

WRONGFUL SELECTION: ASSISTED REPRODUCTIVE TECHNOLOGIES, INTENTIONAL DIMINISHMENT, AND THE PROCREATIVE RIGHT

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I. Introduction

[I]n the realm of bioethics, the evils we face (if indeed they are evils) are intertwined with the goods we so keenly seek: cures for disease, relief of suffering, preservation of life. Distinguishing good and bad thus intermixed is often extremely difficult.¹

A. *The Landscape of Reproductive Issues*

The science of reproduction has advanced dramatically in the last several decades. Whereas in the past, couples experiencing difficulty producing children of their own had little or no recourse beyond adoption, couples today enjoy an array of choices thanks to various assisted-reproductive technologies (ART), from injections or pills designed to stimulate the body's own reproductive capabilities,² to the use of in-vitro fertilization (IVF) techniques to produce viable embryos outside of the body for implantation into the mother,³ to the use of a surrogate mother to carry an embryo,⁴ or to the use of sperm from a surrogate father to create a fertilized embryo.⁵ Incredibly, it is even possible to utilize all of these methods at once by conceiving a child utilizing a donated egg and sperm and implanting the resulting fertilized egg into the uterus of a surrogate mother.⁶

Today, these are relatively common and uncontroversial techniques for creating life. Techniques are now being perfected that lie at the very frontiers of medicine, such as the use of preimplantation genetic diagnosis (PGD) to select for or against certain

¹ Leon R. Kass, Chairman, President's Council on Bioethics, Opening Remarks at the First Meeting of the Council (Jan. 17, 2002), *available at* <http://www.bioethics.gov/about/chairman.html>.

² Fertility LifeLines, Initial Treatments, <http://www.fertilitylifelines.com/initialtreatments/index.jsp> (last visited Jan. 16, 2009).

³ American Pregnancy Association, In Vitro Fertilization: IVF, <http://www.americanpregnancy.org/infertility/ivf.html> (last visited Jan. 16, 2009).

⁴ *E.g.*, Lisa Baker, *A Surrogate Dries Her Tears*, N.Y. TIMES, Dec. 11, 2005, *available at* <http://www.nytimes.com/2005/12/11/fashion/sundaystyles/11LOVE.html>.

⁵ *E.g.*, Katrina Clark, *My Father Was an Anonymous Sperm Donor*, WASH. POST, Dec. 17, 2006, at B01, *available at* <http://www.washingtonpost.com/wp-dyn/content/article/2006/12/15/AR2006121501820.html>.

⁶ Giovanni Frazzetto, *DNA or Loving Care?*, 5 EMBO REP. 1117, 1117 (2004).

characteristics in a fertilized egg⁷ or even “germline” genetic engineering at some point in the not-too-distant future.⁸

As can be imagined, such techniques and the possibilities that they create are infused with controversy. IVF can result in the creation of numerous embryos,⁹ many more than can ever be implanted in the mother, and arguments rage over the legal status of these fertilized eggs and what their eventual fate should be. Some people argue that the embryos should eventually be given over for adoption,¹⁰ and others argue that such embryos provide a promising source of cells for stem-cell research.¹¹ IVF techniques can also result in multiple successfully implanted embryos, forcing parents to choose between selective abortion of some of the resulting fetuses so as to improve the chances of bringing the remainder to term or undergoing a risky multiple-birth pregnancy.¹² Debate also swirls around the possibility of human-reproductive cloning, a process where an exact genetic duplicate of an already existing human being could be created.¹³

⁷ John A. Robertson, *Extending Preimplantation Genetic Diagnosis: Medical and Non-Medical Uses*, 29 J. MED. ETHICS 213, 213 (2003).

⁸ ASS'N OF REPRODUCTIVE HEALTH PROF'L S, HUMAN CLONING AND GENETIC MODIFICATION: THE BASIC SCIENCE YOU NEED TO KNOW 5 (2003), *available at* [http://www.arhp.org/uploadDocs/cloning.pdf#search="HUMAN%20CLONING%20AND%20GENETIC%20MODIFICATION%20THE%20BASIC%20SCIENCE%20YOU%20NEED%20TO%20KNOW%20"](http://www.arhp.org/uploadDocs/cloning.pdf#search=) (“Germline’ genetic engineering is genetic engineering that targets the genes in eggs, sperm, or very early embryos. . . . Germline engineering is banned in many countries but not in the U.S.”)

⁹ Georgia Reproductive Specialists, *In Vitro Fertilization (IVF-ET): Questions and Answers*, <http://www.ivf.com/ivffaq.html> (last visited Jan. 16, 2009) (stating that “25% of pregnancies with IVF are twins” whereas in the “normal population, the rate one set of twins per 80 births”).

¹⁰ *E.g.*, Nightlight Christian Adoptions, *Nightlight Adoptions: Snowflakes Program*, <http://www.nightlight.org/snowflakeadoption.htm> (last visited Jan. 16, 2009).

¹¹ Liza Mundy, *Souls on Ice: America’s Embryo Glut and the Wasted Promise of Stem Cell Research*, MOTHER JONES, July/Aug. 2006, http://www.motherjones.com/news/feature/2006/07/souls_on_ice.html.

¹² Ozkan Ozturk & Allan Templeton, *Multiple Pregnancy in Assisted Reproduction Techniques*, in CURRENT PRACTICES AND CONTROVERSIES IN ASSISTED REPRODUCTION: REPORT OF A MEETING ON “MEDICAL, ETHICAL AND SOCIAL ASPECTS OF ASSISTED REPRODUCTION” HELD AT WHO HEADQUARTERS IN GENEVA, SWITZERLAND 17-21 SEPT. 2001 200, 220-21 (Effy Vayena et al. eds., 2002), *available at* <http://www.who.int/reproductive-health/infertility/report.pdf>.

¹³ Genomics.energy.gov, *Human Genome Project Information: Cloning Fact Sheet*, http://www.ornl.gov/sci/techresources/Human_Genome/elsi/cloning.shtml (last visited Jan. 16, 2009).

Another controversial process involves the use of PGD not only to screen for inheritable diseases in a successfully fertilized egg but also to screen for other inheritable conditions such as eye color, gender, intelligence, or even perfect pitch.¹⁴ In addition, some couples have used ART, and PGD in particular, to intentionally produce disabled children. For example, a deaf, lesbian couple in the United States utilized IVF to increase their odds of having deaf children and have successfully given birth to two deaf children as a result.¹⁵ Another example includes a dwarf couple who wanted to use genetic testing to determine if they could have a child that would inherit their dwarfism.¹⁶ And in 2003, it was reported that a Chicago-area physician was approached by a couple that wanted the physician's assistance in using PGD to enable them to give birth to a child with Down syndrome.¹⁷ The doctor refused, but in 2008, a study in an American medical journal revealed that of 137 clinics in the U.S. that provide IVF, three of them reported offering the procedure to prospective parents who sought to select *for* disabilities,¹⁸ demonstrating that not all doctors face an ethical quandary carrying out such a technique. Though such numbers indicate that the procedure is far from routine, this science is still in its earliest stages. It is not difficult to imagine a future in which the science is more advanced, where the technology exists to permit prospective parents to routinely utilize PGD to select for or against identifiable genetic conditions.

¹⁴ Robertson, *supra* note 7, at 214.

¹⁵ See Liza Mundy, *A World of Their Own*, WASH. POST, Mar. 31, 2002, at W22 (stating that the couple used a deaf sperm donor to increase their chances of having a deaf child and utilized IVF as a method of conceiving).

¹⁶ Peter H. Huang, *Herd Behavior in Designer Genes*, 34 WAKE FOREST L. REV. 639, 642 (2001).

¹⁷ Judith F. Daar, *ART and the Search for Perfectionism: On Selecting Gender, Genes, and Gametes*, 9 J. GENDER, RACE & JUST. 241, 265 (2005).

¹⁸ Susannah Baruch et al., *Genetic Testing of Embryos: Practices and Perspectives of US In Vitro Fertilization Clinics*, 89 FERTILITY & STERILITY 1053 (2008); see William Saletan, *Deformer Babies: The Deliberate Crippling of Children*, Sept. 21, 2006, <http://www.slate.com/id/2149854> (referring to an earlier survey with the same results).

