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# Disabling Dreams of Parenthood: The Fertility Industry, Anti-discrimination, and Parents with Disabilities

Kimberly M. Mutcherson†

## Introduction

To be a reproductive endocrinologist is to wield tremendous power over procreation. On a daily basis, these physicians help hundreds of people around the globe create babies. Critics of the fertility industry frequently lament that those working in the field of reproductive technology are playing God, as they manipulate embryos, create and sustain pregnancies that could not exist or continue without their aid, and bring the gift of biological parenthood to those longing for it.<sup>1</sup> Fertility providers, however, do not just hold embryos in their sway, for these providers also have the power to decide who their patients will be, and it is unclear that decisions made in this vein are bias-free, especially when the patients in question are living with disabilities.

In fertility practice, it is legally and ethically permissible for a physician to refuse care to a patient when a medical assessment reveals either that the patient cannot be helped with existing technology,<sup>2</sup> or that an ensuing pregnancy would seriously compromise the patient's own health. As discussed below, providers frequently justify these decisions with reference to objective medical measures. By contrast, physicians who object to providing care based on amorphous concerns about the parenting skills of the patient and the best interests of the potential child stand on enormously shaky ethical and legal ground. Such

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†. Associate Professor of Law, Rutgers School of Law - Camden. My thanks to the wonderful members of the junior faculty at Rutgers with whom I have had challenging and enlightening conversations about my work. I am extremely grateful to the editors of *and Inequality: A Journal of Theory and Practice* who worked so diligently on this piece and sponsored a wonderful Symposium. And, as always, to Samantha, Max, and Josephine who make the work worthwhile.

1. See, e.g., Hillary Rose and Steven Rose, *Playing God*, GUARDIAN (U.K.), July 3, 2003, <http://www.guardian.co.uk/science/2003/jul/03/genetics.comment> (describing various ethical concerns about emerging reproductive technologies).

2. AMERICAN SOCIETY FOR REPRODUCTIVE MEDICINE (ASRM), FERTILITY TREATMENT WHEN THE PROGNOSIS IS VERY POOR OR FUTILE, available at <http://www.asrm.org/Media/Ethics/futility.pdf> (noting that physicians may refuse to provide fertility treatment if it would be futile).

decisions presume that fertility providers have a right and, perhaps, an obligation to make both medical and social decisions about a potential patient's fitness for both pregnancy and parenting. These assessments raise legitimate concerns about what limits, if any, should be placed on a provider's ability to decide that a person is not fit to receive fertility services due to a risk to the patient from treatment or pregnancy, or a risk to a fetus or future child (either in utero or after birth).

Defining the contours of good parenting is a gargantuan task that is rivaled, if not surpassed, by the challenge of determining if any one individual actually possesses good parenting skills. This assessment is even harder when the individual in question has not yet had a chance to put those skills into practice. When a person stands on the verge of procreation, as does one who seeks fertility treatment, any assessment of future parenting skill risks being reductive and simplified, and may limit the number of individuals allowed to reproduce with medical assistance—without necessarily sparing any future child from harm.

Given that those living with disabilities have frequently been singled out for ill treatment in the realm of procreation and parenting (including a long history of sterilization abuse),<sup>3</sup> viewing fertility care through the lens of discrimination against the disabled provides a strong vantage point from which to evaluate what duties fertility providers owe to patients, and what duties society owes to those who face unjustified discrimination in their quest to become parents. This Article does not claim that fertility providers have no right to screen patients and reject those who are found wanting, but that the reasoning behind such rejections should be transparent and should rest upon concrete evaluations of the proper role to be played by a fertility provider in judging risks to patients and to future children.

Recognizing the complicated relationship between potential patients and fertility doctors, this Article seeks to provide some clarity and guidance to those facing the daunting task of accepting or rejecting patients on the basis of their disability status. Part I describes the various ways that physicians providing fertility services decide to accept or reject patients, and highlights how certain characteristics, such as disability, can lead to

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3. Richard K. Sherlock & Robert D. Sherlock, *Sterilizing the Retarded: Constitutional, Statutory and Policy Alternatives*, 60 N.C.L. REV. 943, 945-54 (1981-1982) (providing a history of eugenic sterilization of the developmentally disabled and urging greater protection of the fundamental rights of this population).

discrimination. Part II explains why it is appropriate to evaluate discrimination in the fertility context as impacting an interest in procreation, rather than an interest in parenting one's biological children or in seeking to adopt children. Part III evaluates the potential difficulties that a disabled person might face when attempting to prove unlawful discrimination under the Americans with Disabilities Act (ADA). Using the examples of an HIV-positive woman and a quadriplegic woman, the Section hypothesizes how such litigants would prove the applicability of the statute and explains why the ADA should be interpreted in a way that protects people with these substantial disabilities from being denied access to treatment by fertility doctors. Finally, Part IV mines the theoretical complications of risks that could warrant denying access to fertility care to women living with HIV or quadriplegia. This Section describes the difference between direct and indirect risks to the patient or the fetus and argues that indirect risk, summarized as the risk of bad parenting, is most often too amorphous to satisfy the ADA inquiry or ethical standards.

## I. Cherry Picking Patients

Physicians in private practice may decline to provide services to a given patient for a variety of reasons, including: an excessive patient load, the patient's inability to pay, personality conflicts, or simple dislike of a patient.<sup>4</sup> In general, none of these reasons for refusing care will subject the physician to a legally valid claim of discrimination.<sup>5</sup> However, refusals to provide care based on factors like race, ethnicity, or disability offend both professional ethics and the law.<sup>6</sup>

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4. The ASRM explains:

Although a strong ethic urges physicians to treat all persons in need, physician and professional autonomy is also an important value. Ordinarily, physicians are free to decide whether to enter into a doctor-patient relationship with a patient, and once in it, whether, with adequate notice to the patients, to terminate that relation. Unless the conditions of their employment require otherwise, physicians providing fertility services are generally free not to provide those services to individuals as they choose, subject only to federal and state laws against unjustified discrimination on the grounds of race, religion, ethnicity, or disability.

ASRM Ethics Comm., *Child-Rearing Ability and the Provision of Fertility Services*, 82 FERTILITY & STERILITY (SUPP. 1) S208, S210 (2004) [hereinafter ASRM].

5. *Id.*

6. See, e.g., Jessamyn S. Berniker, *Legal Implications of Discrimination in Medical Practice*, 28 J. L. MED. & ETHICS 85, 86 (2000) (describing the potential for lawsuits under Title VII of the Civil Rights Act for race-based discrimination in

According to the American Society of Reproductive Medicine (ASRM), the fertility industry in the United States has traditionally not engaged in any “systematic screening of [a prospective patient’s] ability or competency in rearing children . . . .”<sup>7</sup> Rather, the practice has been to treat those seeking pregnancy through the use of technology the same as

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providing healthcare). The ADA, as discussed in much greater detail later in this Article, prohibits discrimination on the basis of disability in public accommodations, including doctor’s offices. 42 U.S.C.A. §§ 12181(7)(F), 12182(a) (West 2008). The concern here is not about bias in how care is provided, though there is a substantial amount of scholarly literature detailing bias in providing care to people of color, especially African-Americans. See Shankar Vedantam, *The Color of Health Care: Diagnosing Bias in Doctors*, WASH. POST, Aug. 13, 2007, at A03 (describing a study by researchers at Massachusetts General Hospital and Harvard University affiliates that “provides empirical evidence for the first time that when it comes to heart disease, bias is the central problem—bias so deeply internalized that people are sincerely unaware that they hold it”). Without necessarily pointing to physician bias as a cause, the federal government has put substantial resources into addressing persistent disparities in healthcare access and outcomes for people of color, noting that even as health and life span have improved over the last part of the twentieth century:

[A]frican Americans, Hispanics, Native Americans, and Asian/Pacific Islanders, who represented 25 percent of the U.S. population, continued to experience striking health disparities, including shorter life expectancy and higher rates of diabetes, cancer, heart disease, stroke, substance abuse, and infant mortality and low birth weight. Scientists believed these health disparities resulted from the complex interaction among several factors such as biology, the environment, and specific behaviours that were significantly impacted by a shortage of racial and ethnic minority health professionals, discrimination, and inequities in income, education, and access to health care.

Nat’l Ctr. on Minority Health & Health Disparities, *Health Disparities—Closing the Gap: Fact Sheet*, [http://ncmhd.nih.gov/hdFactSheet\\_gap.asp](http://ncmhd.nih.gov/hdFactSheet_gap.asp) (last visited Feb. 16, 2009). There is also literature suggesting that people with disabilities may not receive the highest level of medical care to which they are entitled. See, e.g., H. STEVEN KAYE, *DISABILITY WATCH: THE STATUS OF PEOPLE WITH DISABILITIES IN THE UNITED STATES*, VOL. 2, at 3–21 (2001) available at

[http://www.drakelegal.org/downloads/pubs/disability\\_watch\\_2.pdf](http://www.drakelegal.org/downloads/pubs/disability_watch_2.pdf) (describing the many ways in which people with disabilities are disadvantaged in accessing health care and health insurance); Susan M. Haverkamp et al., *Health Disparities Among Adults with Developmental Disabilities, Adults with Other Disabilities, and Adults Not Reporting Disability in North Carolina*, 119 PUB. HEALTH REP. 418, 421 (2004) (concluding in part that there were significant disparities in medical care utilization for breast and cervical cancer screening and in oral health care for adults with developmental disabilities); U.S. Dep’t of Health & Hum. Servs., *Access to Quality Health Services and Disability—A Companion to Chapter 1 of Healthy People 2010*,

[http://www.hhs.gov/od/about/fact\\_sheets/healthypeople2010.html](http://www.hhs.gov/od/about/fact_sheets/healthypeople2010.html) (last visited Feb. 20, 2009) (noting that “many physicians lack the training to meet the full range of health care needs presented by an individual with particular disabling conditions, much less to evaluate and treat that individual in a culturally sensitive and competent manner”). This Article focuses not on bias in care, but rather on physicians who would simply refuse to provide any care to a person based on that patient’s status as a person living with a disability.

7. ASRM, *supra* note 4, at S208.

those who are able to reproduce coitally.<sup>8</sup> In this sense, there has been little attempt to create standards for providing treatment other than those of good medicine, such as determining if a patient is healthy enough to participate in treatment or if the patient can be helped by available treatments.<sup>9</sup> Although screening for parental ability has not been systematic, it is certainly the case that various types of screening for physical fitness are a part of fertility practice.<sup>10</sup>

While available data is slim, it appears that fertility providers use a range of screening tools before determining their willingness to work with a given patient or provide a particular service.<sup>11</sup> As would be expected, providers routinely screen patients—and their partners when relevant—for sexually transmitted infections, including HIV, before attempting to initiate a pregnancy.<sup>12</sup> Patients with specific concerns can also request genetic screening to avoid passing on genes that can lead to debilitating or deadly illnesses.<sup>13</sup> Screening for illness or disease, particularly transmissible diseases, is a required part of good medical practice in terms of ethics, professionalism, and legal

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8. *Id.*

9. See The Practice Comm. of the ASRM, *Optimal Evaluation of the Infertile Female*, 82 FERTILITY & STERILITY (SUPP. 4) S169 (2004) (describing the optimal testing and evaluation of a potential female infertility patient before the onset of fertility treatment).

