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# RACE AND ASSISTED REPRODUCTION: IMPLICATIONS FOR POPULATION HEALTH

Aziza Ahmed\*

## INTRODUCTION

This Article emerges from *Fordham Law Review*'s Symposium on the fiftieth anniversary of *Loving v. Virginia*,<sup>1</sup> the case that found antimiscegenation laws unconstitutional.<sup>2</sup> Inspired by the need to interrogate the regulation of race in the context of family, this Article examines the diffuse regulatory environment around assisted reproductive technology (ART) that shapes procreative decisions and the inequalities that these decisions may engender.<sup>3</sup> ART both centers biology and raises questions about how we imagine our racial futures in the context of family, community, and nation.<sup>4</sup> Importantly, ART demonstrates how both the state and private

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\* Professor of Law, Northeastern University School of Law. Many thanks to Kimani Paul-Emile, Robin Lenhardt, and Tanya Hernández for inviting me to participate in the *Fordham Law Review* Symposium entitled *Fifty Years of Loving v. Virginia and the Continued Pursuit of Racial Equality* held at Fordham University School of Law on November 2–3, 2017. My deep gratitude to Melissa Murray, Jason Jackson, and Libby Adler for their generous comments on an earlier draft of this Article and to Linda McClain and Ashley Shattles for several helpful discussions that helped shape this paper. For an overview of the Symposium, see R.A. Lenhardt, Tanya K. Hernández & Kimani Paul-Emile, *Foreword: Fifty Years of Loving v. Virginia and the Continued Pursuit of Racial Equality*, 86 *FORDHAM L. REV.* 2625 (2018).

1. 388 U.S. 1 (1967).

2. *Id.* at 11–12.

3. Another site of racial regulation in the context of family formation that is not discussed in this Article is adoption. For a discussion of the states' regulation of adoption, see generally R. Richard Banks, *The Color of Desire: Fulfilling Adoptive Parents' Racial Preferences Through Discriminatory State Action*, 107 *YALE L.J.* 875 (1998). In her Article published in this issue, Melissa Murray poignantly highlights how interracial families continue to be punished in the context of child custody as well. See generally Melissa Murray, *Loving's Legacy: Decriminalization and the Regulation of Sex and Sexuality*, 86 *FORDHAM L. REV.* 2671 (2018).

4. Managing race and reproduction has long been in the purview of the state. State rationales for doing so are diverse—from economic and public health concerns to preserving a sense of nationhood and belonging: What kind of country should we be? What kind of citizens should this nation have? Ideas of race and nation are also central to determining who will and will not benefit from the privileges of citizenship. Now-discredited racial science justified the idea that a claim to citizenship should be dependent on race. It relied on the rationale that some races were superior to others and therefore deserving of greater rights with respect to the states. In turn, this logic justified state persecution and prosecution of interracial marriage and procreation. For example, the 1955 Supreme Court of Virginia case *Naim v. Naim* found an interracial marriage void because protecting “the racial integrity” of its citizens and preventing a “mongrel” breed of citizens was seen to be within the state's purview. 87

actors shape family formation along racial lines.<sup>5</sup> By placing a discussion about race and ART in the context of access to new health technologies, this Article argues that assisted reproduction has population-level effects that mirror broader racial disparities in health. In turn, this Article intervenes in a bioethics debate that frequently ignores inequalities in access when thinking through the consequences of ART.

Part I presents a case study of the Sperm Bank of California (SBC) to demonstrate how ART represents a new mode of governing the family that facilitates and encourages the formation and creation of monoracial families.<sup>6</sup> Part II borrows a public health analytic, the “burdens of disease,”<sup>7</sup> to explain how the (re)production of monoracial families has consequences for health at the population level, especially when placed in the context of racially disparate access to ART services. Ultimately, this Article concludes that ART, as it is currently accessed and utilized, maintains racial orders with regard to health given the inequality in access to these services.<sup>8</sup>

### I. THE CASE OF SBC

First utilized in the 1970s, ART is a relatively new means of producing families. The technologies associated with ART allow individuals to reproduce with their own genetic material or to select the sperm, eggs, or embryos of others. The pressure to reproduce one’s racial self is high and, perhaps more problematically, encouraged.<sup>9</sup>

Although it is not possible to generalize from one case, an examination of SBC, a progressive sperm bank with feminist roots,<sup>10</sup> demonstrates the