B. A Survey of In-Vitro Fertilization and Preimplantation Genetic Diagnosis

ART, defined as any procedure that involves the handling of eggs or embryos,¹⁹ is several decades old in the United States. In this Article, the term will be used primarily to refer to methods of conception utilizing IVF, the means by which an egg is fertilized outside of the body and then implanted in a woman's uterus.²⁰

IVF was first developed in the late 1970s and early 1980s, and the first child produced via IVF was born in 1978 in England.²¹ The first child produced by IVF in the United States was born in 1981,²² and since then approximately one million babies have been born in this country utilizing IVF technologies.²³

IVF is a four-step process that is performed over a month-long period.²⁴ The first step involves the stimulation of the woman's ovaries with hormones to induce the ovaries to produce several eggs at one time.²⁵ The eggs are retrieved from the woman's ovaries during a minor surgical procedure and placed in separate petri dishes, after which they are given two to five days (depending on the procedure) to be fertilized by sperm, which are also in the petri dishes.²⁶ Once successful fertilization has taken place, the fertilized

¹⁹ AM. SOC'Y FOR REPROD. MED., ASSISTED REPRODUCTIVE TECHNOLOGIES: A GUIDE FOR PATIENTS 18 (2007), available at <http://www.asrm.org/Patients/patientbooklets/ART.pdf>.

²⁰ Cooper Center for In-Vitro Fertilization, In-Vitro Fertilization, http://www.ccivf.com/in-vitro_fert.html (last visited Jan. 16, 2009).

²¹ Andrea L. Bonnicksen, *In Vitro Fertilization and Embryo Transfer*, in 4 ENCYCLOPEDIA OF BIOETHICS 2307, 2307 (3d ed. 2004); see Patrick Steptoe & Robert Edwards, *Birth After the Reimplantation of a Human Embryo*, 2 LANCET 366 (1978).

²² *First IVF Child in U.S. Meets Doctor: Carr Finally Reunited with Obstetrician*, MSNBC, Oct. 31, 2003, available at <http://www.msnbc.msn.com/id/3088015/>.

²³ PRESIDENT'S COUNCIL ON BIOETHICS, REPROD. & RESPONSIBILITY: THE REGULATION OF NEW BIOTECHNOLOGIES 3 (2004), available at http://www.bioethics.gov/reports/reproductionandresponsibility/_pcbe_final_reproduction_and_responsibility.pdf.

²⁴ See Bonnicksen, *supra* note 21, at 2307; Shared Journey—Your Path to Fertility, What Is IVF?, http://www.sharedjourney.com/ivf/what_is.html (last visited Jan. 16, 2009).

²⁵ Bonnicksen, *supra* note 21, at 2307; see Shared Journey—Your Path to Fertility, Ovulation Induction, <http://www.sharedjourney.com/articles/induc.html> (last visited Jan. 16, 2009).

²⁶ Bonnicksen, *supra* note 21, at 2307; Shared Journey—Your Path to Fertility, Embryo Culture, <http://www.sharedjourney.com/define/culture.html> (last visited Jan. 16, 2009).

eggs—comprised of four to sixteen cells depending on how long they have cultured in the dish—are then transferred to the woman’s uterus two to three days after they were removed.²⁷ Anywhere from two to four embryos may be implanted in the woman’s uterus at the time of transfer in the hopes that one of the embryos will successfully attach to the uterus and begin the process of becoming a fetus.²⁸ Any remaining embryos that are not implanted can be cryo-preserved either for later transfer or disposition, usually in accordance with the wishes of the couple or the woman receiving the IVF treatment.²⁹ After twelve days, the woman returns for a blood test to determine if the embryo has successfully attached to the uterus and pregnancy has been initiated.³⁰

Prospective parents with concerns about the presence of genetic conditions in their children were, in the past, limited to prenatal genetic diagnosis, consisting of one of two tests: (1) chorionic villus sampling, a procedure in which tissue from the placenta is extracted for examination, or (2) amniocentesis, a procedure that utilizes amniotic fluid containing small samples of fetal tissue.³¹ The greatest limitation of these procedures is the fact that neither test can be done until well after the embryo has been implanted in the uterus and developed into a fetus, usually about nine to eighteen weeks after implantation, while an embryo develops into a fetus generally about eight weeks after

²⁷ Bonnicksen, *supra* note 21, at 2307; *see* Shared Journey—Your Path to Fertility, The IVF Process: Embryo Transfer, <http://www.sharedjourney.com/define/transfer.html> (last visited Jan. 16, 2009) [hereinafter The IVF Process: Embryo Transfer].

²⁸ Bonnicksen, *supra* note 21, at 2307; The IVF Process: Embryo Transfer, *supra* note 27.

²⁹ The IVF Process: Embryo Transfer, *supra* note 27; *see* Bonnicksen, *supra* note 21, at 2307.

³⁰ The IVF Process: Embryo Transfer, *supra* note 27.

³¹ Richard J. Tasca & Michael E. McClure, *The Emerging Technology and Application of Preimplantation Genetic Diagnosis*, 26 J.L. MED. & ETHICS 7, 7 (1998); Familydoctor.org, <http://familydoctor.org/online/famdocen/home/women/pregnancy/fetal/144.html> (last visited Jan. 16, 2009) (explaining briefly the amniocentesis and CVS procedures).

implantation.³² This leaves the couple facing the choice of either bringing a fetus to term that will have inherited a genetic disease or aborting the fetus before it is viable.³³

PGD provides an alternative approach.³⁴ After the egg is fertilized and has developed into an embryo consisting of anywhere between six to ten cells, one of the cells is extracted and tested for defective genes or chromosomal abnormalities.³⁵ This procedure is conducted on all of the embryos created from IVF so that a determination can be made as to which ones are free of genetic defects and can be implanted into the uterus.³⁶

However, the use of PGD is not limited to screening for genetic diseases. The procedure's potential is such that it could conceivably be utilized for non-therapeutic purposes such as screening for gender, hair color, or any other number of inheritable conditions.³⁷ A couple or a person armed with detailed knowledge of an embryo's genetic makeup can use that information to select either for or against a particular embryo's genetic features, choosing whether or not to implant an embryo during the IVF process depending on the results of testing. The range of traits that are selected for or against is limited only by our understanding of human genetics and the power of our genes to control physical features or personality³⁸—an understanding that is facilitated by a science that remains in its infancy but is acquiring more knowledge about the human

³² Tasca & McClure, *supra* note 31, at 8.

³³ *Id.* at 7.

³⁴ *Id.* at 8.

³⁵ *Id.* at 11.

³⁶ *See id.*

³⁷ Bratislav Stankovic, "It's a Designer Baby!"—*Opinions on Regulation of Preimplantation Genetic Diagnosis*, 2005 UCLA J.L. & TECH. 1, 2-3 (2005), available at http://www.lawtechjournal.com/articles/2005/03_050713_stankovic.pdf.

³⁸ *See* Patrik S. Florencio, *Genetics, Parenting, and Children's Rights in the Twenty-First Century*, 45 MCGILL L.J. 527, 529-31 (2000).

genetic condition every day.³⁹ Although human genetic engineering remains science fiction at present⁴⁰ and most efforts to conduct gene therapy have so far failed,⁴¹ there is still speculation that at some point in the not-too-distant future, scientists will be able to alter the genetic makeup of both embryos and adult individuals.⁴²

The ability to control the genetic makeup of our children using PGD and selective implantation raises a host of questions for which there are no firm answers yet. To what extent should prospective parents have access to information regarding an embryo's genetic makeup? Should parents be allowed to select for or against certain non-disease characteristics in their children, even if the result is a deliberately disabled child? Is "intentional diminishment," the deliberate selection for disability,⁴³ in the best interests of the children? Is there the possibility of harm to society as a whole if these procedures become widespread and routine? Do we have a right to autonomy in our genetic future even before we come into existence? Or to summarize these questions, do parents have the right to use ART to create the "perfect" child and, by implication, the "imperfect" child that suits their particular desires? If they do have such a right, to what extent and

³⁹ See, e.g., Genomics.energy.gov, Human Genome Project Information: History of the Human Genome Project, http://www.ornl.gov/sci/techresources/Human_Genome/project/hgp.shtml (last visited Jan. 16, 2009).

⁴⁰ See, e.g., *BLADE RUNNER* (Warner Bros. Studios 1982); *AKIRA* (Toho Comp. Ltd. 1988).

⁴¹ See, e.g., Sheryl G. Stolberg, *Scientists Defend Suspended Gene Therapy*, N.Y. TIMES, Feb. 15, 2000, available at <http://query.nytimes.com/gst/fullpage.html?res=9C04E7D81431F936A25751C0A9669C8B63&sec=&spone=&pagewanted=print>. But see Deena Beasley & Ben Hirschler, *Gene Therapy Improves Sight in Near-Blind Patients*, REUTERS, Apr. 27, 2008, <http://www.reuters.com/article/healthNews/idUSN2739550520080427?sp=true> ("Gene therapy for a rare type of inherited blindness has improved the vision of four patients who tried it, boosting hopes for the troubled field of gene repair technology . . .").

⁴² See MARK S. FRANKEL & AUDREY R. CHAPMAN, HUMAN INHERITABLE GENETIC MODIFICATIONS: ASSESSING SCIENTIFIC, ETHICAL, RELIGIOUS AND POLICY ISSUES (2000), available at <http://www.aaas.org/spp/sfirl/projects/germline/report.pdf>.

