

# Punishing Reproductive Choices in the Name of Liberal Genetics

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When the four American moral philosophers who individually have already made the most significant contributions to the ethical analysis of contemporary health care and medicine collaborate, it should come as no surprise that their joint effort is a lucid and powerful analysis of the principles that a just and humane society would employ in setting policies about how the new tools of molecular genetics should be used for human betterment. In *From Chance to Choice: Genetics and Justice*,<sup>1</sup> Allen Buchanan, Dan W. Brock, Norman Daniels, and Daniel Wikler aimed to steer a middle course between two extreme models. The first model is what they termed the public health model, which measures good in terms of improving the genetic health of society.<sup>2</sup> The second model is the personal services model, which measures good in the satisfaction of individual choices.<sup>3</sup> Although the public health model led to the racist and classist eugenics that marred the Progressive Movement in the United States in the early decades of the twentieth century and then culminated in the crimes of Nazism,<sup>4</sup> the reaction to those excesses created the present devotion to “nondirective genetic counseling” that produces excesses of personal autonomy.<sup>5</sup> According to this excess of

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1. ALLEN BUCHANAN ET AL., *FROM CHANCE TO CHOICE: GENETICS AND JUSTICE* (2000).

2. *Id.* at 11.

3. *Id.* at 12.

4. *See id.* at 30–40.

5. Nondirective genetic counseling is an educational process. The patient or

personal autonomy, all choices are equally legitimate, without regard for justice or equality, and are no different than choices about any goods purchased in a marketplace.<sup>6</sup>

In place of these extremes, the authors argued for a system of ethical principles to guide both individuals and institutions, thereby avoiding what they rightly described as ad hoc solutions to new developments.<sup>7</sup> Not surprisingly, much of their effort went into carefully defining terms and making the distinctions necessary for clear analysis, and I admire the care with which they built their arguments, principally in spelling out the implications of different concepts of justice for genetic interventions.<sup>8</sup> When it comes to applying their moral reasoning to social policies, however, I am not persuaded by the authors' conclusions on several points, in part because they have not made all of the necessary distinctions. To explore this issue, this Essay will focus on the authors' arguments about reproductive freedom in chapter 6 that further illustrate the virtues as well as the limitations of their book. This Essay focuses on the connections the authors made between moral principles and policy conclusions and, more generally, the civil, criminal, and regulatory law through which policy is given effect.

The authors made three moves to begin their discussion of reproductive freedom. First, the authors focussed on "issues raised by interventions to prevent genetically transmitted harms."<sup>9</sup> Second, they examined "the moral importance of reproductive freedom" rather than attempting to construct a moral *right* to reproductive freedom "in order to avoid the diversion of having to develop and defend a theory of moral rights."<sup>10</sup> Because the authors were later willing to reason from moral interests to

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family is provided with the facts about the problem, such as diagnosis, prognosis, and identification of family members at risk. The goal of self-determination is advanced from the start, and clients are encouraged to make their own choices without influence from the counselor's personal value system. Ruth L. Silverberg & Lynn Godmilow, *The Process of Genetic Counseling*, in COUNSELING IN GENETICS 283-84 (Y. Edward Hsia et al. eds., 1979).

6. BUCHANAN ET AL., *supra* note 1, at 13.

7. *Id.* at 13-14.

8. Though careful, the work is not free of errors. For example, the authors stated that the Human Genome Project seeks to determine the sequence of three *million* base pairs, *Id.* at 5, although three *billion* is more accurate. Mark S. Boguski, *Hunting for Genes in Computer Data Bases (Molecular Medicine)*, 333 NEW ENG. J. MED. 645, 648 (1995). The authors also derived a homozygous rate for hereditary hemochromatosis of 4:1000 from a carrier rate of 1:10. BUCHANAN ET AL., *supra* note 1, at 8. Actually, when one person in ten is heterozygous, the result is one homozygote per 400 births, while 4:1000 implies a carrier rate of 1:8. Lastly, the authors called Huntington's disease by the outdated term "Huntington's chorea," *Id.* at 230, which only refers to one distinctive symptom of the disease. Joseph B. Martin & James F. Gusella, *Huntington's Disease: Pathogenesis and Management*, 315 NEW ENG. J. MED. 1267, 1267 (1986).

