

NOTE

Disease Prevention and the Genetic Revolution: Defining a Parental Right to Protect the Bodily Integrity of Future Children

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FREEDOM

*Day turned softly to night and the night almost to day,
And in those dusky hours, while Life clenched her hand,
She left our Earth as quietly as that day began.
And She freed herself as She left anguished tears behind,
And the earthly hearts ached and broke with loss
And with the wonder that Love came at such punishing cost.
Good-bye to the world that held Her back.
Good-bye to the body forever a foe.
Good-bye to the suffering that no child should ever know.*

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I. Introduction: Parents and Purpose

Recent advances in genetic and reproductive technology broaden the capacity of parents to make crucial life decisions for their children.¹ Growing support for the Human Genome Initiative,² as well as

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1. See Renee C. Esfandiary, Note, *The Changing World of Genetics and Abortion: Why the Women's Movement Should Advocate for Limitations on the Right to Choose in the*

society's burgeoning genetic consciousness,³ press parents to consider the role of genetic intervention in the procreation of their children.⁴ For parents whose children will inevitably develop severe disabilities⁵ or terminal illnesses,⁶ parental decision making at the embryonic stage⁷ of reproduction can profoundly affect the health, well-being, and quality of life of their future children. The use of technology⁸ to

Area of Genetic Technology, 4 WM. & MARY J. WOMEN & L. 499, 499 (1998) (discussing the general scope of genetic and reproductive technology).

2. See ROBERT BLANK & JANNA MERRICK, HUMAN REPRODUCTION, EMERGING TECHNOLOGIES, AND CONFLICTING RIGHTS 145 (1995) (defining the Human Genome Initiative as "an international research effort whose goal is to analyze the basic genetic structure of human DNA and to determine the location of the estimated 100,000 human genes.").

3. See John A. Robertson, *Genetic Selection of Offspring Characteristics*, 76 B.U. L. REV. 421, 421 (1996) (defining genetic consciousness as "the awareness of the role of genes in human affairs" and recognizing that genetic consciousness "plays an increasingly important role in daily life.").

4. See Vicki G. Norton, Note, *Unnatural Selection: Nontherapeutic Preimplantation Genetic Screening and Proposed Regulation*, 41 UCLA L. REV. 1581, 1601-02 (discussing social pressure to "have highly intelligent, artistically talented, or athletically gifted children.").

5. This Note deals with the highly controversial topic of allowing parents to choose against bearing children who, at the embryonic stage of development, have been determined to carry genes that will manifest in severe disability or terminal illness. The question then becomes: what is a "severe disability" and does the genetic selection discussed in this paper discriminate against already born disabled persons? For the purposes of this Note, I define severe disability as any disease, mutation, or disorder, neurological or otherwise, that causes the prolonged pain and suffering of the affected individual and/or causes the permanent vegetative state of the affected individual. For a discussion of the discrimination issues, see discussion *infra* Part VI.

6. For the purposes of this Note, I only address terminal illnesses that manifest at birth or during early childhood. I define terminal illness as those diseases or progressive debilities that cause inevitable, premature death.

7. Although genetic screening is currently used for in utero testing, this Note deals specifically with in vitro screening. In vitro fertilization is defined as when "an individual sperm is injected directly into a woman's egg in a laboratory petri dish." Esfandiary, *supra* note 2, at 506 (outlining the in vitro fertilization process).

8. This Note considers the constitutional basis for regulating two distinct types of genetic intervention: intervention for disease prevention and intervention for cosmetic selection. Already, geneticists have developed the means to screen embryos for hereditary disease. The procedure screens in vitro embryos for disease and, then, selectively transfers only the healthy embryos to the mother's uterus. The process, therefore, ensures the birth of healthy offspring or, at least, the birth of offspring free from specific disease. See *Healthy Baby Is Born After Test For Deadly Gene*, N.Y. TIMES, Jan. 28, 1994, at A7. Unlike embryonic disease prevention, intervention for cosmetic selection is a creature of the future. The possibility of using non-transfer procedures to select offspring with certain aesthetic attributes or character traits, however, looms on the horizon. See Robertson, *supra* note 4, at 422.

eradicate disease and suffering from potential offspring,⁹ however, places today's parents at a controversial crossroads.¹⁰

Although advances in genetic technology offer parents an effective and compassionate way to prevent the future suffering of their children,¹¹ the genome project¹² also creates the possibility of parental selection for a wide range of other, exceedingly superficial offspring characteristics.¹³ Unfortunately, current legal debate regarding genetic intervention lumps the two types of selection into one controversial category.¹⁴ By equating disease prevention with cosmetic selection,¹⁵ social commentators trivialize the important decisions that some parents must make to protect the health of their children.¹⁶ The

9. This Note deals specifically with preimplantation screening of "potential offspring." Preimplantation screening is the "evaluation of preembryos for disease or birth defect." June Coleman, Note, *Playing God or Playing Scientist: A Constitutional Analysis of State Laws Banning Embryological Procedures*, 27 PAC. L.J. 1331, 1354 (1996). See also Norton, *supra* note 5, at 1592-97 (discussing the intricacies of the preimplantation screening process).

10. See also Dena S. Davis, *Genetic Dilemmas and the Child's Right to an Open Future*, 7 HASTINGS CTR. REP. 1, 11-12 (1997) (discussing that "it is precisely where children are concerned that [parents] are understandably most jealous of their prerogatives to guide and make decisions").

11. Some states define "genetic screening" in specific, non-cosmetic language. See OHIO REV. CODE ANN. § 3901.49 (West 1999) ("Genetic screening or testing' means a laboratory test . . . for abnormalities, defects, or deficiencies, including carrier status, that are linked to physical or mental disorders or impairments, or that indicate a susceptibility to illness, disease, or other disorders, whether physical or mental, which test is a direct test for abnormalities, defects, or deficiencies, and not an indirect manifestation of genetic disorders.").

12. See explanation *supra* note 3. See also Jeffrey M. Weinberg, *Breaking Bonds: Discrimination in the Genetic Revolution*, JAMA, Oct. 7, 1992, at 1767 ("Experiments on gene therapy have begun, as has an initiative to map and sequence the 3 billion bases of the human genome, a project funded at approximately \$3 billion over 15 years in the United States alone.").

13. See Marilyn Moysa, *Critics Fear Embryo Testing Could Be Abused*, OTTAWA CITIZEN, Nov. 29, 1993, at A4 (discussing the possibility of genetic selection for a wide range of physical and mental characteristics).

14. See generally Robertson, *supra* note 3, at 429-40 (arguing that procreative liberty encompasses all decisions regarding embryonic screening).

15. For the purposes of this Note, "cosmetic selection" refers to the use of genetic technology to select or enhance the physical characteristics—such as eye color and weight—of potential offspring. This paper also broadly defines "cosmetic selection" as genetic selection for mental traits, including intelligence and personality.

16. Equating disease prevention and cosmetic selection trivializes the parental decision to forego implantation of disease-affected embryos. Parents who make the decision to prevent the suffering of their future children do not use genetic technology to prevent the births of cosmetically undesirable children.

confusion degrades the significance of parental decision making,¹⁷ as well as undermines the parameters of established reproductive rights.

In light of rapidly advancing technology,¹⁸ solid frameworks must be established to deal with the inevitable concerns—both legal¹⁹ and ethical²⁰—of a reproductive world teeming with genetic possibilities.²¹ This Note proposes a starting point²² for protecting the genetic interests of both parents and children. First, by examining current constitutional bases for disease screening, this Note determines that the protections articulated in the landmark reproductive rights cases²³ are problematic when applied to genetic intervention. Although these precedents both reinforce invaluable fundamental rights and serve as a basic foundation for parental autonomy, the named rights do not explicitly safeguard the special needs of “at risk” parents.²⁴ By tracing the role of parental decision making in various contexts of children’s end-of-life care,²⁵ this Note demonstrates the existence of an unspoken, but customarily accepted, deference to parental autonomy in deciding appropriate life and death decisions for children. This deference, so rooted in American tradition and so thoroughly estab-

17. See Norton, *supra* note 4, at 1610 (discussing the possibility that “the use of [Preimplantation Genetic Screening] to screen for nontherapeutic traits may cause a backlash against those using it for less morally troubling purposes, such as preventing serious and untreatable genetic disease.”).

