

## **APPROPRIATE AIMS: SETTING BOUNDARIES FOR REPROGENETIC TECHNOLOGY**

*Not too long ago, ten fingers and ten toes defined a successful birth. Not too far from now, ten fingers and ten toes will be just the beginning. Parents always hope for a healthy baby, and medical advances continue to help secure the fulfillment of this hope. But rerogenetics, a new combination of technology and science that allows us to choose the genes, and thus the traits, of the children we create, is raising new questions about what it means to have a healthy baby.*

Reprogenetics is a hybrid technology combining reproductive and genetic sciences that has opened the door to new reproductive possibilities. The reproductive technology component, in vitro fertilization, allows a physician to combine egg and sperm in a lab and implant the fertilized egg into the uterus to be carried to term. Using this technique, it is possible for physicians to modify the fertilized egg before implantation. On the scientific front, advances in genetic science have enabled scientists to correlate genes to their resultant traits. By selectively altering genes, physicians would selectively alter traits. With these two tools, rerogenetics makes possible the genetic modification of embryos before implantation.

As the scientific community deepens its understanding of rerogenetics, the rest of the world must wrestle with issues raised by this advance in technology. The following iBrief addresses whether prenatal screening (screening embryos before implantation) is a constitutional exercise of procreative liberty. In contrast to extremist views advocating that prenatal screening should be absolutely permitted or prohibited, this iBrief advocates creating a division among selective traits. The line most consistent with the interests protected by the right to procreate allows preimplantation genetic screening only for traits that substantially affect the responsibilities associated with child rearing.

### **Procreative Liberty and Parental Interests**

The legal analysis of rerogenetics begins with a definition of the right to procreate. At the most basic level, the right to procreate protects a person's right to choose whether or not to have children. The activity of having children has been construed broadly to include choices both before and after conception. In *Griswold v. Connecticut*, the Supreme Court recognized a pre-conception right to procreate by holding that parents may prevent conception through the use of a contraceptive device.<sup>1</sup> The Supreme Court recognized a post-conception right to procreate in *Roe v. Wade* by affirming the right of a

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<sup>1</sup> *Griswold v. Connecticut*, 381 U.S. 479, 499 (1965).

mother to terminate a pregnancy.<sup>2</sup> This entire bundle of rights, from the decision to create an embryo to the decision to create a child, is gathered under the heading of procreative liberty.

That many diverse activities constitute procreative rights leads to a key concept. The right to procreate—the right to decide whether or not to have children—involves parental interests that extend beyond pregnancy. These relevant parental interests are grouped collectively under the right to procreate because they cannot be cleanly separated. In other words, although pre- and post-conception activities can be logistically severed, the parental interests involved in creating an embryo are inextricably linked to the parental interests involved in creating a child. For instance, we protect decisions about whether or not to create an embryo in part because of the ultimate consequence of bringing a child into the world. Conversely, we protect decisions about whether or not to bring a child into this world in part because it deals with the intimate (marital) act of conception. In short, pre- and post-conception interests interrelate with one another. The validity of a new procreative activity implicates this entire bundle of parental interests.

An examination of the parental interests at stake, although seemingly intuitive, deserves elaboration. In one of the earliest procreative liberty cases, Justice Douglas describes procreation as “one of the basic civil rights of man.”<sup>3</sup> Parents have an interest in procreative liberty because reproduction is an essential human function. Reproduction is an essential life function because it is intimately associated with marriage, family, and parenthood. Through these powerful associations, reproduction shapes the way we experience life.

The basis of the legal argument to follow is that the association of reproduction to parenthood forms the foundation of procreative interests. In other words, the decision about whether or not to procreate is most strongly attached to the decision about whether or not to become a parent. To be sure, pregnancy and giving birth are meaningful, life-altering events. However, parenting, the sustained event of raising a child, is certainly even more meaningful and life-altering. Raising a child, more than creating an embryo, changes the way in which we perceive our life experience. Raising a child, more than giving birth, is an event by which we define ourselves. A mere reproductive experience, one that does not involve rearing, “is not a protected aspect of procreative liberty because it is insufficiently involved with the values and interests that make procreation valuable to us.”<sup>4</sup> In short, the commitment to raise a child embodies the most important interest at stake in the decision to procreate.

Consequently, the parental interest of child rearing should be at the forefront of any procreative liberty discussion. The importance of child rearing provides both support and structure for the right to

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<sup>2</sup> *Roe v. Wade*, 410 U.S. 113, 163 (1973).

