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## The Changing World of Genetics and Abortion: Why the Women's Movement Should Advocate for Limitations on the Right to Choose in the Area of Genetic Technology

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## THE CHANGING WORLD OF GENETICS AND ABORTION: WHY THE WOMEN'S MOVEMENT SHOULD ADVOCATE FOR LIMITATIONS ON THE RIGHT TO CHOOSE IN THE AREA OF GENETIC TECHNOLOGY

Advances in genetic technology provide an opportunity to control disease, extend life, and imbue one's offspring with intelligence, beauty and strength.<sup>1</sup> Advances in technology, however, also furnish a forum for mutant species and transformations of the human race.<sup>2</sup> With respect to genetic engineering and morality, the question is clear: which plan of society do we want to follow, that of nature or that of scientists?<sup>3</sup>

Many argue that by subordinating procreation to its producers, genetic fashioning will undermine marriage, parenthood, family, and respect for human life.<sup>4</sup> Developments in genetic engineering may push less fortunate individuals to the sidelines of society by elevating the definition of "normal" and "acceptable." As society focuses on improving the human race, compassion for the disabled may decrease to traumatic levels affording less appreciation for differences between individuals.<sup>5</sup>

From physicians to lawyers, the reaction to genetic engineering ethics, "genethics," is varied.<sup>6</sup> As the biologist Robert L. Sinsheimer stated:

We are among those who were favored in the chromosomal lottery and, in the nature of things, it will be our very conscious choice whether as a species we will continue to accept the innumerable, individual tragedies inherent in the outcome of this mindless, age-old throw of the dice, or instead will shoulder the responsibility for intelligent genetic intervention.<sup>7</sup>

Doctor Sinsheimer suggests that intelligent human intervention is the responsible reaction to breakthroughs in genetic engineering.

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1. See John R. Harding, Jr., Comment, *Beyond Abortion: Human Genetics and the New Eugenics*, 18 PEPP. L. REV. 471, 471 (1991); PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, *SPlicing LIFE* 42 (1982); Sharon Begley, *Outsmarting Your Genes, Be Young Forever*, NEWSWEEK, Jan. 7, 1991, at 49; E. Joshua Rosenkratz, *Custom Kids and the Moral Duty to Genetically Engineer Our Children*, 2 HIGH TECH. L.J. 1, 1 (1987).

2. See Harding, *supra* note 1, at 471.

3. See *id.*

4. See *id.* at 498.

5. See Harding, *supra* note 1, at 499.

6. See DAVID HEYD, *GENETHICS: MORAL ISSUES IN THE CREATION OF PEOPLE* 22 (1992).

7. Alexander Morgan Capron, *Which Ills To Bear?: Reevaluating the "Threat" of Modern Genetics*, 39 EMORY L.J. 665, 668 n.9 (1990).

Paul Freund, Professor of Law at Harvard University, embraces a different position. He argues that the unborn have a right to random genes.<sup>8</sup> Freund states, "The mystery of individual personality, resting on the chance combination of ancestral traits, is the basis of our sense of mutual compassion and at the same time, of accountability."<sup>9</sup> Professor Freund suggests that the ethical approach to advances in genetic technology allows the random assortment of genes to take effect, thereby protecting the sanctity of the human individual.

This paper's purpose is to provide a general overview of genetics, ethics, and the law, and to analyze what effect advances in genetic technologies will have on a woman's right to choose to have an abortion. Further, this paper proposes that the women's movement advocate limitations on abortion rights in order to prevent a backlash against a woman's right to choose.

Part One of this note introduces the history, vocabulary and public opinion on the intersection of a woman's right to choose and genetic pioneering. Part Two provides an introduction to the legal and ethical issues through a discussion of currently available genetic technology. Part Three discusses societal reactions to genetic advances, specifically addressing perceptions of the family, the individual, and women as a whole. Part Four discusses limitations on access to genetic technology and proposes that Rawls' theory of justice is the most applicable ethics theory for access to genetic technology.<sup>10</sup>

Part Five proposes that women's organizations take the lead in the legislative decision-making process, because reproductive choices affect the substance women's decisions as protectors of the home and their own bodies. This part also proposes that the women's movement work to limit access to available technology based on Rawls' theory of justice.<sup>11</sup> Part Six warns that if women's organizations do not direct the movement of reproductive choices, the medical and insurance communities will mark the route for reproductive protections. Part Seven discusses genetic regulation proposals by the executive branch and the medical community which already emulate Rawls' theory of justice. Part Eight analyzes the

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8. See Edward J. Larson, *Review Essay: Human Gene Therapy and the Law: An Introduction to the Literature*, 39 Emory L.J. 855, 861-62 (1990) (citing Paul Freund, *Xeroxing Human Beings*, in HUMAN GENETICS: READINGS ON THE IMPLICATIONS OF GENETIC ENGINEERING 233, 242 (T. Mertens ed., 1978)).

9. *Id.*

10. See JOHN RAWLS, *THEORY OF JUSTICE* (1971).

11. See *id.*

present reactions of state legislatures and the lessons to be learned from them. Part Nine advocates the use of the right of familiar attachment as a legal basis for implementing Rawls' theory of justice.<sup>12</sup> Finally, Part Ten contains draft legislation implementing Rawls' theory of justice.

It is the author's hope that the women's movement will advocate this type of model legislation to prevent a backlash against a woman's right to choose abortion. The author suggests that by defining limitations on women's reproductive choices, the women's movement will allow the judiciary to fully protect a woman's right to choose.

## I. BACKGROUND

### A. Definitions

The lack of precise definitions in the study of genetic engineering, ethics, and eugenics makes discussion of these topics difficult. "Ethics" has been described as "a generic term for several ways of examining the moral life."<sup>13</sup> Black's Law Dictionary defines ethics as the "treating of moral feelings, duties or conduct."<sup>14</sup> Genetic engineering refers to specific "techniques by which scientists can add genetically determined characteristics to cells that would not otherwise have possessed them."<sup>15</sup>

Eugenics has several definitions, including "good in birth"<sup>16</sup> and "a social movement to improve the human species through the use of technology."<sup>17</sup> Eugenics may be categorized as either negative or positive.<sup>18</sup> Negative eugenics seeks to diminish or expel undesired traits, thereby promoting advantageous or welcomed traits. Examples include laws forbidding incest and statutes requiring couples to be screened for genetic disease prior to marriage.<sup>19</sup> Positive

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12. *See id.*

13. TOM L. BEAUCHAMP & JAMES F. CHILDRESS, PRINCIPLES OF BIOMEDICAL ETHICS 9 (3d ed. 1989), cited in John C. Fletcher & Dorothy C. Wertz, *Ethics, Law, and Medical Genetics: After the Human Genome Is Mapped*, 39 EMORY L.J. 749 (1990).