18. See Esfandiary, *supra* note 1, at 504 (discussing the “impossibility” of slowing the advances of genetic technology).

19. See *id.* at 507 (discussing the divisive nature of genetic screening in the legislative and judicial contexts).

20. See Aileen Ballantyne, *Small but Perfectly Formed*, LONDON TIMES, Oct. 24, 1992, at 7 (discussing ethical concerns of genetic screening, including discrimination against families who choose to bear disabled children). See also Weinberg, *supra* note 12, at 1767 (“Genetic information has had broad repercussions on our social structure. Several institutions, such as the insurance and education industries, government, and employers, all have an interest in advocating large-scale genetic disease screening.”).

21. See Norton, *supra* note 4, at 1582-84 (discussing the use of current technology to successfully screen out disease in otherwise affected embryos and the potential use of such technology for discriminatory purposes).

22. The issues discussed in this Note indicate that a larger debate will develop as genetic technology advances. This Note recognizes that legislation and regulation will inevitably follow the growing debate surrounding genetic intervention.

23. See *Roe v. Wade*, 410 U.S. 113 (1973); *Eisenstadt v. Baird*, 405 U.S. 438 (1972); *Griswold v. Connecticut*, 381 U.S. 479 (1965).

24. In the narrow sense, “at risk” parents are those parents whose families have a history of genetic disease. In a broader sense, “at risk” parents are all parents, as mutation and genetic disorder do not selectively operate on the embryos of parents who have known family histories of genetic disease.

25. For the purposes of this Note, I define decisions regarding children’s end-of-life care as parental decisions to either sustain or terminate life for their dying children, including embryos and fetuses.

lished in judicial opinion, confirms the existence of a fundamental right of parents to protect the bodily dignity of their potential offspring.²⁶

Second, this Note argues that the possible use of genetic screening to preselect the cosmetic features²⁷ of children trivializes, and even endangers, the right of parents to prevent serious and debilitating disease in their children. By analyzing genetic intervention under the suggested “parental autonomy” framework, this Note demonstrates that cosmetic intervention—unlike disease prevention—is not guaranteed constitutional protection. As the State steps in to regulate genetic engineering,²⁸ the distinction between cosmetic selection and disease prevention takes on profound meaning.²⁹ Considering a possible moratorium³⁰ on genetic intervention, a fundamental parental autonomy right will provide parents with the means to continue disease prevention techniques and to, subsequently, protect their future children from prolonged suffering.

Third, this Note addresses the criticism that genetically intrusive disease prevention inherently discriminates against disabled people. By differentiating between compassionate intervention at the embryonic level and unacceptable discrimination against already-born disabled persons, this paper refutes the idea that genetic screening devalues the lives of the disabled.

Interwoven in every argument, this Note addresses the balance of rights between parents, children, and the State. This Note assumes that parents, almost invariably, act in the “best interest” of their children.³¹ The presumption is a powerful one, based in natural law, as well as in the dictates of legislative enactment and judicial interpretation. Applying this assumption to genetic intervention, however, raises complicated questions of whether parents are capable of decid-

26. See Davis, *supra* note 10, at 1 (discussing the “respect for patient autonomy” inherent in genetic counseling and decision making).

27. See *supra* note 15 (defining cosmetic selection).

28. See Esfandiary, *supra* note 1, at 501 (“Genetic engineering refers to specific ‘techniques by which scientists can add genetically determined characteristics to cells that would not otherwise have possessed them.’”).

29. In light of inevitable regulation of genetic technology, differentiation between disease prevention and cosmetic selection is imperative for the continuation of disease screening. See discussion *infra* Part V.

30. The controversial nature of genetic selection raises moral concerns akin to those regarding human cloning. In California, ethical concerns influenced a five year moratorium on all human cloning. CAL. BUS. & PROF. CODE § 2260.5 (Deering 2000). This paper addresses the possibility of a similar ban on genetic intervention.

31. See discussion *infra* Part II.

ing the “best interests” of unborn children. This Note argues that parents have a fundamental right to protect the health and bodily integrity of their children by making crucial decisions at all stages of human development.

In sum, this Note focuses on the unique life and death decisions that some parents must make for their children.³² By advocating the use of genetic technology to “screen out” disabling disease, this paper highlights the emotional and physical advantages of parental decision making at the earliest stages of procreation. More specifically, this Note attempts to secure parental discretion in genetic decision making by identifying a fundamental right of parents to protect the bodily integrity of their children, even if that protection arises in the context of decision making at the embryonic stage. By reconceptualizing the existing sources of such a right,³³ this Note demonstrates that the parental right to secure children against bodily indignity allows parents to choose non-life, over disabled life, for their future children. The underlying theory of this Note will provoke criticism from both conservative and feminist points of view;³⁴ nonetheless, the controversial ideas presented in this Note effectively demonstrate the inadequacy of the present system in protecting both the fundamental rights of parents and the bodily integrity of their children.³⁵

II. A Brief Word: Examining the Desire for Disease Prevention

*Every night & every Morn
Some to Misery are Born.
Every Morn & every Night
Some are Born to sweet delight.*³⁶

If the proposed parental autonomy right did exist, not all parents would choose to make use of the correlating disease prevention tech-

32. Parental decisions regarding the premature death of children are “unique” in that most parents assume that they will outlive their children.

33. This Note assumes that a right of parental decision to protect the bodily integrity of future children already exists. The right simply needs clarification. See discussion *infra* Part IV.

34. See discussion *infra* Part VII.

35. The present system of protecting parental rights in the genetic screening context relies on constitutional rights that do not include modern technology. The constitutional right of parents to protect the bodily integrity of future children needs to be more clearly articulated. See discussion *infra* Part IV.

36. William Blake, *Auguries of Innocence*, in PHILLIP KITCHER, *THE LIVES TO COME*, front page (1996).

nology.³⁷ This Note in no way suggests that such important—and fundamental—decision making should be removed from parental control. Quite to the contrary, this Note supports the use of preventative intervention for only those parents who feel that non-life is in the best interest of their potential children.³⁸ The parental autonomy right protects parental discretion, regardless of whether parents choose to sustain or terminate³⁹ the lives of their suffering children.⁴⁰

Parents who choose to bear, raise, and love severely disabled children must be commended for their strength, as the task is a formidable one.⁴¹ It must be noted, however, that not all parents feel that giving life to a severely disabled child is in the best interest of that child. For these parents, the thought of beginning or continuing life for a child whose existence consists entirely of pain, unconsciousness, or both, constitutes unnecessary cruelty.⁴² In these circumstances, parents love and respect their potential children no less than those parents who choose to give life to affected children.⁴³

Although the United States legal system assumes that “natural bonds of affection lead parents to act in the best interests of their children,”⁴⁴ no one static definition of “best interests” exists. In the realm of preventative intervention, the power of a dynamic “best in-

37. See Earl Lane, *Caution Urged in Gene Testing*, NEWSDAY, Nov. 5, 1993, at 17 (discussing a report by the Institute of Medicine, supporting a parental right to have a child with a genetic disease).

38. For a discussion of the parental right to bear children with severe disabilities, see Lois Sheperd, *Protecting Parents' Freedom to Have Children with Genetic Differences*, 1995 U. ILL. L. REV. 761 (1995).

39. For the purposes of this Note, “termination” of life includes discarding diseased embryos, aborting a fetus, and deciding to end life support for critically ill newborns and terminally ill minor children. This Note also recognizes the broad discretion of women to decide the “best interests” of their fetuses, whether that means aborting a healthy fetus or carrying a disabled fetus to term.