<sup>3</sup> *Skinner v. Oklahoma*, 316 U.S. 535, 541 (1942).

procreate. The right to procreate does not extend limitlessly to cover any procreative activity. Instead, the right to procreate should be carefully limited in scope to protect procreative activities that further the most important interest at stake, the parental interest of child rearing.

### **Balancing Parental and Prenatal Interests**

After clarifying the definition and underlying interests of the right to procreate, one can explore the constitutional boundaries of this right. Considering the importance of procreative liberty, it is preferable to err on the side of freedom rather than government interference. John A. Robertson, a prolific author on the subject of rerogenetics, advocates an uninhibited right to procreate. However, his rationale for an unlimited view of procreative liberty possesses at least one crucial flaw.

Robertson supports the right to perform preimplantation screening of embryos based on any criteria because post-implantation screening, i.e. abortion, may be based on any criteria.<sup>5</sup> In other words, because a person may abort an embryo for any reason, a person may prenatally select or deselect traits for any reason. Robertson's argument rests on this supposition that abortion and preimplantation genetic screening are simply two sides of the same coin. He explains: "[The woman's] right to avoid reproduction for any reason would entitle her to avoid reproduction for a particular reason. Similarly, her right to have offspring generally should entitle her to have offspring only if she thinks that offspring will have particular characteristics."<sup>6</sup> Robertson's view on procreative liberty rests on this faulty abortion analogy.

Selection by abortion and selection by preimplantation genetic screening are legally distinguishable. The right to abortion as enunciated in *Roe v. Wade* does not create a precedent broad enough to cover preimplantation screening. Justice Blackmun's opinion in favor of the right to abort does not rest on a broad, overarching right to procreate. Instead, Blackmun's conclusion resulted from examining the delicate balance between conflicting state interests.<sup>7</sup> First, the Court considers the state's "definite interest in protecting the woman's own health and safety."<sup>8</sup> The interests at stake in *Roe v. Wade* "are not based solely upon procreative liberty but also upon rules of personal autonomy and bodily integrity."<sup>9</sup> Next, these parental interests are weighed against the state's interest "in protecting prenatal

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<sup>4</sup> John A. Robertson, *Symposium on John A. Robertson's Children of Choice: Liberalism and the Limits of Procreative Liberty: A Response to my Critics*, 52 WASH. & LEE L. REV. 233, 243 (1995).

<sup>5</sup> John A. Robertson, *Genetic Selection of Offspring Characteristics*, 76 B.U.L. REV. 421, 427 (1996).

<sup>6</sup> *Id.*

<sup>7</sup> *Roe*, 410 U.S. at 149-50.

<sup>8</sup> *Id.* at 150.

<sup>9</sup> Thomas Stuart Paterson, *The Outer Limits of Human Genetic Engineering: A Constitutional Examination of Parents' Procreative Liberty to Genetically Enhance Their Offspring*, 26 HASTINGS CONST. L.Q. 913, 928 (1999).

life.”<sup>10</sup> In the case of abortion, the bundle of parental rights at stake—procreative liberty, personal autonomy, and bodily integrity—outweigh the state’s interest in protecting prenatal life.

The balancing test shifts, however, when the facts change from abortion to preimplantation genetic screening. For the case of preimplantation screening, many of the parental interests at stake in abortion disappear. Paterson explains: “In the genetic engineering scenario, bodily integrity plays absolutely no role. The personal autonomy of the woman will not be affected by inability to genetically engineer her children. Thus, much of the rationale behind the decisions in *Roe* and *Casey*<sup>11</sup> fails to support Robertson’s assertion.”<sup>12</sup> Without these additional factors, the constitutional validity of preimplantation genetic screening hinges on the balance between the remaining interests, the parents’ interest in procreative liberty and the state’s interest in protecting prenatal life. By analyzing the relative strength of these interests, we can predict how courts would hold on the issue under current legislation.

The difficulty in analyzing the relative strengths of the relevant interests arises because these interests are at least highly disputable if not downright indeterminable. What are the interests of an unborn child? Despite the vastly differentiated opinions about prenatal life, at least one definitive fact surfaces: prenatal life has some legal interests. For example, criminal law and inheritance law recognize the interests of even a pre-viable fetus by protecting against physical and economic injury, respectively.<sup>13</sup> With respect to reprobogenetics, prenatal interests may be slight, but surely they weigh more than nothing.

The parental interest in procreative liberty has been elaborated previously in the context of defining the right to procreate. In short, procreative liberty is considered an important right primarily because of the parental interest in child rearing. This interpretation enables a definite, articulated interest to support the intuitive, presumptive importance of the right to procreate. Although procreative liberty may defend a broad range of activities, from creation of an embryo to creation of a child, all of these activities fall under the category of entering parenthood. The interest at the heart of procreative liberty then, is the interest at the heart of parenthood—child rearing.

