of a trait in the presence of a gene, rather than anything genetically determinative.

need for "treatment" or reassurance. For example, prenatal testing is medically indicated for conditions associated with extremely low intelligence. If we develop the means to treat or select against less extreme versions of low intelligence, it may also become medically indicated to treat or select against lower than average intelligence. <sup>199</sup>

On a societal scale, the more we use technology to select against lesser conditions and traits, the more perfectionist we may become as a culture, and the more demanding we may become with respect to what is acceptable, normal, or healthy. The distinction between disease and normalcy may evolve. If enhancement and trait selection are widely used, it is easy to imagine that what was once normal will start to seem abnormal and perhaps disease-like. If we begin to medicalize what we now consider normal traits, enhancement and trait-selection will become more "legitimate" because they will be understood as part of medical treatment, driving people toward using these technologies.

All of these factors—advancing technologies and cultural norms—may exert a coercive effect on individuals' reproductive choices. As the American Medical Association Council on Ethical and Judicial Affairs has stated, the most likely risk today is not "overt eugenics" or "government imposed constraints on marriage and reproduction" but instead "that the aggregate result of individual choices creates societal and cultural norms

<sup>199.</sup> The ability to do so accurately is problematic, but we may find genes that contribute to intelligence, the presence or absence of which may lead to predispositions toward ranges of intelligence. Karen Wright, How Do Cognitive Abilities Relate to General Intelligence?, SCI. AM., May 1998, at 62, 64 ("In the past few decades, genetic studies have convinced most psychologists that heredity exerts considerable influence on intelligence. In fact, research suggests that as much as half of the variation in intelligence among individuals may be attributed to genetic factors."). Of course, the inherent indeterminacy of intelligence is precisely what makes testing and enhancement in this area problematic. See MATT RIDLEY, NATURE VIA NURTURE: GENES, EXPERIENCE, AND WHAT MAKES US HUMAN 90 (2003) [hereinafter RIDLEY, NATURE] ("There is no accepted definition of intelligence. Is it thinking speed, reasoning ability, memory, vocabulary, mental arithmetic, mental energy or simply appetite of somebody for intellectual pursuits that marks them out as intelligent?"); see also Jon W. Gordon, Genetic Enhancement in Humans, 283 Sci. 2023 (1999) ("Where [more] complex traits such as intelligence are concerned, we have no idea what to do, and in fact we may never be able to use gene transfer for enhancement of such phenotypes."); Robert Plomin & John C. DeFries, The Genetics of Cognitive Abilities and Disabilities, SCI. AM., May 1998, at 62, 68 (noting that enhancing intelligence would be much more difficult than preventing many diseases that impair cognitive development because "[n]ormal cognitive functioning . . . is almost certainly orchestrated by many subtly acting genes working together, rather than by single genes operating in isolation").

which substantially influence or limit the scope of autonomous decision making in regard to the use of genetic technology."<sup>200</sup>

## D. Distinctions Between Old and New Eugenics?

Having examined the various current and future technologies that may constitute a form of "neoeugenics," that is, an attempt to influence reproduction to have healthier, fitter offspring, it is worth comparing old eugenics with neoeugenics. "Neoeugenics," as the name suggests, is not precisely the same as classic eugenics. One writer states that "[t]raditional eugenics was an effort to select parents. Modern eugenics is an effort to select children. Or better yet, to design them."<sup>201</sup> Another writes:

Numerous attempts have been made by scientists and politicians alike to denounce any relationship between eugenics in the past and the "new" genetics. In these rhetorical practices, eugenics is most often identified with compulsion, bad science, and state control of reproductive matters. In contrast, the "new" genetics, as it is significantly called, has allied itself with the norms of modern bioethics and legitimates itself with reference to the principles of informed consent and individual rights. <sup>202</sup>

### 1. Presence or Absence of State Coercion

To many the key difference between old and new eugenics is that new eugenics is not marked by state coercion over reproduction. <sup>203</sup> Today, se-

The old eugenics pitted an alleged state interest in the quality of the genetic composition of the community (the gene pool) against individual rights and liberties over reproduction, that is, the value of improving the gene pool versus the value of individual reproductive autonomy . . . . In contrast, the new eugenics pits the alleged interests of an individual against the value the state would find in not having certain human conditions manipulated—against a concern for the stability and harmony of the community.

<sup>200.</sup> AMA Council on Ethical and Judicial Affairs, CEJA Report A – A-91: Ethical Issues in Carrier Screening of Cystic Fibrosis and Other Genetic Disorders (1991), *available at* http://www.ama-assn.org/ama1/pub/upload/mm/369/ceja\_aa91.pdf ("Avoidance of negative consequences, such as increased marginalization of individuals who are affected by genetic disorders or socially coercive attitudes toward certain reproductive choices, requires careful attention to possible conflicts or problems incurred by the implementation of screening.").

<sup>201.</sup> Wachbroit, supra note 153, at 329.

<sup>202.</sup> Koch, supra note 111, at 315.

<sup>203.</sup> *Id.* at 325 ("The role of the state as the prime actor of eugenic practices . . . is often seen as a constitutive political feature of eugenics."); *see also* Wachbroit, *supra* note 153, at 335-36. Wachbroit writes:

lecting against undesirable births is an individual decision. In the classic eugenics era, such selection was often a decision made by the state or by physicians at prisons and institutions for the "feebleminded." This is one of the key features that makes classic eugenics so distasteful. <sup>205</sup>

Yet, many of the features that are used to distinguish neoeugenics from eugenics are not as sharply distinct as many would have us believe. Even the assertions that eugenics represented coercion, whereas neoeugenics reflects voluntarism must be tempered. To be sure, state mandates resulted in shameless compulsory sterilizations, at least in the United States, Germany, and some other countries. But the eugenics era cannot be defined solely in those terms. In England, for the most part, eugenic goals were not compulsory but were encouraged through public education. Even in the United States, much of the eugenic efforts included education, with the hopes that people would adopt these goals. 206 Today, genetics and reproductive technologies are not coerced by the state. Instead, various programs make efforts to educate couples and women about the availability of these technologies. Indeed, as I argued in Section IV.A, although the choice is always the individual's, pressures from providers and society may have coercive effects. In the era of compulsory sterilizations, efforts were made to persuade individuals to make particular reproductive choices. Likewise, in the midst of the voluntarism of neoeugenics, efforts are made to persuade individuals to make particular reproductive choices.<sup>207</sup> Thus, although the landscapes of eugenics and neoeugenics are clearly different, the distinctions are not as extreme as commentators often suggest.

<sup>204.</sup> Of course, as we've seen, *see supra* text accompanying notes 45-46, and as I shall discuss, *see infra* text accompanying note 206, this was not a necessary condition for a practice to be eugenic.

<sup>205.</sup> Koch argues, at least with respect to Scandinavian countries, that the State was not a "unified actor." It was a "fragmented and complex unit . . . [with] no single political direction connecting the various fragmented state actors. Thus, we . . . [cannot] assume that the direction towards which eugenics was heading in practice was at all congruent with the official state political goal that was decided upon by parliament." Koch, *supra* note 111, at 325-26. Similar fragmentation existed within American eugenics programs, since decisions about whether and whom to sterilize were made by physicians within various institutions, each of whom had their own ideas and agendas about the aims of eugenics. *See* Reilly, *supra* note 6, at 208.

<sup>206.</sup> See supra text accompanying notes 37-43.

<sup>207.</sup> Koch puts it perhaps too strongly in asserting that "voluntarism cannot be considered constitutive of a modern reproductive and genetic policy as compulsion cannot be considered constitutive of eugenics." Koch, *supra* note 111, at 322 (noting that in spite of non-directiveness, medical professionals will still sometimes go against the decisions of counselees, for example, by informing high-risk relatives of their genetic risks if the counselees fail to do so).

#### 2. Improvements in Science

Another asserted distinction is that eugenics was just bad science, with an inordinate focus on heredity, whereas our understanding of the role of genetics is vastly more sophisticated today. While our knowledge of genetics is far improved, advances in genetics have revitalized some of the underlying assumptions that motivated the eugenics movement, including a faith in the power of genetics and a belief in genetic determinism. Just as the media popularized eugenics theories in the early 1900s, the "DNA Mystique" looms large in the public mind today. 208 In the eugenics era, the pendulum had swung sharply toward the nature extreme, resulting in hereditary explanations about individual and group characteristics, with little focus on environmental influences.<sup>209</sup> Although the pendulum swung almost as sharply in the other direction in the late 1950s through the 1970s—when the tendency was to dismiss theories of heritability of traits and behaviors<sup>210</sup>—the pendulum is returning again to the nature end of the spectrum. As a result, even though geneticists generally caution against genetic determinism, the popular culture eagerly welcomes genetic explanations for complex traits.<sup>211</sup> The media and public speak in overly simplistic and deterministic terms about the "aggression" gene, the "novelty-seeking" gene, or the "infidelity" gene, to name a few. <sup>212</sup> They often misinterpret genetics research as showing that genes are all or primarily determinative. As we learn more about genetics, there is a growing tendency

<sup>208.</sup> DOROTHY NELKIN & M. SUSAN LINDEE, THE DNA MYSTIQUE: THE GENE AS A CULTURAL ICON (1995); see also, Sonia M. Suter, The Allure and Peril of Genetics Exceptionalism: Do We Need Special Genetics Legislation?, 79 WASH. U. L.Q. 669, 674-700 (2001) [hereinafter Suter, Allure] (describing the allure and mystique of genetics).

<sup>209.</sup> See supra text accompanying notes 24-26.

<sup>210.</sup> DUSTER, *supra* note 118, at 15 ("[T]he *zeitgeist* of the 1960s was such that few would take the *public* stage (or publish in scholarly journals) and argue the 'genetics' of intelligence, crime, or athletic or job performance."); *see also* PAUL, POLITICS, *supra* note 93, at 85 (1998) (Some were "bewildered by the refusal to admit that genes contributed to individual differences in human abilities and aptitudes. But in the politically charged atmosphere of the 1970s, to concede such difference was to risk . . . being seen as aligned . . . with the social views of Arthur Jensen and Richard Herrnstein.").

<sup>211.</sup> For example, the cover of *Time Magazine* once suggested that infidelity may be in our genes. Robert Wright, *Infidelity—It May Be in Our Genes. Our Cheating Hearts*, TIME MAG., Aug. 15, 1994, at 44.

<sup>212.</sup> Studies attempting to locate these genes "have been roundly criticized on methodological grounds. Behavioral genetics is generally highly controversial politically and scientifically." Suter, *Allure*, *supra* note 208, at 675 n.9.

to believe it's "all in our genes." However, genes are not all-determining; "[h]eritability and determinism are very different things." <sup>214</sup>

Even some contemporary scientists have made comments that reinforce the public's belief in genetic determinism. Most famously, Daniel Koshland, Editor-in-Chief of *Science*, wrote in an editorial that the Human Genome Project could provide solutions to many of our social problems, including homelessness and crime. He reasoned that research from the Human Genome Project could eliminate such conditions as manic depression, schizophrenia, and Alzheimer's, which he described as among the root causes of homelessness. <sup>215</sup> In taking "social problems and re-cast[ing] them as essentially medical problems," and in defining medical problems as if primarily genetic, Koshland does not sound so dissimilar from the eugenicists of yesteryear. <sup>216</sup>

#### 3. Ethnic and Racial Bias

Another area where classic eugenics views may reemerge concerns the relationship between inheritance and ethnic or racial groups. <sup>217</sup> Eugenicists were grossly biased and racist in their crude descriptions of ethnic groups, making sweeping and incorrect claims about supposed genetic traits. Future Nobel laureate Hermann J. Muller wrote that by 1935, "eugenics had become 'hopelessly perverted' into a pseudoscientific façade for 'advocates of race and class prejudice, defenders of vested interests of church and state, Fascists, Hitlerites, and reactionaries, generally." <sup>218</sup> To-

<sup>213.</sup> *Id.* at 674-75 (describing the public's view that genes are all (or nearly all) determining).

