

CONCEIVING HARM: DISABILITY DISCRIMINATION IN ASSISTED REPRODUCTIVE TECHNOLOGIES

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Applying the Americans with Disabilities Act (ADA) to denials of treatment by assisted reproductive technology (ART) practitioners raises particularly challenging legal and ethical issues. On the one hand, the danger that physicians will inappropriately deny treatment to patients with disabilities is especially worrisome in the context of ARTs, given the widespread stigma associated with reproduction by individuals with disabilities. On the other hand, patients' disabilities may sometimes have potentially devastating implications for any child resulting from treatment, including the possibility that the child will be born with life-threatening or seriously debilitating impairments. Some physicians have strong ethical objections to helping patients become pregnant in the face of such risks. In this Article, Professor Coleman develops a framework for applying the ADA to disability-based denials of ARTs that addresses these competing considerations. In recognizing risks to the future child as a potential defense to a disability discrimination claim, Professor Coleman rejects the view of some commentators that such risks are relevant to reproductive decisions only if the child is likely to suffer so much that he or she would prefer not to exist. Instead, he proposes that, when a patient's disabilities create significant risks to the future child, the question should not be whether the child's life is likely to be so awful that nonexistence would be preferable, but how the risks and benefits of the requested treatment compare to those associated with other available reproductive and parenting options. Professor Coleman provides a theoretical justification for adopting this comparative framework, and examines how ADA precedents developed in other contexts should be applied to decisions about ARTs.

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INTRODUCTION

Applying the concept of disability discrimination to decisions about medical treatment poses profound challenges for both civil rights law and bioethics. On the one hand, individuals with disabilities have long faced unjustified discrimination in the provision of medical services,¹ and promoting equitable access to treatment for people with disabilities is therefore an important function of disability rights laws. On the other hand, physicians cannot simply ignore patients' disabilities when making treatment decisions, as some disabilities will alter the risks and benefits of otherwise appropriate medical care.² The challenge is to distinguish between appropriate and inappropriate considerations of disability in the context of health care decisions, taking into account the underlying goals of both medical treatment and civil rights law.

To the extent this challenge has been examined in the legal literature, the focus has largely been limited to the application of disability discrimination laws to decisions about life-sustaining medical treatment.³ Treatment decisions for disabled newborns have generated significant attention among

1. See Mary Crossley, *Becoming Visible: The ADA's Impact on Health Care for Persons with Disabilities*, 52 ALA. L. REV. 51, 51 (2000) (noting that the legislative history of the Americans with Disabilities Act (ADA) "includes ample testimony regarding the barriers that people with disabilities faced in obtaining health care").

2. See *Lesley v. Chie*, 250 F.3d 47, 53 (1st Cir. 2001) ("It would be nonsensical, and downright contrary to the purposes of the statute, to read the statute . . . to prohibit medical treatment that is appropriate 'solely because of' a patient's disability."); Crossley, *supra* note 1, at 64 ("[I]t seems nonsensical to say that a physician cannot take a patient's disability into account at all in deciding how to treat a disability-related condition. Undoubtedly, the existence of a disability and its medical effects can be a legitimate factor in choosing appropriate medical treatment.").

3. Outside the area of treatment decisions, health law scholars also have examined the implications of disability discrimination law for decisions about the allocation of health care resources. See, e.g., David Orentlicher, *Destructuring Disability: Rationing of Health Care and Unfair Discrimination Against the Sick*, 31 HARV. C.R.-C.L. L. REV. 49 (1996) [hereinafter *Destructuring Disability*]; David Orentlicher, *Rationing and the Americans with Disabilities Act*, 271 JAMA 308 (1994); Philip G. Peters, Jr., *Health Care Rationing and Disability Rights*, 70 IND. L.J. 491 (1995).

disability scholars, following a series of highly publicized incidents in which potentially life-saving operations were withheld from babies with Down's Syndrome.⁴ Building on the disabled newborn literature, scholars have raised more general questions about the application of the Americans with Disabilities Act (ADA)⁵ to the debate over medical futility, which asks whether physicians may deny treatment requested by patients or their surrogates if, in light of the patient's medical condition, the treatment is unlikely to be effective or to produce an outcome the physician regards as medically beneficial.⁶

Yet, at the other end of life's continuum—decisions about the use of medical procedures to help individuals conceive a child (collectively known as “assisted reproductive technologies,” or ARTs)—the legal implications of disability-related eligibility criteria remain largely unexplored.⁷ This is surprising, as some ART practitioners take a variety of disability-related factors into account in patient selection decisions.⁸ For example, some physicians refuse to provide ARTs to patients who are HIV-positive, to patients with other chronic medical conditions, or to patients with certain genetic diseases.⁹ The extent of disability-related denials of ARTs is impossible to determine, but it is undoubtedly significant. Indeed, until February 2002, the American Society for Reproductive Medicine (ASRM), the primary professional society for ART practitioners, expressly supported the exclusion of HIV-positive patients from ART programs.¹⁰

4. See, e.g., Mary A. Crossley, *Of Diagnosis and Discrimination: Discriminatory Nontreatment of Infants with HIV Infection*, 93 COLUM. L. REV. 1581 (1993).

5. Pub. L. No. 101-336, 104 Stat. 327 (1990) (codified as amended in scattered sections of 42 U.S.C.).

6. See, e.g., Mary A. Crossley, *Medical Futility and Disability Discrimination*, 81 IOWA L. REV. 179 (1995); Maxwell J. Mehlman et al., *When Do Health Care Decisions Discriminate Against Persons with Disabilities?*, 22 J. HEALTH POL., POL'Y & L. 1385, 1393–1402 (1997); E. Haavi Morreim, *Futilitarianism, Exoticare, and Coerced Altruism: The ADA Meets Its Limits*, 25 SETON HALL L. REV. 883 (1995); Philip G. Peters, Jr., *When Physicians Balk at Futile Care: Implications of the Disability Rights Laws*, 91 NW. U. L. REV. 798 (1997).

7. A few law review articles discuss the issue briefly. See, e.g., Taunya Lovell Banks, *The Americans with Disabilities Act and the Reproductive Rights of HIV-Infected Women*, 3 TEX. J. WOMEN & L. 57, 92–95 (1994); Dave Shade, *Empowerment for the Pursuit of Happiness: Parents with Disabilities and the Americans with Disabilities Act*, 16 LAW & INEQ. 153, 168–82 (1998). There is also one reported case involving an ADA challenge to a denial of assisted reproductive technologies (ARTs), but the case was dismissed on procedural grounds without reaching the merits. See *Sheils v. Univ. of Pa. Med. Ctr.*, No. 97-5510, 1998 U.S. Dist. LEXIS 3918, at *8 (E.D. Pa. Mar. 23, 1998) (dismissing an ADA claim against an ART program because the complaint failed to allege that plaintiffs were disabled or that the program's eligibility criteria impermissibly screened out persons with disabilities).

8. Of course, all ART practitioners take disability into account if infertility is considered a disability. See *infra* note 89. The focus of this Article, however, is the denial of ARTs to patients who have disabilities other than (or, in many cases, in addition to) infertility.

9. See *infra* Part I.C.

10. See *infra* note 64–68 and accompanying text.

Applying the ADA to denials of treatment by ART practitioners raises particularly challenging legal and ethical issues. On the one hand, the danger that physicians will inappropriately deny treatment to patients with disabilities—a serious concern in all areas of medicine—is especially worrisome in the context of ARTs. Our society has a long history of efforts to prevent people with disabilities from having children, a history in which the medical profession played an especially prominent role.¹¹ While we no longer embrace the coercive eugenics policies of the early twentieth century, the perception that some individuals with disabilities are inherently incapable of being parents remains common in our society.¹² Hence, there is a real danger that disability-related denials of ARTs will be based on ignorance or bias against people with disabilities, even more so than when physicians deny individuals with disabilities other types of medical care.

On the other hand, ARTs are fundamentally different from other medical treatments because their goal is the conception and birth of a child. In some cases, patients' disabilities may have potentially devastating implications for any child born to the patient, including the possibility that the child will be born with life-threatening or seriously debilitating impairments.¹³ Some physicians may have strong ethical objections to helping patients become pregnant in the face of such risks.¹⁴ Physicians also may be concerned about indirect risks to the child from patients' disabilities, such as the possibility that patients with life-threatening disabilities will die while the child is still young.¹⁵ To the extent physicians' objections to providing ARTs to patients with disabilities are based on the disability's implications for the future child's welfare,¹⁶ they raise unique considerations that do not

11. See *infra* notes 35–45 and accompanying text.

12. See *infra* notes 47–49 and accompanying text.

13. See *infra* note 70 and accompanying text.

14. See *infra* note 202 and accompanying text.

15. See *infra* note 57 and accompanying text.

16. Physicians also might deny ARTs to individuals with disabilities because treatment would pose risks to the individual's own health. See N.Y. STATE TASK FORCE ON LIFE & THE LAW, ASSISTED REPRODUCTIVE TECHNOLOGIES: ANALYSIS AND RECOMMENDATIONS FOR PUBLIC POLICY 190 (1998) [hereinafter ASSISTED REPRODUCTIVE TECHNOLOGIES]. This Article does not consider whether risks to the patient are a permissible reason to deny treatment to individuals with disabilities, as this question is not unique to decisions about ARTs. See, e.g., *Jairath v. Dyer*, 972 F. Supp. 1461, 1470 (N.D. Ga. 1997) (granting summary judgment to a physician who refused to perform cosmetic surgery on an HIV-positive patient because the treatment would pose a risk to the patient's health); *Glanz v. Vernick*, 756 F. Supp. 632, 638 (D. Mass. 1991) (suggesting that the increased risks associated with surgery might constitute a valid defense to a disability discrimination claim against a surgeon who refused to perform ear surgery on a patient with HIV infection); cf. *Chevron U.S.A., Inc. v. Echazabal*, 122 S. Ct. 2045 (2002) (upholding employer's refusal to hire an individual with disabilities because of risks the workplace would pose to the individual's own health).

apply to the use of disability-related eligibility criteria for other types of medical care.

The goal of this Article is to develop a framework for applying the ADA to disability-related denials of ARTs that takes into account both the heightened risk of disability discrimination in the context of reproduction and the fact that some disabilities pose serious risks to the future child's well-being. In recognizing risks to the future child as a legitimate factor to consider, this Article rejects the view of some commentators that such risks are relevant to reproductive decisions only if the child is likely to suffer so much that she would prefer not to exist.¹⁷ Drawing on the philosophical literature concerning the implications for future children of reproductive decisions, this Article proposes a comparative framework for evaluating the potential impact of ARTs on the children who result. Under this approach, when patients' disabilities create significant risks to the future child, the question would not be whether the child's life is likely to be so awful that nonexistence would be preferable, but how the risks and benefits of the treatment requested by the patient compare to those associated with other available reproductive and parenting options. This comparative analysis would be required only when the patient's disability creates a significant risk that the child's health will fall below a minimum threshold; indirect risks to the child resulting from the patient's disability would not be taken into account.

While the approach recommended in this Article would permit physicians to deny ARTs to patients with disabilities in some circumstances, it also would invalidate many disability-based selection criteria currently in use. For example, depending on the particular circumstances, the approach might support a physician's refusal to provide ARTs to patients with uncontrolled diabetes or hypertension, given the danger that pregnancy complications will result in the birth of a severely premature child with life-threatening or seriously debilitating physical impairments.¹⁸ However, it would not support the denial of ARTs to patients who are HIV-positive, as the risk of transmitting the virus during pregnancy or childbirth can now be reduced to extremely low levels.¹⁹ In any given case, the consequences of the patient's requested treatment for the future child's welfare would have to be compared with the benefits and burdens of the alternatives available to the patient, including other means of achieving biological reproduction (such as gamete donation,²⁰ if applicable) or the adoption of an existing child.

17. See *infra* notes 156–157 and accompanying text.

18. See *infra* note 70.

19. See *infra* note 59 and accompanying text.

20. The term "gamete" includes both sperm and eggs. THOMAS LATHROP STEDMAN, STEDMAN'S MEDICAL DICTIONARY 725 (27th ed. 2000).

Part I of this Article provides a brief overview of the process of ARTs and discusses the types of disability-related factors physicians consider in making patient selection decisions. To provide a context for this discussion, it also examines other efforts in our society to limit the ability of people with disabilities to have and raise children. Part II considers the standards for establishing a prima facie case of disability discrimination under the ADA. Proposing an expansive interpretation of the applicable statutory language, this part emphasizes the importance of subjecting disability-related denials of ARTs to judicial review. The remainder of the Article turns to an evaluation of the future child's interests in decisions about the provision of ARTs, concluding that, in exceptional circumstances, physicians should be permitted to deny ARTs to patients with disabilities that pose significant risks to the future child's health. Part III sets forth an analytical framework for considering the future child's interests in treatment decisions. This framework focuses on both the likelihood and the severity of the risks to the potential child and the risks and benefits associated with alternative reproductive and parenting options available to the patient. Next, Part IV evaluates the nature of physicians' stake in decisions about the use of ARTs. Finally, Part V distinguishes situations in which physicians are inappropriately imposing their preferences on patients from those in which they have legitimate objections that deserve the law's respect. Part V also responds to a likely objection to the framework proposed in this Article—that legitimizing a physician's desire to avoid the birth of children with disabilities is inconsistent with the underlying spirit of the ADA.

I. BACKGROUND

A. Assisted Reproductive Technologies: A Brief Overview

ARTs comprise a variety of procedures designed to achieve pregnancy without sexual intercourse.²¹ They are used by persons physically incapable of reproducing through sexual intercourse, as well as by women who seek to have children without partners of the opposite sex.²² The most commonly

21. See generally ASSISTED REPRODUCTIVE TECHNOLOGIES, *supra* note 16, at 37–93 (outlining the medical options available to people with infertility). The New York State Task Force on Life and the Law defined ARTs as techniques “that do not correct the underlying problem leading to infertility but instead bypass it, allowing the individual to achieve pregnancy in a specific treatment cycle.” *Id.* at 1.

22. Although such women may not be infertile, they may seek medical assistance in reproduction to gain access to sperm banks, some of which will release donor sperm only to licensed physicians. See, e.g., OKLA. STAT. tit. 10, § 553 (2000) (providing that only licensed physicians may perform artificial insemination with donor sperm); see also Daniel Wikler & Norma J. Wikler, *Turkey-baster Babies: The Demedicalization of Artificial Insemination*, 69 MILBANK Q. 5, 20–24 (1991)

used ARTs are assisted insemination, assisted ovulation, and in vitro fertilization (IVF).²³

Assisted insemination involves the insertion of semen into the vagina, the cervical opening, or the back of the uterus.²⁴ It is used to overcome problems interfering with the passage of sperm through the reproductive tract, to improve the chances of fertilization for men with low sperm counts, and to facilitate fertilization in other situations in which the causes of infertility may be unclear.²⁵ Assisted insemination also is used for women without fertility problems who want to conceive a child with donor sperm, that is, sperm from someone other than the woman's sexual partner. Intracervical and intrauterine insemination must be performed by a physician, but intravaginal insemination is a simple procedure that can be performed by women at home.²⁶

For women who do not ovulate regularly or who have other hormonal problems that impair their ability to conceive, various drugs may be prescribed in a process known as assisted ovulation.²⁷ Some women undergoing assisted ovulation attempt to conceive through sexual intercourse, while others combine the drugs with assisted insemination. The drugs used in assisted ovulation are also an integral component of IVF.²⁸

IVF, the most widely publicized type of ART, is a multistage process that involves the stimulation of the woman's ovaries, surgical retrieval of the developing eggs, fertilization of the eggs in a petri dish, and transfer of the resulting embryos into the woman's uterus.²⁹ An expensive procedure³⁰ generally not covered by health insurance,³¹ IVF is usually a treatment of last resort. Success rates for IVF vary considerably, depending on factors such as the patient's age and the cause of infertility.³²

(questioning the appropriateness of laws that require physician involvement in assisted insemination).

23. See ASSISTED REPRODUCTIVE TECHNOLOGIES, *supra* note 16, at 43–60.

24. See *id.* at 49–51.

25. *Id.* at 49–50.

26. See Wikler & Wikler, *supra* note 22, at 8.

27. See ASSISTED REPRODUCTIVE TECHNOLOGIES, *supra* note 16, at 43–49.

28. *Id.* at 43.

29. See *id.* at 51–60.

30. The average cost of an IVF cycle is between \$8000 and \$10,000. Thomas D. Flanigan, *Assisted Reproductive Technologies and Insurance Under the Americans with Disabilities Act of 1990*, 38 BRANDEIS L.J. 777, 780 (2000).

31. As of 1999, over 80 percent of private insurance companies in the United States did not cover IVF. See Lisa M. Kerr, *Can Money Buy Happiness? An Examination of the Coverage of Infertility Services Under HMO Contracts*, 49 CASE W. RES. L. REV. 599, 606 (1999).

32. See ASSISTED REPRODUCTIVE TECHNOLOGIES, *supra* note 16, at 59.

According to data from the Centers for Disease Control and Prevention (CDC), 86,822 cycles of IVF and related procedures³³ were performed in 1999, the most recent year for which statistics are available.³⁴ The prevalence of assisted insemination and assisted ovulation (other than assisted ovulation combined with IVF) is more difficult to determine, as such procedures need not be reported to a central authority and are more likely to be performed by general practitioners, rather than by physicians in specialty programs devoted to ARTs.

B. Disability and Reproduction in Historical Context

Despite the prevalence of parents with disabilities,³⁵ individuals with disabilities still “encounter substantial legal, medical, and familial resistance” to their decision to have a child.³⁶ This resistance has deep historical roots. In the early part of the twentieth century, many states passed laws requiring the sterilization of certain categories of persons, a primary goal of which was to prevent people with disabilities from having children.³⁷ The constitutionality of these laws was upheld in *Buck v. Bell*,³⁸ in which Justice Holmes, upholding the involuntary sterilization of an allegedly “feeble minded white woman,” famously declared that “three generations of imbeciles are enough.”³⁹ While *Buck v. Bell* has been criticized extensively,⁴⁰ the U.S. Supreme Court has never expressly overruled it.⁴¹

33. These statistics also include data on gamete intrafallopian transfer (GIFT) and zygote intrafallopian transfer (ZIFT). GIFT and ZIFT, like IVF, begin with ovulation stimulation and egg retrieval. Unlike IVF, GIFT involves the transfer of unfertilized gametes into the fallopian tubes, while with ZIFT the eggs are fertilized in a petri dish and the resulting embryos are transferred into the fallopian tubes. These procedures were developed as potentially more effective alternatives to IVF, but as success rates with IVF have improved, both GIFT and ZIFT have fallen out of favor. See ASSISTED REPRODUCTIVE TECHNOLOGIES, *supra* note 16, at 60–63.