Thus, the balancing test for the constitutionality of reprobogenetics should weigh the concrete, substantial parental interest in child rearing against the prenatal interest, which can be only vaguely described as non-negligible. Under current law, courts will likely allow the use of reprobogenetic technology in so far as it furthers the parental interest of child rearing. Note that this prediction comes with a qualification which sets an important boundary for the use of reprobogenetic technology. The unlimited use of reprobogenetic technology as advocated by Robertson relies too heavily on the undeniable

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<sup>10</sup> *Roe*, 410 U.S. at 150.

<sup>11</sup> *Planned Parenthood of Southeastern Pennsylvania v. Casey*, 505 U.S. 833 (1992).

<sup>12</sup> Paterson, *supra* note 9, at 928.

<sup>13</sup> Paterson, *supra* note 9, at 931-32.

proposition that “[d]rawing the line between protected and unprotected traits and methods is likely to be difficult.”<sup>14</sup> More specifically, Robertson posits that any such line would be too subjective.<sup>15</sup> One can draw a line more easily and objectively by looking less at the interests of individual parents and more at the overarching parental interest of child rearing.

### **The Parental Interest in Child Rearing: the Pre- and Post-Natal Distinction**

The coupling of procreative liberty with child rearing interests brings up another legal analogy. A strong argument in favor of unlimited access to reprogenetic technology stems from the right of parents to mold their child through child rearing decisions.<sup>16</sup> Courts have consistently reserved deference to parental child rearing and education decisions.<sup>17</sup> In other words:

If special tutors and camps, training programs, even the administration of growth hormone to add a few inches to height are within parental rearing discretion, why should genetic interventions to enhance normal offspring traits be any less legitimate? As long as they are safe, effective, and likely to benefit offspring, they would no more impermissibly objectify or commodify offspring than postnatal efforts do.<sup>18</sup>

The distinction between pre- and post-natal molding of offspring really has to do with the distinction between nature and nurture. “In deciding whether who we are as persons is derived from either nature or nurture, ‘a wealth of new research has tipped the scales overwhelmingly toward nature.’”<sup>19</sup> In support of nature playing a dominant role, studies show uncanny similarities between identical twins who have been raised separately, but whose genetic make-up is identical.<sup>20</sup> Despite the uncomfortable implication that a nature-based determinism might have on our sense of free will and autonomy, one cannot ignore the powerful way genes impact identity. For this reason, pre- and post-natal molding of offspring should be considered legally distinct. Unlike educational or other rearing decisions, prenatal genetic screening makes a much more permanent mark on offspring. Additionally, a prenatal genetic change not only alters the current offspring, but also “forever alters future generations.”<sup>21</sup> Even before the current state of scientific knowledge, courts acknowledged the way in which reproductive

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<sup>14</sup> *Genetic Selection of Offspring Characteristics*, *supra* note 5, at 431.

<sup>15</sup> *Id.* at 432.

<sup>16</sup> Paterson, *supra* note 9, at 929-30. See also *Genetic Selection of Offspring Characteristics*, *supra* note 4, at 436.

<sup>17</sup> See *Roe*, 410 U.S. at 153 (citing *Pierce v. Society of Sisters*, 268 U.S. 510, 535 (1925) and *Meyer v. Nebraska*, 262 U.S. 390, 399 (1923)).

<sup>18</sup> Paterson, *supra* note 9, at 930.

<sup>19</sup> Paterson, *supra* note 9, at 920-21 quoting George Howe Colt, *Were you Born That Way?*, LIFE, Apr. 1, 1998, at 40.

<sup>20</sup> Paterson, *supra* note 9, at 921.

<sup>21</sup> *Id.* at 916, quoting Larry Thompson, *Poll Finds Support for Use of Gene Therapy*, WASH. POST, Sept. 25, 1990, at Z9.

choices “may have subtle, far-reaching and devastating effects.”<sup>22</sup> The permanency of the largely unknown (and perhaps unknowable) consequences of rerogenetic choices differentiates them from post-natal rearing choices. Therefore, although the parental interest of child rearing forms the basic structure for rerogenetic choice, it should not be afforded the same leeway as other post-natal child rearing decisions.