14. BLACK'S LAW DICTIONARY 496 (5th ed. 1979).

15. PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, *supra* note 1, at 8.

16. Sheila Jasanoff, *Biology and the Bill of Rights: Can Science Reframe the Constitution?*, 13 AM. J.L. & MED. 249, 266 n.65 (1987).

17. Harding, *supra* note 1, at 477.

18. *See id.* at 478.

19. *See id.*

eugenics seeks to augment humans' biological capabilities.<sup>20</sup> Positive eugenics intensifies the natural unequal distribution of intrinsic ability.<sup>21</sup> The only forms of positive eugenics currently available are selective breeding and selective abortions.<sup>22</sup>

### B. *History of Genetics and Eugenics*

The term "eugenics" was coined in 1883 by Francis Dalton, Charles Darwin's cousin.<sup>23</sup> It was not until the second half of the twentieth century, however, that eugenics became a substantive societal issue. In 1952, frogs were cloned from tadpole cells, a breakthrough in animal cloning.<sup>24</sup> In 1978, Baby Louise became the first child conceived through in vitro fertilization.<sup>25</sup> Baby Louise represented a movement in genetics from animal experimentation to human manipulation. Only with the birth of Baby Louise did the interest in genetics become popular among the general population.

Starting in 1980, developments in genetic technology accelerated at a startling rate. In 1980, Dr. Martine Cline became the first scientist to use recombinant DNA techniques on human subjects.<sup>26</sup> Five years later, Ralph Brinster and his lab created the first transgenic<sup>27</sup> pig.<sup>28</sup> In 1993, a George Washington University embryologist cloned human embryos, but decided not to implant the embryos into a woman's uterus.<sup>29</sup> Most recently, Ian Wilmut and his colleagues at the Roslin Institute in Scotland cloned the first adult mammal, Dolly the sheep.<sup>30</sup>

### C. *Public Opinion*

Public opinion studies show material support for genetic screening and abortion of seriously genetically defective fetuses.

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20. See John B. Attanasio, *The Constitutionality of Regulating Human Genetic Engineering: Where Procreative Liberty and Equal Opportunity Collide*, 53 U. CHI. L. REV. 1274, 1277 (1986).

21. See Harding, *supra* note 1, at 478.

22. See *id.*

23. See Capron, *supra* note 7, at 666 n.5.

24. Sharon Begley, *Little Lamb, Who Made Thee?*, NEWSWEEK, Mar. 10, 1997, at 52, 52.

25. See *id.* at 55.

26. See Jasanoff, *supra* note 16, at 276.

27. See Begley, *supra* note 24, at 56 (A transgenic mammal is an animal with human genes in its DNA.).

28. See *id.*

29. See *id.* at 57.

30. See Tim Friend, *HELLO DOLLY! Breakthrough with Sheep Could Herald Human Cloning*, USA TODAY, Feb. 24, 1997, at 1, 1.

Between seventy-five and seventy-seven percent of persons in the United States support a woman's choice to have an abortion when a fetus has a significant genetic defect.<sup>31</sup> Opposition to abortion, however, increases as the seriousness of the genetic defect decreases.<sup>32</sup> In addition, eighty-nine percent of the American public approves of genetic screening for serious genetic defects.<sup>33</sup> The substantial public support for genetic screening and abortions for fetuses with serious genetic defects is paralleled in the scientific community.

#### *D. Opinion of the Scientific Community*

Generally, geneticists and the scientific community as a whole support a woman's right to choose abortion for fetuses with severe genetic defects. National surveys of geneticists establish common approaches to the protection of privacy and patient autonomy. 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.<sup>34</sup>

Geneticists worldwide, however, hesitate to commit to writing any ethical agreement regarding the use of genetic technology.<sup>35</sup> Reasons for the reluctance to commit to a written genetic code include: genetic advances arise too quickly to create a relevant ethical code; geneticists fear legal responsibility if they do not follow or update ethical codes as necessary; and geneticists are concerned that a majority will dominate a reasonable position of a minority.<sup>36</sup>

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31. See NATIONAL OPINION RESEARCH CENTER, UNIVERSITY OF CHICAGO, GENERAL SOCIAL SURVEYS, 1972-1987: CUMULATIVE CODEBOOK (1987), noted in Fletcher & Wertz, *supra* note 13, at 787 n.56. See also John A. Robertson, *Genetics and the Law: Procreative Liberty and Human Genetics*, 39 EMORY L.J. 697, 713 (1990).

32. See Robertson, *supra* note 31, at 711.

33. See OFFICE OF TECHNOLOGY ASSESSMENT, U.S. CONGRESS, NEW DEVELOPMENTS IN BIOTECHNOLOGY: PUBLIC PERCEPTIONS OF BIOTECHNOLOGY 74-75 (1987).

34. See John A. Robertson, *Embryos, Families, and Procreative Liberty: The Legal Structure of the New Reproduction*, 59 S. CAL. L. REV. 942, 973 (1986).