34. CENTERS FOR DISEASE CONTROL & PREVENTION ET AL., 1999 ASSISTED REPRODUCTIVE TECHNOLOGY SUCCESS RATES 14 (2001), available at <http://www.cdc.gov/nccdphp/drh/art.html>.

35. While data on the number of parents with disabilities are difficult to obtain, see Shade, *supra* note 7, at 158, one disability rights organization estimates that “10.9 percent of all American families with children include at least one parent who has a disability.” Through the Looking Glass, *Parents with Disabilities*, at <http://www.lookingglass.org/parent.php> (last modified July 26, 2002).

36. Adrienne Asch, *Reproductive Technology and Disability*, in REPRODUCTIVE LAWS FOR THE 1990s, at 69, 79 (Sherrill Cohen & Nadine Taub eds., 1989).

37. See Philip R. Reilly, *Eugenics, Ethics, Sterilization Laws*, in 1 ENCYCLOPEDIA OF ETHICAL, LEGAL, AND POLICY ISSUES IN BIOTECHNOLOGY 204, 204–08 (Thomas H. Murray & Maxwell J. Mehlman eds., 2000).

38. 274 U.S. 200 (1927).

39. *Id.* at 207.

40. See, e.g., Paul A. Lombardo, *Three Generations, No Imbeciles: New Light on Buck v. Bell*, 60 N.Y.U. L. REV. 30 (1985).

41. See Chris Watkins, *Beyond Status: The Americans with Disabilities Act and the Parental Rights of People Labeled Developmentally Disabled or Mentally Retarded*, 83 CAL. L. REV. 1415, 1425

Involuntary sterilization laws were a product of the eugenics movement, which sought to improve humanity by ensuring that only the “right” people reproduced.⁴² Physicians played a significant role in the eugenics movement, often justifying coercive legislation in public health terms.⁴³ Eugenics policies in this country had a significant influence on the Nazis,⁴⁴ who cited legislation in California and other states “not only as precedents but also as models.”⁴⁵

While coercive eugenics laws fell out of favor after World War II,⁴⁶ the perception that individuals with disabilities cannot be good parents has remained widespread. In many states, laws governing the termination of parental rights specify a parent’s disability as a factor to consider in terminating the parent’s rights.⁴⁷ Courts sometimes interpret these statutes as creating a presumption that individuals with disabilities are unable to parent:⁴⁸ “[D]eaf parents are thought to be incapable of effectively stimulating language skills; blind parents cannot provide adequate attention or discipline; and parents with spinal cord injuries cannot adequately supervise their children.”⁴⁹

(1995). While the Supreme Court has not overruled *Buck v. Bell*, the continued vitality of its holding was called into question by the Court’s subsequent decision in *Skinner v. Oklahoma*, 316 U.S. 535 (1942). In *Skinner*, the Court held that an Oklahoma statute requiring the sterilization of persons convicted of larceny, but not persons convicted of embezzlement, violated the Equal Protection Clause. *Id.* at 541–42. In reaching its decision, the Court found that “strict scrutiny of the classification which a State makes in a sterilization law is essential.” *Id.* at 541.

42. See DANIEL J. KEVLES, *IN THE NAME OF EUGENICS: GENETICS AND THE USES OF HUMAN HEREDITY* 47 (1985). Eugenics policies in this country appealed to several motivations, including nationalism, class bias, and a “virulent racism.” ALLEN BUCHANAN ET AL., *FROM CHANCE TO CHOICE: GENETICS AND JUSTICE* 34 (2000).

43. See Paul A. Lombardo, *Medicine, Eugenics, and the Supreme Court: From Coercive Sterilization to Reproductive Freedom*, 13 J. CONTEMP. HEALTH L. & POL’Y 1 (1996).

44. LORI B. ANDREWS ET AL., *GENETICS: ETHICS, LAW, AND POLICY* 57 (2002).

45. BUCHANAN ET AL., *supra* note 42, at 38.

46. N.Y. STATE TASK FORCE ON LIFE & THE LAW, *GENETIC TESTING AND SCREENING IN THE AGE OF GENOMIC MEDICINE* 83 (2000) [hereinafter *GENETIC TESTING AND SCREENING*]. Some involuntary sterilization laws remain on the books. See, e.g., N.C. GEN. STAT. §§ 35–36 (2000) (authorizing petitions for sterilization of any “mentally ill or retarded person” based on the person’s best interests “or for the public good”); see also Joe Zumpano-Canto, *Nonconsensual Sterilization of the Mentally Disabled in North Carolina: An Ethics Critique of the Statutory Standard and Its Judicial Interpretation*, 13 J. CONTEMP. HEALTH L. & POL’Y 79, 79 & nn.1–2, 80 (1996) (arguing that North Carolina’s sterilization law unethically infringes on the autonomy of individuals with mental disabilities).

47. Susan Kerr, *The Application of the Americans with Disabilities Act to the Termination of the Parental Rights of Individuals with Mental Disabilities*, 16 J. CONTEMP. HEALTH L. & POL’Y 387, 401 (2000).

48. See, e.g., *In re Amie M.*, 225 Cal. Rptr. 645, 648 (1986) (interpreting a statute governing the termination of parental rights as requiring only proof of the parent’s “mental incapacity or disorder,” regardless of whether there is evidence of a need for “supervision, treatment, care or restraint, or . . . that the parent is dangerous to himself or to others”).

49. Michael Ashley Stein, *Mommy Has a Blue Wheelchair: Recognizing the Parental Rights of Individuals with Disabilities*, 60 BROOK. L. REV. 1069, 1083 (1994) (reviewing JAY MATTHEWS, *A MOTHER’S TOUCH: THE TIFFANY CALLO STORY* (1992)); see also Kerr, *supra* note 47, at 403 (sug-

These beliefs, as Dave Shade notes, reflect the “all-too-familiar picture of the parent with a disability: unable to provide care, unable to provide love, unable to be a parent.”⁵⁰

As the following part suggests, physicians who deny ARTs to patients with disabilities may be motivated by a variety of considerations, not all of which can be dismissed as obviously improper. However, it is important not to lose sight of the context in which disability-based denials of treatment are made. While some considerations of disability by ART practitioners may be legitimate, the stigma associated with reproduction by persons with disabilities makes the danger of inappropriate discrimination a very real concern.

C. Disability-Based Screening by ART Practitioners

ART practitioners consider a variety of factors in determining which patients to accept for treatment.⁵¹ This part examines the extent to which practitioners rely on prospective patients’ medical conditions (other than infertility) in determining whom to accept for treatment. Part II considers whether these medical conditions constitute disabilities under the ADA.

1. HIV

The medical condition most often used as a basis for denying individuals access to ARTs is HIV infection. Until recently, most medical societies supported the denial of ARTs to HIV-positive patients.⁵² In a 1994 policy

gesting that some courts assume that “the mere label of mental disability constitutes grounds for parental rights termination”).

50. Shade, *supra* note 7, at 159; see also Barbara Faye Waxman, *Up Against Eugenics: Disabled Women’s Challenge to Receive Reproductive Health Services*, 12 *SEXUALITY & DISABILITY* 155, 156 (1994) (arguing that “the very nature of a disabled woman’s biological and social bond with a child results in the societal fear of that child becoming physically, socially, psychically, and morally defective”).

51. See generally ASSISTED REPRODUCTIVE TECHNOLOGIES, *supra* note 16, at 177–213 (surveying ART practitioners’ patient screening and selection criteria); Frank Bruni, *The Gods of Fertility: For Reproduction Doctors, The Science Is the Easy Part*, N.Y. TIMES, July 8, 1997, at B1 (describing ethical dilemmas faced by ART practitioners who “must ultimately decide which families they will help create and which they will not”).

52. While there are no recent data indicating the extent to which physicians in the United States deny ARTs to HIV-positive patients, studies in the United Kingdom reveal substantial physician opposition to helping HIV-infected individuals reproduce. See R. Balet et al., *Attitudes Towards Routine Human Immunodeficiency Virus (HIV) Screening and Fertility Treatment in HIV Positive Patients—A UK Survey*, 13 *HUMAN REPRODUCTION* 1085, 1086–87 (1998) (finding that, out of fifty-eight ART programs that responded to a questionnaire, thirty-eight would not treat couples in which the woman was HIV-positive, and nineteen would not treat couples in which either partner was HIV-positive); *IVF Clinics ‘Shun’ HIV Patients*, BBC NEWS, Dec. 2, 2001, at <http://news.bbc.co.uk/1/hi/health/1682749.stm> (reporting that ART programs “were unlikely to offer treatment to couples where only the woman or both partners were infected”).

statement, the ASRM described HIV infection as a “serious contraindication” to the use of ARTs.⁵³ In 1997, the International Federation of Gynecology and Obstetrics issued a more strongly worded statement, providing that “only seronegative individuals should be allowed to participate” in ARTs.⁵⁴

The most frequently cited concern about providing ARTs to HIV-positive patients is that the virus will be transmitted to the child during pregnancy or delivery (a process known as perinatal transmission).⁵⁵ When the ASRM’s 1994 policy was developed, the risk of perinatal transmission was estimated at about 25 percent.⁵⁶ Given the limited treatments available for HIV/AIDS at that time, most of the children born HIV-positive were expected to die within the first few years of life. The limited life expectancy for people with AIDS also meant that children who lived longer (including those who were born uninfected) “were likely to be orphaned in their youth.”⁵⁷

In the past few years, however, both the risk of perinatal transmission and the prognosis for persons infected with HIV have changed dramatically. In 1994, researchers demonstrated that treating women with zidovudine (AZT) during pregnancy reduced the risk of perinatal transmission to ap-

53. Ethics Committee of the American Fertility Society, *Ethical Considerations of Assisted Reproductive Technologies*, 62 FERTILITY & STERILITY 1S, 85S (Supp. 1 1994). The American Fertility Society is the former name of the American Society for Reproductive Medicine (ASRM).

54. Joseph G. Schenker, *FIGO Committee for the Study of Ethical Aspects of Human Reproduction: Guidelines on the Study of AIDS and Human Reproduction*, 12 HUMAN REPRODUCTION 1619, 1619 (1997); see also ASSISTED REPRODUCTIVE TECHNOLOGIES, *supra* note 16, at 209–10 & n.197 (concluding that “[p]hysicians may legitimately decline to provide assisted reproductive services to individuals with medical conditions that make pregnancy dangerous or that are otherwise likely to cause harm to the resulting child” and commenting that “it is arguable that HIV would constitute such a condition at the present time”); Jeffrey Spike & Jane Greenlaw, *Case Study: Ethics Consultation*, 22 J.L. MED. & ETHICS 347, 348 (1994) (defending a hospital ethics committee’s decision to deny ARTs to a couple in which the woman was HIV-positive, based on the Hippocratic obligation to “do no harm”).

55. See Anne Drapkin Lyerly & Jean Anderson, *Human Immunodeficiency Virus and Assisted Reproduction: Reconsidering Evidence, Reframing Ethics*, 75 FERTILITY & STERILITY 843, 850 (2001) (also noting other concerns raised by ART practitioners, including the risk of transmitting the virus between partners and to the staff, and the safety of other embryos and other couples using the facilities).

56. R.S. Sperling et al., *Maternal Viral Load, Zidovudine Treatment, and the Risk of Transmission of Human Immunodeficiency Virus Type 1 from Mother to Infant*, 335 NEW ENG. J. MED. 1621, 1621–23 (1996).

57. Howard Minkoff & Nanette Santoro, *Ethical Considerations in the Treatment of Infertility in Women with Human Immunodeficiency Virus Infection*, 342 NEW ENG. J. MED. 1748, 1748 (2000); cf. Dena Towner & Roberta Springer Loewy, *Ethics of Preimplantation Diagnosis for a Woman Destined to Develop Early-Onset Alzheimer Disease*, 287 JAMA 1038, 1039 (2002) (questioning “the purposive choice of bringing into the world a child for whom the mother will, with near certainty, be unable to provide care”).

proximately 8 percent.⁵⁸ More recent studies have shown that, when AZT is combined with other drugs and cesarean delivery, the risk of transmission can be lowered to less than 2 percent.⁵⁹ At the same time, the development of protease inhibitors and other therapies has significantly increased the life expectancy and the quality of life for both children and adults living with HIV, leading some commentators to characterize HIV as a chronic illness rather than an invariably fatal disease.⁶⁰

These developments have led to a reconsideration of policies discouraging the provision of ARTs to HIV-positive patients. For example, in a June 2000 article in *The New England Journal of Medicine*, two physicians argued that practitioners should “provide full and frank counseling about treatment for infertility” to HIV-positive patients and then “respect the wishes of the couple.”⁶¹ While acknowledging that physicians might appropriately discourage ARTs for patients with other medical conditions,⁶² they argued that HIV should no longer be treated as a contraindication to treatment in all cases.⁶³

In February 2002, the ASRM reexamined its policy on providing ARTs to HIV-positive patients.⁶⁴ In a revised policy statement, the ASRM noted the dramatic reduction in the rate of HIV transmission from infected women

58. Sperling et al., *supra* note 56, at 1621.

59. See The International Perinatal HIV Group, *The Mode of Delivery and the Risk of Vertical Transmission of Human Immunodeficiency Virus Type 1*, 340 *NEW ENG. J. MED.* 977, 984 tbl.3 (1999).

60. See Kent A. Sepkowitz, *AIDS—The First 20 Years*, 344 *NEW ENG. J. MED.* 1764, 1770 (2001); see also Linda Villarosa, *Women Now Look Beyond H.I.V., to Children and Grandchildren*, *N.Y. TIMES*, Aug. 7, 2001, at F7 (noting that improvements in the life expectancy and quality of life for people with AIDS are leading more HIV-positive women to attempt to have children).

61. Minkoff & Santoro, *supra* note 57, at 1750.

62. See *id.* at 1749 (giving the example of “a woman with poorly controlled type 1 diabetes and renal disease”).

63. See *id.* (suggesting, however, that it might be appropriate to exclude “women with AIDS-associated lymphoma that does not respond to a highly active antiretroviral therapy”); see also Carole Gilling-Smith et al., *HIV and Infertility: Time to Treat*, 322 *BRIT. MED. J.* 566, 567 (2001) (arguing that “couples in whom one or both partners are infected should have access to the same fertility advice and treatment as non-infected individuals to allow them to conceive with the minimum of risk to their partners or children”); Lyerly & Anderson, *supra* note 55, at 855 (concluding that “the exclusion of HIV-infected couples from infertility services may no longer be morally or legally defensible”). Even before the development of treatments to reduce the risk of perinatal transmission, some commentators questioned the appropriateness of excluding HIV-positive individuals from ART programs in all cases. Writing in 1994, Taunya Banks argued that “any blanket policy of refusing to provide . . . infertility services constitutes separate, different, unequal, and less effective medical treatment based on a protected physical disability in violation of the ADA.” Banks, *supra* note 7, at 64. In reaching this conclusion, she assumed that the risk of perinatal transmission was “no more than thirty-six percent and . . . possibly as low as thirteen percent.” *Id.* at 63.

64. See Ethics Committee of the American Society for Reproductive Medicine, *Human Immunodeficiency Virus and Infertility Treatment*, 77 *FERTILITY & STERILITY* 218 (2002).

to their offspring, as well as the potential for “specific methods for sperm preparation and testing” to reduce the risk of transmission from infected men to uninfected women.⁶⁵ As long as the provider has the clinical and laboratory facilities necessary to care for HIV-positive patients, the new policy states, “one can argue that health care providers are not acting unethically if they have taken all reasonable precautions to limit the risk of transmitting HIV to offspring or to an uninfected partner.”⁶⁶ Citing the ADA, the report concludes that, “[u]nless health care workers can show that they lack the skill and facilities to treat HIV-positive patients safely or that the patient refused reasonable testing and treatment, they may be legally as well as ethically obligated to provide requested reproductive assistance.”⁶⁷

2. Other Medical Conditions

Much less attention has been devoted to the use of ARTs by patients with medical conditions other than HIV, even when those conditions pose comparable or even greater risks to the potential child. Indeed, some commentators object to the denial of ARTs to HIV-positive patients in part because of their perception that people with HIV are being singled out, while patients with equally serious conditions are offered ARTs without any consideration of the risks.⁶⁸

However, there is evidence that at least some ART programs take a broad range of medical conditions into account in deciding whom to treat.

65. *Id.* at 219 (noting that, in one study involving almost 1600 inseminations of 513 HIV-negative women, no cases of transmission to the women or children were reported). Some physicians who offer this procedure report that they “do not publicize their work to avoid accusations that they place women at risk of HIV infection and opinions that men with the potentially fatal disease do not have a right to father children.” Press Release, Kaiser Family Foundation, Facilities Performing HIV Risk-Reducing IVF Technique Try to Stay “Low Profile,” Apr. 11, 2001, at http://www.kaisernetwork.org/Daily_reports/rep_index.cfm?hint=2&DR_ID=3980. Other physicians regard couples in which the man is HIV-positive as an attractive “market niche” in the highly competitive fertility industry. Gina Kolata, *Fertility Inc.: Clinics Race to Lure Clients*, N.Y. TIMES, Jan. 1, 2002, at F1.

66. Ethics Committee of the American Society for Reproductive Medicine, *supra* note 64, at 220.

67. *Id.* at 221. *But cf.* Press Release, Kaiser Family Foundation, Australian Fertility Specialists Agree to Grant HIV-Positive Women Access to IVF, Aug. 14, 2001, at http://www.kaisernetwork.org/Daily_reports/rep_index.cfm?hint=1&DR_ID=6367 (quoting Helen Szoke, the head of Victoria’s Infertility Treatment Authority, who opined that providing ARTs to HIV-positive patients might violate state laws in Australia that prohibit the use of ARTs by “people who run the risk of a genetic abnormality, or a disease being transmitted to the unborn child”).

68. Minkoff & Santoro, *supra* note 57, at 1748–49; *cf.* Carol Levine & Nancy N. Dubler, *Uncertain Risks and Bitter Realities: The Reproductive Choices of HIV Infected Women*, 68 MILBANK Q. 321, 328–29 (1990) (observing, in response to calls for HIV-positive women to refrain from reproducing, that “[m]any HIV-infected babies are no worse off than babies born with other severe and life-threatening birth conditions, yet there are no comparable claims that all such babies should have been aborted”).