<sup>214.</sup> RIDLEY, supra note 46, at 86.

<sup>215.</sup> Daniel E. Koshland, *Sequences and Consequences of the Human Genome*, 246 SCI. 189 (1989). He also argued for solutions "that involve prevention, not care taking," and that the "great new technology" should be used to "aid the poor, infirm, and underprivileged." *Id.*; *see also* Daniel E. Koshland, *The Rational Approach to the Irrational*, 250 SCI. 189 (1990) ("Advancing research can cure some fraction of these illnesses. It may also provide predictive diagnoses to distinguish those who are severely ill from those who merely represent harmless aberrations from the norms of society.").

<sup>216.</sup> Resta, *supra* note 37, at 234 (describing other examples of research that over-simplified complex traits like race, "religiosity," and "traditionalism").

<sup>217.</sup> Race and ethnicity, of course, are not precisely the same, although in the eugenics era, distinctions were not made between the two. Even today, the two terms are often used interchangeably. Screening tests, for example, are offered on the basis of race or ethnic origin, because both serve as crude proxies for relatedness to certain groups that are prone to certain genetic conditions. *See infra* notes 222-225 and accompanying text.

<sup>218.</sup> KEVLES, *supra* note 9, at 164. We should not forget that during the latter part of the eugenics era, scientists rejected many of the eugenic premises. *Id.*; *see also* PAUL, HEREDITY, *supra* note 42, at 115 (describing T.H. Morgan, a key figure in the development of modern genetics). Morgan argued in 1925 that "almost nothing was known about

day, geneticists often argue that the Human Genome Project has done much to disprove claims of genetic racial distinctions. It has shown that the genetic variation among groups is far less than the variation of individuals within groups. Each of us is an individual, but we share the vast majority (99.9%) of our inherited material with other human beings. 220

Yet, even as geneticists point out the difficulty in defining race in genetic terms, <sup>221</sup> discoveries in molecular biology have shown that certain ethnic groups are more susceptible to certain genetic mutations than others. <sup>222</sup> Mutations—while sometimes the cause of genetic diseases if two

the causes of mental differences among individuals, much less among nations or races," and further "deplored the frequent confusion of nature and nurture, suggesting that much of the behavior associated with feeblemindedness was probably due to 'demoralizing social conditions' rather than to heredity." *Id.*; *see also* ROSEN, *supra* note 92, at 11 (2004) (The "scientifically trained proponents of eugenics often expressed alarm over the eugenic claims made by non-scientists. From the scientists' perspective, amateurs popularized eugenics at the expense of the very science that fueled it. [However,] . . . the eugenics movement benefited from the participation of amateur enthusiasts."). The voices of these more circumspect scientists, however, were overcome by the swell of enthusiasm for "eugenic" science.

219. Luigi Luca Cavalli-Sforza, Remarks Upon Being Awarded the Balzan Prize for The Science of Human Origins (1999) (noting that "we find that any population, however small, has enormous genetic variation; on average, one finds 85% of the total human variation is within populations, and only 15% between"), *cited in* GENETICS, *supra* note 7, at 4.

220. GENETICS, supra note 7, at 6.

221. "[A]lthough everyone, from geneticists to laypersons, tends to use 'race' as if it were a scientific category, with rare exceptions, no one offers a quantifiable definition of what a race is in genetic terms." Richard S. Cooper et al., *Race and Genomics*, 348 NEW ENG. J. MED. 1166, 1168 (2003); *see also* Sharona Hoffman, *Is There a Place for "Race" as a Legal Concept?*, 36 ARIZ. ST. L.J. 1093, 1116 (2004) ("In recent years a vigorous debate has developed in the fields of medicine and genetics concerning the validity of 'racial' categories. Some have asserted that 'race' is 'biologically meaningless,' while others have strongly supported the continued use of 'race' for scientific purposes."); David Rotman, *Genes, Medicine, and the New Race Debate*, TECH. REV., June 2003, at 41, 50 ("It is possible to detect very small genetic differences between different populations if you look closely enough . . . . 'but that doesn't support the idea of race.'").

222. Diseases like cystic fibrosis, a "dangerous disease of the lungs and intestines," RIDLEY, *supra* note 46, at 142; sickle cell anemia, "a condition that impairs a person's red blood cells from carrying oxygen," causing "mild or severe pain in organs, joints or muscles, and in extreme cases even death," Jonathan Kahn, *How a Drug Becomes "Ethnic": Law, Commerce, and the Production of Racial Categories in Medicine*, 4 YALE J. HEALTH POL'Y L. & ETHICS 1, 38 (2004); and Tay Sachs, "a progressive neurological disorder that usually strikes in infancy and results in . . . death by the age of two to three years after" a previously normal child develops 'dementia, blindness, paralysis, and death," Sonia M. Suter, *Whose Genes Are These Anyway?: Familial Conflicts Over Access to Genetic Information*, 91 MICH. L. REV. 1854, 1861 n.47 (1993) [hereinafter Suter,

copies are inherited (one from each parent)—may provide selective advantages against environmental insults if one copy is inherited (making one a carrier). If groups from a particular region intermarried, then evolutionary pressures would have led to an increase in the number of carriers of the advantageous mutation. Since evolution is a slow process, these effects last long after the groups have moved or the environmental insults have changed. Consequently, racial categories central to genetic diagnosis are "entrenched in genetic research, and pervade scientific and medical journals." Unfortunately, the focus on racial classification may "indirectly . . . legitimate and reinvigorate the old nature-nurture debate over the issues of race, ethnicity, gender, and mental capacity." Although the

Whose Genes], are all more prevalent in certain ethnic groups because the incidence of carriers in these groups is higher than average. Carriers are not affected by the disease, but have a 1/4 chance of having a child with the condition if their partner is also a carrier. Suter, *Routinization*, *supra* note 151, at 235 n.13. "For example, 1/25 of Caucasians (particularly those of Northern European descent) carries the gene for cystic fibrosis, 1/12 of African Americans carries the gene for sickle-cell anemia and 1/30 of Jews of Ashkenazi descent carries the Tay Sachs gene. Asian, Mediterranean, and Middle Eastern populations are at varyingly increased risks of carrying the gene for thalassemia," *id.*, another form of anemia, RIDLEY, *supra* note 46, at 141.

- 223. For example, carriers of the gene for sickle cell anemia and thalassemia "are largely resistant to malaria." RIDLEY, *supra* note 46, at 141-42. In addition, studies suggest that carriers of cystic fibrosis are "almost immune to the debilitating dysentery and fever caused by typhoid." *Id.* at 142. "Some have theorized that Tay-Sachs carriers were more resistant to tuberculosis, which ran rampant among many Ashkenazi Jews in urban settings." Suter, *Whose Genes, supra* note 222, at 1861 n.47.
- 224. Suter, *Whose Genes*, *supra* note 222, at 1861 n.47. An additional explanation for the disproportionate presence of a mutation in an ethnic group is the founder effect. That is to say, "the common ancestry has allowed a single mutation to pass 'silently' through a multitude of generations because recessive genes remain unexpressed unless paired with another similar recessive gene." *Id.*
- 225. David J. Rothman & Sheila M. Rothman, *Race Without Racism?*, NEW REPUBLIC ONLINE, Nov. 14, 2005, http://www.tnr.com/docprint.mhtml?i= 20051114&s=rothman111405 ("Francis Collins, head of the Human Genome Project . . . , is one of many who justify applications of racial categories on pragmatic grounds: they are a convenient tool for exploring the genetic origins of disease[, such as] the link that has been forged between Ashkenazi Jews and breast cancer.").
- 226. DUSTER, *supra* note 118, at 3. *Compare* RICHARD J. HERRNSTEIN & CHARLES MURRAY, THE BELL CURVE (1994) (arguing that intelligence is genetically determined and the major cause of socioeconomic success, and that therefore socioeconomic success, crime rates, and academic success between classes and races are genetic and not environmental in origin, and further that social welfare, affirmative action, and similar ideas are doomed to failure), *and* J. PHILIPPE RUSHTON, RACE, EVOLUTION & BEHAVIOR (1994) (arguing that race is a valid scientific category and that racial differences are due to genetic, not environmental factors), *and* SEYMOUR W. ITZKOFF, THE DECLINE OF INTELLIGENCE IN AMERICA (1994) (arguing that intelligence is falling because lower classes are

geneticists of today do not draw the careless, racist conclusions about ethnicity and behavior of the eugenicists, the work of genetics has made it difficult to remove inheritance from the discussion of race or ethnicity.

Unfortunately such findings have led those inclined to understand race in biological terms to ask, "If genetic disorders are differentially distributed by race and ethnicity, why aren't other human traits and characteristics?" One doesn't have to look too far to find groups that rely on some of these data to make claims that sound frighteningly like those from the era of classic eugenics. Numerous websites espouse the virtues of eugenics and its underlying goals of racial and genetic cleansing. Many la-

procreating more than others), with Alan H. Goodman, The Race Pit, ANTHROPOLOGY NEWSL., May 1998, at 50 ("Falling into the race pit starts with thinking that race is a biological and scientific concept . . . . [which prevents the understanding of] human variation. Medical proclamations made without a biological basis result in a great deal of unseen harm . . . [and sometimes] feed political abuse."), and James J. Heckman, Lessons from the Bell Curve, 103 J. Pol. Econ. 1091-2020 (1995) (discussing five critical flaws regarding the use of the data presented by Herrnstein and Murray).