35. See Fletcher & Wertz, *supra* note 13, at 760.

36. See *id.*

*E. Assumption That Halting Developments in Genetic Technology Is Impossible*

This note presumes that thwarting advances in genetic technology is impossible. "The suppression of knowledge appears . . . unthinkable, not only on ideological, but on merely logical grounds. How can the ignorant know what they should not know?"<sup>37</sup>

Scientists, especially geneticists, do not forgo their scientific research without quarrel. For example, Mark H. Houghes, a Georgetown University geneticist, resigned this year as head of the Institute for Molecular and Human Genetics rather than give up his research on genetic screening.<sup>38</sup> Houghes' research enabled physicians to select, for in vitro fertilization implantation, genetically healthy embryos from a pool of embryos including diseased genes.<sup>39</sup> Houghes' experimentation violated a congressional ban on the use of federal funds for embryonic research.<sup>40</sup> Houghes, a renowned scientist, refused to give up his investigations stating, "This work is of crucial importance to me and, I believe to prospective parents around the world."<sup>41</sup>

In addition to scientists' unwillingness to give up their research, the judicial branch protects the scientific community's right to conduct research. The language of the First Amendment, which states that Congress shall make no law "abridging the freedom of speech or of the press" protects scientific research and communication.<sup>42</sup> The Supreme Court in 1980 held that genetically altered organisms could be patented.<sup>43</sup> In this decision, the Court espoused Thomas Jefferson's philosophy that "ingenuity should receive a liberal encouragement."<sup>44</sup>

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37. Joshua Lenderberg, *Orthobiosis: The Perfect Man*, in *THE PLACE OF VALUE IN A WORLD OF FACTS* 29, 54 (Arne Tiselius & Sam Nilsson eds., 1970), noted in Capron, *supra* note 7, at 667.

38. See Rick Weiss, *Controversial Geneticist Resigns from Georgetown*, WASH. POST, Feb. 4, 1997, at A3.

39. See *id.*

40. See *id.*

41. See *id.*

42. Jasanoff, *supra* note 16, at 282 (citing U.S. CONST. amend. I).

43. *Diamond v. Chakrabarty*, 447 U.S. 303, 308 (1980).

44. *Id.* at 308.

## II. INTRODUCTION TO THE ETHICAL AND LEGAL ISSUES THROUGH A DISCUSSION OF CURRENTLY AVAILABLE GENETIC TECHNOLOGY

### A. Sterilization

Sterilization prevents humans' reproductive ability by removing the sex organs or inhibiting their function.<sup>45</sup> Starting in the early 1900s, numerous states enacted legislation granting the state the power to sterilize certain classes of people such as the insane, the feeble-minded and the habitually criminal.<sup>46</sup>

In *Buck v. Bell*, the Supreme Court upheld a court order for the sterilization of a seventeen-year-old woman stating, "[t]hree generations of imbeciles are enough."<sup>47</sup> Although the concept of sterilization appears to invade personal liberty, the Court has never explicitly overruled *Buck v. Bell*.

The Court in *Skinner v. Oklahoma*, however, invalidated a state sterilization statute on equal protection grounds.<sup>48</sup> The state statute legalized sterilization for persons convicted three times of larceny. The statute, however, did not permit sterilization for white collar embezzlement crimes.<sup>49</sup> The Court held the sterilization statute unconstitutional because it treated people differently with respect to similar crimes. *Buck v. Bell* and *Skinner v. Oklahoma* illustrate how the case law on genetic technology is modest and unfulfilling.

Public welfare arguments swayed the Court in *Buck v. Bell*. Although the decision may be unjust due to personal liberty elements, the validity of the public welfare argument with regard to genetic engineering is still relevant. Individuals with serious genetic defects who choose to forgo sterilization or genetic manipulation, may place the cost of rearing their children on society.

### B. Artificial Insemination

#### 1. Surrogacy

Surrogacy is the introduction, by artificial insemination, of the sperm of a man (whose wife is usually infertile) into the uterus of

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45. See WEBSTER'S THIRD NEW INTERNATIONAL DICTIONARY 2238 (1986).

46. See Jasanoff, *supra* note 16, at 266.

47. *Buck v. Bell*, 274 U.S. 200, 207 (1927).

48. *Skinner v. Oklahoma ex rel. Williamson*, 316 U.S. 535, 538 (1942).

49. See *id.* at 539.



a third-party woman.<sup>50</sup> The third-party woman has agreed, often by contract, to bear the conceived child and then relinquish the child to the couple after birth.<sup>51</sup>

In the highly publicized *Baby M* case, the Supreme Court invalidated the surrogacy contract because it would deprive the "surrogate who voluntarily chooses to enter such a contract . . . of a constitutionally protected right to perform services."<sup>52</sup> The *Baby M* case exhibited a view of reproduction that was not based on the sanctity of family but rather on a contractual right. The *Baby M* case illustrates how genetic technology can disassociate childbirth from the family.

## 2. *Assisted Reproduction*

Assisted reproduction allows men who are infertile, because their sperm are not powerful enough to penetrate the women's egg, to reproduce.<sup>53</sup> In assisted reproduction, an individual sperm is injected directly into a woman's egg in a laboratory petri dish.<sup>54</sup> This relieves the sperm of the need to pursue and pierce the egg.<sup>55</sup>

Assisted reproduction raises the rate of inherited infertility among children of assisted reproduction<sup>56</sup> by transferring a genetic defect that would have been prevented by natural biological safeguards.<sup>57</sup> Assisted reproduction creates the alternate genetic problem of multiplying the infertility defect. The unnatural representation of infertility defects in the population created by assisted reproduction is one of the potential effects central to the geneticist's concerns with upsetting the genetic marketplace.

## C. *Genetic Screening*

Genetic screening provides couples who wish to procreate with information on the probability of an offspring having a certain

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50. See MICROSOFT ENCARTA 96 ENCYCLOPEDIA, *Parent and Child* (Microsoft Corp. 1993-95).

51. See *id.*

52. *In re Baby M*, 525 A.2d 1128, 1165 (N.J. Super. Ct. App. Div. 1987).

53. See Rick Weiss, *Fertilization Method Is Linked to Gene Defect*, WASH. POST, Feb. 20, 1997, at A20.

54. See *id.*

55. See *id.*

56. See *id.*

57. See *id.*

genetic defect. In the future, genetic screening may predict an offspring's performance.<sup>58</sup>

Genetic screening is useful to couples who want to have a child without a presently reconicable specific genetic defect. Parents, after learning that they are both carriers of a recessive genetic defect, may decide not to have children, to adopt, or to conceive through in vitro fertilization and screen embryos, or to abort affected fetuses.<sup>59</sup>

The right to genetic information will be an important and divisive subject for the legislative and judicial systems. The Supreme Court's precedents in the area of right to privacy have established a woman's right not to reproduce. If a woman has this right, then she should also have a right to information relevant to that decision.<sup>60</sup> As a limitation, however, a woman should not have a right to genetic information about her fetus if the mother is going to use the information to the fetus' detriment.