According to a 1998 study by the New York State Task Force on Life and the Law, ART practitioners in New York State have denied treatment to prospective patients who had severe lupus with limited kidney function, uncontrolled diabetes, and uncontrolled hypertension, based on both the risk to the woman's own health and the risk to the potential child resulting from pregnancy complications.⁶⁹ The risks to the child are primarily those related to prematurity and low birth weight, which substantially increase the risk of neonatal death and lifelong disability.⁷⁰

Some practitioners also have expressed an unwillingness to treat patients because of their risk of transmitting genetic diseases to their offspring. A 1987 survey by the federal Office of Technology Assessment found that 79 percent of practitioners would deny ARTs to patients at risk of transmitting a "serious genetic disorder[]" to their offspring.⁷¹ Some commentators have supported such exclusions, arguing that physicians should not provide ARTs to carriers of serious disorders like Tay-Sachs, a seriously debilitating and ultimately fatal neurological condition, if they will not use pre-implantation or prenatal diagnosis to avoid the birth of affected children.⁷² In practice, however, most physicians do not suggest genetic testing for couples who do not raise the issue on their own.⁷³

Patients with mental disabilities also may experience difficulties obtaining ARTs. Some physicians attempt to screen out patients who are expected to have difficulties complying with the difficult treatment regimen required of IVF patients,⁷⁴ based partly on evaluations of the patient's overall mental health. Depending on how this type of screening is applied, it may disproportionately exclude patients with diagnosable mental disorders. In

69. ASSISTED REPRODUCTIVE TECHNOLOGIES, *supra* note 16, at 190.

70. See Geoffrey Chamberlain, *Medical Problems in Pregnancy—I*, 302 BRIT. MED. J. 1262, 1262 (1991) (describing pregnancy complications experienced by women with chronic diseases, including heart disease, diabetes, thyroid disease, jaundice, anemia, and urinary tract infections); Chang-Ryul Kim et al., *Effects of Maternal Hypertension in Very-Low-Birth-Weight Infants*, 150 ARCHIVES PEDIATRICS & ADOLESCENT MED. 686, 686 (1996) (stating that mothers with hypertension have an increased incidence of low-birth-weight infants); Kristine Y. Lain & James M. Roberts, *Contemporary Concepts of the Pathogenesis and Management of Preeclampsia*, 287 JAMA 3183, 3183 (2002) (identifying chronic hypertension and diabetes as risk factors for preeclampsia, and noting that "[i]nfants of women with preeclampsia have a 5-fold increase in mortality compared with infants of mothers without the disorder"); Joseph J. Volpe, *Neurologic Outcome of Prematurity*, 55 ARCHIVES NEUROLOGY 297, 297 (1998) (noting that 15 percent of very-low-birth-weight infants do not survive, and that those who survive often experience neurological problems).

71. U.S. CONGRESSIONAL OFFICE OF TECHNOLOGY ASSESSMENT, ARTIFICIAL INSEMINATION: PRACTICE IN THE UNITED STATES: SUMMARY OF A 1987 SURVEY—BACKGROUND PAPER 29–30 (1988), available at http://www.wws.princeton.edu/~ota/disk2/1988/8804_n.html.

72. See Spike & Greenlaw, *supra* note 54, at 349.

73. See ASSISTED REPRODUCTIVE TECHNOLOGIES, *supra* note 16, at 191.

74. See *id.* at 195. The IVF process, which involves frequent office visits and regular, self-administered injections, is both time-consuming and emotionally difficult. See *id.* at 120–24 (noting that infertility treatment is often described as "an emotional roller-coaster").

addition, some physicians will not treat patients who appear incapable of providing stable home environments for their children.⁷⁵ In some cases, predictions about parenting ability may be based on formal or informal evaluations of prospective patients' mental health.⁷⁶

Because denials of treatment take place in private and may not be reported, it is likely that the extent of medically based treatment denials is greater than the few cases reported in the literature. For practitioners concerned about the impact of treatment on the potential child's welfare, numerous medical conditions in addition to those discussed above might be considered contraindications to the provision of ARTs. For example, children born to women with phenylketonuria (PKU), an enzyme disorder, face a greater than 90 percent risk of mental retardation and a 12 to 15 percent risk of other congenital birth defects.⁷⁷ While these risks can be minimized if the woman follows a special diet during pregnancy, compliance with the diet is extremely difficult, and most pregnancies among women with PKU are not well controlled.⁷⁸

II. THE ADA AND ARTS: ESTABLISHING A PRIMA FACIE CASE

The general rule in this country is that physicians are under no obligation to treat persons seeking medical treatment. Even in emergencies, physicians are free to walk away from individuals in need of medical attention, unless they have a preexisting physician-patient relationship with the individual or have assumed a contractual duty to accept new patients under particular circumstances.⁷⁹ Like employers making decisions about hiring and firing, however, physicians may not exercise their discretion to pick and choose patients in a manner that violates applicable civil rights laws. Aside from laws prohibiting discrimination on the basis of race, religion, and national origin⁸⁰—factors that ART practitioners do not claim any right to

75. See *id.* at 181; see also National Advisory Board on Ethics in Reproduction, *Ethical and Policy Issues Related to Oocyte Recipients in the Clinical Setting*, in *NEW WAYS OF MAKING BABIES: THE CASE OF EGG DONATION* 248, 257–58 (Cynthia B. Cohen ed., 1996) (endorsing the limited use of psychological screening to identify individuals likely to be unfit parents).

76. See *ASSISTED REPRODUCTIVE TECHNOLOGIES*, *supra* note 16, at 192.

77. See D.B. Paul, *The History of Newborn Phenylketonuria Screening in the U.S.*, in *PROMOTING SAFE AND EFFECTIVE GENETIC TESTING IN THE UNITED STATES: FINAL REPORT OF THE TASK FORCE ON GENETIC TESTING* 137, 146 (Neil A. Holtzman & Michael S. Watson eds., 1998).

78. See *GENETIC TESTING AND SCREENING*, *supra* note 46, at 163.

79. See Maxwell J. Mehlman, *The Patient-Physician Relationship in an Era of Scarce Resources: Is There a Duty to Treat?* 25 *CONN. L. REV.* 349, 360 (1993) (“[T]he physician must agree to enter into a relationship with a patient before he is required to treat the patient and to fulfill the other duties externally imposed upon him. He cannot be forced to assume these obligations against his will.”).

80. See, e.g., 42 U.S.C. §§ 2000a, 2000d (2000).

consider in determining eligibility criteria⁸¹—the most important constraint on physicians' discretion over patient selection decisions is Title III of the ADA, which prohibits disability discrimination in places of public accommodation, including private physicians' offices.⁸²

To establish a *prima facie* case of disability discrimination under the ADA, an individual denied ARTs because of one of the medical conditions discussed in Part I would have to make two showings. First, she would have to establish that she was denied ARTs because of a condition that constitutes a "disability" under the statute.⁸³ Second, she would have to establish that the decision amounted to "discrimination on the basis of disability" within the meaning of Title III.⁸⁴

Both of these elements present significant hurdles for ADA plaintiffs. Indeed, as discussed below, courts seeking to avoid reaching the merits of these cases could interpret the statutory language in a manner that excludes many of the medically based screening criteria discussed in Part I. Interpreting the ADA in this fashion, however, would frustrate the goals of the statute. The fact that patients' disabilities often will be relevant to medical decisions may actually increase the likelihood of inappropriate disability dis-

81. Although physicians do not claim the right to consider race in determining eligibility for ARTs, some commentators have found "evidence that some physicians and fertility clinics may deliberately steer Black patients away from reproductive technologies." Dorothy E. Roberts, *Race and the New Reproduction*, 47 HASTINGS L.J. 935, 940 (1996). In addition, physicians who deny ARTs to couples at risk of transmitting recessive genetic disorders might disproportionately exclude members of certain racial groups; for example, African Americans are more likely than Caucasians to be carriers of sickle cell disease. See INSTITUTE OF MEDICINE COMMITTEE ON ASSESSING GENETIC RISKS, ASSESSING GENETIC RISKS: IMPLICATIONS FOR HEALTH AND SOCIAL POLICY 41 (Lori B. Andrews et al. eds., 1994). However, few ART practitioners require genetic testing for patients who do not request it themselves. See *supra* text accompanying note 73.

82. 42 U.S.C. § 12181(7)(F) (2000). Title III also requires physicians to make reasonable accommodations to their physical facilities so that they are accessible to individuals with disabilities. See *id.* at § 12182(b)(2)(A)(iv). In addition to the ADA, all states have their own laws against disability discrimination, some of which provide broader protections to individuals with disabilities than the ADA. See David W. Webber & Lawrence O. Gostin, *Discrimination Based on HIV/AIDS and Other Health Conditions: "Disability" as Defined Under Federal and State Law*, 3 J. HEALTH CARE L. & POLY 266, 286–87 (2000). Many states and localities have additional civil rights laws that apply to patient selection decisions by health care practitioners, such as laws barring discrimination on the basis of marital status or sexual orientation. See, e.g., New Jersey Law Against Discrimination, N.J. STAT. ANN. § 10:5 (West 1993). However, the application of these laws to denials of treatment by ART practitioners remains unclear. See ASSISTED REPRODUCTIVE TECHNOLOGIES, *supra* note 16, at 186 (suggesting that, in jurisdictions that prohibit discrimination against unmarried persons, "it is possible that [ART] programs could limit their services to cases of diagnosed infertility, thereby excluding single women who wish to reproduce with donor semen solely because they do not have partners of the opposite sex"); Julien S. Murphy, *Should Lesbians Count as Infertile Couples? Antilebian Discrimination in Assisted Reproduction*, in EMBODYING BIOETHICS: RECENT FEMINIST ADVANCES 103, 105–10 (Anne Donchin & Laura M. Purdy eds., 1999) (discussing strategies for promoting access to ARTs by lesbian couples).

83. See *infra* Part II.A.

84. See *infra* Part II.B.

crimination in the context of health care. Unlike, for example, a store owner, who has no reason to think that any disability-based denial of services would ever be permissible, physicians are likely to view patients' disabilities as a legitimate factor to take into account—and, in some cases, they may be correct. The danger is that physicians will become accustomed to making decisions based on their patients' disabilities, without recognizing when they have crossed the line between appropriate medical considerations and inappropriate social judgments.

This danger is particularly pronounced in the area of ARTs, given the stigma associated with reproduction and parenting by individuals with disabilities.⁸⁵ This stigma is particularly pronounced for individuals with disabilities that may be transmitted to offspring, or that create risks of pregnancy complications that endanger the future child's health.⁸⁶ Even when physicians sincerely believe they are basing their decisions on legitimate medical factors, they may be motivated by ignorance about the parenting ability of people with disabilities, or by unconscious biases that affect their evaluation of the medical facts.

Accordingly, this part argues that courts should interpret "disability" and "discrimination on the basis of disability" broadly in the context of ART decisions, in order to facilitate patients' ability to establish a *prima facie* case. Such an approach would not necessarily lead to a finding of unlawful discrimination, but it would ensure that the physician's reasons for denying the patient treatment are subject to judicial review.

A. Definition of Disability

The ADA defines a "person with a disability" as an individual who (1) has "a physical or mental impairment that substantially limits one or more of the major life activities of such individual," (2) has "a record of such an impairment," or (3) is "regarded as having such an impairment."⁸⁷ The Su-

85. Cf. Samuel R. Bagenstos, *Subordination, Stigma, and "Disability,"* 86 VA. L. REV. 397, 445 (2000) (arguing that "[t]he statutory 'disability' category should embrace those actual, past, and perceived impairments that subject people to systematic disadvantages in society," and that "[i]mpairments that are stigmatized—that type people who have them as 'abnormal or defective in mind or body'—are particularly likely to meet the systematic disadvantage standard") (quoting Carol J. Gill, *Questioning Continuum*, in *THE RAGGED EDGE: THE DISABILITY EXPERIENCE FROM THE PAGES OF THE FIRST FIFTEEN YEARS OF THE DISABILITY RAG* 42, 44 (Barrett Shaw ed., 1994)).

86. See *id.* at 486 n.334 (arguing that "even exposing one's unborn child to the risk of a relatively minor physical condition can be quite stigmatizing"). As an example, Samuel Bagenstos refers to the "public outcry" that occurred when Bree Walker Lampley, a newscaster in Los Angeles, became pregnant. Ms. Lampley had ectrodactylism, a genetic condition in which the bones of the hands and feet are fused. See *id.*

87. 42 U.S.C. § 12102(2) (2000).

preme Court's 1998 decision in *Bragdon v. Abbott*⁸⁸ is likely to be the starting point for a court applying this definition to individuals denied ARTs because of impairments associated with reproductive risks.

In *Bragdon*, a woman who was infected with HIV but who had not yet developed symptoms of AIDS sued a dentist who refused to fill her cavity outside a hospital. Rejecting the defendant's contention that the plaintiff was not disabled because she remained asymptomatic, the Court held that HIV infection is a physical impairment that substantially limited the plaintiff's ability to reproduce, which the Court characterized as a major life activity.⁸⁹ The Court reasoned that, if an HIV-positive woman attempts to have a child, she risks infecting her partner and transmitting the virus to her offspring during pregnancy and childbirth.⁹⁰ Although the Court recognized that the risk of perinatal transmission could be substantially reduced through antiretroviral therapy, it was unwilling to rule "that an 8% risk of transmitting a dread and fatal disease to one's child does not represent a substantial limitation on reproduction."⁹¹ Rejecting the dissent's effort to limit the definition of disability to conditions that make it impossible to engage in major life activities, the Court concluded that "[w]hen significant limitations result from the impairment, the definition [of disability] is met even if the difficulties are not insurmountable."⁹² Moreover, the Court noted, while "[c]onception and childbirth are not impossible for an HIV victim, . . . without doubt, [they] are dangerous to the public health."⁹³

The Court's recognition of reproduction as a "major life activity," and its finding that risks to offspring can constitute a "substantial limitation" on reproduction, are potentially applicable to a broad range of medical conditions associated with reproductive risks. For example, diabetes, hypertension, and certain cancers can make pregnancy dangerous to both the woman

88. 524 U.S. 624 (1998).

89. *Id.* at 638. *Bragdon's* finding that reproduction is a major life activity suggests that infertility constitutes a disability, as infertility is by definition a substantial limitation on the ability to reproduce. See Kimberly Horvath, *Does Bragdon v. Abbott Provide the Missing Link for Infertile Couples Seeking Protection Under the ADA?*, 2 DEPAUL J. HEALTH CARE L. 819, 839 (1999). For purposes of the issues addressed in this Article, however, whether infertility constitutes a disability is largely irrelevant. Even if most individuals denied ARTs are disabled because they are infertile, their infertility would not be the basis of the denial of treatment. The population of prospective ART patients is overwhelmingly infertile; physicians who deny ARTs to persons who are infertile do so despite their infertility, not because of it.

90. See *Bragdon*, 524 U.S. at 639–40. The Court's assumption that reproduction by an HIV-positive woman would require exposing the woman's partner to HIV was incorrect, as the risk of female-to-male transmission easily could be eliminated by using artificial insemination.

91. *Id.* at 641. The risk of perinatal transmission is now thought to be lower than 2 percent. See *supra* note 59 and accompanying text.

92. *Bragdon*, 524 U.S. at 641.

93. *Id.*

and the potential child.⁹⁴ Under *Bragdon*, if the risks associated with these conditions are found to “substantially limit” reproduction, persons with these conditions might be considered individuals with disabilities under the ADA.⁹⁵

It is possible, however, that courts might find the logic of *Bragdon* inapplicable to persons denied ARTs, even if they have medical conditions associated with significant reproductive risks. Unlike the plaintiff in *Bragdon*, whose HIV infection led her to forego having children,⁹⁶ individuals who seek ARTs are actively attempting to reproduce. Under a narrow reading of *Bragdon*, a court might find that a medical condition “substantially limits” reproduction for a particular individual only if the condition’s reproductive risks lead that person to refrain from having children. If proof of the specific plaintiff’s unwillingness to reproduce is necessary to establish a reproductive disability under *Bragdon*, persons seeking to have children through ARTs could not claim they are disabled because they have medical conditions associated with reproductive risks.⁹⁷

Such a narrow interpretation of *Bragdon* would significantly reduce the scope of ADA protection for persons denied ARTs on the basis of medical conditions. Nonetheless, even with this narrow interpretation some people would still fit within the statute’s definition of disability because they are substantially limited in major life activities unrelated to reproduction. For example, the statute would clearly apply to persons denied ARTs because they are blind or deaf.⁹⁸

Moreover, there is no reason to assume that courts will choose to interpret *Bragdon* so narrowly. While *Bragdon* did not establish that HIV infection is a per se disability,⁹⁹ it made clear that “the disability definition does

94. See *supra* notes 69–70 and accompanying text.

95. See *Berk v. Bates Adver. USA, Inc.*, 25 F. Supp. 2d 265, 268 (S.D.N.Y. 1998) (finding that a woman with breast cancer was disabled in part because the cancer made pregnancy unduly risky).

96. In *Bragdon*, the plaintiff testified that “her HIV infection controlled her decision not to have a child.” *Bragdon*, 524 U.S. at 641. Because the case was decided on cross-motions for summary judgment, the Court assumed for purposes of its decision that this unchallenged testimony was true. See *id.*

97. See *Webber & Gostin, supra* note 82, at 285 (suggesting that the plaintiff in *Bragdon* might not have been considered disabled if she “had not asserted that HIV was the reason for her declining to bear children,” but concluding that “[i]f this is indeed the intention of the Court, it makes little sense”).

98. See *Bryant v. Better Bus. Bureau*, 923 F. Supp. 720, 743 (D. Md. 1996) (recognizing that deafness is a disability under the ADA); *Anderson v. Gus Mayer Boston Store*, 924 F. Supp. 763, 774–75 (E.D. Tex. 1996) (finding that blindness constitutes an ADA disability). Other conditions that also might remain covered include cystic fibrosis, which has been held to substantially limit the major life activity of breathing. See *Emery v. Caravan of Dreams, Inc.*, 879 F. Supp. 640, 643 (N.D. Tex. 1995), *aff’d*, 85 F.3d 622 (5th Cir. 1996).

99. See *Bragdon*, 524 U.S. at 642.

not turn on personal choice.”¹⁰⁰ In addition, in *Sutton v. United Airlines*,¹⁰¹ the Court noted that persons may be substantially limited in a major life activity even if they have overcome a disability’s primary burdens.¹⁰² This may be the case for persons who seek to reproduce despite medical conditions involving reproductive risks. As the Court recognized in *Bragdon*, HIV-positive persons who choose to reproduce face “economic and legal consequences” that other people need not confront.¹⁰³ In addition, some medical conditions may make pregnancy especially dangerous,¹⁰⁴ or they may require the woman to stop taking her usual medications to minimize risks to the fetus.¹⁰⁵ For individuals willing to reproduce despite these consequences, the additional burdens associated with having a child might constitute substantial limitations on reproduction in and of themselves.¹⁰⁶

If courts adopt this broader perspective, individuals denied access to ARTs because of medical conditions that make reproduction more dangerous, costly, or otherwise burdensome might be considered substantially limited in their ability to reproduce, even though those limitations have not led them to forego reproduction entirely. Presumably, this would mean that persons denied ARTs because they are HIV-positive would be considered disabled.¹⁰⁷ Even though the risk of perinatal transmission has been reduced

100. *Id.* at 641.