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S.E.2d 749, 756 (Va.), *vacated*, 350 U.S. 891 (1955); *id.* at 751 (“Marriage, as creating the most important relation in life, as having more to do with the morals and civilization of a people than any other institution, has always been subject to the control of the legislature.” (quoting *Maynard v. Hill*, 125 U.S. 190, 205 (1888))). *But see Loving*, 388 U.S. at 7–8 (finding that the state’s ability to regulate marriage is bound by the Fourteenth Amendment). For an overview, see generally DOROTHY ROBERTS, *FATAL INVENTION: HOW SCIENCE, POLITICS, AND BIG BUSINESS RE-CREATE RACE IN THE TWENTY-FIRST CENTURY* (2011).

5. See *infra* Parts I–II.

6. See generally Angela Onwuachi-Willig & Jacob Willig-Onwuachi, *A House Divided: The Invisibility of the Multiracial Family*, 44 HARV. C.R.-C.L.L. REV. 231 (2009) (arguing that, despite *Loving*, the normative family ideal is both monoracial and heterosexual).

7. See *Global Burden of Disease*, WORLD HEALTH ORG., [http://www.who.int/topics/global\\_burden\\_of\\_disease/en/](http://www.who.int/topics/global_burden_of_disease/en/) [https://perma.cc/J3UW-AZHV] (last visited Apr. 13, 2018).

8. There is a large amount of literature on racial disparities with regard to health in both law and public health. See, e.g., KHIARA M. BRIDGES, *REPRODUCING RACE: AN ETHNOGRAPHY OF PREGNANCY AS A SITE OF RACIALIZATION* (2011); DAYNA BOWEN MATTHEW, *JUST MEDICINE: A CURE FOR RACIAL INEQUALITY IN AMERICAN HEALTH CARE* (2015); Nancy Krieger, *Embodying Inequality: A Review of Concepts, Measures, and Methods for Studying Health Consequences of Discrimination*, 29 INT’L J. HEALTH SERVICES 295 (1999). Race also plays a role in doctor-patient relationships. See generally Kimani Paul-Emile et al., *Dealing with Racist Patients*, 374 NEW ENG. J. MED. 708 (2016).

9. For a detailed account of how providers pressure individuals to choose same-race gametes, see generally Robin Lenhardt, *The Color of Kinship*, 102 IOWA L. REV. 2071 (2017).

10. SBC was formerly a project of the Oakland Feminist Women’s Health Center. *History*, SPERM BANK CAL., <https://www.thespermbankofca.org/content/history> [https://perma.cc/ZA92-RY3R] (last visited Apr. 13, 2018).

explicit way in which reproducing oneself racially with the goal of a monoracial family is promoted by reproductive-health service providers. SBC's website claims that the organization is a "trusted friend by your side on your parenthood journey" that has an "unwavering commitment to the well-being of parents, children, and donors."<sup>11</sup> In turn, SBC offers advice and guidance on the selection of sperm—making "ethnicity" central to choosing the sperm.<sup>12</sup> The word "ethnicity" on the website appears to be a stand-in for the word race. The website begins with a reminder that SBC's goal is to "help contribute to your future child's and family's long-term well-being" and, in turn, "present[s] reasons to consider selecting a donor who looks like you, your partner, and the people who will surround your child as they grow up."<sup>13</sup> This statement seems intended to soften a strong line taken by SBC that individuals race match.

SBC provides a range of justifications for why it is important to choose a sperm donor of a similar ethnic background.<sup>14</sup> These include that children "want to belong" and that having the same physical characteristics as their parents will contribute to a child's sense of acceptance.<sup>15</sup> Alternatively, parents, the website argues, will not be able to adequately prepare children for the racial discrimination they may face.<sup>16</sup> The message is clear: select gametes of the same race as you or your family will face ongoing challenges.<sup>17</sup> Interestingly, SBC argues this is important to consider even where there is a known donor.<sup>18</sup> In other words, even when individuals may have a friend or family member of a different ethnicity that they would utilize as a sperm donor, SBC's website encourages individuals to acquire sperm of the same ethnicity as the future parents because of the negative ramifications of having a mixed-race family.<sup>19</sup>

Legal discourse also contributes to the informal regulation of racial selection. The site features a link to a story published in an *Our Family Coalition* newsletter; the story is an autobiographical account of a lesbian couple considering various sperm samples for insemination.<sup>20</sup> Ilana Sherer, who authors the account, takes readers through the couple's thought process in selecting a sperm donor.<sup>21</sup> Initially, the couple sought sperm that would

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11. *Why Choose TSBC*, SPERM BANK CAL., <https://www.thespermbankofca.org/why-choose-tsbc> [https://perma.cc/5AQL-SPQ2] (last visited Apr. 13, 2018).