227. DUSTER, *supra* note 118, at 3.

228. See, e.g., NeoEugenics' Web Site, http://neoeugenics.home.comcast.net/ (last visited Aug. 18, 2006); Welcome to Simon O's Conscious Evolution, http://www.euvolu tion.com/ (last visited Feb. 6, 2007); Future Generations, http://www.eugenics.net/ (last visited Feb. 24, 2007); Eugenics—A Planned **Evolution** http://www.onelife.com/ ethics/eugenics.html (last visited Aug. 18, 2006); Millennium: A Better Future, http://www.childrenofmillennium.org/eugenics.htm (last visited Aug. 18, 2006); Future Human Evolution: Eugenics in the Twenty-First Century, http://www.whatwemaybe.org/ (last visited Feb. 24, 2007); Richard Lynn, http://www.rlynn.co.uk/ (last visited Feb. 24, 2007); Yahoo! Tech Groups, e-l: Eugenics List, http://tech.groups.yahoo.com/group/e-l/ (last visited Feb. 24, 2007) (describing a "Eugenics List . . . formed to shed light on the concept of eugenics, the world's most misunderstood subject," to disabuse the world of the notion that it is "the ultimate form of cruelty"); Editor's Note: Science of Scandalizing the Eugenics. http://theoccidentalquarterly.com/vol4no1/toq-editnote4-1.html (last visited Feb. 24, 2007); Noontide Press, Race and Culture, http://www.noontidepress.com/catalog/index.php?cPath=22&sort=2a (last visited Feb. 24, 2007) (selling white supremacist literature and media, including JAMES HART, EUGENICS MANIFESTO); Center for Genetics and Society, Advocacy by Supporters of Traditional Eugenics and Neo-Eugenics, http://www.genetics-and-society.org/analysis/

promoencouraging/tradeugenics.html (last visited Mar. 26, 2007) (including links to various websites "Encouraging Public Acceptance of the New Eugenics"). Not all focus on racial differences. *See*, *e.g.*, Center for Genetics and Society, Advocacy by Supporters of Traditional Eugenics and Neo-Eugenics, http://www.genetics-and-society.org/analysis/pro-moencouraging/tradeugenics.html (last modified Nov. 16, 2004) ("Traditional eugenicists tend to focus on the perennial topics of racial and group differences in intelligence and behavior, [whereas] Neo-eugenicists incorporate some of the futurist visions promoted by the transhumanists."). The Center for Genetics and Society website also provides links to various transhumanist societies.

ment the degeneration of the genome. For example, one website proclaims that:

Those handicapped in body, mind or criminal inclination, those who are not able to care for themselves within normal society and require public assistance, must be taken care of in the most humane and economical way possible - through institutions. To allow these groups to have more children is stupid, not from a genetics standpoint, but from the standpoint of the welfare of the child and its burden on the producing portion of the society. . . The human genome was certainly not designed for modern living, and is now degenerating under an evolution which we have crippled. <sup>229</sup>

The solution, they argue, is to "change the innate nature of humans" and to "encourage the breeding of people with a higher intellect, people better able to understand what motivates them and who can eventually revolt against the subjugation by the state or the controlling elite." Unfortunately, some of these notions of ethnic and genetic inferiority are not limited to fringe websites, but appear in popular publications such as *The Bell Curve*. <sup>231</sup>

<sup>229.</sup> Eugenics—A Planned Evolution for Life, http://www.onelife.com/ethics/eugen ics.html (last visited Aug. 18, 2006); *see also* Millennium: A Better Future, http://www.childrenofmillennium.org/eugenics.htm (last visited Aug. 18, 2006) ("Humanity is losing its edge. Fertility rates among the gifted are low. By contrast, the unintelligent thrive. The outcome of this is obvious: Intelligence is declining. And before too long, civilization itself will fall."); Future Human Evolution: Eugenics in the Twenty-First Century, http://www.whatwemaybe.org/ (last visited Feb. 24, 2007) ("Formerly, natural selection took place largely as a result of differential mortality, but now . . . selection is determined largely by differential fertility. Aside from genetic illnesses, this new selection is also characterized by a negative correlation between fertility and intelligence—the core of eugenic concern for over a century.").

<sup>230.</sup> NeoEugenics' Web Site, http://neoeugenics.home.comcast.net/ (last visited Aug. 18, 2006); Yahoo! Tech Groups, e-l: Eugenics List, http://tech.groups.yahoo.com/group/e-l/ (last visited Feb. 24, 2007) (arguing that "[e]ugenics has the potential to alleviate suffering on a vast scale"); Center for Genetics and Society, Advocacy by Supporters of Traditional Eugenics and Neo-Eugenics, http://www.genetics-and-society.org/analysis/promoencouraging/tradeugenics.html (last visited Mar. 26, 2007) ("[H]uman genetic modification comes easily to eugenicists, who see it as an efficient, rapid and powerful means of encouraging the spread of desirable traits and decreasing the incidence of undesirable traits."); Future Generations, http://www.eugenics.net/ (last visited Feb. 24, 2007) (promoting "humanitarian eugenics," which "strives to leave a genuine legacy of love to future generations: good health, high intelligence, and noble character," and advocates "measures to improve the innate quality of humankind which are entirely voluntary").

<sup>231.</sup> HERRNSTEIN & MURRAY, supra note 226, at 269-369 (1994).

Even if our attitudes generally are not as widely racist as those of the eugenics movement, there is reason to worry about potential harm to ethnic groups in the name of genetics. Motivated by good intentions and public health concerns, as were many eugenicists, some state legislatures in the 1970s mandated that African Americans be screened for sickle cell anemia, an inherited disease most common within this group. <sup>232</sup> In spite of good intentions, the legislation was problematic in several respects:

Several criticisms were leveled at these statutes (and even those that made genetic testing voluntary) including: the fact that testing was limited to only African-Americans, when other ethnic groups, such as those of Mediterranean origin, can also carry the gene; the "scientific inaccuracy" of much of the legislation, which led to confusion and stigmatization of unaffected carriers of the disease gene (those who had one, as opposed to two, copies of the disease gene); and the lack of protective safeguards to ensure confidentiality of results, genetic counseling, and education.<sup>233</sup>

More recently, some Jewish groups have expressed concern that their population has been studied more than most other groups. Like the Finns, it is a highly homogenous group, making it ideal for genetic research.<sup>234</sup> But this fact, coupled with the isolation of so many genes associated with Ashkenazi Jews,<sup>235</sup> has led some within the Jewish community to criticize the "creepy irony of using Jews as guinea pigs for their genes," both for symbolic reasons and because of the risks of discrimination to their community.<sup>236</sup>

As we compare the modern era with the eugenic era, it is easy to pat ourselves on the back and dismiss classic eugenics as unscientific and amateurish. But we should not forget that "eugenic ideas could not be

<sup>232.</sup> Howard Markel, The Stigma of Disease: Implications of Genetic Screening, 93 Am. J. MED. 209, 212 (1992).

<sup>233.</sup> Suter, Allure, supra note 208, at 676 n.21.

<sup>234.</sup> Masha Gessen, Jewish Guinea Pigs: What If a Gene Patent Is Bad for the Jews?, SLATE, July 26, 2005, http://www.slate.com/id/2123397/. In addition, "Ashkenazi Jews... offer the advantage of geographical diversity: They are found everywhere and even seem to have a certain propensity for settling near major research centers." Id.

<sup>235.</sup> Rothman & Rothman, *supra* note 225. ("Only a few years ago, the term [Ashkenazi Jew] was relatively obscure to anyone outside the group; now it is common in breast cancer literature. 'AJ' is a well-known medical acronym in publications and medical charts . . . . ").

<sup>236.</sup> Gessen, *supra* note 234. Of course, these views are not unanimous within the Jewish culture. Some American rabbis have "enthusiastically embraced the research and introduced genetic screening programs in their communities." *Id.* 

called unscientific by the standards of the day."<sup>237</sup> As our understanding of science advances, the standards by which we evaluate science will similarly evolve. Although the science of eugenics does not live up to modern standards, "the same could be said of most of the science produced in the past—and probably could be said of much of today's science if scrutinized fifty years from now."<sup>238</sup> We should, therefore, be careful not to privilege our contemporary standards of science; such privileging of science contributed to the problems with eugenics.

#### 4. Societal Versus Individual Benefit

Another distinction made between eugenics and neoeugenics is that the former was justified by general societal welfare, whereas reproductive choices today are justified in terms of beneficence toward the future child or family. In fact, in both periods, the motives were mixed. The classic rationale for eugenic sterilization included benefits to the sterilized individual. Indeed, such claims were crucial to garnering widespread support for a practice that many find abominable today. It is tempting, though not fair, to describe eugenics as "bad science practiced by bad people." Most eugenicists viewed their mission as a form of charity and assistance. <sup>239</sup> As Dr. John H. Bell, the superintendent at the colony where Carrie Buck was institutionalized, described in 1929:

[T]he parole of mental defectives without sterilization is, on account of their propensity for the production of defective children, fraught with considerable danger both to the *individual* and the State. . . . [I]t is vastly *more humane* to relieve these individuals of a function which they cannot properly use and allow them to return to their homes or society, than to keep them confined in an institution for the greater part of their young lives. . . . <sup>240</sup>

<sup>237.</sup> Koch, *supra* note 111, at 323.

<sup>238.</sup> Id. at 323-24.

<sup>239.</sup> *Id.* at 329 ("Ironically most eugenicists of the 1930s and 1940s considered eugenics a progressive, rational, and scientifically based humanitarian project as compared to the [past practice of] incarcerat[ing] and punish[ing] the asocial elements of society rather than re-socializ[ing], steriliz[ing], and subsequently releas[ing] them."); Resta, *supra* note 37, at 233.

<sup>240.</sup> John Bell, Eugenical Sterilization 3-4 (May 13, 1929) (unpublished paper presented at a meeting of the American Psychiatric Association, Atlanta, Georgia) (emphasis added) (["I]t is also sound economic policy in that it converts a definite liability into a reasonable asset."), *quoted in* Cynkar, *supra* note 33, at 1430; *see also* Cynkar, *supra* note 33, at 1450 (noting that Strode "maintained that sterilization was the most humane way to deal with the feebleminded").

Similarly, Dr. Priddy, who argued that the Virginia sterilization laws should be held constitutional in *Buck v. Bell*, claimed, somewhat self-servingly, that his patients "clamor[ed] for" eugenic sterilization. <sup>241</sup> Others spoke of the despair one would feel on behalf of their child, if they were to give birth to a "feebleminded" individual, <sup>242</sup> suggesting that eugenical sterilization benefitted the unborn as much as the sterilized "feebleminded." Modern prenatal testing is also often motivated by similar concerns for the well-being of the unborn child. To prevent suffering, many believe, good parents should avoid giving birth to a child with genetic defects. <sup>243</sup>

Just as classic eugenics was not motivated solely by social well-being, current and future reproductive technologies are advocated not solely to allow individuals to make decisions compatible with their values and goals. The technologies are also promoted and encouraged as socially responsible. The success of prenatal screening programs is often measured in terms of the savings to society by reducing the incidence of children born with certain genetic conditions. For example, analysis for the federal government in 1974 estimated that voluntary prenatal testing at a cost of \$5 billion over 20 years would save \$18 billion by reducing the incidence of Down syndrome. In other words, our judgments today about appro-

<sup>241.</sup> Cynkar, *supra* note 33, at 1439.

<sup>242. &</sup>quot;For our own sakes—for our children's sakes—' plead the mothers, 'help us!' . . . . The women who thus cry out are pleading not only for themselves and their children but for society itself." MARGARET SANGER, *Cries and Despair, in* WOMAN AND THE NEW RACE 72, 78-82 (1920) (introducing a chapter entitled "Cries and Despair, which excerpts some of the many letters received from "unfortunate" women, including one from "a woman praying for help to avoid adding to the number of mentally helpless," one from an insane woman seeking to protect herself and society from perpetuating that insanity by giving birth, and another from a woman who "prayed and prayed that [her children] would die when they were born" because she knew she had no right to bring such children into the world.).

