

## EMBRYONIC GENETICS

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### I. INTRODUCTION

Advances in reproductive medicine are notorious for yielding previously unthinkable methods of enhancing human procreation, alongside equally unanticipated ethical and social dilemmas. The introduction of preimplantation genetic diagnosis (PGD) produced such dual consequences and continues to challenge traditional notions of health and medical decision-making. PGD is a medical technique originally developed in England in the late 1980s as a method of detecting single-gene disorders in unimplanted three-day old embryos.<sup>1</sup> The basic PGD procedure involves the creation of embryos via in vitro fertilization (IVF), followed by the extraction via biopsy of a single cell, known as a blastomere, from the three-day old, eight-celled embryo.<sup>2</sup> Because each blastomere is totipotent in the early embryo—meaning it has “all potential” and can develop into a separate, wholly intact new embryo—studying this single cell reveals the genetic make-up of the embryo from which it was taken.<sup>3</sup> PGD can detect

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1. A.H. Handyside et al., *Biopsy of Human Preimplantation Embryos and Sexing by DNA Amplification*, LANCET, Feb. 18, 1989, at 347, 348; KRISTINE BARLOW-STEWART & MONA SALEH, CENTRE FOR GENETICS EDUCATION, FACT SHEET 18, at 1 (2007), available at [www.genetics.edu.au/pdf/factsheets/fs18.pdf](http://www.genetics.edu.au/pdf/factsheets/fs18.pdf) (last visited Feb. 3, 2009).

2. See AUDREY HUANG, GENETICS & PUB. POL’Y CTR., PREIMPLANTATION GENETIC DIAGNOSIS (2006), available at [www.dnapolicy.org/images/issuebriefpdfs/PGD\\_Issue\\_Brief.pdf](http://www.dnapolicy.org/images/issuebriefpdfs/PGD_Issue_Brief.pdf) (last visited Feb. 3, 2009); Handyside et al., *supra* note 1.

3. According to Dr. Mabelle M. Seibel, “Preimplantation genetic diagnosis (PGD) is very much like an amniocentesis performed after fertilization but before the pregnancy is implanted. IVF is performed, and the embryo is allowed to divide up to at least four cells and usually up to eight cells. A small hole is made in the zona pellucida and one or two cells of

whether an embryo is genetically normal, or whether it expresses a genetic anomaly associated with a disease or disorder.<sup>4</sup>

Because of its role in assisted conception, PGD joins the sundry medical techniques under the rubric “assisted reproductive technologies” (ART). PGD’s initial usage was limited to prospective parents anxious to birth a child unaffected by a genetic disorder that had plagued the family’s lineage for generations.<sup>5</sup> Inevitably, interest in surveying the genetic make-up of early embryos grew to encompass clinical scenarios likely not contemplated by the technique’s originators.<sup>6</sup> In addition to screening to discover the genetic health of the conceptus, today ART physicians can use PGD to screen embryos so that, if later born alive, the resulting children’s blood, organs, or tissues can be used to support the health of another person, often a whole blood sibling.<sup>7</sup> An even more recent use of PGD is the selection of embryos based on parental preferences for offspring whose sensory or mobility capabilities reflect that of their genetic parent or

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the embryo are removed, fixed on a slide and analyzed by molecular biology testing. The molecular biology tools used to perform PGD are either polymerase chain reaction (PCR), which is a method that amplifies a single gene defect so that it can be seen on a gel electrophoresis, or fluorescent in situ hybridization (FISH), which stains a particular piece of DNA with a fluorescent color that can be seen using a special microscope. The diagnosis is made within a few days, and the unaffected embryos are then transferred into the mother’s uterus so that pregnancy can occur.” AMY BERLIN COOK ET AL., *ADOPTION AND REPRODUCTIVE TECHNOLOGY LAW IN MASSACHUSETTS* §9.7 (Susan L. Crockin ed., 2000); Ashley Bumgarner, Note, *A Right to Choose?: Sex Selection in the International Context*, 14 *DUKE J. GENDER L. & POL’Y* 1289, 1294 (2007).

4. PGD is used to detect two types of genetic anomalies: (1) inherited chromosomal abnormalities in which a gene or portion of a gene contains a mutation, causing such disorders as Tay-Sachs disease, Duchene muscular dystrophy, cystic fibrosis, and Huntington’s disease, or (2) sporadic (non-inherited) aneuploidy, in which the genome contains either too few or too many chromosome in one or more of the 23 pairs. See HUANG, *supra* note 2 (discussing aneuploidy and inherited genetic disorders). Some of the more well-known disorders associated with aneuploidy include Down syndrome (also known as “Trisomy 21,” or three chromosomes in 21<sup>st</sup> pair), Edwards syndrome (Trisomy 18), Patau syndrome (Trisomy 13) and Klinefelter syndrome (XXY, having an extra “X” sex chromosome). See NAT’L HUM. GENOME RESEARCH INST., *CHROMOSOME ANALYSIS* (2005), available at [www.genome.gov/Pages/Education/Modules/ChromosomeAnalysis.pdf](http://www.genome.gov/Pages/Education/Modules/ChromosomeAnalysis.pdf) (last visited Feb. 3, 2009) (discussing chromosomal disorders).

5. See Susannah Baruch et al., *Genetic Testing of Embryos: Practices and Perspectives of U.S. In Vitro Fertilization Clinics*, 89 *FERTILITY & STERILITY* 1053, 1053 (2008).

6. See, e.g., *id.* at 1055 (though PGD was developed to screen unborn children for genetic disorders, today PGD can be used to select the sex of an embryo “to satisfy the preferences of the future parents.”).

7. *Id.*; Bill Radford, *The Designer Baby: Right or Wrong?*, *BALTIMORE SUN*, Jan. 14, 2001, at 1N.

parents.<sup>8</sup> The following true-life stories explain each of three PGD scenarios.

*Vignette 1: Using PGD for the Health of the Embryo.* Chicago resident Chad Kingsbury suffered the loss of his mother, maternal grandfather, and two maternal uncles from an inherited form of colon cancer.<sup>9</sup> As a carrier of the genetic mutation associated with familial susceptibility to the adult-onset disease, Chad was terrified that his children would inherit his predisposition to colon cancer.<sup>10</sup> For the Kingsburys, PGD “offered them a way to reload the genetic dice.”<sup>11</sup> The couple joined a growing pool of prospective parents with heritable cancer-susceptibility genes who turned to ART to assure the birth of a child free of the family genetic mutation.<sup>12</sup> In addition to colon cancer susceptibility, PGD can now be used to screen for other genetically-based adult-onset diseases including Huntington’s disease, Alzheimer disease, and breast cancer.<sup>13</sup> While the Kingsburys took months to make the decision to use PGD, the result was a child free of the colon cancer gene.<sup>14</sup> While talking to reporters about his child’s conception, Chad Kingsbury gazed at daughter Chloe and remarked, “I couldn’t imagine them telling me my daughter has cancer . . . when I could have stopped it.”<sup>15</sup>

*Vignette 2: Using PGD for the Health of Another Person.* By 1999, Lisa and Jack Nash’s five-year old daughter Molly was nearing death from Fanconi’s anemia, an inherited genetic disorder that leads to bone marrow failure and early forms of cancer.<sup>16</sup> Her only hope for recovery was a compatible stem cell donor, but exhaustive searches within her family and her community failed to produce a suitable donor.<sup>17</sup> The Nashes consulted Yuri Verlinsky, director of the Reproductive Genetics Institute in Chicago,

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8. Liza Mundy, *A World of Their Own*, WASH. POST, Mar. 31, 2002 (Magazine), at 22.

9. Amy Harmon, *Couples Cull Embryos to Halt Heritage of Cancer*, N.Y. TIMES, Sept. 3, 2006, at A1. (reporting that “one in every 200 Americans carry a genetic mutation that makes them susceptible to breast or colon cancer.”).

10. *Id.*

11. *Id.* at A20.

12. *Id.*

13. A recent survey reveals that twenty-eight percent of ART “clinics have provided PGD to avoid an adult-onset disease such as Huntington disease, hereditary breast cancer, or Alzheimer disease.” Baruch et al., *supra* note 5, at 1055.

14. Harmon, *supra* note 9, at A20.

15. *Id.*

16. See Dan Vergano, *Custom Baby Saves a Life*, USA TODAY, Jan. 8, 2001, at 7D; Radford, *supra* note 7; Deborah Josefson, *Couple Select Healthy Embryo to Provide Stem Cells for Sister*, 321 BRIT. MED. J., 917, 917 (2000).

17. Radford, *supra* note 7, at 9N; Liza Acevedo, *Stem Cell Siblings*, SCIENCENTRAL, Sept. 9, 2004, at [www.sciencentral.com/articles/view.php3?article\\_id=218392351&cat=3\\_2](http://www.sciencentral.com/articles/view.php3?article_id=218392351&cat=3_2) (last visited Feb. 3, 2009).

who pioneered the technique of testing embryos for genes that make antigens—structures that determine whether tissues will be compatible with a transplant recipient.<sup>18</sup> Using IVF and PGD, physicians were able to identify which of the Nashes' embryos were both free of the Fanconi's anemia gene and a tissue match for Molly.<sup>19</sup> On August 29, 2000, the family welcomed Adam, a healthy child whose umbilical cord blood was prepared for transfer into Molly.<sup>20</sup> Within a few months, Molly had regained much of her strength and thereafter went on to make near full recovery.<sup>21</sup>

*Vignette 3: Using PGD to Satisfy Parental Preferences.* Long-time partners Sharon Duchesneau and Candace McCullough wanted a child that resembled them in one important way.<sup>22</sup> The couple was deaf, and their idea of the perfect child was one who could move in and appreciate the deaf culture that was defining for the prospective parents.<sup>23</sup> The women inquired of the local sperm bank, only to learn that deafness is a disqualifying trait for sperm donors; thus no suitable sperm was available in the marketplace.<sup>24</sup> Determined to maximize the chances their child would be deaf, they turned to a deaf friend who agreed to serve as a sperm donor.<sup>25</sup> Six years later, the couple were parents to a daughter and a son, both deaf.<sup>26</sup> Though Sharon and Candace's journey to parenthood did not involve the use of PGD (which can detect genetic deafness), their story prompted researchers to ask whether physicians would be willing to provide the technique to cull embryos for certain genetic anomalies.<sup>27</sup> A survey published in 2006 indicates that at least a few IVF centers have assisted in selecting for a "disability" such as deafness or dwarfism.<sup>28</sup>

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18. Radford, *supra* note 7, at 9N; Acevedo, *supra* note 17; Scott Gottlieb, *Scientists Screen Embryo for Genetic Predisposition to Cancer*, 322 BRIT. MED. J. 1505, 1505 (2001).

19. See Gottlieb, *supra* note 18.

20. See Josefson, *supra* note 16.

21. Radford, *supra* note 7; Cable News Network, Health, *Genetic Selection Gives Girl a Brother and a Second Chance*, Oct. 3, 2000, at <http://archives.cnn.com/2000/HEALTH/10/03/testube.brother/> (last visited Nov. 21, 2008) (having received a transplant from sibling, Molly now has an eighty-five percent chance survival rate; Molly will not recover fully and will continue experiencing other symptoms of the disease throughout her lifetime).

22. See Mundy, *supra* note 8, at 24; Darshak M. Sanghavi, *Wanting Babies Like Themselves, Some Parents Choose Genetic Defects*, N.Y. TIMES, Dec. 5, 2006, at F5.

23. See Mundy, *supra* note 8, at 25.

24. See *id.* at 24.

25. See *id.*

26. See *id.* at 26.

27. See Sanghavi, *supra* note 22.

28. Baruch et al., *supra* note 5, at 1055 (noting that "[t]hree percent of IVF-PGD clinics report having provided PGD to couples who seek to use PGD to select an embryo for the presence of a [disease or] disability.").

The availability and use of PGD layers a social choice atop a medical decision. Parents who choose to implant only those embryos that offer compatible tissue for an ailing child simultaneously make the decision to discard or defer development of otherwise healthy embryos because they lack utility for an immediate purpose. Parents whose family trees are dotted with relatives devastated by certain genetically-based diseases must decide in the earliest moments of conception whether to eliminate embryos that bear the mutation, or entrust the health of their offspring to the uncertainty of future medical advances. Parents with sensory or other deficits who desire a similarly-abled child may discard genetically healthy embryos in pursuit of their vision of the perfect child. Each of these scenarios calls into question traditional notions of health, disability and reproductive choice.

Part II of this article chronicles the use of PGD and other reproductive technologies from their inception to current practices, observing that each advance has produced some unintended consequence. The ability to mesh human gametes in the laboratory, form embryos, freeze embryos for later use, and cull embryonic cells for their rich genetic story has been essential to family formation. Yet these advances have simultaneously introduced conflicts and harms that were unimaginable in a pre-ART world. Part II briefly surveys a few of the inadvertent consequences wrought by a staple in the ART arsenal—IVF. Examples include genetic parenthood after divorce, after death, and even after learning that one's embryos were mistakenly transferred to another patient with an overlapping clinic appointment. The law can and has responded to these scenarios with familiar tools borrowed from family law, tort law, contract law, and other sources. PGD, as the newest reproductive technology, can draw upon some of the same disciplines when mishaps occur, but the unintended consequences of embryonic genetics are more subtle and arguably more globally problematic.