10. As “[p]reliminary preparation for an ART [assisted reproductive technology] procedure may be as important as the procedure itself,” the ASRM notes that “testing for ovarian reserve may be recommended in order to predict how the ovaries will respond to fertility medication.” ASRM, ASSISTED REPRODUCTIVE TECHNOLOGIES: A GUIDE FOR PATIENTS 14 (2008), available at <http://www.asrm.org/Patients/patientbooklets/ART.pdf>. Patients may also require procedures to correct “[u]terine cavity abnormalities such as *fibroids*, *polyps*, or a *septum* . . .” *Id.* Potential patients should also address “lifestyle issues,” such as smoking, that can reduce the chance of pregnancy. *Id.* at 15. Finally, all potential patients should receive “[a] complete exam and Pap smear” to identify problems that should be corrected prior to attempting pregnancy. *Id.*

11. The Society for Assisted Reproductive Technology (SART) indicates that a woman seeking to become pregnant using in vitro fertilization (IVF) should receive the following tests: HIV, Hepatitis B antigen, Hepatitis C antibody, RPR, blood group, Rh, and antibody screen. She should also have a Pap smear. SART, *Prerequisite Testing*, [http://www.sart.org/Guide\\_PrerequisiteTesting.html](http://www.sart.org/Guide_PrerequisiteTesting.html) (last visited Feb. 16, 2009). Presumably, these tests would also be required of a patient using other forms of reproductive technology to become pregnant.

12. *Id.*

13. *Id.* (suggesting that patients of Jewish descent may choose to test for Tay-Sachs and a variety of other diseases, patients who are African-American might test for sickle-cell trait, and patients with a family history of developmental disabilities might test for Fragile X).

liability.<sup>14</sup> The greater challenge is deciding on what basis providers can and should engage in screening intended not to make determinations of health, but to make determinations of parental fitness unrelated to health.

Most fertility providers believe that their work obligates them to consider both the welfare of the fertility patient or patients and the welfare of a future child prior to agreeing to help a patient achieve pregnancy. One study on the screening<sup>15</sup> practices of Assisted Reproductive Technology (ART) programs found that though 59% of responding ART program directors believe that everyone has a right to have a child, 64% of these directors also believe “in their responsibility to consider a parent’s fitness before helping them conceive.”<sup>16</sup> That only a minority (18%) of responding ART programs asked potential patients to meet with a social worker or psychologist during their patient screening process raises serious questions about how these programs accurately and adequately evaluate parental fitness without the aid of trained and skilled providers.<sup>17</sup> This small number of evaluations conducted by social workers and psychologists starkly contrasts with the 80% of programs in which potential patients meet with a financial coordinator.<sup>18</sup>

The study’s authors identify two key values that guide screening practices in the responding ART programs: “ensuring a prospective child’s safety and welfare and not risking the welfare of the prospective mother.”<sup>19</sup> The answers that the directors provided to questions about turning away hypothetical patients somewhat reflect these core values. Fifty-nine percent of responding program directors would be very or extremely likely to refuse service to an HIV-positive woman, while 55% felt the same regarding a diabetic woman with a 10% chance of dying as a result of her pregnancy.<sup>20</sup> Eighty-one percent of programs indicated that they would be very or extremely likely to turn away a couple

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14. *Id.* (explaining that some of the tests listed are required by law, while some are required by “standards of care”).

15. As used in this study, “screening” refers to “the assessment and consideration of factors other than those that impact fertility and treatment success or ability to pay in decisions about the provision of ART services.” Andrea D. Gurmankin et al., *Screening Practices and Beliefs of Assisted Reproductive Technology Programs*, 83 *FERTILITY & STERILITY* 61, 62 (2005).

16. *Id.* at 63.

17. *Id.*

18. *Id.*

19. *Id.* at 64–65.

20. *Id.* at 63, 65.

where the man has been physically abusive to an existing child.<sup>21</sup> Fifty-three percent would be very or extremely likely to turn away a man who does not have a wife/partner, and 48% would turn away a gay couple seeking to use a surrogate to become pregnant.<sup>22</sup>

By contrast, 77% of respondents would be not at all likely or slightly likely to turn away a woman who lacks a husband/partner and 82% would be not at all likely or slightly likely to turn away a lesbian couple hoping to achieve pregnancy through artificial insemination.<sup>23</sup> Sixty percent of the clinics would be not at all likely or slightly likely to turn away couples where the woman has a history of attempted suicide, and 68% answered similarly regarding a couple where both members have limited intellectual ability.<sup>24</sup> Finally, 66% would work with a woman with bipolar disorder, and 91% would work with a couple where both members had become blind from a car accident.<sup>25</sup>

At the very least, these statistics indicate that certain patients seeking fertility treatment may have to engage in "fertility forum shopping" in order to find a provider willing to work with them. As long as there is a provider willing to work with the patient, it is assumed that the system, as it currently exists, functions well enough. However, if there are valid societal reasons to believe that limits should be placed upon a provider's ability to refuse service to prospective parents, then the law should not turn a blind eye to this form of discrimination. Further, the discrimination occurring in this context may not be easily discovered and rectified. Providers may not always be straightforward about why they are refusing care to a client and, as a result, the patient will not be aware that she has been turned away because of bias. Some patients may be aware of discrimination but may still choose not to pursue a legal remedy, either to protect their privacy or because they are not interested in receiving care from a provider who discriminates. Therefore, it may be even more critical that those cases that do appear in court are given a fair hearing.

These disparities in provider responses also reflect that there is no overarching authoritative statement from a regulatory body on what responsibilities, if any, healthcare providers have to

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21. *Id.* at 65.

22. *Id.*

23. *Id.*

24. *Id.*

25. *Id.*



prospective parents seeking fertility services.<sup>26</sup> This lack of clarity starkly contrasts with the United Kingdom, where the Human Fertilisation and Embryology Authority (HFEA), a regulatory agency, specifically mandates that healthcare providers consider the potential welfare of the child before providing fertility services to prospective parents.<sup>27</sup> This assessment includes considering factors that “are likely to cause serious physical, psychological or medical harm, either to the child to be born or to any existing child of the family.”<sup>28</sup> The HFEA requires that providers factor in “any aspect of the patient’s (or, where applicable, their partner’s) past or current circumstances which means that either the child to be born or any existing child of the family is likely to experience serious physical or psychological harm or neglect.”<sup>29</sup> Providers should be concerned about any circumstances that would “likely lead to an inability to care for the child to be born throughout its childhood or which are already seriously impairing the care of any existing child of the family.”<sup>30</sup> In this context, the HFEA flags a prospective parent’s “mental or physical conditions,”<sup>31</sup> “drug or alcohol abuse,”<sup>32</sup> or “any aspect of the patient’s . . . medical history which means that the child to be born is likely to suffer from a serious medical condition.”<sup>33</sup>

As this suggests, the provision of fertility services is closely regulated in the United Kingdom, and the HFEA both supports and demands thorough screening of potential parents. The U.K.

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26. In its 2004 report on the ethics and practice of ART in the United States, the President’s Council on Bioethics provided a thorough overview of regulation affecting the fertility industry. See PRESIDENT’S COUNCIL ON BIOETHICS, REPROD. AND RESPONSIBILITY: THE REG. OF NEW BIOTECHNOLOGIES 46–71 (2004). The authors note that some federal agencies play a limited role in regulating the fertility industry. *Id.* at 47–51, 54–64. For instance, the Centers for Disease Control and Prevention (CDC) is charged with publishing an annual report on ART clinic success rates. *Id.* at 47–51 (citing the Fertility Clinic Success Rate and Certification Act of 1992, Pub. L. No. 102-493, 106 Stat. 3146 (1992) (codified at 42 U.S.C. § 263a-1 *et seq.*)). State regulation is generally limited to statutes focused on issues of access and insurance. *Id.* at 51. There is also some indirect regulation of the industry, such as the Food and Drug Administration’s role in approving certain devices used in ART and the role of civil litigation in helping to set standards for practice. *Id.* at 54–58, 69. However, there is no ultimate authority comparable to the United Kingdom’s Human Fertilisation and Embryology Authority (HFEA) that controls the fertility industry in the United States.

27. HFEA, CODE OF PRACTICE § G.3 (7th ed. 2007), available at [http://cop.hfea.gov.uk/cop/pdf/CodeOfPracticeVR\\_4.pdf](http://cop.hfea.gov.uk/cop/pdf/CodeOfPracticeVR_4.pdf).

28. *Id.* § G.3.3.2.

29. *Id.* § G.3.3.2(a).

30. *Id.* § G.3.3.2(b).

31. *Id.* § G.3.3.2(b)(i).

32. *Id.* § G.3.3.2(b)(ii).

33. *Id.* § G.3.3.2(c).

system is premised on the idea that the government's obligations to children, specifically to protect future children from the possibility of physical or emotional harm, is a sufficient basis for refusing care to an individual whose circumstances create a risk of subpar parenting.<sup>34</sup> In the United States, however, the fertility industry is premised on a privatized consumer-focused model.<sup>35</sup>

Within the U.S. model, patient screening is conducted in a haphazard manner, based on criteria fashioned by individual providers that may or may not conform to the voluntary codes of professional organizations like the ASRM. The ASRM, for example, states that fertility providers "may withhold services from prospective patients on the basis of well-substantiated judgments" that the child would not be adequately provided for.<sup>36</sup> The ASRM specifically singles out parents with disabilities as a group to whom services should not be denied "except in rare cases," and then only when "a well-substantiated basis exists for thinking that they cannot provide or have others provide adequate child-rearing for offspring."<sup>37</sup> This ethics opinion, however, has no binding force, and providers need not worry that they will be subject to legal sanction for failure to conform to the recommendations of ASRM.<sup>38</sup> There is no overarching regulatory body like the HFEA to subject them to fines or the loss of a license, which could help to compel conformance to any particular set of

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34. The HFEA makes clear that its code of practice is guided by several principles, including: fair and reasonable consideration of prospective parents; the duty of providers to not unfairly discriminate; and concern for the welfare and best interests of the potential child. *Id.* § 1.2.

35. As author Debora Spar has written:

In the United States, however, regulatory and legislative authorities have largely ignored the market for reproductive services. There are very few restrictions on fertility treatments and little regulation of providers. Instead, the market for fertility in the United States is vibrant, competitive, and expanding in the absence of any kind of formal controls. Because the United States is such a large and technically advanced market, moreover, it serves as a magnet for infertile couples around the world.

DEBORA SPAR, *THE BABY BUSINESS* 5 (2006).