### III. SOCIETAL REACTIONS TO DEVELOPMENTS IN GENETIC TECHNOLOGY

#### A. *Genetic Advances and Perceptions of the Human Race*

Genetic pioneering concerns not only the procreative right to privacy, but also decisions that implicate what type of society humanity wants to create and inhabit.<sup>61</sup> With genetic manipulation, parents and physicians determine what permanent changes should be made to a fetus.<sup>62</sup> On the other hand, genetic advances allow a child to more easily achieve his or her life goals through enhanced intelligence, beauty, or strength.<sup>63</sup> In addition, genetic advances may increase an individual's aptitude and articulation skills, and thereby advance society through the discovery and communication made possible by this enlightened learning.<sup>64</sup>

Advances in genetic technology may also bolster the perception that humans are more alike than they are different. "Genetics, by illuminating the ways in which the line of difference between [normality and abnormality] may be nothing more than the rearrange-

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58. See Harding, *supra* note 1, at 476.

59. See Robertson, *supra* note 31, at 698.

60. See *id.* at 699.

61. See Attanasio, *supra* note 20, at 1288.

62. See *id.* at 1291.

63. See *id.* at 1292.

64. See *id.*

ment of a single DNA base-pair (out of the billions in every cell), may make abnormalities less strange and 'different.'<sup>65</sup> Genetics has the potential to be a strong equalizer by allowing individuals to understand that they suffer from many handicaps and diseases because of their genetic makeup.<sup>66</sup> As all humans have between five and seven lethal recessive genes,<sup>67</sup> more knowledge about these lethal genes may equalize individuals' perceptions of each other.

### *B. Genetic Advances and the Family*

As genetic technology advances, it will call into question many of society's views of family life. What it means to be a "good parent," "defective," or "normal" will be altered by the ability to treat genetic diseases prenatally.<sup>68</sup> The union between man and woman may no longer be a physical act but rather a decision to go to a geneticist or obstetrician. Breakthroughs in genetic technology could effect the relationship between men and women and their decision to procreate. Reproduction will no longer require physical sex. Instead, the joining of pre-selected eggs and sperm and the placement of those cells in a woman's uterus will represent reproduction. Thus, reproduction could be partly externalized — taken away from the bedroom and placed in a petri dish.

In addition, parents could so drastically change their children's DNA makeup that both parents may feel psychological dissociation from the child. Also, if parents ask third-parties to introduce genetic material into the child there will be further confusion in the definition of parents.<sup>69</sup>

Still, it is questionable whether a large dissociation will truly occur among love, reproduction, and the family. Parents of adopted children feel emotionally attached to their children even though they do not share the same DNA. Furthermore, it is unlikely that growth of a fetus will occur outside of a woman's womb. Therefore, women will still be emotionally and physically involved in the birth of their genetically created or altered children.

Genetic manipulation will have effects beyond our generation. Parents' choices with regard to genetic technology for their children have repercussions beyond the death of both the parents and the

65. Capron, *supra* note 7, at 694.

66. See Fletcher & Wertz, *supra* note 13, at 757.

67. See Kristie A. Deyerle, *Genetic Testing in the Workplace*, 18 COMP. LAB. L. 547, 551 (1997).

68. Capron, *supra* note 7, at 677 n.28.

69. See Robertson, *supra* note 34, at 953.

children.<sup>70</sup> There is nothing more intimate to a parent's decision to reproduce "than how he or she chooses to influence the trajectory of his or her descendants."<sup>71</sup> Therefore, to avoid drastic transformations of the human race, efforts should be made to ensure that changes in genetic makeup occur at a moderate rate.

### C. *Genetic Advances and the Individual*

The relative sanctity of the human individual decreases as genetic technology advances. The inviolability of embryos is, for the most part, due to their individual and irreplaceable nature. As genetic manipulation becomes feasible, however, the genetic makeup of offspring can be altered to make fetuses more like something else. Once science is able to change or adjust the genetic makeup of the fetus, reconstructing and refining may become the emphasis of reproduction. Transforming and modifying genetic makeup does not correlate with respecting individuality. The consideration of genetic makeup when making reproductive decisions suggests that the value of an individual is not based on their intrinsic worth, but instead is dependent on their genetic makeup.<sup>72</sup> Human dignity is compromised when individuals know that they are the product of genetic manipulation.<sup>73</sup>

As genetic technology develops, the inalienability of the human person is questioned. The marketing of human organs and tissue, and the growing practice of surrogacy for revenue serve to challenge the concept of the inalienability of the human body.<sup>74</sup> Such a concept exists to prevent individuals from entering a financial market, based on supply and demand, for fetuses and human tissue. In addition, inalienability protects the integrity of the individual.<sup>75</sup> By ending slavery society renounced the concept of the alienability of the human person, but practices such as the sale of human organs and surrogacy could lead again to human alienability.<sup>76</sup> Although autopsies, vaccinations and transplants question the basic integrity of human identities, there has been no

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70. See Owen D. Jones, *Reproductive Autonomy and Evolutionary Biology: A Regulatory Framework for Trait-Selection Technologies*, 19 AM. J.L. & MED. 187, 208 (1993).

71. *Id.* at 210.

72. See Robertson, *supra* note 31, at 697 n.2.

73. See Attanasio, *supra* note 20, at 1296.

74. See Bartha M. Knoppers & Sonia LeBris, *Recent Advances in Medically Assisted Conception: Legal, Ethical and Social Issues*, 17 AM. J.L. & MED. 329, 356 (1991).

75. See *id.* at 358.

76. See *id.* at 353.

dramatic change in the inalienability rights of the individual.<sup>77</sup> Although protecting the inalienability right of the individual is important, one may argue that respect for human inalienability is so inherent that advances in genetic technology that simply increase a women's opportunities to have a healthy offspring do not compromise that right.

#### *D. Genetic Advances and Women*

Genetic technology will allow older women to have healthy offspring, thereby eliminating one of women's greatest problems with aging. As technology increases, the age of a mother will become less relevant to the health of the fetus. There will be less of a correlation between increased age and decreased offspring capability. Thirty-five will no longer be considered too old for a woman to have children.