12. *Donor Ethnicity, Your Family and Your Future Child*, SPERM BANK CAL., <https://www.thespermbankofca.org/tsbcfile/choosing-ethnicity-my-donor> [https://perma.cc/FJ4A-FK8Q] (last visited Apr. 13, 2018).

13. *Id.*

14. *Id.*

15. *Id.*

16. *Id.* These arguments mirror broader concerns raised in the context of adoption. See generally Banks, *supra* note 3; Elizabeth Bartholet, *Where Do Black Children Belong?: The Politics of Race Matching in Adoption*, 139 U. PA. L. REV. 1163 (1991).

17. See *Donor Ethnicity, Your Family and Your Future Child*, *supra* note 12.

18. *Id.*

19. *Id.*

20. Ilana Sherer, *Known and Unknowns*, OUR FAM. COALITION (Our Family Coal., S.F., Cal.), Winter 2015, at 1, [https://drive.google.com/file/d/0B1klt\\_1MTF7malozavJtbkNTMFU/view](https://drive.google.com/file/d/0B1klt_1MTF7malozavJtbkNTMFU/view) [https://perma.cc/5GJB-XXFY].

21. *Id.*

account for the appearance of Sherer, the noncarrying partner.<sup>22</sup> Sherer describes herself as an “Eastern European Jew[]” with “kinky curly dark hair and olive skin”<sup>23</sup> and notes that the couple considered Arab, Latino, and Native American sperm.<sup>24</sup> In describing their struggle to choose the right sperm, Sherer references<sup>25</sup> the infamous case of *Cramblett v. Midwest Sperm Bank, LLC*.<sup>26</sup>

*Cramblett* is controversial case given the national dialogue it generated about race and assisted reproduction.<sup>27</sup> The case involves Jennifer Cramblett and her partner.<sup>28</sup> The couple, both white, chose the sperm coded as white for insemination.<sup>29</sup> Instead of the chosen sperm, Cramblett was mistakenly given sperm from an African American donor due to an error in handwriting.<sup>30</sup> In her complaint to the court, Cramblett describes her reaction to learning she had been impregnated with African American sperm.<sup>31</sup> She was “crying, confused and upset,” and felt “anger, disappointment and fear.”<sup>32</sup> After speaking to the sperm bank (which she described as being abrupt with her), she cried uncontrollably and began to shake, and “her hands and feet became numb.”<sup>33</sup> Since the birth of the child, she argued that they have had great difficulty: they have racist family members, their daughter’s hair requires trips to a faraway hair salon in a Black neighborhood that does not entirely accept her, and Jennifer did not know any African Americans until college.<sup>34</sup> To be sure, it is likely upsetting to be pregnant with sperm you did not select. But what makes this so problematic is that it is quite clear that their reaction was based not only on the incorrect sperm but that it was African American sperm.

Meaningfully, the Sherer family’s logic for choosing a white child draws in part on the wrongful-birth case of the Cramblett. As Sherer explains:

[W]hen I first heard the story of the white Ohio couple who mistakenly conceived with sperm from an African-American donor[,] I was of course shocked and embarrassed to hear that the parents of a healthy lovely bi-racial child would sue for wrongful birth, but I also understood and respected the challenges they articulated and the unpreparedness they felt in raising their bi-racial child. In my perspective, they should be able to

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22. *Id.*

23. *Id.*

24. *Id.* at 13.

25. *Id.*

26. 230 F. Supp. 3d 865 (N.D. Ill. 2017).

27. See, e.g., Lenhardt, *supra* note 9; Patricia J. Williams, *Babies, Bodies and Buyers*, 33 COLUM. J. GENDER & L. 11 (2016).

28. *Cramblett*, 230 F. Supp. 3d at 867–68.

29. *Id.* at 867.