36. ASRM, *supra* note 4, at S208.

37. *Id.*

38. The ASRM has a policy allowing for disciplinary actions, including removal, if a member engages in conduct that is "injurious to the good order, peace, reputation, or best interest of the Society, or is derogatory to its dignity, inconsistent with its purposes, or shows a failure to maintain high ethical standards." ASRM, ASRM Disciplinary Policy, [http://www.asrm.org/Professionals/Membership/disciplinary\\_policy.html](http://www.asrm.org/Professionals/Membership/disciplinary_policy.html) (last visited Feb. 23, 2009). The ASRM, however, is a professional organization and membership in that organization is not a requirement for medical licensing of healthcare providers.

non-discrimination practices.<sup>39</sup>

The U.S. model's lack of governmental control or oversight does not automatically imply that it is flawed. However, the absence of a uniform, overarching body for setting patient screening standards means that prospective parents are at risk of unfair discrimination, and future children may be denied the opportunity to be raised by loving and competent parents. As such, it is critical to consider the ramifications of ceding such an important function—screening potential parents—to an industry that lacks the ability to ensure the fairness and accuracy of such assessments.

One tool for identifying and reining in abusive practices is the existing body of anti-discrimination law, including the ADA,<sup>40</sup> which purports to protect people with disabilities from discriminatory treatment when accessing public accommodations, including healthcare.<sup>41</sup> In the absence of regulation, private actions under applicable statutes may be the best—and perhaps only—way to ensure equal access to fertility services to people with disabilities.

## II. Rejecting Parents

Before tackling some of the intricacies of the statutory law on issues of disability discrimination, it is prudent to explain why, as a normative matter, discriminating in access to parenting on the basis of disability is a personal and societal wrong. In formulating a solid argument about non-discrimination in the context of fertility treatment, one must assert, as this Article does, that the right to reproduce encompasses a positive right not to be discriminated against in seeking the tools to create pregnancy, rather than simply a negative right to be left alone to reproduce.<sup>42</sup>

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39. HFEA, *supra* note 27, § 1.3.

40. Americans with Disabilities Act of 1990 (ADA), Pub. L. No. 101-336, 104 Stat. 327 (1990) (codified at 42 U.S.C. §§ 12101–12213 (2008)).

41. 42 U.S.C. §§ 12181–12184. In addition to the ADA, people living with disabilities (including HIV or AIDS) who believe that they have been discriminated against in accessing healthcare may sue under § 504 of the Rehabilitation Act, which prohibits entities receiving federal aid from discriminating against otherwise qualified people living with disabilities. See Rehabilitation Act of 1973 § 504, 29 U.S.C. § 794(d) (2002).

42. See Elizabeth Price Foley, *Human Cloning and the Right to Reproduce*, 65 ALB. L. REV. 625, 630 (2002) (“Whether this positive right [to reproduce], however, also extends to non-coital forms of procreation—including widely used technologies such as in vitro fertilization (IVF) and artificial insemination—is a matter of conjecture to which one can only make an educated guess.”); cf. JOHN A. ROBERTSON, *CHILDREN OF CHOICE: FREEDOM AND THE NEW REPRODUCTIVE TECHNOLOGIES* 23, 116–18 (Princeton Univ. Press 1996) (1994) (stating that as a

The ADA, as discussed in detail later in this Article, does not create a right to medical care; it simply says that a person with disabilities should be able to seek medical care on the same terms as a person who is not disabled.<sup>43</sup> Thus, while a person living with a disability could not claim that a physician must work with her even if she could not pay, it is perfectly appropriate to be placed on equal footing with other patients who meet the logical criteria for care.

To justify denying access to fertility treatment for certain potential patients, one could make the analogy to the ways in which a State may interfere with an individual's fundamental right to the care and custody of a child.<sup>44</sup> The argument generally holds that if the right to legally parent can be withdrawn, manipulated, or completely withheld (particularly as it comes into conflict with the State's *parens patriae* interest in protecting children) then it is appropriate to act even earlier and avoid ever placing a child in harm's way.<sup>45</sup>

State laws that provide for the termination of parental rights can and have been used to temporarily and permanently remove children from the care of parents who, by reason of their physical or mental disabilities, have proven themselves incapable of

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matter of constitutional law, procreative liberty is solely a negative right; however, as a matter of social justice, the exercise of the right may be "severely constrained by social and economic circumstances").

43. 42 U.S.C.A. §§ 12181(7)(F), 12182(a) (West 2008).

44. Every state has statutes that allow for the termination of parental rights when a parent is accused of abusing or neglecting a dependent child. *See, e.g.*, ALA. CODE § 26-18-7 (1995 & Supp. 2008), *renumbered as* § 12-15-319 (effective Jan. 1, 2009) (listing grounds for termination of parental rights and factors to be considered); IDAHO CODE § 16-2005 (2001 & Supp. 2008) (describing conditions under which termination of parental rights may be granted); MASS. GEN. LAWS ch. 119, §§ 26 & 29C & ch. 210, § 3 (2003 & Supp. 2009) (describing standards for the protection and care of children, judicial certification of the need to remove children from the home, and dispensing with required consent in certain adoptions); N.J. STAT. ANN. §§ 30:4C-11.2, 30:4C-15 (2008) (noting that reasonable efforts to prevent placement of a child are not required in certain situations of parental abuse, and describing guardianship in cases of parental abuse).

45. Arthur Caplan from the Center for Bioethics at the University of Pennsylvania has written:

With all due respect, the idea that doctors should not set limits on who can use reproductive technology to make babies is ethically bonkers. . . . Doctors have an obligation to consider patients' requests for treatment, but they do not have to honor them. One very good reason not to do so is if a doctor believes that what the patient wants would put children at grave risk.

Arthur Caplan, *Ethics and Octuplets: Society Is Responsible*, PHILADELPHIA INQUIRER, Feb. 6, 2009, available at <http://www.philly.com/inquirer/opinion/39190377.html>.

providing a safe and stable home.<sup>46</sup> Many of the cases involve parents with developmental disabilities or mental health diagnoses.<sup>47</sup> While a review of these cases suggests that these parents often have limitations on their parenting ability beyond their disabilities, their disability status coupled with its impact on parenting skills is a solid and supportable basis for severing the relationship between a parent and her child.<sup>48</sup> Certainly these disabled parents have the same fundamental right to the care and custody of a child as their non-disabled counterparts.<sup>49</sup> That right, however, cannot prevail when a court finds that a parent's disability has contributed to circumstances in which a child is endangered or neglected. Many state statutes specifically list disability as a reason why a parent might lose custody of a child.<sup>50</sup> Although disability alone is not a sufficient cause for a child's removal from the care of a parent, a disability significant enough to impact parenting abilities is certainly a sufficient basis to terminate parental rights.<sup>51</sup>

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46. See, e.g., *In re M.F.*, 762 N.E.2d 701 (Ill. App. Ct. 2002) (upholding a finding of parental unfitness in a case involving a schizophrenic mother); *Bartell v. Lohiser*, 12 F. Supp. 2d 640 (E.D. Mich. 1998) (upholding the termination of parental rights of a developmentally-disabled mother).

47. See, e.g., *In re C.S.*, 878 N.E.2d 110 (Ill. App. Ct. 2007) (holding that a schizophrenic parent was entitled to a mental examination prior to being judged unfit); *In re Cornica J.*, 814 N.E.2d 618 (Ill. App. Ct. 2004) (holding that developmentally-disabled parents were unfit).

48. See, e.g., *In re B.S.*, 740 N.E.2d 404 (Ill. App. Ct. 2000) (severing the parental rights of a mother with drug dependency and mental health issues), *overruled by In re R.C.*, 745 N.E.2d 1233 (Ill. 2001) (stating that strict scrutiny review must be met before the parent-child relationship can be severed on grounds of disability).

49. One court contending with the issue of terminating the parental rights of a mentally-retarded parent wrote:

Consequently, certain personal rights have been deemed fundamental to the concept of ordered liberty and worthy of constitutional protection. Among these are the rights to marry, procreate, use contraceptives, undergo abortion, engage in family relationships and rear and educate children. These rights are conferred upon all persons, including the retarded. Therefore, as a result of the impact of section 8 of the Adoption Act upon parental rights, the interest affected in this case is no less than the right of a parent who has been adjudicated mentally retarded to "establish a home and bring up children."

*Helvey v. Rednour*, 408 N.E.2d 17, 21 (Ill. App. Ct. 1980) (citations omitted).

50. CHILD WELFARE INFO. GATEWAY, GROUNDS FOR INVOLUNTARY TERMINATION OF PARENTAL RIGHTS: SUMMARY OF STATE LAWS 2, available at [http://www.childwelfare.gov/systemwide/laws\\_policies/statutes/groundterminall.pdf](http://www.childwelfare.gov/systemwide/laws_policies/statutes/groundterminall.pdf) (noting that "long-term mental illness or deficiency of the parent(s)" is a ground for involuntary termination of parental rights in most states).

51. See, e.g., *In re Interest of C.A.K.*, 652 P.2d 603 (Colo. 1982) (*en banc*) (holding that the evidence sustained a finding that the mother's mental disability was of such a duration and nature to render her unlikely to provide reasonable care for her child); *Helvey*, 408 N.E.2d at 21-22 (citations omitted) (holding that before

Many state agencies provide services to a parent in order to allow the parent to maintain a relationship with the child, but there are limits on the level of service that they must provide, especially when it appears that the parent is not cooperating with the agency's efforts.<sup>52</sup> Some parents have attempted to use the ADA to force child welfare agencies to provide services to help ameliorate the consequences of a disability.<sup>53</sup> Thus far, state courts have not been amenable to using the ADA in this way, and have rejected arguments claiming a lack of reasonable accommodations for a mentally disabled parent faced with family court proceedings.<sup>54</sup>

It is certainly the case that once a child exists, the State need not ignore a parent's disability, and perhaps need not make significant concessions to that disability in determining whether a child should remain with a parent or be removed on a temporary or permanent basis.<sup>55</sup> Comparisons to the right to parent, however, are not particularly helpful in this context. First, the right to parent, most often understood as the fundamental right to the care and custody of one's children, is separate and apart from a right to procreate.<sup>56</sup> One need not have been involved in creating

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the mother could be deprived of her right to raise her child, a hearing had to be held to determine her fitness under the Adoption Act).

52. Under the Federal Adoption and Safe Families Act and state law, child welfare agencies are obligated to make reasonable efforts to reunite a child with her family of origin. CHILD WELFARE INFO. GATEWAY, REASONABLE EFFORTS TO PRESERVE OR REUNIFY FAMILIES AND ACHIEVE PERMANENCY FOR CHILDREN: SUMMARY OF STATE LAWS 2, available at [http://www.childwelfare.gov/systemwide/laws\\_policies/statutes/reunifyall.pdf](http://www.childwelfare.gov/systemwide/laws_policies/statutes/reunifyall.pdf) [hereinafter CHILD WELFARE INFO. GATEWAY, REUNIFICATION]. These efforts can be dispensed with in extreme circumstances, such as when the parent has been convicted of homicide or has been accused of abandonment, chronic abuse, or sexual abuse. *Id.*

53. See *Bartell v. Lohiser*, 12 F. Supp. 2d 640 (S.D. Miss. 1998).

54. CHILD WELFARE INFO. GATEWAY, REUNIFICATION, *supra* note 52, at 2.

55. See, e.g., *Stone v. Daviess County Div. of Children & Family Servs.*, 656 N.E.2d 824 (Ind. Ct. App. 1995) (terminating the parental rights of developmentally disabled parents); *In re K.H.K.*, 1999 WL 1191509 (Mont. Dec. 7, 1999) (terminating the parental rights of a developmentally-disabled parent).