Part III of this article surveys the use of PGD as described in Vignette 1—to assess embryonic health as a means of birthing a child free of known genetic anomalies.<sup>29</sup> At least three conundrums emerge when parents

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29. Vignettes 2 and 3, using PGD for the health of another, and for the preferences of the parents, are not treated in depth herein, though each scenario has generated robust discussion in the legal literature. For discussion on genetic enhancement and engineering, as well as issues arising from the use of PGD see, for example, Kirsten Rabe Smolensky, *Creating Children with Disabilities: Parental Tort Liability for Preimplantation Genetic Interventions*, 60 HASTINGS L.J. 299 (2008); Dov Fox, *Silver Spoons and Golden Genes: Genetic Engineering and the Egalitarian Ethos*, 33 AM. J. LAW & MED. 567 (2007); Michele Goodwin, *My Sister's Keeper?: Law, Children, and Compelled Donation*, 29 W. NEW ENG. L. REV. 357 (2007); Donna M. Gitter, *Am I My Brother's Keeper? The Use of Preimplantation Genetic Diagnosis to Create a Donor of Transplantable Stem Cells for an Older Sibling Suffering from a Genetic Disorder*, 13 GEO. MASON L. REV. 975 (2006); Lindsey A. Vacco, Comment, *Preimplantation*

attempt to orchestrate the implantation of a genetically healthy child. First, there is what I'll call "the spectrum problem." PGD can detect whether the offspring will be likely or even certain to express symptoms of the identified condition, but it often cannot determine the severity of such manifestation.<sup>30</sup> Moreover, as we increasingly recognize the genetic basis of human health, we are able to detect propensity for diseases that will not manifest until the fourth or fifth decade of life. Distinguishing between childhood and adult-onset diseases, as well as between severe, mild, and benign conditions, is both morally and medically difficult in the context of adjusting access to genetic technologies. This essay offers an assessment tool, in the form of a multi-factorial questionnaire with assigned point values for each response, as one response to the spectrum problem. Fixing values, even crudely, to factors such as severity of symptoms and timing of disease onset, may aid in understanding the proper uses of PGD to maximize embryo health.

A second conundrum evoked by PGD is its shifting of responsibility for health from person to parent. Part III describes "the shifting problem," noting that PGD may also shift the way we view health in the future. A parent's ability to spare a child from a disease for which the parent has a genetic susceptibility means that parent and child may act very differently in their health-related decisions. While the parent may make lifestyle choices to reduce the risk of disease onset, including the use of therapeutics or even prophylactic surgeries, the child will be medically unburdened, possibly unprepared to accept anything less than perfect health that could come in the form of sporadic disease or traumatic injury. Additionally, as control over health shifts from person to parent, those prospective parents who access reproductive technologies (and even those who do not) may come under increasing pressure to use PGD to avoid even mild anomalies. This pressure to utilize genetic technologies to avoid all genetic anomalies—herein labeled "the expectation problem"—represents the third conundrum in the trilogy. Part III discusses the expectation interests that genetic technologies raise, focusing on the expectations of prospective parents and the society into which their children are born.

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*Genetic Diagnosis: From Preventing Genetic Disease to Customizing Children. Can the Technology Be Regulated Based on the Parents' Intent?*, 49 ST. LOUIS U. L.J. 1181 (2005); Susan M. Wolf et al., *Using Preimplantation Genetic Diagnosis to Create a Stem Cell Donor: Issues, Guidelines & Limits*, 31 J. LAW, MED. & ETHICS 327 (2003). The goal of this article is to examine the motivations, expectations, and consequences that can accompany a decision to use PGD for the health of the embryo. It is my hope that these foundational observations will inform future discussions about other PGD uses.

30. Human Genetics Alert, *Response to HFEA Consultation on Sixth Edition of the Code of Practice*, at [www.hgalert.org/topics/geneticSelection/hga\\_response.htm](http://www.hgalert.org/topics/geneticSelection/hga_response.htm) (last visited Feb. 3, 2009).

Advances in reproductive medicine can evoke the myth of Sisyphus pushing his stone up a mountain only to see it roll back as he nears the summit.<sup>31</sup> In a crude sense, today's version of the myth pits reproductive scientists, who toil to advance the technology surrounding assisted conception, against observers who sometimes push back against advances that alter the traditional course of reproduction. The introduction and subsequent refinement of PGD display these push-pull qualities, producing stunning achievements in reproductive medicine, while instilling enormous unease over our newfound ability to manipulate the human genome. What follows are arguments for pushing the nascent science of rerogenic medicine up the mountain, and counterarguments for letting it roll right back down. In my view, at the end of the day, unlike Sisyphus, PGD will make sustainable and essential progress in advancing human health.

## II. UNINTENDED CONSEQUENCES IN ART

Breakthroughs in the nascent field of reproductive medicine have yielded a host of unintended consequences. Since the introduction of IVF in 1978,<sup>32</sup> the technique is credited with the birth of over three million children worldwide.<sup>33</sup> Combined with other ARTs such as artificial insemination by donor, oocyte donation, and surrogate parenting arrangement, IVF gives prospective parents increasing choice and control over their reproductive futures. The successful integration of ART into modern society is evident by the numbers alone: today, three out of every one hundred children in the U.S. are born as a result of some form of assisted conception.<sup>34</sup> Moreover,

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31. See ALBERT CAMUS, *THE MYTH OF SISYPHUS* 5 (Raymond Soulard, Jr. & Cassandra Soulard eds., 2006) (1942).

32. The world's first "test tube" baby, Louise Brown, was born outside London on July 25, 1978. See Peter Gwynne, *All About That Baby*, *NEWSWEEK*, Aug. 7, 1978, at 66, 67. Louise was conceived using IVF, a medical technique in which the egg and sperm are introduced under the glare of a laboratory petri dish, instead of in the dark quiet recesses of a woman's fallopian tube. *Id.* Once the sperm fertilizes the egg, the resulting embryo is nurtured in the lab for several days and then transferred into a woman's uterus where it will, hopefully, implant and develop until birth. *Id.*

33. See *European Society for Human Reproduction and Embryology; Three Million Babies Have Been Born Using Assisted Reproductive Technologies*, *WOMEN'S HEALTH LAW WKLY.*, July 16, 2006, at 77 (referencing a 2006 report by the International Committee for Monitoring Assisted Reproductive Technologies estimating the use of one million ART cycles a year, producing approximately 200,000 babies worldwide).

34. According to an annual report published by the Centers for Disease Control and Prevention (CDC), in 2005 (the most recent year for which figures are available) there were 52,041 children born in the U.S. who were conceived using some form of assisted reproductive technology (ART), as defined by the CDC to include only those techniques in which both the egg and the sperm are handled. In 2005, ninety-nine percent of all ART cycles measured by the CDC used IVF, with fewer than one percent using the related techniques of

the use of ART, particularly IVF, has increased every year since 1995, the first year in which such data was collected.<sup>35</sup> Though fundamentally grounded in medicine, today's reproductive technologies nimbly navigate from petri dish culture to business culture<sup>36</sup> to popular culture.<sup>37</sup> Yet despite

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gamete intrafallopian transfer (in which eggs and sperm are transferred into the fallopian tube) and zygote intrafallopian transfer (in which the early embryo is transferred into the fallopian tube). See CTRS. FOR DISEASE CONTROL & PREVENTION, U.S. DEP'T. OF HEALTH & HUM. SERVS., 2005 ASSISTED REPRODUCTIVE TECHNOLOGY SUCCESS RATES: NATIONAL SUMMARY AND FERTILITY CLINIC REPORTS 61, 85 (2007), available at [www.cdc.gov/ART/ART2005/508PDF/2005ART508.pdf](http://www.cdc.gov/ART/ART2005/508PDF/2005ART508.pdf) (last visited Feb. 3, 2009) [hereinafter 2005 ART REPORT]. In addition to IVF births, it is estimated that 60,000 children are born annually via artificial insemination by donor (AID), a technique in which only the sperm is handled (and thus births by AID are not included in the annual CDC report). See Inst. for Sci., Law & Tech. Working Group, *ART into Science: Regulation of Fertility Techniques*, 281 SCIENCE 651 (1998). Births via IVF and AID bring the total number of children born through assisted conception to roughly 110,000; the total birth rate for 2005 was slightly over four million. See CTRS. FOR DISEASE CONTROL & PREVENTION, U.S. DEP'T. OF HEALTH & HUM. SERVS., *Births: Final Data for 2005*, 56 NATIONAL VITAL STATISTICS REPORTS, Dec. 5, 2007, 1, at 1, available at [www.cdc.gov/nchs/data/nvsr/nvsr54/nvsr54\\_02.pdf](http://www.cdc.gov/nchs/data/nvsr/nvsr54/nvsr54_02.pdf) (last visited Feb. 3, 2009) (reporting 4,138,349 live births in the U.S. in 2005, up by approximately one percent from 2004). Thus, total ART births in the U.S. in 2005 comprised slightly over 2.7% of all live births).

35. See 2005 ART REPORT, *supra* note 34, at 61 (showing ten-year trends in the number of ART cycles performed from 1996-2005, as well as the number of live-birth deliveries during that same period using ART. Both ART cycles and deliveries increased by more than double. The CDC data on ART trends captures data from 1996 forward, excluding data from 1995 because it did not include all reporting U.S. ART clinics).

36. See Michele Goodwin, *Assisted Reproductive Technology and the Double Bind: The Illusory Choice of Motherhood*, 9 J. GENDER RACE & JUST. 1, 5, 46-49 (2005). Professor Goodwin argues that access to ART creates a "double bind" for women in the workplace, especially professional women whose superiors place subtle pressure on younger women to defer childbearing to increase their chances of "fair" opportunities at law firms, businesses, or university posts. ART is seen as a technological bail out for women who put off childbearing, thus encouraging continued participation in the workplace. Pregnancy and motherhood discrimination, Professor Goodwin argues, are soft but real discrimination that create "double binds" for women who believe they must choose between career and early motherhood. See *generally id.*

37. The well-publicized use of IVF and gestational surrogacy by celebrities, as well as incorporation of ART into movie and television plots has contributed to its role in popular culture. See, e.g., *Celebrities Who Have Used IVF and Surrogacy, Part 2*, at <http://egg-donation-directory.blogspot.com/2007/10/celebrities-who-have-used-ivf-and.html> (last visited Feb. 3, 2009) (listing model and actress Cindy Margolis, actor Chris Meloni, actress Laurie Metcalf, and anchorwoman Joan Lunden as patrons of gestational surrogates); *BABY MAMA* (Universal Studios 2008); see also Internet Movie Database, *Synopsis for Baby Mama*, at [www.imdb.com/title/tt0871426/synopsis](http://www.imdb.com/title/tt0871426/synopsis) (last visited Feb. 3, 2009); Press Release, Nat'l Infertility Ass'n, *Internet Icon, Supermodel Cindy Margolis to Serve as National Spokesperson for Resolve: The National Infertility Association* (June 7, 2005), at [www.resolve.org/site/PageServer?pagename=fmed\\_mcpr20050607](http://www.resolve.org/site/PageServer?pagename=fmed_mcpr20050607) (last visited Feb. 3, 2009). The hit ABC primetime series *Ugly Betty* included a plot twist involving the use of IVF and surrogacy in early



ART's seemingly seamless adoption as a procreative alternative, its rapidly advancing technical prowess has spawned numerous unexpected dilemmas.

ART's unintended consequences are best viewed from the perspective of its two major purposes—to treat infertility and to promote the health of offspring. Infertility treatment is based on a model in which gametes are extracted from the body and melded into embryos, many of which are frozen for later use.<sup>38</sup> The presence of gametes and embryos outside the body, subject to human manipulation, invites scenarios that are only possible in an ART world. In one New York fertility clinic, a white patient became pregnant with twin boys, one white and one black, because a laboratory technician mixed-up two couples' embryos on the day of transfer.<sup>39</sup> The white couple's "successful" use of ART inadvertently wrought tremendous pain and suffering to the black couple whose embryo was negligently misdirected. After a two-year legal battle, the black child was ordered returned to his genetic parents, but the debacle caused irreparable harm to both sets of parents.<sup>40</sup> This case and others like it disaggregate the roles of race, genetics, and gestation in determining parenthood, three factors that had heretofore vested in a single individual.

The freezing of sperm, eggs, and embryos can also produced unintended results. When a happily married couple undergoes IVF and freezes excess embryos for future use, they likely do not intend to later divorce and squabble bitterly over the disposition of those embryos, but such cases abound.<sup>41</sup> When a couple agrees to freeze embryos, neither party anticipates that the embryos will be released to the other without mutual consent, but at least several children have been born after their mothers forged their (non-consenting) fathers' name on the authorizing documentation.<sup>42</sup> Equally unexpected are decisions about the fate of

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2008. *Ugly Betty: A Thousand Words by Friday* (ABC television broadcast Jan. 24, 2008); see also ABC.com, *Ugly Betty Episode Recaps*, at <http://abc.go.com/primetime/uglybetty/index?pn=index> (last visited Feb. 3, 2009).

38. See 2005 ART REPORT, *supra* note 34, at 3, 4.

39. *Perry-Rogers v. Fasano*, 715 N.Y.S. 2d 19, 21-22 (2000).