### **Examples and Explanations**

In sum, a line that allows preimplantation genetic screening only for traits that substantially alter the responsibilities associated with child rearing is most consistent with the interests protected by the right to procreate. In the next portion, this test will be fleshed out through an exploration of several scenarios posed by Robertson.<sup>23</sup>

### **Avoidance of Offspring with Disability**

Preventing offspring with a severe genetic disability presents the most compelling case. The results under the proposed test vary depending on the particular disease at issue. For the most severe cases, prenatal genetic screening would certainly be allowed. Thus, parents could screen to prevent a disease like Tay Sachs, which causes serious medical problems and fatality in infancy.<sup>24</sup> Without a doubt, the effects of Tay Sachs substantially affect the responsibilities associated with child rearing in terms of both financial and emotional commitment. The test is appropriately flexible to allow screening for less severe, but similarly compelling cases. For example, cystic fibrosis and Down’s syndrome greatly increase the parental responsibilities associated with child rearing although they may not produce childhood fatality.

Of course, the “substantially affects” aspect of this test creates some uncertainty. What about “genetically-based illnesses, like phenylketonuria, which can cause severe mental retardation but that doctors can treat by special diets and constant monitoring of offspring”?<sup>25</sup> Or how would the test stand on a genetic trait such as attention deficit disorder (ADD) which may require diagnostic expenses, medication, and extra emotional investment? In my opinion, parents should not be allowed to screen against these traits because the type of commitment involved seems more akin to average child rearing responsibilities. Many children require special diets due to lactose intolerance or allergies. Parents and schools often modify the educational setting to accommodate learning disabled or gifted children. Thus, these traits do not substantially affect the child rearing commitment. The test does occasionally require

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<sup>22</sup> Skinner, *supra* note 3, at 541.

<sup>23</sup> See *Genetic Selection of Offspring Characteristics*, *supra* note 5, at 432-36.

<sup>24</sup> See NEIL A. CAMPBELL, *BIOLOGY* 254 (4th ed. 1996).

<sup>25</sup> *Genetic Selection of Offspring Characteristics*, *supra* note 5, at 432-33.

subjective judgment; it is not a bright line test. Nevertheless, drawing a line that becomes blurred in borderline cases should not deter courts from drawing the line at all.

### **Late-Onset Genetic Disease and Susceptibility Traits**

Parents may want to screen against late-onset traits such as Huntington's disease, Alzheimer's disease, or breast cancer susceptibility. Under the child rearing criterion, parents would be prohibited from using reprogenetic technology to select against these diseases. By definition, the additional responsibilities associated with the care of people with late-onset genetic disease arise only later in life. Such additional responsibilities, then, do not substantially affect the legal responsibility of child rearing. Often, parents view the commitment to their children as a lifelong one. However, the legal duty of parents to care for children ends with childhood.<sup>26</sup> To oppose such a heavy-handed application of the test in the face of such compelling human interest, one may argue to reject the strictly legal sense of child rearing duties. By adopting the view that child rearing responsibilities are indefinite, courts might allow screening to prevent late-onset genetic diseases.

Screening for susceptibility traits causes additional concerns. Some traits directly correlate to a particular gene. Others, like breast cancer, are extremely intricate and involve many different genetic and non-genetic factors. Because the long-term effects of tinkering with genes are largely unknown, parents and physicians should approach this technology with caution to avoid unpredictable and undesirable effects.<sup>27</sup>

### **Gender Selection**

Because the gender of a child does not substantially affect child rearing responsibilities, gender selection should be prohibited. The straightforward case of gender selection presents difficulty when gender is used as "a proxy for severe disease."<sup>28</sup> For example, X-linked genetic diseases, such as hemophilia and Duchenne's muscular dystrophy, affect only males while female offspring would be asymptomatic carriers.<sup>29</sup> Instead of choosing to directly manipulate the genome, parents might instead wish to select for a female child. The use of gender selection for these purposes, if allowed at all, should only be used to prevent diseases that parents could directly screen out. Because the use of this indirect screening technique is consistent with the interests at the heart of procreative liberty, the use of gender selection in this limited context would probably be permitted. Although this exception to the general rule against gender selection creates some possibility for abuse, the potential for abuse is limited by the

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<sup>26</sup> Irwin J. Schiffres and Wanda Ellen Wakefield, 23 Am. Jur. 2d *Desertion and Nonsupport* §51 (2000).

<sup>27</sup> See Paterson, *supra* note 9, at 917-18.

<sup>28</sup> *Genetic Selection of Offspring Characteristics*, *supra* note 5, at 434.

<sup>29</sup> *Id.* at n.51.

relatively small number of parents affected and outweighed by the direct implication of child rearing interests.