56. The rights to marry and to procreate are "fundamental to the very existence and survival of the race" and, therefore, an individual's ability to reproduce is not to be taken away without exacting scrutiny being applied to such a measure. *Skinner v. Oklahoma*, 316 U.S. 535, 541 (1942). The right to parent, as articulated by the Court in cases like *Prince v. Massachusetts*, 321 U.S. 158, 166 (1944), does not refer to procreation, but to the cardinal notion that:

the custody, care and nurture of the child reside first in the parents, whose primary function and freedom include preparation for obligations the state can neither supply nor hinder. . . . And it is in recognition of this that these decisions have respected the private realm of family life which the state cannot enter.

a child in order to become that child's parent, and part of the rationale of denying access to genetically-shared embryos is the belief that those who are denied this method of procreation are not necessarily denied any right to procreate.<sup>57</sup> Unlike with parenting, however, States have much less leeway in interfering with procreative choice, and accessing ART is much more akin to exercising one's right to procreate than it is to exercising one's right to parent.<sup>58</sup>

The limited legal value of any perceived right to parent is understood when reviewing how the law deals with those seeking to adopt children. Adoption agencies routinely set limits on who can adopt a child.<sup>59</sup> These agencies screen for age, income, and disability and disease status.<sup>60</sup> There is no fundamental right to adopt that is equivalent to the fundamental right to the care and custody of a child or the fundamental right to procreate.<sup>61</sup> It is widely understood that adoption agencies, both public and private, engage in rampant discrimination when determining who can and cannot adopt a child.<sup>62</sup> I use the term discrimination here in a

*Id.*

57. *Kass v. Kass*, 696 N.E.2d 174, 181–82 (N.Y. 1998) (upholding an agreement between parties regarding the disposition of frozen embryos); *Davis v. Davis*, 842 S.W.2d 588, 603–04 (Tenn. 1992) (holding that a party wishing to avoid procreation should usually prevail in a dispute over frozen embryos).

58. *See, e.g., Griswold v. Connecticut*, 381 U.S. 479 (1965) (defining individuals' rights concerning procreation); *Skinner*, 316 U.S. at 541 (defining individuals' rights concerning sterilization and procreation).

59. ADOPTION & CHILD WELFARE LAW SITE, WHO MAY ADOPT & WHO MAY BE ADOPTED, [http://www.adoptionchildwelfarelaw.org/faq\\_detail.php?id=97](http://www.adoptionchildwelfarelaw.org/faq_detail.php?id=97) (last visited May 5, 2009) (describing some limitations on who may adopt a child).

60. Adoption.com, *Review of Qualification Requirements for Prospective Adoptive Parents*, <http://adopting.adoption.com/child/review-of-qualification-requirements-for-prospective-adoptive-parents,4.html> (last visited Apr. 1, 2009).

61. *Lindley v. Sullivan*, 889 F.2d 124, 131 (7th Cir. 1989) (finding "neither a fundamental right nor a privacy interest in adopting a child"); *see also Martin v. Putnam*, 427 So. 2d 1373, 1377 (Miss. 1983) (stating that adoption statutes confer a privilege, not a right, to adopt); *In re Adoption of Charles B.*, 552 N.E.2d 884, 886 (Ohio 1990) (finding the right to adopt to be permissive and not absolute).

62. For instance, some agencies may be reluctant to work with single people, older parents, gays and lesbians, or people with disabilities. Lucia Moses, *Special Circumstances*,

<http://www.theadoptionguide.com/advice/articles/special-circumstances.php> (last visited Apr. 1, 2009). In the past, concerns about racial discrimination in adoption placements prompted Congress to act to end practices that could lead to extended stays in foster care for hard-to-place children, including children of color. U.S. DEP'T OF HEALTH & HUM. SERVS., PROTECTION FROM RACIAL DISCRIMINATION IN ADOPTION AND FOSTER CARE, <http://www.hhs.gov/ocr/civilrights/resources/specialtopics/adoption/sec1808asumma>

neutral sense, as opposed to implying that these choices to exclude people from being potential adoptive parents are legally or necessarily morally suspect. Adoption agencies screen potential parents for histories of criminal conduct or abuse of children.<sup>63</sup> They conduct home studies to ensure that a child's new home is a safe and nurturing environment, both in terms of the physical space and the characteristics of the adoptive parents.<sup>64</sup> A home study may cost up to \$3,000 and generally consists of at least one visit to the prospective adoptive home by a social worker.<sup>65</sup> This process requires the adoptive parents to open up their lives to strangers. Potential adoptive parents will be asked questions about their family history, finances (including tax returns), medical information, alcohol and drug use history, employment status, support systems, readiness for parenting, past experiences with children, work history, theories on parenting, feelings about adoption, and personal relationships.<sup>66</sup> Prospective parents may be subjected to psychological evaluations and, in private adoptions, they may participate in interviews with birth parents in order to be selected as the recipients of a particular woman's baby.<sup>67</sup> Thus, the adoption paradigm is one of limitations and exclusions.

To the extent that adoption is about parenting and not procreation, it is arguably justified that those seeking to adopt a child should be treated differently than those who opt to become parents by exercising their right to procreate. Adoption involves an actual child, rather than a hypothetical child, or at least an actual fetus in need of caretakers, thus avoiding the conceptual difficulty of determining the scope of one's duty to a non-entity. As such, adoption seeks to find parents for a child who, in some sense, has already been put at risk because she is being born to parents

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ry.html (last visited Apr. 1, 2009). Many agencies set criteria intended to screen out supposedly undesirable parents, such as single people or same sex couples. *See, e.g.*, FLA. STAT. ANN. § 63.042(3) (West 1985 & Supp. 1995) (forbidding gays and lesbians from acting as foster or adoptive parents). Some adoption agencies have a specific religious agenda that places limits on the prospective parents with whom they will work. *See, e.g.*, Christian World Adoption, <http://www.cwa.org/> (last visited Apr. 1, 2009) (describing itself as a Christian International Adoption Agency that believes that "God is in Control of Our Agency & Your Adoption").

63. Lucia Moses, *Surviving the Homestudy*, <http://www.theadoptionguide.com/process/articles/surviving-the-homestudy> (last visited Apr. 1, 2009).

64. ADOPTIVE FAMILIES, PREPARING FOR YOUR HOMESTUDY (2005), *available at* <http://www.theadoptionguide.com/files/Homestudy.pdf>.

65. *See* Moses, *supra* note 63.

66. *See* ADOPTIVE FAMILIES, *supra* note 64.

67. Lois Gilman & Susan Freivalds, *Adoption Options* (2009), *available at* <http://www.theadoptionguide.com/options/articles/adoption-options.php>.



incapable or unwilling to parent, or because her parents have already abused or neglected her according to an adjudicating court. When a child has already suffered or is certain to suffer, the impetus to find stable, well-qualified parents is justifiably strong and controlling.

In general, the fertility industry has not modeled itself after the adoption paradigm.<sup>68</sup> Instead, the industry has focused on playing a minimal role in screening, and thus maximizing opportunity for those who seek fertility services.<sup>69</sup> Psychological screening, pre-conception interviews, home studies, and criminal background checks are in no way a standard part of fertility practice.<sup>70</sup> In fact, most clinics report little to no parental fitness screening of potential patients, and some express a certain level of discomfort with the idea of being asked or required to engage in this type of intensive and invasive screening process.<sup>71</sup> Given that access to treatment, assuming the required financial resources, is fairly relaxed, it is prudent to query whether there are valid reasons for disability to become one of a miniscule number of reasons why fertility providers move away from their basic stance of providing services without prejudice.

### III. Different Disabilities, Different Decisions

To challenge the accuracy of these screening decision assumptions about parenting ability, this Article evaluates two forms of disability—HIV-positive status and quadriplegia—and the relationship of each to the fertility industry and to the anti-discrimination principles espoused by the ADA. As mentioned earlier, one study indicates that 59% of fertility clinics would be very or extremely likely to turn away a couple where the woman is HIV-positive.<sup>72</sup> Therefore, the first topic for consideration is discrimination against potential parents living with HIV, with a focus on an HIV-positive woman seeking to become pregnant. The

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68. See ASRM, *supra* note 4, at S208 (“While some psychological or social screening may occur in determining whether a person or couple will be able to understand, tolerate, and comply with the demands of infertility treatment, much less attention ordinarily is focused on the home or rearing situation of children born as a result of treatment.”).

69. See *id.* (“As with persons who reproduce coitally, no systemic screening of their ability or competency in rearing children has traditionally occurred or been thought to be appropriate, as would ordinarily occur in adoption.”).

70. *Id.*

71. Gurmankin et al., *supra* note 15, at 62; see also BETH KOHL, EMBRYO CULTURE: MAKING BABIES IN THE TWENTY-FIRST CENTURY 149–54 (discussing the various age limitations enforced by fertility clinics on prospective mothers).

72. Gurmankin et al., *supra* note 15, at 65.

second topic addresses physical disability in the form of quadriplegia, focusing on the mothering and pregnancy choices of a quadriplegic woman. I chose these extreme examples to highlight both the different ways that concerns about children can be expressed in fertility treatment discourse, and the range of disabilities that could trigger bias.

The focus on women is appropriate for several reasons. First, while infertility appears to strike men and women in fairly equal numbers,<sup>73</sup> any successful solution to a fertility problem will necessarily involve creating a pregnancy that can only be carried by a person with the capacity to become pregnant.<sup>74</sup> Second, pregnancy itself carries specific risks for the woman and for her fetus that merit special consideration. Furthermore, despite some shifts in gender roles, women, even those who work outside of the home, are frequently the primary caretakers of children born into a family.<sup>75</sup> Therefore, a potential mother's parental fitness may be subject to greater scrutiny than the parental fitness of a potential father.

In this Section, I will first evaluate potential barriers to ADA protection for individuals living with HIV or quadriplegia who seek access to fertility services. Next, I will explain why the ADA should protect people with these substantial disabilities from being denied access to treatment by fertility doctors. Though a woman with either of the described conditions should be able to meet the Act's definition of disability, some of the Act's limitations, specifically those dealing with direct threat or reasonable accommodation, would make proving a case of unlawful discrimination more difficult than it might first appear.

#### A. *The HIV-Positive Patient*

Since the beginning of the HIV epidemic, HIV-positive

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73. The ASRM reports that “[i]nfertility affects about 7.3 million women and their partners in the U.S.—about 12% of the reproductive-age population” and that the disease affects men and women equally. ASRM, *Frequently Asked Questions About Infertility*, <http://www.asrm.org/Patients/faqs.html> (last visited Feb. 16, 2009) (citing CDC, NATIONAL SURVEY OF FAMILY GROWTH 14 (2002), available at [http://www.cdc.gov/nchs/data/series/sr\\_23/sr23\\_025.pdf](http://www.cdc.gov/nchs/data/series/sr_23/sr23_025.pdf)).