40. *Id.* at 27; see also *IVF Mix-Up Heads for Court*, BBC NEWS, July 8, 2002, at <http://news.bbc.co.uk/2/hi/health/2115522.stm> (last visited Feb. 3, 2009) (summarizing several cases across Europe and the U.S. in which laboratory mix-ups involving sperm, eggs, or embryos have resulted in the birth of offspring).

41. See, e.g., *Davis v. Davis*, 842 S.W.2d 588, 589 (Tenn. 1992); *Kass v. Kass*, 91 N.Y.2d 554, 560 (1998); *A.Z. v. B.Z.*, 725 N.E.2d 1051, 1053 (Mass. 2000); *J.B. v. M.B.*, 783 A.2d 707, 710 (N.J. 2001); *In Re Marriage of Witten*, 672 N.W.2d 768, 768 (Iowa 2003) (all involving litigation over the disposition of frozen embryos upon divorce of the intended parents).

42. See, e.g., Sarah-Kate Templeton, *Wife's Embryo Fraud Makes Estranged Husband a Father*, SUNDAY TIMES (London), Mar. 2, 2008, at 7, at [www.timesonline.co.uk/tol/news/uk/article3466762.ece](http://www.timesonline.co.uk/tol/news/uk/article3466762.ece) (last visited Feb. 3, 2009).

gametes and embryos after the death of one or more of the intended parents. With sperm and embryo banks willing to keep material in frozen storage for decades,<sup>43</sup> the phenomenon of posthumous birth—the birth of genetic offspring after the death of a genetic parent—will become more routine.<sup>44</sup>

A final noteworthy unintended consequence of fertility treatment is its spillover into the emerging world of embryonic stem cell research. When researchers at the University of Wisconsin announced in the fall of 1998 they had succeeded in isolating and cultivating stem cells from human embryos, ART suddenly developed a second identity as a potential for medical cures.<sup>45</sup> The Wisconsin stem cell lines were developed from embryos donated by couples who had previously undergone IVF for reproductive purposes.<sup>46</sup> Seeing ART through the fresh lens of stem cell research focused attention on questions that were part of the backdrop of assisted conception, but had largely escaped the scrutiny that this type of research unleashed. Questions about the moral wisdom and legal authority surrounding the intentional destruction of embryos for research purposes, as well as the consent necessary to utilize gametes and embryos in medical experiments, moved front and center in the minds of stakeholders and observers alike.<sup>47</sup>

Stem cell research brought public attention to the possible medical benefits of ART apart from treating infertility, thus broadening the impact of advances in reproductive medicine from personal and procreative to global

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43. On November 1, 2007, a child was born to a forty-three-year old Canadian man who had stored sperm prior to chemotherapy in 1985. The child's conception using decades old thawed sperm, however, was not a record. "The longest-known storage period of sperm resulting in a live birth is 28 years, according to a 2005 report in the American medical journal *Fertility and Sterility*." Lena Sin, *Baby Conceived with Sperm Frozen Long Ago*, at [www.canada.com/story.html?id=973186](http://www.canada.com/story.html?id=973186) (last visited Feb. 3, 2009).

44. Several U.S. courts have already grappled with the question of whether a posthumously born child can be considered the heir of their predeceased parent for purposes of probate law, with most answering in the affirmative. See, e.g., *In re Gillett-Netting v. Barnhart*, 371 F.3d 593, 593-94, 599 (9th Cir. 2004) (all finding in favor of heirship for posthumously born children); *Woodward v. Comm'r of Soc. Sec.*, 760 N.E.2d 257, 272 (Mass. 2002); *Estate of Kolacy*, 753 A.2d 1257, 1258 (N.J. 2000). But see *Khabbaz v. Comm'r, Soc. Sec. Admin.*, 930 A.2d 1180, 1182 (N.H. 2007) (finding child was not a "surviving issue" of father under state law).

45. See James A. Thomson et al., *Embryonic Stem Cell Lines Derived from Human Blastocysts*, 282 *SCIENCE* 1145, 1145, 1147 (1998).

46. *Id.* at 1145.

47. See generally RUSSELL KOROBKIN & STEPHEN R. MUNZER, *STEM CELL CENTURY: LAW & POLICY FOR A BREAKTHROUGH TECHNOLOGY* (2007) (providing a comprehensive discussion of these and other issues surrounding embryonic stem cell research).

and life-saving.<sup>48</sup> While ART as a medical therapy may have first emerged in the public eye with embryonic stem cell research, its origins can be traced back to PGD.<sup>49</sup> Private individuals with family histories of genetic disorders learned decade earlier of reproductive medicine's ability to address human health outside the infertility context.<sup>50</sup> PGD made its entrance into medical literature in 1990 as a method of detecting lethal genetic anomalies in early embryos, but has since expanded to permit reproductive decision-making on the basis of speculative health and social criteria.<sup>51</sup> Today's prospective parents who access PGD can decide how much genetic health to require of their early embryos, a decision with potential consequences far beyond the birth of any resulting offspring.<sup>52</sup>

### III. THE USE OF PGD TO ASSURE OFFSPRING HEALTH

The array of genetic disorders and characteristics that PGD can detect grows with each passing year. Currently, PGD is performed for approximately one hundred genetic conditions, each carrying a unique profile in terms of severity of impact on overall health and onset of somatic symptoms.<sup>53</sup> Some of the detected conditions are fatal in the first years of life, such as Tay-Sachs disease; others pose serious health risks and often cause death in early adulthood, such as cystic fibrosis and Huntington's disease; still others are associated with an increased predisposition to adult-onset diseases such as colon and breast cancer.<sup>54</sup> The ability to access this vast array of genetic information, only some of which is reliably predictive of disease, enables prospective parents to decide what is, and is not, an acceptable level of health for their future children.

This power to orchestrate offspring health, however, is rife with problems of imprecision. Just as geneticists are unable to predict the severity of certain conditions, parents are likewise unable to predict the impact these health choices will have on their offspring, on themselves, and on society at large. What follows is an effort to isolate, describe, and analyze the

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48. See Sarah Franklin, *Embryonic Economies: The Double Reproductive Value of Stem Cells*, 1 BIOSOCIETIES 71, 71, 80 (2006) (discussing the influence of IVF on stem cell research).

49. See Carl T. Hall, *Stem Cell Research May Be Boon to Fertility Clinics*, S.F. CHRON., Feb. 21, 2005, at A6.

50. See Howard W. Jones, Jr. & Jean Cohen, *Chapter 14: Preimplantation Genetic Diagnosis*, 87 FERTILITY & STERILITY (Supplement 1) S47, S47 (2007).

51. *Id.* at S47, S49.

52. *Id.*

53. See HUANG, *supra* note 2.

54. See Baruch et al., *supra* note 5, at 1054; Press Release, Human Fertilisation & Embryology Authority, HFEA Licenses PGD for Inherited Colon Cancer (Nov. 1 2004), at [www.hfea.gov.uk/en/1049.html](http://www.hfea.gov.uk/en/1049.html) (last visited Feb. 3, 2009).

variables associated with the use of PGD to detect embryo health. For ease of reference, I categorize the variables into three areas which I'll label "the spectrum problem," "the shifting problem," and "the expectation problem."

#### A. *The Spectrum Problem*

If medicine is an art, then medical genetics may be best described as abstract expressionism for its break from the traditions of the past in a manner that can be jarring and incomprehensible. But as any fan of Willem de Kooning will croon, the vibrancy and energy of his colorful abstract canvases helped pave the way for a new generation of artists.<sup>55</sup> Likewise medical genetics breaks from the diagnostic practices of the past, offering predictions and prophylaxis long before any symptoms present. Our current understanding of genetics provides clarity with respect to certain disease processes, while remaining frustratingly out of focus for a host of other genetic anomalies. Questions of when, whether, and how severely a disease will manifest embody the spectrum problem.

PGD can detect whether a resulting child's genome will contain a genetic anomaly associated with a particular disease, but often it cannot predict how the disease will be expressed during the child's life.<sup>56</sup> For example, both Down syndrome and cystic fibrosis can be detected through PGD, but to date there is no clinical measure for the severity of symptoms associated with the diseases. According to the National Institutes of Health, "Down syndrome symptoms vary from person to person and can range from mild to severe."<sup>57</sup> The National Down Syndrome Congress concurs, adding that "[t]here is wide variation in mental abilities, behavior and physical development in individuals with Down syndrome. Each individual has his/her own unique personality, capabilities and talents."<sup>58</sup> The Cystic Fibrosis Foundation likewise advises that the course of cystic fibrosis varies

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55. For information about Willem de Kooning, see Guggenheim Collection, Artist - de Kooning - Biography, at [www.guggenheimcollection.org/site/artist\\_bio\\_36.html](http://www.guggenheimcollection.org/site/artist_bio_36.html) (last visited Feb. 3, 2009).

56. PGD remains susceptible to human and laboratory error, and misdiagnosis is a clinical reality. See, e.g., Y. Verlinsky et al., *Accuracy and Outcomes of 3631 Preimplantation Genetic Diagnosis (PGD) Cycles Performed in One Center*, 84 *FERTILITY & STERILITY* (Supplement 1) S98 (2005) (reporting misdiagnosis in PGD, resulting in an accuracy rate of 99.5%).

57. U.S. NAT'L LIBRARY OF MEDICINE & NAT'L INST. OF HEALTH, *MEDICAL ENCYCLOPEDIA: DOWN SYNDROME*, at [www.nlm.nih.gov/medlineplus/ency/article/000997.htm](http://www.nlm.nih.gov/medlineplus/ency/article/000997.htm) (last visited Feb. 3, 2009).

58. Nat'l Down Syndrome Congress (NDSC), *Facts About Down Syndrome*, at [www.ndsccenter.org/resources/package3.php](http://www.ndsccenter.org/resources/package3.php) (last visited Feb. 3, 2009).

from person to person.<sup>59</sup> Symptoms such as lung infections and coughing can be mild or severe.<sup>60</sup> On a hopeful note, the Foundation reports that the predicted median age of survival of a cystic fibrosis patient rose to 36.5 years in 2008, up from 32 years in 2000.<sup>61</sup>

Genetic diseases can also vary in terms of the phase in life in which they manifest. While diseases such as Tay-Sachs<sup>62</sup> and Fanconi's anemia<sup>63</sup> manifest at or near birth, other disorders such as Alzheimer disease<sup>64</sup> and Huntington's disease<sup>65</sup> may not become clinically noticeable until adulthood. Still other PGD-detectible genetic anomalies are associated with disease susceptibility, as opposed to disease certainty.<sup>66</sup> For example, families in which many individuals have been diagnosed with breast or colon cancer may share a genetic mutation that increases an affected individual's chances of developing the disease in adulthood.<sup>67</sup> Women who

59. See Cystic Fibrosis Found., Frequently Asked Questions, at [www.cff.org/AboutCF/Faqs/](http://www.cff.org/AboutCF/Faqs/) (last visited Feb. 3, 2009).

60. See *id.*

61. See *id.*

62. According to the National Institute of Neurologic Disorders and Stroke, "[e]ven with the best of care, children with Tay-Sachs disease usually die by age 4, from recurring infection." Nat'l. Inst. of Neurological Disorders and Stroke, Nat'l Inst. of Health, NINDS Tay-Sachs Disease Information Page, at [www.ninds.nih.gov/disorders/taysachs/taysachs.htm](http://www.ninds.nih.gov/disorders/taysachs/taysachs.htm) (last visited Feb. 3, 2009).

63. Fanconi's anemia is a form of inherited anemia that leads to bone marrow failure. See Fanconi Anemia Research Fund, Diagnosis, at [www.fanconi.org/aboutfa/Diagnosis.htm](http://www.fanconi.org/aboutfa/Diagnosis.htm) (last visited Feb. 3, 2009). Fanconi's anemia usually reveals itself before children are twelve years old, with symptoms such as skeletal anomalies, kidney problems, and blood abnormalities. *Id.*

64. While most forms of Alzheimer's disease are thought to be sporadic, a small percentage are considered familial. Inherited Alzheimer disease is associated with earlier onset of symptoms, sometimes as soon as age thirty-five, compared to the average age of sixty for other forms of the disease. See Found. for Genomics & Population Health, IVF Embryos to Undergo Screening for Early-Onset Alzheimer's Disease (Oct. 1, 2007), at [www.phg.foundations.org/news/3778/](http://www.phg.foundations.org/news/3778/) (last visited Feb. 3, 2009); ALZHEIMER'S DISEASE EDUC. & REFERRAL CTR., NAT'L INST. ON AGING, NAT'L INST. OF HEALTH, FACT SHEET: ALZHEIMER'S DISEASE, at 1, available at [www.nia.nih.gov/NR/rdonlyres/7DCA00DB-1362-4755-9E87-96DF669EAE20/11209/84206ADEARFactsheetAlzDiseaseFINAL08DEC23.pdf](http://www.nia.nih.gov/NR/rdonlyres/7DCA00DB-1362-4755-9E87-96DF669EAE20/11209/84206ADEARFactsheetAlzDiseaseFINAL08DEC23.pdf) (last visited Feb. 3, 2009).