<sup>243.</sup> See supra text accompanying notes 153-157; see also Karen H. Rothenberg & R. Alta Charo, The Good Mother: The Limits of Reproductive Responsibility and Genetic Choice, in WOMEN & PRENATAL TESTING: FACING THE CHALLENGES OF GENETIC TECHNOLOGY 116 (Karen Rothenberg & Elizabeth Thomson eds., 1994) ("There is strong public sentiment against bringing children into the world knowing they will suffer debilitating and painful illness."); Jeffrey R. Botkin, Symposium: Prenatal Diagnosis and the Selection of Children, 30 FLA. ST. U. L. REV., 265, 272 (2003) (noting that one geneticist and attorney would sanction wrongful birth suits against parents for "knowingly bringing a child to birth with a genetic condition" since they have added to familial burdens, incurred a cost to society, and, "caused needless suffering in their child.").

<sup>244.</sup> BUCHANAN ET AL., *supra* note 34, at 55 ("[A]ssuming a reduction of 50 percent [, voluntary prenatal testing could] save the United States more than \$18 billion, and other screening programs had the potential to save another \$75 to \$100 billion." (citing KEVLES, *supra* note 9)).

priate reproductive decisions are not wholly divorced from social welfare concerns.<sup>245</sup> We may focus far more on reproductive autonomy than in the last century; but, just as eugenicists saw sterilization or segregation programs as valuable because of cost savings to society, many advocate voluntary prenatal testing and termination for the same reasons.<sup>246</sup>

### V. WHAT'S WRONG WITH (NEO)EUGENICS?

As we've seen, neoeugenics is not identical to eugenics. Indeed, it does not share some of the most troubling features of the American eugenics movement: it is not a state-imposed restriction on reproduction, indeed, it is voluntary; it is not implemented in the context of insidious and widespread racism, with the goal of eliminating or reducing the prevalence of ethnic groups; and it is not based on oversimplified notions of the inheritance of complex traits and behaviors. As a result, neoeugenics appears less threatening than eugenics. If those three elements were the only ones that constituted eugenics or that made eugenics troubling, then perhaps few concerns would exist regarding genetic and reproductive technologies. But, as Part IV suggested, some of the attitudes and concerns of eugenics remain today—a focus on the heritability of traits, a tendency toward genetic determinism, a privileging of science, a focus on societal benefits of genetic technologies, and most important, societal pressure to increase the chances of having "well-born" children or to decrease the incidence of "less fit" children. "At its root, eugenics simply concerns perceptions of improvement."<sup>247</sup> Our notions of what constitutes an improvement may not be precisely the same today, but the fundamental goal of improving our unborn children remains.

This goal of improvement, perhaps more than any other, is what many mean when they describe modern reproductive genetics as neoeugenic. Such a description is usually laden with condemnation, an epithet of sorts.<sup>248</sup> To determine whether the label should appropriately be treated as

<sup>245.</sup> Koch, *supra* note 111, at 322 ("The preventive practices of clinical genetics have sometimes been interpreted as neo-eugenic attempts to improve the genetic health of the population.").

<sup>246.</sup> *Id.* at 326 ("Cost benefit considerations, which are often seen as an ethically problematic eugenic motive, are not obsolete either."); *see also* note 165 (describing the societal benefits associated with prenatal screening).

<sup>247.</sup> Jones, *supra* note 2, at 215 (emphasis added); *see also* Wachbroit, *supra* note 153, at 329 ("Eugenics... was an effort to improve the human race by applying the wisdom of animal breeders.").

<sup>248.</sup> Jones, *supra* note 2, at 213 ("[M]any use the term 'eugenics' pejoratively (and almost reflexively), attaching to it a payload of disturbing connotations . . . .").

an epithet, we should examine whether the concerns attached to classic eugenics remain today. If we evaluate eugenics through a Kantian notion of autonomy, then neoeugenics seems less problematic given that our laws and cultural norms have largely overcome the shackles of governmental and medical restrictions on reproductive and medical decision making. Section V.A, however, offers a more contextual, relationship-based conception of autonomy through which to evaluate neoeugenics. Using this lens, Section V.B shows the contextual importance of evaluating eugenics. It suggests that the concerns regarding eugenics are broader than state and medical tyranny, and that some of those problems still exist with neoeugenics. Nevertheless, some of the concerns are speculative and not unique to eugenics or neoeugenics. In short, I argue that the propriety of neoeugenics, or eugenics for that matter, depends on motivation, context, and results; it cannot easily be categorized as always or never problematic.

#### A. A Relational Account of Autonomy

It seems difficult to criticize, on its face, the underlying goal of eugenics—improving birth—especially when expressed through individual decision making, without state interference. As I shall argue below, however, the practice as applied may be troubling in many instances. Because neoeugenics involves fundamental decisions about parenting, including whether to retain the capacity to become a parent or whether actually to become a parent, some aspects of it arguably fall within a fundamental liberty or privacy interest. The Supreme Court has explicitly treated parenting decisions concerning education, religion, and procreation as constitutionally protected interests, describing them as "involving the most intimate and personal choices a person may make in a lifetime, choices

<sup>249.</sup> My goal here is to introduce the concept of relational autonomy to draw parallels between classic eugenics and neoeugenics. I realize, however, that much more could be said about this theory than is possible in this Article and I plan to develop a fuller account of the theory in future works.

<sup>250.</sup> Wisconsin v. Yoder, 406 U.S. 205, 232 (1972) ("[The] primary role of the parents in the upbringing of their children is now established beyond debate."); Prince v. Massachusetts, 321 U.S. 158, 166 (1944) (reciting precedent that recognizes the "private realm of family life which the state cannot enter"); Pierce v. Soc'y of Sisters, 268 U.S. 510, 534-35 (1925) (recognizing parental liberty with respect to child rearing and education); Meyer v. Nebraska, 262 U.S. 390, 399-401 (1923) (same).

<sup>251.</sup> Planned Parenthood of Se. Pa. v. Casey, 505 U.S. 833, 870 (1992) (recognizing a constitutionally protected interest in abortion); Roe v. Wade, 410 U.S. 113, 164-65 (1973) (same); Eisenstadt v. Baird, 405 U.S. 438, 453-54, 463-66 (1972) (extending recognition of privacy interests in making decisions with respect to contraception to unmarried individuals); Griswold v. Connecticut, 381 U.S. 479, 486 (1965) (recognizing constitutional interests in making decisions with respect to contraception).

central to personal dignity and autonomy . . . . "252 Whether they include all manner of neoeugenic reproductive decisions remains to be seen. Only one court has addressed this issue, and only in part, deciding that reproductive interests include the ability to use reproductive technologies to bring about pregnancy and submit to prenatal testing.<sup>253</sup> One of the biggest proponents of reproductive technologies is John Robertson, who describes "procreative liberty" as "freedom in activities and choices related to procreation."254 He has argued that "if bearing, begetting, or parenting children is protected as part of personal privacy or liberty, those experiences should be protected whether they are achieved coitally or noncoitally,"<sup>255</sup> and thus these liberties include in vitro fertilization and other techniques to treat infertility, 256 decisions whether or not to engage in "selection of offspring characteristics,"257 and some decisions to engage in reproductive cloning.<sup>258</sup> Of course, even if parental autonomy encompasses much of neoeugenics technology, it does not legitimate every such use of this technology. Some uses may be so harmful that the state could lawfully limit such rights, which of course are not absolute. The presumption, however, is in favor of allowing choice because it sets a "high standard for determining when harmful consequences justify overriding reproductive choice."259

Much of historical eugenics was harmful because physicians and the state grievously impinged on the procreative autonomy of thousands by

<sup>252.</sup> Casey, 505 U.S. at 851.

<sup>253.</sup> Lifchez v. Hartigan, 735 F. Supp. 1361, 1377 (N.D. Ill. 1990) (recognizing that "within the cluster of constitutionally protected choices . . . must be . . . the right to submit to a medical procedure that may bring about, rather than prevent, pregnancy . . . [and] the right to submit to [prenatal testing,] which can then lead to a decision to abort").

<sup>254.</sup> John A. Robertson, Embryos, Families, and Procreative Liberty: The Legal Structure of the New Reproduction, 59 S. CAL. L. REV. 942, 955 (1986).

<sup>255.</sup> John A. Robertson, Children of Choice: Freedom and the New Reproductive Technologies 39 (1994).

<sup>256.</sup> Id. at 100.

<sup>257.</sup> *Id.* at 153 (suggesting that these techniques fall within these liberty interests if they are "determinative of decisions to procreate"). Robertson argues that mandatory carrier or prenatal screening does not interfere with procreative liberty interests because one is free to ignore the results, though he argues that such state actions would interfere with privacy interests and interests in bodily integrity. *Id.* 

<sup>258.</sup> John A. Robertson, *Why Human Reproductive Cloning Should Not in All Cases Be Prohibited*, 4 N.Y.U. J. LEGIS. & PUB. POL'Y 35, 39 (2000) (arguing that reproductive cloning to treat infertility or address the risk of serious genetic disorders falls "within our standard conceptions of family or procreative liberty," though remaining agnostic about "the question of whether one has the right not only to reproduce, but also to totally select the genome of his or her offspring").

<sup>259.</sup> ROBERTSON, supra note 255, at 153.

taking away the right to make decisions about a matter so "central to [their] personal dignity and autonomy."<sup>260</sup> Some might claim that prohibiting certain uses of genetic technology—trait selection, for example—is an infringement of reproductive choices and thus harkens back to the eugenics era. This argument would suggest that the crucial distinction between neoeugenics and eugenics is whether people can freely exercise their procreative autonomy. It suggests that as long as people can make procreative choices unimpeded by state restrictions (except perhaps where the state interest is compelling or does not impose an undue burden),<sup>261</sup> we avoid the concerns of eugenics.

The problem with this argument is that the concerns regarding eugenics, as we shall see in Section V.B below, are more complex; they do not simply include limits on reproductive freedoms. 262 Moreover, this argument suggests a thin conception of autonomy and decisional privacy interests, which tends to minimize consideration of other social concerns<sup>263</sup> that also apply to some aspects of eugenics and neoeugenics. Our culture seems to have adopted an "atomistic conception of self-definition, in which the individual shapes herself without reference to others."<sup>264</sup> Indeed, Justices Souter, Kennedy, and O'Connor reflected such views in Planned Parenthood of Southeastern Pennsylvania v. Casey, when they wrote: "[A]t the heart of liberty is the right to define one's own concept of existence, of meaning, of the universe, and of the mystery of human life. Beliefs about these matters could not define the attributes of personhood were they formed under compulsion of the State."265 This conception of personhood sees the self "in terms of mere isolated actions" or as "independent from the interests and attachments we may have at any moment, never identified by our aims but always capable of standing back to survey

<sup>260.</sup> Planned Parenthood of Se. Pa. v. Casey, 505 U.S. 833, 851 (1992).

<sup>261.</sup> See Gonzales v. Carhart, 2007 U.S. LEXIS 4338 (2007) (finding that a statute that prohibits partial birth abortion is as not on its face an undue burden and is therefore constitutional).

<sup>262.</sup> See infra Section V.B.

<sup>263.</sup> This is not to say that social interests are irrelevant under this version of autonomy. But it does mean that the presumption is in favor of not interfering with the autonomy interest because the libertarian conception of autonomy sets a high standard for determining when harmful consequences can justify overriding the individual's presumptive right. *See supra* text accompanying note 259.