⁴³ Dana Ziker, Comment, *Appropriate Aims: Setting Boundaries for Reproductive Technology*, 2002 DUKE L. & TECH. REV. 0011, 9 (2002), available at <http://www.law.duke.edu/journals/dltr/articles/pdf/2002DLTR0011.pdf>.

by what means can it be proscribed, if at all? This Article argues that ART have developed in an era of lax regulation and that greater regulation of these technologies and their possibilities is necessary to prevent harm to the children that will be born of these processes.⁴⁴ It surveys a variety of arguments both for and against regulation of intentional diminishment and provides examples of the means by which regulation can be accomplished.⁴⁵

II. THE MORAL, ETHICAL, AND LEGAL ISSUES SURROUNDING THE USE OF PREIMPLANTATION GENETIC DIAGNOSIS TO SELECT FOR GENETIC CHARACTERISTICS

A. The Legal Background

At present, there is no federal legislation that proscribes the use of PGD in general, including the use of PGD to screen for both positive and negative inheritable characteristics.⁴⁶ A minority of states regulate the use of human embryos for research.⁴⁷ Only some states have enacted legislation that loosely regulates PGD,⁴⁸ and none of them proscribes the use of PGD to select for genetic characteristics.⁴⁹ While in the United States major legal battles have been waged over the issue of abortion,⁵⁰ there has been little public debate over issues related to assisted reproduction, and the federal and states governments have adopted a largely hands-off approach.⁵¹ Consequently, an understanding of the moral and legal issues surrounding ART, and PGD in particular,

⁴⁴ See *infra* Part II.A.

⁴⁵ See *infra* Parts II.B, III.

⁴⁶ Stankovic, *supra* note 37, at 5.

⁴⁷ *Id.*

⁴⁸ Michelle A. Groman, Note, *Regulating Preimplantation Genetic Diagnosis: The Pathologization Problem*, 118 HARV. L. REV. 2770, 2773 (2005).

⁴⁹ See Brooke McConnell, *Quality Control: The Implications of Negative Genetic Selection and Pre-Birth Genetic Enhancement*, 15 UCLA WOMEN'S L.J. 47, 54-58 (2006).

⁵⁰ See *id.*

⁵¹ See John A. Robertson, *Procreative Liberty in the Era of Genomics*, 29 AM. J. L. & MED. 439, 482-84 (2003).

must begin with an understanding of the right to procreate and to parent under the U.S. Constitution and what effect U.S. Supreme Court holdings in this regard have on any prospective regulation of PGD.

The jurisprudence of procreation consists of two often intermingling strains of U.S. Supreme Court holdings: the first involves the right to procreate and rear children and the second involves the right to avoid reproduction.⁵² A general right to privacy was first advocated by Louis Brandeis and Samuel Warren in an 1890 law-review article entitled *The Right to Privacy*,⁵³ but the right was not articulated by the Court until seventy-five years later in *Griswold v. Connecticut*, a case challenging the authority of the state to proscribe contraception for married couples.⁵⁴ The Court relied on previous case law to hold that a number of unstated protections emanated from the Bill of Rights that fell under the “penumbra” of a general right to privacy that protected the marital relationship.⁵⁵ The Court extended this general right of privacy to protect the contraception choices of unmarried persons in *Eisenstadt v. Baird*⁵⁶ and of minors in *Carey v. Population Services International*.⁵⁷ The Court further extended the right to privacy in the procreative sphere in *Roe v. Wade*, holding that the right protected the freedom of women to obtain an abortion at the pre-viability stage of the pregnancy.⁵⁸ The Court refined its treatment of the issue in *Planned Parenthood v. Casey* by crafting a

⁵² McConnell, *supra* note 49, at 58.

⁵³ Samuel Warren & Louis Brandeis, *The Right to Privacy*, 4 HARV. L. REV. 193 (1890).

⁵⁴ 381 U.S. 479, 486 (1965).

⁵⁵ *Id.* at 484.

⁵⁶ 405 U.S. 438, 453 (1972).

⁵⁷ 431 U.S. 678, 693 (1977).

⁵⁸ 410 U.S. 113, 163 (1973).

test that struck down statutes that placed an undue burden on a woman's right to obtain an abortion.⁵⁹

As the Court has expanded its holdings to provide greater protection of the right to terminate a pregnancy, so has the Court recognized a right to procreate and rear children as the parents see fit.⁶⁰ In *Meyer v. Nebraska*, the Court struck down a statute that prohibited teaching German to young students, finding that it violated the Due Process Clause of the Constitution and stating in dicta that to deprive parents of the decision over what their children may be taught in schools was depriving them of a liberty interest.⁶¹ In *Skinner v. Oklahoma*, the Court struck down a statute that mandated the sterilization of habitual criminals, and it stated that the ability to procreate is "one of the basic civil rights of man."⁶² And in a 1972 case, *Stanley v. Illinois*, the Court struck down a statute that presumed the parental unfitness of unwed fathers in a custody action, holding that the presumption violated the Equal Protection Clause.⁶³

From these holdings, it is possible to surmise that the Court treats issues regarding child bearing (including the right not to have children) and child rearing with great sensitivity and will carefully review statutes that infringe on either of those rights. Nonetheless, states do have a substantial interest in family matters, and every state has drafted numerous laws as part of their inherent authority to regulate the family.⁶⁴ Such authority even extends into the delicate relationship between the mother and father of a

⁵⁹ 505 U.S. 833, 877 (1992).

⁶⁰ See *Stanley v. Illinois*, 405 U.S. 645 (1972); *Skinner v. Oklahoma*, 316 U.S. 535 (1942); *Meyer v. Nebraska*, 262 U.S. 390 (1923).

⁶¹ *Meyer*, 262 U.S. at 399, 402.

⁶² *Skinner*, 316 U.S. at 541.

⁶³ *Stanley*, 405 U.S. at 658.

⁶⁴ See *White v. Chambliss*, 112 F.3d 731, 735 (4th Cir. 1997) ("The parent's right to custody is subject to the child's interest in his personal health and safety and the state's interest as *parens patriae* in protecting that interest." (citing *Jordan v. Jackson*, 15 F.3d 333, 346 (4th Cir. 1994))); Vivian Hamilton, *Principles of U.S. Family Law*, 75 *FORDHAM L. REV.* 31, 63-64 (2006).

child upon divorce,⁶⁵ and it is premised on the desire to protect a child's best interests.⁶⁶ States may also intervene to limit the ability of parents to refuse medical treatment for their children as well as to restrict the parents' access to "inappropriate treatment" on behalf of their children.⁶⁷ At present, no court has ruled on whether a parent has a right to choose the traits of their children,⁶⁸ and the extent of parental authority in this field remains an open question. Clearly though, any effort to regulate the use of PGD to select for inheritable traits steps into a background already well trodden by the state legislatures and the judiciary.

B. The Implications of Preimplantation Genetic Diagnosis and Intentional Diminishment: Arguments for and Against Strict Regulation

There are many contrary views about the propriety of using PGD to select for genetic characteristics and to what extent PGD should be regulated or restricted as a result, especially where the prospective parents deliberately select for characteristics that will produce a disabled child. There are those who adopt a view that PGD should be strictly regulated and such a use should be illegal, and there are those who adopt a more libertarian position and argue that there should be little to no restriction of the procedure.⁶⁹

At the heart of many of these arguments lies the right to procreate, a right that opponents of regulation argue also protects the manner of procreation.⁷⁰ They argue that

⁶⁵ See Helen M. Alvaré, *The Case for Regulating Collaborate Reproduction: A Children's Rights Perspective*, 40 HARV. J. ON LEGIS. 1, 49 (2003).

⁶⁶ See Loretta M. Kopelman, *The Best Interests Standard for Incompetent or Incapacitated Persons of All Ages*, 35 J.L. MED. & ETHICS 187, 187-88 (2007).

⁶⁷ Florencio, *supra* note 38, at 546.

⁶⁸ Lindsey A. Vacco, Comment, *Preimplantation 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, 1216-17 (2005) (citation omitted).

⁶⁹ Robertson, *supra* note 51, at 442-44.