65. Huntington's disease is a "hereditary, degenerative brain disorder for which there is, at present, no effective treatment or cure." Huntington's Disease Soc'y of America, What is Huntington's Disease (HD), at [www.hdsa.org/about/our-mission/what-is-hd.html](http://www.hdsa.org/about/our-mission/what-is-hd.html) (last visited Feb. 3, 2009). According to the Huntington's Disease Society of America, "HD typically begins in mid-life, between the ages of 30 and 50, though onset may occur as early as the age of 2. Children who develop the juvenile form of the disease rarely live to adulthood." *Id.*

66. See HUANG, *supra* note 2.

67. NAT'L CANCER INST., NAT'L INST. OF HEALTH, FACT SHEET: GENETIC TESTING FOR BRCA1 AND BRCA2: IT'S YOUR CHOICE at 1-2 (2002), available at [www.cancer.gov/images/Documents/abcb7812-a132-4e78-a532-f002c92fa9b9/fs3\\_62.pdf](http://www.cancer.gov/images/Documents/abcb7812-a132-4e78-a532-f002c92fa9b9/fs3_62.pdf) (last visited Feb. 3,

possess the gene mutation associated with the inherited form of breast cancer are three to seven times more likely to develop the disease than women without the genetic mutation.<sup>68</sup> Individuals with certain forms of inherited colon cancer are highly likely, but not absolutely certain, to develop the disease before the age of fifty.<sup>69</sup> Calculating the likelihood of disease expression—referred to as “penetrance”<sup>70</sup>—is further complicated by the availability of prophylactic surgery. In some cases, the onset of cancer may be avoided by removing the susceptible organs and tissues from the body.

These spectra of symptoms, time of onset, penetrance, and availability of treatment or prophylaxis create challenges for promulgating a monolithic view on the use of PGD to screen for embryo health. That said, absolutist views have been expressed. PGD is prohibited in several countries<sup>71</sup> and is opposed by the Catholic Church, which teaches that all embryos “ought always to be born from an act of love and should already be treated as a person.”<sup>72</sup> The basis for PGD, the creation of extracorporeal embryos using IVF, is a per se violation of the Catholic requirement that embryonic life result only from heterosexual intercourse.<sup>73</sup> To add clarity to this rejection of PGD, in March of 2008 the Church added certain “destructive bioethics practices” to its list of mortal sins, including “experiments that manipulate DNA or harm embryos”.<sup>74</sup> While PGD itself was not named as a specific

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2009) [hereinafter NAT’L CANCER INST., BRCA1 AND BRCA2 FACT SHEET]; see American Cancer Soc’y, *Heredity and Cancer*, at [www.cancer.org/docroot/CRI/content/CRI\\_2\\_6x\\_Heredity\\_and\\_Cancer.asp](http://www.cancer.org/docroot/CRI/content/CRI_2_6x_Heredity_and_Cancer.asp) (last visited Feb. 3, 2009) [hereinafter ACS, *Heredity and Cancer*].

68. NAT’L CANCER INST., BRCA1 AND BRCA2 FACT SHEET, *supra* note 67, at 1.

69. See ACS, *Heredity and Cancer*, *supra* note 67.

70. The penetrance of a genetic anomaly is defined as “the probability that the genotype will be reflected in the phenotype and will have consequences for health.” Guido de Wert & Joep P.M. Geraedts, *Preimplantation Genetic Diagnosis for Hereditary Disorders that Do Not Show a Simple Mendelian Pattern: An Ethical Exploration*, in CONTEMPORARY ETHICAL DILEMMAS IN ASSISTED REPRODUCTION 85, 88 (Françoise Shenfield & Claude Sureau eds., 2006).

71. PGD is prohibited by law in Germany, Italy, and Switzerland. Jones & Cohen, *supra* note 50.

72. See Address of His Holiness Benedict XVI to the Participants in the Plenary Assembly of the Pontifical Council for the Family (May 13, 2006), at [www.vatican.va/holy\\_father/benedict\\_xvi/speeches/2006/may/documents/hf\\_ben-xvi\\_spe\\_20060513\\_pc-family\\_en.html](http://www.vatican.va/holy_father/benedict_xvi/speeches/2006/may/documents/hf_ben-xvi_spe_20060513_pc-family_en.html) (last visited Feb. 3, 2009).

73. See, e.g., Address of His Holiness Pius XII to the Second World Congress in Naples on Human Reproduction and Sterility (May 19, 1956).

74. Steven Ertelt, *Catholic Church Says Abortion, Cloning, Embryo Destruction Are Sinful Practices*, LIFENEWS.COM, (Mar. 10, 2008), at [www.lifenews.com/int652.html](http://www.lifenews.com/int652.html) (last visited Feb. 3, 2009).

sin, its requisite extraction of embryonic DNA could be interpreted as both manipulative and harmful to embryos.<sup>75</sup>

In December of 2008 the Church updated its absolutist position on ART in the "Instruction on *Dignitas Personae* on Certain Bioethical Questions."<sup>76</sup> This Instruction, issued in response to the development of "new biomedical technologies," specifically addressed PGD and declared that the procedure "constitutes an act of abortion" because it "is directed toward the qualitative selection and consequent destruction of embryos."<sup>77</sup> The Church categorized PGD as an

expression of a eugenic mentality that 'accepts selective abortion in order to prevent the birth of children affected by various types of anomalies. Such an attitude is shameful and utterly reprehensible, since it presumes to measure the value of a human life only within the parameters of "normality" and physical well-being, thus opening the way to legitimizing infanticide and euthanasia as well.'<sup>78</sup>

Absolutist views in favor of PGD for medical screening of embryos have also appeared.<sup>79</sup> At least two subsets of absolutism co-exist in the ethics literature on the subject of prenatal genetic technologies.<sup>80</sup> One subset advocates that prospective parents have a positive moral duty to use genetic technologies to enhance the well-being of their offspring, enabling them to live longer, run faster, think clearer, and so on.<sup>81</sup> A second subset frames the positive duty in terms of preventing foreseeable medical harm to children by selecting against embryos that bear a known genetic anomaly.<sup>82</sup> The former subset is perhaps best represented by John Harris, a Professor of Bioethics at the University of Manchester, who argues in his recent book that

75. *Id.* The issue of physical harm to the long-term health of the embryo has been studied, and recent reports indicate that PGD does not negatively affect embryo health and development. See Jeanine Cieslak-Janzen et al., *Multiple Micromanipulations for Preimplantation Genetic Diagnosis Do Not Affect Embryo Development to the Blastocyst Stage*, 85 FERTILITY & STERILITY 1826, 1828 (2006).

76. The Holy See, Congregation for the Doctrine of the Faith, Instruction, *Dignitas Personae on Certain Bioethical Questions*, at [www.vatican.va/roman\\_curia/congregations/cfaith/documents/rc\\_con\\_cfaith\\_doc\\_20081208\\_dignitas-personae\\_en.html](http://www.vatican.va/roman_curia/congregations/cfaith/documents/rc_con_cfaith_doc_20081208_dignitas-personae_en.html) (last visited Feb. 3, 2009).

77. *Id.*

78. *Id.* (citing John Paul II, Encyclical Letter *Evangelium Vitae* (Mar. 25, 1995), at [www.vatican.va/holy\\_father/john\\_paul\\_ii/encyclicals/documents/hf\\_jp-ii\\_enc\\_25031995\\_evangelium-vitae\\_en.htm](http://www.vatican.va/holy_father/john_paul_ii/encyclicals/documents/hf_jp-ii_enc_25031995_evangelium-vitae_en.htm)) (last visited Feb. 3, 2009).

79. See John Harris, *Getting Better All the Time*, 122 NEW HUMANIST, Nov/Dec 2007, at 20, 20; see also ALLEN BUCHANAN ET AL., FROM CHANCE TO CHOICE: GENETICS AND JUSTICE 18-19 *passim* (2000).

80. See Harris, *supra* note 79, at 20-21; see BUCHANAN ET AL., *supra* note 79.

81. See Harris, *supra* note 79, at 20-21.

82. See BUCHANAN ET AL., *supra* note 79, at 156.

“it is not only feasible to use genetic technology to make people more healthy, intelligent and longer-lived, it’s our moral duty to do so.”<sup>83</sup> Harris considers that “[t]he denial of beneficial enhancements to others, whether they are our children or strangers, would be a breach of two of the most powerful moral principles, the duty to do good and the duty not to harm; whereas the consequences of that denial would leave someone more vulnerable to harm and less able to lead a healthy, fulfilling life.”<sup>84</sup> These outcomes, Harris argues, support a positive moral duty to utilize genetic enhancements, including PGD.<sup>85</sup>

The latter absolutist approach, which favors a positive duty to prevent offspring harm (but not necessarily a duty to enhance an otherwise healthy individual), is adopted by philosophers Allen Buchanan, Dan Brock, Norman Daniels, and Daniel Wikler in their book, *From Chance to Choice: Genetics and Justice*.<sup>86</sup> These esteemed moral and political philosophers debate the uses of genetic screening technologies and enhancements, concluding “that both justice and our obligations to prevent harm make genetic interventions to prevent disabilities not only permissible but also obligatory.”<sup>87</sup> Absolutist views that PGD must be used by prospective parents—either to maximally enhance their offspring’s physical and mental attributes, or to prevent known genetically-based disabilities—dismiss the spectrum problem as irrelevant. As long as the child could experience some deficit as a result of a genetic anomaly, the moral balance weighs in favor of PGD use and embryo selection. Absolutist views that PGD must never be used are likewise refractory to the spectrum problem. Since respect for embryos is the central feature of this position, no degree of disability would justify screening or discarding early human life.<sup>88</sup>

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83. Harris, *supra* note 79, at 20. Professor Harris’ book, *ENHANCING EVOLUTION: THE ETHICAL CASE FOR MAKING PEOPLE BETTER* “champions the possibility of influencing the very course of evolution to give us increased mental and physical powers—from reasoning, concentration, and memory to strength, stamina, and reaction speed. Indeed, he supports enhancing ourselves in almost any way we desire. And it’s not only morally defensible to enhance ourselves, Harris says. In some cases, it’s morally obligatory.” Princeton Univ. Press, Harris, J.: *Enhancing Evolution: The Ethical Case for Making Better People*, at <http://press.princeton.edu/titles/8480.html> (last visited Feb. 3, 2009).

84. Harris, *supra* note 79, at 21.

85. *Id.*

86. BUCHANAN ET AL., *supra* note 79, 156-257 (discussing implications of “Genetic Perfection” and the duty to prevent harm).

87. *Id.* at 302.

88. While absolutist views have been expressed on the use of PGD, numerous middle ground positions pepper the debate over the use of PGD. See generally NICHOLAS AGAR, *LIBERAL EUGENICS: IN DEFENCE OF HUMAN ENHANCEMENT* (2004) (explaining that some commentators take the view that parents should have autonomy to utilize available technologies to determine what is in the best interest of their future children—but they should



Adopting an absolutist view toward the use of PGD for medical screening has the benefit of nullifying the spectrum problem. If one is always in favor of or always against PGD, then the clinical realities of particular genetic disorders will hold no sway over the absolutist's position. But if one is open to weighing the merits of PGD on a case-by-case basis, or along some multi-factorial algorithm, then it would be useful to marshal the various points along the spectra identified with genetic disease. Such an algorithm could be used to identify the instances when the use of PGD is most acceptable, such as to avoid transmission of fatal childhood disorder, or when its use is more questionable, such as when the genetic anomaly has low penetrance and produces mild, treatable symptoms in the later decades of life.

Table 1 provides a tool for the numeric assessment of the merits of PGD for embryo health screening. The Table sets out four factors that determine the clinical significance of a given genetic anomaly—severity of disease, onset of disease, penetrance of disease, and availability of treatment or prophylaxis—together with three points along the spectrum for each factor. Using a point allocation system, basic parameters for the non-absolutist position on PGD can be set out. The strongest cases mark the end points. For example, lethal Tay-Sachs disease would fall in the “should be permitted” category, while a (as of now theoretical) mutation that poses a 5 percent likelihood of causing color blindness in late adulthood would represent the “should be discouraged” category. The majority of cases would fall somewhere in between the end points, in the neutral “can be permitted” arena. Even in these cases, it may be possible to more definitively resolve the question of whether PGD offers greater benefit than

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not be compelled to do so. Coined “liberal eugenics,” this discipline respects the voluntary choices of parents to use genetic techniques that will benefit the child in some way). Authors Guido de Wert and Joep P.M. Geraedts assert that two philosopher scholars—Carson Strong and Bonnie Steinbock—have espoused support for open access to PGD for prospective parents striving to assure maximal health for their offspring. Carson Strong urges adoption of a medical model in which physicians are “non-directive” toward parental requests for PGD, meaning they offer unconditional support for this reasonable request for service. See de Wert & Geraedts, *supra* note 70, at 87-88 (citing CARSON STRONG, *ETHICS IN REPRODUCTIVE AND PERINATAL MEDICINE: A NEW FRAMEWORK* 180 (1997)). Steinbock adopts a reproductive freedom framework, urging that a woman's right to control her reproductive life includes the right to access information that she deems relevant to any procreative decision. While doctors can discuss concerns about the use of PGD in certain situations, ultimately the decision rests with the patient. *Id.* at 87 (citing BONNIE STEINBOCK, *PREIMPLANTATION GENETIC DIAGNOSIS AND EMBRYO SELECTION, A COMPANION TO GENETICS* 147-57 in *A COMPANION TO GENETICS* (C. Burley & J. Harris eds., 2002)).

harm.<sup>89</sup> A disease that is fatal, or highly debilitating may rank as PGD-worthy even if its penetrance is low or it is an adult-onset disorder.