9. BUCHANAN ET AL., *supra* note 1, at 206.

10. *Id.* at 207.

legal rights and obligations, their reluctance to develop a full-blown theory of moral rights does not impede their conclusions. Third, the authors applied the conventional distinction between negative and positive freedoms to the reproductive sphere.<sup>11</sup> Though the authors suggested that such freedoms are usually correlative,<sup>12</sup> they argued that sometimes it may be wrong to interfere with a negative component of reproductive freedom, such as preventing an individual from accessing relevant genetic information, without it also being wrong to fail to enable the individual to obtain such information.<sup>13</sup>

This framework of analysis seems entirely justifiable, but it leaves one basic issue unexplored: does reproductive freedom attach to people as individuals or only as part of a pair? The authors appear at odds with themselves on this point. For example, the first component of reproductive freedom is “uncoerced choice about whether to procreate at all, or, more precisely, whether to participate in procreative activity with a willing partner.”<sup>14</sup> It seems that individuals have what might be termed an incomplete freedom, while the complete version of reproductive freedom attaches only to male and female pairs.<sup>15</sup> That is, individuals have a reproductive interest both in not being deprived of whatever ability they possess to procreate and in having access to the information needed to exercise that ability in an informed fashion, such as by obtaining accurate results of genetic tests. However, this version of reproductive freedom is incomplete because it does not include any moral claim on being able to reproduce in the absence of agreement of another individual who also possesses the same freedom. Two conclusions follow from this distinction. First, individuals do not have a claim, either in positive or negative terms, to become biological parents in the absence of a willing partner. This amounts to a strong reading of what the authors meant when they wrote about what is more precisely

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11. *Id.* at 208.

12. *Id.*

13. An example would come about when “some very expensive genetic intervention” is of too great cost and too limited benefit to justify making it “available at public expense to anyone who wants it.” *Id.*

14. *Id.* at 209.

15. Two clarifications may be in order. First, this premise has no implication regarding individuals’ ability to become or to function as parents outside of a male and female pair (parenting not being the same as reproducing). Second, this premise is based on existing methods of human reproduction, which are all sexual, whatever the future possibilities of asexual reproduction.

involved in reproductive freedom.<sup>16</sup> Second, reproductive freedom entails the full and continuing exercise of choice by both members of the pair to reproduce, so that the present unwillingness or inability of either individual to consent removes the mantle of reproductive freedom from the act of the other. Examples of this include a woman seeking to have sperm extracted from the testes of her recently deceased fiancé who never expressed the desire for her to become pregnant by him posthumously, and a man seeking access to frozen embryos created with gametes from himself and his ex-wife who does not want to have children by him.

In some ways, this insistence on the nature of reproductive freedom is perhaps more central to the authors' discussion of genetic enhancement in chapter 7 because this view provides a means of drawing a line between actions that are within parents' reproductive freedom and those that fall outside that realm. Yet it is also useful to begin by locating reproductive freedom within this dyadic model because doing so serves as a reminder that we are not dealing with the fulfillment of a single individual's wishes, but rather with a project that involves accommodation of another person's wishes. Of course, the choices made by the couple may still be portrayed, as the authors suggest, as embodying a radical, even market-oriented, version of autonomy.<sup>17</sup> However, as I will further explore in a moment, if we move from abstractions to the world of actual decisions, made by human beings in relationship to other human beings, the reality of negotiation with, and even deference to, the wishes and needs of another person that characterize most real exercises of reproductive choice is much more complex than the language of autonomy might imply. This Essay does not mean in the least to denigrate the authors' fine statement of the range of choices encompassed within reproductive freedom<sup>18</sup> or their catalogue of the interests and values that determine the moral importance of reproductive freedom.<sup>19</sup> Yet the latter, which are framed in individualist terms, take on a somewhat different cast if they are read through the dyadic lenses here proposed. In other words, while we can regard things such as the choice to have or to not have children in purely individualistic terms, most reproductive decisions, and *all* those that involve creating children as opposed to avoiding them, involve two people in some relationship to

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16. BUCHANAN ET AL., *supra* note 1, at 209.

17. *Id.* at 13.

18. These choices include whether to procreate, with whom, by what means, when to procreate, how many children to have, what kind of children to have, and whether to have biologically related children. *Id.* at 209–11. It is surprising, however, to see “access to new reproductive techniques,” with no qualification of which techniques might be encompassed, simply assumed to be part of “procreative activity with a willing partner,” without discussion or justification. *Id.* at 209.