<sup>264.</sup> Sonia M. Suter, *Disentangling Privacy from Property*, 72 GEO. WASH. L. REV. 737, 772 (2004) [hereinafter Suter, *Disentangling Privacy*].

<sup>265. 505</sup> U.S. at 851 (plurality opinion).

<sup>266.</sup> CHARLES TAYLOR, SOURCES OF THE SELF: THE MAKING OF MODERN IDENTITY 206 (1989) (citing ALASDAIR MACINTYRE, AFTER VIRTUE: A STUDY IN MORAL THEORY 217 (1981)); Suter, *Disentangling Privacy*, *supra* note 264, at 770.

and assess and possibly to revise them."<sup>267</sup> Two philosophers describe and criticize this individualist account:

[Charles] Taylor describes a common view of the self as making life plans and seeking relationships only insofar as they are "fulfilling" and "largely based on ignoring our embedding in webs of interlocution." . . . [Alasdair] MacIntyre describes "modern individualism" as holding that "I am what I myself choose to be. I can always, if I wish to, put in question what are taken to be the merely contingent social features of my existence."<sup>268</sup>

The development of modern bioethics, in response to abuses of human research subjects and medical paternalism, has largely promoted and privileged a notion of autonomy modeled after a Kantian or "deontological self," the "moral frailty" of which Michael Sandel rightly criticizes. He describes such an "unencumbered" and "independent" self as "essentially dispossessed" and "too thin to be capable of desert in the ordinary sense. . . . To imagine a person incapable of constitutive attachments . . . is not to conceive an ideally free and rational agent, but to imagine a person wholly without character, without moral depth." This notion of procreative autonomy focuses "on our individual goals [which] dissolves community and divides us from each other." From this perspective, neoeugenic choices rarely seem problematic as long as they are motivated by the individual's procreative goals and self-definition (and they do not interfere with a compelling state interest). This is so even if the procreative choices were not necessarily in the best interest of the child or society. 272

<sup>267.</sup> Michael H. Sandel, Liberalism and the Limits of Justice 175, 178 (1987).

<sup>268.</sup> Suter, Disentangling Privacy, supra note 264, at 773 n.173.

<sup>269.</sup> Tom L. Beauchamp & James F. Childress, Principles of Biomedical Ethics 348-55 (5th ed. 2001) (providing an overview of Kantianism); Barry R. Furrow et al., Bioethics: Health Care Law and Ethics 19 (5th ed. 2004) (noting the widespread acceptance of Kantian individualism in bioethics because "many people have come to regard the Kantian emphasis on individual rights as a necessary corrective to the crude tendency of utilitarianism to sacrifice the individual for the greater good" and "the emphasis on moral sovereignty of the individual strongly appeals to the individualistic ethos of our culture"); see also Barbara Secker, The Appearance of Kant's Deontology in Contemporary Kantianism: Concepts of Patient Autonomy, 24 J. Med. & Phil. 43, 43-44 (1999) ("[A] Kantian concept of autonomy and the principle of respect for autonomy find their inspiration in Kant's deontology, which is one of the major theoretical frameworks underlying bioethical argumentation.").

<sup>270.</sup> SANDEL, supra note 267, at 178-79.

<sup>271.</sup> TAYLOR, *supra* note 266, at 500-01.

<sup>272.</sup> This approach protects individualism to a strong degree. It is not purely individualistic, because individual autonomy rights are not absolute. But the presumption is strongly in favor of individual choice. Of course, this analysis says nothing about com-

But this Kantian account is not the only conception of autonomy. Evaluating the concerns of eugenics requires us to consider what we mean by self-definition and personhood—terms which underlie our conception of reproductive autonomy and decisional privacy. In another piece conceptualizing privacy interests, I argued for a notion of personhood that is "bound up and expressed in relation to others" 273 and does not focus on individual goals that are disaggregated from community and personal history. Our autonomy and privacy interests in making self-defining decisions, such as those linked to procreation, are empty and thin unless we define ourselves and our "moral identity in and through its membership in communities such as those of the family, the neighborhood, the city and the tribe."<sup>274</sup> Certain strands of feminism have similarly argued for a more relationship-based conception of procreative autonomy, criticizing a libertarian conception "for its tendency to treat individuals atomistically, emphasizing rights rather than relationships and responsibilities for others as well as for oneself."<sup>275</sup>

peting moral arguments that might suggest that, even if this conception of procreative autonomy justifies the choice, other moral arguments do not.

273. Suter, *Disentangling Privacy*, *supra* note 264, at 763. *See generally id.* at 737; Robert W. Tuttle, *Reviving Privacy*?, 67 GEO. WASH. L. REV. 1183, 1189-91 (1999) (arguing that "the absolute value of self-fulfillment ends in self-defeat").

274. MACINTYRE, *supra* note 266, at 205. MacIntyre writes: [T]he story of my life is always embedded in the story of those communities from which I derive my identity. I am born with a past; and to try to cut myself off from the past, in the individualist mode, is to deform my present relationships . . . . What I am, therefore, is in key part what I inherit, a specific past that is present to some degree in my pre-

*Id.*; see also id. at 200 ("We live out our lives, both individually and in our relationships with each other, in light of certain conceptions of a possible shared future."); id. at 201 ("We enter human society . . . with one or more imputed characters—roles into which we have been drafted—and we have to learn what they are in order to . . . understand how others respond to us and how our responses to them are apt to be construed.").

275. Mary B. Mahowald, *Genetic Technologies and Their Implications for Women*, 3 U. CHI. L. SCH. ROUNDTABLE 439, 458 (1996) ("What is essential to that critique is that it starts with a concept of human beings not as isolated individuals but as individuals whose meaning and reality are definable and sustainable only in the context of their relationships."); *see also* CAROL GILLIGAN, IN A DIFFERENT VOICE: PSYCHOLOGICAL THEORY AND WOMEN'S DEVELOPMENT (1993); NEL NODDINGS, CARING: A FEMININE APPROACH TO ETHICS AND MORAL EDUCATION 43, 79-81 (1984) (describing care models of moral reasoning). They also suggest that because atomistic notions of liberty and autonomy tend to focus on rationality and privilege mind over body, they indirectly devalue women, who are tied so much to the physical when their bodies are so central to "gestation, birth, and early nurturance of children." Mahowald, *supra*, at 456.

As Section V.B below will show, this conception of personhood and autonomy yields more complex conclusions as to the legitimacy of certain neoeugenic choices. Whereas the atomistic conception of autonomy justifies decisions as long as they are an exercise of individual decision making, the relationship-based conception of autonomy would evaluate neoeugenic or eugenic choices in terms of the self in relation to our families and community. Under this conception, choices would not be "central to dignity and autonomy" merely because they promoted atomistic self-definition. They must also be choices central to the development and expression of the relational self. Of course, as we shall see, the calculus can be complex: the motivations and responses may be multiple and sometimes conflicting, perhaps not fully clear to the individual making the choice, or subject to change once the child is born.

# B. Evaluating Eugenics Through the Lens of Relational Autonomy

As discussed above, contemporary developments in law, medicine, and ethics, which have privileged the principle of autonomy, have done much to eradicate some of the grave injustices associated with the eugenics movement. However, the lens of relational autonomy focuses on intent and motivation and reveals problems with neoeugenics that are more subtle and contextual than state interference with reproductive and medical decision making. By asking us to think about procreative autonomy in terms of a self connected with family, friends, community, nation, and even world, this analysis asks us to consider the effects of our neoeugenic choices on all of the worlds of which we are a part. It forces us to confront underlying prejudices that may motivate our choices and to consider the larger societal impact of making such choices. We must also think about the nature of our community and how our choices will affect the less fortunate with respect to both discrimination and inequities. Further, we should consider what our goals are in influencing reproduction and what effect they may have on our future children, existing children, marriage, family, and community.

One of the key criticisms of eugenics under this analysis is the underlying prejudice and stereotyping regarding race, ethnicity, class, "tem-

<sup>276.</sup> Libertarian autonomy generally justifies a decision as long as it reflects unencumbered individual choice. In contrast, relational autonomy asks not merely whether a choice is unencumbered but whether the choice considers the self in its full relational capacity. Again, as suggested in note 272, *supra*, autonomy interests under either theory are not absolute and may be overridden by certain compelling state interests.

perament," and cultural attitudes.<sup>277</sup> Unfortunately, similar concerns exist today with respect to neoeugenics, which may ultimately contribute to and be shaped by prejudice and stereotypes of different groups. An extensive literature describes the way in which these technologies are harmful to the disabled community or any community possessing a trait that is selected against. By promoting technologies to avoid the birth of children with genetic conditions or unwanted traits, we define the "unfit" (though perhaps we don't use precisely that expression) in terms of that disability or trait. This fact alone may devalue the lives of those with the trait.<sup>278</sup> Majority views regarding disabilities often reflect the able-bodieds' misperceptions and stereotypes about the experiences of the disabled, in large part, because of lack of experience with the disabled community.<sup>279</sup> If reproductive technologies are used widely enough to reduce the incidence of children born with disabilities,<sup>280</sup> then our social awareness of and sensitivity

Tom Shakespeare, Eugenics, Genetics and Disability Equality, 13 DISABILITY & SOC'Y 665, 669 (1998); see also Jerry Alan Winter, The Development of the Disability Rights Movement as a Social Problem Solver, 23 DISABILITY STUD. Q. 33, 43 (2003) (noting that the social model views "disabled persons . . . as the collective victims of an uncaring or unknowing society rather than as individual victims of circumstances [such as impairment]" and that "while not denying 'the significance of impairment in people's lives' . . . the social model holds that 'people with . . . impairments are disabled by society's blatant failure to accommodate to their needs." (citation omitted)).

280. For example, "[p]renatal diagnosis and genetic counseling have drastically reduced the incidence of births of Tay-Sachs children; in 1980, only 13 cases were reported in the North American Jewish population." Nancy K. Rhoden, *Treatment Dilemmas for Imperiled Newborns: Why Quality of Life Counts*, 58 S. CAL. L. REV. 1283, 1292 n.70 (1985); *see also* Dorothy C. Wertz & John C. Fletcher, *A Critique of Some Feminist Challenges to Prenatal Diagnosis*, 2 J. WOMEN'S HEALTH 173 (1993) ("The sharp reduction in incidence of certain birth defects, such as Tay-Sachs in the United States and spina bifida or thalassemia in the United Kingdom, suggests that families are making what amount to 'eugenic' decisions in regard to these disorders, which most people regard as serious."). *But see* Weil, *supra* note 154, at 51 ("There's enough evil and caprice to always assure there will be disabilities." (quoting Professor Laurie Zoloth)); Wertz & Fletcher, *supra* ("For less serious disorders, . . . it is less likely that individual decisions will have a eugenic effect in a pluralistic society . . . . Even if every pregnancy underwent

<sup>277.</sup> See supra text accompanying notes 28-29, 88-90, 93, 116, 218.

<sup>278.</sup> See, e.g., Wachbroit, *supra* note 153, at 334 (stating that what is "prima facie wrong" with using sex selection to select males "is that it insults the dignity of women; it demeans the value of being female").