74. While it is true that transgender men have—famously in the case of Thomas Beatie—chosen to become pregnant, it is also true that one must possess the biologically female characteristics of a woman, specifically a uterus, in order to become pregnant and bear a child. Thomas Beatie, *Labor of Love*, THE ADVOC., Apr. 8, 2008, at 24. Interestingly, Beatie reports that he and his wife experienced discrimination in their attempt to find a fertility doctor who would work with them and eventually the two opted to perform inseminations at home. *Id.*

75. See JUDITH WARNER, PERFECT MADNESS 117 (2005).

patients have felt the reluctance of some healthcare providers, for legitimate or illegitimate reasons, to provide services to them.<sup>76</sup> As one study notes, “[a]lthough still an ongoing problem, over time and with better knowledge of transmission risks, discrimination toward HIV-1 seropositive patients has declined. Patients with infertility, however, have typically been denied therapy, partly because of the unique medical and ethical concerns surrounding reproduction.”<sup>77</sup> As of 2003, “[l]ess than 5% of [ART] clinics in the United States [offered] reproductive care to HIV-1 serodiscordant couples.”<sup>78</sup> Even as the severity of discrimination wanes, people seeking access to fertility treatment may still find that their HIV-positive status acts as a bar to treatment. Physician concerns tend to center around “the potential risk of transmitting [the] virus to the embryo, fetus, or mother, as well as worries over the socioeconomic impact of raising a child by a parent with a potentially fatal disease.”<sup>79</sup>

Every person who has AIDS is HIV-positive, but not every person who is HIV-positive has AIDS.<sup>80</sup> HIV is a progressive disease that, especially when left untreated, leads to a breakdown of the immune system in most people.<sup>81</sup> As a result, people who are HIV-positive are at risk for opportunistic infections (OI) that can be disabling and/or life-threatening.<sup>82</sup> A physician will diagnose an HIV-positive person with AIDS when the individual’s immune system is severely weakened such that the patient’s

76. See, e.g., *Bragdon v. Abbott*, 524 U.S. 624, 651–55 (1998) (involving a dentist’s refusal to provide in-office, routine dental care to an asymptomatic HIV-positive patient); *Lesley v. Chie*, 250 F.3d 47, 58 (1st Cir. 2001) (involving an obstetrician who transferred care of an HIV-positive woman to a specialist).

77. Klein et al., *Understanding the Motivations, Concerns, and Desires of Human Immunodeficiency Virus 1–Serodiscordant Couples Wishing to Have Children Through Assisted Reproduction*, 101 *OBSTETRICS & GYNECOLOGY* 987, 987 (2003).

78. Mark V. Sauer, *Providing Fertility Care to Those with HIV: Time to Re-Examine Healthcare Policy*, 3 *AM. J. BIOETHICS* 33, 38 (2003).

79. *Id.* at 33.

80. See CDC, *What is AIDS, Basic Information*, <http://cdc.gov/hiv/topics/basic/index.htm> (last visited Aug. 3, 2009) (“AIDS is the final stage of HIV infection. It can take years for a person infected with HIV . . . to reach this stage.”).

81. See National Institutes of Health (NIH), *HIV and Its Treatment: What You Should Know*, Dec. 2008, available at [http://aidsinfo.nih.gov/contentfiles/HIVandItsTreatment\\_cbrochure\\_en.pdf](http://aidsinfo.nih.gov/contentfiles/HIVandItsTreatment_cbrochure_en.pdf) [hereinafter NIH] (“[I]f left untreated, HIV infection damages a person’s immune system and can progress to AIDS.”).

82. See Sauer, *supra* note 78, at 33 (“[AIDS] remains a serious disease; if not treated, patients typically succumb to either opportunistic infections or cancer.”).

CD4<sup>83</sup> count drops below 200 cells/mm<sup>3</sup> or if she develops an AIDS-defining condition, meaning an illness seldom seen in someone who is not living with HIV.<sup>84</sup> HIV specialists monitor their patients' CD4 count, which measures the presence of the white blood cells that normally fight infection in the body and which are targeted for destruction by HIV.<sup>85</sup> Physicians also monitor the patient's viral load. This gauges the amount of HIV circulating in a person's blood, and is an indicator of how well an individual's treatment regimen is working.<sup>86</sup>

For people living in relatively resource-rich settings, like the United States, physicians recommend early treatment for HIV infection to delay the onset of AIDS, reduce susceptibility to opportunistic infections, and protect the health of the immune system.<sup>87</sup> The standard of care is for a person to take Highly Active Antiretroviral Therapy (HAART), which consists of daily therapy with three or more antiretroviral drugs.<sup>88</sup> While the treatment has proven to be enormously successful in saving and extending the lives of many people living with HIV,<sup>89</sup> it is not without its drawbacks. First, side effects from the medications can be significant and include "liver problems . . . , diabetes . . . , high cholesterol . . . , high levels of lactate in the blood . . . , abnormal fat distribution (lipodystrophy syndrome) . . . , decreased bone density . . . , skin rash . . . , pancreatitis (inflammation of the pancreas) . . . , nerve problems . . . [and] increased bleeding in patients with hemophilia."<sup>90</sup> Second, the discipline involved in taking the medications can be a stretch for some people,<sup>91</sup> and

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83. "CD4 cells are a type of white blood cell that fights infection." See NIH, *supra* note 81.

84. *Id.*

85. See *id.* ("When HIV enters a person's CD4 cells, it uses the cells to make copies of itself. This process destroys cells, and the CD4 count goes down.")

86. See *id.* ("A viral load test measures the amount of HIV in a sample of blood. This test shows how well your immune system is controlling the virus.")

87. See CDC, *HIV Testing*,

[http://www.cdc.gov/hiv/topics/testing/resources/qa/qa\\_professional.htm](http://www.cdc.gov/hiv/topics/testing/resources/qa/qa_professional.htm) (last visited Apr. 27, 2009) (discussing the benefits of early treatment versus the substantial costs incurred).

88. See NIH, *supra* note 81 ("These guidelines recommend that you take a combination of three or more medications from different classes . . . in a regimen called Highly Active Antiretroviral Therapy (HAART).")

89. See Sauer, *supra* note 78, at 35 ("The use of highly active antiretroviral therapy (HAART) has extended the life expectancy of most patients indefinitely.")

90. NIH, *supra* note 81.

91. See *id.* ("Many people adhere well to their treatment early on but find adherence becomes more difficult over time.")

failing to take doses as required can lead to drug resistance.<sup>92</sup> Third, the substantial cost of medications can be prohibitive.<sup>93</sup> Despite the significant advances in treatment for people with HIV,<sup>94</sup> the reality of the illness is that the disease itself or its treatment can substantially compromise the quality of an infected person's life. There is no cure, and the infection is both life-altering and life-ending.<sup>95</sup> Though HAART is not a cure, access to such therapy has encouraged an evolution in attitudes toward people living with HIV and "[t]oday, HIV-1-infected individuals with access to highly active antiretroviral therapy are living longer, healthier lives, and most physicians now consider the illness to be of a chronic rather than a terminal nature."<sup>96</sup>

Faced with the complications and difficulties of life with HIV, some women opt not to pursue pregnancy,<sup>97</sup> but many others will not let their diagnosis keep them from pursuing dreams of biological parenthood, particularly given that many U.S. women living with HIV are of childbearing age.<sup>98</sup> Undoubtedly, many of those women have health concerns, especially those related to the potential transmission of HIV to a future child or a sexual partner, and these concerns will be of paramount concern when considering

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92. *Id.* ("When you skip a medication dose, even just once, the virus has the opportunity to reproduce more rapidly.")

93. One study estimated the average cost of HAART at \$2,100–\$4,700 per month depending upon a person's health status when she begins treatment. CBS News, *Got HIV? Lifetime Cost: \$618,900*, Nov. 2, 2006, <http://www.cbsnews.com/stories/2006/11/02/health/webmd/main2147219.shtml>.

94. See Sauer, *supra* note 78, at 33 ("HAART has dramatically altered the clinical course of [HIV-1].")

95. See NIH, *supra* note 81 (discussing the negative side effects of treatment, which may prolong life but will not cure HIV infections).

96. Klein et al., *supra* note 77, at 987.

97. In one study of women living with HIV or AIDS in the Midwest, researchers found that only 25.7% of women studied chose to become pregnant after their diagnosis as HIV-positive. Shonda M. Craft et al., *Pregnancy Decisions Among Women with HIV*, 11 AIDS BEHAV. 927, 930 (2007). Women under the age of 30 were more likely to seek pregnancy than those over age 30. *Id.* at 931 ("Among women aged 30 and under, 39.5% chose to become pregnant while only 11.1% did among women over 30.")

98. In August 2008, the CDC wrote, "[f]or women of all races and ethnicities, the largest number of HIV/AIDS diagnoses during recent years was for women aged 15–39." CDC, HIV/AIDS AMONG WOMEN (2008), <http://www.cdc.gov/hiv/topics/women/resources/factsheets/pdf/women.pdf>; see also, Tamara Zutlevics, *Should ART be Offered to HIV-serodiscordant and HIV-seroconcordant Couples?: An Ethical Discussion*, 21 HUM. REPROD., 1956, 1956 (2006) ("[W]hilst the number of women with HIV approaching clinics is in general below 1% of all clients, it is inevitable that the demand will increase, necessitating a carefully considered response by clinics.")

pregnancy.<sup>99</sup> The modern availability of various pre- and post-pregnancy technologies that minimize transmission risk will be welcome, even though many HIV-positive women lack the resources to avail themselves of all options.<sup>100</sup> For any HIV-positive woman seeking pregnancy, consultation with medical personnel will be critically important before, during, and after pregnancy and childbirth.<sup>101</sup> Keeping the nature of the disease in mind, this Article will describe the interplay among HIV status, fertility treatment, and the ADA.

The ADA requires a multi-step inquiry in order to determine whether the statute's protections against unlawful discrimination apply to disabled persons seeking fertility treatment.<sup>102</sup> Litigants claiming discrimination in the provision of reproductive health services on the basis of HIV status must meet the threshold requirements of the ADA: first, that the plaintiff is disabled as defined by the Act;<sup>103</sup> and second, the conduct complained of does in fact violate the statute's prohibition on discrimination because there is a readily achievable reasonable accommodation to be made for the patient, or because the patient does not present a direct threat to herself or others.<sup>104</sup> Under Subchapter III of the Act, pertaining to public accommodations, healthcare providers are prohibited from discriminating against disabled patients in the provision of health services.<sup>105</sup>

Any successful ADA claim begins with a person who is disabled under the meaning of the Act. This requires "(A) a physical or mental impairment that substantially limits one or more of the major life activities of such individual; (B) a record of such an impairment; or (C) being regarded as having such an impairment."<sup>106</sup>

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99. See Craft et al., *supra* note 97, at 931 (discussing the main factors in the "decision-making process concerning pregnancy-related issues" found in the study).