⁷⁰ See *id.* at 462, 467-68.

just as the state may not proscribe when individuals can conceive children, it also cannot proscribe the means by which prospective parents choose to conceive, especially when those means are necessary to conceive at all.⁷¹ Those in favor of regulation argue that the procreative right is not an unlimited right and that there are several compelling rationales for limiting the use of PGD to select for disability.⁷²

Arguments by many commentators for the regulation of PGD to prevent the selection of disabling traits begin by considering the personal autonomy of the child that will be born with the disabling condition.⁷³ Professor Helen Alvaré has noted the prevalence of the attitude among prospective parents utilizing ART that because they are paying considerable sums of money to acquire a child, they should be entitled to exactly the kind of child that they want.⁷⁴ Of course, all parents seek to control the upbringing, characteristics, and attitudes of their children to some extent. However, parents who conceive by “natural” means have little to no control of how their paired DNA will express itself in their children in either physical or behavioral characteristics, and they must be content to guide and direct their children by virtue of their role as teachers combined with their ability to influence or control their child’s choices. In contrast, individuals who must utilize ART to conceive a child and elect to use PGD to screen for the genetic condition of the embryo are limited only by how much genetic information about the embryo they desire to seek, what they elect to do with that information, and by

⁷¹ See *id.* at 468.

⁷² See Vacco, *supra* note 68, at 1218-25; see also Alvaré, *supra* note 65; Florencio, *supra* note 38.

⁷³ Alvaré, *supra* note 65, at 59; K.W. Antsey, *Are Attempts To Have Impaired Children Justifiable?*, 28 J. MED. ETHICS 286, 286 (2002); Florencio, *supra* note 38, at 541 (“Until the risks of significant genetic tampering are better understood, *primum non nocere* should be our guiding principle.”); Sonia M. Suter, *A Brave New World of Designer Babies?*, 22 BERKLEY TECH. L.J. 897, 960 (2007); Vacco, *supra* note 68, at 1224.

⁷⁴ Alvaré, *supra* note 65, at 54. Helen M. Alvaré is an Associate Professor of Law at the Catholic University of America, Columbus School of Law. *Id.* at 43.

the limits of science to understand how genes express themselves and can be manipulated. It is not difficult to imagine that as genetic technology matures, there are those individuals who would choose to utilize ART techniques, such as PGD or even germline genetic engineering (genetic manipulation of sperm, eggs, or an embryo),⁷⁵ even though they do not strictly need these measures to conceive.⁷⁶ What then might stop some individuals from manipulating every aspect of their children that is within their power to control?⁷⁷

Professor Alvaré summarizes what can be considered a more traditional view of parents as “recipients of a very vulnerable gift, as lovers of an *unknown* person.”⁷⁸ This stands in contrast to the view of children as “products” of the parents who create them.⁷⁹ Nearly all parents have certain expectations for their children, but as Professor Alvaré notes above, parents who are capable of controlling the genetic makeup of their children may have expectations beyond those of typical parents for the children’s behavior or even who they should grow up to be.⁸⁰ “Conditional parenting” exists where “children live out the possible self-serving preferences of their parents,”⁸¹ but in all such instances, it is still possible for children to grow up to rebel against their parents’ wishes and enjoy their own

⁷⁵ Although human germline genetic engineering is not illegal in the United States, the American Association for the Advancement of Science placed a moratorium on germline genetic engineering in 2000, and it has been in effect since then. Therefore, “[g]ermline gene therapy is not being actively investigated in larger animals and humans for safety and ethical reasons.” American Medical Association (AMA): Gene Therapy, <http://www.ama-assn.org/ama/pub/category/2827.html> (last visited Jan. 16, 2009).

⁷⁶ Vacco, *supra* note 68, at 1193-1200.

⁷⁷ Alvaré, *supra* note 65, at 59.

Collaborative reproduction is a choosing of traits with the child’s creation directly and solely in mind. Like cloning also, the techniques of collaborative reproduction open the door to genetic manipulation; once the embryo is ex-utero and available for inspection and even alteration, the scientific and medical imperatives toward health and improvement become difficult to resist.

Id.

⁷⁸ *Id.* at 54 (emphasis added).

⁷⁹ *Id.* at 59.

⁸⁰ *See id.* at 54.

⁸¹ Vacco, *supra* note 68, at 1225.

unique life experiences.⁸² But, where the parent is able to select for certain genetic traits, the parent has left an indelible mark on the child that will remain with the child for life.⁸³ Children who are aware of this may feel pressure to meet their parents' expectations, knowing they were *made* to do so.⁸⁴ Or they may not have any choice in the matter, being afflicted with a genetic condition that cannot be repaired.⁸⁵

In the example of the deaf couple mentioned in Part I.A., one of the children was born with partial hearing in one ear.⁸⁶ The child's doctor recommended a hearing aid at an early age to give him the greatest opportunity to learn spoken English.⁸⁷ The couple did not permit this, stating that they would permit him to have a hearing aid when he was older if he so desired.⁸⁸ But would the child choose to do so knowing that his parents underwent procedures in an express effort to produce a deaf child and knowing his parent's strong belief in the idea of the deaf culture and community?⁸⁹ Even if he eventually decides to act independently and wear a hearing aid, he cannot escape the additional difficulty that he will experience in learning language as an older child or an adult—deprived as he was during the prime opportunity to learn a spoken language when he was too young to express a desire one way or the other.⁹⁰ Whether or not he chooses

⁸² FRANCIS FUKUYAMA, *OUR POSTHUMAN FUTURE: CONSEQUENCES OF THE BIOTECHNOLOGY REVOLUTION* 94 (2002).

⁸³ Ziker, *supra* note 43, at 5 (noting that not only will this mark remain with the child for life, but “a parental genetic change not only alters the current offspring, but also ‘forever alters future generations’” (quoting Larry Thompson, *Poll Finds Support for Use of Gene Therapy*, WASH. POST, Sept. 25, 1990, at Z9)).

⁸⁴ Vacco, *supra* note 68, at 1225.

⁸⁵ See Ziker, *supra* note 43, at 5-6.

⁸⁶ Merle Spriggs, *Lesbian Couple Create a Child Who Is Deaf like Them*, 28 J. MED. ETHICS 283, 283 (2002).

⁸⁷ *Id.*

⁸⁸ *Id.* (citation omitted).

⁸⁹ See *id.* (“Like many others in the deaf community, the couple don’t view deafness as a disability. They see deafness as a cultural identity and the sophisticated sign language that enables them to communicate fully with other signers as the defining and unifying feature of their culture.”).

⁹⁰ See *id.*

to wear a hearing aid, the choice as to whether he could hear naturally was made before he was born, and, barring advances in medical science, he will live with that choice for the rest of his life regardless of his own wishes.⁹¹

A counterargument to this is that selection for certain genetic characteristics, including disability, is merely part of an effort to produce a child that shares significant aspects of the parents.⁹² Because this is a legitimate goal of parents who conceive naturally, it should not be an illegitimate goal for parents who conceive utilizing PGD to screen in favor of a disability.⁹³ As for the deaf couple, there are some who believe that deafness is not a disability but a unique culture worth preserving and advancing by bringing deaf children into the world deliberately.⁹⁴ In that sense, having a deaf child is no different than having a child and bringing the child up in the parents' ethnic or national culture, something that all parents do whether they conceive naturally or from ART. However, this still appears to be a minority view even among the disabled, and in addition to commentators like those mentioned above who hold that selecting for disability is still "diminishment," there are those who do not believe that having a disability is a condition for being a member of a particular group or culture.⁹⁵

Professor John Robertson has argued that positive alteration of a child's genetic makeup from genetic engineering fails to serve important reproductive goals.⁹⁶ He argues that for such techniques to be constitutionally permissible, parents would have to

⁹¹ *See id.*

⁹² Antsey, *supra* note 73, at 286.

⁹³ *See id.*

⁹⁴ N. Levy, *Deafness, Culture and Choice*, 28 J. MED. ETHICS 284, 284 (2002).

⁹⁵ Antsey, *supra* note 73, at 287.

⁹⁶ Robertson, *supra* note 51, at 474. John A. Robertson holds the Vinson and Elkins Chair at the University of Texas School of Law at Austin. He has written and lectured widely on law and bioethical issues. He is currently Chair of the Ethics Committee of the American Society for Reproductive Medicine. University of Texas at Austin: School of Law Faculty & Administration, <http://www.utexas.edu/law/faculty/profile.php?id=jr43> (last visited at Jan. 16, 2009).

show that any alteration is not being made out of mere preference “but is essential to whether they will reproduce [at] all.”⁹⁷ In one of his articles, Professor Robertson was referring to genetic enhancement,⁹⁸ but the same logic can be applied to intentional diminishment, which has no arguable purpose except as an expression of the parents’ desires for a disabled child. At the same time, under Professor Robertson’s reasoning, prospective parents would still be entitled, under the procreative liberty, to select for a genetically disabled child if that is a condition to their having a child at all.⁹⁹ Of course, such a determination requires the effort of looking into the intentions of prospective parents for having or not having children,¹⁰⁰ something that would not only be difficult but is also not constitutionally permissible.¹⁰¹

A more confounding argument is presented in the idea that in deliberately creating a disabled child, parents are perpetuating a “wrongful life,” a notion that one commentator refers to as a “metaphysical conundrum.”¹⁰² An action for wrongful life is generally understood to be one that is brought on behalf of a child who is born with a disability against the medical provider for failing to provide the parents with sufficient

⁹⁷ *Id.*

⁹⁸ John A. Robertson, *Genetic Selection of Offspring Characteristics*, 76 B.U. L. REV. 421, 438 (1996).