<sup>279. [</sup>T]he disability movement, and many others, would contest [the medical community's] labeling of all human genetic variation as "disease".... In general, the disability movement rejects the "medical model" focus on impairment as the defining characteristic of life as a disabled person, [arguing] it is social barriers which create disability, and that the difficulties of living as a disabled person are due to discrimination and prejudice, rather than impairment.

to the disabled community may further diminish. Misunderstandings about quality of life for the disabled will only increase if fewer disabled people inhabit the world.

Similarly, if certain traits—e.g., short stature, gender, certain bodytypes, etc.—can be selected against and are widely disfavored, individual choices, in the aggregate, may lead to fewer people with those traits. The resulting lack of diversity may be problematic in several ways. First, it may contribute to a lack of tolerance for diversity and enhance existing prejudices against individuals with the particular trait. As fewer individuals exist with particular traits, we may increasingly think about those individuals in terms of their traits or disabilities, rather than for who they are. As such traits or disabilities become rarer, our increasing lack of experience with them may increase our ignorance about the effect of those traits on the individuals and perhaps create some discomfort regarding those traits. The ultimate fear is that such attitudes would reinforce the very prejudices that initially drove people to select against these traits, <sup>282</sup> just as ignorance and prejudice regarding undesirable traits escalated during the eugenics era. <sup>283</sup>

Relational autonomy raises special concerns with respect to prenatal testing for diseases for which no treatment is available, i.e., selecting against genetic disease by selecting against the diseased individual. To some, the choice seems like a decision about who should exist and who should not. It tends "to reduce fetuses to a single trait, their impairment," which may threaten the disabled community or the community that possesses the trait selected against. To phrase this criticism slightly differently, the eugenics of yesteryear and the neoeugenics of today seek "better' (or 'fortunate') people rather than people who are made 'better'

<sup>...</sup> prenatal diagnosis ... and every woman agreed to abortion ..., society would still have children with [genetic] birth defects ...").

<sup>281.</sup> See Bob Sapey, From Stigma to the Social Exclusion of Disabled People, in STIGMA AND SOCIAL EXCLUSION IN HEALTHCARE 270 (Tom Mason et al. eds., 2001) (describing how deafness is viewed as "a minor problem, rather than a major misfortune" in a community where deafness is common and individuals with disabilities were valued by relatives for "characteristics other than their impairments, although to outsiders they continued to elicit negative responses").

<sup>282.</sup> The effects of certain traits becoming rare can, of course, be complicated. For example, if sex selection were to lead to a shortage of females, their scarcity might make them more desirable, if nothing else, for purposes of procreation. But they might then become commodified, and hence devalued, if they were desired primarily for their capacity to bear children.

<sup>283.</sup> See supra text accompanying notes 28-29, 88-90, 93, 116, 218.

<sup>284.</sup> Weil, supra note 154, at 51.

(or 'fortunate')."<sup>285</sup> Until we can treat diagnosable genetic conditions, prenatal testing cures or improves no one; instead, individuals are "benefited" by being prevented from existing.

Of course many decisions we make as a society or individually influence who will come into existence and who will not. Decisions such as whom to marry, when or whether to procreate, as well as decisions about health policy and social services, for example, all influence who will be born and who will not.<sup>286</sup> But in these examples, the effect is not always intended; with classic eugenics or neoeugenics, the goal *is* to influence who will exist and who will not. Yet, the intentionality alone is not sufficient to condemn eugenics. We do not view all intentionality with respect to reproduction as problematic. For example, we do not condemn the choice of a mate on the grounds of the kind of parent he or she would be.<sup>287</sup> It is certain *kinds* of reproductive choices that are troubling, not the mere fact of making a reproductive choice.

When the intent to influence reproduction is grounded in prejudice or defining the fetus solely in terms of the undesirable trait or disease, then it becomes problematic under a relational-autonomy analysis. It promotes a fragmented conception of individuals with those traits or diseases and limits us from seeing them in their wholeness as humans. When the state determines which lives are unacceptable (whether based on devaluation of certain traits or to prevent suffering) or desirable (whether based on valuing certain traits or wanting to enhance opportunities), it raises acute concerns about society's devaluing (or privileging) certain groups. If individuals make such decisions, the concerns are somewhat lessened. Individuals will differ in their determinations about which lives are worth bringing into existence. Moreover, neoeugenics avoids the problem of one entity—the empowered—imposing reproductive values and choices on another—the disempowered. Nevertheless, while we are in this pre-

<sup>285.</sup> Wikler, *supra* note 2, at 187 (noting that this "complaint faults eugenics for posing as a doctrine of benevolence").

<sup>286.</sup> DEREK PARFIT, REASONS AND PERSONS (1984); Wikler, *supra* note 2, at 188.

<sup>287.</sup> Wikler, *supra* note 2, at 188.

<sup>288.</sup> See Jones, supra note 2, at 215.

<sup>289.</sup> See Weil, supra note 154, at 51 ("There's enough evil and caprice to always assure there will be disabilities." (quoting Professor Laurie Zoloth)); Wertz & Fletcher, supra ("For less serious disorders, . . . it is less likely that individual decisions will have a eugenic effect in a pluralistic society . . . . Even if every pregnancy underwent . . . prenatal diagnosis . . . and every woman agreed to abortion . . . , society would still have children with [genetic] birth defects . . .").

<sup>290.</sup> Of course, one might argue that in one sense the problem is not altogether avoided since the embryo is clearly disempowered. But at least neoeugenics avoids the

therapeutic stage where "treatment" means termination, neoeugenics creates an uneasy tension between individual reproductive interests and concerns about harms to particular groups since social norms push individuals toward similar attitudes and decisions.<sup>291</sup>

To the extent that neoeugenics can enhance the tendency to identify individuals solely in terms of their disabilities or undesirable traits, it becomes problematic under norms of relational autonomy. This is another way of undermining the relationship between an individual and some of the vulnerable members of the community of which she is a part, which further "dissolves community and divides us from each other." No easy resolution can alleviate this tension, though thoughtful consideration of the meaning of "disability" within our community and among individuals facing these reproductive choices is a necessary first step. Indeed, these very tensions should be part of the moral deliberation faced by individuals, couples, and families as they confront the difficult choices about which children they do or do not want to bring into the world. The goal of relational autonomy here is to promote consideration of the full effects of reproductive choices on ourselves, those with whom we have relationships, and the larger community of which we are a part.

As relational autonomy shows, these contextual concerns lie not with reproductive technologies or eugenics per se, but with cultural attitudes and prejudice. In fact, to the extent that "stereotypes or prejudices are a problem, they are a problem for environmental interventions as well."293 Of course, we should be concerned about actions and trends that exacerbate harmful attitudes, just as we should worry about how prejudice drives other choices made by individuals or society. But "evil use does not make eugenics evil in nature."294 Classic eugenics was so wrong in large part

problem of one person imposing values on another, if one accepts the view that an embryo, while full of potential, is not a person.

<sup>291.</sup> See Koch, supra note 111, at 316 (noting that some express concerns that "cultural pressures and informal forms of coercion, such as social expectations or economic considerations, shape individual choices toward a common norm"); Suter, Routinization, supra note 151; supra Part IV.

<sup>292.</sup> SANDEL, supra note 267, at 178. Such a choice would be an example of the kind of individualism that impoverishes our conception of the self. See MACINTYRE, supra note 266, at 220-21 (criticizing such individualism for failing to recognize that "I inherit from the past of my family, my city, my tribe, my nation, a variety of debts, inheritances, rightful expectations and obligations. These constitute the given of my life . . . . This is what gives my life its own moral particularity"); TAYLOR, supra note 266, at 506-08 (describing the danger of giving primacy to self-definition at the expense of other moral demands, which results in, among other things, a disintegration of community affiliations).

<sup>293.</sup> BUCHANAN ET AL., supra note 34.

<sup>294.</sup> Jones, *supra* note 2, at 215.

because it was deeply grounded in strong, pernicious prejudices and stereotypes. As we move into the era of neoeugenics, we will face the difficult question as to whether individuals will be able to make reproductive choices that are grounded in thoughtful consideration of the implications to the self, family, and community, instead of choices grounded in uneducated prejudice and stereotyping. We may well conclude that "evil uses"—in this case prejudicially motivated choices—are unavoidable or too difficult to prevent, and therefore present a reason to limit neoeugenics. Such a conclusion, however, is not a rejection of neoeugenics per se, but a statement about our inabilities to pursue its goals fairly and justly.

Viewed through the lens of relational autonomy and self-hood, neoeugenics raises additional concerns in light of existing inequalities. Those with the greatest advantages in society (and often with the traits most widely favored) will often have greater resources and therefore greater access to technologies that allow them to select against certain traits or disease or to enhance certain traits. One could imagine a scenario where undesirable traits or disease become less prevalent, proportionately, among the advantaged and more prevalent, proportionately, among the more socially disadvantaged. Such an outcome would further exacerbate negative associations with such traits and exacerbate inequities, further fragmenting society and the individuals within it: "dissolving community" in pernicious ways.

Here again, the concern is not unique to neoeugenics; all sorts of opportunities that confer societal advantages are not equally available. Education, health care, housing, and clean environments, for example, are not evenly distributed within our culture today any more than they were during the eugenics era. These underlying inequities, not eugenic goals, raise deep and difficult challenges regarding distributive justice. Similar concerns applied to classic eugenics, including a fear that the Social Darwinism that inspired eugenics did nothing to overcome such inequalities, but instead excused them. <sup>296</sup> As a society, we will have to decide whether the fragmentation will be too great and whether we should avoid adding one more advantage to the collection of advantages that are distributed unequally. But we should recognize that, again, we are condemning the consequences of underlying inequities, not neoeugenics per se.

Relational autonomy raises additional concerns about the possible harm to the community at large if there were to be an aggregate effect of

<sup>295.</sup> Sandel, however, contends that this argument assumes that enhancements are good and therefore it is the disadvantaged who are deprived here. But, if enhancement is in fact not good, than the inequality cuts the other way. Sandel, *supra* note 149, at 50.

<sup>296.</sup> See HALLER, supra note 89, at 84.

many individuals selecting against certain disabilities or traits. Some have argued that a reduction in diversity may be evolutionarily problematic if we end up eliminating genes that would have, at some point in the future, provided a selective advantage against environmental insults. To some extent this concern depends on how genetically homogenous the population would become. It is unlikely that the choices among the population would be so uniform as to move us toward a population with no genetic diversity. "A standard calculation from population genetics shows that reducing the frequency of a recessive gene from 5 percent to 2.5 percent, even with a vigorous eugenics program, would take more than two hundred generations."297 Moreover, medical treatments generally interfere with the "natural" process of evolution, and yet, for the most part, we welcome medical advancements. Some might argue, in fact, that such advancements reflect a kind of evolution of our intellectual capacity. Ultimately, the concern seems too speculative and not sufficiently unique to condemn neoeugenics, as opposed to other medical "treatments."

Perhaps one of the chief concerns that relational autonomy highlights with respect to eugenics is the risk that it commodifies reproduction: that is, that we may come to see the child as a commodity, not a "gift" to be accepted as he or she is.<sup>298</sup> The essence of this claim is that commodifica-

<sup>297.</sup> Wachbroit, supra note 153, at 335.