101. 527 U.S. 471 (1999).

102. *Id.* at 488; cf. *Christian v. St. Anthony Med. Ctr.*, 117 F.3d 1051, 1052 (7th Cir. 1997) (“[I]f a medical condition that is not itself disabling nevertheless requires, in the prudent judgment of the medical profession, treatment that is disabling, then the individual has a disability within the meaning of the Act, even though the disability is, as it were, at one remove from the condition.”).

103. *Bragdon*, 524 U.S. at 641.

104. See *supra* note 70.

105. See Mohammad M. Iqbal et al., *The Effects of Lithium, Valproic Acid, and Carbamazepine During Pregnancy and Lactation*, 4 J. TOXICOLOGY: CLINICAL TOXICOLOGY 381, 388 (2001) (concluding that women treated with drugs for manic depression are at high risk for fetal complications during pregnancy); Cheryl H. Waters et al., *Outcomes of Pregnancy Associated with Antiepileptic Drugs*, 51 ARCHIVES NEUROLOGY 250, 250 (1994) (noting that all three major antiepileptic drugs are associated with an increased risk of fetal death and anomalies).

106. Samuel Bagenstos makes a similar point when explaining why some infertile individuals should be considered disabled even if they are able to reproduce through ARTs. Bagenstos argues that even though

[m]edical treatments may allow a person with infertility to have a child, . . . that fact alone does not necessarily relieve the substantial limitation in the major life activity of reproduction. When gestation can occur only through a burdensome and stigmatizing course of treatment, a person’s medically generated ability to reproduce will not eliminate the substantial limitation on reproduction.

Bagenstos, *supra* note 85, at 498–99.

107. Even if persons seeking ARTs cannot establish that they have been substantially limited in their ability to reproduce, it is possible that HIV-positive individuals would be considered disabled for reasons unrelated to reproduction. See *Bragdon*, 524 U.S. at 637 (“Given the pervasive, and invariably fatal, course of the disease, its effect on major life activities of many sorts might have been relevant to our inquiry.”).

significantly since *Bragdon* was decided,¹⁰⁸ having a child while HIV-positive still entails significant medical, economic, and social burdens, including those directly associated with efforts to reduce the risk of perinatal transmission.¹⁰⁹ Prospective ART patients with other conditions that make pregnancy dangerous¹¹⁰ also might be able to claim that they are disabled because they can reproduce only by assuming significant medical risks to themselves and their offspring.

Yet, even under this broader interpretation of *Bragdon*, individuals denied ARTs for medical reasons would not necessarily satisfy the definition of disability under the ADA. One category of prospective patients that would probably fall outside the scope of ADA protection would be persons denied treatment because of genetic mutations that do not affect their own health, but that nonetheless create risks to the health of their future children. For example, persons with one copy of the genetic mutation associated with Tay-Sachs disease do not and never will have Tay-Sachs themselves, but if two Tay-Sachs carriers reproduce, their children face a 25 percent chance of being born with the disease.¹¹¹ While a 25 percent chance of transmitting Tay-Sachs is clearly significant, it is unlikely that Tay-Sachs carriers would be considered disabled under the ADA. First, it is doubtful that genetic mutations that do not affect an individual's own health would constitute "physical impairments" under the ADA's definition of disability.¹¹² Second,

108. See *supra* text accompanying note 59.

109. The additional reproductive burdens associated with efforts to avoid HIV transmission also suggest that HIV-positive men are substantially limited in their ability to reproduce, even if the risk of transmission to their partners or offspring can be eliminated entirely. See Ethics Committee of the American Society for Reproductive Medicine, *supra* note 64, at 219 (concluding that, for couples in which only the male partner is HIV-positive, attempting to reproduce through sexual intercourse is "unsafe and . . . not recommended," and suggesting that such couples consider undergoing ARTs using "specific methods for sperm preparation and testing that can substantially reduce the chance of HIV transmission to the female partner and child"); cf. *Rollf v. Interim Pers., Inc.*, No. 2:99CV44, 1999 U.S. Dist. LEXIS 18096, at *10 (E.D. Mo. Nov. 4, 1999) (finding that a man with Hepatitis C was substantially limited in his ability to reproduce even if he could reproduce safely through artificial insemination). But see *Cruz Carrillo v. AMR Eagle, Inc.*, 148 F. Supp. 2d 142, 145 (D.P.R. 2001) (declining to find an HIV-positive man disabled under the ADA because the man "failed to introduce into evidence any medical evidence from which a reasonable jury could find that HIV substantially limits a man's ability to reproduce").

110. See *supra* text accompanying notes 69–70.

111. See GENETIC TESTING AND SCREENING, *supra* note 46, at 16.

112. See Mary Crossley, *The Disability Kaleidoscope*, 74 NOTRE DAME L. REV. 621, 707 (1999) ("Unless the mutation is currently causing some impact on bodily systems, it does not seem to fit within the definition of 'impairment.'"); Laura F. Rothstein, *Genetic Discrimination: Why Bragdon Does Not Ensure Protection*, 3 J. HEALTH CARE L. & POL'Y 330, 342 (2000) ("Individuals who are unaffected carriers of recessive disorders . . . would not be covered under even the most expansive reading of *Bragdon*."). Because asymptomatic genetic mutations do not adversely affect individuals' bodily systems, they are distinguishable from asymptomatic HIV infection, which, as the Supreme Court noted in *Bragdon*, has a "constant and detrimental effect on the infected person's hemic and lymphatic systems from the moment of infection." *Bragdon*, 524 U.S. at 637. But see Joseph S.

the risks associated with recessive disorders exist only when both partners are carriers; if a carrier reproduces with a noncarrier, it is impossible for their child to be born with the disease. Courts might be unwilling to recognize a disability that exists only in the context of particular relationships.¹¹³

Nonetheless, there is a third possible way to interpret *Bragdon's* application to decisions by ART practitioners, one that would subject most of the screening criteria discussed in Part I to the scrutiny of the ADA. This interpretation would combine *Bragdon's* finding that reproduction is a major life activity with the ADA's inclusion of individuals who are "regarded as" disabled in the statutory definition of disability.¹¹⁴ Under the "regarded as" definition, individuals are considered disabled if the "covered entity"—in this case, the ART practitioner—mistakenly believes that (1) the individual "has a physical impairment that substantially limits one or more [of the individual's] major life activities," or (2) "an actual, nonlimiting impairment substantially limits one or more major life activities."¹¹⁵ In light of *Bragdon*, a court might conclude that *whenever* a physician refuses to provide ARTs based on his or her judgment that an individual's medical condition makes reproduction inadvisable, the physician is expressing the belief that the condition substantially limits the individual's ability to reproduce. In these cases, the denial of treatment itself would be evidence that the physician "regards" the person as someone who, like the plaintiff in *Bragdon*, is unable to reproduce safely.¹¹⁶ If this interpretation is correct, the ADA would extend to any situation in which a physician refuses to provide ARTs based on the reproductive risks associated with a medical condition, even if those conditions would not be considered disabilities in situations not involving

Alper, *Does the ADA Provide Protection Against Discrimination on the Basis of Genotype?*, 23 J.L. MED. & ETHICS 167, 168 (1995) (arguing that "[a] carrier of a recessive trait . . . suffers from an impairment," because "it is the function of the reproductive system of an organism to produce healthy offspring").

113. See George J. Annas, *Protecting Patients from Discrimination—The Americans with Disabilities Act and HIV Infection*, 339 NEW ENG. J. MED. 1255, 1257 (1998) (suggesting that the ADA would not offer protection if "only the couple as a couple . . . is disabled").

114. See *supra* text accompanying note 87.

115. *Sutton v. United Airlines*, 527 U.S. 471, 489 (1999).

116. This argument is different from the "regarded as" claim rejected by the Supreme Court in *Sutton*. In that case, an airline refused to hire twin sisters because of their visual impairments, even though their vision could be fully corrected with glasses. *Id.* at 475–76. The Court rejected the women's argument that the employer had "regarded" them as disabled, as the evidence showed only that the employer regarded them as incapable of working as global airline pilots. *Id.* at 490. "Because the position of global airline pilot is a single job," the Court held, "this allegation does not support the claim that respondent regards petitioners as having a substantially limiting impairment." *Id.* at 493. By contrast, when a physician refuses to provide ARTs to an individual who has an impairment associated with reproductive risks, the physician is regarding the individual as incapable of reproducing safely, which, under *Bragdon*, constitutes a substantial limitation on a major life activity. See *supra* text accompanying notes 88–93.

ARTs.¹¹⁷ This logic might even extend to individuals with recessive genetic mutations for conditions like Tay-Sachs, as long as the physician regards the mutation as a physical impairment that substantially limits the ability to reproduce.¹¹⁸

B. Disability Discrimination Under Title III

Title III of the ADA prohibits discrimination “on the basis of disability” in places of public accommodation.¹¹⁹ In addition, the definition of “discrimination” under Title III encompasses “eligibility criteria that screen out or tend to screen out an individual with a disability or any class of individuals with disabilities,” unless those criteria are “necessary” for the services being offered.¹²⁰ Most commentators agree that, in light of this language, facially neutral eligibility criteria with a disparate impact on people with disabilities also can constitute discrimination “on the basis of disability” in violation of Title III.¹²¹

117. For example, most courts have concluded that obesity is not a disability. See, e.g., *Hazeldine v. Beverage Media, Ltd.*, 954 F. Supp. 697, 704–05 (S.D.N.Y. 1997). However, if a physician refuses to provide ARTs to an obese woman because of the risk to the future child, see generally *Florence Galtier-Dereure et al., Obesity and Pregnancy: Complications and Cost*, 71 AM. J. CLINICAL NUTRITION 1242S (2000), which describes pregnancy-related risks associated with obesity, arguably the physician “regards” the woman as substantially limited in the major life activity of reproduction.

118. Even if genetic carriers are not considered disabled under the ADA, they might fit within the definition of disability under some state antidiscrimination laws. For example, a “disability” under New York’s disability discrimination law includes “[a] genetic . . . condition[] which prevents the exercise of a normal bodily function or is demonstrable by medically accepted clinical or laboratory diagnostic techniques.” N.Y. EXEC. LAW § 292(21) (McKinney 2001) (emphasis added). Under this definition, a genetic mutation might be considered a disability even if it has no impact on an individual’s bodily functions, as long as the mutation is “demonstrable” through scientific testing.

119. 42 U.S.C. § 12182(a) (2000).

120. *Id.* at § 12182(b)(2)(A)(i).

121. See, e.g., *Crossley*, *supra* note 1, at 68 (“The ADA clearly contemplates reaching at least some forms of disparate impact discrimination . . .”); Wendy E. Parmet, *Discrimination and Disability: The Challenges of the ADA*, 18 L. MED. & HEALTH CARE 331, 336 (1990) (noting “the ADA’s open embrace of disparate impact analysis”). It is true that, in other contexts involving health care, courts have upheld facially neutral policies despite significant burdens on people with disabilities. For example, in *Alexander v. Choate*, 469 U.S. 287 (1985), the Supreme Court upheld a state policy limiting Medicaid coverage for inpatient care to fourteen days, despite the fact that the policy “affected three persons with a disability for every nondisabled person who was affected.” *Mehlman et al.*, *supra* note 6, at 1400 (suggesting that, in light of *Alexander*, “the protection afforded by the prohibition against disparate impact is very limited”). *Alexander*, however, involved a challenge to the scope of benefits offered by a program, not a determination as to whether individuals with disabilities are eligible to receive the benefits the program makes available to individuals who are not disabled. Moreover, in *Alexander*, the Court emphasized that the state’s policy did not have the effect of denying individuals with disabilities “meaningful access” to the services in question. *Alexander*, 469 U.S. at 302.

In the context of ARTs, a straightforward application of Title III suggests that a refusal to treat patients because of medical conditions that constitute disabilities, such as a refusal to provide ARTs to patients who are HIV-positive or who have certain types of cancers, would be presumptively unlawful. In addition, facially neutral eligibility criteria that disproportionately burden people with disabilities, such as policies denying treatment to patients at high risk of developing pregnancy complications, or patients likely to die before their children reach adulthood, also might implicate the statute, despite the fact that those criteria might be applied to some patients who would not be considered disabled under the statutory definition.¹²²

Because disability-related considerations are often an unavoidable component of medical judgment, however, some courts have held that disability discrimination laws should be construed more narrowly in cases involving medical treatment decisions. For example, in *United States v. University Hospital*,¹²³ the U.S. Court of Appeals for the Second Circuit observed that “where medical treatment is at issue, it is typically the handicap itself that gives rise to, or at least contributes to, the need for services.”¹²⁴ Finding that unlawful discrimination occurs “only where the individual’s handicap is unrelated to, and thus improper to consideration of, the services in question,”¹²⁵ the court concluded that physicians may legitimately consider disabilities that are related to the patient’s need for care.¹²⁶ On this basis, the court rejected the application of federal disability discrimination law to a hospital’s decision not to perform corrective surgery on a baby born with spina bifida, microcephaly, and hydrocephalus. Other courts have endorsed the Second Circuit’s focus on relatedness, finding that unlawful disability

122. For example, such policies might be applied to older women seeking to reproduce with donor eggs. See, e.g., Tony Hope et al., *Should Older Women Be Offered In Vitro Fertilisation? The Interests of the Potential Child*, 310 BRIT. MED. J. 1455, 1456 (1995). Some policies that have a disparate impact on individuals with disabilities, however, might be considered “necessary” for the effective provision of services. For example, even if denying ARTs to individuals likely to have difficulty complying with the treatment regimen has a disparate impact on individuals with mental disabilities, see *supra* text accompanying note 74, it might be considered necessary for physicians to limit their services to patients with a reasonable chance of completing treatment. Cf. Peters, *supra* note 6, at 833 n.174 (suggesting that a patient’s “[c]apacity to benefit is presumably a permissible eligibility criterion”).

123. 729 F.2d 144 (2d Cir. 1984). Although *University Hospital* was decided under Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. 794 (2000), not the ADA, “the basic application of both statutes to medical treatment decisions that take disability into account is the same.” Peters, *supra* note 6, at 807–08.

124. *Univ. Hosp.*, 729 F.2d at 156.

125. *Id.*

126. The court’s rationale was that such individuals cannot be considered “otherwise qualified” for the treatment. See *id.* While Title III of the ADA does not contain the Rehabilitation Act’s “qualifications” language, it “achieves the same result by permitting the exclusion of disabled persons who cannot meet ‘necessary’ eligibility criteria.” Peters, *supra* note 6, at 809.

discrimination occurs only when the patient's disability is unrelated to the condition for which treatment was denied.¹²⁷

If courts follow the *University Hospital* approach, it is possible that at least some disability-related denials of ARTs would not be covered by the ADA. For example, both spinal cord injuries and HIV infection are associated with higher rates of infertility,¹²⁸ suggesting that these conditions "give[] rise to, or at least contribute[] to, the need for services"¹²⁹ for at least some patients seeking ARTs. If courts focus solely on the relationship between the patient's disability and her need for medical treatment, denials of ARTs to patients with these conditions might not constitute disability discrimination under Title III.

It would be unwise, however, for courts to permit physicians to deny ARTs to certain disabled patients simply because their disabilities are causally connected to infertility, while subjecting treatment denials based on other disabilities to the scrutiny of the ADA. While the *University Hospital* opinion emphasized the causal relationship between the patient's disability and the condition requiring medical treatment, the court appeared to be thinking primarily of situations involving treatment for the disability itself.¹³⁰ In those situations, it would be difficult for plaintiffs to show that they were denied treatment that would have been given to patients without the disability, as patients without the disability would have no need for the particular treatment at issue.¹³¹ This concern does not apply when physicians deny ARTs to patients with disabilities that are causally connected to infertility, such as HIV infection or spinal cord injury, as the patient can prove discrimination by showing that the physician has treated patients with comparable types of infertility who did not have the disabilities in question.

Moreover, the Second Circuit's focus on the relationship between treatment decisions and the patient's disability has not enjoyed universal

127. See *Grzan v. Charter Hosp.*, 104 F.3d 116, 121 (7th Cir. 1997); *Johnson v. Thompson*, 971 F.2d 1487, 1493–94 (10th Cir. 1992).

128. See U.S. CONGRESSIONAL OFFICE OF TECHNOLOGY ASSESSMENT, *INFERTILITY: MEDICAL AND SOCIAL CHOICES* 71 (1988) (spinal cord injury); Minkoff & Santoro, *supra* note 57, at 1748 (HIV).

129. *Univ. Hosp.*, 729 F.2d at 156.

130. The government tried to avoid this outcome by identifying the "handicapping condition" as the baby's microcephaly, which was allegedly the reason the baby was not treated for the separate conditions of spina bifida and hydrocephalus. See *id.* at 150 (noting the government's effort to compare the baby's nontreatment to the hospital's usual practice in cases of babies "suffering from spina bifida and hydrocephalus, but not microcephaly"). However, the court did not accept the government's view "that Baby Jane Doe can be viewed as suffering from not one, but multiple handicaps." *Id.* at 156.

131. See Peters, *supra* note 6, at 813 (suggesting that the court was concerned that "plaintiffs in these cases would not be able to prove their discrimination claims in the classic style of civil rights litigation").

acceptance. Some courts have dispensed entirely with the relatedness analysis,¹³² while others have focused on the relationship between the disability and the patient's ability to benefit from treatment, as opposed to the disability's impact on the patient's need for care.¹³³ If the patient's capacity to benefit is the issue, the fact that a disability is causally related to the patient's need for ARTs would not mean that denials of ARTs on the basis of the disability are exempt from the coverage of Title III.¹³⁴

As an alternative to the Second Circuit's relatedness analysis, Mary Crossley has argued that courts should distinguish between differential treatment "based simply on the disability's existence" and "consideration of any relevant medical effects a disability produces."¹³⁵ According to Crossley, disability discrimination in the medical context occurs when physicians use disability "as a proxy for an individualized, factual assessment of the disabled person's condition."¹³⁶ When, by contrast, physicians consider patients' disabilities in order to make "a thorough assessment of their individual conditions and prognoses," reliance on disability should not be considered discrimination under the ADA.¹³⁷ Under this approach, courts might prohibit ART practitioners from making blanket judgments about the impact of a patient's disability on the outcome of treatment—for example, assuming that all patients with diabetes will experience dangerous pregnancy complications, ignoring the fact that many patients with diabetes do not face such risks. However, they might permit physicians to deny treatment based on an individualized assessment of the potential impact of the disability in the particular patient's case.¹³⁸

While this approach represents a significant improvement over the Second Circuit's relatedness analysis, it would still leave patients with disabilities vulnerable to potentially inappropriate denials of treatment. The

132. See *In re Baby K*, 832 F. Supp. 1022, 1028 (E.D. Va. 1993), *aff'd on other grounds*, 16 F.3d 590 (4th Cir. 1994).

133. See *Glanz v. Vernick*, 750 F. Supp. 39, 46 (D. Mass. 1990).

134. Possible exceptions would be when an individual's disability reduces the likelihood that she will become pregnant or carry the pregnancy to term.