30. *Id.* For more scholarship on *Cramblett*, see Lenhardt, *supra* note 9, at 2088 (urging that increased attention be paid to both how race shapes families’ functions and how structural inequality shapes notions of race in the family); Williams, *supra* note 27, at 11 (discussing the advent of new genetic technologies and arguing that the “ultra-contractarianism of our neoliberal moment” compromises the goals of public accommodation).

31. Complaint at 4–7, *Cramblett*, 230 F. Supp. 3d 865 (No. 16-C-4553).

32. *Id.* at 4–5.

33. *Id.*

34. *Id.* at 6–7.

sue for breach of contract as they did not receive the sperm they had selected, but the manner they articulated the issue as a wrongful birth suit was absolutely heartbreaking. At the same time, I am glad that they did name the same struggles that many of us (white prospective parents) go through when choosing a sperm donor. So often we see public figures and celebrities adopting multi-racial children without comment, yet presenting their family as “race blind” is ignoring the reality of institutionalized racism. We felt that as a white couple, using a donor of color would feel like we were intentionally trying to exotify our family and using white privilege to appropriate and potentially whiten another’s cultural heritage.<sup>35</sup>

In making these arguments, they go further than the Cramblett. Sherer gives the sperm not only a race but suggests the sperm has a culture. In doing so, she likens adopting a child of color with gestating a mixed-race child.<sup>36</sup> The couple ultimately concluded that it was better to get a child whose “ethnic background matched” their own.<sup>37</sup> The struggle of the Sherer family demonstrates how the attention generated by litigation helps to shape the social context in which individuals choose gametes.

The operationalization of assisted reproductive technologies is shaped by the way we imagine our communities and futures—one in which racial homogeneity is a ticket to being part of a self-preserving family. SBC’s website makes this clear: “Resemblance is one signal of kinship. For the child, physical resemblance helps create bonds and has the capacity to create a feeling of connectedness. Without resemblance, there can be an experience of unfamiliarity, unpredictability, of being the ‘other.’”<sup>38</sup>

The case of the SBC provides a view into how law and ART services—in this case, sperm banks—constitute what it means to have not only a biological connection but also a sense of kinship that is rooted in ideas about race.<sup>39</sup> These informal modes of regulation provide the context in which individuals shape racialized decision-making about reproduction.<sup>40</sup>

## II. THE IMPLICATIONS OF ACCESS

In her article, *The Color of Kinship*, Professor Robin Lenhardt begins to theorize the ways in which the pressure to form racially homogenous families has structural implications:

We have not yet begun to grapple in earnest with the role of family and family law in racial formation in the United States. This can only change, however, if scholars begin to internalize the importance of race “as an organizing principle of social relationships” in society that affects not just

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35. Sherer, *supra* note 20, at 13.

36. *See id.*

37. *Id.*

38. *Donor Ethnicity, Your Family and Your Future Child*, *supra* note 12.

39. *See* Lenhardt, *supra* note 9, at 2075 (“[K]inships, whether old or new, have been framed as essentially race-neutral relationships and affective ties that implicate matters of gender, sexuality, and even class, but exist before or somehow outside of race. . . . [N]othing could be farther from the truth. Kinship has a color.”).

40. *See id.* at 2078–79.

minorities, but *all* members of society . . . . On this account, race stands not as a biological trait, but a social construction that functions as a multi-valent mechanism for racial signification and hierarchy that both draws on and reconstitutes “the racial legacies” of the past—e.g., slavery and Jim Crow segregation. And it does this through a constantly shifting web of practices and systems that structure society and, to that extent, directly inform the functioning of social units, to include families. Familial norms and laws, especially those bearing on marriage, parenting, and familial roles, help to determine both how race is defined and experienced as well as the social location that a familial unit will occupy at a given point in time. Understanding this fully means greater attentiveness to the role of family systems and structures in producing race and structure of opportunity for kin groups.<sup>41</sup>

Following Lenhardt’s call to interrogate race and family formation, this Part explores the implications of unequal access to the new reproductive technologies. Specifically, it explores how, when placed within the context of the racial disparities associated with access to ART, the drive to produce monoracial families reproduces disparate population-level health effects along racial lines. This Part begins by describing how access and utilization of ART is divided along racial lines. The racial disparity in utilizing ART services results in an uneven utilization of new technologies, including genetic testing, to limit the possibility of poor health outcomes.<sup>42</sup> Drawing on the public health analytic “burdens of disease,” this Part argues that disparate access to new reproductive technologies, alongside the push to create monoracial families, will result in disproportionate morbidity and mortality for racial minorities.

