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A CHOICE OF EVILS IN PRENATAL TESTING

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INTRODUCTION

The aim of this paper is to examine the comparative strengths and weaknesses of two approaches to mitigating the offense given, and harm threatened, by prenatal testing for impairments:[1] limiting such testing to the most severe diseases and impairments, or imposing no medical limits at all. Although I favor the latter approach, I will argue that the alternatives present a choice between distinct evils.

To set the stage for this discussion, it is necessary to challenge the conventional picture of prenatal testing, its purposes, and its dangers. On this conventional view, prenatal testing serves the legitimate medical function of preventing severe diseases in future children, as well as the associated health threats to the parents and families of those children.[2] Because of the small number of conditions that are currently detectable, such testing is largely used for the appropriate purpose of preventing such severe conditions as cystic fibrosis (CF), spina bifida, Duchenne's Muscular Dystrophy (DMD), as well as Down syndrome and several other trisomies. There is one glaring exception: sex-selection, which is devoid of medical justifica-

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1. I will refer to prenatal testing for "impairments," rather than "disabilities," to reflect the now-conventional understanding of impairment as physical or mental abnormality, and disability as an interaction between such limitations and an individual's environment. Clearly, a disability so understood is not the kind of condition that can be tested for prenatally, or genetically.

2. *See*, *e.g.*, COMM. ON ASSESSING GENETIC RISKS, DIV. OF HEALTH SCIS. POLICY, INST. OF MED., ASSESSING GENETIC RISKS: IMPLICATIONS FOR HEALTH AND SOCIAL POLICY (Lori B. Andrews et al. eds., 1994) [hereinafter ASSESSING GENETIC RISKS]; PRESIDENT'S COMM'N FOR THE STUDY OF ETHICAL PROBLEMS IN MED. & BIOMED. RESEARCH, SCREENING AND COUNSELING FOR GENETIC CONDITIONS (1983) [hereinafter SCREENING AND COUNSELING]; Wolfram Henn, *Consumerism in Prenatal Diagnosis: A Challenge for Ethical Guidelines*, 26 J. MED. ETHICS 444 (2000).

tion except for sex-linked diseases. Fortunately, however, there is little demand for prenatal sex selection in the United States, even for the relatively benign purpose of family balance; such testing is discouraged or condemned by professional organizations and, in some places, by law.[3]

But, according to this conventional view, a serious threat is just over the biotechnological horizon. "[T]he age of positive eugenics is almost upon us."[4] It will soon be possible to do prenatal genetic testing for minor disorders, and for minor risks of severe disorders; in the not so distant future, genetic tests will be available for positive traits as well, like intelligence. The medical community, particularly the obstetric establishment, views this prospect, with sanctimonious horror:

> It may be too early to warn that we are at the edge of a slippery slope towards a new dimension of eugenics, but we must realise that new tools to fulfill the tempting wish to have not only healthy, but gifted children will soon be in our hands.[5]

This is not a wish, however tempting, that doctors should help their patients to fulfill, because terminating a pregnancy of a baby expected to be healthy is "counterintutive to the Hippocratic ideas of health care."[6] To avoid this kind of professional abuse, "there is an urgent need to extend the current ban on prenatal paternity and gender testing to *any* parameter of prenatal genetic diagnosis that is not immediately related to severe disease in the prospective child."[7]

A clue that there is something very wrong in this picture should come from the restriction to "severe disease." It would be considered not only unnecessary but unethical and perverse for doctors to refuse to provide preventative or therapeutic services to their patients, or the public, for *minor* diseases (except in cases of extreme scarcity). Indeed, much of our current health care budget, and our public funding for research, prevention, and treatment, is directed towards arguably minor, or at least non-severe diseases. If prenatal testing serves the legitimate medical function of preventing diseases, why should it be wrong (if less urgent) to extend it to minor diseases? This restriction should make us question whether prenatal testing can be seen as a medical function at all, in the widely-accepted sense of a function serving to protect or restore the health of individual pa-

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3. ASSESSING GENETIC RISKS, *supra* note 2, at 8, 85-86; Ethics Comm. of the Am. Soc'y for Reprod. Med., *Preconception Gender Selection for Non-Medical Reasons*, 75 FERTILITY & STERILITY 861 (2001); J. McMillan, *Sex Selection in the United Kingdom*, HASTINGS CENTER REP., Jan.-Feb. 2002, at 28.

4. Henn, *supra* note 2, at 445.

5. *Id.* at 446.

6. *Id.*

7. *Id.* at 445.

tients. If it is not, however, we are not at the edge of a slippery slope, but already in an ethical limbo, facing unresolved questions about the basic legitimacy of a non-medical practice carried out by doctors and other health professionals.

I. DEMEDICALIZING PRENATAL DIAGNOSIS

Prenatal diagnosis—whether through amniocentesis, chorionic villuis sampling, or preimplantation genetic diagnosis; whether for Down, CF, female gender, or blue eyes—needs to be seen for what it is, or more importantly, what it is not. It is not a medical procedure—a procedure intended to protect or restore an individual's health—unless it is undertaken to protect the mother's health, or the health of the fetus or infant, through early intervention. It is, typically, a procedure to identify and destroy unwanted organisms. But to say that it is not a medical procedure is not to say that it is wrong, or even wrong for a doctor to perform. A pregnancy test for an unmarried adolescent, undertaken to procure an abortion at the earliest possible date (if the test is positive), is not a medical procedure either, unless it is intended to protect the health of the adolescent, which it rarely is (except in the expansive World Health Organization (WHO) sense of "health" in which avoiding the social burden of adolescent child-rearing is a matter of health). It is quite possible to regard abortion as justifiable, and to regard doctors as the appropriate agents to carry it out, while denying that it serves to protect or restore the health of individual patients. One can take a similar view of physician-assisted suicide—the fact that suicide is not health-protecting or restoring does not mean that doctors should not assist it.