40. See Moysa, *supra* note 13, at A4 (quoting a lawyer for the Canadian Disability Rights Council: “The real meaning of the word choice . . . includes the option of having a disabled child.”).

41. See *infra* note 103.

42. See Moysa, *supra* note 13, at A4 (quoting a Canadian reproductive specialist: “All you have to do is talk to these people to know what I mean. . . . Anyone who has to think about giving birth to a child and then watching them gradually die over five years, I mean, it's horrible.”).

43. See Arthur L. Caplan, *Hard Cases Make Bad Law: The Legacy of the Baby Doe Controversy*, in COMPELLED COMPASSION 121 (Arthur Caplan et al. eds., 1992) (“Public policy must presume that parents love their children, seek what is best for them, and act accordingly. The burden should be on others, be they providers or government officials, to show that these presumptions are false.”).

44. *Parham v. J.R.*, 442 U.S. 584, 602 (1979) (quoting *Pierce v. Society of Sisters*, 268 U.S. 510, 535 (1925)) (citations omitted).

terests" standard is paramount. The proposed right of parents to decide the best interests of their children, at any stage in their children's lives, recognizes and supports the divergent outcomes inherent in parental decision making.⁴⁵ As each set of parents separately understands the ramifications of giving life to a severely disabled child,⁴⁶ each set of parents should have the discretion to decide whether life is indeed in the best interest of their potential child.⁴⁷

In arguing for the establishment of just such discretion, this Note recognizes the further tragedy that would befall parents if the State imposed one "best interests" standard on all parents. In light of the severe infringement on fundamental rights, the possibility of the State mandating the destruction of all diseased embryos appears slim.⁴⁸ A blanket ban on genetic intervention,⁴⁹ however, is a legitimate concern and would increase the level of desperation exerted on parents who, because of the lack of adequate safeguards,⁵⁰ bear unhealthy children. In some cases, parents may resort to extreme measures to eliminate their children's suffering and to protect what they feel is the best interest of their children.⁵¹ Additionally, parents who would

45. See *Planned Parenthood v. Casey*, 505 U.S. 833, 859 (1992) (stating that "it is clear that among the decisions that an individual may make without unjustified government interference are personal decisions 'relating to marriage, procreation, contraception, family relationships, and child rearing and education.'") (internal citations omitted).

46. See Ballantyne, *supra* note 20, at 2 (discussing the benefit of genetic screening for parents "choosing to have a handicapped child . . . Such parents are able to prepare themselves and do everything possible, from birth, for that child.").

47. See Lois A. Weithorn & Mary Ann McCabe, *Emerging Ethical Issues in Pediatric Psychology*, in *HANDBOOK OF PEDIATRIC PSYCHOLOGY* 577 (Donald K. Routh ed., 1988) ("A child is born into a family that, on some continuum, is able or motivated, or unable or unmotivated, to care for [a disabled] infant. Although it is not clear *how* family actors should be weighed, the reality is that the capacity of family members to provide for the child's emotional, physical, and financial needs does affect the child's future well-being.") (emphasis in original).

48. See *supra* note 46. See discussion *infra* note 63 and accompanying text.

49. See Coleman, *supra* note 9, at 1398 (stating that "[w]hile total bans may be unconstitutional, the state concerns that prompted regulation are valid and provide further impetus to enact national guidelines for embryological research."). This Note recognizes the need for government regulation in the genetic arena; however, such regulation cannot infringe on the constitutional right of parents to decide the best interests of their future children. See discussion in text *supra* Part II.

50. If both disease screening at the embryonic stage and late-term abortion are prohibited, women who become pregnant and discover late in pregnancy that their fetus is severely disabled will be forced to bear critically ill, suffering children. For a discussion on women's reliance on abortion as a safeguard against bearing critically ill children, see David A. Grimes, *The Continuing Need for Late Abortions*, *JAMA*, Aug. 26, 1998, at 747.

51. See generally *Griffith v. Florida*, 548 So. 2d 244, 245 (Fla. App. 1989) (father shoots three-year-old [Persistent Vegetative State] daughter in her hospital bed because "I didn't want her to suffer anymore.").

have chosen non-life for their disabled children may feel the double-bind of a society that first forces them to bear special needs children and then abandons⁵² the parents and children to face physical and emotional hardship⁵³ in isolation.⁵⁴ The devastating effects of a possible moratorium on genetic intervention inspires this Note to articulate a compassionate and constitutionally sound means of protecting the best interests of parents and children alike.

III. Reproductive Rights: The Wrong Direction for Disease Prevention

*[T]he freedom to bear and beget children if one chooses. . . is an important freedom that is widely accepted as a basic, human right. But its various components and dimensions have never been fully analyzed, as technologies of conception and selection now force us to do.*⁵⁵

The majority of Americans take procreative freedom for granted. Although reproductive rights mark the foundation of family and the basis for bodily autonomy, many people fail to consider the actual extent of procreative liberty.⁵⁶ As the genetic revolution gains momentum, the boundaries of reproductive freedom will be questioned. The limitations on exactly how and for what reasons parents are able to reproduce will need to be definitively articulated.⁵⁷

In the case of genetic intervention, clearly defined rights are crucial to the protection of parental decision making. Regrettably, most advocates of genetic intervention rely solely on existing reproductive

52. See *SSI Families Say They Are Too Frightened and Intimidated to Challenge Funding Cutoffs for Disabled Children*, 25 WTR. HUM. RTS. 22 (1998) (discussing disabled children's increased ineligibility for Supplemental Security Income (SSI) under welfare reform's stringent new guidelines). As of late 1998, more than 138,000 children have been terminated from SSI benefits. See *id.* at 23.

53. Financial hardship can also be a legitimate problem for families with limited economic resources, see Elizabeth J. Jameson & Stephen C. King, *The Failure of the Federal Government to Care for Disabled Children: A Critical Analysis of the Supplemental Security Income Program*, 20 COLUM. HUM. RTS. L. REV. 309, 310-13 (1989).

54. See Weithorn & McCabe, *supra* note 47, at 577 ("It is our opinion that governmental policies that require vigorous life-saving efforts with handicapped infants *must* be accompanied by consistent and generous programs offering health, educational, and other supportive benefits to the children and their families throughout the individuals life span.").

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

56. See SUZANNE STAGGENBORG, *THE PRO-CHOICE MOVEMENT; ORGANIZATION AND ACTIVISM IN THE ABORTION CONFLICT* 150-55 (1991) (discussing the dilemma of pro-choice activists in mobilizing political support, especially in times when reproductive rights appear relatively secure).

57. See discussion *supra* Part II.

rights doctrine⁵⁸ to justify the use of embryonic screening. By broadly construing procreative liberty, these commentators create vast umbrellas under which just about any procreative technique—however objectionable—will find protection. This approach is highly problematic. Not only do these loose constructions of liberty undermine the foundations of established doctrine, but they also fail to address the novelty of genetic technology. Furthermore, vast interpretations of procreative freedom will likely provoke fear-based restrictions on genetic intervention, thereby limiting or even destroying access to disease prevention techniques. Exclusive reliance on sweeping reproductive rights ideologies, therefore, fails to adequately protect the parental interest in bearing healthy children. Although procreative liberty cannot stand alone as the basis for a parental right to intervene in the genetics of future children, the established reproductive rights are an essential foundation for the construction of more definitive parental autonomy rights.