#### A. Access to ART

Access to ART is deeply divided on race and class lines given the expense of accessing ART services.<sup>43</sup> This inequality of access is furthered by the high cost of, and lack of insurance coverage for, these services.<sup>44</sup> As of 2014, only fifteen states have laws that require some insurance coverage for assisted reproductive technology.<sup>45</sup> Of those, many of the laws do not cover in vitro fertilization (IVF)—the most expensive fertility treatment—or more

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41. *Id.* at 2100 (footnotes omitted) (first quoting Eduardo Bonilla-Silva, *Rethinking Racism: Toward a Structural Interpretation*, 62 AM. SOC. REV. 465, 466 (1997)).

42. While it is possible to have genetic selection in a nonassisted pregnancy, this Article focuses on the testing and consequences derived from a bioethical debate on use of ART services, such as intracytoplasmic sperm injection and in vitro fertilization.

43. See generally Alicia Armstrong & Torie C. Plowden, *Ethnicity and Assisted Reproductive Technologies*, 9 CLINICAL PRAC. 651 (2012); Karni Kissil & Maureen Davey, *Health Disparities in Procreation: Unequal Access to Assisted Reproductive Technologies*, 24 J. FEMINIST FAM. THERAPY 197 (2012); Molly Quinn & Victor Fujimoto, *Racial and Ethnic Disparities in Assisted Reproductive Technology Access and Outcomes*, 105 FERTILITY & STERILITY 1119 (2016).

44. *State Laws Related to Insurance Coverage for Infertility Treatment*, NAT’L CONF. ST. LEGISLATURES (June 1, 2014), <http://www.ncsl.org/research/health/insurance-coverage-for-infertility-laws.aspx> [<https://perma.cc/K684-DMK4>].

45. *Id.*

than one round of IVF, or they instead establish specific criteria that a patient must satisfy in order to qualify for the coverage.<sup>46</sup> The average IVF cycle costs approximately \$12,500 and requires a flexible work schedule to attend the numerous appointments.<sup>47</sup> As a result, vast segments of the population are unable to access new reproductive technologies.<sup>48</sup>

This, of course, has distributional consequences. It is clear that, like most health services, there are extreme inequalities with regard to who is able to access ART.<sup>49</sup> These inequalities play out in predictably race- and class-based ways.<sup>50</sup> Plainly speaking, African Americans, immigrants, and others with little insurance coverage cannot access ART services unless they are able to pay high out-of-pocket fees.<sup>51</sup> Alongside the inability to pay, there are unidentified barriers for racial minorities in accessing ART. Epidemiological data suggest that the people who access reproductive technology are largely white.<sup>52</sup> This holds even in states that mandate coverage for fertility services<sup>53</sup> and despite the fact that the highest rates of infertility are found among African American women.<sup>54</sup> Thus, it is necessary to explore how assisted reproduction becomes an axis upon which health outcomes are distributed.

If an individual or couple engages in assisted reproduction, they may also, although not always, engage in preimplantation genetic screening (PGS) or diagnosis (PGD), alongside a host of other genetic screenings over the course of a pregnancy.<sup>55</sup> IVF and intracytoplasmic sperm injection (ICSI) both involve the production of embryos outside of the uterus, which provides an opportunity for genetic testing before implantation.<sup>56</sup> Gamete and embryo testing, coupled with gamete and embryo selection, makes it possible to eliminate genetic conditions prior to their implantation.<sup>57</sup> These new technologies allow parents to eliminate embryos that have particular conditions, including Tay-Sachs disease and trisomy 21 (Down syndrome).<sup>58</sup> This has resulted in a vigorous and rich bioethics debate on what it means to

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46. *Id.* Specific communities, including the lesbian, gay, bisexual, and transgender (LGBT) communities, face unique barriers to accessing ART services. Kissil & Davey, *supra* note 43, at 199–203 (outlining how different segments of the population are presented with barriers to ART services based on cost and socioeconomic status, race and ethnicity, marital status and sexual orientation, age, and illnesses).

47. Armstrong & Plowden, *supra* note 43, at 652.

48. *Id.*

49. *Id.*; Kissil & Davey, *supra* note 43, at 199.