What this does suggest, however, is that mainstream opponents of prenatal sex-selection cannot reject it on the grounds that it is not a bona-fide medical service. When groups such as the Institute of Medicine piously condemn genetic testing and abortion for sex-selection on the grounds that it is "a misuse of genetic services,"[8] they need to explain why abortion for child- or disability-prevention is any less of an abuse, since neither typically serves to promote or protect the health of any individual human being. If doctors can legitimately perform non-healing functions in aborting the unwanted fetus carried by an adolescent girl, or in honoring the express desire of an elderly patient to avoid a lingering death, then why would they not perform a legitimate function by letting parents have the kind of children they want—male, brown-eyed, or unimpaired? The reason cannot be simply that facilitating such parental choice is not a medical

8. ASSESSING GENETIC RISKS, *supra* note 2, at 105.

function.

The standard critique of sex selection conflates two distinctions: between pathological and normal human variations (or disease and non-disease states), and between medical and non-medical functions. Unlike many disability scholars and bioethicists, I believe there can be a plausible biological basis for the former distinction, between pathological and normal states; that the distinction need not reflect social, cultural, or moral values.[9] But while this first distinction is needed to explain the second, which concerns the protection or restoration of health, the two distinctions are not identical. A doctor who prevents the existence of someone who will have certain pathological states—diseases or impairments—is not performing a medical function (although he may be performing a public-health function). The doctor who selects among in vitro embryos to find a compatible marrow-donor for an ailing child is performing a medical function for that child, but not for those embryos. If the rationale for the doctor's services to enhance the couple's freedom of choice or to save an ailing child (when no else else's rights are violated), why should it matter if the conditions they "prevent," unlike female sex or brown eyes, are abnormal, pathological, or inherently undesirable? There need not be anything wrong in a doctor's performing a non-medical function; the job descriptions of professionals often change, and sometimes for the better.[10]

II. TWO EVILS

The more credible concern about the expansion of prenatal testing is that doctors who assist their patients in aborting fetuses or discarding embryos, on the basis of sex or marrow-incompatibility, are doing something wrong, not because it is non-medical, but because it abets the degradation of the parental role and the commodification of children. The concern is that once parents who intend to have children can set conditions on the kind of children they will have, they slough off the commitment to loving and rearing whatever child they have and start down the slope towards designer babies; toward the corruption of child-making by a consumer mentality.[11] This concern, however, grounds an objection to prenatal testing for disease and disability, as well as for sex and marrow-compatibility.

I do not want to dismiss this concern, because I think that the threat is real, if exaggerated. Moreover, I agree that autonomy has

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9. *See generally* Robert Wachbroit, *Health and Disease, Concepts of*, *in* 2 ENCYCLOPEDIA OF APPLIED ETHICS 533 (1998).

10. *See*, *e.g.*, John D. Arras, *Physician-Assisted Suicide: A Tragic View*, 13 J. CONTEMP. HEALTH L. & POL'Y 361 (1997).

11. *See*, *e.g.*, SCREENING AND COUNSELING, *supra* note 2, at 57-58.

enjoyed an unwarranted ascendancy as the "master value" in bioethics, and that its promotion must often yield to other concerns.[12] But I will argue that the threat of insufficient commitment and commodification is not the only one raised by prenatal testing for disability, and that it may be the lesser of two evils. If such testing can be seen as the first step towards a noxious and destructive finickyness in the creation of children and families, it can also be seen as something very different and less novel. The phenomenology of selecting *against* disability and selecting *for* desired traits may be quite different, even if certain moral theories, such as standard act-utilitarianism, treat them as similar.[13] Eliminating disabled fetuses or embryos may be seen as applying modern technology to the ancient imperative of discarding defective children, rather than to the (alleged) contemporary desire for "a perfect baby."[14]

The classical Greeks who left defective children on mountainsides were not nascent perfectionists; they were more likely to have been frightened, superstitious parents anxious to rid themselves of children with the marks of divine disapproval. Like modern parents who will not abort after the second trimester, ancient parents got rid of defective children with some scruples and constraints—they would not kill the children directly, but only facilitate their death from natural causes such as exposure.[15] Beyond avoiding stigma and divine displeasure, their aspirations for their children may have been exceedingly modest.

The most effective way of counteracting the contemporary expression of those enduring fears and superstitions in the demand for prenatal disability testing may be to refuse to dignify such testing as a medical function; to treat it instead as a consumer service. The likelihood of serious impairment would be neither a necessary nor sufficient condition for that service. Permitting or requiring doctors to offer prospective parents the widest available menu of prenatal tests, including but not limited to tests for various impairments, might help to de-stigmatize disability. But such reproductive freedom would not be a "positive good," or an unmixed blessing. A regime of unfettered parental choice would take the focus off disability only by further corrupting the process of child-making, encouraging a finicky

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12. *See*, *e.g.*, Susan Sherwin, *Feminism and Bioethics*, *in* FEMINISM & BIOETHICS: BEYOND REPRODUCTION 47, 52-53 (Susan M. Wolf ed., 1996).