Long before the landmark reproductive rights cases of the late 1960's and early 1970's,⁵⁹ the United States Supreme Court began to lay the foundation for recognizing procreative liberty. In 1942, by refusing to allow mandatory sterilization as a form of criminal punishment, the Court established that "procreation [is] fundamental to the very existence and survival of the race."⁶⁰ Although the Court suggested a human interest in protecting reproductive capacity, the opinion failed to explicitly acknowledge a fundamental right to procreate. The Court's vague consideration of reproductive liberty premised an ongoing trend in judicial opinion: the failure to articulate procreative freedom as an absolute right.⁶¹

As the landmark reproductive rights cases reveal, reproduction is a "negative right against public or private interference, not a positive right to the services or the resources needed to reproduce."⁶² The limited scope of procreative liberty,⁶³ therefore, does little to protect

58. See discussion *infra* Part III.

59. See *supra* note 22.

60. *Skinner v. Oklahoma*, 316 U.S. 535, 541 (1942).

61. See ROBERTSON, *supra* note 55, at 23. See generally *Roe v. Wade*, 410 U.S. 113 (1973) (holding that the State retains the right to limit access to abortion); *Planned Parenthood v. Casey*, 505 U.S. 833 (1992) (reconfirming the State's right to intervene in abortion decisions).

62. ROBERTSON, *supra* note 55, at 29.

63. *But see Norton*, *supra* note 4, at 1620-21 (arguing that "the [Supreme] Court's holdings which recognize a right to *not* procreate would almost certainly extend to an affirmative right to procreate.") (emphasis in original).

parental discretion in embryonic decision making.⁶⁴ The established reproductive rights, however, are essential to protecting choice in the abortion context. By bringing controversial notions of genetic technology under traditional reproductive rights protections, the somewhat tenuous abortion rights⁶⁵ are misconstrued and, subsequently, degraded.

Premised on the bodily autonomy of women, the fundamental right to "bear or beget" children is rather limited.⁶⁶ In the narrow sense, procreative liberty safeguards women's choices in deciding the direction of their reproductive lives.⁶⁷ Although the right to abortion is not absolute, until the State deems the interests of the unborn child to outweigh those of the mother,⁶⁸ women can terminate a pregnancy for any reason.⁶⁹ The allure of such broad discretion is understandably great for proponents of genetic technology;⁷⁰ however, the incompatibility of abortion doctrine and genetic intervention is infinitely significant.

Speculation regarding the Supreme Court Justices' intentions in the contraception and abortion cases⁷¹ sheds light on the major flaws of the reproductive rights-genetic intervention analysis. When the cases were decided, the potential of genetic technology did not exist. Given the wide variation in genetic possibilities, contemporary commentators cannot accurately assume that the Justices intended to draw vast future technologies under the protective wings of reproductive

64. *But see* Esfandiary, *supra* note 1, at 507 (discussing a woman's right to not reproduce and the subsequent "right to information relevant to that decision.").

65. Although recent Supreme Court cases have upheld a woman's right to abortion, the Court's decisions have moved from a rule based right toward a standard based right, giving states and courts more discretion in restricting abortion access. For example, in *Casey*, *see supra* note 45, the Court moved from trimester regulation to an undue burden standard, allowing more flexibility in the ways abortion can be restricted. The switch to an undue burden standard increased the role of the State in women's reproductive decisions, while simultaneously diminishing the fundamental rights of women.

66. *See id.*

67. Even if procreative liberty is viewed more broadly, the "right to 'bear or beget' does not necessarily include the right to bear or beget a beautiful or talented child." Norton, *supra* note 4, at 1629.

68. *See* Coleman, *supra* note 9, at 1374-77 (1998) (discussing the moral status of the human embryo).

69. *See generally* *Roe v. Wade*, 410 U.S. 113 (1973). *See also* Norton, *supra* note 4, at 1621-22, 1627 (analogizing a woman's decision to use preimplantation genetic screening to a woman's constitutionally protected interest in having a pre-viability abortion, arguing that a woman's interest in abortion is not seen "as the 'liberty to choose nontherapeutic abortion,' but rather as the 'liberty to choose abortion.'" (internal citations omitted).

70. *See* Sheperd, *supra* note 38, at 766-67 (discussing the broad "popular appeal" of extending bodily autonomy rights to include reproductive rights).

71. *See supra* notes 23 & 45.

freedom. Quite to the contrary, the Justices specifically protected the privacy interests of women to decide—up until a certain point—the course of their procreative lives.⁷² Grounded in the social ideology of the times,⁷³ the holdings protected women's bodily autonomy and specifically denounced the pre-viability interests of the unborn.⁷⁴ The distinction is essential to demonstrating why reproductive rights clearly cannot be the sole basis for safeguarding genetic intervention.

In stark contrast to the rationale of the abortion decisions, an underlying tenet of the genetic revolution is that advancing technology will improve the quality of life for future children.⁷⁵ The divergent purposes of abortion protection and genetic intervention, therefore, cannot be reconciled.⁷⁶ The conflict of purpose expels genetic technology from the safeguards of established reproductive rights doctrine. By thrusting genetic technology into the guarded arena of procreative liberty, the flagrant clash of purpose attracts unnecessary scrutiny of existing reproductive rights.⁷⁷ Considering the encroaching restrictions on reproductive liberty,⁷⁸ the result of increased scrutiny regarding fetal interests⁷⁹ could be devastating to women's

72. See also Esfandiary, *supra* note 1, at 514 (discussing women's right to pre-viability abortions when prenatal tests determine serious or congenital fetal disorders).

73. See BLANK & MERRICK, *supra* note 2, at 226 ("Technological change can progress without restriction, but only if there is a positive social climate. Just as the climate of the 1960s was ripe for the contraceptive revolution, that of the 1980s was receptive to technological change.").

74. See *Roe*, 410 U.S. at 156-57.

75. See discussion *infra* Part IV, D.

76. See also Norton, *supra* note 4, at 1619 (discussing an alternative approach to differentiating disease prevention and cosmetic selection: "care must be taken to distinguish therapeutic procedures which benefit the health of the mother or child from nontherapeutic or experimental procedures which do not benefit the health of the mother or child.").

77. See Esfandiary, *supra* note 1, at 518-19 (discussing the need to protect women's genetic choices beyond the judicial branch's tremendous accomplishment in protecting reproductive choices).

78. Encroaching restrictions on women's procreative liberty include bans on late-term abortion, as well as child abuse prosecutions for expectant mothers who ingest narcotics. In both instances, the State weighs the rights of the fetus over the rights of the potential mother. See "Banning Late-term Abortions: Bad Medicine, Bad Policy," factsheet, California Abortion and Reproductive Rights Action League (CARAL) (1998); *Johnson v. Florida*, 578 So. 2d 419 (Fla. Dist. Ct. App. 1991) (upholding child abuse conviction for mother who ingested cocaine during pregnancy).

79. Fetal rights legislation pits women's right to choose against a supposed fetal interest in being born. In the first three months of 1999, 14 states have introduced legislation that weighs the rights of fetuses over the rights of women. See *State of the States REPRODUCTIVE FREEDOM NEWS*, Mar. 1999, at 3.

procreative autonomy.⁸⁰ A new, more relevant and less destructive⁸¹ approach to protect genetic intervention is therefore needed.

As evidenced by the potential impact on women's rights, the concern with protecting genetic intervention is that such protection will have negative repercussions on existing fundamental rights and social dynamics. Although "we hope that not all [the children's] sufferings, and the grief of their families, need be repeated, . . . we should also remember the other images and beware lest, in our eagerness to stifle one source of anguish, we produce other terrible forms of human suffering."⁸² In order to prevent negative outcomes such as cosmetic selection or gender preference, the right that protects disease prevention must be narrowly drawn and preferably grounded in existing fundamental liberties. A fundamental right of parents to protect the bodily dignity of their children fits these requirements. Although somewhat amorphous, such a right already exists. Living in the shadows of more explicitly stated parental rights, the right of parents to protect their children from pain and suffering deserves more prominent recognition.