135. Crossley, *supra* note 4, at 1651.

136. *Id.* at 1654. Mary Crossley acknowledges that it would be appropriate to rely on the existence of a disability as a proxy for an individualized determination when "the simple fact of a certain disability is proven to have a high statistical correlation with certain medical effects." *Id.* at 1654 n.279.

137. *Id.* at 1655. The U.S. Court of Appeals for the First Circuit has indicated its support for this approach. See *Lesley v. Chie*, 250 F.3d 47, 55 (1st Cir. 2001) (suggesting that a patient denied treatment because of a disability "may argue that her physician's decision was discriminatory on its face, because it rested on stereotypes of the disabled rather than an individualized inquiry into the patient's condition").

138. Because this approach focuses on the "medical effects" of a disability, it would probably not permit physicians to deny ARTs to patients with disabilities because of concerns about the disability's impact on the patient's parenting ability or life expectancy.

problem is that physicians can make an accurate, individualized judgment about the medical effects of patients' disabilities but then rely on those medical effects in a manner that has a discriminatory effect. For example, a physician may accurately determine that a particular HIV-positive patient has a 1 to 2 percent chance of transmitting the virus to her child, and then rely on that risk as a basis for denying the patient ARTs. Such a decision would be discriminatory if the physician does not deny ARTs to patients with comparable risks of transmitting different, but equally serious, conditions to their offspring.¹³⁹ Even if there are no equivalent medical conditions against which to compare a particular denial of treatment, denying ARTs based on medical risks experienced solely by patients with disabilities would "tend to screen out" patients with disabilities, and it would therefore constitute discrimination on the basis of disability under Title III.¹⁴⁰

Whether a treatment denial is appropriate should be based on the nature of the particular medical effect at issue, not simply on whether the physician has engaged in an individualized determination. The best way to determine appropriateness would be to consider any decision based on a disability presumptively unlawful, and then determine whether the medical considerations constitute a legitimate defense. The next part therefore examines the defenses to disability discrimination under Title III.

III. THE DIRECT THREAT DEFENSE AND THE FUTURE CHILD'S INTERESTS

Even if denying ARTs to patients with disabilities constitutes disability discrimination under Title III, it would be permissible if it is necessary to avoid "a direct threat to the health or safety of others."¹⁴¹ In *Bragdon*, the Supreme Court explained that the direct threat defense is designed to reconcile the "importance of prohibiting discrimination against individuals with disabilities" with the need to "protect[] others from significant health and

139. See Minkoff & Santoro, *supra* note 57, at 1748 (noting that some physicians unwilling to provide ARTs to HIV-positive patients are willing to treat patients at greater risk of transmitting equally serious genetic diseases to their offspring).

140. See *supra* text accompanying note 120. As David Orentlicher argues, one of the reasons some individuals with disabilities face increased risks from medical treatment is that society has devoted insufficient resources to addressing their medical needs. Because "even meaningful medical differences" may be the result of "past invidious bias or other unfair biases in social structure," he argues, those differences should not be used to justify a disability-related denial of treatment unless the differences in expected benefits are substantial. See *Destructuring Disability*, *supra* note 3, at 69–72.

141. 42 U.S.C. § 12182(b)(3) (2000). See generally Ann Hubbard, *Understanding and Implementing the ADA's Direct Threat Defense*, 95 Nw. U. L. REV. 1279 (2001).

safety risks, resulting, for instance, from a contagious disease.”¹⁴² This part considers whether the direct threat defense can be invoked when a physician refuses to provide ARTs based on concerns about the impact of an individual’s disability on the future child.¹⁴³ It begins by considering, and then rejecting, an interpretation of the direct threat defense based on the approach courts have adopted in the context of “wrongful life” cases. It then proposes an alternative framework for evaluating the impact of ARTs on the resulting child’s interests, based on a comparative evaluation of the risks and benefits of the treatment requested by the patient versus those associated with alternative reproductive and family-building options.¹⁴⁴

A. The Wrongful Life Analogy

One way to determine whether a patient’s disabilities pose a “direct threat” to the future child would be to analyze the question from the perspective of a hypothetical child born following the provision of ARTs in particular circumstances. Thus, we might assume that a physician agrees to provide ARTs to a patient with a certain disability and that, as a result of the disability, the resulting child is born severely impaired. If it is possible to say that this child has been “harmed” by being born under these circumstances, risking such an outcome might be considered a “direct threat” to the future child’s health.

Such an approach, however, would make the direct threat defense all but irrelevant to cases involving the refusal to provide ARTs. Once the perspective of a particular child is assumed, it becomes virtually impossible to say that ARTs have “harmed” that child, even if the child is born severely impaired. Withholding ARTs would not have led to the birth of the child without the impairments; instead, if ARTs were withheld, the child would

142. *Bragdon*, 524 U.S. at 649. The direct threat defense has been used to justify a number of actions that would otherwise have violated the ADA’s prohibitions. See, e.g., *Montalvo v. Radcliffe*, 167 F.3d 873, 879 (4th Cir. 1999) (excluding a person with AIDS from a group karate class); *Breece v. Alliance Tractor-Trailer Training II*, 824 F. Supp. 576, 580 (E.D. Va. 1993) (excluding a hearing-impaired applicant from a tractor trailer training school).

143. Whether the direct threat defense would apply when treatment poses risks to the patient’s own health is beyond the scope of this Article. See *supra* note 16.

144. While this part focuses on the ADA’s “direct threat” defense, the definition of discrimination under Title III provides another possible basis for taking the future child’s interests into account. As discussed above, see *supra* text accompanying note 120, Title III includes in its definition of discrimination “eligibility criteria that screen out or tend to screen out an individual with a disability or any class of individuals with disabilities,” unless those criteria are “necessary” for the services being offered. 42 U.S.C. § 12182(b)(2)(A)(i) (2000). Based on this language, if a physician could demonstrate that the comparative risk-benefit analysis proposed in this part is a “necessary” component of ethical decisionmaking, relying on that analysis would not constitute discrimination under Title III.

never have existed at all.¹⁴⁵ The only situation in which it would make sense to say that a particular child has been harmed by being born with significant impairments is when the burdens of life with the impairments are so severe that existence itself is a net disadvantage—that is, if the child, once alive, would prefer that she had never been born.¹⁴⁶

Whether being born under particularly disadvantageous circumstances can be considered harmful to the child is the issue in cases alleging the tort of “wrongful life.” In these cases, children born with severe impairments have claimed that they were harmed by the negligent failure of the physicians providing prenatal care to detect the impairments in time for the parents to abort. While a few jurisdictions have recognized the tort of wrongful life,¹⁴⁷ the majority of courts to confront the issue have rejected the claim.¹⁴⁸

145. Thus, these situations are different from cases like *Renslow v. Mennonite Hosp.*, 367 N.E.2d 1250 (Ill. 1977), in which the court permitted a child to sue for injuries resulting from the preconception transfusion of its Rh-negative mother with Rh-positive blood. See *id.* at 1251, 1255. In that case, the plaintiff’s theory was that the transfusion harmed the child by causing prenatal injuries and leading to the child’s premature birth. See *id.* at 1251. Had the transfusions not been performed, the same child could have been born uninjured.

146. See Joel Feinberg, *Wrongful Life and the Counterfactual Element in Harming*, 4 SOC. PHIL. & POL’Y 145, 159 (1986) (“If nonexistence in a given case would have been objectively preferable to existence, as judged for example by the law’s convenient ‘reasonable person,’ then any wrongful act or omission that caused (permitted) the child to be born can be judged to have harmed the child.”). This understanding of “harming” differs from Feinberg’s usual definition of the concept, which focuses on whether an individual has been made “worse off than she would have been” had a particular action not been taken. See *id.* at 149. According to Feinberg, the usual definition of harming cannot logically be applied to actions that result in a person’s existence: “If A had prevented B’s birth . . . B would not have been better off as a result, for B would not have been as a result.” *Id.* at 158. Nonetheless, he argues, when a person has been brought into the world in unbearable circumstances, it makes sense to say that the person has been harmed. Properly understood, the claim is not that the person has been made worse off than she would have been had she never been born (a logical impossibility), but that, *once she is alive*, she would prefer that she did not exist. See *id.* at 158–59. “Whether true or not,” Feinberg concludes, “this is an intelligible claim without contradiction or paradox.” *Id.* at 159.

147. See *Turpin v. Sortini*, 643 P.2d 954, 966 (Cal. 1982); *Procanik v. Cillo*, 478 A.2d 755, 764 (N.J. 1984); *Harbeson v. Parke-Davis, Inc.*, 656 P.2d 483, 497 (Wash. 1983). In 2001, the French Cour de Cassation, the highest court in the country, held that children born with severe disabilities may bring actions for wrongful life against the physicians who failed to detect their abnormalities prenatally. Elizabeth Bryant, *Lawmakers Limit Wrongful Birth Suits*, UPI, Jan. 10, 2002, LexisNexis UPI File. However, the decision sparked a widespread public outcry, and it was reversed by the legislature in 2002. See *id.*

148. See, e.g., *Siemieniec v. Lutheran Gen. Hosp.*, 512 N.E.2d 691, 702 (Ill. 1987); *Miller v. Duhart*, 637 S.W.2d 183 (Mo. Ct. App. 1982); *Smith v. Cote*, 513 A.2d 341, 355 (N.H. 1986); *Becker v. Schwartz*, 386 N.E.2d 807, 811–12 (N.Y. 1978); *Ellis v. Sherman*, 515 A.2d 1327, 1329–30 (Pa. 1986). Although most courts have rejected wrongful life claims, many courts have upheld claims for wrongful birth, which allege that a physician’s failure to diagnose fetal abnormalities harmed the child’s parents. See generally Mark Strasser, *Wrongful Life, Wrongful Birth, Wrongful Death, and the Right to Refuse Treatment: Can Reasonable Jurisdictions Recognize All But One?* 64 MO. L. REV. 29 (1999) (summarizing the state of the law and criticizing the distinctions courts use in cases alleging negligent prenatal diagnosis).

Many of these courts have concluded that courts cannot rationally determine whether the burdens of a particular existence outweigh the benefits of life itself.¹⁴⁹

As many commentators have noted, the claim that existence can never constitute a net disadvantage seems overly broad.¹⁵⁰ While it is probably true that most persons are glad to be alive even under extremely difficult circumstances, some situations involve such unqualified suffering that, given a choice, it might be better not to have been born at all.¹⁵¹ If a child is born with a condition that imposes such significant suffering that the burdens of being alive are disproportionate to the benefits, it might be said to have been better for the child not to have been conceived—just as it becomes appropriate at some point not to forestall death for someone who is suffering at the end of life.¹⁵² When a child's existence is, and always has been, excessively burdensome to her, it is not unreasonable to say that the child was harmed by the technologies that enabled her to be born.¹⁵³

Nonetheless, even recognizing that conception can sometimes harm the resulting child, it still would be difficult for physicians to show that such an outcome is likely at the time ARTs are provided. As Bonnie Steinbock points out, the number of situations in which children can be considered harmed by being brought into existence “appears vanishingly small. Only for conditions which combine excruciating and unrelievable physical pain and such a brief life span that the child is unable to develop any compensat-

149. See, e.g., *Becker*, 386 N.E.2d at 812 (“Whether it is better never to have been born at all than to have been born with even gross deficiencies is a mystery more properly to be left to the philosophers and the theologians.”); *Ellis*, 515 A.2d at 1329 (“[W]e regard the assertion that the child has been injured by its existence as too speculative for us to determine.”).

150. See, e.g., Philip G. Peters, Jr., *Protecting the Unconceived: Nonexistence, Avoidability, and Reproductive Technology*, 31 ARIZ. L. REV. 487, 502–03 (1989); Strasser, *supra* note 148, at 57–58.

151. As examples, Philip Peters suggests Tay-Sachs disease (“a genetically based enzyme deficiency that is characterized by self-mutilation and severe motor defects and leads to death in childhood”), Lesch-Nyhan syndrome (“a disease which involves uncontrollable spasms, mental retardation, compulsive self-mutilation, and early death”), polycystic kidney disease (“invariably fatal in infancy”), and “the more severe forms of spina bifida, brain malformation or severe retardation, especially if combined with chronic pain, paralysis, incontinence, deafness or blindness.” Peters, *supra* note 150, at 502–03.

152. Most state laws on surrogate decisionmaking recognize that, in some cases, the withholding or withdrawal of life-sustaining treatment can be in the best interests of dying patients. See generally Charles P. Sabatino, *The Legal and Functional Status of the Medical Proxy: Suggestions for Statutory Reform*, 27 J.L. MED. & ETHICS 52 (1999) (surveying state laws).

153. For Feinberg, the wrongful life standard would be satisfied if a “proxy chooser” would find that “whatever interests the impaired party might have, or come to have, they would already be doomed to defeat by his present incurable condition.” Feinberg, *supra* note 146, at 164. In such circumstances, he concludes, “it would be irrational—contrary to what reason decrees—for a representative and protector of those interests to prefer the continuance of that condition to nonexistence.” *Id.*

ing abilities could we assert the claim with any confidence.”¹⁵⁴ Even when such situations occur, it may not have been possible to predict them at the time of conception. Because the significance of a risk depends on both its severity and the likelihood it will materialize, a remote possibility of harm to the child probably would not satisfy the direct threat defense.¹⁵⁵

The difficulty of showing that children are harmed by being born with even severe impairments has led some commentators to conclude that the interests of future children will rarely provide a sufficient reason to object to the use of ARTs. According to John Robertson, for example, even if the children resulting from ARTs are likely to suffer tremendous disadvantages, “[r]isking damage to offspring would not seem to wrong the offspring if it were not possible for them to be conceived or born without undergoing the risk of damage.”¹⁵⁶ The only exception Robertson would recognize is when the risks to the child are so significant that the child’s birth would satisfy the wrongful life standard—in other words, if “any life at all with the conditions of [the child’s] birth would be so harmful to him that from his perspective he would prefer not to live.”¹⁵⁷ Given the rarity of such circumstances, if the wrongful life standard were applied to the ADA’s direct threat defense, the defense might never be available to ART practitioners, even when patients’ disabilities pose substantial reproductive risks.

154. Bonnie Steinbock, *Harm and Future Persons* (2000) (manuscript at 18–19, on file with the author); see also Bonnie Steinbock & Ron McClamrock, *When Is Birth Unfair to the Child?* 24 HASTINGS CENTER REP., Nov.–Dec. 1994, at 15, 16 (noting the “highly limited applicability” of the wrongful life standard).

155. Cf. Hubbard, *supra* note 141, at 1322 (arguing that, under Title I of the ADA, “the fact that the potential harm is severe, or even fatal, does not justify an employment decision based on a risk that is speculative or remote, particularly if the risk is of a magnitude the employer routinely tolerates”).

156. John A. Robertson, *Embryos, Families, and Procreative Liberty: The Legal Structure of the New Reproduction*, 59 S. CAL. L. REV. 939, 988 (1986); see also JOHN A. ROBERTSON, *CHILDREN OF CHOICE: FREEDOM AND THE NEW REPRODUCTIVE TECHNOLOGIES* 75 (1994) (“[A] child’s interests are hardly protected by preventing the child’s existence.”).

157. ROBERTSON, *supra* note 156, at 75; see also Ruth Macklin, *Splitting Embryos on the Slippery Slope: Ethics and Public Policy*, 4 KENNEDY INST. ETHICS J. 209, 219–21 (1994) (agreeing with John Robertson that the interests of future children are relevant only when the burdens of existence will outweigh the benefits). The claim that reproduction is inconsistent with the interests of the resulting child only when the child is likely to suffer so much she would prefer not to exist has been used to justify a variety of controversial reproductive decisions. See, e.g., Hope et al., *supra* note 122, at 1456 (arguing that to consider a fifty-nine-year-old woman’s limited life expectancy “as a sufficient reason for denying fertility treatment is tantamount to claiming that it is better never to have existed than for one’s mother to have died when one is still quite young”); Richard A. Posner, *The Ethics and Economics of Enforcing Contracts of Surrogate Motherhood*, 5 J. CONTEMP. HEALTH L. & POL’Y 21, 23 (1989) (defending surrogate parenting contracts in part because “without the contract the baby probably wouldn’t be born at all,” and doubting that “there is any evidence that such babies, when they become adults, decide they’d rather not have been born”).

B. Problems with the Wrongful Life Analogy

The mistake in applying the wrongful life standard to decisions about the provision of ARTs is that it starts by assuming the very question at issue—the birth of the child.¹⁵⁸ Once a person exists, her life has significant benefits that outweigh even the worst of disadvantages; thus, if we start by assuming the child's existence it will be virtually impossible to justify taking that existence away. At the time decisions about ARTs are made, however, there is not yet a child with an interest in existing.¹⁵⁹ From the *preconception* perspective, the question is whether it makes sense to bring a person into the world with a particular set of benefits and burdens, not whether a specific child, once born, would prefer to have her existence taken away. The fallacy of the wrongful life analogy is the assumption that the standard for resolving these questions is necessarily symmetrical. As Philip Peters puts it, “the instinct of self-preservation, along with other related feelings like hope and faith, may explain the conclusion that a miserable life is worth continuing, but not worth receiving.”¹⁶⁰

Failure to recognize this distinction produces results that, from an intuitive perspective, are extremely difficult to defend.¹⁶¹ For example, the wrongful life analogy implies that there would be nothing wrong with two cystic fibrosis carriers undergoing IVF, screening their embryos prior to implantation, and then deliberately selecting the embryo *with* cystic fibrosis to bring to term. Although cystic fibrosis can lead to serious health problems, and individuals with the disease have a median survival age of only thirty years,¹⁶² it would be hard to say that life with cystic fibrosis is worse than not existing. Under the wrongful life standard, then, deliberately selecting the embryo with cystic fibrosis would be perfectly acceptable because it would not harm the interests of anyone at all.¹⁶³

158. ASSISTED REPRODUCTIVE TECHNOLOGIES, *supra* note 16, at 210 (arguing that relying on the wrongful life standard to evaluate the consequences of ARTs “assumes the very factor under deliberation—the child’s conception and birth” (quoting N.Y. STATE TASK FORCE ON LIFE & THE LAW, SURROGATE PARENTING: ANALYSIS AND RECOMMENDATIONS FOR PUBLIC POLICY 120 (1988))).