13. *See*, *e.g.*, Julian Savulescu, *Procreative Beneficence: Why We Should Select the Best Children*, 15 BIOETHICS 413 (2001).

14. *See* GLENN MCGEE, THE PERFECT BABY (2000).

15. For the classical Greek practice of exposing unwanted or defective children, see SOPHOCLES, OEDIPUS REX (Roger D. Dawe ed., 1982). For a discussion of the classical Greek attitudes towards causation action and responsibility, see ARTHUR W.H. ADKINS, MERIT AND RESPONSIBILITY: A STUDY IN GREEK VALUES (1975).

consumer mentality or a vulgar perfectionism on the part of prospective parents. Some would argue that this would be too high a price to pay for alleviating the stigma of disability; others would argue that it would fail, or backfire, increasing intolerance for disability.

III. TWO APPROACHES

There are two approaches to regulating prenatal testing that appear to parallel the two concerns about commodification and stigma. One approach would limit testing/responsibility/liability to a small subset of severe or widespread disabilities; the other would expand testing/responsibility/liability beyond disability to a full range of conditions that parents might seek to avoid, with the "burden of disability" merely one factor in the assessment of duties and damages. Dorothy Wertz and Jeff Botkin have offered very different versions of the former approach;[16] I favor the latter approach and will defend it here, not as a means of promoting parental autonomy, which I regard as a suspect or overrated goal, but as a way of mitigating the harm and muting the expressive significance of prenatal testing for people with disabilities.

I will argue that these approaches should be seen as responsive to the two distinct concerns about prenatal testing I have sketched above: the growing sway of a consumer mentality toward procreation, and the continuing stigmatization of disabilities. Although both threats involve a degradation of the parental role, resistance to them may pull us in opposite directions. Disabilities may be less stigmatized in a reproductive regime in which neither they, nor any subset of them, have a special role in legitimizing abortion; consumerism may have less sway in a regime that permits testing only for the most severe disabilities. But the former takes the onus off disability by promoting a broader consumer mentality, while the latter discourages such a mentality by keeping the onus squarely on disability. Since it is neither feasible nor morally acceptable to prohibit all prenatal testing, we will be faced with a choice of evils.

To make the distinction between these two purposes is not to deny that some people with specific impairments, or their advocates, favor a narrowing approach that excludes their impairment, or even to deny that the dominant motivation for a narrowing approach may be to avoid the stigmatization of as many impairments as possible. But there is considerable force to the argument made by critics of line-

16. Dorothy C. Wertz, *Drawing Lines: Notes for Policymakers*, *in* PRENATAL TESTING AND DISABILITY RIGHTS 261 (Erik Parens & Adrienne Asch eds., 2000); Jeffrey R. Botkin, *Fetal Privacy and Confidentiality*, HASTINGS CENTER REP., Sept.-Oct. 1995, at 32 [hereinafter Botkin, *Fetal Privacy*]; Jeffrey R. Botkin, *Line Drawing: Developing Professional Standards for Prenatal Diagnostic Services*, *in* PRENATAL TESTING AND DISABILITY RIGHTS, *supra*, at 288 [hereinafter Botkin, *Line Drawing*].

drawing that, if this is its purpose, it is self-defeating; that the focus and debate on the placement of the line will only serve to re-affirm the legitimacy of impairment in general as a basis for abortion.[17] Those impairments placed on the near side of the line may enjoy little or no reduction in stigma, since their exclusion as grounds for abortion may be perceived as the result of balancing or compromise, not as the result of substantially changed beliefs about the burden they impose.

The tension between narrowing and widening approaches has a rough counterpart or analogue in debates about employee drug testing and airport profiling; between those who favor ever-greater refinement in the criteria for imposing an intrusive or demeaning procedure and those who favor its universalization. In the latter cases, the imposition of the same drug tests and security tests on everyone largely eliminates the insult to the preponderantly innocent members of suspect groups, at the cost of small inconvenience to everyone, great administrative burdens, and a more pervasive threat to civil liberties; in the case of prenatal testing, the costs of "universalization" are far less tangible: the corruption of parental attachment by a consumer mentality. As in prenatal testing, the costs of further refinement in drug testing are the greater stigmatization of those selected against by the more refined procedure, and the "penumbral" stigmatization of those who barely pass.

In the next Section, I will offer a critique of the most fully developed narrowing proposal. In the final Sections, I will take up two significant challenges to the alternative approach of consumer sovereignty: that it will increase, not reduce, the stigmatization of people with disabilities, and that it cannot accommodate wrongful life or wrongful birth actions under the rubric of medical malpractice or autonomy violation.

IV. PROPOSALS FOR RESTRICTING PRENATAL TESTING

Jeff Botkin and Dorothy Wertz have proposed quite different narrowing approaches, with very different kinds of restrictions on prenatal testing, both designed to maintain the medical legitimacy of the procedure.[18] Botkin would permit testing only for conditions expected to impose serious burdens on parents and families,[19] while Wertz would permit testing for any pathological condition for which the future child was at high risk, regardless of severity. Wertz's approach

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17. *See* Erik Parens & Adrienne Asch, *The Disability Rights Critique of Prenatal Genetic Testing: Reflections and Recommendations*, *in* PRENATAL TESTING AND DISABILITY RIGHTS, *supra* note 16, at 3, 30-31.