Genetic technology may also allow women to separate themselves from the stereotypes of baby machines and child-rearers.<sup>78</sup> It also possible that women will be separated from their special role in society, resulting from their unique role in reproduction and birth. As genetic technology improves and reproduction is severed from sexuality, there is the threat that women may lose some of their reproductive freedom if the judiciary associates reproduction with genetics rather than the family. Although this possibility is remote, women's organizations should work to ensure that a woman's right to choose is protected. It is women, not men, who will carry and give birth to children. Women's organizations therefore must ensure that women's reproductive choices are not subject to the reproductive goals of obstetricians and geneticists.

### IV. ACCESS TO GENETIC TECHNOLOGY

#### *A. Limitations on Access to Genetic Technology and Relevant Ethics Theories*

Using genetic technology or eliciting genetic information is expensive, which limits access to these procedures. Parents with a high socio-economic status have easier access to genetic technology. For example, women in higher socio-economic strata have greater

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77. *See id.*

78. *See Robertson, supra note 34, at 954.*

access to amniocentesis.<sup>79</sup> This is true even in Canada, where there is no direct charge for genetic screening.<sup>80</sup>

At one end of the access spectrum, the United States is a country based on equal opportunity, attempting to ensure that valuable genetic information is available to all. At the other end of the spectrum, this is a country based on a capital market theory, encouraging those with means to acquire genetic technology and information. The United States is part of the worldwide economic contest, and it is necessary for this country to keep up with every form of technology, including genetic, in order to maintain its dominance.<sup>81</sup>

The question becomes, where on the spectrum should access to genetic technology lie? In the past, biomedical ethics has emphasized individual rather than communal benefits. Individual good, however, does not equate with common good.<sup>82</sup> In contrast to biomedical ethics, Utilitarianism embraces the concept that net suffering and unhappiness should be minimized while inherent net pleasure and comfort should be maximized. Distribution of advantages should optimize the total amount of good and satisfaction.

Countering Utilitarianism is Rawls' theory of justice which proposes that inherent differences in individuals should be utilized for the benefit of all.<sup>83</sup> Opportunities should be distributed to the least advantaged, to the extent that the benefits of the advantaged are not decreased to a level that prevents the advantaged from providing benefits for all.<sup>84</sup> Applying Rawls' theory to genetic engineering, genetic technology opportunities should be available to individuals with severe genetic diseases.<sup>85</sup> Providing opportunities for genetic improvement to the least advantaged prevents the spread of many serious genetic defects and provides justice by granting all individuals an equal opportunity in life. Ultimately, application of Rawls' theory creates an equal starting block for future generations.<sup>86</sup>

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79. See Harding, *supra* note 1, at 487.

80. See Abby Lippman, *The Human Genome Initiative and the Impact of Genetic Testing and Screening Technologies: Prenatal Genetic Testing and Screening: Constructing Needs and Reinforcing Inequities*, 17 AM. J.L. & MED. 15, 42 (1991).

81. See Harding, *supra* note 1, at 511.

82. See Lippman, *supra* note 80, at 47.

83. See RAWLS, *supra* note 10, at 83-95.

84. See *id.*

85. See *id.*

86. See *id.*

*B. Rawls' Theory of Justice: The Most Applicable Ethics Theory for Access to Genetic Technology and Information*

Rawls' theory of justice is the most applicable ethics theory for access to genetic technology and information. By limiting the genetic opportunities of the more genetically advantaged, Rawls' theory addresses societal fears of creation of a master race.<sup>87</sup> Rawls' theory allows only those most needy to acquire the help they require; it provides the option closest to equal opportunity. In addition, it decreases aggregate costs by emphasizing common good rather than benefits.

Finally, Rawls' theory respects human dignity.<sup>88</sup> It attempts to improve those considered below normal human capacity rather than attempting to improve the human species as a whole.<sup>89</sup> Rawls' theory of justice addresses the problem of disrespect for the human individual.<sup>90</sup> If genetic manipulation is practiced only on individuals that would benefit the most, the sanctity of the individual should not decrease. In the future, individuals who know that they avoided, with the help of genetic technology, a serious genetic disease such as Down's Syndrome, will not feel their human dignity was compromised. Creating a genetic remedy for serious human diseases does not sacrifice human dignity but rather respects it by allowing individuals to achieve their potential with an equal opportunity. Rawls' theory of justice does not create a setting where imperfect will be defined as anything that has yet to be diagnosed or changed.<sup>91</sup>

## V. WHY AND HOW WOMEN'S ORGANIZATIONS SHOULD BE INVOLVED IN THE DECISION MAKING PROCESS

As genetic engineering begins effecting the society in which we live, women's organizations should lead the decision-making and legislation-creating processes. By defining the limitations to be set on reproductive choices, women's organizations can intercept a backlash against abortion rights.<sup>92</sup>

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87. *See id.*

88. *See id.*

89. *See id.*

90. *See id.*

91. *But see* Lippman, *supra* note 80, at 22 (describing the commodification of life and making "blue ribbon" babies).

92. *See generally* NEAL DEVINS, *SHAPING CONSTITUTIONAL VALUES* 3, 62 (1996) (arguing that the strength of the pro-life movement is, to a large extent, a backlash reaction to *Roe v. Wade*).

### A. *Advocacy by Women's Organizations for Rawls' Theory*

Women's organizations should advocate Rawls' theory of justice to protect reproductive rights as they relate to developments in genetic technology. Genetic engineering legislation should follow Rawls' theory of justice so that those most in need, and those that can provide the most benefit to society, receive the benefits of genetic technology. In the aggregate, this should decrease the total financial cost to society as individuals who would have otherwise drained resources may instead contribute to the financial market. There will be a societal investment in providing these individuals with genetic technology. On balance, this investment will benefit society. Therefore, women's organizations should encourage legislatures to create statutes that exemplify Rawls' theory of justice. As a result, a woman's reproductive choice would be limited where the genetic engineering technique she desires does not benefit society as a whole.<sup>93</sup>

### B. *Decision-Making Control*

To protect the sanctity of the parental family, gamete suppliers should have the principal decision-making power over the future of their DNA.<sup>94</sup> By making gamete providers the principal decision makers, society protects individuals' rights to control their family and the destiny of their offspring. Designating gamete providers as the protected decision makers places paternal and maternal rights on equal ground, ensuring the protection of a father's right to control the creation of his descendants with his biological makeup.