100. Tarun Jain & Mark D. Hornstein, *Disparities in Access to Infertility Services in a State with Mandated Insurance Coverage*, 84 FERTILITY & STERILITY 221, 222 (2005) (noting that even with mandated insurance coverage, disparities in fertility coverage exist, with most of those availing themselves of treatment being White, highly educated, and upper income).

101. See, e.g., Craft et al., *supra* note 97, at 931 ("[W]omen with HIV who chose to continue their pregnancies did so, in part, with an intention to continue or begin HIV medications.").

102. 42 U.S.C.A. § 12182 (West 2008).

103. *Id.* § 12102(2).

104. *Id.* § 12182.

105. *Id.* § 12181(7)(F) (defining a public accommodation to include the "professional office of a health care provider").

106. *Id.* § 12102(2).

In interpreting the statutory language, the Supreme Court has determined that even asymptomatic HIV infection<sup>107</sup> is a disability for purposes of ADA analysis.<sup>108</sup> The Court also determined that reproduction is a major life activity,<sup>109</sup> and that women living with HIV are substantially impaired in their ability to reproduce in two ways.<sup>110</sup> First, an HIV-positive woman seeking to become pregnant through unprotected sexual intercourse poses a transmission risk to her sexual partner.<sup>111</sup> The Court cited studies indicating “20% of male partners of women with HIV became HIV-positive themselves, with a majority of the studies finding a statistically significant risk of infection.”<sup>112</sup> Second, a woman living with HIV who becomes pregnant poses a transmission risk to her fetus and future child.<sup>113</sup> The Court was not persuaded by the argument that treatment with antiretrovirals during pregnancy and labor could lower the risk of vertical (mother-to-child) transmission sufficiently to remove the disability.<sup>114</sup> Declining to decide whether the disabled person had to be evaluated in a mitigated or unmitigated state, the Court determined that “[i]t cannot be said as a matter of law that an 8% risk of transmitting a dread and fatal disease to one’s child does not represent a substantial limitation on reproduction.”<sup>115</sup> The fact that a person could choose to confront these risks did not persuade the Court that the individual therefore was not

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107. “Asymptomatic HIV infection is a phase of chronic infection with human immunodeficiency virus (HIV) during which there are no symptoms of HIV infection.” U.S. Nat’l Library of Med. and the NIH, *Medline Plus Medical Encyclopedia*, <http://www.nlm.nih.gov/medlineplus/ency/article/000682.htm> (last visited Feb. 16, 2009) [hereinafter NIH, *Medical Encyclopedia*].

108. *Bragdon v. Abbott*, 524 U.S. 624, 637 (1998) (“In light of the immediacy with which the virus begins to damage the infected person’s white blood cells and the severity of the disease, we hold it is an impairment from the moment of infection.”).

109. *Id.* at 638 (“Reproduction falls well within the phrase ‘major life activity.’ Reproduction and the sexual dynamics surrounding it are central to the life process itself.”).

110. *Id.* at 639 (describing two ways in which HIV “substantially limit[s] the] ability to reproduce”).

111. *Id.* (“[A] woman infected with HIV who tries to conceive a child imposes on the man a significant risk of becoming infected.”).

112. *Id.* (holding that HIV substantially limits the major life activity of reproduction).

113. *Id.* at 640 (“[A]n infected woman risks infecting her child during gestation and childbirth.”).

114. *Id.* at 640–41.

115. *Id.* at 641.

substantially impaired in the major life activity of reproduction.<sup>116</sup> The Court wrote:

The Act addresses substantial limitations on major life activities, not utter inabilities. Conception and childbirth are not impossible for an HIV victim but, without doubt, are dangerous to the public health. This meets the definition of a substantial limitation. The decision to reproduce carries economic and legal consequences as well. There are added costs for antiretroviral therapy, supplemental insurance, and long-term health care for the child who must be examined and, tragic to think, treated for the infection. The laws of some States, moreover, forbid persons infected with HIV to have sex with others, regardless of consent. . . . In the end, the disability definition does not turn on personal choice. When significant limitations result from the impairment, the definition is met even if the difficulties are not insurmountable. For the statistical and other reasons we have cited, of course, the limitations on reproduction may be insurmountable here. Testimony from the respondent that her HIV infection controlled her decision not to have a child is unchallenged.<sup>117</sup>

Based on *Bragdon*, it is possible to successfully argue that a person living with HIV, who is in the best of health,<sup>118</sup> could still be disabled for purposes of an ADA evaluation because a woman's ability to reproduce is severely impaired by the fact that she is HIV-positive, regardless of her present health status.<sup>119</sup> The *Bragdon* decision, however, was not the Court's final interpretation of the ADA.<sup>120</sup>

In the years following *Bragdon*, the Supreme Court decided several cases in which it placed significant limitations on the use of the Act to protect people with disabilities from discrimination.

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116. *Id.*

117. *Id.*

118. An individual with an asymptomatic HIV infection has a low viral load, no opportunistic infections, and no significant side effects from medication. See, e.g., NIH, *Medical Encyclopedia*, *supra* note 107 (describing the characteristics of asymptomatic HIV infection, and noting that some people can remain asymptomatic for 10 years or longer); see also NIH, *supra* note 81 (describing HIV and its treatment, and noting that a positive HIV test result does not mean that a person has AIDS).

119. *Bragdon*, 524 U.S. at 643 ("Based on the medical knowledge available to us, we believe that it is reasonable to conclude that the life activity of procreation . . . is substantially limited for an asymptomatic HIV-infected individual." (quoting 12 Op. Off. Legal Counsel 264, 273 (1988))).

120. See, e.g., *US Airways, Inc. v. Barnett*, 535 U.S. 391 (2002) (interpreting the reasonable accommodations requirement of the ADA); *Toyota Motor Mfg., Ky. Inc. v. Williams*, 534 U.S. 184 (2002) (interpreting the "substantially limited" language of the ADA's disability definition).



For example, in *Sutton v. United Air Lines*,<sup>121</sup> the Court decided the mitigation question that it declined to address in *Bragdon*, holding that a person claiming disability discrimination must be evaluated in a mitigated state in order to determine if she meets the threshold disability criteria for seeking protection under the Act.<sup>122</sup> The consequences of *Sutton* for people living with treatable ailments were significant. In the years following *Sutton*, courts denied ADA protection to individuals with insulin-dependent diabetes because use of insulin ameliorates the impairment associated with the underlying disease.<sup>123</sup> Courts dismissed these cases at the summary judgment stage even when an employer admitted to taking adverse action against an employee because of that individual's status as a diabetic.<sup>124</sup> In the *Sutton* era, advocates for people living with HIV feared that an HIV-positive victim of discrimination, whose health status was well controlled through the use of powerful medications, might be unable to prevail on a claim where a defendant argued that, with treatment, the HIV-positive person was no longer substantially impaired. Under this logic, HIV medications act like insulin or corrective lenses, in that they remove the substantial impairment. In such a case, were the Court's reasoning in *Sutton* allowed to stand, an HIV-positive plaintiff might fail to meet the threshold requirement

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121. *Sutton v. United Air Lines*, 527 U.S. 471 (1999) *superseded by statute*, ADA Amendments Act of 2008, Pub. L. No. 110-325, 122 Stat. 3553 (2008).

122. *Id.*

123. *See, e.g.*, *Collado v. UPS*, 419 F.3d 1143, 1157–58 (11th Cir. 2005) (finding that summary judgment was appropriate where an insulin dependent diabetic could not show that he was substantially impaired in any major life activity); *Shultz v. Potter*, 142 F. App'x 598, 599 (3d Cir. 2005) (holding that summary judgment was appropriate where a diabetic plaintiff could not show that she was impaired in any major life activity due to her illness). *But see* *Fraser v. Goodale*, 342 F.3d 1032, 1044 (9th Cir. 2003) (holding that a diabetic employee demonstrated a material issue of fact on the question of whether her illness substantially impaired the major life activity of eating).

124. *See, e.g.*, *Scheerer v. Potter*, 443 F.3d 916 (7th Cir. 2006) (granting summary judgment in favor of a postmaster general in a case brought by a diabetic postal employee claiming a failure to reasonably accommodate his symptoms under the Rehabilitation Act); *Shultz*, 142 F. App'x 598 (holding that summary judgment was appropriate where a diabetic plaintiff could not show that she was impaired in any major life activity due to her illness); *Salim v. MGM Grand Detroit*, 106 F. App'x 454 (6th Cir. 2004) (affirming summary judgment in favor of the employer because the employee failed to prove that she was disabled in bringing suit for common law slander, discriminatory discharge, and other discrimination under the ADA and the Michigan Persons with Disabilities Rights Act); *Orr v.*

*Wal-Mart Stores, Inc.*, 297 F.3d 720 (8th Cir. 2002) (granting summary judgment to an employer because a diabetic pharmacist was not disabled under the ADA); *Nordwall v. Sears Roebuck & Co.*, 46 F. App'x 364 (7th Cir. 2002) (granting summary judgment to an employer because the employee was not "disabled" within the meaning of the ADA).

for a successful ADA claim.

Such an absurd result can now be avoided in the wake of amendments to the ADA that went into effect on January 1, 2009.<sup>125</sup> Recognizing that the Court's interpretations of the ADA had led to significant and unwarranted narrowing of the statute's scope, Congress amended the ADA to reinstate the broad definition of disability that it originally intended.<sup>126</sup> The ADA Amendments Act of 2008 (Amendments Act) makes several specific references to *Sutton*, including noting in its purpose section that the Act sought "to reject the requirement enunciated by the Supreme Court in *Sutton v. United Air Lines, Inc.*, [sic] 527 U.S. 471 (1999) and its companion cases that whether an impairment substantially limits a major life activity is to be determined with reference to the ameliorative effects of mitigating measures."<sup>127</sup> The Amendments Act also rejects the Supreme Court's holdings in the post-*Sutton* case of *Toyota Motor Manufacturing, Kentucky, Inc. v. Williams*,<sup>128</sup> which heightened the threshold for proving impairment, making it less likely that a plaintiff could establish that she was substantially impaired.<sup>129</sup>

The amendments to the ADA make clear that the Act should be read expansively to protect disabled people from

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125. See ADA Amendments Act of 2008, Pub. L. 110-325, 122 Stat. 3553, 3554 (2008).

126. *Id.* § 2(a)(4) (finding that "the holdings of the Supreme Court in *Sutton v. United Air Lines, Inc.*, [sic] 527 U.S. 471 (1999) and its companion cases have narrowed the broad scope of protection intended to be afforded by the ADA, thus eliminating protection for many individuals whom Congress intended to protect").

127. *Id.* § 2(b)(2).

128. *Toyota Motor Mfg., Ky., Inc. v. Williams*, 534 U.S. 184 (2002), *superseded by statute*, ADA Amendments Act of 2008, Pub. L. No. 110-325, 122 Stat. 3553 (2008).