18. Botkin, *Line Drawing*, *supra* note 16; Wertz, *supra* note 16.

19. Botkin, *Fetal Privacy*, *supra* note 16; Botkin, *Line Drawing*, *supra* note 16.

has the virtue of unprincipled consistency; it would permit testing and termination for any condition deemed pathological, however minor, from color-blindness to a missing toe.[20] This permissive approach would be rejected by most defenders of current practice. I will have nothing further to say about it here, since I will be advocating the even more permissive alternative of eliminating the requirement that the condition tested for be pathological.

Botkin would drop the fiction that prenatal testing served any medical function for future children, but he argues that it does, or could serve, a legitimate medical function for actual parents and families—to protect them from harm arising from the birth and upkeep of children with severe impairments.[21] While a notion of "family health" would be highly suspect, having the same pretextual quality as "maternal anxiety" as a medical justification for abortion in general, Botkin bases his standard on family welfare, not health.[22] This commits him to a broader conception of the doctor's professional role than many doctors and bioethicists would be willing to accept. But since I see no reason for restricting the doctor's role to the protection and promotion of health, narrowly conceived, I have no criticism of Botkin on this ground.

I will not argue, however, that Botkin's standard is untenable. He claims that the line he proposes will not only arrest the slide down the slippery slope toward "designer babies," but mitigate the adverse impact of prenatal testing on people with disabilities.[23] I do not know whether the implementation of his standard would reduce the adverse social and psychological impact on people with disabilities, though I am skeptical that it would. What I will claim is that the proposal to restrict offers of prenatal testing to conditions likely to have a substantial impact on family welfare is ambiguous and unworkable. Because the correlation between the medical severity of the conditions tested for and the psychological impact on families is much weaker and less susceptible to generalization than Botkin recognizes, it is not clear how he can develop a standard of care that would protect the welfare of families who had strong but idiosyncratic reactions to traits like female gender or webbed fingers. And to the extent that generalizations can be made about family welfare, they will license the offer of prenatal testing for traits such as female gender or webbed fingers in societies where the birth of children with those traits will be expected to have a significant impact on family welfare.

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20. Wertz, *supra* note 16, at 274-78.
21. Botkin, *Line Drawing*, *supra* note 16, at 300.
22. Botkin, *Fetal Privacy*, *supra* note 16, at 37-38.
23. Botkin, *Line Drawing*, *supra* note 16, at 305.

In the final Sections, I will take up two significant challenges to the alternative approach of consumer sovereignty: that it will increase, not reduce, the stigmatization of people with disabilities, and that it cannot accommodate wrongful life or wrongful birth actions under the rubric of medical malpractice or autonomy violation.

V. FETAL IMPAIRMENT AND PARENTAL WELFARE

Botkin's "family welfare" standard is an unstable hybrid, because there is only a tenuous link between the medical severity of the fetal abnormality and the welfare of the family. As a medical notion, "severity" offers a workable if vague standard, at least if it is taken to involve only an ordinal comparison: most professionals and laypeople would rate Tay Sachs more severe than CF; CF more severe than color-blindness. But a standard based on "the impact of the medical condition on the family," authorizing testing for "conditions that may significantly impair the legitimate interests of the parents [and other children]"[24] will either yield highly objectionable results in many cases or end up as little more than a variant of the parental-preference standard that Botkin rejects.

In an earlier article, Botkin proposes offering tests for conditions that would threaten harms to parents "of approximately the same magnitude as the harms of an unwanted pregnancy."[25] His list includes diseases "often fatal in childhood," chronic illnesses "requir[ing] repeated hospitalization," conditions that would not allow a child "to achieve independence in his or her adult years," and conditions "of such severity that there are constant demands on the parents for time, effort, and financial resources."[26] As Adrienne Asch has argued,[27] these features—particularly the last two—have a much more contingent relationship than Botkin assumes to the specific medical conditions he cites as examples, such as Down and CF. Frequent, extended hospitalizations and life-long dependence may arise from deficient, discriminatory, and malleable social arrangements rather than from anything inherent in those medical conditions. Even if we accept, for the sake of argument, that these burdens are inherent in those conditions Botkin cites, it is not clear why these burdens should be regarded as worse than those of many conditions

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24. *Id.* at 300.

25. Botkin, *Fetal Privacy*, *supra* note 16, at 36. Botkin arrives at this standard by arguing that it represents the same balancing of parental and family interests with fetal privacy and confidentiality that permits general abortions through the second trimester. Since I do not think fetuses have interests in privacy or confidentiality, I think Botkin's derivation of this standard is mistaken, but this is not the place to make that argument.

26. *Id.* at 37-38.

27. Adrienne Asch, *Prenatal Diagnosis and Selective Abortion: A Challenge to Practice and Policy*, 89 AM. J. PUB. HEALTH 1649, 1653 (1999).

he would exclude, such as Huntington's. Many parents, I suspect, would not regard it as a greater harm to raise a child who required frequent hospitalization or continuing support than to raise a child with a fifty percent chance of premature death from the same degenerative condition that they or their spouse will soon die from. Although Botkin's more recent paper talks about welfare rather than harm,[28] the problem is the same: he neither supplies an account of harm or welfare that would draw the line where he wants it, nor offers evidence of a broad consensus on what counts as a significant harm or threat to welfare.