19. *Id.* at 214–22.

each other and to their joint *project* in which the most extreme forms of individualism are inevitably mitigated.<sup>20</sup> For example, a woman achieving pregnancy through artificial insemination with sperm from an anonymous, yet still consenting, man would be an extreme form of individualism, but mitigated by the fact that consent from the donor was still achieved in some way.

This real world context is vitally important in analyzing the major effort that the authors undertook in chapter 5, namely to construct a basis for overriding the reproductive choices of parents that would otherwise produce children whose lives would be overwhelmingly burdened by a genetic condition.<sup>21</sup> The case that the authors made for preventing the occurrence of these conditions is a powerful one. It is pleasing to find that their philosophical dissection of the so-called wrongful life cases supports the criticism that I have raised to judicial refusal to allow such suits by children against physicians or other healthcare providers whose wrongful failure to provide necessary information to parents resulted in the children being born with serious genetic diseases.<sup>22</sup> Courts and commentators objecting to such suits have argued that wrongs may not occur before a legal person exists,<sup>23</sup> that the genetic condition was inherent in the child's existence,<sup>24</sup> or that harm cannot be measured in terms of the diminution from a normal condition that the child would otherwise have enjoyed.<sup>25</sup> The authors demonstrated that none of these

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20. Of course, in some cases the relationship itself is attenuated, and certain acts of reproduction in this context have a large measure of singular individualism about them, such as a single individual attempting to have a child without seeking approval from someone of the opposite sex, for example, a single woman using a sperm bank.

21. BUCHANAN ET AL., *supra* note 1, at 181–96.

22. Alexander Morgan Capron, *Informed Decisionmaking in Genetic Counseling: A Dissent to the "Wrongful Life" Debate*, 48 IND. L.J. 581 (1973) (arguing that in genetic counseling, the parents have a legal right to be fully informed decisionmakers about whether to have a child; and, likewise, the genetic counselor has the duty to convey to those he advises a clear and comprehensible picture of the options open to them, the relative risks and benefits, and the foreseeable consequences of each one); Alexander Morgan Capron, *Tort Liability in Genetic Counseling*, 79 COLUM. L. REV. 618 (1979) (highlighting early uncertainty in the field of genetic counseling, and the resulting legal liabilities the job entails).

23. BUCHANAN ET AL., *supra* note 1, at 236.

24. *Gleitman v. Cosgrove*, 227 A.2d 689, 692 (N.J. 1967) (stating that for purposes of measuring damages, the plaintiff is required to say not that he should have been born without defects but rather that he should not have been born at all); *see also* BUCHANAN ET AL., *supra* note 1, at 236.

25. *Wilson v. Kuenzi*, 751 S.W.2d 741, 743 (Mo. 1988) (denying the plaintiff's claims because of difficulties in calculating damages created by the necessity of comparing

objections stand in the way of a coherent statement that the child has suffered a moral wrong.<sup>26</sup>

However, it is at this point that I disagree with the authors' conclusion that parents, rather than only healthcare professionals, can be held liable for such a wrong.<sup>27</sup> The authors seemed concerned with preventing harm, which implies some sort of injunctive measure. Such a measure would apparently include a temporary or even permanent prevention of conception, or abortion of an existing, affected fetus.<sup>28</sup> The authors recognized that another way to achieve the desired result would be, as in child abuse laws, to threaten to punish violations criminally.<sup>29</sup> If this were allowed, the lesser punishment of civil suits for damages would also appear legitimate. Thus, the reader may be excused a sense of amazement when, after all this hinting that their development of a moral right is intended to buttress public policy, the authors suddenly proclaimed: "[w]rongful life conceptions are sufficiently uncommon, and practical and moral difficulties in using the coercive power of government to prevent them sufficiently great, to rule out policies that prevent people from conceiving wrongful lives. Coercive government intrusion into reproductive freedom to prevent wrongful life would be wrong."<sup>30</sup> Frankly, it is not clear from this statement whether the authors meant to allow after-the-fact remedies which stop short of forced sterilization or abortion. Fines and civil damages can, after all, be conceived as placing a price on certain choices without necessarily coercing people into behaving differently. Or perhaps, having seen where their moral arguments would take them, the authors wished suddenly to abandon what otherwise seems to be an exercise in practical, as opposed to purely abstract, philosophy. Whichever reading is correct, this Essay will now expand on why the authors were right to conclude that the law ought not to treat parental choices to give birth to a child with a genetic problem as the basis for either criminal or civil action.<sup>31</sup> Additionally, this Essay expands upon why this conclusion casts doubt on the authors' underlying conclusion that parents who go forward with

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impaired life with nonexistence); *see also* BUCHANAN ET AL., *supra* note 1, at 234.