129. The ADA Amendments Act of 2008 § 2(b) states that it was enacted:

(4) to reject the standards enunciated by the Supreme Court in *Toyota Motor Manufacturing, Kentucky, Inc. v. Williams*, [sic] 534 U.S. 184 (2002), that the terms "substantially" and "major" in the definition of disability under the ADA "need to be interpreted strictly to create a demanding standard for qualifying as disabled," and that to be substantially limited in performing a major life activity under the ADA "an individual must have an impairment that prevents or severely restricts the individual from doing activities that are of central importance to most people's daily lives";

(5) to convey congressional intent that the standard created by the Supreme Court in the case of *Toyota Motor Manufacturing, Kentucky, Inc. v. Williams*, [sic] 534 U.S. 184 (2002) for "substantially limits", and applied by lower courts in numerous decisions, has created an inappropriately high level of limitation necessary to obtain coverage under the ADA, to convey that it is the intent of Congress that the primary object of attention in cases brought under the ADA should be whether entities covered under the ADA have complied with their obligations, and to convey that the question of whether an individual's impairment is a disability under the ADA should not demand extensive analysis.

discrimination.<sup>130</sup> Thus, a person living with HIV might have several routes to proving her status as disabled under the Act. First, a potential plaintiff could proceed on the basis of a record of impairment, or being perceived as impaired even if she is not in fact impaired.<sup>131</sup> Even during the *Sutton* era, these elements of the statute remained available for people living with disabilities.<sup>132</sup> Second, the Amendments Act makes clear that the basic premise of *Bragdon*, that impairment is not to be judged on the basis of “utter inabilities” to engage in a major life activity, remains intact.<sup>133</sup> Even as medicine makes access to biological parenthood increasingly possible for HIV-positive people by decreasing the risk of transmission, the ADA should still apply because the fact remains that procreating under these circumstances presents risks to the public health and carries economic and potentially legal consequences.<sup>134</sup>

Even if the HIV-positive plaintiff established her disability for purposes of the ADA, her claim might not prevail. A defendant physician could still argue that there was no obligation to treat her because, as the Department of Justice (DOJ) makes clear, a physician is not obliged to provide medical care to every HIV-positive patient. The DOJ explains:

A health care provider is not required to treat a person who is seeking or requires treatment or services outside the provider's area of expertise. However, a health care provider cannot simply refer a patient with HIV/AIDS to another provider simply because the patient has HIV/AIDS. The referral must be based on the treatment the patient is seeking,

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§ 2(b)(1) (quoting *Toyota Motor Mfg., Ky., Inc. v. Williams*, 543 U.S. 184 (2002)).

130. *Id.* (noting that one purpose of the amendments is “to carry out the ADA’s objectives of providing ‘a clear and comprehensive national mandate for the elimination of discrimination’ and ‘clear, strong, consistent, enforceable standards addressing discrimination’ by reinstating a broad scope of protection to be available under the ADA”).

131. 42 U.S.C. § 12102(2).

132. *See id.* § 12102(1)(A) (2008) (defining disability with respect to an individual).

133. *Bragdon v. Abbott*, 524 U.S. 624, 641 (“The Act addresses substantial limitations on major life activities, not utter inabilities.”).

134. *Id.* The Court wrote:

Conception and childbirth are not impossible for an HIV victim but, without doubt, are dangerous to the public health. This meets the definition of a substantial limitation. The decision to reproduce carries economic and legal consequences as well. There are added costs for antiretroviral therapy, supplemental insurance, and long-term health care for the child who must be examined and, tragic to think, treated for the infection. The laws of some States, moreover, forbid persons infected with HIV from having sex with others, regardless of consent.

*Id.* (citations omitted).

not the patient's HIV status alone.<sup>135</sup>

When a healthcare provider categorically denied fertility treatment to persons living with HIV, it would be difficult, if not impossible, to argue that such a denial did not violate the ADA.<sup>136</sup> Instead, a physician seeking to avoid providing treatment based on a patient's HIV status must conduct an individualized analysis of whether there are appropriate medical reasons to turn that particular HIV-positive patient away from care.<sup>137</sup>

Physicians could argue a lack of expertise in working with gametes harboring possible HIV infection. Since the readily achievable, standard infectious disease protocol is to employ universal precautions in the handling of all gametes, this asserted lack of expertise would not be a useful ploy for avoiding liability.<sup>138</sup>

To justify denying an HIV-positive woman care, a physician might also claim that providing standard fertility treatments to an HIV-positive person requires specialized skills.<sup>139</sup> However, a

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135. DOJ, *Questions and Answers: The Americans with Disabilities Act and Persons with HIV/AIDS*, <http://www.usdoj.gov/crt/ada/pubs/hivqanda.txt>. (last visited Apr. 11, 2009) [hereinafter DOJ, *Questions and Answers*].

136. The DOJ writes, "Persons with HIV/AIDS will rarely, if ever, pose a direct threat in the public accommodations context." *Id.*

137. The DOJ stated:

The determination that a person poses a direct threat to the health or safety of others may not be based on generalizations or stereotypes about the effects of a particular disability; it must be based on an individual assessment that considers the particular activity and the actual abilities and disabilities of the individual. The individual assessment must be based on reasonable judgment that relies on current medical evidence.

*Id.*

138. The CDC has long recommended that facilities use universal precautions when handling any material that potentially contains HIV. See CDC, *Universal Precautions for Prevention of Transmission of HIV and Other Bloodborne Infections*, available at [http://www.cdc.gov/ncidod/dhqp/bp\\_universal\\_precautions.html](http://www.cdc.gov/ncidod/dhqp/bp_universal_precautions.html); see also ASRM Ethics Comm., *Human Immunodeficiency Virus and Infertility Treatment*, 77 FERTILITY & STERILITY 218, 219, 223 (2002), available at <http://www.asrm.org/media/ethics/hivethics> ("If standard universal precautions to prevent infectious disease transmission are taken, the risk of virus transmission to medical caregivers is very small and, in itself, is not a sufficient reason to deny reproductive services to HIV-infected individuals and couples."). Others have urged ART laboratories to go beyond the basics of universal precautions when dealing with known infected material. See Carole Gilling-Smith, *Laboratory Safety During Assisted Reproduction in Patients with Blood-borne Viruses*, 20 HUM. REPROD. 1433, 1435 (2005) ("Therefore, when treating known infectious cases (or unscreened samples), we recommend that, over and above universal precautions, working surfaces and equipment used are cleaned with additional disinfecting agents, e.g. Virkon, to further minimize potential cross-contamination risk.").

139. Cf. *Lesley v. Chie*, 250 F.3d 47, 58 (2001) (holding that the defendant obstetrician's referral of an HIV-positive woman to a hospital with an HIV program, rather than providing her with care himself, was acceptable).

person seeking the same treatment that a physician provides to all other patients would not necessarily need specialized care due to HIV status because the procedures to be performed are fairly standard.<sup>140</sup> Artificial insemination, in vitro fertilization (IVF), and other modes of treating infertility are employed the same way for people living with HIV as they are for any patient.<sup>141</sup> A legitimate issue is whether the facility has the appropriate equipment to handle gametes that might contaminate other specimens.<sup>142</sup> Some procedures (such as sperm washing) may require skills, equipment, or lab expertise that a physician does not have. Even basic storage of gametes might—in some small minority of cases where universal precautions were somehow inadequate—present a substantial obstacle to providing care to people living with HIV.

In cases when a physician or facility lacked the skill or equipment to properly provide care or store gametes, and when it would be cost prohibitive to alter the facility, the defendant would be able to claim that accommodating the needs of the HIV-positive patient was not readily achievable.<sup>143</sup> In this small subset of cases, the healthcare provider could legitimately claim that referral to another physician or facility was appropriate and did not violate the ADA, either because the patient (or her gametes) posed a direct threat of transmission to others in the facility<sup>144</sup> or because the physician lacked the necessary skills to provide care that is not routine.<sup>145</sup> Importantly, the claim here is not that the physician or healthcare workers might contract HIV from the patient in the context of providing care, but that other patients may be at risk.<sup>146</sup> Thus, the number of instances in which a

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140. See generally ASRM Ethics Comm., *supra* note 138 (failing to mention a need to modify procedures in order to care for HIV-positive patients).

141. *Id.* (noting no differences in treatment for HIV-positive patients).

142. Yvon Englert et al., *Medically Assisted Reproduction in the Presence of Chronic Viral Diseases*, 10 HUM. REPROD. UPDATE 149, 151–53 (2004) (discussing techniques to decontaminate sperm samples).

143. See 42 U.S.C. § 12181.

144. See *infra* Part IV.C.

145. According to the Federal Regulations:

A health care provider may refer an individual with a disability to another provider, if that individual is seeking, or requires, treatment or services outside of the referring provider's area of specialization, and if the referring provider would make a similar referral for an individual without a disability who seeks or requires the same treatment or services.

28 CFR § 36.302 (2004).

146. See generally *Bragdon v. Abbott*, 524 U.S. 624, 637 (1998) (holding that a generalized fear of HIV transmission resulting from providing standard healthcare treatments was insufficient to satisfy the direct threat requirement).

healthcare provider could legitimately claim a solid medical reason for refusing care to a person living with HIV is few.

Alternatively, a fertility specialist who chose not to treat a person living with HIV could seek safe harbor in the direct threat provision of the ADA.<sup>147</sup> This provision allows a physician to refuse care when providing such care presents a direct threat to the patient or to others.<sup>148</sup> The unique nature of fertility treatment makes this inquiry especially complicated; therefore, I will address the question of direct threat in Part IV.C.

### *B. The Quadriplegic Patient*

At the age of 23, Michelle Carson became paralyzed after a devastating car accident.<sup>149</sup> Ms. Carson is a quadriplegic, which means that she lives her life in a wheelchair.<sup>150</sup> She cannot move herself in and out of that chair; she cannot feed, bathe, or clothe herself.<sup>151</sup> She cannot drive a car.<sup>152</sup> She cannot cook a meal, or engage in a wide range of actions that would be required in order for her to live an independent life.<sup>153</sup> She has a husband and several caregivers who ensure that her physical needs are met.<sup>154</sup> A documentary chronicled Carson as she went through her final weeks of pregnancy, labored to deliver her son, and brought him home to begin his life as the child of a quadriplegic woman and a non-quadruplegic man.<sup>155</sup> Due to her disability, her son is washed, fed, and clothed by others.<sup>156</sup> In the documentary, Carson says she is enjoying holding him on her lap while he is still a newborn because as soon as he is able to wriggle away from her, she will no longer be able to hold him.<sup>157</sup> Carson's disability did not negatively impact her reproductive capacity, and she and her husband were able to achieve pregnancy without technological assistance.<sup>158</sup> However, if she had needed the aid of ART, it is certainly possible that some physicians would have preferred not

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147. See 28 C.F.R. § 36.208 (2004).

148. *Id.*

149. *Paralyzed & Pregnant* (Discovery Health Channel 2008), available at <http://health.discovery.com/videos/baby-week-paralyzed-pregnant-part-1.html> and <http://health.discovery.com/videos/baby-week-paralyzed-pregnant-part-2.html>.

150. *Id.*

151. *Id.*

152. *Id.*

153. *Id.*

154. *Id.*

155. See *id.*

156. *Id.*

157. *Id.*

158. *Id.*

to treat her because of her profound disability.