A growing body of research suggests that families with severely impaired children do not differ significantly in stresses and burdens from families with normal children.[29] These findings weaken any presumption that family welfare will be damaged by the birth of an impaired child. Botkin might deny that evidence of the resilience and flourishing of families with severely impaired children would weigh against his current proposal. He insists that his standard now gauges family "impact," not "burden,"[30] so that only evidence of slight magnitude, not positive valence, would count against it. But he cannot maintain this value neutrality for even a single page. Just a paragraph above his declaration of neutrality, he asserts that "practitioners should provide information on conditions that may significantly *impair* the legitimate interests of the parents."[31] But talk of conditions that "impair" rather than "affect" is hardly more neutral than talk of "burden" rather than "impact." Moreover, Botkin would have practitioners assess the "severity" of impact,[32] a term which is hardly neutral. People ecstatically transformed by birth, marriage, or other blessed events would hardly describe the impact of those events as "severe."

More important than Botkin's inconsistency is the problem he would confront if he were consistent: the birth of any child, especially a first child, is such a transformative event that it may be difficult to claim that the birth of a child with a severe impairment will generally have a more substantial impact. Even if that claim can be established by definitional fiat—Botkin would offer testing only for conditions that typically involved extraordinary impacts, such as frequent hospitalization, intensive daily medical care, or life-long dependency—his proposal would also require offers of testing for genetically-

28. Botkin, *Line Drawing*, *supra* note 16, at 300.

29. *See generally* Phillip M. Ferguson et al., *The Experience of Disability in Families: A Synthesis of Research and Parent Narratives*, *in* PRENATAL TESTING AND DISABILITY RIGHTS, *supra* note 16, at 72.

30. Botkin, *Line Drawing*, *supra* note 16, at 288, 300.

31. *Id.* (emphasis added).

32. *Id.*

detectable athletic, musical, or intellectual prodigy. As Asch points out, the additional impact of child prodigies on their families may be at least as great as that of children with Down or CF.[33]

Even if Botkin were able to support the generalizations he offers, and the lines he expects them to yield, he would have to face the problem of exceptions. Taking what is often regarded as a clear case, Botkin maintains that

> [p]hysicians should not be obligated to offer prenatal gender testing to all parents, even if we can find justification in isolated cases. In general terms, the impact of a child of the unwanted gender on the parents is not sufficiently severe to warrant offers of gender selection as the standard of care.[34]

It is hard to disagree with Botkin that an average American couple's preference for a boy, or a girl, or a "gender-balanced" family, does not implicate their family's welfare enough to warrant an offer of testing. But such a couple is unlikely to want testing specifically for that purpose. It is not clear what Botkin would propose in the case of a couple or family for whom the birth of a child of the unwanted gender might well have a severe impact: if, say, the prospective father or an older sibling had a history of sexual abuse toward girls. Presumably, Botkin would regard the doctor as obliged to offer prenatal gender testing to such parents, *if she knew of these unusual circumstances*. But she would not know unless she asked or inquired.

Perhaps Botkin would respond that the doctor was not obliged to find out if there were circumstances that made particular fetal traits a threat to family welfare. But this would be a striking departure from normal medical practice. Doctors are obliged, for example, to ask if patients have (relatively rare) allergic response to common antibiotics. If, on the other hand, a doctor would be obliged to ask or inquire about circumstances that made even common fetal traits like female gender risky to family welfare, then it is not clear what role Botkin's "standard of care" would be left to play. The comparison to allergies suggests that the need for inquiry would be, if anything, greater in the case of prenatal testing, because threats to family welfare are harder to assess than reactions to antibiotics. If the doctor is protecting the parents' welfare rather than simply fulfilling their wishes, she must assess whether the birth of a child with a particular trait would in fact have (or be likely to have) a substantial impact on the family's welfare. She cannot make that assessment simply by asking the parents—they often do not know, and are likely to be wrong.

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33. Asch, *supra* note 27, at 1653-56.
34. Botkin, *Line Drawing*, *supra* note 16, at 301.

The point is not that physicians should decline to raise the prospect of testing, but that families' actual responses to children with a variety of normal and abnormal traits are sufficiently varied to call almost any generalization into question. Botkin's "standard of care" would require an inquiry into family strengths and vulnerabilities that would precede or accompany any offer of testing. But such an inquiry would eliminate the justification for a standard offer, or a routine multiplex test, because the doctor should offer whatever tests her inquiry indicates are warranted. Even if those tests in many cases were the very ones that would be on Botkin's standard list, they would not enjoy the privileged status that his proposal confers on them.

There is a further problem with Botkin's standard as it applies to social and cultural settings where his seemingly uncontroversial generalizations wouldn't hold. It simply may be false in India, or in a number of Muslim countries, that "[i]n general terms, the impact of a child of the unwanted gender on the parents is not sufficiently severe to warrant offers of gender selection as the standard of care."[35] The birth of a girl, or another girl, may mean impoverishment or stigmatization for the family. In other societies, the birth of a child with mild but visible deformities such as webbed fingers may have a similar impact on the family. Perhaps Botkin would contend that the parents would not have a "legitimate interest" in avoiding such consequences, even if they were innocent of the underlying prejudices. But it seems unreasonably harsh or demanding to claim that parents have no legitimate interest in avoiding poverty or ostracism based on the prejudices of the society in which they happen to live. Surely there is a case to be made at the policy level in these countries for limiting gender- and disability-testing, but doctors serving the welfare of their individual patients are hardly the appropriate instruments for that policy. Much like Erik Nord's proposal to elicit social values as a basis for distributing scarce health-care resources,[36] Botkin's standard appears defenseless against profoundly inegalitarian social values.