Casting the spectrum problem as a mathematical equation will do little to solve the ethical conundrums that PGD poses for non-absolutists, but organizing the data in a uniform manner can create a template for debate. While the factors included may not be exhaustive, and the spectrum points can invite wild speculation about unknowable clinical phenomena, a numeric approach does provide a means of assessing the relative merits of individual cases. In an era in which PGD tends to be accessed only by those with the means to pay its approximately \$15,000 price tag,<sup>90</sup> questions about whether it should be made available are suppressed by prevailing market forces in which supply capably meets demands. Should PGD become more widely available through expanded health insurance coverage, or even government mandates to provide, a rubric for comparing essential and nonessential uses of PGD will be invaluable.

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89. Admittedly, the terms “benefit” and “harm” are ill-defined in this context. Benefit could be measured by parental happiness wrought by the ability to control reproductive choice, or by offspring genetic health. Harm may refer to the risk of damage to or loss of embryos attributable to the PGD process, or to the morbidity associated with IVF in general. Moreover, balancing benefits and harms pays homage to a utilitarian calculus, in which actions are judged ethically acceptable when they produce greater benefits than harms overall.

90. See Barbara Collura, Nat’l Infertility Ass’n, *The Costs of Infertility Treatment*, at [www.resolve.org/site/PageServer?pagename=lrn\\_mta\\_cost](http://www.resolve.org/site/PageServer?pagename=lrn_mta_cost) (last visited Feb. 3, 2009).

Table 1. Assessing the Merits of PGD for Medical Screening of Embryos

<u>Factor 1</u>	<u>Factor 2</u>	<u>Factor 3</u>	<u>Factor 4</u>
Severity of Disease	Onset of Disease	Likelihood of Disease/ Penetrance	Availability of Treatment or Prophylaxis
a) The disease is fatal	a) At birth or early childhood	a) 100% likely to appear	a) No treatment or prophylaxis
b) The disease is non-fatal but debilitating	b) In early adulthood	b) Greater than 50% likely to appear	b) Some treatment for symptom control
c) The disease is mild or benign	c) In later adulthood	c) Less than 50% likely to appear	c) Effective prophylaxis available

a = 1, b = 2, c = 3.

Assessing Outcomes by Total Points:

- 4-6 PGD avoid serious harm and should be permitted
- 7-9 PGD avoids some harm and can be permitted
- 10-12 PGD poses more risk than benefit and should be discouraged

B. *The Shifting Problem*

A parent’s ability to select for or against certain genetic traits in offspring challenges the way we have historically viewed health in our society. Shifting control and responsibility for health status from person to parent could fundamentally change the way future generations view health risks, altering their behavior toward themselves and others. What follows is a discussion of the current landscape of health perspectives and its possible shift in light of emerging genetic technologies.

1. The Person-Public Dichotomy

Our current world view of health tends to vest responsibility for its maintenance in two actors: person and public.<sup>91</sup> From the person

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91. See BUCHANAN ET AL., *supra* note 79, at 11-12 (discussing the two perspectives for viewing genetic intervention, the “public health model” and the “personal choice model,”

perspective, an adult individual enjoys the benefits of maintaining, or suffers the consequences of neglecting, bodily and mental functions that generally comprise human health.<sup>92</sup> A child's health is likewise subject to a person-affecting model, with parents or guardians imbued with decision-making authority over offspring and minor charges.<sup>93</sup> While environmental, familial, social, and a host of other factors impact on a person's health, the person-affecting model dominates contemporary American constructs of health care decision-making. So essential is the right of the person to control his or her health and health care that the principle of patient autonomy sits at the nadir of contemporary bioethics.<sup>94</sup> Autonomous decision-making about individual health is of such moment in our culture that it currently occupies the highest echelon of constitutional protection—a right protected against government interference under the liberty interest of the Due Process Clause of the Fourteenth Amendment to the U.S. Constitution.<sup>95</sup> Individual rights and responsibilities largely drive health decision-making in the U.S.<sup>96</sup>

While the person may be supreme, the public health model also occupies a significant role in directing health in our society. Aided by early recognition of the need for public health measures in modern society,<sup>97</sup>

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Buchanan writes that the public health model “stresses the production of benefits and the avoidance of harms for groups[,]” while the personal choice model is based upon on “individual autonomy.”).

92. See *id.* at 12.

93. See *id.* at 13.

94. See generally TOM L. BEAUCHAMP & JAMES F. CHILDRESS, *PRINCIPLES OF BIOMEDICAL ETHICS* 99-148 (6th ed. 2008) (1979) (discussing the connection between patient autonomy and health care decision-making).

95. *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 278 (1990) (writing for the majority, Justice Rehnquist acknowledges, “[t]he principle that a competent person has a constitutionally protected liberty interest in refusing unwanted medical treatment may be inferred from our prior decisions.”). The question of whether the right to refuse medical treatment is a fundamental right is unanswered by the *Cruzan* majority, though commentators have posited that because the Court did not use strict scrutiny or expressly say that there was a fundamental right, no such right arose in the case. *E.g.*, Erwin Chemerinsky, *In Defense of Roe and Professor Tribe*, 42 *TULSA L. REV.* 833, 833 (2007). In the *Cruzan* dissent, Justice Brennan, joined by Justices Marshall and Blackmun, said that there is a “fundamental right to be free of unwanted artificial nutrition and hydration[.]” *Cruzan*, 497 U.S. at 302. As to a protected right to consent to medical care, the Court cited to an oft-quoted early twentieth century New York Court of Appeals decision, in which Justice Cardozo observed, “[e]very human being of adult years and sound mind has a right to determine what shall be done with his own body[.]” *Id.* at 269 (quoting *Schloendorff v. Soc’y of N.Y. Hosp.*, 105 N.E. 92, 93 (1914)).

96. See Candace Cummins Gauthier, *The Virtue of Moral Responsibility in Healthcare Decisionmaking*, 11 *CAMBRIDGE Q. OF HEALTHCARE ETHICS* 273, 273-75 (2002).

97. See *Jacobson v. Massachusetts*, 197 U.S. 11 (1905). In upholding a compulsory vaccination law as a valid exercise of the state's police power, the *Jacobson* Court acknowledged the right of an individual to assert supremacy over the government, but also

those currently responsible for protecting the public's health play an essential role in charting the course for human health. In a sense, public health principles act as a filter through which individual decisions about health pass, permitting a broader view of the impact that person-affecting conduct has on society at large.<sup>98</sup> Focusing on population rather than person, the public health perspective aims to maximize health for the many, even if it means sacrificing the rights of a few.<sup>99</sup>

In an era of reproductive genetics in general, and PGD in particular, applying the person-public dichotomy yields two distinct views of the value of preimplantation embryo selection. As discussed *supra*, Philosophers Allen Buchanan, Dan Brock, Norman Daniels, and Daniel Wikler describe the dual perspectives from which embryonic genetic intervention can be viewed as the "public health model" and the "personal choice model."<sup>100</sup> The public health model relies on "simple and unqualified consequentialist reasoning" and "looks only to the aggregate balance of good over bad."<sup>101</sup> If PGD, or any genetic intervention, produces an overall benefit for society (for example, by the birthing of fewer babies with genetic diseases), then the technique would be assessed as ethically sound.

The utilitarian calculus embedded in the public health model is laudable for its ease of use, but is often subject to criticism for its failure to recognize the rights, needs, and harms to individuals. Viewing genetic technologies from a utilitarian perspective is particularly nettlesome given the devastation wrought by the early 20th century American eugenics movement.<sup>102</sup> "Eugenicists believed that most social problems were caused by hereditary faults of those afflicted by the problem, and they sought to eventually eliminate these problems from society through selective breeding."<sup>103</sup> Using a combination of law and social pressure, American eugenicists convinced many that society's greater good would be served by sacrificing the

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stated, "it is equally true that in every well-ordered society charged with the duty of conserving the safety of its members the rights of the individual in respect of his liberty may at times, under the pressure of great dangers, be subjected to such restraint, to be enforced by reasonable regulations, as the safety of the general public may demand." *Id.* at 29.

98. See *id.* at 38-39 (holding a state's interest in protecting its citizens may at times override individual rights).

99. See BUCHANAN ET AL., *supra* note 79, at 11.

100. *Id.*

101. *Id.*

102. See, e.g., DANIEL J. KEVLES, IN THE NAME OF EUGENICS: GENETICS AND THE USES OF HUMAN HEREDITY 46-48 (1985); PAUL A. LOMBARDO, THREE GENERATIONS, NO IMBECILES: EUGENICS, THE SUPREME COURT AND *BUCK V. BELL* 104, 116 (2008); Alexandra Minna Stern, *Sterilized in the Name of Public Health*, 95 AM. J. PUB. HEALTH 1128, 1131-32 (2005).

103. Lisa Powell, Note, *Eugenics and Equality: Does the Constitution Allow Policies Designed to Discourage Reproduction Among Disfavored Groups?*, 20 YALE L. & POL'Y REV. 481, 483 (2002).

reproductive rights of a few.<sup>104</sup> The eugenics legacy continues to linger as a cautionary note to the application of a public health model to advances in reproductive medicine.<sup>105</sup>

The personal service model of genetic technologies, according to Buchanan and his colleagues, protects private choice as an exercise of individual autonomy.<sup>106</sup> Parents would be free to use PGD, or to decline to use PGD, as a matter of personal choice irrespective of the consequences to others.<sup>107</sup> The philosophers critique the personal service model for its elevation of autonomy over all other values, and thereby its potential to subordinate the autonomy of offspring to that of their parents.<sup>108</sup> Despite these criticisms, the use of PGD in the U.S. today most closely resembles the personal service model: its availability is based upon a parent's ability to pay and a provider's willingness to supply.<sup>109</sup>

## 2. From Person to Parent

The longstanding person-public perspectives on health are well-suited to a construct in which medical decisions affect the well-being of an existing individual, but they display signs of obsolescence when health choices are made on behalf of future generations. The use of PGD allows parents to wrest control over the health status of their offspring from nature itself. Moreover, by taking this prenatal control over offspring health, parents can now make health-related decisions that would heretofore have been made by the individual—the person whose health is at issue. Thus, PGD shifts responsibility for basic health status from person to parent, adding a third lens through which to view the choices and behaviors surrounding health. Shifting responsibility for health-related decision-making from person to parent can alter the actions of both person and parent.

In the health paradigm in which an individual's actions can affect the well-being of that person's mind or body, the individual is incentivized to act

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104. See *id.* at 483-484 (quoting HARRY H. LAUGHLIN, *EUGENICAL STERILIZATION IN THE UNITED STATES, A REPORT OF THE PSYCHOPATHIC LABORATORY OF THE MUNICIPAL COURT OF CHICAGO* 446-47 (1922)). "Between 1900 and 1963, at least 60,000 Americans were sterilized pursuant to eugenic sterilization laws" passed in more than thirty states. *Id.* "In response to a lawsuit in 1974 the federal government adopted regulations banning sterilization without consent in hospitals that receive federal funds, but reports of violations surface periodically." *Id.* at 484.

105. See, e.g., Michael J. Malinowski, *Choosing the Genetic Makeup of Children: Our Eugenics Past—Present, and Future?*, 36 *CONN. L. REV.* 125, 131-132 (2003).

106. BUCHANAN ET AL., *supra* note 79, at 12-13.

107. See *id.*

108. *Id.* at 13.

109. See generally Baruch et al., *supra* note 5, at 1055-56 (surveying PGD providers' willingness to perform the technique for medical and social reasons).

in a way that maximizes health. A person's understanding of their own health vulnerabilities are gleaned through various channels providing both specific and general health information. A person can learn directly about his or her own health from bouts of ill health, visits with health care providers, or results of medical testing. In addition, public education plays a role in individual health by the dissemination of information about risks and benefits to health via certain activities, foods, and therapeutics. An individual armed with specific and general health information can adjust behaviors to promote good health.

For example, a woman with a family history of breast cancer can undergo a genetic test to see if she possesses any of the genetic mutations associated with inherited forms of breast cancer.<sup>110</sup> If so, she can take several steps to reduce and possibly avoid onset of the disease. She can modify her lifestyle to include a healthier diet and more exercise, both shown to reduce the risk of disease onset in women with the genetic marker for breast cancer.<sup>111</sup> She can consider taking a drug regimen which studies show can reduce the chances of developing the disease in some cases.<sup>112</sup> And she can opt for prophylactic surgery in which susceptible breast tissue is removed, thus substantially reducing her chances of developing breast cancer.<sup>113</sup> A woman who knows she is highly susceptible to breast cancer may be super vigilant about her health in general, taking far fewer health risks than someone with no such predisposition.

It is understandable that a woman whose life is affected by her genetic predisposition to breast cancer would want to spare her children such trauma. Today such a woman could use PGD to select both male and female embryos that do not bear the known genetic mutation.<sup>114</sup> How

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110. NAT'L CANCER INST., NAT'L INST. OF HEALTH, U.S. DEP'T OF HEALTH & HUM. SERV., PUB NO. 05-4252, *GENETIC TESTING FOR BREAST AND OVARIAN CANCER RISK: IT'S YOUR CHOICE 2-3* (2005), available at [www.cancer.gov/cancertopics/Genetic-Testing-for-Breast-and-Ovarian-Cancer-Risk/pdf](http://www.cancer.gov/cancertopics/Genetic-Testing-for-Breast-and-Ovarian-Cancer-Risk/pdf) (last visited Feb. 3, 2009).