IV. An Unspoken Liberty: Protecting Children's Bodily Integrity

*[F]or centuries it has been a canon of the common law that parents speak for their minor children. So deeply embedded in our traditions is this principle of law that the Constitution itself may compel a State to protect it.*⁸³

Care-giver. Provider. Guardian. The function of parents in American society is undeniable. From decisions surrounding conception and birth to choices of end-of-life care, parents occupy a critical decision making role in the lives of their children. The legal roots of current parenting ideology emphasize the inherent discretion of parents to decide the best interests of their children.⁸⁴ In the context of

80. See also Coleman, *supra* note 9, at 1350-51 (discussing the broad scope and legislative intent of fetal rights legislation).

81. See also Bruce Nolan, *Louisiana Rejects OK on Embryo Tests*, NEW ORLEANS TIMES-PICAYUNE, Oct. 2, 1994, at A1 (discussing the ramifications of labeling in vitro embryos "judicial person[s]"). Cf. Norton, *supra* note 4, at 1610 (discussing the "fear that the use of abortion for a purpose that is ethically more questionable than therapeutic or nonselective abortion may trigger a greater protest against abortion.").

82. KITCHER, *supra* note 36, at 22.

83. *Parham v. J.R.*, 442 U.S. 584, 621 (1979) (Stewart, J., concurring).

84. See generally *Meyer v. Nebraska*, 261 U.S. 390 (1923) (recognizing the general right to raise children); *Pierce v. Society of Sisters*, 268 U.S. 510 (1925) (recognizing parents = liberty to direct the education of their children).

genetic intervention, the parameters of parental discretion are yet undefined. By identifying the established boundaries of parental discretion in situations of abortion, severely disabled newborns, and minor children's end-of-life care, a clear standard emerges for the protection of preventative, genetic intervention. In light of the agonizing decisions that some parents must make for their existing children or fetuses, a decision made well in advance of childhood suffering⁸⁵ seems a logical extension of already recognized parental discretion.⁸⁶ Although the concerns regarding overbroad protections are legitimate, the construction of a narrowly defined right—grounded in existing fundamental liberties—eliminates the possibility of using genetic intervention for superficial and socially damaging purposes.⁸⁷

A. Abortion Decisions

Politically speaking, the decision to have an abortion can be one of the most controversial choices of a woman's life.⁸⁸ Despite the contentious aspects of the abortion debate, the abortion decision remains, for the most part, a private one. Although every Supreme Court abortion decision explicitly preserves the State's authority to regulate access to post-viability abortion,⁸⁹ before viability, the decision to bear or beget a child resides solely with the pregnant woman.⁹⁰ As confirmed by the Court, this broad decisional autonomy bears testament to the capacity of women to decide what is in their own best interest, as well as in the best interest of their potential children.⁹¹ Regardless of fetal health or the probable health of potential children, pre-viability abortion decisions are for women alone to make.⁹²

Irrespective of possible limitations on genetic intervention, post-viability abortion restrictions regulate parental decision making at the earliest allowed stage of parenthood. By intervening in women's abortion decisions, the State removes the presumption that mothers

85. See *supra* note 42 & *infra* note 103.

86. See also Sheperd, *supra* note 38, at 793-808 (discussing author's "attachment theory" as an alternative means of protecting genetic selection).

87. See ROBERTSON, *supra* note 55, at 150 (discussing the potentially harmful role of genetic intervention in the commodification of children).

88. See Grimes, *supra* note 50, at 747 (citing abortion as "the most divisive social issue of our times.").

89. See discussion *supra* Part III.

90. See Coleman, *supra* note 9, at 1377 (discussing the Court's consideration of women's particular life situations in assessing an unlimited right to pre-viable abortion).

91. See *supra* notes 41 & 46.

92. See Coleman, *supra* note 9, at 1377 (discussing the Court's decision to refuse "a complete ban on abortions.").

who carry viable fetuses will act in their potential children's best interest. Although these restrictions are offensive to broad notions of women's bodily autonomy, the restrictions highlight an important point in favor of preventative intervention arguments: the best interests of potential children are paramount.⁹³ The point is further supported by the exceptions to most post-viability restrictions that permit women to abort when the lives or health of their potential children are compromised by either disease or deformity.⁹⁴ The message is clear. Although the State reserves the authority to prevent post-viability abortion, the State cedes this authority when a maternal decision to abort would prevent the suffering or death of a potential child and thus would protect the best interest of the potential child.⁹⁵ This rationale lends great support for parental decision making at the embryonic level.

The right of mothers, as potential parents, to make prenatal decisions regarding the health and well-being of their unborn children is a clearly defined right. Considering the extent of pre-viability fetal development and the parental discretion allowed in terminating a pregnancy at the pre-viable stage, the elimination of possible life at the genetic level also warrants constitutional protection.⁹⁶ Although abortion rights are premised in bodily autonomy arguments, abortion restrictions are premised on the best interests of potential children. In deciding the limits of abortion rights, the State must weigh the best interests of both potential parents and potential children, especially when the interests of the parties conflict. In the case of genetic intervention for disease prevention, where the best interests of parents and future children are aligned, the State should have no trouble supporting the use of preventative technology.⁹⁷ Parental discretion in ge-

93. This is a controversial point. Recognizing the interests of fetal life—at any stage of development—places women's reproductive rights in a precarious position. The more recognition of fetal rights, the less discretion women are afforded in the context of abortion and other procreative decisions.

94. See "Banning Late-term Abortions: Bad Medicine, Bad Policy," Factsheet, CARAL (1998) (noting that late-term abortions "are generally performed only in the most severe of circumstances: because the woman's life or health is endangered, or because the fetus suffers severe abnormalities.").

95. See Esfandiary, *supra* note 1, at 502 ("Public opinion studies show material support for genetic screening and abortion of seriously genetically defective fetuses.").

96. See Coleman, *supra* note 9, at 1379 ("Because a state's interests are slight while the embryo is not viable, those interests do not override the parental interests, and as bans [on genetic intervention] would . . . unduly burden reproductive decision-making.").

97. See Esfandiary, *supra* note 1, at 503 ("In general, geneticists support the notion that the potential life of a fetus, without some minimal functioning nervous system, should not have a protected right of life.").

netic intervention is, therefore, a logical extension of the maternal discretion inherent in the decisions to terminate pre-viable or ill-fated pregnancies.⁹⁸

B. Life or Death Decisions for Critically Ill Newborns

The birth of critically ill or severely disabled newborns places parents in the unenviable position of deciding the proper course of treatment for their children. Not only do these parents have to confront the painful reality of their newborns' permanent and life-limiting disabilities, but they must also restructure, or even bury, expectations regarding their children's quality of life. After weighing the possibilities, parents can make one of two choices. By using extraordinary medical efforts,⁹⁹ parents can choose to sustain or attempt to sustain the lives of their infant children. Alternatively, by choosing to cease nourishment or forego life-saving procedures, parents can decide to end the lives of their newborns.¹⁰⁰ Although a right of parents to end the lives of their critically ill newborns does not explicitly exist, the presumption that parents will act in the best interest of their children, again, gives credence to broad parental discretion.

Although opponents of non-treatment have aimed restrictive legislation at parents who forego sustenance for their critically ill newborns,¹⁰¹ in most cases, courts have refused to apply the suggested prohibitions.¹⁰² When applied to the circumstance of severely disabled newborns, judicial support for parental decision making further suggests a general right of parents to protect the bodily integrity of

98. See Coleman, *supra* note 9, at 1365 (discussing "the constitutional choices that include the right to abort a fetus within the first trimester must also include the right to submit to a procedure designed to give information about that fetus which can then lead to a decision to abort.") (internal citations omitted).

99. See HELGA KUHSE & PETER SINGER, *SHOULD THE BABY LIVE? THE PROBLEM OF HANDICAPPED INFANTS* 33 (1985) ("Extraordinary means . . . include all medicines, treatments and operations which cannot be obtained without excessive expense, pain or inconvenience, or which, if used, would not offer a reasonable hope of benefit.").