### **Non-medical traits**

In general, no non-medical trait presents a convincing argument for substantially affecting child rearing responsibilities. The non-medical traits that Robertson had in mind include “hair or eye color, length of nose, intelligence, or sexual preference.”<sup>30</sup> One might argue that drastic differences in IQ require additional parental resources. Another might cite evidence that raising a homosexual child in today’s climate requires an increased commitment. These arguments creatively stretch the limits of the substantial effects test. Keeping in mind the most compelling case for reprobogenetics, Tay Sachs disease and the like, IQ or homosexuality seem unlikely candidates for acceptable criteria. Avoiding severe diseases constitutes a compelling objective for reprobogenetics. Pursuit of the perfect baby through nontherapeutic genetic enhancement does not.

Furthermore, non-medical traits are often multifactorial, meaning that they require the expression of multiple genes.<sup>31</sup> Because non-medical traits often result from the effects of multiple genes plus environmental factors, selecting for these traits is not yet technically possible.<sup>32</sup> As opposed to suggesting that science will never make selection of non-medical traits possible, let me suggest this. Indirect correlation of gene expression and trait expression invites scientists to creatively strengthen the link, especially for traits surrounded by intense social opinion. For example, in the 1920’s, courts hid behind science to achieve political objectives. The science of inheritable traits legitimized the sterilization of the less privileged.<sup>33</sup> Many look back with shame and disbelief at how easily principals can be swayed by questionable science.

When genes and traits do not correlate directly, opportunity for shoddy science arises. However, when the complicated correlation involves traits that invoke strong public opinion, the opportunity for shoddy science abounds. Before grasping at tenuous links between genes and non-medical traits, it is important to remember that science is often wrong in hindsight. Thus, selection for non-medical traits should be prohibited first because only weak arguments exist to support a substantial effect on child rearing and second because of the increased likelihood of shoddy science.

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<sup>30</sup> *Genetic Selection of Offspring Characteristics*, *supra* note 5, at 434.

<sup>31</sup> *Id.* at 436.

<sup>32</sup> *Id.*

<sup>33</sup> Paul A. Lombardo, *Medicine, Eugenics, and the Supreme Court: From Coercive Sterilization to Reproductive Freedom*, 13 J. CONTEMP. HEALTH L. & POL’Y 1, 6-7 (1996). *See also* *Buck v. Bell*, 274 U.S. 200 (1927).

## **Intentional Diminishment**

Instead of attempting to genetically enhance a child, some couples have strong feelings about intentionally altering “a child who would otherwise have been born with normal capacities.”<sup>34</sup> For example, a deaf couple may hope for a deaf child in accordance with a firm belief that deafness initiates membership to a valuable community as opposed to viewing deafness as a disability.<sup>35</sup> At first blush, the use of reprogenetic technology for intentional diminishment seems permissible under the proposed test. However, a closer look at the test and its objectives rules out intentional diminishment as an acceptable use.

To be sure, whether a child has congenital deafness substantially affects child rearing responsibilities. Accordingly, if parents wanted to use reprogenetic selection to prevent congenital deafness, such a use seems to fit squarely within the articulated limits of procreative liberty. Why then, when parents want to use the same selection criterion to produce the opposite result do we instinctively hesitate to protect procreative liberty? The answer lies in the implicit intention of the substantially affects test. Thus far, the test has been applied unilaterally. The phrase “substantially affects” has been equivalent to “substantially increase” the responsibilities of child rearing. For most cases, the distinction is irrelevant. For intentional diminishment, the distinction becomes determinative.

Consistently interpreting the test unilaterally furthers the foremost objective of reprogenetics: to help parents have healthy children. The objective should be appropriately limited by discerning the precise parental interest at stake, child rearing. However, the objective should not be directly subverted in such a way that contradicts generally accepted principles about the aims of healthcare. The test serves to increase objectivity in defining acceptable uses of reprogenetic technology. In this way, the test caters to the conceptual parental interests at stake rather than the interests of particular parents.

## **Conclusion**

Reprogenetic technology brings a world of opportunity within our grasp. Like any other extraordinary power, the power to manipulate genes comes with responsibilities and temptations. As individuals, the most delectable temptation, the pursuit of perfection, may prove irresistible. Using a more detached perspective, the legislature and courts must guide the use of reprogenetic technology toward appropriate objectives. To define appropriate objectives, one should look beyond the general importance of procreative liberty. Rather, one should look to the specific parental interest of child rearing, the interest that makes procreation essential to the human experience.

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<sup>34</sup> *Genetic Selection of Offspring Characteristics*, *supra* note 5, at 437.

<sup>35</sup> Liza Mundy, *A World of Their Own*, WASH. POST, Mar. 27, 2002, at W22.