Women should continue to have protected rights as the fetus carrier. A woman carrying the child of her spouse should have rights that supersede her husband's in making decisions about the future of their unborn child. In a surrogate mother situation, however, the gametic parents should have equal rights with respect to one another in protecting the future of their child. The gametic parents' rights should, however, dominate the rights of the surrogate mother. The rights of the fetus carrier are therefore a type of "bonus" rights. Therefore, if the mother is the gametic parent and the fetus carrier, then she should have rights that supersede the gametic father. If the fetus carrier is not the gametic parent,

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93. *But see infra* Part X (noting an exception).

94. *See* Robertson, *supra* note 34, at 976.



however, then her rights should be subject to those of the gametic parents.

## VI. THE INFLUENCE OF THE MEDICAL AND INSURANCE COMMUNITIES AND THEIR REPERCUSSIONS

### A. *The Medical Community*

Obstetricians, both individually and as a group, play a large role in the exercise of a woman's right to choose. Obstetricians and geneticists may also have a large influence on a woman's decisions relating to her fetus' genetic health. For example, physicians often advise patients on the health of an unborn child.<sup>95</sup> This leads to the possibility that physicians will determine the definition of "genetic health."<sup>96</sup>

Physicians' influence on women's reproductive rights is evident in other areas. For example, "the availability of amniocentesis 'influenced legislation so that the upper limit of gestational age for legally tolerated termination of pregnancy was adjusted to the requirements of second trimester prenatal diagnosis in several countries.' Evidently, geneticists can accomplish what women's groups cannot: a revisioning of abortion."<sup>97</sup>

Geneticists' organizations, not women's organizations, have prepared for the issues surrounding both a woman's right to choose and advances in genetic technology. The American Society of Human Genetics has proposed as model legislation the following restrictions on abortion:

Any pregnant female whose pregnancy has not reached the point of viability and who has been informed by a licensed or certified health care professional that her fetus (or fetuses) is/are likely to have a serious genetic or congenital disorder shall have the right, among other options, to choose to terminate her pregnancy. This right shall extend to situations where the female is at significantly increased risk for bearing a child with a serious disorder for which precise prenatal diagnosis is not available.<sup>98</sup>

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95. See Lippman, *supra* note 80, at 34.

96. See *id.* at 47.

97. See *id.* at 34 n.86 (citations omitted).

98. See *id.* at 35 n.91 (citations omitted).

### B. *The Insurance Community*

Insurance companies play a large role in women's reproductive choices. Genetic screening of phenylketonuria (PKU) suggests that the insurance community has already dominated women's reproductive choices. In forty-six states insurance providers do not provide coverage for women who have knowledge of a PKU fetus and do not abort. Even so, newborn screening for PKU is carried out in the United States with universal approval.<sup>99</sup>

As with geneticists, insurance companies have already stated their position on reproductive choices and advances in genetic technology. In January of 1990, the American Council for Life Insurance and the Health Insurance Association of America convened the Task Force on Genetic Screening.<sup>100</sup> The Task Force recommendation stated that genetic information is "as potentially relevant to risk classification as any other medical information" and that the industry should "aggressively defend the need to have access to and to consider any relevant health information for underwriting purposes, including genetic information."<sup>101</sup>

### C. *The Repercussions*

There are many repercussions when physicians have such a large role in reproductive choices. Physicians must create an equilibrium between the principles of autonomy and the duty of beneficence.<sup>102</sup>

The physician-patient relationship is traditionally a personal one, with the objective being to maintain the health of the individual. Genetics, as a clinical discipline, adds another dimension to this traditional responsibility: the ability to predict, intervene, and prevent heritable disorders not only in the individual, but in the patient's nuclear and extended family as well.<sup>103</sup>

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99. See *id.* at 35.

100. See Philip R. Reilly, *Biomedical Technology, Ethics, Public Policy, and the Law: Public Policy and Legal Issues Raised by Advances in Genetic Screening and Testing*, 27 SUFFOLK U. L. REV. 1327, 1354 (1993) (citing AMERICAN COUNCIL OF LIFE INSURANCE, SUBCOMMITTEE ON PRIVACY LEGISLATION, GENETIC TEST INFORMATION AND INSURANCE: CONFIDENTIALITY CONCERNS AND RECOMMENDATIONS 3 (1992)).

101. *Id.*

102. See Louis J. Elsas II, *A Clinical Approach to Legal and Ethical Problems in Human Genetics*, 39 EMORY L.J. 811, 815 (1990).

103. *Id.* at 818.

While physicians concern themselves with questions of beneficence and autonomy with regard to individual genetic care, legislatures and policy-makers concern themselves with questions of public reaction, justice, and utilitarian ethics.<sup>104</sup> To ensure the application of Rawls' theory of justice in the legislature, the women's movement must set the ball in motion.

#### VII. RAWL'S THEORY OF JUSTICE: THE MEDICAL COMMUNITY'S AND THE EXECUTIVE BRANCH'S PROPOSALS

Organizations within the United States differ in their proposals for genetic regulation. Similarities in the proposals, however, can be summarized as an acceptance of Rawls' theory of justice. Most organizations have come to some agreement that advancements in genetic technology should benefit those most in need; genetic screening, therefore, should be limited to detecting only virulent genetic diseases. Medical organizations, such as the National Institute of Health (NIH), suggest screening for highly detrimental diseases. NIH has suggested population-based screening for carriers of cystic fibrosis if a ninety-five percent level of carrier detection becomes possible and "substantial educational and counseling guidelines could be satisfied."<sup>105</sup> In 1975, the National Academy of Sciences concluded that the only permissible objectives for genetic screening programs were for health and the study of human distinctions.<sup>106</sup>

At least one organization in the United States has determined that a woman's right to reproductive choices should always be protected. In 1975, the Committee on Inborn Errors in Metabolism, as part of the National Academy of Sciences, concluded that the privacy right should be the governing factor in all decisions, not secondary to other interests.

In 1983, President Bush created the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. The Commission formulated the following principles of genetic screening

1. The disorder should be of high burden to the affected individual.

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104. *See id.* at 837.