100. See *infra* notes 102-04 and accompanying text.

101. See James Bopp, Jr. & Mary Nimz, *A Legal Analysis of the Child Abuse Amendments of 1984*, in *COMPELLED COMPASSION: GOVERNMENT INTERVENTION IN THE TREATMENT OF CRITICALLY ILL NEWBORNS* 74-103 (Arthur L. Caplan et al., eds. 1992) (discussing the reaction of the Reagan administration to the deaths of Baby Doe and Baby Jane Doe).

102. See *id.* at 76 (discussing *Bowen v. American Hosp. Assn.*, 476 U.S. 610 (1986), where the Supreme Court held that "in situations in which parents withhold consent to treatment for their disabled child, the child is not 'otherwise qualified' to receive treatment.").

their children.¹⁰³ In allowing parents to decide the fate of suffering infants, judges again weigh the interests of children, parents and State. Considering the debilitating effects of severe disability and the cruel thought of forcing children and parents alike to endure unnecessary suffering, judicial prerogative tends to agree that the interests of all three parties are aligned in protecting the bodily dignity of the child.

The discretion afforded parents in the newborn context again suggests the relevance of disease prevention strategies at earlier stages of human development. More importantly, the extent of discretion given to parents of already born infants implies that such a right should be upheld at the embryonic level, when non-transfer of embryos has far less of a social impact than cessation of infant life.¹⁰⁴

C. Minor Children and End-of-Life Decisions

Of all the possible decisions that parents must make, the choice to forego life support for minor children is the most heart-wrenching. Unlike parental decisions regarding embryos, fetuses or newborns, life or death choices concerning children include deep emotions flowing from established parent-child relationships. Even in cases where children have always lacked cognitive ability, the attachment that parents feel for these children aggravates the immeasurable agony inherent in affirmative decisions to end life support or refuse life-prolonging treatment.

For parents who choose to end life support to protect their children from either intolerable suffering or a severely degraded quality of life,¹⁰⁵ State restrictions on parental discretion augment the pain of both children and their families.¹⁰⁶ Fortunately for parents, [t]he

103. Courts increasingly hear cases dealing with hospitals' refusal to follow parents' wishes regarding their critically ill newborns. See Julie Gannon Shoop, *Parents of Disabled Child Win Punitive Damages for 'Wrongful Birth,'* 34 TRIAL 16 (1998) (discussing multi-million dollar verdict for the parents of an infant who was resuscitated against her parents' wishes). Shoop's article demonstrates judicial support for parental decision making, especially in cases where the hospital's resuscitation severely compromises the bodily integrity of the infant. Shoop discusses a case where the resuscitated child—now seven years old—is "profoundly retarded, suffers from cerebral palsy, and cannot see, walk, talk, roll over, or feed herself." *Id.*

104. For a cross-cultural perspective on when infant life becomes valued, see KUHSE & SINGER, *supra* note 99, at 98-117 (discussing the role of infanticide in non-Western culture).

105. This Note only considers circumstances where minor children are incapable, due to the debilitating nature of their disease or disability, of voicing opinions regarding their future medical treatment.

106. See Ann MacLean Massie, *Withdrawal of Treatment for Minors in a Persistent Vegetative State: Parents Should Decide*, 35 ARIZ. L. REV. 173, 176 (1993) ("Loving parents may be unable to bring closure to a nightmare that precludes the possibility of even the

number of court cases involving children is much smaller than that concerning adult patients, which is probably explained by the lesser uncertainty about the authority of parents to make such decisions for their minor children”¹⁰⁷ Although formal prohibitions supposedly apply to end-of-life decisions for children, many courts, physicians and ethics committees recognize the eminent capacity of parents to decide what is in the best interests of their suffering children.¹⁰⁸

The discretion provided to parents in deciding appropriate end-of-life care for their children provides strong support for protecting disease prevention strategies at the embryonic level. By locating and eliminating inevitable suffering, genetic screening gives parents the tools to avoid agonizing end-of-life decisions and, more importantly, the means to prevent the unnecessary pain and discomfort of their children.¹⁰⁹ In the context of disease and illness, parental decision making is difficult at any stage of a child’s—or potential child’s—life. The decision to forego implantation of diseased embryos, however, cannot compare to the anguish experienced by parents who are forced to decide the life or death of their existing children. Given the discretion in the latter context, as well as the non-recognition of embryonic rights,¹¹⁰ protection of disease prevention technology seems a logical and compassionate extension of parental decision making.¹¹¹

D. Result of the Analogies

Parental decision making, at all stages of children’s development, is a discretion that has traditionally been afforded great protection.

normal grieving process facing those who lose a child—at least, not without resort to the time-consuming and costly legal procedures that only add to an already overwhelming emotional burden.”).

107. *Id.* at 218 note 22 (internal citation omitted).

108. *See id.* at 218 n.120 (quoting *In re Barry*, 445 So. 2d 365, 371 (Fla. Dist. Ct. App. 1984): “[D]ecisions of this character have traditionally been made within the privacy of the family relationship based on competent medical advice and consultation by the family with their religious advisors, if that be their persuasion.”).

109. *See also* Lawrence O. Gostin, *Deciding Life and Death in the Courtroom: From Quinlan to Cruzan, Glucksberg, and Vacco—A Brief History and Analysis of Constitutional Protection of the ‘Right to Die,’* JAMA, Nov. 12, 1997, at 1523 (noting that “thoughtful opinion in medicine and ethics holds that physicians have a duty to honor patients’ wishes, provide comfort, and relieve suffering.”). This Note argues that this physician duty extends to future children, whether they are fetuses or embryos.

110. *See* KITCHER, *supra* note 36, at 229 (“When a presentient fetus dies, either naturally or through human intervention, there is no violation of rights or interests because there is bearer of rights”).

111. *Cf.* Gostin, *supra* note 109, at 1523 (discussing an unstated constitutional right to die with dignity). This Note argues that this right extends to disease-affected embryos and fetuses.

Although not explicitly cited in support of parental decisions regarding abortion, critically ill newborns, and minor children's end-of-life care, the right of parents to protect their children's—or potential children's—bodily integrity underlies the judicial and medical endorsement of parental discretion in those contexts. The right applies equally to existing and future children, thereby protecting decision making at the embryonic level.¹¹² Unlike the limits on reproductive rights, the right to protect children's bodily dignity is more thoroughly grounded in fundamental rights doctrine and, therefore, provides a more trustworthy means of protecting parental discretion in making difficult procreative choices.¹¹³

V. An Exclusive Right: Alienating Superficial Interventions

*We should be worried about the future and where this might take us. The whole definition of normal could well be changed. The issue becomes not the ability of the child to be happy but rather our ability to be happy with the child.*¹¹⁴

The far reaching and potentially discriminatory consequences of embryonic intervention compel a thorough examination of the motives underlying the use of genetic technology. Already "many aspects of appearance and personality are under fairly simple genetic control,"¹¹⁵ suggesting that substantial interest exists to further cosmetic, personality, and gender selection. Shallow notions of social acceptability define who is attractive, desirable, and respected in human society and, subsequently, devalue the lives of people who do not fit the socially constructed "norm." Unlike genetic intervention to prevent suffering and disease, cosmetic selection is equivalent to the horrors of past human disasters,¹¹⁶ such as the Holocaust¹¹⁷ and the institutionalization of American slavery. The championing of value-

112. See also Norton, *supra* note 4, at 1599 (discussing the physical and psychological impact of discarding disease-affected embryos versus aborting disease-affected fetuses).

113. See also Coleman, *supra* note 9, at 1380 (discussing parents' interests in genetic screening outweighing state interests due to screening's "close link" to procreative freedom).