VI. IS UNRESTRICTED TESTING A BETTER ALTERNATIVE?

As I suggested earlier, I am willing to assume, for the sake of argument, a claim of Botkin's that many disability critics reject: that line-drawing on the basis of parental or family welfare would reduce rather than exacerbate the adverse social and psychological effects of prenatal testing and selective abortion on existing people with disabilities. My argument has been that his proposal is unworkable as

35. *Id.*
36. *See* ERIK NORD, COST-VALUE ANALYSIS IN HEALTH CARE (1999).

the basis for a standard of care; that it will either yield a morally problematic failure to offer testing to families whose welfare is likely to be substantially affected by the birth of a child with certain "normal" traits or medically minor impairments, or else will undermine the justification for a standard offer, and instead require complex, individualized inquiries into family welfare.

The comparative virtue of the alternative approach—of offering any and all available testing—is that it would give no official or privileged role to impairments in the determination of whether to offer testing or abortion. I do not know whether such a regime would provide social and psychological benefit to existing people with disabilities. Botkin argues forcefully that it would not:

> [I]t hardly seems beneficial to the welfare of the disabled community to advocate that all conditions be subject to prenatal diagnosis and selective termination. This would appear to be the fast lane to "perfectibilism" and intolerance for progressively less severe disabilities. If society condones and promotes prenatal diagnosis for the full spectrum of medical (and nonmedical) conditions, what message does that send? If we want to promote inclusiveness, understanding, and support for those with disabilities, requiring the extensive provision of prenatal diagnostic information and services would appear to be a poor strategy. My concern is that the attempt to eliminate the hurtful effects of line drawing in prenatal diagnosis will fuel a broader set of discriminatory attitudes in society that will be much more hurtful to those with disabilities in the long run.[37]

Forceful as this passage is, it conflates two distinct concerns: the social and psychological impact of a prenatal testing regime on people with disabilities, and the "kind of message it sends"—its expressive significance. I have argued that the stigmatization of impairments and the craving for perfection should not be seen as falling on some continuum of intolerance, but rather are quite distinct, at least in theory. There is no logical reason, and no psychological evidence I know of, that people who strive for perfection in themselves or their children are *comparatively* less tolerant of impairments than of imperfections or limitations that fall within the normal range for human beings. A relentless perfectionist can, quite consistently, be a universalist about impairment, finding all of us "impaired" when measured against his impossible ideal. A perfectionist may tend to minimize the differences between imperfections which are medically abnormal and normal.

I concede that I may be wrong about the psychology and social impact of perfectionism. Perhaps an unrestricted prenatal-testing re-

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37. Botkin, *Line Drawing*, *supra* note 16, at 305.

gime would in fact increase the stigmatization of impairments and discrimination against the people who bear them. Or perhaps it would make little or no difference, because most prospective parents would end up testing only for medically severe impairments in any case, in part because they shared in the stigmatization of those impairments, in part because those conditions were more readily tested for—not only because they have more detectable genetic links, but because the scientific development of prenatal tests reflects the popular stigmatization of the conditions tested for.

But this is not all that matters in gauging the expressive significance of a prenatal-testing regime. A testing policy that gave no special status to medical impairments, that did not treat them as providing even a presumptively stronger basis for termination than any other human trait or variation, would emphatically reject the exceptionalism about impairment that has dominated prenatal testing since its inception. It would "send the message," to use Botkin's phrase, that the prospect of impairment did not give parents a privileged or especially strong reason to abort; that impairments were just some among the indefinite number of variations that might be relevant to the decisions of prospective parents about whether to bring a child into the world.

VII. DUTY AND BREACH: THE DUTY TO INFORM AND THE FUTURE OF WRONGFUL BIRTH CLAIMS IN AN UNRESTRICTED PRENATAL TESTING REGIME

There is considerable uncertainty about the scope of the doctor's duties to inform and test under an unrestricted testing regime.[38] While this is not the place, and I am not the person, to suggest a protocol for assessing the preferences of prospective parents, several features seem clear. First, it would not require what Botkin calls "full disclosure"[39]—the breathless recitation of every conceivable condition for which testing may be available. While some parents may want such disclosure, most will want far less, and some, none at all. The doctor should begin by asking the couple whether they want testing at all, or would rather take whatever nature yields. In the still-distant future when prenatal therapy is available, this may no longer

38. Julian Savulescu proposes a similar testing regime, in which "doctors are expected to disclose those facts which each individual patient would find relevant to her decision making" and in which any test she deemed relevant would be available "consistent with the fair allocation of limited health resources." Julian Savulescu, Editorial, *Is There a Right Not to be Born? Reproductive Decision Making, Options, and the Right to Information*, 28 J. MED. ETHICS 65, 66 (2002). Savulescu favors parental autonomy because he believes that parents are the best judges of their own, and their children's, well-being, and that we should aim to maximize well-being—a very different rationale than one based on respect for the dignity and equality of people with disabilities.