105. Robertson, *supra* note 31, at 70 (citing *Statement From the National Institutes of Health Workshop on Population Screening for Cystic Fibrosis Gene*, 323 NEW ENG. J. MED. 70 (1990)).

106. *See Jasanoff, supra* note 16, at 258.

2. The inheritance and pathogenesis of the disorder should be understood.
3. The disorder should be preventable and practical therapy available, including genetic counseling and reproductive alternatives.
4. Patient's right to informed consent, voluntary participation, and confidentiality should be protected.
5. The benefit to cost ratio to the patient (public) should be greater than one.
6. The laboratory screening method should minimize false positive and exclude all false negative results.
7. A diagnostic test should be available.
8. Both screening and diagnostic tests should be available to all who require it.<sup>107</sup>

The Commission reflects Rawls' theory of justice by emphasizing the highly detrimental effect of the disease, while balancing the cost-benefit ratio to society. The successor to the President's Commission was the Biomedical Ethics Advisory Committee (BEAC). It was to discuss the issues of genetic alteration and the definition of human nature, but abortion politics deadlocked the Congressional Biomedical Ethics Board to which the BEAC reports.<sup>108</sup>

#### VIII. THE PRESENT REACTION OF STATE LEGISLATURES AND THE LESSONS TO BE LEARNED FOR FUTURE LEGISLATION

State legislatures have already enacted statutes to prevent genetic procedures from inducing abortions.<sup>109</sup> For example, Pennsylvania recently passed a statute that reads:

Any person who knowingly performs any type of nontherapeutic experimentation or nontherapeutic medical procedure . . . upon any unborn child or upon any child born alive during the course of an abortion, commits a felony of the third degree. "Nontherapeutic" means that which is not intended to preserve the life or health of the child upon whom it is performed.<sup>110</sup>

The state of Illinois had a similar statute which stated: "No person shall sell or experiment upon a fetus produced by the fertilization of a human ovum by a human sperm unless such

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107. Elsas, *supra* note 102, at 838 (citations omitted).

108. See Capron, *supra* note 7, at 677.

109. See Neil Davis, *The Constitutionality of Fetal Experimentation Statutes: The Case of Lifchez v. Hartigan*, 25 J. HEALTH & HOSP. L. 37 (1992).

110. 18 PA. CONS. STAT. § 3216 (1991), *cited in* Davis, *supra* note 109, at 43 n.4.

experimentation is therapeutic to the fetus thereby produced."<sup>111</sup> The Supreme Court of Illinois, in *Lifchez v. Hartigan*, overturned the statute on vagueness and reproductive privacy grounds.<sup>112</sup> The court held that the statute unconstitutionally restrained the fundamental right to privacy by denying a woman's right to make reproductive choices free from governmental interference.<sup>113</sup> The language of *Lifchez* appears to legalize any genetic technique relating to a woman's decision to abort within the first trimester.<sup>114</sup> The broad holding may even permit genetic practices such as sex selection and recombinant DNA research involving hybrid species.<sup>115</sup> Women's groups need to respond to this type of judicial interpretation.

A second lesson may be learned from the *Lifchez* decision. A statute regulating genetic screening must thoughtfully characterize the terms "nontherapeutic" and "experimentation" in order to withstand a constitutional vagueness challenge.<sup>116</sup>

Although the protection of reproductive choices by the judicial branch is a tremendous accomplishment for the women's movement, this progress must be protected. To prevent a backlash, women's organizations should fight for limited legislative restraints on a woman's right to choose in the area of genetic technology. Women would be protecting their role as parental and family decision-makers while still defending their fundamental right to choose.

## IX. THE REACTION OF THE JUDICIARY

### A. *Limited Reproductive Choices in the Legislature Would Allow the Judiciary To Protect a Woman's Right To Choose*

Women's organizations should encourage the legislature to put limited restrictions on a woman's right to choose in the area of genetic technology. This will allow the judicial branch to fully protect a woman's right to choose to have a child with a randomly selected genetic pool. The right to be born with a "sound mind and

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111. 720 ILL. COMP. STAT. ANN. 510/6-7 (West 1998).

112. *Lifchez v. Hartigan*, 735 F. Supp. 1361 (N.D. Ill. 1990).

113. See Davis, *supra* note 109, at 37 (citing *Lifchez*, 735 F. Supp. at 1376).

114. See *id.* at 41.

115. See *id.*

116. Vicki G. Norton, *Unnatural Selection: Nontherapeutic Preimplantation Genetic Screening and Proposed Regulation*, 41 UCLA L. REV. 1581, 1616 (1994).

body" would protect offspring from unnecessarily enduring avoidable genetic defects.<sup>117</sup>

### B. *The Right to Familial Attachment*

Lois Shepard, in her article *Protecting Parents' Freedom To Have Children with Genetic Differences*, proposes a right of familial attachment as an appropriate judicial standard regarding a woman's right to choose the genetic makeup of her child.<sup>118</sup> The right of familial attachment allows parents to make decisions regarding the genetic makeup of their children as long as the parents' relationship with the offspring is not adversarial.<sup>119</sup> Parents would be permitted to modify their offspring's genetic makeup to create more opportunities for the child. In contrast, if a parent did not have the right of familial attachment, offspring would have a cause of action against his or her parents if they did not participate in genetic screening or manipulation to prevent certain unwanted traits.

The courts would find an exception to the right of familial attachment when a parent had an adversarial intent for the child. Shepard's proposal has strong validity in light of the language used by some courts in defining the right to begin life with a "sound mind and body."<sup>120</sup> For example, the Michigan Supreme Court has stated,

[A] child has a legal right to begin life with a sound mind and body. If the wrongful conduct of another interferes with that right, and it can be established by competent proof that there is a causal connection between the wrongful interference and the harm suffered by the child when born, damages for such harm should be recoverable by the child.<sup>121</sup>

Similarly, in *Grodin v. Grodin*, the court determined that a parent could be liable for failure to seek prenatal care when the failure was unreasonable in relationship to the magnitude of the risk created.<sup>122</sup> Shepard's proposal would allow parents to bring

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117. *Womack v. Buckthorn*, 187 N.W.2d 218, 222 (Mich. 1971).