114. Geoffrey Cowley et al., *Made to Order Babies*, NEWSWEEK, Spring 1991, at 94 (quoting George Annas).

115. *Id.*

116. See Weinberg, *supra* note 12, at 1767 (discussing past ramifications of genetic discrimination).

117. See Norton, *supra* note 4, at 1612-13 (discussing the role of genetic differences in the Holocaust).

laden intervention proposes, in effect, a return to eugenicism¹¹⁸ and the promulgation of intolerance. If unchecked, the use of superficial selection criteria¹¹⁹ will effectuate a caste system, where the disparity between the wealthy and the poor,¹²⁰ the accepted and the undesirable, will further stratify society and undermine the fundamental rights of all people. The decision to use technology to advance such self-interested goals affronts fundamental guarantees of equality and individual worth and is in no way supported by either American legal tradition or this paper's proposed constitutional standard.¹²¹

As genetic technology advances, appropriate regulations will need to address the divergent purposes of intervention. By supporting the use of disease screening technology, regulation can curb needless childhood suffering and, subsequently, reduce the chances of familial tragedy. Alternatively, by supporting broad interventions, regardless of the intervention's purpose, regulation can instigate social stratification and oppression. Keeping the best interests of children and society in mind, the decision to forego sweeping acceptance of genetic intervention is obvious. The challenge, therefore, lies in creating a protection that excludes offensive superficial intervention, but safeguards the important function of disease prevention. The answer lies in the application of the parental right, articulated above, to protect the bodily integrity of children.

Although the proposed right safeguards parental discretion, the motivating purpose of the right is the protection of children's health and well-being.¹²² As exemplified by current protections for parental decisions in children's end-of-life care, application of a right of parental discretion focuses on life and death decisions regarding children. The current application draws a bright line between critical parental decisions that safeguard their children from suffering or bodily indignity and superficial parental desires to enhance the appearances of

118. See Esfandiary, *supra* note 1, at 501 ("Eugenics has several definitions, including 'good in birth' and 'a social movement to improve the human species through the use of technology.'"). See also *id.* at 501-03 (discussing the history of eugenics in the United States).

119. In defining superficial selection criteria, one doctor notes that occasionally potential parents "have a sort of new-car mentality. . . . [The baby's] got to be perfect, and if it isn't you take it back to the lot and get a new one." Cowley, *supra* note 114, at 94.

120. The high cost of genetic engineering excludes the poor from available genetic intervention techniques. See also *infra* note 127.

121. See also Norton, *supra* note 4, at 1603-10 (discussing the moral objections to cosmetic selection).

122. See also Sheperd, *supra* note 38, at 799 (noting that for genetic screening decisions "it is generally best for children, or children-to-be, for parents to make these decisions.").

their children.¹²³ The purpose of the intervention is, therefore, taken into account when analyzing which parental choices fall within the protected right.

Some might argue that superficial selection—by eliminating obesity or increasing intelligence—will improve potential children's quality of life and, thus, fall into the category of protecting bodily integrity. The argument fails for two reasons. First, the parental protection of children's bodily integrity already exists and, as currently applied, does not extend beyond life or death decisions for children. And second, the true motivation for trivial intervention is not the health of children, but rather the desire to manufacture offspring in order to ensure parental acceptance.¹²⁴ This purpose offends traditional notions of unconditional parental love, as well as encourages society to create value systems based on physical appearance. Furthermore, equating the trivial results of cosmetic selection with critical decisions that prevent human pain and suffering degrades the role of parents as the protectors of children.

Outlined in the end-of-life choices regarding children, the parameters of parental discretion are clearly limited to decisions based on children's health, well-being, and bodily integrity. Superficial interventions do not fall within the boundaries of the right's protection. Disease prevention, however, is clearly within the "best interests" discretion traditionally afforded to American parents. Application of the parental discretion standard, therefore, differentiates between genetic intervention for superficial selection and genetic intervention for disease prevention. In light of future regulation of genetic technology, the difference is of utmost significance. Grounded in decades of support for fundamental parental rights, parental discretion in protecting children's bodily integrity will inevitably safeguard the use of disease prevention against regulation. Thus, while cosmetic selection awaits intense scrutinization and ethical validation, a clear articulation of the parental discretion right preserves the best interests—in the context of disease prevention—of both parents and children.

123. See Coleman, *supra* note 9, at 1381 ("The compelling state interest appears to override parents' interests when nontherapeutic genetic screening is done, such as screening for certain sex or hair color traits.").

124. See *id.* at 1381-82 (discussing the parameters of government regulation of embryos and genetic intervention).

VI. *Compassion v. Discrimination: A Note on Differentiation*

*There will always be people who have disabilities that are not detected by this screening. Their disability could be acquired later in life because of accident or illness. What happens to them if we declare disabled fetuses and embryos undesirable?*¹²⁵

Although the relatively high costs¹²⁶ of genetic intervention keep the correlating technology—for the time being—in the hands of the wealthy,¹²⁷ the impact of disease screening is felt throughout society.¹²⁸ The choice to forego pregnancies that will result in disability implies, on some level, a social intolerance of physical difference.¹²⁹ For some disabled people, the “screening out” process screams of discrimination and devaluation.¹³⁰ At first glance, the argument seems plausible: the choice to abandon diseased embryos expresses an intolerance, aversion or disdain for disabled life.¹³¹ The argument, however, is over-simplified and—in many ways—as “discriminatory” as the genetic choices that the argument so vehemently denounces.

The capacity of some disabled opponents to articulate concerns regarding genetic screening demonstrates the wide range of disability that disease can cause. There are many disabled people who, although physically impaired, actively think, reason, aspire, achieve, and thrive. For these individuals, life is a valuable, precious commodity and should not be denied to them. On the other hand, there are many

125. Moysa, *supra* note 14, at A4 (quoting a lawyer for the Canadian Disability Rights Council).

126. See *Cell Testing Finds Abnormality Early*, SAN DIEGO UNION-TRIBUNE, Oct. 21, 1992, at E4 (citing the expense of disease prevention screening).

127. See Norton, *supra* note 4, at 1597-99 (discussing the deterrent effect of high genetic screening costs).

128. See *id.* at 1586-88 (discussing past discrimination based on genetic composition of individuals, including the eugenics movement, Supreme Court decisions, and discrimination in the armed forces).

129. See Esfandiary, *supra* note 1, at 499 (“Developments in genetic engineering may push less fortunate individuals to the sidelines of society by elevating the definition of ‘normal’ and ‘acceptable.’”).

130. See KIRCHER, *supra* note 36, at 221-22 (“Men and women who have overcome hereditary disabilities . . . believe that the use of abortion as a tool degrades the value of life, even when it is employed by those who are otherwise well intentioned and far seeing. Troubled by current practices of amnioscentesis and selective abortion, and foreseeing a proliferation of prenatal tests, they are daunted by the prospect of a world in which life becomes a commodity, something to be stamped with approval before birth or labeled ‘defective’ and discarded.”).

131. See Esfandiary, *supra* note 1, at 499 (“As society focuses on improving the human race, compassion for the disabled may decrease to traumatic levels affording less appreciation for differences between individuals.”).

disabled people who have no cognitive ability, who do not understand nor appreciate the life around them, who know only pain. For these individuals, pre-implantation parental discretion spares them the bodily indignity that life inevitably holds. By assuming that all disabled people share an appreciation for human life, disabled opponents of genetic intervention assume one static definition of disability. Reality proves that, in the worst circumstances, life brings some disabled children only pain, hopelessness, and bodily degradation.¹³² Unlike discrimination, disease prevention's benevolent purpose encourages cognitive, compassionate people, whether physically disabled or undeniably healthy, to recognize the humanity inherent in the prevention of needless suffering.