⁹⁹ *Id.* at 439.

¹⁰⁰ *Id.* at 427.

¹⁰¹ *Planned Parenthood v. Casey*, 505 U.S. 833, 852-53 (1992)

It should be recognized, moreover, that in some critical respects the abortion decision is of the same character as the decision to use contraception, to which *Griswold v. Connecticut*, *Eisenstadt v. Baird*, and *Carey v. Population Services International* afford constitutional protection. . . . They support the reasoning in *Roe* relating to the woman’s liberty because they involve personal decisions concerning not only the meaning of procreation but also human responsibility and respect for it. . . . These are intimate views with infinite variations, and their deep, personal character underlay our decisions in *Griswold*, *Eisenstadt*, and *Carey*.

Id.

¹⁰² Alan J. Belsky, *Injury as a Matter of Law: Is This the Answer to the Wrongful Life Dilemma?*, 22 U. BALT. L. REV. 185, 187, 222 (1993) (“In theory, the wrongful life action provides the framework upon which a child may recover pecuniary (special) and nonpecuniary (general) damages after convincing the trier of fact that she would have been better off not having been born than to live life with severe disability.” (citation omitted)).

information to make an informed decision about whether or not to carry full-term or terminate a pregnancy.¹⁰³ The difficulty of wrestling with the metaphysical implications of wrongful life led courts to dismiss it as a valid cause of action for over a decade after it was first brought to court,¹⁰⁴ and courts refused to recognize the tort until 1978.¹⁰⁵

The central difficulty in wrongful life is identifying the harm that the child born disabled has suffered. A child born without a disability is, by most, considered better off than a child born with a disability. But what of a child who would not be born but for the disability? Critics of a regulatory approach toward PGD can argue that if a child would not be born but for the use of PGD to select a disabling characteristic, is the child that is born as a result truly in a worse position than the child would have been not being born at all?¹⁰⁶ The difficulty in answering that question is what prompted many courts to avoid answering it at all for over a decade. How is there harm in a disabled existence, even when that existence is accompanied by physical or mental limitations, when compared to no existence at all?

The difficulty posed by this question is plainly at odds with what appears to many to be a clearly harmful act—the decision to knowingly select for a disabled child when it would be possible to bring a perfectly healthy child into the world instead.¹⁰⁷ It simplifies matters somewhat to consider cases in which a child is deliberately afflicted with a disease that makes life not worth living, such as a condition that will lead to an

¹⁰³ *Id.* at 189.

¹⁰⁴ Dennis J. McCann, *Liability for Negligent Prenatal Diagnosis: Parents' Right to a "Perfect" Child?*, 42 OHIO ST. L.J. 551, 557-58 (1981).

¹⁰⁵ *Becker v. Schwartz*, 386 N.E.2d 807, 813-14 (N.Y. 1978) (holding that the parents of a developmentally disabled child can recover pecuniary losses for the birth of the child).

¹⁰⁶ Robertson, *supra* note 51, at 486.

¹⁰⁷ *Id.*

early death or a condition that makes the child incapable of experiencing the world.¹⁰⁸ In such instances the harm done to a child by bringing the child into the world in a disabled condition may be more than the harm of non-existence by any reasonable standards. However, none of the aforementioned examples involved parents trying to bring children into the world that would experience lives of suffering so great that they would be better off having not been born.¹⁰⁹ Deafness, dwarfism, and Down syndrome are not conditions that destroy the possibility of the enjoyment of life in some capacity.¹¹⁰ However, nothing in the current regulatory scheme would prevent parents utilizing PGD from selecting an especially debilitating or lethal condition.¹¹¹ Opponents of regulation may argue that it is impossible to imagine that any parent would deliberately bring a child into the world that was fated to suffer a short and painful life, but proponents of regulation point out that there are no statutes to prevent just that.¹¹² At the same time, neither are there statutes that prevent a couple from bringing a severely disabled child into the world so long as they conceive the child naturally, even if they are aware of the high odds of conceiving a disabled child because of their own personal genetic makeup—a disparity that opponents of regulation could decry as unfair for the duty it imposes upon prospective parents utilizing PGD that is not imposed upon those who are not.

However, it is possible to construct a counterargument to the wrongful life conundrum. Alan Belsky, managing partner of Belsky, Weinberg, & Horowitz, LLC,

¹⁰⁸ Belsky, *supra* note 102, at 230-31.

¹⁰⁹ *See supra* Part I.A.

¹¹⁰ *See* Suzanne Levant, Comment, *Natural Death: An Alternative in New Jersey* In *Re Conroy*, 98 N.J. 321, 486 A.2d 1209 (1985), 73 GEO. L.J. 1331, 1348 (1985) (stating that Down syndrome does not make the enjoyment of life impossible); *see generally* Adrienne Asch, *Critical Race Theory, Feminism, and Disability: Reflections on Social Justice, and Personal Identity*, 62 OHIO ST. L.J. 391 (2001) (discussing deafness as a “community” and the ability of a deaf person to enjoy life).

¹¹¹ *See* Stankovic, *supra* note 37, at 5-6 (discussing federal regulations, including that the FDA does not regulate fertility procedures).

¹¹² *See id.* at 4.

specializing in personal-injury law, argues that such an approach can be found when the wrongful life is analogized to the circumstances present in right-to-die cases.¹¹³

Although courts have been reluctant to compare the value of a lived-but-deficient life to a hypothetical non-life, many have clearly recognized that, to some, non-existence is preferable to existence.¹¹⁴ Because many of the terminally ill or profoundly disabled who are at the center of these cases are incapable of exercising their own judgment, courts have crafted the substituted-judgment doctrine—a legal fiction that provides that an otherwise incompetent patient can, through a proxy, refuse medical care that would prolong the patient’s life.¹¹⁵ As Belsky explains,

The significance of [*In re*] *Quinlan*’s substituted judgment approach to the wrongful life action lies in the inherent notion that action upon the patient’s unexpressed but probable desire to forego life sustaining treatment is, in essence, promoting a patient’s right to choose, even when the patient can not do so expressly.¹¹⁶

Belsky wrote in the context of wrongful-life jurisprudence, arguing that parents’ substituted judgments in regards to what their unborn child would choose bolsters support of the inherent notion of wrongful life as a tort.¹¹⁷ But his arguments can also be applied to the debate over intentional diminishment. If non-existence is preferable to a life currently being lived, then non-existence might also be preferable to a diminished life that has yet to be lived. Of course, the right-to-die cases involve the destruction of fundamental faculties that comprise a functioning human being to the point that the

¹¹³ Belsky, *supra* note 102, at 223.

¹¹⁴ *Id.*

¹¹⁵ *Id.* at 224; e.g., *Superintendent of Belchertown State Sch. v. Saikewicz*, 370 N.E.2d 417, 431 (Mass. 1977); *In re Quinlan*, 355 A.2d 647, 666 (N.J. 1976).

¹¹⁶ Belsky, *supra* note 102, at 225 (referring to *Quinlan*, 355 A.2d 647).

¹¹⁷ *See id.* at 229.

disabled or terminally ill person may have no understanding or awareness of the world.¹¹⁸

Critics of regulation might argue that no such trauma is contemplated by parents who elect to have a child that has Down syndrome or dwarfism and that lives with such conditions would not satisfy the substituted-judgment standard in the right-to-die cases. Nonetheless, Belsky's argument is an important counter to the grass-is-greener philosophy of critics of regulation who believe that even a profoundly disabled life is better than no life at all. As Belsky demonstrates, courts have reluctantly been forced to accept that some lives are simply not worth living—that the grass is not always greener on the other side after all.¹¹⁹

There are also slippery-slope arguments that can be made against allowing the use of PGD to select for disabilities. One is that allowing the use of PGD to select for any disabling condition makes it difficult to draw the line at which conditions are *too* disabling.¹²⁰ At what point is a differentiation made among conditions that are only mildly disabling, to conditions that are moderately disabling, to conditions that are extremely disabling? If parents can select for hearing loss, can they also select for blindness? If they can select for dwarfism, can they also select for gigantism, a condition that often results in a shorter life span? If parents can select for Down syndrome, can they then select for autism? Who determines which conditions are permissible to select for and which are not? Second, a rationale that supports the use of PGD to select for disability premised on the right of the parent to control the traits and characteristics of the

¹¹⁸ See, e.g., *Quinlan*, 355 A.2d at 655 (explaining that the patient, Quinlan, existed in a persistent vegetative state and had no awareness of her surroundings).