26. BUCHANAN ET AL., *supra* note 1, at 226–56.

27. *Id.* at 237.

28. The authors stated that it would be “virtually never morally justified,” which assumably means that it would be justified in extreme cases. *Id.* at 241. From the viewpoint of public acceptance, forced abortion seems no more likely, however, than the alternative that the authors find morally preferable, “withholding life support even over [the child’s] parents’ objections,” though they do recognize that it would not conceivably be acceptable as a matter of policy. *Id.*

29. *Id.* at 237, 240.

30. *Id.* at 242.

31. *Id.*

reproduction under these circumstances have committed something that the rest of us should label a moral wrong.<sup>32</sup>

There are at least four reasons for doubting the conclusion that parents commit a moral wrong in these circumstances. First, the category of harms is too ill-defined. The authors distinguished conditions that make life not worth living, which they called wrongful life, from those that burden life but do not outweigh its worth, which they called wrongful disability.<sup>33</sup> The imprecision of this distinction is a fatal defect. The authors' application of non-person-affecting principles<sup>34</sup> led them to conclude that the child born with wrongful disabilities has not been harmed, even if it is wrong for the parent to have produced that child.<sup>35</sup> Plainly, in both criminal and civil terms, the consequences of these two wrongs would be very different. In these circumstances, it is not enough simply to admit that there is no precise line for what counts as a burden that is morally wrong to impose. Indeed, the very examples that the authors use, Lesch-Nyhan disease and Tay-Sachs disease, demonstrate this point.<sup>36</sup> While the self-mutilation involved in Lesch-Nyhan disease seems Jobian in its horror, the lack of awareness of self-suffering that seems to characterize the neurological collapse of infants affected by Tay-Sachs disease would lead many people to say that the latter is a condition that is nearly unbearable for the child's parents rather than for the child.

Second, while chapter 2 of the book makes clear the dangers of eugenics,<sup>37</sup> the whole decision to set up a category of genetic conditions as special instances of parental wrongdoing singles out genetics and

32. *Id.* at 237.

33. *Id.* at 225.

34. *See id.* at 227.

35. *Id.* at 226 (claiming that in wrongful disability cases, while standard accounts of harm cannot be applied, those accounts can be revised or extended to fit the circumstances of wrongful disabilities; and that wrongful disability cases do in fact constitute serious moral wrongs).

36. *Id.* at 233. *See generally* William L. Nyhan & Dean F. Wong, *New Approaches to Understanding Lesch-Nyhan Disease*, 334 *NEW ENG. J. MED.* 1602, 1603 (1996) ("The neurological features of Lesch-Nyhan disease include delayed motor development, severe spasticity, opisthotonos, and choreic, athetoid, or dystonic movements. The characteristic behavior is . . . aggressive, compulsive, and self-injurious. In these patients, the most typical feature is loss of tissue from biting themselves, even though they are not insensitive to pain."); *ATTORNEYS' TEXTBOOK OF MEDICINE* ¶ 17.21(3) (Roscoe N. Gray & Louise J. Gordy eds., 3d. ed. 2002) (Stating that symptoms of Tay-Sachs disease "begin in infancy and include hypotonia, progressive loss of vision, loss of interest in surroundings, and loss of attained milestones, with death occurring at about the age of 4").

37. *See* BUCHANAN ET AL., *supra* note 1, at 30–40.

opens the backdoor to eugenic reasoning. If we are really concerned with harms to children, then focusing solely on genetic harms would seem merely precious if it did not also amount to a diversion from what ought to be our greater concern—harms that are not prevented because of parental ignorance or lack of access to basic healthcare services. The simple picture of cause and effect that makes genetic diseases so easy to understand<sup>38</sup> also makes genetic diseases easier to deal with as a policy matter than the complex relationship between living conditions, nutrition, education, and other aspects of the welfare of prospective parents and the health status of their offspring.