50. Armstrong & Plowden, *supra* note 43, at 652–653; Kissil & Davey, *supra* note 43, at 199–201.

51. Armstrong & Plowden, *supra* note 43, at 652.

52. *Id.*

53. *Id.*

54. *Id.* at 657.

55. Practice Comm. of the Soc’y for Assisted Reprod. Tech. & Practice Comm. of the Am. Soc’y for Reprod. Med., *Preimplantation Genetic Testing: A Practice Committee Opinion*, 90 FERTILITY & STERILITY S136, S136 (2008).

56. *Id.*

57. *Id.*

58. *Genetic Selection*, CTR. FOR GENETICS & SOC’Y, <https://www.geneticsandsociety.org/topics/genetic-selection> [<https://perma.cc/XQ2E-4QXN>] (last visited Apr. 13, 2018).



choose embryos—a debate that includes responses from the disability-rights community.<sup>59</sup> These discussions, however, often do not consider the new structural inequalities produced by existing inequalities in access to new reproductive health technologies. Instead, the debates are frequently centered on the theoretical possibilities of eliminating particular disabilities as a form of eugenics, the possibilities of “designer babies,” and the scientific possibilities associated with genetic testing.<sup>60</sup> A broader discussion of how class or inequality will shape the experience of assisted reproduction is missing.

*B. Burden of Disease: Applying a Public Health Frame to ART*

We can see how inequality structures population-level health effects vis-à-vis assisted reproduction using the example of breast cancer. A relatively recent innovation in reproductive technologies is the ability to use PGD testing to reduce the chance of having biological offspring with BRCA-1 and BRCA-2, the genetic mutations associated with higher rates of breast

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59. The disability-rights arguments are varied. A report published by the Hastings Center summarized several of these critiques: that abortion based on genetic testing expresses a discriminatory attitude toward the disabled; that parents have a false impression that they can create perfection; that prenatal testing and genetic counseling are based on misinformation founded on a lack of experience with disabled children; and that genetic testing occurs in a world in which ideas of normalcy are loaded with judgment yet treated as natural. *See generally* Erik Parens & Adrienne Asch, *The Disability Rights Critique of Prenatal Genetic Testing: Reflections & Recommendations*, HASTINGS CTR. REP., Sept.–Oct. 1999, at S1. The authors of the report further outline three primary arguments made by the disability-rights community that place a greater emphasis on the expectations of parents:

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

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

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

*Id.* at S2 (quoting Adrienne Asch, *Reproductive Technology and Disability*, in *REPRODUCTIVE LAWS FOR THE 1990S*, at 69, 86 (Sherrill Cohen & Nadine Taub eds., 1989)).

60. *See generally* MICHAEL J. SANDEL, *THE CASE AGAINST PERFECTION* (2007). Sandel traces some of these debates in his book and presents arguments for and against “perfection.” Those who support human enhancement have revived the language of eugenics by calling for “liberal eugenics.” *Id.* at 75–76. Sandel describes that what differentiates the old eugenics from a newer, liberal eugenics, as argued by bioethicists who defend the idea, is that the benefits and burdens of a liberal eugenics would be fairly distributed rather than burdening only the weak and the poor. *Id.* at 76.

cancer.<sup>61</sup> PGD testing allows embryos to be tested for the genetic mutations and then eliminated if they are found to carry the mutation.<sup>62</sup> PGD testing requires that a couple utilize IVF to first extract gametes and then produce an embryo in a lab that can be tested.<sup>63</sup>

This technology, despite its revolutionary capacity to eliminate forms of cancer, is nowhere near universally available.<sup>64</sup> In fact, in the United States, this service would likely require an out-of-pocket payment of approximately \$20,000 per cycle (if a person pays for PGD as well as IVF).<sup>65</sup> As described, insurance frequently does not cover these services.<sup>66</sup> Thus, it is only a select segment of society with access to the necessary resources, or insurance coverage, who would theoretically be able to reduce the possibility of breast cancer in their families. And, in a world in which the few individuals with access to ART are concerned about reproducing themselves, there is the added effect of concentrating the benefits of genetic testing among certain populations.