<sup>298.</sup> See Sandel, supra note 149, at 55 (claiming that genetic engineering challenges parents' ability to "appreciate children as gifts [and] to accept them as they come, not as objects of our design or products of our will or instruments of our ambition"); BARUCH ET AL., supra note 177, at 6 ("Rather than the currently prevailing view of reproduction as a mysterious process that results in the miraculous gift of a child, human reproduction could come to be seen more as the province of technology and children the end result of a series of meticulous, technology-driven choices."); THE PRESIDENT'S COUNCIL ON BIO-ETHICS, HUMAN CLONING AND HUMAN DIGNITY: AN ETHICAL INQUIRY XXIX (2002), available at http://www.bioethics.gov/reports/cloningreport/pcbe cloning report.pdf (expressing concerns that children created from technologies like cloning "might come to be considered more like products of a designed manufacturing process than 'gifts' whom their parents are prepared to accept as they are"); THE PRESIDENT'S COUNCIL ON BIO-ETHICS, BEYOND THERAPY: BIOTECHNOLOGY AND THE PURSUIT OF PERFECTION 37 (2003), available at http://www.bioethics.gov/reports/beyondtherapy/beyond\_therapy\_ final\_webcorrected.pdf (Prenatal screening may "be shifting parental and societal attitudes toward prospective children: from simple acceptance to judgment and control, from seeing a child as an unconditionally welcome gift to seeing him as a conditionally acceptable product . . . . [Such attitudes] might feed the desire for better—and still better children."); cf. Gleitman v. Cosgrove, 227 A.2d 689, 693 (N.J. 1967) (discussing the merits of a malpractice action for failure to inform parents about risk of birth defects and concluding that a "court cannot say what defects should prevent an embryo from being allowed life . . . . A child need not be perfect to have a worthwhile life . . . . Eugenic con-

tion *intrinsically* harms our human spirit by altering our relationship with procreation and our children because it transforms reproduction into a process akin to manufacture.<sup>299</sup> If neoeugenics results in such commodification, which I shall argue it sometimes will and sometimes won't, then it threatens relational autonomy because it promotes a view of the future child not in terms of his or her potential fullness, but in terms of the trait chosen or rejected. Commodification fragments our relationship with the experience of reproduction by diminishing our connection with our future child. Instead of viewing the future child as part of the community that defines us, we view it as something separate from us and our deep relationships. The risk is that we will see the future child as "thing" rather than as another human being.

The concerns regarding commodification, however, are to some extent speculative. The mere fact that individuals are interested in "improving" the birth of their children does not in and of itself mean that reproduction and the child will be commodified, or worse, that they will be solely viewed as a commodity. Simply because parents try to control the outcome of reproduction, rather than to allow things to happen "naturally," does not preclude them from viewing their children as a gift. As we have seen in several other instances, the evaluation of neoeugenics in terms of relational autonomy depends on motivation and intention. If, while making reproductive choices, parents are able simultaneously to view the process of reproduction as something richer than manufacture, and their resulting children as a gift, then commodification concerns are reduced. As reproductive options develop, we should pay close attention to the changes in psychological dynamics experienced by parents in terms of their relationship with reproduction and their future children. We cannot dismiss neoeugenics on the grounds of commodification without further evidence that the risk is more than speculative. Nevertheless, we should be mindful of this possibility, and providers of reproductive technologies would do well to draw this to the attention of future parents.

Fears of commodification also raise some consequentialist concerns. If we understand reproduction as the "manufacture" of children, perhaps we

siderations are not controlling. We are not talking here about the breeding of prize cattle").

<sup>299.</sup> See LEON R. KASS, LIFE, LIBERTY AND THE DEFENSE OF DIGNITY 159-60 (2002) ("Human cloning would . . . represent a giant step toward the transformation of . . . procreation into manufacture . . . [which] has already begun with *in vitro* fertilization and genetic testing of embryos . . . . Procreation dehumanized into manufacture is further degraded by . . . allowing babymaking to proceed under the banner of commerce.").

will engage in their "quality control."<sup>300</sup> It is worth recognizing, however, that in many different ways, parents actively try to influence and shape a child to enhance qualities the parents value and believe will benefit the child. Parents discipline and educate their children, have them vaccinated, pay enormous sums to orthodontists, send their children to sports or music camps, and even take prenatal vitamins before becoming pregnant, all with the goal of improving their children morally, socially, intellectually, and physically. These goals of improvement are commended, not condemned.

Therefore, it seems that attempts to improve our children cannot be what principally troubles individuals about eugenics, unless improvement at the genetic level is fundamentally different. Perhaps the concerns stem from deeply held notions of genetics essentialism or determinism—ideas that our genes go to the essence of who we are and that to alter them in any way is to alter ourselves fundamentally. Such views, of course, overstate the importance of genetics and understate the importance of environment. Our essence in many ways is influenced by the combination of genes we have. But our education, family, culture, and social experiences also play a tremendous role in shaping our character. In addition, genes and environment interact in complex ways. Environment can influence gene expression, and genes can affect the way environment influences us. Thus, it cannot alone be the fact of altering one's genes as opposed to altering other aspects of the individual that is problematic. "For each of us, it is particular elements of our phenotype, not every element of our ge-

When an infant is vaccinated, the vaccine triggers an immune reaction that permanently affects the ability of the immune system to respond to particular bacteria or viruses . . . . If it were any one of us, we would not be inclined to muse, "I wonder who I would have been had my parents not altered my immune-system gene in this way."

BUCHANAN ET AL., supra note 34, at 160.

<sup>300.</sup> BARBARA K. ROTHMAN, THE TENTATIVE PREGNANCY: HOW AMNIOCENTESIS CHANGES THE EXPERIENCE OF MOTHERHOOD 11 (1996) ("In gaining the choice to control the quality of our children, we may rapidly lose the choice not to control the quality, the choice of simply accepting them as they are.").

<sup>301.</sup> For example:

<sup>302.</sup> Id. at 160-61.

<sup>303.</sup> See generally RIDLEY, NATURE, supra note 199 (discussing how environment affects the way genes express themselves).

<sup>304.</sup> *Id.* at 149-50 (describing the way long-term stress created by external events like the loss of a loved one causes the body to produce increased amounts of the hormone cortisol, which causes certain genes to be expressed, which in turn activates other genes).

notype, that we take to be central to our conceptions of self and to our essence as an individual." $^{305}$ 

An additional concern is that parents who engage in "quality control" of their children may become less willing to accept their children as they are because these parents will be less tolerant of imperfections and deviations from the norm. 306 This lack of tolerance may lead the parents to impose considerable pressure on the child to develop the traits or characteristics that the parents sought through neoeugenics. The child born with enhanced intelligence (presuming intelligence can be enhanced genetically) may feel compelled to perform exceptionally well in school; the child that develops from an embryo selected in favor of others with genes predisposing them to short stature may feel pressure to become an accomplished basketball player. If parents care strongly enough about certain traits to manipulate reproduction, their expectations may be overwhelming for the future child. In addition, instead of basing their relationship with the child on the person the child becomes, the relationship may center on the child's capacity to fulfill the parental expectations that drove their reproductive choices. The fear is that the relationship would be superficial and thin because it would not embrace the fullness of the child. Again, relational autonomy raises concerns of fragmentation of relationships and also fragmentation of the self because it argues that these relationships are central to the self.

Yet again these concerns are not limited to eugenics. Parents who have not manipulated reproduction may also have overbearing expectations for their children, relating to them only in terms of traits they value, while ignoring fundamental elements of the child's personality and life. Imagine the following scenario borrowed from the television series, *Real Housewives of Orange County*. A teenager whose father and grandfather were professional baseball players is raised with the constant message that he has the "genes" for baseball and an "obligation" to fulfill his family's dreams of his becoming another professional player. If the father's relationship with him centers almost exclusively on baseball, the son may adopt a similarly narrow outlook, deciding that little else matters. In addition, the father's relationship with other children may suffer if there is no baseball connection through which to bond. The son is not valued for himself and encouraged to develop broadly. Instead he is valued for his ability to fulfill parental expectations, measured narrowly by proficiency with

<sup>305.</sup> BUCHANAN ET AL., supra note 34, at 161.

<sup>306.</sup> This can result in the concern described earlier of reduced tolerance for diversity or imperfection, generally. *See supra* text accompanying notes 159, 198-200.

respect to a particular skill.<sup>307</sup> Unfortunately, all of us could describe similar stories based on people in literature, film, or our lives. The harm in these anecdotes is not attempting to control reproduction, but attempting to control the existing child. The harm is not valuing athletic skills, intelligence, artistic ability, or any other talents, but doing so to the exclusion of other aspects of the child and failing to value the child's fullness as a human being.<sup>308</sup>

Concerns about overbearing parental expectations in the context of neoeugenics seem to presume that the hopes underlying the reproductive choices will increase the possibility of being overbearing. Perhaps that is true if the parents engaging in neoeugenics take a genetics essentialist perspective. But, whether parents try to shape their children through neoeugenics or environmental influences, "the experience of childrearing will sometimes transform [one's] initial impulses, making them caring, respectful, and even self-sacrificing." <sup>309</sup> Of course, "[t]he pace and extent of moral development among parents ... is infinitely variable"310 and some parents, as in the baseball example, do not easily overcome the more detrimental impulses, whether or not they use neoeugenics. To presume that certain hopes and expectations influencing neoeugenics will crowdout others or will diminish the capacity to experience the fullness of the child is not only speculative, but seems to dismiss the "moral complexities of parenting."311 If parental pressure ends up being too great in this context, "we would have cause to say that [such parents] wronged their chil-

<sup>307.</sup> The Real Housewives of Orange County, a television series that explores the sociological milieu of a wealthy, insular community in Southern California, starkly presents the way in which highly superficial attitudes can impoverish parent-child relationships, including a situation much like the one I describe. When the teenage son is drafted for professional baseball in the 36th round, the father is disappointed because he was not selected by the 6th or 7th round. Ironically, the pressure to focus solely on baseball results in the son's poor academic performance and inability to play baseball on his high school team his senior year, which ultimately harmed his drafting potential. In addition, the daughter, who excels in school, is largely ignored by her father because she does not have the baseball connection with her father. This story is one of many in a series that exposes the thinness and superficiality of a culture that values appearance, wealth, and status over substance.

<sup>308.</sup> It is understandable that a family that values baseball might hope their child would have potential as a baseball player. It is how these hopes are expressed and the extent to which they crowd out an interest in and engagement with other aspects of the child that matters.

<sup>309.</sup> Robert Wachbroit, *Genetic Encores: The Ethics of Human Cloning*, REPORT FROM THE INSTITUTE OF PHILOSOPHY AND PUBLIC POLICY, Fall 1997, at 6, *available at* http://www.publicpolicy.umd.edu/IPPP/Fall97Report/cloning.htm.

<sup>310.</sup> *Id*. 311. *Id*.

dren only because of their subsequent, and avoidable, sins of bad parenting—not because they had chosen to create the child in the first place."<sup>312</sup> Nevertheless, we should be concerned about the growing and cumulative ways in which parents may be tempted in this direction.