Third, the authors acknowledged that most prospective parents who are provided with information about either their own genetic risks in reproducing or a serious genetic condition affecting their fetus would want to act in the best interests of their future child.<sup>39</sup> Having said this, the authors then aimed their critique at the hypothetical parents who “evidence little concern for their children’s well-being”<sup>40</sup> and give birth to children with very serious burdens.<sup>41</sup> Think for a moment, however, about this issue the authors raise. Unless the discussion has been arbitrarily confined to people who act while they are decisionally impaired, we would, in the model of nondirective counseling of which the authors are so critical,<sup>42</sup> be talking about people who decided to go ahead with a pregnancy having been informed about everything their genetic advisors could tell them concerning the probability of harm, the nature of the harm, the degree of the harm, and the degree to which the harm could be remediated after birth. If the parents proceeded, it would seem to me that, rather than label them moral wrongdoers, it is more reasonable to describe them as people who give different weights to the factors involved. These could include people who regard the life as one that may be severely disabled, in the way the authors use the term,<sup>43</sup> but with compensating benefits that make it still worth living.<sup>44</sup> Furthermore, the range of parents caught up in this process, and hence the number likely to reach a different

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38. It is easy to understand until we begin to appreciate the huge variability that attaches to most genetic conditions, and the complex patterns of multifactorial and multigenic causation.

39. BUCHANAN ET AL., *supra* note 1, at 256.

40. *Id.* at 257.

41. The authors also suggested that some parents do not act in their children’s best interests, “because there are genuine and unavoidable conflicts of interest between parents and their children,” yet the authors offer the reader no clue about what category of interests (beyond reproductive freedom) they have in mind. *Id.*

42. Silverberg & Godmilow, *supra* note 5, at 283–84.

43. *Id.* at 285–87.

44. Referring to benefits such as curb breaks to make streets navigable for those in wheelchairs, ramps so that these individuals can enter public buildings, Braille signs in elevators, and so forth. *Id.*

view than the experts regarding moral behavior is certain to increase with increases in genetic technology. After all, a few years ago none of these parents would have been said to have committed a moral wrong because the means to diagnose and to treat these genetic conditions prenatally did not exist. Are parents who reject these means of treatment, including contraception, abortion, or preconceptual or prenatal genetic manipulation, now running the risk of being judged unfit?

A final reason for being skeptical about a moral, much less a legal, basis for claiming that parents commit a wrong emerges when we remember the concept of wrongful life. In 1963, the Illinois Court of Appeals rejected the notion that children should ever be permitted to claim that their parents had wronged them because of the circumstances of their birth.<sup>45</sup> In *Zepeda v. Zepeda*, the court explicitly hypothesized that beyond palpable medical burdens, some children could reasonably claim that they were given a poor start in life by their parents' lack of wealth or income, by their parents' race or ethnicity, or by their parents' other characteristics that proved to be inherited by the children, such as being ugly, or slow, or stupid.<sup>46</sup> Subsequent courts misapplied the *Zepeda* holding by extending this wrongful life doctrine to insulate physicians and other professionals from liability.<sup>47</sup> This extension is not appropriate because healthcare professionals do have an affirmative duty of care toward the children that is breached when the children's parents are not given relevant information.<sup>48</sup> Nonetheless, the *Zepeda* court was right in saying that were one to establish the principle that parents owe their children any particular start in life, one would have opened the door to an endlessly expansive duty.<sup>49</sup>

The question for the authors, then, is whether, in light of chapter 6, they would be comfortable with the implication of that duty, which would require the use of measures to improve genetic fitness and not merely to avoid genetic unfitness. It would be ironic if a work that is

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45. *Zepeda v. Zepeda*, 190 N.E.2d 849 (Ill. App. Ct. 1963).

46. *Id.* at 858.

47. *See, e.g.*, *Gleitman v. Cosgrove*, 227 A.2d 689 (N.J. 1967); *Berman v. Allan*, 404 A.2d 8 (N.J. 1979); *Williams v. State*, 223 N.E.2d 343 (N.Y. 1966).

48. *Santana v. Zilog, Inc.*, 95 F.3d 780, 786 (9th Cir. 1996) ("Generally, wrongful birth imposes liability for breach of a physician's duty of care to ensure that parents can make an informed decision with respect to their right to prevent birth or conception of children.").

49. *See Zepeda*, 190 N.E.2d at 858.

as sensitive to the harms caused by past eugenic abuses provided a rationale for mandating a more far-reaching modern version of eugenics under the banner of reproductive freedom.