¹¹⁹ See Belsky, *supra* note 102, at 234.

¹²⁰ Cf. David King, *Preimplantation Genetic Diagnosis and 'Slippery Slopes'*, BIONEWS, May 13, 2007, 2006 WLNR 9110233 (arguing that the word "serious" in the phrase "serious medical condition" is ambiguous in discussions about PGD).

future child also supports the use of genetic engineering or reproductive cloning for the same purpose—technologies that many may find more frightening in their capabilities.¹²¹

Responses to such arguments by opponents of regulation hinge on the procreative liberty interest.¹²² Opponents of strict regulation argue that just as people have the right not to reproduce because of a child’s genetic characteristics, they have the right to reproduce to have a child with particular characteristics.¹²³ Consequently, because parents who are able to procreate without the use of ART, or PGD in particular, have no duty to obtain genetic information about their children and make reproductive decisions based on that information even if the result is the birth of a disabled child, parents who must use ART and PGD to procreate should not be foreclosed from the ability to gather detailed genetic information about their children to deliberately produce a disabled child.¹²⁴ A person who procreates naturally knowing that reproduction will produce a disabled child is exercising a right to procreate as much as someone who procreates using PGD to produce a disabled child.¹²⁵

Opponents of strict regulation also believe that parents are in the best position to judge whether reproduction is in their own best interests and in the best interests of their children.¹²⁶ These opponents point out that the common presumption is that parents will act in the best interests of their children, and it is presumed precisely because such a presumption is more likely to produce the best results for children than state intervention can provide.¹²⁷ The fact that such a rule does not always produce the best results for

¹²¹ See Alvaré, *supra* note 65, at 59.

¹²² See Robertson, *supra* note 51, at 447.

¹²³ See *id.* at 447-48.

¹²⁴ See *id.*

¹²⁵ See *id.*

¹²⁶ See *id.* at 468.

¹²⁷ Suter, *supra* note 73, at 965.

children is not reason enough to do away with the presumption.¹²⁸ The presumption that parents act in the best interests of their children can be applied to instances where parents use PGD to select for disability and is supported by anecdotes like the one above regarding the deaf couple who sought to produce deaf children. They believed that they were acting in the best interests of their children, and the presumption respects that belief even if others disagree.¹²⁹

It can be pointed out that the presumption assumes that parents know what is in the best interests of their children.¹³⁰ Generally, this is true of parents who are in the process of raising their children, but does it hold true for parents who are weighing whether or not to bring children into the world based on whether or not they have a disability? Perhaps parents are no more able to weigh the life of chosen disability against no life at all any more effectively than the courts are; though opponents of regulation could argue that if that is the case, then the power to decide should still rest with the people who will raise the child born with the disability and not with the courts or the state.

There are limitations on the freedom of parents to make decisions on behalf of their children even if they believe they are acting in their child's best interest. Parents cannot choose not to provide medical treatment to a child when it is necessary to preserve the health or life of the child,¹³¹ even if they do so because they believe that it is in the child's best interest for religious reasons or otherwise not to receive such treatment.¹³²

¹²⁸ *Id.*

¹²⁹ *Id.* at 966-67.

¹³⁰ *Id.* at 965.

¹³¹ See Robertson, *supra* note 98, at 470; Prince v. Mass, 321 U.S. 158, 166-67 (1944) (discussing states' powers versus religious freedoms).

¹³² *Prince*, 321 U.S. at 166.

As Professor Robertson has pointed out, it might then follow that parents “have a moral duty to provide the treatment before birth if post-birth treatments are not feasible and if there is a safe, effective, and minimally intrusive prenatal treatment available” and that such a duty should only be limited by the infringement it makes on the procreative liberty.¹³³

There are also numerous policy arguments both for and against stricter regulation. Proponents of stricter regulation believe that permitting intentional diminishment and genetic tailoring (both diminishment and enhancement) threatens society as a whole.¹³⁴ For one, disabled children generally have unique medical and educational needs that may require state assistance.¹³⁵ Parents may bring disabled children into the world with every intention of providing for them only to find that they cannot meet their child’s special needs because of a change in circumstances. Or they may bring a disabled child into the world knowing the child will need assistance that they will not be able to provide. It does seem possible to distinguish between parents who anticipate bringing a healthy child into the world but give birth to a disabled child instead because they refuse to terminate their pregnancy and parents who bring a disabled child into the world deliberately. In the former case, the parents are merely making a decision to *not* take an active step necessary to terminate a pregnancy. In the latter, parents must take several active steps, from engaging in IVF to utilizing PGD to select for a disabled child to implanting the genetically defective embryo into the mother’s body.

¹³³ Robertson, *supra* note 98, at 470.

¹³⁴ *Id.* at 471-72.

¹³⁵ *Id.*

Second, permitting parents to select for disability perpetuates the idea that individuals are primarily a product of their genetic heritage.¹³⁶ In many instances of disability, it is clear that the disability is the direct result of genetic makeup.¹³⁷ In other instances, such as autism, however, it is not yet clear what role genes play in the expression of the condition.¹³⁸ The fear is that in an era of such incomplete understanding, permitting parents to select for characteristics perpetuates the idea of “neurogenetic determinism,” the belief that there is a “direct and causal relationship between genetics and behaviour.”¹³⁹ Belief in such a relationship then perpetuates the idea that because some individuals are more or less products of their DNA, they are more or less responsible for their behavior.¹⁴⁰ And while some in society might be less willing to hold individuals responsible for their behavior, others might be willing to discriminate against those based on their genetic makeup or even as a result of the rise in genetic testing that would follow from an increase in selection for disability.¹⁴¹

Another, more expansive, argument is that allowing parents to select either for or against certain genetic traits could circumvent the natural process of evolution.¹⁴² By retaining or weeding out certain traits, humans could be altering their genetic heritage with an insufficient understanding of either the short- or long-term consequences.

¹³⁶ See Florencio, *supra* note 38, at 537 (“Some commentators have voiced their concern that society will begin to believe in the existence of a direct and casual relationship between genetics and behavior.”).

¹³⁷ See, e.g., Children’s Hospital of the King’s Daughters, Medical Genetics: Down Syndrome (Trisomy 21), <http://www.chkd.org/HealthLibrary/content.aspx?pageid=P02121> (last visited Jan. 16, 2009).

¹³⁸ Rebecca Muhle et al., *The Genetics of Autism*, 113 PEDIATRICS 472, 482 (2004) (discussing the complex genetic and behavioral background of autism).

¹³⁹ Florencio, *supra* note 38, at 537 (citation omitted).

¹⁴⁰ *Id.*

¹⁴¹ *Id.* at 538 (“Genetic discrimination is one of the most salient dangers associated with genetic testing.”).

¹⁴² Jason C. Roberts, *Customizing Conception: A Survey of Preimplantation Genetic Diagnosis and the Resulting Social, Ethical, and Legal Dilemmas*, 2002 DUKE L. & TECH. REV. 12, 24 (2002).

However, critics of this argument can reply that humans have been doing this for as long as they have permitted disabled persons to survive long enough to procreate.

Opponents of regulation have policy arguments in their favor as well. One of these is what can be referred to as the “pathologization problem”¹⁴³ or the idea that certain traits or characteristics that should be recognized as representing a more generous understanding of human diversity are instead labeled as diseases or disabilities. As discussed above, the deaf couple who utilized IVF to conceive two deaf children regard deafness not in the context of a disability, but in the context of culture and diversity.¹⁴⁴ To them, the idea of deafness as a disability is a social construction that reflects a value judgment—not a medical judgment—by society.¹⁴⁵ In the context of the use of PGD to select *against* disability, their greatest fear is that such a use stigmatizes the deaf community, devalues the lives of the deaf, reinforces the disability label, and limits the choices of those who are members of the deaf community.¹⁴⁶ The same logic holds true for preventing deaf couples, or those with disabilities in general, from utilizing PGD to perpetuate the condition that others regard as a disability but they regard as normal; preventing them from producing children with their condition stigmatizes their community. It follows that the reverse—allowing them to utilize PGD to produce children with their disability—allows them to perpetuate their community and attack the stigmatization of their condition. However, this view is not held by all of those who are disabled,¹⁴⁷ and an argument can be made that the lives of those who are disabled can be

¹⁴³ Groman, *supra* note 48, at 2770.

¹⁴⁴ See *supra* Part I.A. and note 15 and accompanying text.

¹⁴⁵ Groman, *supra* note 48, at 2783.

¹⁴⁶ *Id.*

¹⁴⁷ Spriggs, *supra* note 86.

respected at the same time that ART or genetic technologies are used to prevent or circumvent disability.