39. Botkin, *Fetal Privacy*, *supra* note 16, at 34.

be an appropriate lead question, for the doctor may not be able to conscientiously take "no" for an answer. But for now, a blanket refusal to be tested should be conclusive, no matter how great the probability of a genetic abnormality, except perhaps in cases where the doctor has reason to suspect a substantial probability of a genetic or chromosomal condition that would, arguably, make the child's life not worth living, his very birth a harm, for example, Tay Sachs, Lesch-Nyhans, Trisomies 13 or 18. (Of course, many couples would want to know why the doctor is asking, making the Gricean assumption that there must be some heightened risk to trigger the inquiry.) The doctor might present an overview of the range of normal and abnormal phenotypes, from female gender to Tay Sachs, perhaps with accompanying frequencies for sample conditions. It would then be up to the couple (or woman—but I will assume for simplicity's sake that the doctor is addressing a couple) to decide whether they wanted to know more about particular conditions, or about the probabilities for those conditions, given their ages and family histories. And it would then be up to the couple to decide what tests, if any, to obtain. Some minimum probability for the tested condition might be required—but not a minimum varying with "severity" in any sense of that term.

The obvious question of who would pay could be addressed either by offering different health-insurance policies, with higher premiums for fuller coverage, or by adopting the usual co-pay mechanism. The former might be unreasonably difficult, since couples would have to decide on testing coverage well before they decided whether to have children. The latter might be fairer, and consistent with a general destigmatization policy if the charges for tests were based on their actual cost, not on some professional judgment of their medical appropriateness or urgency. Admittedly, those costs, as well as the very existence of the tests, might reflect professional judgments about priorities in genetic research and development. But the very fact that it was not the doctor, hospital, or insurer who was making those judgments would mute their expressive significance.

Under such a consumer-sovereignty/parental autonomy regime, standards for reasonable competence and adequacy in informing, testing, and reporting would evolve in practice, perhaps guided by model protocols or scripts by professional associations. The breach of a doctor's duty to inform or perform with reasonable competence would be regarded as infringing the parents' procreative autonomy. Claims for damages and offsets would be treated similarly for healthy and disabled children, since all are rewarding, expensive, and challenging, to varying degrees.[40] An autonomy-based approach

40. The question would arise about whether one can suffer a loss of autonomy in being denied or misled about information that may be of dubious or exaggerated relevance—

would clearly favor uniform damages, punitive more than compensatory, reflecting the slight to the parents' freedom and dignity rather than the impact on their budget or their emotions.

VIII. THE DEATH OF WRONGFUL LIFE CLAIMS?

The expressive significance of a refusal to limit wrongful birth suits to cases of impairment would be muted or lost if children were allowed to sue for wrongful life only on the basis of their impairments. One alternative would be to deny wrongful life suits altogether, or to limit them to conditions so severe that they arguably rendered life not worth living—including Tay Sachs, Lesch Nyhans, Trisomies 13 and 18, but little else.[41] The other alternative, which I want to conclude by exploring, would be to extend the approach I have suggested for wrongful birth claims to wrongful life claims, so that they were not limited to impairment, but covered any significant and foreseeable harm the child suffered.

According to a line of argument that has enjoyed some recent currency, it is presumptively wrong to bring *any* child into the world, not just a severely disabled child. This argument rests on a claimed asymmetry between non-creation and creation: while it is not bad to fail to confer the goods of life, it is good to avoid the bads of life. Thus, the argument goes, because there is no bad in never existing, while there is good in avoiding the harms of existence, the good of existence is balanced or offset by the good of non-existence, so that the inevitable harms and sorrows of living make existence a net bad, and make creation a presumptive wrong.[42]

I think this argument is profoundly mistaken. But it suggests an approach to wrongful life cases that does not treat the birth of a disabled child any differently in principle than the birth of a normal child. Those intentionally or negligently responsible for creating any child are presumptively responsible for the harms it suffers. In the case of parents, the care, nurturing, and material support they give

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does autonomy involve acting on right reasons or merely reasons of one's own choosing? For example, what if a doctor negligently misreports fetal sex to a couple who had requested that information and who would have aborted a female fetus merely to achieve gender-balance? The testing regime I am sketching would be committed to the latter conception of autonomy, and would have to respond similarly to all failures to disclose information deemed relevant by the prospective parents.

41. Few jurisdictions in fact recognize wrongful life claims for any conditions. A useful review of legal and policy issues in wrongful birth and wrongful life actions can be found in Jeffrey R. Botkin, *Reproduction, Law, Wrongful Birth, and Wrongful Life Actions*, *in* 2 ENCYLOPEDIA OF ETHICAL, LEGAL, AND POLICY ISSUES IN BIOTECHNOLOGY 996 (Thomas H. Murray & Maxwell J. Mehlman eds., 2000).

42. For variations on this argument, see David Benatar, *Why it is Better Never to Come into Existence*, 34 AM. PHIL. Q. 345 (1997); Seana Valentine Shiffrin, *Wrongful Life, Procreative Responsibility, and the Significance of Harm*, 5 LEGAL THEORY 117 (1999).

their children would generally discharge any obligations arising from the infliction of these harms. In the case of third-parties like doctors, any responsibility/liability they have is superceded or nullified by their duty to the parents to provide assistance in bringing the child into existence. But when they breach their duty to the parents, either by failing to prevent pregnancy or by failing to disclose risk factors that would lead the parents to test and terminate, they are liable for the harms of the child's existence. As a practical matter, they become liable for the costs of raising the child and covering his medical expenses, costs that will obviously be greater with some impairments but will be considerable even for a normal child conceived through the doctor's negligence.