159. See Cynthia B. Cohen, “Give Me Children or I Shall Die!” *New Reproductive Technologies and Harm to Children*, HASTINGS CENTER REP., Mar.–Apr. 1996, at 19, 21 (criticizing the assumption “that children with an interest in existing are waiting in a spectral world of nonexistence where their situation is less desirable than it would be were they released into this world”).

160. Peters, *supra* note 150, at 541.

161. Cf. Cohen, *supra* note 159, at 19 (characterizing as “startling” the claim that the interests of the children resulting from ARTs are irrelevant to an ethical analysis).

162. See Trisha Brown & Elinor Langfelder Schwind, *Update and Review: Cystic Fibrosis*, 8 J. GENETIC COUNSELING 137, 151 (1999).

163. While this example may seem far-fetched, efforts to increase the likelihood of having offspring with a specific disability are not unknown. See, e.g., Liza Mundy, *A World of Their Own*,

Yet, the conclusion that the two persons in the above hypothetical did nothing wrong seems implausible. Even if it is impossible to say that the child resulting from the couple's actions has been "harmed," deliberately selecting the embryo with cystic fibrosis is no more defensible than imposing cystic fibrosis on an otherwise healthy child. Joel Feinberg, for example, argues that "behavior that brings a human being and its unhappiness-engendering impairment into existence at one stroke" is wrong even if the action does not technically cause anyone harm.¹⁶⁴ What makes such behavior wrong, he suggests, is that it causes individuals to suffer without their consent. While a liberal society must defer to individuals' autonomous choices to injure their own well-being, Feinberg argues, "in the case of wrongly conceived infants, the infants' autonomy is not an issue."¹⁶⁵ Thus, even in a society committed to respect for individual autonomy, no one has a right to "wantonly introduce . . . avoidable human suffering into the world."¹⁶⁶

Requiring physicians to provide ARTs except in situations that satisfy the wrongful life standard also would be difficult to reconcile with the Supreme Court's analysis of the definition of disability in *Bragdon*. Under *Bragdon*, the reason certain medical conditions are considered disabilities is that they are associated with such significant risks to potential offspring that people with such conditions are likely to refrain from reproducing.¹⁶⁷ Unless the risks to the child also are considered in evaluating the direct threat defense, however, physicians might have to help affected individuals attempt to become pregnant—even though it was the risks associated with pregnancy that triggered coverage of the condition under the ADA in the first place. Moreover, in *Bragdon*, the Court's statement that "conception and

WASH. POST MAG., Mar. 31, 2002, at W22 (describing a deaf couple's efforts to have a deaf child by seeking out a deaf sperm donor).

164. JOEL FEINBERG, HARMLESS WRONGDOING 328 (1988); see also Dan W. Brock, *Procreative Liberty*, 74 TEX. L. REV. 187, 205 (1995) (reviewing ROBERTSON, *supra* note 156) (suggesting that, "in wrongful handicap cases the action is wrong, although the person who suffers the handicap is not harmed," and that "such nonharmful wrongs could justify limitation of or interference with procreative liberty").

165. FEINBERG, *supra* note 164, at 328.

166. *Id.* Building on Feinberg's analysis, Dena Davis argues that having a child likely to suffer considerably is wrong because it violates the Kantian maxim that people should be treated as ends in themselves. Dena S. Davis, *Genetic Dilemmas and the Child's Right to an Open Future*, 28 RUTGERS L.J. 549, 569–70 (1997). Thus, she concludes that it is wrong for deaf parents to use pre-implantation genetic diagnosis to ensure that their children will also be deaf, because "[d]eliberately creating a child who will be forced irreversibly into the parents' notion of 'the good life' violates the Kantian principle of treating each person as an end in herself and never as a means only." *Id.* at 569. Acknowledging that people often have children for self-interested reasons, Davis argues that "[g]ood parenthood requires a balance between having a child for our own sakes and being open to the moral reality that the child will exist for *her* own sake." *Id.* at 570.

167. See *supra* text accompanying notes 90–93.

childbirth” by persons with HIV are “dangerous to the public health” immediately followed its observations about the risk of perinatal transmission.¹⁶⁸ If a particular risk constitutes a public health danger, it is reasonable to assume that it constitutes a direct threat to *somebody’s* health.¹⁶⁹

Furthermore, characterizing ARTs as a direct threat to the future child’s health or safety would raise few of the policy concerns that arise in wrongful life cases. Because ADA cases would arise before any particular child has been conceived, courts would not be characterizing any particular person’s life as a net disadvantage; prior to conception, no particular person can be said to exist. Thus, unlike in wrongful life cases, a court would not need to worry that its decision might disparage the worth of an existing person. In addition, the court would not be required to quantify the extent to which the child’s life is worse than nonexistence, as there would be no need to award damages based on the amount the child has been harmed.

C. An Alternative Framework

This part argues that, instead of interpreting the direct threat defense according to the wrongful life standard, courts should evaluate the risks and benefits of ARTs in relation to the other reproductive and parenting options available under the circumstances. Thus, rather than looking at the impact of reproductive decisions on a particular child in isolation, the analysis would consist of a comparative assessment of a broad range of future scenarios involving hypothetical children. Under this framework, even if it is impossible say that a particular reproductive decision will harm a specific child, a decision might be objectionable because it would result in *unnecessary* suffering, given the option of having a different child who would suffer less.¹⁷⁰

168. *Bragdon v. Abbott*, 524 U.S. 624, 641 (1998).

169. It is possible that the Court was referring to the danger that the plaintiff would expose her partner to HIV if the couple attempted to reproduce through unprotected sexual intercourse. However, as noted above, the Court’s assumption that taking such a risk was necessary for the plaintiff to reproduce was incorrect. See *supra* note 90.

170. Cf. Philip G. Peters, Jr., *Harming Future Persons: Obligations to the Children of Reproductive Technology*, 8 S. CAL. INTERDISC. L.J. 375, 383–84 (1999) (arguing that a fertility clinic that implants a large number of embryos in order to maximize its pregnancy rates, despite the risk of dangerous multiple pregnancies, acts wrongfully by “tak[ing] a risky route to reproduction when a safer one was available”). Jeffrey Gaba relies on an analysis grounded in virtue ethics to reach a similar conclusion in the context of environmental policy. Jeffrey M. Gaba, *Environmental Ethics and Our Moral Relationship to Future Generations: Future Rights and Present Virtue*, 24 COLUM. J. ENVTL. L. 249, 283–87 (1999). Instead of focusing on our moral relationship to future generations in terms of rights and obligations, Gaba claims, we should ask whether particular actions “represent an expression of our best moral character.” *Id.* at 287. Thus, even if an action will not harm a specific future person, it may be wrong because it is inconsistent with “the virtue of benevolence

The comparative approach rests on a fundamentally different set of moral assumptions than the wrongful life analogy. In focusing on the perspective of a particular child resulting from the provision of ARTs under specific circumstances, the wrongful life analogy is an example of a “person-affecting” theory of moral reasoning. Such theories evaluate the morality of actions by asking whether those actions would result in better or worse circumstances for specific persons.¹⁷¹ Under a person-affecting approach, the interests of future children are largely irrelevant to individuals’ reproductive choices because, in the vast majority of circumstances, no particular person is harmed by being brought into the world. If the disadvantages likely to be experienced by future children have any bearing on reproductive decisions, it is only insofar as they impose burdens on the rights and interests of already-existing people, such as those of the prospective parents, the parents’ other children, or society at large.¹⁷²

The comparative approach, by contrast, looks not only at an action’s consequences for specific persons, but also at the legitimacy of causing those consequences in light of the other options that exist. Derek Parfit offers the example of a situation in which risks to one child easily can be avoided by having a different child a few months later. In the example, a woman is told by her physician that she should delay pregnancy for two months because she has a condition that is likely to cause any child she conceives to be born with a birth defect. If she waits to conceive until her condition disappears, she can avoid this risk completely.¹⁷³ While most people would undoubtedly wait to become pregnant under those circumstances, and would justify the decision with reference to the future child’s best interests, person-affecting principles cannot explain why it makes sense to wait.¹⁷⁴ If the woman disre-

which expresses the rightness of promoting the well-being and quality of life of humanity.” *Id.* at 285.

171. See MELINDA A. ROBERTS, CHILD VERSUS CHILDMAKER: FUTURE PERSONS AND PRESENT DUTIES IN ETHICS AND THE LAW 2 (1998) (“[W]here other forms of consequentialism identify conduct that is wrong *simpliciter*, the person-affecting intuition takes the view that to do something wrong is always a matter of, and ultimately explicable in terms of, wronging *some person*.”).

172. David Heyd, for example, argues that “genesis choices can and should be guided exclusively by reference to the interests, welfare, ideals, rights, and duties of those making the choice, the ‘generators,’ the creators, or the procreators.” DAVID HEYD, GENETHICS: MORAL ISSUES IN THE CREATION OF PEOPLE 96 (1992). Thus, Heyd argues that it might be inappropriate for a woman with rubella to intentionally conceive a child, given the risk the child will be born deaf, but the reason “relat[es] to the extra burden of the existence of a deaf person on the parents, on society, or on existing siblings in the family,” not to the impact of deafness on the future child herself. *Id.* at 105–06.

173. Derek Parfit, *On Doing the Best for Our Children*, in ETHICS & POPULATION 100–01 (Michael D. Bayles ed., 1976). See generally DEREK PARFIT, REASONS AND PERSONS 351–79 (1984) (discussing the “non-identity problem”).

174. That is, unless waiting would benefit persons other than the potential child, such as the mother’s other children. See *supra* note 172 and accompanying text.

gards the physician's advice and becomes pregnant immediately, no harm is done to the resulting child. Despite being born with an impairment, the child will probably value its existence, and if the woman had waited that particular child would not exist at all. While the woman could have had a child without the impairment by simply waiting two months, waiting would have given rise to a different child, formed by the union of a different egg and different sperm. Thus, if the woman should wait, it is not because doing so will benefit a specific person; it is because waiting provides an alternative means of achieving the woman's reproductive aspirations while creating less overall suffering in the world.

The most straightforward cases for applying the comparative approach are situations similar to Parfit's example, in which a reproductive risk can be avoided without changing the number of persons brought into the world.¹⁷⁵ This possibility exists in many situations in which patients' disabilities pose reproductive risks. Some genetic risks, for example, can be avoided by using pre-implantation genetic diagnosis and transferring only those embryos found not to be affected with the relevant disorder.¹⁷⁶ Genetic risks for which screening is unavailable can be avoided by using donor sperm, eggs, or embryos in place of one or both partners' gametes. For women at risk of developing serious pregnancy complications because of hypertension or diabetes, medical treatments before or during pregnancy may reduce the risks. Gestational surrogacy¹⁷⁷ also may be an option in some situations. In all of these cases, even if the risks associated with ARTs do not threaten to "harm" the resulting child, other means of reproducing may result in a different child likely to suffer less.

Of course, the availability of less-risky reproductive alternatives cannot be the only consideration. If every reproductive decision had to be weighed against the full range of alternatives that are theoretically available, almost every decision to have a child could be criticized as ethically problematic.

175. For such cases, Derek Parfit proposed what he called the "same number quality claim," or principle "Q": "If in either of two outcomes the same number of people would ever live, it would be bad if those who live are worse off, or have a lower quality of life, than those who would have lived." PARFIT, *supra* note 173, at 360; see also Peters, *supra* note 170, at 399 (arguing that the failure to choose the safest procreative option harms "future children as a class," even if it does not harm any individual child); Peters, *supra* note 150, at 488 ("When injuries are avoidable by substitution, the nonexistence test should be replaced by direct consideration of the relative safety of the procreative options.").

176. See generally Y. Verlinsky et al., *Preimplantation Genetic Diagnosis—An Integral Part of Assisted Reproduction, Report of the 9th Annual Meeting of the International Working Group on Preimplantation Genetics, in Association with the 11th IVF Congress, Sydney, Australia, May 10, 1999*, 17 J. ASSISTED REPROD. & GENETICS 75 (2000).

177. In gestational surrogacy, embryos are created with the gametes of the intended parents (or with the gametes of one of the intended parents and donor gametes) and then implanted in a woman who agrees to carry the embryos to term and then relinquish the resulting child to the intended parents. ASSISTED REPRODUCTIVE TECHNOLOGIES, *supra* note 16, at 84–85.

As Madison Powers has argued, “[w]e would be forced to conclude that any child is harmed by virtue of being born, at least any child born short of perfection (whatever that is), simply because there always would be some causal factors we could point to as reducing an actual child’s quality of life below what is hypothetically possible.”¹⁷⁸ Thus, there must be some threshold level of risk to offspring below which consideration of reproductive alternatives is not required at all. Ronald Green suggests that concerns about offspring welfare become significant when reproductive choices will likely lead to the birth of children unable to enjoy the “expected health condition and the level of life prospects of others in the child’s birth cohort.”¹⁷⁹ Similarly, Laura Purdy argues that reproductive decisions should seek to give children “minimally satisfying lives,” evaluated in terms of a particular culture’s understanding of “normal health.”¹⁸⁰

In addition, the burdens of alternative reproductive strategies on the prospective parents must be taken into account.¹⁸¹ Undergoing medical

178. Madison Powers, *The Moral Right to Have Children*, in *HIV, AIDS AND CHILDBEARING: PUBLIC POLICY, PRIVATE LIVES* 320, 333 (Ruth R. Faden & Nancy E. Kass eds., 1996).

179. Ronald M. Green, *Parental Autonomy and the Obligation Not to Harm One’s Child Genetically*, 25 *J.L. MED. & ETHICS* 5, 10 (1997). Green further argues that parents (and, by extension, those who assist them in effecting their reproductive choices) . . . have a *prima facie* obligation not to bring a child into being deliberately or negligently with a health status likely to result in significantly greater disability or suffering, or significantly reduced life options relative to the other children with whom he/she will grow up.

Id. According to Green, this standard is one that rational persons would select in order to fashion a public rule of reproductive conduct most likely to protect the vital interests of real persons. Hence, whether an identifiable person is made worse off by our reproductive decision is beside the point. What is important is the public rule of conduct meant to shape people’s reproductive behavior in ways that reduce likely harm to born persons.

Id. at 9.

180. LAURA M. PURDY, *Genetics and Reproductive Risk: Can Having Children Be Immoral?*, in *REPRODUCING PERSONS: ISSUES IN FEMINIST BIOETHICS* 39, 45–46 (1996); see also John D. Arras & Jeffrey Blustein, *Reproductive Responsibility and Long-Term Contraceptives*, in *COERCED CONTRACEPTION? MORAL AND POLICY CHALLENGES OF LONG-ACTING BIRTH CONTROL* 108, 114 (Ellen H. Moskowitz & Bruce Jennings eds., 1996) (arguing that reproduction is irresponsible if the child is likely to suffer “grievous burdens,” even if those burdens would be outweighed by the benefit of life); Steinbock & McClamrock, *supra* note 154, at 17 (arguing that “the decision to have children when a decent minimum cannot be provided can be criticized on moral grounds”).

181. See Peters, *supra* note 150, at 518 (“The significance of treating failure to substitute as a *prima facie* basis for state action is not that it requires intervention, but that it requires justification. The interests of the children must still be balanced against those of the parents or providers.”). Dan Brock’s reformulation of Parfit’s “same number quality claim” reflects these additional considerations:

Individuals are morally required not to let any possible child or other dependent person for whose welfare they are responsible experience serious suffering or limited opportunity if they can act so that, *without imposing substantial burdens or costs on themselves or others*, any alternative possible child or other dependent person for whose welfare they would be responsible will not experience serious suffering or limited opportunity.

treatment to reduce a reproductive risk may pose risks to the woman's own health. Pre-implantation genetic diagnosis is expensive and, because it requires the use of IVF, it poses particular burdens for people who otherwise could reproduce with less extensive ARTs.¹⁸² Alternatives that require one or both parents to forego genetic or gestational connections with their offspring entail considerable sacrifices. For some people, using a gamete donor or gestational surrogate may take away one of the most important aspects of having a child. These procedures also raise significant religious and ethical concerns for many individuals,¹⁸³ and, in some states, legal considerations may make the option of gestational surrogacy effectively unavailable.¹⁸⁴

The most difficult cases are those in which the only way to avoid a reproductive risk is to forego reproduction entirely. This would be the case for HIV-positive women, who cannot eliminate the risk of exposing their future children to the virus even with gestational surrogacy.¹⁸⁵ In other situations, pre-implantation diagnosis, gamete donation, or gestational surrogacy may be theoretical alternatives, but the patient may be unable to afford them or may be opposed to them for religious, ethical, or other reasons. In the absence of any reasonably available reproductive alternatives, some commentators maintain that proceeding with ARTs would be ethically acceptable unless the resulting child is likely to suffer so much he or she would prefer not to exist.¹⁸⁶ Yet, when ARTs entail serious risks to the future child's well-being, the alternative of adopting an existing child will often be

Dan W. Brock, *The Non-Identity Problem and Genetic Harms—The Case of Wrongful Handicaps*, 9 *BIOETHICS* 269, 273 (1995) (emphasis added); see also BUCHANAN ET AL., *supra* note 42, at 250 (noting the importance of weighing both the "seriousness of suffering and loss of opportunity, or loss of happiness and good that could be prevented" by having a different child, and the burdens such alternatives would impose on the parents, including "moral objections . . . financial costs or medical risks").

182. In addition, it is available in only about forty institutions worldwide. See Joe Leigh Simpson, Book Review, 76 *FERTILITY & STERILITY* 219, 219 (2001) (reviewing *AN ATLAS OF PREIMPLANTATION GENETIC DIAGNOSIS* (Yury Verlinsky & Anver Kuliev eds. 2000)).

183. See generally *ASSISTED REPRODUCTIVE TECHNOLOGIES*, *supra* note 16, at 95–115 (discussing ethical and religious perspectives on ARTs).

184. While no state prohibits gestational surrogacy, many states render surrogacy contracts unenforceable. See, e.g., N.Y. DOM. REL. LAW §§ 121–124 (McKinney 2001). See generally *ASSISTED REPRODUCTIVE TECHNOLOGIES*, *supra* note 16, at 334–39 (surveying state laws).

185. See Nathan Rojansky & Joseph G. Schenker, *Ethical Aspects of Assisted Reproduction in AIDS Patients*, 12 *J. ASSISTED REPROD. & GENETICS* 537, 537 (1995) ("While oocytes are not attacked by the HIV virus, associated lymphocytes and monocytes, aspirated during retrieval, may be infected and transmit the virus through ovum donation to the recipient woman or even to a surrogate mother.").