III. OPTIONS TOWARD REGULATING THE USE OF PREIMPLANTATION GENETIC DIAGNOSIS TO INTENTIONALLY CREATE DISABLED CHILDREN

While there are a variety of arguments both for and against restricting the use of PGD to create disabled children, it would seem that society has at least some minimum interest in providing that children are not born disabled who, but for the procreative choices of their parents, could have been born healthy. The difficulty lies in determining how such an interest could be furthered. Should it be regulated by state law? Federal regulation? Some combination of the two? Or should it be non-coercive, in the form of professional self-regulation or public opinion?

A. Federal Regulation

One approach would be to extend federal regulation of assisted reproduction, including the use of PGD. The federal government regulates IVF clinics in part through the Centers for Disease Control, which is directed to collect information regarding the procedures utilized at IVF clinics,¹⁴⁸ and through the Federal Trade Commission, which has the general authority to investigate false and misleading advertising.¹⁴⁹ But more substantial authority rests with the Food and Drug Administration (FDA), which in 1998 announced its intention to regulate IVF clinics through its authority over tissue and cellular-based products.¹⁵⁰ There is little question that the FDA can regulate techniques that might inadvertently harm the implanted embryo or the mother, but there is not as much authority for the proposition that the FDA could regulate techniques like human

¹⁴⁸ Lars Noah, *Assisted Reproductive Technologies and the Pitfalls of Unregulated Biomedical Innovation*, 55 FLA. L. REV. 603, 649 (2003) (citing 42 U.S.C. §§ 263a-1(a), 263a-2(a)(1), 263a-3(a), 263a-5 (2000)).

¹⁴⁹ *Id.* (citations omitted).

¹⁵⁰ *Id.* at 650.

cloning, which implicate reproductive choices rather than techniques.¹⁵¹ Such regulation would probably be insupportable absent clearer statutory guidance.

Another novel proposal calls for the creation of a separate regulatory agency whose purpose would be to monitor IVF clinics and approve applications for new PGD techniques and methods, an approach that has been adopted in the United Kingdom.¹⁵² A federal statute that would provide for the creation of an organization that has the authority to inspect clinics, grant licenses for types of treatments, and regulate what procedures may and may not be utilized would have considerably less statutory and regulatory ambiguity than an agency that is attempting to expand outside of the normal scope of its authority.¹⁵³ Also, absent a statutory proclamation, a court may find that the government has not asserted a compelling enough interest in the regulation of PGD and ART.¹⁵⁴

B. State Legislation

As noted earlier, a minority of states has enacted statutes that seek to regulate IVF clinics, and none of those states have passed legislation that proscribes or limits the use of PGD for non-therapeutic purposes. Approaches range from prohibiting PGD for research purposes to prohibiting PGD unless it is “beneficial or risk-free to the embryo.”¹⁵⁵ Louisiana, in another issue related to IVF, has passed legislation that requires the recognition of embryos as a juridical person.¹⁵⁶ But beyond those limited statutes, the use

¹⁵¹ *Id.* at 651-52.

¹⁵² Roberts, *supra* note 142, at 17 (citation omitted).

¹⁵³ *Id.*

¹⁵⁴ Noah, *supra* note 148, at 651-52.

¹⁵⁵ Groman, *supra* note 48, at 2773.

¹⁵⁶ Sarah A. Weber, *Dismantling the Dictated Moral Code: Modifying Louisiana’s In Vitro Fertilization Statutes To Protect Patients’ Procreative Liberty*, 51 LOY. L. REV. 549, 550 (2005). Although the Louisiana statute purports only to grant embryos such status in relation to the matter of their cryo-preservation, it is hard to see how granting such status would not have some effect on the matter of embryos, PGD, and intentional diminishment. See LA. REV. STAT. ANN. §§ 9:123, 129, 130 (2006).

of PGD is unregulated by the states, and it is perfectly legal for IVF clinics to aid parents who seek to produce disabled children.

One approach is simply to ban the use of PGD altogether, giving parents no option to screen for inheritable diseases or conditions either positive or negative. This is the approach that is adopted more or less in Germany, where popular public opinion is still largely against the use of PGD for any purpose.¹⁵⁷ Another approach is to ban the use of PGD to intentionally create disabled children; this approach is used in the United Kingdom and does not permit the use of PGD except to prevent genetic disorders from being passed on.¹⁵⁸ However, both of these options tread most directly on the procreative liberty that is constitutionally protected in the United States.¹⁵⁹ A flat ban on PGD, even to screen against inheritable disorders, would face the most difficulty passing constitutional muster, but any restriction of the use of PGD will face constitutional challenge from those who believe it infringes a nearly unlimited procreative right.¹⁶⁰

The U.S. Constitution does not permit states to impose their moral beliefs on the personal lives of their citizens.¹⁶¹ Consequently, a state cannot simply decree that PGD is illegal because it contradicts the legislature's collective moral values. Because the use of PGD touches on a fundamental liberty, there are limitations on how a state may act to regulate it. A state may not attempt to limit abortion rights or undermine the holdings in *Roe* and *Casey*, nor can the state curtail personal autonomy and bodily integrity.¹⁶²

¹⁵⁷ Vacco, *supra* note 68, at 1205-06 (citations omitted).

¹⁵⁸ *Id.* at 1201 (stating that England's Human Fertilization and Embryology Act of 1990 "created the Human Fertilisation and Embryology Authority ('HFEA'), which licenses and regulates the use of PGD and generally regulates clinics offering assisted reproductive procedures. . . . [C]linics cannot perform any other tests or treat individuals for new disorders without approval" (internal citations omitted)).

¹⁵⁹ *Roe v. Wade*, 410 U.S. 113, 152-53 (1973).

¹⁶⁰ Stankovic, *supra* note 37, at 12-19.

¹⁶¹ *Lawrence v. Texas*, 539 U.S. 558, 585 (2003).

¹⁶² Stankovic, *supra* note 37, at 14-15; *see Lawrence*, 539 U.S. at 567, 574, 578.

Instead, legislation must be focused on the state's compelling interest in the preservation and protection of potential life,¹⁶³ and the state must demonstrate that the use of PGD to select for disability risks the commodification of human life and causes harm to children who are produced via the procedure as a result.¹⁶⁴

Although critics of regulation argue that any effort to proscribe PGD infringes upon the procreative right, other commentators disagree. Dr. Laura Shanner argues that there are fundamental differences in the right to procreate, the right to an abortion, the right to contraception, and the right to avoid forced sterilization.¹⁶⁵ She distinguishes negative rights, the right to act free of any government forbearance, from positive rights, the right to some form of entitlement or assistance.¹⁶⁶ She distinguishes PGD and other assisted-reproductive techniques, which require assistance from the IVF clinic to bring about pregnancy and can be characterized as a positive right, from abortion, which necessitates assistance from a clinic or doctor but also implicates a negative right the woman has in avoiding the burden of being required to bear a fetus to term.¹⁶⁷ In this analysis, abortion is the expression of a negative right that cannot be interfered with by

¹⁶³ Stankovic, *supra* note 37, at 15.

¹⁶⁴ *Id.* (“These harms could include but are not limited to: destruction of embryos, commodification of human life, gender- and disability-based discrimination, and easing the way to non-medical enhancement.” (citing Robertson, *Genetic Selection of Offspring Characteristics*, *supra* note 98, at 429)).

¹⁶⁵ Laura A. Shanner, *The Right To Procreate: When Rights Claims Have Gone Wrong*, 40 McGill L.J. 823, 823 (1995). “Dr. Shanner is an Associate Professor in the School of Public Health Sciences with a joint appointment to the John Dossetor Health Ethics Centre, University of Alberta, [Canada]. She obtained her Ph.D. in Philosophy-Bioethics from Georgetown University, following training in pre-clinical sciences.” University of Alberta, John Dossetor Health Ethics Centre, Laura Shanner, http://www.ualberta.ca/BIOETHICS/Profiles-1/Profiles-1_files/page0005.htm (last visited Jan. 16, 2009).

¹⁶⁶ Shanner, *supra* 165, at 839-40.