111. See A. Nkondjock et al., *Diet, Lifestyle and BRCA-Related Breast Cancer Risk Among French Canadians*, 98 *BREAST CANCER RES. & TREATMENT* 285, 292 (2006).

112. See Mary-Claire King et al., *Tamoxifen and Breast Cancer Incidence Among Women with Inherited Mutations in BRCA1 and BRCA2: National Surgical Adjuvant Breast and Bowel Project (NSABP-P1) Breast Cancer Prevention Trial*, 286 *JAMA* 2251, 2255 (2001) (suggesting that prophylactic tamoxifen treatment may be effective for women with BRCA2 mutations, but not for women with BRCA1 mutations. The study tested the efficacy of tamoxifen in reducing occurrences of breast cancer among cancer-free women with BRCA1 and BRCA2 mutations.).

113. See *id.*

114. Males who possess the genetic mutations BRCA1 or BRCA2 are at increased risk of developing breast cancer. Yu Chuan Tai et al., *Breast Cancer Risk Among Male BRCA1 and BRCA2 Mutation Carriers*, 99 *J. NAT'L CANCER INST.* 1811, 1813 (2007); see also *Science Daily*, *Breast Cancer Risk Elevated in Male BRCA Mutation Carriers*, at [www.sciencedaily.com/releases/2007/11/071127171305.htm](http://www.sciencedaily.com/releases/2007/11/071127171305.htm) (last visited Feb. 3, 2009).

might such a decision impact on the child's life? At least two possible behavioral scenarios emerge.

If the child is told about the orchestrated origins of their conception, he or she might be grateful to the parent for eliminating that particular cancer risk from their bloodline. But a sense of invincibility could follow. The child, or later the adult, may feel little incentive to adhere to a healthy lifestyle, believing that the parent has absorbed all responsibility for the child's health. Just as a person with a genetic predisposition can overemphasize health in their lifestyle, a person purposefully conceived to be free of the predisposition may be lackadaisical toward their health in general, perhaps increasing the risk of sporadic illness or traumatic injury. Moreover, a person who ignores or downplays health maintenance could be woefully unprepared to cope with injury or illness, compared to a person who does not take good health for granted.

Alternatively, a person born into a family whose adult members have suffered the devastating effects of inherited breast cancer may feel both relief and appreciation for their genetic good fortune. They may have an enhanced sense of the importance of good health, taking measures to protect themselves against known health diminishers. At least in the first generation of PGD use, children born without the genetic mutation will belong to families in which one or several members are affected by the cancer susceptibility gene. Watching a loved one suffer can be a powerful incentive to guard one's own good health.

I find the latter scenario far more likely and far more consistent with our past experiences with breakthroughs in disease prevention. PGD may have certain unique qualities, but it is not the first medical advance to offer parents an opportunity to protect their children against disease. The introduction of childhood vaccines allows, and in some cases mandates,<sup>115</sup> parents to eliminate the possible onset of harmful diseases including smallpox,<sup>116</sup> polio,<sup>117</sup> measles,<sup>118</sup> and whooping cough.<sup>119</sup> Professor Ronald

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115. See Steve P. Calandrillo, *Vanishing Vaccinations: Why Are So Many Americans Opting Out of Vaccinating Their Children?*, 37 U. MICH. J. L. REFORM 353, 358, 381-82 & n.199 (2004) (stating that fifty states have enacted compulsory childhood vaccination laws to stop the spread of preventable diseases. "The laws require proof of certain immunizations prior to a child's entry into daycare or school, and provide for exclusion of children not in conformity." Nearly all states provide religious exemptions, and about a dozen now have philosophical opt-outs).

116. Smallpox, "[a]lso known as variola, [is] a highly contagious and frequently fatal viral disease characterized by a biphasic fever and a distinctive skin rash that left pock marks in its wake. . . . The disease is caused by the variola virus. The incubation period is about 12 days (range: 7 to 17 days) following exposure. Initial symptoms include high fever, fatigue, and head and back aches. A characteristic rash, most prominent on the face, arms, and legs, follows in 2-3 days. . . . The majority of patients with smallpox recover, but death occurs in



Green makes an interesting point about the use of vaccines in his recent book assessing the ethics of PGD.<sup>120</sup> In comparing vaccines (disease prevention) to PGD (genetic enhancement), Green observes, “[w]hen we are inoculated, the DNA in our white blood cells undergoes irreversible genetic changes, initiating the synthesis of antibodies to many viruses and bacteria.

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up to 30% of cases. Smallpox is spread from one person to another by infected saliva droplets that expose a susceptible person having face-to-face contact with the ill person.” MedicineNet.com, Definition of Smallpox, at [www.medterms.com/script/main/art.asp?articlekey=6328](http://www.medterms.com/script/main/art.asp?articlekey=6328) (last visited Feb. 3, 2009).

117. Polio, short for poliomyelitis, “is a viral disease that can affect nerves and lead to paralysis. . . . The virus spreads by direct person-to-person contact, by contact with infected mucus or phlegm from the nose or mouth, or by contact with infected feces. The virus enters through the mouth and nose, multiplies in the throat and intestinal tract, and then is absorbed and spread through the blood and lymph system. . . . Between 1840 and the 1950s, polio was a worldwide epidemic. Since the development of polio vaccines, the incidence of the disease has been greatly reduced. Polio has been wiped out in a number of countries. There have been very few cases of polio in the Western hemisphere since the late 1970s. Children in the United States are now routinely vaccinated against the disease.” U.S. Nat’l Lib. of Med., MedlinePlus, Poliomyelitis, at [www.nlm.nih.gov/medlineplus/ency/article/001402.htm](http://www.nlm.nih.gov/medlineplus/ency/article/001402.htm) (last visited Feb. 3, 2009).

118. Measles is caused by a highly contagious virus. “The infection is spread by contact with droplets from the nose, mouth, or throat of an infected person. For example, sneezing and coughing can put contaminated droplets into the air. . . . Persons with the measles typically have a fever, cough, redness and irritation of the eyes (conjunctivitis), and a rash that spreads. Those who have had an active measles infection or who have been vaccinated against the measles have immunity to the disease. Before widespread immunization, measles was so common during childhood that most people became sick with the disease by age 20. While the number of measles cases dropped over the last several decades to virtually none in the U.S. and Canada, rates have started to rise again recently.” U.S. Nat’l Lib. of Med., MedlinePlus, Measles, at [www.nlm.nih.gov/medlineplus/ency/article/001569.htm](http://www.nlm.nih.gov/medlineplus/ency/article/001569.htm) (last visited Feb. 3, 2009).

119. Whooping cough, also known as pertussis, “is a highly contagious bacterial disease that causes uncontrollable, violent coughing. The coughing can make it hard to breathe. A deep ‘whooping’ sound is often heard when the patient tries to take a breath. . . . When an infected person sneezes or coughs, tiny droplets containing the bacteria move through the air, and the disease is easily spread from person to person. . . . Whooping cough can affect people of any age. Before vaccines were widely available, the disease was most common in infants and young children. Now that most children are immunized before entering school, the higher percentage of cases is seen among adolescents and adults.” U.S. Nat’l Lib. of Med., MedlinePlus, Pertussis, at [www.nlm.nih.gov/medlineplus/ency/article/001561.htm](http://www.nlm.nih.gov/medlineplus/ency/article/001561.htm) (last visited Feb. 3, 2009).

120. Ronald Green is the Eunice & Julian Cohen Professor for the Study of Ethics and Human Values and director of the Ethics Institute at Dartmouth College. Dartmouth College, Ethics Institute, Ronald M. Green, at [www.dartmouth.edu/~ethics/about/ronaldgreen.html](http://www.dartmouth.edu/~ethics/about/ronaldgreen.html) (last visited Feb. 3, 2009); RONALD M. GREEN, *BABIES BY DESIGN: THE ETHICS OF GENETIC CHOICE* (2007) [hereinafter *BABIES BY DESIGN*].

Vaccinations make us superhumans, but no one ridicules enhancements of this sort.”<sup>121</sup>

Vaccines, viewed as genetic enhancements or disease prevention, have not affected the way the inoculated view health in general. Knowing that one cannot be infected with smallpox or polio does not translate into recklessness or fearlessness about other health matters. Likewise, PGD, viewed either as a form of genetic enhancement or disease prevention, would not affect the way the resulting offspring view their general health. Knowing that one is protected against a particular disease (inherited forms of breast or colon cancer, for example) does not change one’s perceived vulnerability, or lack thereof, toward the myriad other diseases that plague the human race. While a PGD-selected adult may be less vigilant about certain diseases, protection against one or several genetic disorders is a proverbial drop in the bucket when it comes to the array of health maladies that lurk in any lifetime.

PGD does shift some medical decision-making from person to parent, but the shift is subtle in the context of the resulting child’s (and later adult’s) overall health status. Whether disease prevention occurs prenatally or postnatally is of little moment in the lifetime of the individual spared from diseases that sickened prior generations. Allowing parents to make choices that avoid harm to their children seems consistent with the traditional role that parents have played in protecting and defending the health of their children. Since disease prevention measures are best practiced sooner than later in the human life cycle, better we honor the shift of medical decision-making from person to parent when deleterious genetic anomalies can be avoided. Parental stewardship may require nothing less, a debatable point I refer to as “the expectation problem,” to which I now turn.

### C. *The Expectation Problem*

Since its introduction nearly two decades ago, PGD has received its share of criticism from the academic ethics community whose concerns range from the intentional destruction of human embryos to the creation of a genetic overclass bred to dominate those less-genetically well endowed.<sup>122</sup>

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121. GREEN, *BABIES BY DESIGN*, *supra* note 120, at 60.

122. Professor Janet Dolgin provides a succinct summary of the main objections to PGD in her article titled *Method, Mediations, and the Moral Dimensions of Preimplantation Genetic Diagnosis*. She cites the five main moral objections to PGD as: (1) the technique involves embryo destruction, an impermissible act to those who adhere to the belief that personhood begins at conception; (2) it commodifies children by reducing their value to the sum of their distinct traits, rather than their personhood as a whole; (3) it is a form of eugenics because it allows the selection of embryos (and later persons) with favored traits and the destruction of embryos with disfavored traits; (4) its high cost impacts principles of distributive justice, because it is available only to wealthier parents, leaving less wealthy individuals more likely to

In the context of selection (and thereby deselection) of embryos to maximize the health of the resulting child, one critique dominates—the concern that a parent’s choice to use PGD to assure offspring health will convert into parental duty to do so.<sup>123</sup> As the technique is perfected and becomes more widely available, social pressure will mount to form an expectation that a child’s well-being is served only by prenatal manipulation of the offspring’s health status. This “expectation problem” is described by the President’s Council on Bioethics in their 2004 report, *Reproduction and Responsibility*, which warns that “[a]s the aggregate effect of parental choices reshapes society’s understanding of ‘normal’ or ‘acceptable’ phenotypes, parents might feel social pressure to undergo PGD, as many pregnant women are now pressured to undergo amniocentesis.”<sup>124</sup>

The expectation problem is comprised of two dependent components—the expectation to use PGD and the expectation to then discard embryos with genetic anomalies. I label these components as dependent because the clinical reality is that parents who seek out PGD to detect the health of their embryos do so in order to implant only those that do not bear an unhealthy genome.<sup>125</sup> What concerns many about the expectation problem is the lack of boundaries surrounding acceptable uses of the screening technology. As discussed in Part III(A), the spectrum of genetic disease penetrance and severity is wide, admitting the possibility that an embryo with a low likelihood of developing a highly manageable disease could fall prey

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birth children with genetic anomalies; and (5) it is an affront to the disabilities community for its expression of rejection of physical or mental difference in society. See Janet L. Dolgin, *Methods, Mediations, and the Moral Dimensions of Preimplantation Genetic Diagnosis*, 35 CUMB. L. REV. 519, 522-26 (2005). Critiques of PGD for its potential to create a genetic overclass worry “[w]hat the emergence of a genetic overclass will do to the idea of universal human dignity. . . . [T]o the extent that [young people] become ‘children of choice’ who have been genetically selected by their parents for certain characteristics, they may come to believe increasingly that their success is a matter not just of luck but of good choices and planning on the part of their parents, and hence something deserved. They will look, think, act, and perhaps even feel differently from those who were not similarly chosen, and may come in time to think of themselves as different kinds of creatures. They may, in short, feel themselves to be aristocrats, and unlike aristocrats of old, their claim to better birth will be rooted in nature and not convention.” FRANCIS FUKUYAMA, *OUR POSTHUMAN FUTURE: CONSEQUENCES OF THE BIOTECHNOLOGY REVOLUTION* 157 (2002).

123. THE PRESIDENT’S COUNCIL ON BIOETHICS, *REPROD. AND RESP.: THE REG. OF NEW BIOTECHNOLOGIES* 96 (2004) (noting that parents might feel socially pressured to undergo PGD. In addition to social pressure, parents might feel compelled to use PGD for financial reasons, to avoid having a child with debilitating and costly genetic disorder).