While relational autonomy raises several concerns that apply to neoeugenics, it also potentially justifies one of the most frequently voiced arguments in favor of neoeugenics. The State and others should not interfere with parental decision making (except in extreme cases) because we presume that parents will act in the best interests of their children. In other words, "good parents" will use genetic reproductive technologies to make choices in the best interest of their children, either to prevent suffering or to enhance opportunities. This perspective acknowledges that parents may not always get it right, and perhaps sometimes will not act in the best interests of their children. But it is a kind of rule-utilitarian argument: it presumes that the best decision makers on behalf of the child will generally be the parents, and thus, by allowing parents to make such decisions, we set in place a procedure that is most likely to achieve the best results for children. 313

The force of the relational-autonomy justification, however, depends on the assumption that parents can know what the best interests are in this context.<sup>314</sup> Because of the current inability to treat the disease or undesirable trait, a parent's decision to select against a particular fetus to prevent suffering, for example, raises a complex and perplexing philosophical

<sup>312.</sup> Id. at 2.

<sup>313.</sup> The "good parenting" claim is sometimes offered to argue for the moral desirability of neoeugenics; that is, it suggests that, at least in some instances, we would *expect* parents to engage in this process, just as parents have a duty to provide the best life for their children in other areas. *See* BUCHANAN ET AL., *supra* note 34, at 156; Laura Purdy, *Genetic Diseases: Can Having Children Be Immoral?*, in GENETICS NOW: ETHICAL ISSUES IN GENETIC RESEARCH (John J. Buckley, Jr. ed., 1994). More frequently, the "good parenting" claim is weaker. It argues merely that these choices are legitimate, not because they are necessarily morally desirable choices (sometimes they will be, sometimes they will not be), but because they are within the legitimate authority of parents. BUCHANAN ET AL., *supra* note 34, at 162-63.

<sup>314.</sup> Note that while liberal autonomy would also argue against interference with reproductive decision making, the rationale is different—maximizing the individual's ability to make personal choices without impediment. Under relational autonomy, in contrast, the argument for avoiding undue interference with parental decision making is that such decisions are often made in light of relational considerations. Parents make decisions about whether to undergo reproductive testing or preimplantation genetic diagnosis, for example, not solely based on their needs and desires, but also generally in the interests of their future children. Such an approach seems entirely consistent with relational autonomy—at least in theory.

question: Is it morally preferable to prevent the child's existence or to bring the child into the world with the disease or trait?<sup>315</sup> Some individuals with serious disabilities have declared that they would not have children if they knew they would suffer from the same condition;<sup>316</sup> others have taken precisely the opposite view.<sup>317</sup> Many argue that conditions such as Tay Sachs<sup>318</sup> are so severe and cause so much suffering that non-existence is preferable to existence with the condition. On the other hand, they argue, disabilities such as deafness<sup>319</sup> do not impose much suffering or limit one's capacity and therefore most people would choose existence with those disabilities over non-existence. Although these arguments are motivated by proper relational autonomy concerns, they risk overstating our capacity to decide what the best interests are of those who are denied existence. Parents may genuinely believe they are acting in the best interest of

#### 315. BUCHANAN ET AL., supra note 34, at 225.

Standard accounts of harm compare the condition of an individual before a putative harm has occurred with the condition of that same individual after the putative harm has occurred; the individual has been harmed only if he or she is worse off in the latter condition as a result of the adverse effect of an action or event on his or her interests. But when the only alternative to the putatively harmful condition is not to exist or not to have existed at all, there is no unharmed condition, because there is no unharmed individual with whom to make the comparison.

Id.

- 316. The documentary, THE BOY WHOSE SKIN FELL OFF, offers a heart wrenching and uplifting account of a man who lived 36 years with a genetic condition called Dystrophic Epidermolysis Bullosa, which causes constant pain because the skin is constantly peeling off, exposing the individual to sores all over his body. Despite living heroically and as fully as possible, while also preparing for his death (emotionally and practically), he nevertheless declares that he would not have wanted to bring a child into the world with his condition. *See* TLC.com, About the Film: The Boy Whose Skin Fell Off, http://tlc.discovery.com/fansites/boywhoseskinfelloff/about.html (last visited Mar. 19, 2007).
- 317. See Harriet M. Johnson, The Disability Gulag, N.Y. TIMES MAG., Nov. 23, 2003, at 59; see also Darshak M. Sanghavi, Wanting Babies Like Themselves, Some Parents Choose Genetic Defects, N.Y. TIMES, Dec. 5, 2006, at F1 (describing some parents who are attempting actively to select for certain conditions such as dwarfism or deafness). Dena Davis has criticized such choices when they limit a child's right to an open future. See generally Dena S. Davis, Genetic Dilemmas and the Child's Right to an Open Future, 28 RUTGERS L.J. 549 (1997). Her approach is consistent with relational autonomy because it considers the impact of reproductive decisions on the child.
  - 318. See supra note 222 for a description of Tay Sachs.
- 319. "In [a] case in which the plaintiff's only affliction is deafness, it seems quite unlikely that a jury would ever conclude that life with such a condition is worse than not being born at all." Turpin v. Sortini, 643 P.2d 954, 962 (Cal. 1982) (discussing a wrongful birth case concerning a child born with deafness).

the child they will not bring into existence, but it is virtually impossible to know whether they are right, especially since one would tend to project one's own views about best interests on the person denied existence. How are we to know what the best interests of such a person would be?

It may be true that, in some instances, selecting against a fetus with a particular condition will be in the best interest of the individual who will not come into existence, although the instances would probably differ according to the severity of disease or disability, the nature of the person the fetus would have or has become, and the environment in which they would have lived or do live. Whether parents' beliefs about the best interests of the fetus are correct (or whether mere mortals can know whether the right choice was made) is a real problem. Although this approach is consistent with relational autonomy concerns, we should be wary about relying too much on this rationale in making reproductive choices because of the difficulties of establishing the best interests in this context.

While it may be difficult to determine the best interests of those not yet in existence, we can make better assessments of the best interests of others affected by reproductive decisions—the parents, siblings, other family members, and even community. In my prior experience as a genetic counselor, it often seemed that families spoke about making reproductive decisions to serve the best interests of the unborn child when they were really addressing the best interests of their family. Choices about whether to terminate a pregnancy or to prevent the implantation of certain embryos based on consideration of the best interests of siblings, parents, and family may nevertheless be consistent with relational autonomy concerns because these decisions consider whether the choices enrich the self as understood in relation to family and larger community. In other words, considerations about the effects on the family of having a child who will suffer physically are among the kinds of considerations that relational autonomy demands.

<sup>320.</sup> It is beyond the scope of this Article to discuss whether in some situations no life is preferable to a life with some degree of suffering or disability and, if so, what those situations would be.

<sup>321.</sup> See Speck v. Finegold, 408 A.2d 496, 508 (Pa. 1979) ("Whether it is better to have never been born at all rather than to have been born with serious mental defects is a mystery more properly left to the philosophers and theologians, a mystery . . . beyond the realm of our understanding or ability to solve."). There may be instances where the assertion that non-existence is preferable to existence with a disease is false. There may be instances in which decisions to enhance the fetus are detrimental to the well-being of the future child. Or there may be instances in which, even if the neoeugenic choices benefit the fetus or future child, they interfere with other moral obligations that parents might have. See BUCHANAN ET AL., supra note 34, at 162.

In all of these instances discussed in this Section, our evaluation of neoeugenic choices has less to do with trying to influence reproductive outcomes or genotype, than the motivation and, even more important, the response to the results. Preferring a male child over a female child cannot be deemed problematic on its face. To evaluate such a choice one would need to know the reasons for such a choice and the reactions to the reproductive outcomes. Reproductive choices made solely to promote parental goals of status or prestige—selecting the tallest child because of values with respect to sports, or the smartest embryo because of values related to intellect—seem to impoverish, not promote the dignity of this broader conception of self. A parent's decision to select against or for a trait in a child because of concerns about personal prestige, but also because of concerns about the well-being of that future child, is a more complicated choice—a choice more in keeping with relational autonomy concerns than the prior example. Parents who choose to undergo prenatal selection because they believe they cannot otherwise fulfill their obligations to their existing children, spouses, employers, or themselves are making a choice consistent with procreative autonomy.

The dignity of the relational self depends not only on promoting and nurturing relationships with others, both intimate and less intimate, but also in nurturing the individual. Sometimes choices may benefit others at the expense of the individual; in these instances, evaluation of choices depends on whether the analysis also considers the individual in its fullness, in relation to others and individually. How one approaches these choices is central to assessing whether the choice violates norms of relational autonomy. It seems difficult, given the complexity of human relationships, hopes, and expectations, to condemn most reproductive decisions on their face without understanding their context. Sometimes context will reveal the problematic aspects of the choice; other times it will show that the choice is consistent with relational autonomy.

### VI. CONCLUSION

The goal of this Article is to suggest, first, that although neoeugenics is not identical to the eugenics of yesteryear, many of the same impulses and

<sup>322. &</sup>quot;Anything you might say about the wrongfulness or the rightness of a birth, . . . the particularity of that choice is only, and always, experienced by a particular set of parents in a particular family with certain grandparents, certain aunts and uncles, in a certain religion on a certain block in a certain neighborhood. These are circumstances that as professionals, and certainly as bioethicists, it's nearly impossible to fully understand. And then, of course, we have the luxury of walking away." Weil, *supra* note 154, at 53 (quoting bioethicist, Laurie Zoloth).

drives exist today; most notably, the desire to improve the human species and our children through reproductive choices. That eugenics has been so roundly criticized, rightly so, for abuses of fundamental human rights does not mean that the underlying goal is objectionable per se. Eugenics was problematic because of the manner in which the underlying goal was pursued—through involuntary restrictions of reproductive autonomy, which were applied discriminatorily against the weak, disempowered, and disenfranchised—not because of the goal itself.

Neoeugenics avoids some of these deeply threatening aspects of classic eugenics. Nevertheless, when examined through the lens of relational autonomy, it remains problematic when applied in ways that reflect underlying discriminatory attitudes, exacerbate inequities, or commodify individuals or reproduction. Here again, the concern does not reject the underlying goal of neoeugenics. Instead, it objects to unfortunate injustices and attitudes in our culture that are problematic with respect to many choices we might make, including reproductive choices. Neoeugenics as a practice should trouble us if the underlying intent is not focused on the best interests of the child or family, but instead is built on discriminatory attitudes, concerns about prestige, or narrow conceptions of the full value of the future child. Legally, we may be able to justify many reproductive choices based on the libertarian conception of reproductive autonomy; such choices, however, are morally suspect unless they are grounded in a relational conception of reproductive autonomy. In future works, I hope to apply this analysis to evaluate in detail the various kinds of choices that could be made with each of the existing and emerging technologies such as prenatal testing to select against serious disease, lesser disease, or traits; preimplantation genetic diagnosis to select against disease or traits; and genetic transfer to treat disease or to enhance abilities or traits.

The eugenics of yesteryear erred in privileging concerns about the social good (which were grounded on mistaken notions about what this constituted). The current neoeugenics may err in privileging concerns about a narrow conception of individual rights. A theory of procreative autonomy that is built on a notion of the self defined in terms of one's relation to family and community achieves a healthier balance between these two extremes, and thus may be the most useful tool for evaluating the evolving technologies.