¹⁶⁷ *Id.* at 841; *see* *Webster v. Reprod. Health Servs.*, 492 U.S. 490, 510 (1989) (noting the Court's application of this dichotomy in the abortion context and finding that while the state may not proscribe the right of a woman to an abortion at the pre-viability stage, neither is the state required to provide women with access to an abortion); *Harris v. McRae*, 448 U.S. 297, 316 (1980) (noting the Court's explanation that the negative right to obtain an abortion does not implicate a positive right to the financial resources to afford an abortion).

the state before viability, whereas assisted reproduction is a positive right that invites acquiescence by the state. As Dr. Shanner explains,

As is the case with women seeking abortions, the persons or couples seeking infertility treatment are asking medical and social institutions to help them achieve what they cannot accomplish on their own. Unlike the abortion case, however, there is no concomitant negative claim akin to that of the pregnant woman's desire to restore her bodily integrity by choosing not to share her body with a fetus. The goal is actually the opposite: to initiate the sharing of a woman's body with the fetus. The patients in the infertility clinic are thus clearly not asking for forbearance; they are asking for help.¹⁶⁸

It is, of course, impossible to know if the U.S. Supreme Court, in interpreting any provision that seeks to proscribe the use of PGD for certain purposes, would interpret its own holdings in such a manner (and in fact, one federal district court has not);¹⁶⁹ but, there is some precedent for believing that the Court would be reluctant to extend the right to procreate to specific forms of procreation, especially when the form involves the deliberate creation of a disabled child.¹⁷⁰

Similarly, it can be argued that PGD can be regulated because it bears more on the type of child that parents would like to have, not on whether or not they may have a child at all.¹⁷¹ Under this view, parents who are trying to conceive from PGD and other methods of assisted reproduction are trying to invoke more than their right to have a child; they are trying to control the traits and characteristics of their future child, a matter that affects the health and well-being of that child and, as such, is more likely to come under state purview.¹⁷²

¹⁶⁸ Shanner, *supra* note 165, at 842.

¹⁶⁹ *Lifchez v. Hartigan*, 735 F. Supp. 1361, 1376 (N.D. Ill. 1990); Groman, *supra* note 48, at 2773.

¹⁷⁰ Note, *Human Cloning and Substantive Due Process*, 111 HARV. L. REV. 2348, 2354 (1998).

¹⁷¹ *Vacco*, *supra* note 68, at 1220 (“The right to ‘bear and beget a child’ does not invoke a right to a ‘beautiful or talented child.’”) (citations omitted).

¹⁷² *Id.* at 1221.

Whatever the approach, it would be necessary for the state to demonstrate a substantial and compelling interest in the well-being of the children being produced utilizing PGD.¹⁷³ The state's interest in how children are reared (as opposed to whether or not they are born at all) supports an interest in the use of PGD sufficient to justify stricter regulation,¹⁷⁴ and the "[p]ursuit of the perfect baby through nontherapeutic genetic enhancement[s]" does not trump this claim¹⁷⁵ (and by implication, neither does the pursuit of the "imperfect" baby through PGD or genetic diminishment). In addition, courts have recognized the state's legitimate interest in the child's best interests in the context of frozen embryos, supporting the idea that state interest in protecting human life does not begin only at the point of viability but extends also to the manner and method of procreation.¹⁷⁶

One commentator has argued that the state also has an interest, though perhaps a less compelling one, in the doctor-patient relationship that exists between the prospective parents and the doctors seeking to assist them in procreation.¹⁷⁷ In this view, the state regulating PGD relieves the physician of making a determination in each instance of the appropriateness of the prospective parents' desires.¹⁷⁸ Physicians would assist couples making difficult choices who use PGD for therapeutic purposes, but the state would make the determination that non-therapeutic uses are insupportable.¹⁷⁹

¹⁷³ Stankovic, *supra* note 37, at 12.

¹⁷⁴ Vacco, *supra* note 68, at 1221; Ziker, *supra* note 43, at 8 ("Avoiding severe [genetic] diseases constitute a compelling objective for reproductives [(PGD)].").

¹⁷⁵ Ziker, *supra* note 43, at 8.

¹⁷⁶ Stankovic, *supra* note 37, at 19.

¹⁷⁷ *Id.* at 18.

¹⁷⁸ *Id.*

¹⁷⁹ *Id.*

Another view, put forth by Professor Alvaré, argues that parental duties to their future children run concomitant with the procreative right.¹⁸⁰ She points out several instances in which the Court has endorsed the notion that parental rights flow from the fulfilling of parental duties, and she believes that this would also extend to constitutional rights.¹⁸¹ In her view, because access to PGD is “unrelated to the exercise of any parental duties,” the state may legitimately proscribe it.¹⁸²

It may also be possible to regulate PGD in a way that does not require a specific ban on a particular use of the procedure. Professor Patrik S. Florencio advocates for a more general limitation on parents’ access to the genetic information.¹⁸³ This approach is premised on objectives and interests referenced above, such as a desire to avoid harm to the future child, the state’s interest in the best interests of a future child, and respect for the future child’s autonomy.¹⁸⁴ The denial of access to genetic information would be facilitated by leaving the decision as to whether the parents’ desired use of the information is in the child’s best interests¹⁸⁵ or by legislating for what purposes the information can be collected and to what use it can be put.¹⁸⁶

C. Methods of Regulation Not Involving State Intervention

Methods of regulation that are non-coercive and do not involve the power of the state may also be utilized if laws are ineffective or fail to survive constitutional challenges.¹⁸⁷ One of these methods is the use of self-imposed regulation by professional

¹⁸⁰ Alvaré, *supra* note 65, at 44.

¹⁸¹ *Id.* at 46.

¹⁸² *Id.*

¹⁸³ Florencio, *supra* note 38, at 545.

¹⁸⁴ *Id.* at 547-51.

¹⁸⁵ *Id.* at 551.

¹⁸⁶ *Id.* at 555.

¹⁸⁷ See Maxwell J. Mehlman, *How Will We Regulate Genetic Enhancement?*, 34 WAKE FOREST L. REV. 671, 689-95, 699-703 (1999).

associations.¹⁸⁸ For example, the American Medical Association (AMA) has addressed genetic enhancement, stating that it should generally be reserved only for therapeutic purposes and finding that enhancement to improve human traits is “contrary . . . to the ethical tradition of medicine.”¹⁸⁹ The AMA has also found genetic selection for non-disease related traits to be unethical, stating that all procreative and gene therapies should be to “alleviate human suffering and disease by remedying disorders for which available therapies are not satisfactory.”¹⁹⁰ Similarly, the World Medical Association has stated that physicians who provide assisted reproductive services “should always consider their ethical responsibilities toward any child who may be born as a result of the treatment” and that treatment should not be provided if serious harm to the child will result.¹⁹¹ Of course, despite the dim view that these professional associations take toward non-therapeutic uses of ART, only the willingness to enforce professional sanctions might prevent physicians who disagree with the associations’ views from utilizing PGD to enable parents to procure disabled children. Unfortunately, as the anecdotes referenced earlier make clear, that threat has not so far prevented isolated efforts.¹⁹²

Lastly, there is the option of relying upon self-regulation on the part of prospective parents¹⁹³ (an option that may be inevitable if constitutional challenges to the regulation of PGD are successful). This is simply another way of expressing reliance upon the belief that parents are better at deciding what is in their child’s best interest than

¹⁸⁸ See *id.* at 692-93.

¹⁸⁹ AM. MED. ASS’N, AMA CODE OF MEDICAL ETHICS: CURRENT OPINIONS WITH ANNOTATIONS, 2006-2007, 2.11 Gene Therapy, available at http://www.ama-assn.org/ama1/pub/upload/mm/Code_of_Med_Eth/opinion/opinion211.html.

¹⁹⁰ *Id.*

¹⁹¹ World Medical Association, The World Medical Association Statement on Assisted Reproductive Technologies, at Preamble (adopted Oct. 2006), available at <http://www.wma.net/e/policy/r3.htm>.

¹⁹² See *supra* Part I.A.

¹⁹³ See McConnell, *supra* note 49, at 60.

any other societal entity, including courts or legislatures. The viability of this notion seems premised on whether or not society is willing to tolerate the minority of parents who might not be acting in their child's best interests or who act based on a flawed understanding of their child's best interests in bringing disabled children into the world.¹⁹⁴

IV. CONCLUSION

As this Article has demonstrated, there are a variety of rationales that would support the regulation of PGD to prevent cases of intentional diminishment and a variety of means by which such regulation could be carried out. ART have provided great hope to individuals who would otherwise be unable to bear children. The study of the human genome has revealed great wonders about human diversity and holds the key to the eradication of dreaded genetic diseases. But, these technologies also give individuals the means to write their parental preferences into the DNA of their children. A survey of the issues reveals that society has a compelling interest in regulating the use of PGD to prevent intentional diminishment. This interest is premised on the need to act in the best interests of future children by protecting them from the harm that follows from being born disabled as a result of an exercise of their parents' procreative preferences. But, whether the legislation necessary to further such interests would survive a constitutional challenge cannot be clear until legislation is passed by the states that specifically proscribes certain uses of PGD. For now, it seems the real effort lies in educating the public about the potential pitfalls of unregulated use of PGD so as to encourage reasoned debate over which uses are and are not appropriate and to avoid any regulatory overreactions that might follow after learning how the technology has already been put to

¹⁹⁴ *See id.*

use. Only with such education and debate can society determine the amount of protection that we should accord children born from these procedures, the right of parents to utilize these procedures to further their procreative interests, and the potential consequences of the failure to regulate intentional diminishment, PGD, and ART.