Many people would recoil at the idea that parents' duties to their children have a corrective or compensatory character—to redress the wrong doing by bringing them into existence. More broadly, this approach appears to involve much the same kind of suspect moral accounting as negative utilitarianism: only (non-comparative) bads are counted, with no offset for goods. (The actual accounting is not quite the same, because negative utilitarians look only at bads, while those who treat life-creation as a presumptive wrong either: (1) treat the good of existence as balanced or cancelled by the good of *avoiding* the bads of existence,[43] or (2) contend that only the avoidance of bad, and not the attainment of good, can justify potentially harmful interventions without consent.)[44]

A more modest approach may be available to impose liability for the foreseeable harms suffered by a child, impaired or not, who would not be alive but for professional negligence. On a more plausible accounting, we count goods and bads, but only if they can be attributed to the agent. With this approach, the asymmetry is in the attribution: the bads in a child's life may be more readily attributable to the agent than the goods in that life.[45] But why shouldn't a doctor whose negligent diagnosis averts an abortion that would otherwise have occurred get credit for the good as well as the bad of the impaired life that results? It is only in a "same number" case[46]—where the parents are committed to a fixed number of children—that the doctor could be said to be responsible in a but-for sense *only* for the bad, since the parents would have gone on to have a normal child had they aborted this time around. And making the doctor liable only in same-number cases would be highly problematic. The problem is not only epistemic; in knowing what in fact counts as a same number

43. Benatar, *supra* note 42.
44. Shiffrin, *supra* note 42.
45. *See* Matthew Hanser, *Harming Future People*, 19 PHIL. & PUB. AFF. 47 (1990).
46. The term comes from DEREK PARFIT, REASONS AND PERSONS (1984).

case; it is conceptual, in determining what the criteria for such cases are. The problem is also moral, because the two most plausible criteria for distinguishing same (and different) number cases both place the doctor's liability beyond his control—parental intentions with respect to the number of children they will have under different circumstances, which the doctor will not, and perhaps could or should not know; or the actual number of people who will ever exist in the world, an utterly contingent matter which no one can assess at the present time.

It is necessary to argue that there may be different states of mind required, or different causal connections, for the attribution of benefits and burdens, or even for particular benefits and burdens. Thus, it could be argued that only an individual with procreative intentions or "parental attachment"[47] can claim credit for the good of, and goods in, a child's existence, states of mind that a negligent physician will rarely possess. Or it could be argued that the adaptive processes that make life not only worthwhile, but incommensurably good for people with various disabilities, or that transform the attitudes of their parents from dread and despair to joy and enthusiasm, are, in effect, superceding causes, that block any attribution to the physician or other third parties for the benefits arising from those transformations. This approach would justify both of the lawsuits arising from J. Bopp's hypothetical traffic accident:[48] the negligent ob/gyn is responsible for the woman's grief and burden, or at least the additional medical costs of raising an impaired child; the reckless driver is responsible for the traumatic loss of consortium between mother and child. The doctor receives no credit or offset for the transformation in the mother's attitude that brought her joy and made her subsequent loss so traumatic; the driver receives no credit or offset for relieving the mother of her pre-transformation burden. The wrongful-life analogue would be a severely impaired child suing a negligent doctor for medical expenses while suing a third-party for attempted murder. The doctor would get no credit or offset in the adaptation that made the child's life so valuable to him, and that arguably aggravated the harm threatened by his post-natal assailant; the assailant would get no credit or offset for attempting to remove his pre-adaptation burden.

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47. *See* Lois Shepherd, *Protecting Parents' Freedom to Have Children with Genetic Differences*, 1995 U. ILL. L. REV. 761.

48. James Bopp, Jr. et al., *The "Rights" and "Wrongs" of Wrongful Birth and Wrongful Life: A Jurisprudential Analysis of Birth Related Torts*, 27 DUQ. L. REV. 461 (1989).

CONCLUSION

I have argued, often in a somewhat oblique way, for the comparative virtues of an unrestricted regime of prenatal testing over a regime restricted by a criterion of "severity"—the severity of either the medical condition of the fetus, or the impact on the family. My primary argument has been a moral, not an empirical one—that an unrestricted regime will avoid or mute the expressive significance of prenatal selection for impairment: the "message" that the prospect of severe impairment provides a categorically better reason for refusing to bring a child into the world than the indefinite number of other potentially burdensome traits and conditions that a child may have. A testing regime that limited prenatal testing to severe impairments would obviously send that message, while a regime that limited such testing to conditions likely to have a severe impact on family welfare would either have similar expressive significance, in its reliance on presumptions about the impact of severe impairments, or else require a complex, individualized inquiry into family welfare that would render it impracticable.

I have conceded both that an unrestricted testing regime might not reduce the adverse social and psychological impact of prenatal testing on people with impairments, and that it might promote a noxious consumerism or perfectionism about the creation of children. Perhaps I underestimate the risks I concede, but my preference for incurring them has a moral basis as well—I think the further stigmatization of impairments, which an unrestricted regime would be directed against, would be a greater evil than the further commodification of children. But this moral conviction may rest in part on an empirical conviction, and perhaps a naive one—that the tendency to stigmatize physical and mental differences is deeply engrained and recalcitrant, whereas the tendency to treat children as commodities will be largely offset by the transformative effect of actually raising them.