186. See, e.g., Jonathan Glover, *Future People, Disability, and Screening*, in *JUSTICE BETWEEN AGE GROUPS AND GENERATIONS* 127, 143 (Peter Laslett & James S. Fishkin eds., 1992); cf. Gregory S. Kavka, *The Paradox of Future Individuals*, 11 *PHIL. & PUB. AFF.* 93, 105 n.24 (1982) (relying on the "moral right to 'have' (some) children" to justify reproduction by slaves even though the resulting children will be born into slavery).

available. While adoption is not a means of reproduction, it enables people to become parents and sometimes is pursued as an alternative family-building strategy by people undergoing ARTs.¹⁸⁷ Adoption does not result in the creation of a new person,¹⁸⁸ but it provides an enormous benefit to an existing child in need of a home. Indeed, adoption is arguably a more compelling alternative than having a different child, as “the children who will benefit are actually living, unlike Parfit’s unconceived healthy child.”¹⁸⁹

While it is true that adoption, like gamete donation, would require the prospective parents to forego a genetic connection with their child, a desire for biological reproduction should not justify unlimited risks to the future child’s well-being.¹⁹⁰ Instead, when a serious reproductive risk can be avoided through adoption, the burden on the prospective parents of pursuing adoption instead of reproduction should be factored into the comparative assessment of the available alternatives. Because the burdens to the prospective parents of foregoing biological reproduction are likely to be considerable, the risk to the child would have to be particularly significant to justify a refusal to provide ARTs.

That the desire for a genetic connection with one’s offspring does not justify unlimited reproductive risks is a widely shared premise in our society. If this were not the case, it would be difficult to explain the widespread support for efforts to ban human reproductive cloning, an option that could provide an alternative to gamete donation for persons unable to have genetically related children using available ARTs. As the National Bioethics Advisory Commission concluded, the danger that cloning would lead to serious birth defects is so significant that attempting to have a child through clon-

187. See ASSISTED REPRODUCTIVE TECHNOLOGIES, *supra* note 16, at 120 (noting that “[a] minority of people explore adoption prior to, or simultaneously with, infertility treatment”).

188. As such, Parfit’s “same number quality claim,” *see supra* note 175, does not apply when adoption is used instead of reproduction, as substituting adoption for reproduction changes the total number of people who will exist. Of course, it has this effect only when viewed in terms of the *prospective parent’s* actions. If the situation is analyzed from the *physician’s* perspective, it may be possible to show that denying ARTs to patient A enables the physician to provide ARTs to patient B, thereby leaving the total number of future persons the same. Whether this in fact is the case would depend on a variety of factors, including whether the physician is practicing at full capacity, and whether individuals unable to begin treatment with the physician wait until an opening is available or instead seek ARTs from a different practitioner.

189. Peters, *supra* note 170, at 400 n.84 (1999). In a related context—disputes over the disposition of frozen embryos—courts have suggested that the alternative of adoption should be considered in determining whether the party who wishes to have a child would be able to do so without using the embryos. See *Davis v. Davis*, 842 S.W.2d 588, 604 (Tenn. 1992).

190. Cf. Julian Savulescu, *Should Doctors Intentionally Do Less Than the Best?* 25 J. MED. ETHICS 121, 124 (1999) (arguing that “[w]hile genetic relatedness may have some instrumental value, it has very little intrinsic value,” and that physicians should therefore not provide ARTs to individuals likely to have children with serious genetic diseases when the option of using donor gametes is available).

ing would be ethically unacceptable, even if it represents the only possible means for some people to have genetically related children.¹⁹¹ Risks to offspring would probably lead to a similarly cautious approach to other, less novel reproductive methods. As Philip Peters observes, "Is there any doubt that the Food and Drug Administration (FDA) would disapprove a fertility drug that produced birth defects similar to those associated with thalidomide even if the alternative for the affected children was nonexistence?"¹⁹² In both of these examples, the fact that gamete donation or adoption may be the only available alternatives to a risky reproductive strategy does not preclude a judgment that the risks are unacceptably high and therefore should not be taken.

Ultimately, the comparative risk/benefit approach described above is simply an analytical framework; weighing the risks and benefits of a requested ART and comparing them to the available alternatives depends on subjective factors about which reasonable people can disagree. In contrast to the wrongful life standard, however, the approach would expand the circumstances in which the future child's welfare could be factored into the analysis. It makes it possible to object to efforts to bring about the birth of a child likely to suffer considerably even if the child, once born, would not consider her life a net disadvantage. The objection would not be to the harm caused to a specific individual, but to the imposition of gratuitous suffering, defined as suffering that is unnecessary in light of the alternatives available for achieving the patient's parenting goals.

IV. THE ROLE OF PHYSICIANS IN THE ART PROCESS

The discussion above suggests that concerns about the well-being of the children resulting from reproductive decisions are relevant, even when the children are not likely to suffer so much as to wish they had never been born. It might be argued, however, that the welfare of future children is a factor for the prospective parents to consider, not the ART practitioner. When patients and physicians disagree about the implications of reproduction for the future child's well-being, why is the physician's assessment of the situation entitled to legal respect?

Determining the appropriate role for physicians in decisions about the use of ARTs requires a closer examination of physicians' stake in medical treatment generally, particularly regarding requests to provide what a physician regards as inappropriate or unethical medical care. This issue is central to the debate over medical futility, which asks whether physicians may deny

191. NATIONAL BIOETHICS ADVISORY COMMISSION, 1 CLONING HUMAN BEINGS 61 (1997).

192. Peters, *supra* note 150, at 519.

treatment requested by patients or their surrogates when the treatment is unlikely to be effective or to produce an outcome the physician regards as medically beneficial.¹⁹³ While the few judicial decisions in this area have generally rejected physicians' objections to providing disputed medical treatments in the context of existing physician-patient relationships,¹⁹⁴ the law is still in its infancy, and many commentators have called for greater attention to physicians' independent interests in making decisions about disputed questions of medical care. As stated by one group of physicians, "The ideals of medical professionals include respect for patients' wishes, to be sure, but they also include other values, such as compassionate action and the minimization of suffering."¹⁹⁵ To ignore this perspective, they suggest, "is to deny an essential part of what it means to practice medicine."¹⁹⁶ Physicians are moral agents, not "medical vending machines,"¹⁹⁷ Judith Daar reminds us, and "both courts and legislatures have historically regarded a physician's comfort with his or her actions as a high priority."¹⁹⁸ For example, states generally permit physicians to assert "conscience objections" to the withdrawal of life-sustaining treatment or to participation in abortion, even if they would otherwise be required to participate in those activities based on a contract of employment or an ongoing physician-patient relationship.¹⁹⁹ Haavi Morreim argues that situations involving "irresolvable value conflict" require particular sensitivity to physicians' beliefs.²⁰⁰ "Where the dispute concerns fundamental values rather than facts," she argues, "neither side can rationally command the moral high ground, nor should they coercively grab it."²⁰¹

The point is not that physicians' values should trump patients' choices whenever disputes over sensitive medical treatments arise. Rather, it is that physicians have an independent moral stake in the consequences of their actions; they are not simply disinterested parties attempting to produce a desired physiological effect. While patients' preferences regarding treatment

193. For a general discussion of futility, see sources cited *supra* note 6. See also Kathleen M. Boozang, *Death Wish: Resuscitating Self-Determination for the Critically Ill*, 35 ARIZ. L. REV. 23, 62-79 (1993); Judith F. Daar, *A Clash at the Bedside: Patient Autonomy v. a Physician's Professional Conscience*, 44 HASTINGS L.J. 1241, 1248-59 (1993) [hereinafter *A Clash at the Bedside*]; Judith F. Daar, *Medical Futility and Implications for Physician Autonomy*, 21 AM. J.L. & MED. 221 (1995).

194. See Boozang, *supra* note 193, at 72.

195. Robert D. Truog et al., *The Problem with Futility*, 326 NEW ENG. J. MED. 1560, 1562 (1992).

196. *Id.*

197. *A Clash at the Bedside*, *supra* note 193, at 1245.

198. *Id.* at 1260.

199. *Id.* at 1274-80; see also Bruce G. Davis, *Defining the Employment Rights of Medical Personnel Within the Parameters of Personal Conscience*, 1986 DETROIT C.L. REV. 847, 862-66.

200. E. Haavi Morreim, *Profoundly Diminished Life: The Casualties of Coercion*, HASTINGS CENTER REP., Jan.-Feb. 1994, at 33, 34.

201. Morreim, *supra* note 6, at 906.

generally should be controlling, this does not mean that physicians lack standing to raise their own ethical concerns.

Recognizing physicians' standing to consider the ethical implications of treatment decisions is especially appropriate in the context of ARTs. ARTs are fundamentally different from other medical procedures because the result of treatment is the conception and birth of a child, an independent person with interests of her own. In addition, physicians are not simply passive participants in the ART process. On the contrary, they are engaged in what can be viewed as a unique form of quasi-procreative activity. While the physicians are not themselves reproducing, their actions directly bring about the existence of persons who otherwise would never be born. Given their critical role in the procreative endeavor, it is understandable that ART practitioners feel some responsibility for the well-being of the children who result from their efforts.²⁰²

The ART physician's direct participation in the child's conception distinguishes these situations from *U.A.W. v. Johnson Controls*.²⁰³ That case involved an employer's refusal to hire fertile women for jobs involving exposure to lead, given the possibility of fetal harm if the women became pregnant. Striking down the policy, the Supreme Court held that decisions about the appropriateness of taking reproductive risks should be left "to the woman as hers to make."²⁰⁴ The employer in *Johnson Controls*, however, was not forced to *help* women become pregnant while exposed to the toxins; it was simply prevented from denying them jobs.²⁰⁵ The situation is also not equivalent to efforts to compel pregnant women to undergo cesareans or other interventions for the sake of their fetuses.²⁰⁶ While those situations

202. See Bruni, *supra* note 51 (quoting one ART physician as stating "I have two ethical obligations. One to the patient and one to the child."). Guido de Wert argues that

A doctor assisting in reproduction shares the responsibility for creating a new human being. Assisting in reproduction is as little morally neutral as is reproducing. From a moral point of view the physician is in some sort of triangle: he should consider the wishes and interests of his patients as well as the interests of the prospective children

Guido de Wert, *The Post-Menopause: Playground for Reproductive Technology? Some Ethical Reflections*, in *THE FUTURE OF HUMAN REPRODUCTION* 221, 231 (John Harris & Søren Holm eds., 1998).

203. 499 U.S. 187 (1991).

204. *Id.* at 211.

205. Furthermore, what made the employer's policy in *Johnson Controls* unlawful was that it discriminated on the basis of sex. See *id.* at 198 (noting that the policy was concerned only with reproductive risks that affected female workers, even though workplace hazards also affected male workers' reproductive systems). In the ART context, differential treatment of male and female reproductive risks also would be inappropriate.

206. See, e.g., *In re A.C.*, 573 A.2d 1235, 1252-53 (D.C. 1990) (en banc) (setting aside a court-ordered cesarean section for a dying woman who was pregnant with a viable fetus, on the ground that the decision should have been based on the patient's wishes, not on the state's interest in preserving the potential life of the fetus); *In re Baby Boy Doe*, 632 N.E.2d 326, 326 (Ill. App. Ct. 1994) (holding that a woman's right to refuse a cesarean section must be honored even if doing so would be harmful to a viable fetus); see also Radhika Rao, *Property, Privacy, and the Human Body*,

also may be motivated by concern for the prospective child, overriding the woman's wishes in those cases would require invading her bodily integrity. That issue does not arise when a physician declines to provide ARTs.²⁰⁷

At the same time, the claim for absolute deference to patients' choices is weaker in the context of ARTs than in many other situations in which conflicts between patients and physicians have arisen. For example, in decisions about life-sustaining treatment by competent patients, it is the patient requesting treatment who will experience the primary benefits and burdens of the decision; in addition, the decision is particularly weighty because it may affect whether the patient lives or dies.²⁰⁸ When patients request ARTs, by contrast, the decision has direct implications not only for the patient but also for the potential offspring. In this respect, decisions about ARTs combine elements of medical decisionmaking by competent patients with surrogate decisions by parents or other third parties regarding treatment of another person.²⁰⁹ While the law is generally reluctant to interfere with treatment decisions by competent individuals, decisions by parents or other surrogates are subject to more extensive review.²¹⁰

The appropriate question, therefore, is not *whether* physicians have a stake in decisions about the provision of ARTs, but *when*—if ever—that stake justifies a decision to withhold care. Authorizing physicians to assert “conscience objections” to the provision of ARTs whenever they have concerns about the prospective child's welfare would be overly broad, as it would

80 B.U. L. REV. 359, 393–95 (2000) (discussing forced cesarean cases as an example of the right to bodily integrity).

207. See Spike & Greenlaw, *supra* note 54, at 349. The importance of bodily integrity also explains why the impact of individuals' disabilities on their future children would not justify efforts to restrict the reproductive capacity of fertile individuals, as any such restrictions would require forcible physical invasions, such as mandatory sterilizations.

208. See Boozang, *supra* note 193, at 66 (“Because the conflict between physician and patient autonomy implicates whether the patient will live or die, the patient's autonomy must supersede.”). Moreover, for patients who are dying, the option of finding another physician is often not feasible. See *A Clash at the Bedside*, *supra* note 193, at 1273 (“Forcing a dying patient to leave a setting that has become familiar, if not comforting, seems nonsensical at best; such a change would likely be emotionally and psychologically devastating to patients and their families.”).

209. Cf. Arras & Blustein, *supra* note 180, at 127 (arguing that the impact of reproductive decisions on other persons, including the potential children, “moves reproduction out of the private domain and into the sphere of what John Stuart Mill referred to as ‘other regarding behavior’—that is, conduct that can affect the morally significant interests of others in profoundly detrimental ways” (citation omitted)).

210. See generally Jennifer L. Rosato, *Using Bioethics Discourse to Determine When Parents Should Make Health Care Decisions for Their Children: Is Deference Justified?* 73 TEMP. L. REV. 1 (2000) (examining parents' authority to make treatment decisions for children); Sabatino, *supra* note 152 (surveying state laws on surrogate decisionmaking); cf. Peters, *supra* note 6, at 841 (suggesting that physicians should have greater freedom to deny treatment requested by surrogate decisionmakers than treatment requested by patients themselves, as conflicts between physicians and surrogates “are not about paternalism, but about the allocation of power between third parties who disagree about the patient's welfare”).

allow physicians to trump patients' decisions in virtually all cases. Given the importance of promoting access to treatment for patients with disabilities, the scope of the physician's decisionmaking authority must remain narrower than that of the patient. Accordingly, the next part seeks to distinguish situations in which physicians are inappropriately imposing their preferences on patients from cases in which physicians have legitimate objections that deserve respect.

V. DISTINGUISHING APPROPRIATE AND INAPPROPRIATE DECISIONS

The fact that physicians may reasonably take into account the implications of ARTs for the resulting children does not mean they should be permitted to consider the full range of factors that prospective parents consider in deciding whether to reproduce. Individuals making reproductive decisions for themselves are free to act on virtually any idiosyncratic reproductive preference, including those that are irrational or biased. For example, it is perfectly legal for individuals to engage in race discrimination in their choice of reproductive partners; indeed, gamete donation programs commonly attempt to facilitate prospective parents' desire to have children of a particular race.²¹¹ When ART physicians cite the interests of children in making patient selection decisions, however, they should not expect to enjoy such broad discretion. As licensed professionals, they should be limited to rational considerations that society is prepared to recognize as fair.²¹² Moreover, if the basis of the physician's concern is the avoidance of gratuitous suffering, the physician's objections should be defensible under the comparative risk/benefit framework set forth above.²¹³ Thus, there should be a significant likelihood that the child's quality of life will fall below a minimally adequate threshold. In addition, the balance between the benefits and burdens of an alternative parenting option should be more favorable than that associated with providing ARTs.

Concerns about the impact of a patient's disabilities on her ability to care for a child will rarely be sufficient to satisfy these principles. Predictions about the parenting ability of patients with disabilities are especially

211. See Lori B. Andrews & Lisa Douglass, *Alternative Reproduction*, 65 S. CAL. L. REV. 623, 663–64 (1991) (noting that gamete donation programs typically match donors and recipients on the basis of race); see also Jonathan M. Berkowitz & Jack W. Snyder, *Racism and Sexism in Medically Assisted Conception*, 12 *BIOETHICS* 25, 25 (1998) (describing cases in which couples used gamete donation to have children with different racial backgrounds than those of the couples themselves).

212. Cf. Lois Shepherd, *HIV, the ADA, and the Duty to Treat*, 37 *HOUS. L. REV.* 1055, 1090 (2000) (arguing that “we might seek an undertaking from physicians to treat all those who seek their care (unless there is a good reason to refuse) in exchange for their self-regulated monopoly”).

213. See *supra* text accompanying notes 170–192.

prone to error and bias.²¹⁴ Even when patients' disabilities affect their ability to parent effectively, they may be able to compensate for any deficiencies with the assistance of family members, friends, or other support networks. The same is true for patients who have limited life expectancies as a result of a disability. While the death of a parent is undeniably a terrible experience for a child, it is not the sort of experience that precludes a decent quality of life. The relevant question should not be whether the patient will be able to raise the child single-handedly, but whether the child's need for care has been adequately addressed.²¹⁵

Under the comparative risk/benefit framework discussed above, the implications of a patient's inability to care for a child would have to be truly extraordinary to justify a decision to withhold ARTs. Unlike a determination that an alternative parenting option would produce a more favorable balance of benefits and burdens than proceeding with ARTs, a denial of treatment based on concerns about a patient's parenting ability or life expectancy presumes that it would be better if the patient refrained from raising *any* children. Because the alternative of remaining childless would impose significant burdens on the patient without any benefit to an existing or future child, it will almost always yield a less favorable risk/benefit ratio than proceeding with treatment.²¹⁶

In many cases, concerns about the impact of patients' disabilities on the health of a future child also will be an insufficient basis for refusing to provide ARTs.²¹⁷ Physiological limitations, even those that might constitute disabilities under the ADA, are not necessarily inconsistent with a decent quality of life. In addition, many of the disadvantages associated with disabilities are the result of societal practices that ignore the needs of persons with disabilities, rather than inherent limitations of a disability itself.²¹⁸ For example, most of the limitations associated with conditions like achondro-

214. See Watkins, *supra* note 41, at 1454 (noting that, for parents with disabilities, "the available research suggests that factors unrelated to disability often have a more significant impact on parental fitness than does disability itself").

215. Cf. Marcia Angell, *Pregnant at 63? Why Not?* N.Y. TIMES, April 25, 1997, at A27 (arguing, in response to critics of the use of egg donation by postmenopausal women, that "any responsible mother, young or old, should make provisions for the care of her baby should she die before her child is grown").