118. See Lois Shepard, *Protecting Parents' Freedom To Have Children with Genetic Differences*, 1995 U. ILL. L. REV. 761, 768 (1995).

119. See *id.*

120. *Womack*, 187 N.W.2d at 222.

121. *Id.*

122. See *Grodin v. Grodin*, 301 N.W.2d 869 (Mich. Ct. App. 1980). In this case the mother had failed to tell her physician she was taking tetracycline which caused discoloration of her child's teeth. See *id.* But see *Ellis v. Target Stores*, 842 F. Supp. 465, 470 (S.D. Mich. 1993) (holding that the emphasis should not be on the reasonableness of the parent's conduct, but

children into the world with naturally selected genetic differences by insuring that offspring would not have a cause of action against their parents. Parents should be unburdened in their decision to reproduce, without mandated interference of genetic screening or manipulation.<sup>123</sup> If offspring with naturally selected genes have a cause of action against their parents for imperfect mind or body, this will surely inhibit parents' ability to forgo genetic screening or operations.

As the Human Genome Project identifies the genes responsible for genetic abnormalities, screening tests for multiple defects could become routine and therefore increase parents' possible liability if the right to familial attachment is not adopted by the court system.<sup>124</sup> In addition, a sound mind and body standard would encourage the perception that naturally selected characteristics are less valued than genetically engineered characteristics.<sup>125</sup> Furthermore, a sound mind and body standard would encourage parents to abort natural selection genetics.

The right of familial attachment is also necessary to protect the ability of physicians to deliver appropriate medical care to pregnant women. In *Reed v. Campagnolo*, the Maryland Court of Appeals found a cause of action for wrongful birth against a physician who failed to inform parents about the existence of, or need for, a genetic screening test.<sup>126</sup> Because of the decision in *Reed*, physicians may fear liability and will hesitate to allow parents to forgo genetic screening or operations. Physicians may provide patients with overwhelming information on the importance of genetic testing and screening to avoid failure to inform liability.<sup>127</sup> Even without physicians trying to prevent liability, obstetricians' promotion of genetic screening itself effects the decision making of parents. When physicians "off[er] carrier screening to assist couples in making reproductive decisions [it] is not a neutral activity but, rather, implies that some action should be taken on the basis of the result of the test."<sup>128</sup>

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if the acts were unreasonable whether the parents be shielded from liability).

123. See Shepard, *supra* note 118, at 771.

124. See *id.* at 775.

125. See *id.* at 781.

126. See *Reed v. Campagnolo*, 630 A.2d 1145, 1152, 1154 (Md. 1993).

127. See Shepard, *supra* note 118, at 776.

128. Sherman Elias & George J. Annas, *Genetic Consent for Genetic Screening*, 330 NEW ENG. J. MED. 1611, 1613 (1994).

## X. DRAFT LEGISLATION

The women's movement should pilot model legislation limiting a woman's right to choose in relation to advances in genetic technology. The following paragraphs contain the author's proposed draft legislation relating to a woman's right to choose in the area of genetic technology:

### § 1 - Definitions

a. "Adversarial" means a relationship in which the mother is hostile to the interests of the child.

b. "Eugenics" means improving the qualities of the human race; or a general desire to encourage the reproduction of favorable traits; or a desire to prevent the reproduction of inferior or undesirable traits. "Eugenics" does not include abortions of fetuses with severe genetic defects.

c. "Fetus" means the product of conception from the time of conception until the expulsion or extraction of the fetus or the opening of the uterine cavity, but shall not include the placenta, extraembryonic membranes, [or] umbilical cord . . . ."<sup>129</sup>

d. "Genetic engineering" means any biomedical modification of a fetus' DNA. "Genetic engineering" does not include diagnostic testing, treatment, therapy or related procedures conducted by formal protocols deemed necessary for the health of the mother. "Genetic engineering" shall not include human in vitro fertilization performed to treat infertility.

e. "In vitro fertilization" means any fertilization of human ova which occurs outside the body of a female, either through a mixture of donor sperm and ova or by any other means.<sup>130</sup>

f. "Severe genetic defects" means a fetus who at birth would have one of the following syndromes: Down's Syndrome, Martin Bell Syndrome, Prader-Willi Syndrome, Angelman Syndrome, Rett Syndrome, Gaucher, Tay-Sachs Disease, Niemann-Pick Disease, Sandhoff Disease, Krabbe Disease, Sly Syndrome, Batten Disease, Canavan's Disease and any other disorder with a large error in genetic material.<sup>131</sup> The definition of "severe genetic defect" should be modified by the legislature every five years in order to assure adequate protection for parents in regard to advances in genetic technology.

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129. N.M. STAT. ANN. § 24-9A-1(G) (Michie 1998).

130. See *id.* § 24-9A-1(K).

131. See, KAREN BELLENIR, GENETIC DISORDER SOURCEBOOK v-vi (1996).



## § 2 - Protection of Decisions To Undergo Genetic Engineering

a. A women's choice not to undergo genetic engineering of her fetus for any reason is fully protected. This includes situations where the fetus has severe genetic defects.

b. A limited exception occurs when the fetus' and mother's relationship is adversarial and the fetus has a serious genetic defect. In this limited situation, the offspring may have a common law cause of action.

c. A woman's choice to undergo genetic engineering for her fetus is protected only in situations where the fetus suffers from a severe genetic defect.

## § 3 - Protection of Abortion Decisions

a. No physician may stipulate that a woman must abort in the event her pregnancy should produce a child with a severe genetic defect, or for any other reason.

b. A woman may abort a fetus for any reason, unless the women's primary motivation is eugenics.

### Comments:

## § 3 - Protection of Abortion Decisions

The eugenics exception is applicable to situations where by clear and convincing evidence it is determined that the mother's sole motivation for the abortion is eugenics. The legislature does not foresee a situation where § 3(b) would be applicable unless the woman declared the motivation for abortion as eugenic.

## XI. CONCLUSION

By limiting the right to choose in the area of genetic technology, women will protect their position both as protectors of bodily integrity and family decision makers. If women's organizations do not take action regarding this issue, decisions about reproductive choices and genetic developments will be left in the hands of physicians, geneticists, and a predominantly male Congress. Alternatively, the judiciary may react to reproductive choices in a manner that limits women's freedom and opportunities.

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