124. *Id.*

125. The use of PGD for so-called intentional diminishment, described in *Vignette 3: Using PGD to Satisfy Parental Preferences*, *supra* notes 22-28 and accompanying text, could be viewed as an exception to the general use of the technique to assure the good health and function of the resulting offspring.

to the expectation of discard once PGD is performed. While the desire to avoid birthing a child with a lethal anomaly such as Tay-Sachs disease might strike all but the most ardent embryo defenders as morally acceptable, there is growing concern that parents will be pressured to discard embryos with mild or even benign deviations from the norm.<sup>126</sup>

The critique that the mere presence of prenatal screening technologies pressures parents into rejecting “imperfect” offspring is not unique to PGD. In her book, *The Dream of the Perfect Child*, Joan Rothschild argues that all forms of prenatal diagnosis, from ultrasound to amniocentesis to chorionic villus sampling to PGD,<sup>127</sup> create what she terms a “discourse of the perfect child.”<sup>128</sup> This discourse demands that parents reject, via abortion or embryo discard, anything less than a perfectly healthy child.<sup>129</sup> Professor

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126. See Jason Christopher Roberts, *Customizing Conception: A Survey of Preimplantation Genetic Diagnosis and the Resulting Social, Ethical, and Legal Dilemmas*, 2002 DUKE L. & TECH. REV., 0012 § IV. Roberts suggests that when multiple embryos are screened there is “inherent pressure to select only the most desirable traits.” *Id.* While it is currently not possible to screen for physical and behavioral traits, there is risk that parents will select only the most desirable traits, leaving others to “drift randomly among the families of the underclass.” *Id.* (quoting LEE SILVER, *REMAKING EDEN: CLONING AND BEYOND IN A BRAVE NEW WORLD* 225 (1997)).

127. JOAN ROTHSCHILD, *THE DREAM OF THE PERFECT CHILD* 76-88 (2005). The armamentarium of prenatal tests began to build in the late 1950s and early 1960s with the introduction of ultrasound into obstetric practice. Cynthia M. Powell, *The Current State of Prenatal Genetic Testing in the United States*, in *PRENATAL TESTING AND DISABILITY RIGHTS* 46 (Erik Parens & Adreinne Asch eds., 2000). In the 1970s, physicians began to routinely offer their pregnant patients maternal serum screening—via a simple blood test—to measure biochemical markers associated with several conditions in the fetus, including neural tube impairments such as spina bifida and anencephaly, and Down syndrome. *Id.* at 45-46. Today’s pregnant woman can also undergo amniocentesis and chorionic villus sampling (CVS) to detect fetal chromosomal abnormalities. *Id.* at 44-48.

According to the Centers for Disease Control and Prevention (CDC), “in 2003, 67 percent of women who had live births [in the U.S.] received ultrasound,” a steady increase from 47.6% in 1989. CTRS. FOR DISEASE CONTROL & PREVENTION, U.S. DEP’T. OF HEALTH & HUMAN SERVS., PUB. NO. (PHS) 2005-1120, *Births: Final Data for 2003*, NATIONAL VITAL STATISTICS REPS., 1, 13 (2005). The rate of amniocentesis for 2003 was 1.7%, a decline from the 3.2% reported in 1989, due in large measure to the increased use of noninvasive screening tests such as ultrasound and measurement of maternal serum markers. *Id.* at 14. The use of maternal serum markers to assess fetal health, commonly referred to as a “triple screen,” looks for three types of biochemical markers in a pregnant woman’s blood during the second trimester of pregnancy. Powell, *The Current State of Prenatal Genetic Testing in the United States*, *supra*, at 45-46. Elevated and low levels of certain markers can be associated with certain neural tube and genetic defects, and often prompt women to follow up an abnormal finding with ultrasound or amniocentesis. *Id.*

128. ROTHSCHILD, *supra* note 127, at 3.

129. See *id.* at 3-4, 105 (stating that the discourse of the imperfect child arises in clinical setting, where the parents have to decide whether to keep the pregnancy or terminate it, if the prenatal diagnosis unveils an imperfect child).

Rothschild laments the increasingly routine use of prenatal testing, which fuels the expectation on the part of medical personnel and society at large that the purpose of testing is to eliminate those with anomalies from the population.<sup>130</sup> “The discourse that emerges in reproductive medicine characterizes the birth of a child with ‘defects’ as a tragedy, to be avoided by every means that science and technology can muster.”<sup>131</sup>

The discourse of the perfect child is particularly troubling to the disability rights community, who view the discard of “imperfect” embryos as discrimination against existing persons with disabilities. As explained by Professors Adrienne Asch and Erik Parens, when a child has a disability, “a single trait stands in for the whole, the trait obliterates the whole[]” with “no need to find out about the rest.”<sup>132</sup> In the context of disabilities and prenatal testing, detection of a genetic disability often leads to selective abortion because the parents view the fetus only in terms of the disability, paying no regard to the many other qualities of the potential child.<sup>133</sup> The parent sees the prospective child only as the disability, and this single trait enables the parents to justify their action.<sup>134</sup> The abortion is ridding society of the disability—not of a child who, despite or possibly because of the disability, could lead a productive and happy life.<sup>135</sup>

This sequence of events—prenatal diagnosis followed by embryo discard or selective abortion—sends a message “that disability itself, not societal discrimination against people with disabilities, is the problem to be solved.”<sup>136</sup> Biologic elimination trumps social accommodation when the collective decision of prospective parents is to avoid the birth of a child with

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130. See *id.* at 6. Professor Rothschild writes that the promise of a “perfect baby” comes in the form of technology which is misunderstood “as a guarantor of perfection.” *Id.* She argues that while technology allows medical practitioners to cure diseases in adults, children and fetuses, it also serves “to discover and weed out the imperfect.” *Id.*

131. *Id.* at 105.

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

133. See *id.* at 14.

134. See *id.* at 13-14. Asch and Parens argue that persons with disabilities are discriminated against because of a single trait that they bear. *Id.* Prenatal testing is a form of discrimination because a single trait revealed during prenatal testing can be enough to warrant an abortion. *Id.* at 14. Parents may choose to abort an otherwise wanted fetus because they see an undesirable trait, not a child as a whole. *Id.*

135. See *id.* at 12-17 (Professors Parens & Asch argue that selective abortion discriminates against disability. With prenatal diagnosis we are trying to screen out and prevent the birth of children with what we perceive to be undesirable characteristics. Thus, we allow a single trait to “stand in for the whole” and “obliterate the whole.”).

136. *Id.* at 13.

disabilities.<sup>137</sup> Why is disability itself a problem, query Asch and Parens?<sup>138</sup> The disability rights critique argues that disability is seen as a problem not to the disabled person (whose main problem is the attitudes of others toward disability), but rather as a diminishment to the parental experience.<sup>139</sup> Having a disabled child, prospective parents worry, will rob them of their anticipated rearing experience.<sup>140</sup> Thus, refusing to gestate or aborting a disabled child is a way of preserving and upholding parental notions about the role that reproduction will play in their lives.<sup>141</sup> Viewed from the disability rights perspective, the societal expectation problem described at the outset is merely a reflection of individual expectations surrounding reproduction.

Understandably, the disability rights community views the expectation problem as gravely troubling, posing a “fear of elimination” as parents select against more and milder anomalies.<sup>142</sup> But others defend the expected use of PGD as a valid, even required, exercise of parental responsibility. Philosopher Janet Malek stakes out what she calls “the Strong Claim” on the use of PGD.<sup>143</sup> “There are some situations,” she posits, “in which potential parents are morally required to use reproductive genetic technologies to reduce the likelihood that their future child will have a disabling condition.”<sup>144</sup> Dr. Malek argues that acting in accordance with the Strong Claim maximizes the future child’s opportunities and well-being,

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137. See generally Parens & Asch, *supra* note 132, at 12-29.

138. *Id.* at 13-15, 17-90. In addition to noting that a single trait stands in for the whole when parents decide whether to have a child with a disability, Parens & Asch present their “parental attitude argument,” contending that disability becomes an issue when prospective parents allow it. *Id.* “If prospective parents imagine that disability precludes everything else that could be wonderful about a child, they are likely acting on misinformation and stereotypes.” *Id.* at 17. If parents understand that a disability is only one of a “fetus’s characteristics” than they can enjoy being a parent to a child with a disability without “turning the child into someone she is not.” *Id.* at 17-18.

139. *Id.* at 13.

140. *Id.*

141. See *id.* Professors Parens and Asch lament this parental view as “unfortunate, often misinformed” because they overestimate the negative aspects and underestimate the value and satisfaction of parenting a disabled child. *Id.*

142. See Suzanne Holland, *Selecting Against Difference: Assisted Reproduction, Disability and Regulation*, 30 FLA. ST. U. L. REV., 401, 407-08 (2003) (noting the fear of many disabled people and some homosexuals that society would wish to eliminate them through prenatal genetic testing).

143. Janet Malek, Assistant Professor, Dep’t of Med. Human., Brody Sch. of Med., E. Carolina Univ., Presented at the Saint Louis University School of Law 20<sup>th</sup> Annual Health Law Symposium: Disability and the Duties of Potential Parents (Apr. 4, 2008) (PowerPoint presentation on file with author).

144. *Id.*

a special responsibility that parents are ethically obligated to undertake.<sup>145</sup> Because parents of existing children are obligated to reduce the likelihood that they will become disabled, for example by obtaining care for treatable diseases, the obligation to future children is no weaker.<sup>146</sup> She acknowledges the disability rights critique, but finds that the sources, incidence, and views of disability are too diverse to be significantly impacted by the use of PGD.<sup>147</sup> On balance, she concludes that the ethical demand for parental partiality toward their children tip the scales in favor of the Strong Claim in cases of disabling conditions.<sup>148</sup>

Both the disability rights critique and the Strong Claim offer commentary on the expectation problem engendered by the use of PGD to assure embryo health. The disability community finds the expectation problematic because it is based on and is calibrated to increase discrimination against persons with disabilities. From this perspective, PGD is used to eliminate a would-be person, resulting in negative attitudes and ill-treatment of existing persons with disabilities. Defenders of the Strong Claim view the expectation to use PGD as a moral requisite to good parenting because it avoids harm to a particular person—the offspring to whom parents owe a duty of care. Seen from this perspective, PGD eliminates disease, thus fulfilling the duty of existing persons—the prospective parents.

Is it possible to reconcile these two seemingly opposite views of the expected use of PGD to assure embryo health? A place to begin may be with the language, and corresponding perceptions, adopted by each side. Instead of viewing PGD as a tool for elimination (person/disease), it should be seen as a means of preventing harm. If both foes and advocates can agree that harm prevention is a good worth pursuing, then a dialogue can begin about which harms are worth preventing, and in whom the harms should be prevented. As to the latter issue of who should be protected from harm, both sides seem to agree that existing persons, or those likely to come into existence, are the ones who should be protected from harm. The existing person category includes persons with disabilities, prospective parents, and the “healthy” embryos selected for implantation.<sup>149</sup>

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145. *Id.*

146. *Id.*

147. *Id.*

148. Malek, *supra* note 143; see also, Harris, *supra* note 79, at 21 (discussing what Dr. Malek terms “the Strong Claim”).

149. This categorization assumes that adherents to the disability rights critique and the Strong Claim do not subscribe to the view that all preimplantation embryos are existing persons, and thus must be implanted in order to avoid harm to the embryos themselves. This view, advocated by the Catholic Church, represents an absolutist view of PGD that shuns all use of the technique. See *supra* notes 72-78 and accompanying text. I do not read the disability rights critique to say that PGD should never be used because it may lead to embryo

There appears nothing mutually exclusive about preventing harm to all three groups within the category of existing persons. Even if one favors greater protection for one group, the other groups need not be made vulnerable to harm as in a zero-sum game. The key to achieving equipoise in group harm prevention is in agreeing which harms are worth preventing. This determination is where the two perspectives are most likely to diverge. Whereas the Strong Claim may advocate for PGD to select against embryos that are certain or likely to experience mobility or sensory disabilities such as paraplegia, blindness, or deafness, the disability rights critique may argue these conditions do not pose harm to the individual and therefore selecting against them is a form of discrimination against existing persons with the deficits. Even if the disability community agreed that it is better for a child to be born fully ambulatory with all senses intact, it would continue to worry about the slippery slope upon which PGD is sure to fall. Selecting against severe mobility and sensory deficits could easily morph into deselecting embryos with extremely mild forms of the disability, such as those destined to be pigeon toed, color blind, or tone deaf, should these conditions ever be traced to a genetic cause.

Will the ability to prevent harm to offspring that is both grave and trivial translate into the use of PGD to discard all but the Renaissance embryos of the twenty-first century? I think the answer is no. First, from an efficiency standpoint, it seems unlikely that IVF plus PGD will ever overtake the old-fashioned way of reproducing. The cost, time, and surgical invasion<sup>150</sup> required make it an unlikely rival for natural conception. Still, the worry remains that the small subset of parents who do invoke PGD will ratchet up the indications for its use, widening the circle from individuals with a family history of a devastating disease to those bent on eliminating even slight imperfections in their family tree. If this wider clientele does emerge, will a more routine use of PGD impact the way we view illness and health in our society, as some critics have worried? Will our ability to select against mild and manageable disease translate into intolerance of those with such genetic disorders? Again, I am persuaded to answer in the negative.