This Note does not suggest that disabilities should be weighed by degree or disparity of affliction. This Note does, however, recognize the right of parents to assess the future of their potential children and to decide, according to their own belief systems, what disabilities will adversely affect the best interests of their offspring.¹³³ Given the discretion afforded parents in treatment decisions regarding already-born disabled children, the use of preventative non-implantation techniques is no less an act of protecting bodily integrity than refusing sustenance for a critically ill newborn or opting to terminate life support for a suffering child. The decision to forego implantation of diseased embryos and, thus, forego an ill-fated pregnancy does not equate affirmative discrimination against disabled people. Disease prevention, rather, speaks to a well-defined parental right to protect children from pain and suffering, using whatever means are legally available. Any decision to forego human life will inevitably draw accusations of discrimination and intolerance. For the time being, however, decisions regarding pre-viable life remain in the hands and consciences of potential parents. Instead of stirring public accusations of discrimination, decisions to use disease prevention technology should, and do, fall within the protected parameters of private, interfamilial discussion and decision making.

132. *See supra* note 103.

133. Although this note supports fairly unrestrained parental discretion in disease prevention decisions, this note also recognizes the need for regulation to prevent the abuse of disease prevention technology. Future regulation within the realm of preventative procedures, however, will not be addressed in this Note.

VII. Criticism: Conservatives and Feminists Take Aim

*The silence of the law on many areas of individual choice reflects the value this country places on pluralism. Nowhere is the need for freedom to pursue divergent conceptions of the good more deeply felt than in decisions concerning reproduction.*¹³⁴

The potential abuse of genetic technology¹³⁵ is a legitimate concern for disabled individuals and their advocates.¹³⁶ In the event of increased support for genetic intervention, the discrimination concerns must be adequately addressed by specific judicial, legislative, or regulatory language. The legitimate concerns of disability discrimination can be successfully mitigated by a compassionate and succinct approach to regulating disease prevention.¹³⁷ There are, however, more potent political forces that could conceivably derail efforts to protect parental decision making.¹³⁸ This Note specifically recognizes established conservative¹³⁹ and feminist¹⁴⁰ ideologies as possible threats to the proposed parental right to safeguard the bodily integrity of future children.

When parents decide to use disease prevention technology, the subsequent conception of a healthy embryo almost invariably guarantees the implantation and gestation of the screened embryo. The “chosen” embryo is therefore labeled a potential life, a life that—given the massive reproductive effort of the parents involved—is very much a wanted life.¹⁴¹ The arbitrary nature of assigning life status to only healthy embryos is, at first glance, problematic. In light of recent attempts by political conservatives to protect all potential life,¹⁴² some critics of disease prevention technology might argue that merely labeling a fertilized ovum a “defective embryo” does not erase the capacity for life inherent in the embryo. Unfortunately, this so-called protec-

134. Davis, *supra* note 10, at 4-5 (internal citations omitted).

135. See discussion *supra* Part V.

136. See *id.*

137. See *id.*

138. “Parental decision making” refers to parental autonomy in deciding to use disease prevention techniques.

139. This Note addresses only one facet of the broad—and arguably diverse—conservative agenda: the “pro-life” stance.

140. This Note recognizes that feminists have diverse opinions regarding abortion. For example, some feminists believe that fetal life is not yet human life. Other feminists believe that fetal life is human life, but this life is trumped by maternal choice and autonomy. For the purposes of this Note, I define the feminist position as a general pro-choice conviction.

141. See discussion *supra* Part II.

142. See *supra* notes 78-79.

tion of human life fails to consider the compassion underlying parents' decisions to prevent the suffering of their potential children.

In the recent past, conservative efforts have resulted in laws that value fetal life over maternal decision making and maternal health.¹⁴³ Whether at the state¹⁴⁴ or federal¹⁴⁵ level, the attack on women's right to choose abortion, even at the preivable stage,¹⁴⁶ does not lend much support to a parental right to discard disease-affected embryos. Ironically, the arguments made in favor of protecting potential life parallel the arguments made by parents desperate to protect the bodily integrity of their future children. In sum, parents who use disease screening and anti-abortion activists share a common goal: protection of the unborn. In the case of parental use of disease screening, however, protection of unborn children—embryos included—is defined more broadly. Parents who choose to assess the genetic health of their potential offspring ensure the birth of the selected embryo, as well as the health and well-being of their future children. In this sense, parents who utilize disease screening actually go beyond the conservative goal of protecting fetal interests.¹⁴⁷ The parents who choose disease prevention protect fetal interests, as well as the interests of the children that the embryos and fetuses will inevitably become.

Although the broad construction of fetal protection refutes conservative criticism, this Note's mention of fetal interests will invariably offend feminist groups determined to keep fetal language out of the abortion debate.¹⁴⁸ The parental right to protect the bodily integrity of future children, however, also withstands feminist critique. The parental right to use disease prevention¹⁴⁹ is not a mandate. Rather the right to use disease screening is a negative right against public or private interference.¹⁵⁰ In the context of disease screening, fetal interests are not a premise on which the parental right depends. Instead, fetal

143. *See id.*

144. *See id.*

145. *See* STAGGENBORG, *supra* note 56, at 81-83 (discussing the Hyde Amendment—a federal law that banned Medicaid spending for abortion—and the subsequent expansion of the anti-choice movement).

146. Many of the late-term abortion bans include language that, if construed broadly, would prohibit abortion at any stage. *See supra* notes 78-79.

147. This Note attempts to reconcile conservative viewpoints with parental rights in the context of disease screening. This Note does not attempt to reconcile the issues that conservative observers might have with abortion and end-of-life care for children with the more 'liberal' stance taken in this Note. *See supra* text Part IV.

148. *See supra* notes 78-79.

149. The right to protect the bodily integrity of future children encompasses the right to use disease prevention. *See discussion supra* Part IV.

150. *See* ROBERTSON, *supra* note 55 and accompanying text.

interests arise as a result of a parental choice to protect those interests. The parental choice¹⁵¹ to carry the screened embryo to term is central to the right to protect the bodily integrity of future children. The proposed right, therefore, relies on the same constitutional rights as those protected by pro-choice feminists.¹⁵²

Surprisingly, the parental right to protect potential children simultaneously appeases the concerns of conservatives and feminists. By protecting, in the most compassionate sense, the lives of potential children, the proposed right aligns with conservative goals. By protecting, and even broadening, parental decision making regarding reproduction, the proposed right in no way endangers feminist conceptions of choice. In the context of genetic screening, where the interests of parents and potential children are fundamentally aligned, criticisms of a parental right to protect future children need more than political agendas to survive refutation.

VIII. Conclusion: Children First

*When a child is conceived, a dream is born. The dream imagines a healthy, strong, and clever child, who with confidence and success, fulfills a desire to bear a child. That vision turns into a nightmare when the doctor says there are some problems. What could the problems be?*¹⁵³

As genetic and reproductive technology advance, the boundaries of parental decision making will radically expand, challenging society to redefine traditional notions of reproduction and parenthood. For those parents whose children will inevitably experience debilitating disease, genetic intervention offers a compassionate means of preventing childhood suffering. The rapid augmentation in procreative ability, however, also creates the possibility of human engineering and abuse of genetic technology. The challenge, therefore, becomes devising a safeguard for disease prevention that excludes offensive and socially destructive genetic interventions. Fortunately for many parents and children, the mechanism for exclusively protecting disease prevention technology already exists.

151. This Note also advocates the broad right of pregnant women to abort for reasons other than fetal deformity. The topic of abortion, however, is not specifically addressed in this Note.

152. See *supra* notes 23 & 45.

153. Karen Hinderliter, *Death of a Dream*, EXCEPTIONAL PARENT, Jan./Feb. 1988, at 48.

American legal tradition has long recognized the right of parents to protect the bodily integrity of their children. The right manifests in the context of parental discretion in children's end-of-life care and inherently recognizes the capacity of parents to decide the best interests of their children. The right logically extends into the embryonic realm, compassionately preventing both the onset of childhood suffering, as well as the agonizing life or death decisions that some parents must make for their beloved children. The advent of the genetic revolution bestows parents with the extraordinary means to protect their children's bodily dignity at all stages of human development. The right of parents to prevent the needless suffering of their children is thoroughly grounded in traditional parental protections and deserves more prominent recognition as an effective and admirable way of safeguarding the best interests of both parents and their potential children.