216. Indeed, the only circumstance in which this would not be true is when proceeding with ARTs would violate the wrongful life standard. See *supra* note 146 and accompanying text.

217. As Ann Hubbard has argued in the context of employment decisions, the "seductive appeal" of concerns about risks to others makes it particularly important for courts to be skeptical about any assertion of the direct threat defense. Hubbard, *supra* note 141, at 1279–80.

218. See Bagenstos, *supra* note 85, at 431 (describing the position of disability rights advocates that disability "must be understood as the result of an interaction between biological restrictions and the broader physical and social environment—and that the greater part of the disadvantage attached to 'disability' is best addressed through attempts to change the environment").

plasia (a recessive genetic condition that causes dwarfism) or deafness are due to the fact that our society is designed around the needs of average-sized persons who are capable of hearing. One of the ADA's goals is to instigate societal changes to accommodate the needs of persons who are different. The failure to achieve these goals should not be used to justify physicians' denial of care.

However, it would be a mistake to conclude that, whenever a physician objects to providing ARTs because of the consequences of a disability for the future child's health, the physician's concerns reflect nothing more than prejudice against people with disabilities or ignorance about the impact of disabilities on the child's quality of life.²¹⁹ Some medical conditions impose serious disadvantages under even the best of circumstances. Even if children born with these conditions are not "harmed," in the sense that the burdens of the condition do not outweigh the benefits of existence, the inherent physiological consequences of the condition may foreclose "important options and experiences" that preclude a minimally decent quality of life.²²⁰ If that were not the case—if all biological differences were simply "forms of variation"²²¹ that are inherently neither good nor bad—there would be no reason to attempt to prevent or treat medical conditions that are potentially disabling. Instead, the appropriate response would be to change the social practices that make a particular condition disabling, rather than attempting to eliminate the condition itself.

While some disability rights advocates might support such an approach,²²² the premise of our health care system is just the opposite. Indeed, a variety of social practices, professional norms, and public policies have as

219. As Peter Singer argues:

It is one thing to argue that people with disabilities who want to live their lives to the full should be given every possible assistance in doing so. It is another, and quite different thing, to argue that if we are in a position to choose, for our next child, whether that child shall begin life with or without a disability, it is mere prejudice or bias that leads us to choose to have a child without a disability.

PETER SINGER, *PRACTICAL ETHICS* 54 (2d ed. 1993).

220. John Harris, *Is There a Coherent Social Conception of Disability?* 26 *J. MED. ETHICS* 95, 98 (2000).

221. Bonnie Steinbock, *Disability, Prenatal Testing, and Selective Abortion*, in *PRENATAL TESTING AND DISABILITY RIGHTS* 108, 108 (Erik Parens & Adrienne Asch eds., 2000) (describing the position of some disability rights advocates).

222. For example, Solveig Magnus Reindal argues that

The very idea of "curing" disability is the core element in the discrimination of disabled people because the "curing ideal" resides in conformity and normalcy. . . .

To continue to persist with individual models of disability, equating the problem of disability to impairments and individual conditions, is itself a discrimination against disabled people.

Solveig Magnus Reindal, *Disability, Gene Therapy, and Eugenics—A Challenge to John Harris*, 26 *J. MED. ETHICS* 89, 92–93 (2000).

their goal the creation of a world in which serious disease and disability no longer exist. For example, carrier testing for recessive genetic conditions like Tay-Sachs and sickle-cell disease is routinely offered to at-risk individuals considering having a child,²²³ in order to reduce the future prevalence of these debilitating diseases. Genetic testing during pregnancy is also a common practice.²²⁴ In California, physicians are legally required to offer prenatal testing to pregnant women in time for the women to consider terminating their pregnancies.²²⁵ Reducing the prevalence of disability in future generations also is the goal of a broad range of federal public health activities, ranging from campaigns to encourage women to take folic acid supplements²²⁶ to surveillance and research activities to reduce birth defects.²²⁷

In this regard, disability is fundamentally different from other characteristics that have historically been the basis of societal discrimination, such as race or gender.²²⁸ Even if it were possible to eliminate racial differences in future generations, most people would be appalled if such methods were proposed as a means to avoid problems resulting from racial prejudice. The reason is that the disadvantages experienced by people of particular races are due *solely* to individual attitudes and social conditions; racial differences in and of themselves are inherently neither good nor bad.²²⁹ Some disabilities, however, entail real physiological limitations. In addition to problems of

223. See GENETIC TESTING AND SCREENING, *supra* note 46, at 112–16. In 1997, a National Institutes of Health (NIH) consensus conference recommended that cystic fibrosis carrier testing should be offered to couples planning to become pregnant. See *id.* at 117.

224. See *id.* at 51–53.

225. See CAL. CODE REGS. tit. 17, § 6527(a) (2002). Specifically, the regulations provide: Clinicians shall provide or cause to be provided to all pregnant women in their care before the 140th day of gestation, or before the 126th day from conception, as estimated by medical history or clinical testing, information regarding the use and availability of prenatal screening for birth defects of the fetus.

Id.

226. See Lorenzo D. Botto et al., *Neural Tube Defects*, 341 NEW ENG. J. MED. 1509, 1509, 1517 n.6 (1999) (discussing Food and Drug Administration standards for fortifying cereal products with folic acid and recommendations by the Institute of Medicine and the Public Health Service that women who could become pregnant supplement their diet with folic acid).

227. See National Center on Birth Defects and Developmental Disabilities, *Birth Defects*, <http://www.cdc.gov/ncbddd/bd/default.htm> (last visited May 27, 2002) (describing federal efforts to reduce birth defects).

228. *But cf.* Asch, *supra* note 36, at 85–86 (questioning why some people consider it inappropriate to have children likely to be seriously disabled while no one challenges the right of women of color to “bring children into the world even knowing that their children will grow up in a racist society, and may suffer economically, socially, emotionally, and psychologically as a result”).

229. Indeed, the very concept of “race” is largely a social construction. See Robert S. Schwartz, *Racial Profiling in Medical Research*, 344 NEW ENG. J. MED. 1392, 1392 (2001) (calling race “a social construct, not a scientific classification”); see also Ian F. Haney López, *The Social Construction of Race: Some Observations on Illusion, Fabrication, and Choice*, 29 HARV. C.R.-C.L. L. REV. 1, 5 (1994) (criticizing “the fallacies and fictions on which ideas of race depend”).

ignorance and prejudice, people with disabilities suffer from real disadvantages that reasonable people legitimately can seek to avoid.

Admittedly, there are many disability scholars who would find this distinction objectionable. It is sometimes argued that all efforts to avoid the birth of children with disabilities are a form of disability discrimination, as they contain an implicit message that people with disabilities do not deserve to exist.²³⁰ For example, David King argues that the growing interest in prenatal testing reflects a widespread bias against people with disabilities: "[I]n a society which had overcome its fears of disability and truly considered disabled people as equal members of the community," he argues, interest in techniques to avoid the birth of children with disabilities would be far less widespread.²³¹ Many in the disability rights community also believe that societal pressure to avoid the birth of children with disabilities will lead to increased discrimination against people with disabilities who are already alive. Deborah Kaplan, for example, worries that "women and couples who go through prenatal screening may become less accepting of disabilities and disabled people."²³² Some commentators also suggest that society would be worse off if all disabilities somehow could be eradicated. While persons with serious disabilities may suffer certain disadvantages, it is argued, they also contribute to a more diverse and culturally rich society in which individual differences are respected and valued.²³³

The danger that efforts to reduce the prevalence of disability in society might undermine respect for existing persons with disabilities deserves to be taken seriously. However, it is possible to be concerned about the impact of

230. See, e.g., Banks, *supra* note 7, at 78 (arguing that attempting to avoid the birth of children with disabilities "denigrates the personal worth of people with disabilities and runs counter to the objectives of the ADA"); Kathleen O. Steel, *The Road That I See: Implications of New Reproductive Technologies*, 4 CAMBRIDGE Q. HEALTHCARE ETHICS 351, 351 (1995) ("It is difficult to feel that discrimination does not exist when a branch of medicine is intent on eradicating disabled people."). See generally Erik Parens & Adrienne Asch, *The Disability Rights Critique of Prenatal Genetic Testing: Reflections and Recommendations*, HASTINGS CENTER REP., Sept.-Oct. 1999, at S1 (surveying positions on the issue).

231. David S. King, *Preimplantation Genetic Diagnosis and the 'New' Eugenics*, 25 J. MED. ETHICS 176, 181 (1999); see also Asch, *supra* note 36, at 86 (arguing that, "[i]f we believed that the world was a problem to the child and not the child a problem to the world," the fact that a child might be born with a disability would not be viewed as a reason to avoid the child's birth).

232. Deborah Kaplan, *Disability Rights Perspectives on Reproductive Technologies and Public Policy*, in REPRODUCTIVE LAWS FOR THE 1990s, *supra* note 36, at 241, 245.

233. For example, Jonathan Drimmer argues that:

Disabled culture should be encouraged, celebrated, and given room to flourish; credence should be given to the experiences of people with disabilities as a minority group. The alternative perspectives offered by the disabled culture will raise the national consciousness, and should be supported and encouraged by society at large From a diversity of culture and experience comes national strength, tolerance, and understanding.

Jonathan C. Drimmer, *Cripples, Overcomers, and Civil Rights: Tracing the Evolution of Federal Legislation and Social Policy for People with Disabilities*, 40 UCLA L. REV. 1341, 1408 (1993).

serious disabilities on future children without denigrating the value of people with disabilities who are already alive.²³⁴ As James Lindemann Nelson argues, people often make reproductive choices based on their assessment of a future child's best interests, yet these assessments are generally not viewed as comments on the value of existing people in society. For example, a struggling couple that decides not to have a child because it will be born into poverty is not seen as disparaging the inherent worth of children who are poor.²³⁵ While it may be true that the existence of disabilities contributes to a more diverse and tolerant society, this does not mean that physicians should be forced to help bring more people with serious disabilities into the world. There are many situations in life in which adversity ultimately produces positive benefits, but most people still seek to avoid adversity. There also are important differences between assuming burdens for oneself in order to promote diversity and tolerance and imposing those burdens on children without their consent.²³⁶

The difficult question, of course, is determining when a physician's objections to providing ARTs based on concerns about a future child's welfare become sufficiently compelling to justify a disability-related denial of care. While it is impossible to delineate a precise boundary between appropriate and inappropriate disability-related considerations, several general principles seem to be appropriate starting points. First, it is worth emphasizing that reproduction is always a risky endeavor; any physician unwilling to accept some degree of uncertainty clearly is not suited to the practice of ARTs. Before a physician denies ARTs to an individual seeking treatment, it should be clear that there is a significant likelihood the child's health status will fall below a minimally decent threshold.²³⁷ Some conditions are far too

234. As Jonathan Glover argues:

Aiming for the conception and birth of normal people, for instance, is perfectly compatible with insisting that the rights of disabled people be fully respected and with seeing them as equals. . . . [I]t is true of all of us that someone better in some ways could have been conceived instead. Accepting this about a particular person does not mean that one feels contempt or condescension toward him or her.

Glover, *supra* note 186, at 134; *see also* Green, *supra* note 179, at 12 ("It is possible for us to hold that it is not wise or ethical deliberately to add to the normal risks of disability or suffering a child may face, while also insisting that a child actually born with problems deserves all the support we can give it.").

235. James Lindemann Nelson, *The Meaning of the Act: Reflections on the Expressive Force of Reproductive Decision Making and Policies*, in *PRENATAL TESTING AND DISABILITY RIGHTS* 196, 204 (Erik Parens & Adrienne Asch eds., 2000).

236. Cf. FEINBERG, *supra* note 164, at 328 (arguing that "wrongly conceived infants . . . did not consent to the risks in their being born").

237. *See supra* text accompanying notes 178–180. In the context of prenatal testing, however, some disability rights advocates oppose efforts to identify such a "minimally decent threshold." For example, Adrienne Asch believes that

We should eschew the temptation to accept some limits on testing for non-health-related characteristics, or for only what professionals decide are severe and burdensome condi-

inconsequential to justify a denial of treatment, while others are more significant but less likely to occur. An example of the former might be genetic conditions associated with minor disfigurement, such as ectrodactylism.²³⁸ An example of the latter might be HIV infection. While it may have been appropriate for physicians to deny ARTs to HIV-positive patients in 1994, when the risk of perinatal transmission was approximately 25 percent, now that the risk of transmission is less than 2 percent—lower than the general risk of serious congenital abnormalities in a typical pregnancy²³⁹—it is difficult to justify turning patients away.

The consistency of the physician's determinations also is a critical factor. Even when the risk of perinatal HIV transmission was higher than it is today, some physicians categorically denied ARTs to HIV-positive women but were willing to provide treatment to patients with other medical conditions posing even greater reproductive risks.²⁴⁰ The "selective application of ethical principles"²⁴¹ suggests that appeals to the interests of the future child may simply be pretexts for decisions motivated by illegitimate considerations, such as bias against people with particular disabilities.²⁴²

Because the physician's standing to raise objections is grounded in concern for the prospective child's welfare, it also is important to consider how particular health conditions are likely to be experienced by the child herself.²⁴³ Some conditions, such as mental retardation, may be perceived as seriously disabling by the general public but are not experienced as burdensome by persons who are affected with them, as they do not entail pain or suffering or any perception of a diminished quality of life. The issue is not whether the child will have a condition that satisfies the ADA's definition of disability, but whether the child is likely to experience a minimally decent quality of life.

tions. . . . Saying that color blindness and tone deafness are too trivial, but that blindness and deafness are serious enough to warrant testing and abortion, will not increase recognition of the humanity of people who are blind or deaf.

Adrienne Asch, *Why I Haven't Changed My Mind About Prenatal Diagnosis: Reflections and Refinements*, in *PRENATAL TESTING AND DISABILITY RIGHTS*, *supra* note 235, at 234, 252–53.

238. *See supra* note 86.

239. *See* Minkoff & Santoro, *supra* note 57, at 1748.

240. *See id.* (suggesting that most physicians unwilling to provide ARTs to HIV-positive patients would not deny treatment to couples at risk of transmitting Tay-Sachs to their offspring).

241. *Id.*

242. *Cf. McDonnell Douglas Corp. v. Green*, 411 U.S. 792, 807 (1973) (giving employees the opportunity to show that an employer's asserted reason for an adverse employment decision was a pretext for unlawful discrimination).

243. *Cf. PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT* 219 (1983) (providing that a parent making treatment decisions for a disabled newborn "is obligated to try to evaluate benefits and burdens from the infant's own perspective").

In all cases, physicians' views about a potential child's welfare must be balanced against the burden of alternative options on the person seeking treatment. Thus, physicians' objections are entitled to the greatest deference when there are alternative practitioners readily available to provide the patient's requested treatment, as the burden to the patient is simply the inconvenience of using a different physician. The burdens to the future child should be greater before a physician conditions treatment on the use of pre-implantation genetic diagnosis or other medical interventions, and greater still if the physician refuses to provide ARTs unless the patient uses donor gametes.

Denials of treatment are most problematic when the risks to a future child are avoidable only by foregoing reproduction entirely. To justify a refusal to provide ARTs in such circumstances, the likelihood and magnitude of the burdens to the expected child would have to be considerable. The 25 percent risk of perinatal HIV transmission in 1994 was arguably such a situation, particularly because no effective treatments then existed for infected children. Today, denying ARTs to HIV-positive patients no longer seems appropriate, but other medical conditions, such as poorly controlled diabetes and renal failure,²⁴⁴ may entail such significant risks that a physician would be justified in turning a patient away.

The need to engage in an individualized assessment of each patient's particular circumstances makes it difficult to set forth any categorical rules. Ultimately, the comparative risk/benefit approach requires a fact-specific analysis of the risks, benefits, and alternatives on a case-by-case basis. The goal should be to determine whether, on balance, more good and less bad will result from choosing an available reproductive or parenting alternative as compared to proceeding with the patient's requested treatment in the face of serious reproductive risks.

CONCLUSION

Ensuring equitable access to medical treatment for individuals with disabilities is a critically important societal value, but so too is avoiding unnecessary suffering in future generations and recognizing physicians' standing as moral agents. In some cases, it will be impossible to reconcile all of these values. When such cases arise, a court must reach a resolution, knowing that whichever values it favors will have both advantages and costs.

The framework proposed in this Article seeks to balance the competing factors on a case-by-case basis, comparing the risks and benefits of the patient's requested treatment with the other available reproductive and parent-

244. See Minkoff & Santoro, *supra* note 57, at 1749.

ing options. The advantage of this approach is that it recognizes each of the considerations as important values, and it prioritizes them based on an individualized assessment of a particular case. The drawback, however, is the difficulty of line-drawing. The line between appropriate and inappropriate denials of treatment is far from bright, and undoubtedly it will prove difficult to determine when that line has been crossed. There is a real danger that seemingly objective determinations about a future child's best interests will be influenced by pervasive, and often unconscious, biases and stereotypes about people with disabilities. To the extent that consistency and predictability are important legal values, an argument can be made for a bright-line solution—either treating ART practitioners like common carriers, with an obligation to accept any patient who is willing to pay, or giving them unbridled discretion to select patients as they please.

But, while any system that requires drawing distinctions is prone to error, the tolerable margin of error depends on the purpose of the distinctions. It would be one thing if the law sought to specify circumstances in which physicians would be *prohibited* from providing ARTs to particular patients. In such a system, the tolerable margin of error would be extremely narrow, as the ability of individuals with disabilities to use ARTs would depend exclusively on how those circumstances were defined. The framework proposed in this Article, by contrast, seeks only to identify circumstances in which concerns about the future child should be accepted as a reasonable justification for withholding treatment—if a physician chooses to assert those concerns. Physicians would still be permitted to provide treatment in such situations if doing so were consistent with their own ethical views, and it can be expected that many physicians will do so.²⁴⁵ Thus, the tolerable margin of error is greater, because the consequences of drawing the line in a particular place are far less severe.

Moreover, while consistency and predictability are important considerations, they are not the only values the law must consider. Attempting to accommodate competing considerations is unlikely to yield a simple solution, but in ethically charged contexts simplicity is rarely an attainable goal. Courts confronted with ADA challenges to decisions about ARTs should avoid the temptation to find an easy way out of the ethical thicket. The comparative framework proposed in this Article provides an approach to resolving these dilemmas that takes seriously the risk of disability discrimination in the context of reproduction, while acknowledging physicians' legitimate desire to avoid serious risks to the future child's well-being.

245. Cf. Kolata, *supra* note 65 (noting that some ART practitioners see a competitive advantage in accepting patients other physicians might be unwilling to treat).