The trajectory of modern medicine suggests that we will continue to search out causes and cures for a broad range of maladies, but that such

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discard. Nothing in its concern for the lives of individuals with disabilities suggests that it insists on birthing infants whose life span would be a handful of years and who would suffer great pain throughout. Instead, the critique reads as a plea for society to recognize the beneficial and productive lives that persons with disabilities lead.

150. The surgical invasion refers to the surgery required to extract mature eggs from a woman's ovaries in order to form embryos using IVF. PGD can only be performed on extracorporeal embryos, thus IVF is an essential first step to genetic testing of preimplantation embryos. See COOK ET AL., *supra* note 3, at §9.7.



discoveries will have little impact on how we view those afflicted with the ailments. The use of vaccines to prevent harm from disease provides a nice counterpart to the use of PGD to prevent harm from genetic anomaly. While vaccines are administered postnatally, and PGD is used prenatally, both aim to prevent the onset of health diminishing conditions. Though PGD is still in its infancy, it appears to be traveling a path similar to that paved by vaccine development, initially targeting severe, life-threatening diseases then gradually addressing less severe conditions as more is learned about the technology.

As noted previously, PGD was developed in the late 1980s to detect mostly lethal single-gene disorders that displayed high penetrance in affected families, such as Tay-Sachs disease and Huntington's disease.<sup>151</sup> Today, embryologists can use PGD to detect over one hundred genetic conditions, some of which are nonfatal, such as familial high cholesterol, and others which pose a mere susceptibility to adult-onset disease, such as breast or colon cancer.<sup>152</sup> This pattern repeats the development of vaccines, which at first were used to prevent fatal communicable diseases, but today are routinely administered to avoid generally mild symptoms of common childhood infections.

The first successful vaccination was created by Edward Jenner in 1796 to combat smallpox, a contagious disease that had plagued humankind for centuries.<sup>153</sup> A vaccination for yellow fever followed in 1937, and the well-known polio vaccine was introduced in a large scale trial in 1954.<sup>154</sup> The President of the March of Dimes, Basil O'Connor, said of the polio vaccine at its introduction:

I have just figured out that during the coming summer, thirty or forty thousand children will get polio. About fifteen thousand of them will be paralyzed and more than a thousand will die. If we have the capacity to prevent this, we have a social responsibility . . . we are supported by the

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151. See *supra* notes 50-54 and accompanying text.

152. Johns Hopkins U., The Genetics & Pub. Pol'y Ctr., Issue Brief: Preimplantation Genetic Diagnosis (Feb. 27, 2006), at [http://www.dnapolicy.org/policy.issue.php?action=detail&issuebrief\\_id=7](http://www.dnapolicy.org/policy.issue.php?action=detail&issuebrief_id=7) (last visited Feb. 3, 2009).

153. Smithsonian, Nat'l Museum Am. Hist., *Whatever Happened to Polio?: Two Vaccines*, at <http://americanhistory.si.edu/polio/virusvaccine/vacraces.htm> (last visited Feb. 3, 2009) [hereinafter *Whatever Happened to Polio?*]; see generally Stefan Riedel, *Edward Jenner and the History of Smallpox and Vaccination*, 18 PROC. (BAYLOR UNIV. MED. CENT.) 21 *passim* (2005), at [www.pubmedcentral.nih.gov/articlerender.fcgi?artid=1200696](http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=1200696) (last visited Feb. 3, 2009) (describing the history of smallpox and its role in the development of the field of immunology).

154. *Whatever Happened to Polio?*, *supra* note 153.

people and it is our duty to save lives no matter how many difficulties may be involved.<sup>155</sup>

Perhaps Mr. O'Connor expressed the first iteration of the Strong Claim by framing the polio vaccine in terms of duty, but would he have been as strong an advocate for inoculating infants against a less deadly disease? If we have the capacity to prevent disease through vaccination, do we have a social responsibility (duty) to do so? American pediatricians seem to answer in the affirmative, in the form of their recommendations to parents regarding childhood vaccinations. Today the American Academy of Pediatrics recommends that children be vaccinated against fifteen diseases, some of which overwhelmingly produce only mild symptoms in their host.<sup>156</sup> For example, the vaccination for chicken pox was introduced in the U.S. in 1995, and is now widely used despite the medical fact that the disease is generally mild and short-lived in the vast majority of those affected.<sup>157</sup> But its severity in a small number of infected individuals supports its use as a public health matter.<sup>158</sup>

In terms of the expectation problem, we should query whether the widespread, although not universal, use of childhood vaccines has changed the way we view children and adults who manifest the targeted disease. Epidemiologic data suggests that over ninety percent of children old enough to receive vaccinations do receive the inoculations, leaving around ten percent of the population voluntarily or inadvertently unvaccinated.<sup>159</sup> As a result of either vaccine ineffectiveness, or the exposure of unvaccinated

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155. *Id.* (quoting Basil O'Connor, President of March of Dimes, 1954).

156. CTRS. FOR DISEASE CONTROL & PREVENTION, RECOMMENDED IMMUNIZATION SCHEDULE FOR PERSONS AGED 0-6 YEARS—UNITED STATES: 2008, available at [www.cdc.gov/vaccines/recs/schedules/downloads/child/2008/08\\_0-6yrs\\_schedule\\_pr.pdf](http://www.cdc.gov/vaccines/recs/schedules/downloads/child/2008/08_0-6yrs_schedule_pr.pdf) (last visited Feb. 3, 2009).

157. See generally CTRS. FOR DISEASE CONTROL & PREVENTION, CHICKEN POX VACCINE: WHAT YOU NEED TO KNOW, available at [www.cdc.gov/vaccines/pubs/vis/downloads/vis-varicella.pdf](http://www.cdc.gov/vaccines/pubs/vis/downloads/vis-varicella.pdf) (last visited Feb. 3, 2009) ("Chickenpox (also called varicella) is a common childhood disease. It is usually mild, but it can be serious, especially in young infants and adults. It causes a rash, itching, fever, and tiredness. It can lead to severe skin infection, scars, pneumonia, brain damage, or death. The chickenpox virus can be spread from person to person through the air, or by contact with fluid from chickenpox blisters. . . . Before the vaccine, about 11,000 people were hospitalized for chickenpox each year in the United States. Before the vaccine, about 100 people died each year as a result of chickenpox in the United States.").

158. *Id.*; see also U.S. Nat'l Libr. of Med., Medline Plus, Chickenpox, at [www.nlm.nih.gov/medlineplus/ency/article/001592.htm](http://www.nlm.nih.gov/medlineplus/ency/article/001592.htm) (last visited Feb. 3, 2009).

159. See Jennifer Steinhauer, *Rising Public Health Risk Seen as More Parents Reject Vaccines*, N.Y. TIMES, Mar. 21, 2008, at A1 (explaining that most unvaccinated children in the U.S. are parented by "vaccine skeptics[.]" parents who seek exemption from state child vaccination laws out of a personal belief that vaccines are either dangerous or unnecessary).

individuals to the particular viruses, outbreaks do periodically occur.<sup>160</sup> Loosely applying the disability rights critique to these incidents of (largely) preventable diseases, we would expect to see widespread discrimination against individuals (or their parents) whose voluntary refusal to be vaccinated caused their disease syndrome. That is, if an individual has the opportunity to prevent disease, then declines such opportunity, that individual should be derided once the disease manifests for failing to protect herself and possibly her community from harm.

Instead of shunning “vaccine deviants,” society appears to have accepted them and accommodated their difference. For example, several pediatric practices advertise their willingness to work with vaccine-adverse parents, permitting them to sign an “informed refusal” form declining vaccinations on behalf of their children.<sup>161</sup> Also, a number of states have enacted broad exemptions to their vaccine mandates, allowing parents to opt out of required inoculations so long as they agree to keep their children out of school during known outbreaks.<sup>162</sup> While the presence of preventable—and communicable—disease is concerning for the commonweal, it has not wrought isolation, denial of treatment, or discrimination against those who choose to live outside the bounds of accepted medical practice. Being different, even “imperfect” from a disease-resistance perspective, has not produced widespread social harm to affected populations.

The take away message from the vaccine experience may be that the ability to prevent disease does not necessarily translate into discrimination against those who manifest the disease. Shifting back to PGD, there is reason to believe that this observation will hold true for disease prevention in the form of embryo selection. Allowing parents to choose to birth a child free of known genetic disorders—even those associated with mild symptomology or asymptomatic carrier status—should have little or no impact on the treatment of living or to-be-born individuals who express those genetic anomalies. Alternatively, permitting parents to forgo PGD and risk birthing a child with genetic anomalies, while frowned upon as a breach

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160. *Id.* (describing recent outbreaks of measles, mumps and pertussis).

161. For example, Dr. Robert Sears, a pediatrician and author of *THE VACCINE BOOK* (2007), describes himself as a “vaccine-friendly” practitioner, meaning he is willing to accept patients in his practice that wish to delay or decline vaccinations for their children. His website compiles and lists other “vaccine friendly” pediatricians. See AskDrSears.com, *What is a Vaccine-Friendly Doctor?*, at [www.askdrsears.com/thevaccinebook/Vaccine\\_Friendly\\_Doctors.asp](http://www.askdrsears.com/thevaccinebook/Vaccine_Friendly_Doctors.asp) (last visited Feb. 3, 2009).

162. *Id.* *But see* Calandrillo, *supra* note 115 (expressing concern over growing use of vaccine exemptions and recommending greater scrutiny of exemption requests). See Ctrs. for Disease Control & Prevention, Nat’l. Vaccine Program Office: Immunization Laws, at [www.dhhs.gov/nvpo/law.htm](http://www.dhhs.gov/nvpo/law.htm) (last updated Feb. 3, 2009).

of parental duty by the Strong Claim, should likewise have no impact on society's perception of that individual's worth. Disease prevention technologies should be celebrated as a collective benefit when they succeed, but their failures should never rest on the shoulders of any affected individual.

In sum, it is likely that PGD will continue to gain audience as its ability to reveal the embryonic genome improves. At the same time, it seems equally unlikely that PGD will be a routine part of reproduction, as its cost and risk barriers make it unattractive to most of the world's prospective parents. Still, for the subset that wishes to screen and choose among their early embryos, the expectation problem will present. The expectation that parents should routinely use PGD will likely impact only those parents who are already predisposed to accessing prenatal genetic technologies. For these reprotch-inclined parents, PGD is the latest entry on the ART continuum that has been in development for over three decades. This group may regard PGD as a "must have" because it expedites the delivery of genetic information and eliminates the abortion dilemma that accompanies other forms of prenatal genetic testing. But the idea of a universal expectation to use PGD seems clinically unrealistic. Mother Nature is a far more compelling, efficient, and successful alternative to technically-assisted procreation.

As for the second part of the expectation problem—that once PGD is used it will result in deselection of embryos for milder and more benign conditions—this is likely to be the case. PGD, like other forms of disease prevention, will begin by tackling life-threatening conditions and gradually expand to address less serious, albeit life-affecting, syndromes. Will this incremental expansion change the way we view disease or those with disease in our society? I think not. We will continue to seek out cures and treatments for diseases grave and trivial because those who aspire for greater health in our society demand and deserve nothing less.

Instead of fostering discrimination against those with lesser health, advances in the treatment and prevention of serious diseases may instead yield, as a byproduct, therapies useful for treating less devastating illness. A modern day example of such fortuity can be found in the research surrounding smallpox. We recently learned that after centuries of work to combat, and virtually rid the world of smallpox, a drug used for this deadly disease may also be useful in treating a far less serious, though annoying, health scourge—the common cold. In May 2008, scientists announced the successful application of a smallpox drug to protect against adenovirus,

a.k.a. the common cold, in animal studies.<sup>163</sup> Such is a common trajectory in medical research— with a destination in mind, researchers stay alert to useful detours along the way.

#### IV. CONCLUSION

Genetic technologies have and will continue to change the way we think about our own health and that of our children. The ability to select or discard early embryos on the basis of genetic health empowers parents to make earlier and more profound medical decisions on behalf of their offspring, possibly disrupting long held views about an individual's capacity to control his or her own health. PGD, with its increased sensitivity to detect milder and later-onset diseases, actively shifts decision-making about health from the affected person to the controlling parent, while tempting users to eliminate even slight imperfections in their offspring. While worries about that PGD will promote recklessness toward health in children spared of familial diseases, and disdain for those who do manifest genetic anomalies, nothing in our past treatment of sickness and health suggests such a future.

The path of our plodding journey to improve human health was recently described by Harvard Professor of Psychology Steven Pinker in response to concerns that advances in technology will rob us of our basic human dignity. "The reality is that biomedical research[,]” Professor Pinker observed, “is a Sisyphean struggle to eke small increments in health from a staggeringly complex, entropy-beset human body. It is not, and probably never will be, a runaway train.”<sup>164</sup> While some may yearn for PGD to forge full-steam ahead to reveal more and more about the early human genome, thus enabling greater micromanagement of our genetic offspring, what we really should expect are baby steps in this neophyte technology whose own life cycle will surely long outlast each of our own.

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163. See *Smallpox Drug May Protect Against Common Cold*, U.S. NEWS & WORLD REP., May 20, 2008, at <http://health.usnews.com/articles/health/healthday/2008/05/20/smallpox-drug-may-protect-against--common-cold.html> (last visited Feb. 3, 2009).

164. Steven Pinker, *The Stupidity of Dignity*, NEW REPUBLIC, May 28, 2008, at 28, 31.