Utilizing the “burden of disease” analytic borrowed from public health helps to think through the political and economic dimensions of gamete selection. Burden of disease refers to quantification of the morbidity and mortality of a particular population based on the consequences of ill health.<sup>67</sup> What is clear from an examination of data collected under the burdens-of-disease rubric is that ill health is both the product and cause of economic and racial disparity.<sup>68</sup> This is particularly stark with regard to illnesses that have been virtually eliminated from developed countries but continue to exist in the developing world.<sup>69</sup> Diseases like polio and tuberculosis, for example, were largely eradicated from the developed world long ago due to the advent of new technologies.<sup>70</sup> The lack of access to these technologies results in the prevalence of such illnesses, sometimes on a mass scale, in poor communities and many developing countries.<sup>71</sup> This is true even within the United

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61. Joyce C. Harper et al., *Views of BRCA Gene Mutation Carriers on Preimplantation Genetic Diagnosis as a Reproductive Option for Hereditary Breast and Ovarian Cancer*, 22 HUM. REPROD. 1573, 1573 (2007).

62. Kenneth Offit et al., *Preimplantation Genetic Diagnosis for Cancer Syndromes: A New Challenge for Preventive Medicine*, 296 JAMA 2727, 2727 (2006).

63. *Id.*

64. *Id.* (noting that access to PGD testing is currently very limited).

65. See Colleen Joy McCullough, *Young Feminist: Genetic Segregation: The Next Frontier of American Inequality?*, NAT'L WOMEN'S HEALTH NETWORK, <https://www.nwhn.org/young-feminist-genetic-segregation-the-next-frontier-of-american-inequality/> [<https://perma.cc/7XZR-VLZK>] (last visited Apr. 13, 2018) (arguing that women of color will not have access to new genetic technologies for cancer prevention).

66. See *supra* notes 44–48 and accompanying text. For an example of an insurance policy and coverage limitations, see *Medical Necessity Guidelines: Preimplantation Genetic Diagnosis (PGD)*, TUFTS HEALTH PLAN, <https://tuftshealthplan.com/documents/providers/guidelines/medical-necessity-guidelines/pgd> [<https://perma.cc/8EMW-B5ZQ>] (last visited Apr. 13, 2018).

67. *Global Burden of Disease*, *supra* note 7.

68. See generally Catherine M. Michaud et al., *The Burden of Disease and Injury in the United States*, POPULATION HEALTH METRICS, Oct. 2006, at 1.

69. See *id.* at 20–21.

70. See *id.*

71. See *id.*

States.<sup>72</sup> Data suggest that the burden of disease for illnesses including cancers, cardiovascular conditions, diabetes, and others had the greatest impact on racial minorities.<sup>73</sup> In fact, for racial minorities, the burden of disease frequently appears more similar to that in developing countries.<sup>74</sup>

As new technologies develop, lack of access to these technologies may further inequalities of illness and worsen the burden of disease for particular communities. As preventive medicine continues to develop with a focus on genetics, reproductive technology is implicated in the assessments of burdens of disease, as ART becomes a gateway for accessing genetic testing and, in turn, eliminating embryos that carry genetic mutations. ART access is racialized, however.<sup>75</sup> And, when in a clinic, the small set of people that utilize these services are encouraged to select racially homogenous gametes, the reproduction of race and health begin to look more like broader structural inequalities along the lines of race.

Existing inequalities with regard to accessing technologies may help to predict the population-level outcomes of disparate access to the genetic-testing technologies associated with ART. In the United States, it is racial minorities, particularly Black, Latino, and immigrant communities, that bear the adverse consequences of ill health due to poverty, lack of insurance, and, in turn, lack of access to health services and technologies.<sup>76</sup> Bracketing the much larger and important conversation on disability rights, it is clear that the aggregate impact of access to genetic testing and gamete selection to remove particular traits would result in a maldistribution of health-related challenges.

#### CONCLUSION

This Article explores how state and private actors shape decision-making on race in the context of family formation and reproduction and its impact on public health. The selection of gametes and genetic material for the purpose of reproduction raises core questions about the centrality of race in discussions on family and kinship. Service providers aid in the regulation of racial selection of families, typically by recommending that families race match in the gamete-selection process. Race matching, in the context of racial inequality in access to ART services, will have aggregate population-level effects along racial lines reflecting larger structural inequalities. These structural considerations have largely been ignored in the broader bioethical debate on assisted reproduction and genetics.

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72. *See id.* at 21–25.

73. *See id.* at 7, 10.

74. *See id.* at 1.

75. Quinn & Fujimoto, *supra* note 43, at 1119–21.

76. *See* Michaud et al., *supra* note 68, at 21–23.