As described in the previous Section, a physician could not categorically deny care to women who are quadriplegic, but would need to make individualized determinations about providing treatment.<sup>159</sup> A woman denied care by a fertility specialist on the basis of her status as a quadriplegic would first need to establish that she is a disabled person as defined by the statute.<sup>160</sup> Given the substantial physical impairment inherent in quadriplegia, this would not be difficult to establish, even in the face of various technical advances that make it possible for Ms. Carson and other quadriplegics to engage in multiple activities.<sup>161</sup> There are so many things that she cannot do and for which she needs assistance that she is, without question, disabled under the terms of the statute.<sup>162</sup>

Again, to defeat a claim of illegal discrimination, the fertility specialist might assert a lack of expertise in working with quadriplegics as a basis to deny care.<sup>163</sup> As is true with HIV infection or AIDS, the actual care provided to Ms. Carson would not be substantially different than that provided to any other patient.<sup>164</sup> As a quadriplegic, she is at greater risk for some of the typical complications of pregnancy, but these are complications with which any qualified obstetrical provider should be able to

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159. According to the Federal Regulations:

In determining whether an individual poses a direct threat to the health or safety of others, a public accommodation must make an individualized assessment, based on reasonable judgment that relies on current medical knowledge or on the best available objective evidence, to ascertain: the nature, duration, and severity of the risk; the probability that the potential injury will actually occur; and whether reasonable modifications of policies, practices, or procedures will mitigate the risk.

28 C.F.R. § 36.208(c) (2004).

160. *Id.* § 36.104.

161. See, e.g., Sci-Info-Pages, *Assistive Technology & Adaptive Equipment*, <http://www.sci-info-pages.com/adaptive.html> (last visited Apr. 28, 2009) (listing various adaptive technologies for quadriplegics, including communication devices, hand grips, on-screen keyboards, and scooters).

162. The Act's definition of physical or mental impairment is: "Any physiological disorder or condition, cosmetic disfigurement, or anatomical loss affecting one or more of the following body systems: neurological; musculoskeletal; special sense organs; respiratory, including speech organs; cardiovascular; reproductive; digestive; genitourinary; hemic and lymphatic; skin; and endocrine." *Id.* § 36.104(1)(i).

163. See *id.* § 36.302(b).

164. See generally American College of Obstetricians & Gynecologists (ACOG) Comm., *Opinion No. 275, Obstetric Management of Patients with Spinal Cord Injuries*, 100 OBSTETRICS & GYNECOLOGY 625, 625-27 (2002) (describing the specific medical problems presented by pregnant women with spinal cord injuries, and how these problems should be managed).

cope. For example, paralyzed pregnant women are at risk for urinary tract infections, anemia, complications with their medications, mobility issues requiring bed rest, and delivery complications necessitating a cesarean section.<sup>165</sup> Any qualified obstetrical provider would be able to deal with these routine types of complications.<sup>166</sup> To the extent that there are specific complications relevant to women with spinal cord injuries, the American College of Obstetricians & Gynecologists stresses the importance of becoming acquainted with problems related to spinal cord injuries that can occur during pregnancy, but the organization does not intimate that only specialized providers can appropriately care for such women.<sup>167</sup> Further, the level of obstetrical care is an issue to be determined between the pregnant woman and her healthcare provider once she achieves pregnancy.<sup>168</sup> Therefore, the claim of inadequate skill or expertise would not be a strong one.

As is true in the case of HIV, then, the final refuge of a physician seeking to avoid helping a quadriplegic woman achieve pregnancy would be the direct threat provisions of the ADA.<sup>169</sup> Part IV will examine the concept of direct threat and how it could be used as a defense against women with HIV or quadriplegia in a claimed ADA violation.

#### IV. Threatening Pregnancies and Threatening Parents

There are multiple concerns in a discussion about what it means for a potential parent to pose a direct threat to herself or to her children, such that it would be appropriate to deny her access to fertility services. First, is there anything about the fertility treatment itself that poses a threat to the patient's health? Second, is there anything about a pregnancy that poses a direct

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165. See CenterSite.net, *Pregnancy-Special Considerations: Heart Disease, Paralysis, Obesity*,

[http://www.centersite.net/poc/view\\_doc.php?type=doc&id=6151&cn=282](http://www.centersite.net/poc/view_doc.php?type=doc&id=6151&cn=282)

(last visited Apr. 11, 2009); see also JUDITH ROGERS, *THE DISABLED WOMAN'S GUIDE TO PREGNANCY AND BIRTH* 50 (Demos Medical Publishing 2006) (1991) (describing pregnancy complications that can arise in women with spinal cord injuries).

166. See Am. Bd. of Obstetrics and Gynecology, *Frequently Asked Questions*, <http://www.abog.org/faq.asp> (last visited Mar. 10, 2009) (detailing the training and certification of an obstetrician-gynecologist).

167. See ACOG Comm., *supra* note 164, at 625 ("It is important that obstetricians caring for such patients acquaint themselves with the problems relating to SCIs [spinal cord injuries] that may occur throughout pregnancy.")

168. See *id.*

169. See 28 U.S.C. § 36.208 (2004).



threat to the patient or to the fetus? Third, is there anything about the parent that poses a direct threat to the health, safety, or welfare of the future child? It is this last question that is potentially most contentious and least amenable to medical or scientific scrutiny, as it squarely confronts the role of the fertility provider in determining who is fit to parent.

The previous Parts identified some of the threshold issues inherent in disability discrimination claims regarding the provision of fertility treatment. For women living with HIV or quadriplegia, at first glance the ADA appears to provide protection from discrimination.<sup>170</sup> The unique nature of the goal of fertility treatment, however, warrants a more nuanced evaluation of whether the ADA's direct threat provisions can be used to protect a physician who chooses not to provide fertility care to women with significant disabilities.

The direct threat provisions of the ADA allow a physician to lawfully refuse care to a patient when the patient poses a direct threat to others,<sup>171</sup> or where providing the care would pose a direct threat to the patient.<sup>172</sup> A direct threat is "a significant risk of substantial harm to the health or safety of the individual or others that cannot be eliminated or reduced by reasonable accommodation."<sup>173</sup> Direct threat determinations must be based on an "individualized assessment" of the patient's present ability to receive the service, and that assessment must rely on "the most current medical knowledge and/or on the best available objective evidence."<sup>174</sup> Those charged with evaluating a direct threat claim will consider four factors: "(1) the duration of the risk; (2) the nature and severity of the potential harm; (3) the likelihood that the potential harm will occur; and (4) the imminence of the potential harm."<sup>175</sup> Physicians must consider any reasonable accommodations that would eliminate the risk of harm or reduce it

170. See discussion *supra* Part III.

171. See, e.g., *Bragdon v. Abbott*, 524 U.S. 624, 648 (1998) ("[P]etitioner could have refused to treat her if her infectious condition 'pose[d] a direct threat to health or safety of others.'" (quoting 42 U.S.C.A. § 12182(b)(3) (West 2008))).

172. See, e.g., *Jairath v. Dyer*, 972 F.Supp. 1461, 1469 (N.D. Ga. 1997) ("The legality of the defendant's medical decision not to treat plaintiff therefore depends on whether the cosmetic surgery actually posed a 'direct threat' to plaintiff's health.").

173. 29 C.F.R. § 1630.2(r) (2008).

174. EQUAL EMPLOYMENT OPPORTUNITIES COMM'N, EEOC ENFORCEMENT GUIDANCE ON THE AMERICANS WITH DISABILITY ACT AND PSYCHIATRIC DISABILITIES (1997), available at <http://www.eeoc.gov/policy/docs/psych.html>.

175. 29 C.F.R. § 1630.2(r)(1)-(4).

to an acceptable level.<sup>176</sup> Importantly, the direct threat determination must be based on “objective, factual evidence—not on subjective perceptions, irrational fears, patronizing attitudes, or stereotypes—about the nature or effect of a particular disability or of disability generally.”<sup>177</sup>

Given this guidance, direct threat evaluations must be made to minimize the denial of services based on irrational fear and stereotypes, yet to allow care to be refused when objective evidence warrants that refusal. While a physician might lawfully refuse to perform surgery on an HIV-positive patient whose disease puts her at greater risk for post-surgical complications<sup>178</sup> (a threat to the patient), a physician could not refuse to operate on that same patient based on an unfounded fear that the patient’s disease will somehow be spread to others during surgery<sup>179</sup> (a readily reducible risk to others).

Evaluating the threat-to-self claims that could be made in the context of disability suggests that such claims should largely fail. Taking each disability example in turn, pregnancy presents inimitable challenges for an HIV-positive woman and has been found, in some circumstances, to compromise a woman’s health.<sup>180</sup> Other sources, however, suggest that pregnancy can actually improve the health of an HIV-positive woman.<sup>181</sup> It is irrefutably the case that thousands of HIV-positive women have given birth—most of them to healthy children—since the start of the epidemic, and it cannot be conclusively shown that pregnancy severely compromises the life span of an HIV-positive woman.<sup>182</sup> Even if pregnancy was detrimental, arguably the decision whether to risk a shortened life span in the interest of having biological children is a choice to be made by the woman seeking pregnancy, and not by a

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176. *Id.* § 1630.9 (describing the “reasonable accommodations” requirements).

177. 29 C.F.R. Pt. 1630, App., § 1630.2(r) (2008).

178. *See, e.g.,* *Jairath v. Dyer*, 972 F.Supp. 1461 (N.D. Ga. 1997) (holding that a doctor’s belief that the requested surgery was a threat to the patient’s health was a nondiscriminatory reason for refusal).

179. *See, e.g.,* *Bragdon v. Abbott*, 524 U.S. 624, 649 (1998) (finding that a refusal to perform surgery must be based on “objective, scientific information”).

180. *See* Anne Drapkin Lyerly & Jean Anderson, *Human Immunodeficiency Virus and Assisted Reproduction: Reconsidering Evidence, Reframing Ethics*, 75 FERTILITY & STERILITY 843, 847 (2001) (describing the “increased risk of certain pregnancy complications” in HIV-infected mothers).

181. *See* Jennifer H. Tai et al., *Pregnancy and HIV Disease Progression During the Era of Highly Active Antiretroviral Therapy*, 196 J. INFECTIOUS DISEASES 1044, 1051 (2007) (“Our data suggest that, in a setting with high rates of HAART use, pregnancy is independently associated with a decreased risk of HIV disease progression.”).

182. *Id.*

physician.<sup>183</sup> Thus, while a fertility specialist could choose not to assist an HIV-positive woman for fear that her pregnancy would pose undue risk to her own health, the claim of direct threat to the patient is specious at best and subterfuge to conceal illegal discrimination at worst.

The direct-threat-to-self claim also falters in the case of quadriplegic women. Such pregnancies entail risks, as do all pregnancies,<sup>184</sup> but those risks can be well managed by obstetrical providers, thus negating a plausible claim of direct-threat-to-self. The quadriplegic woman may require a more exacting level of monitoring than would a woman without such a disability, but the same is true for women who are diabetic, over the age of thirty-five, or have a history of miscarriages.<sup>185</sup> Thus, the argument of direct-threat-to-self is a poor one for fertility providers who are hoping to avoid caring for women with substantial physical disabilities.

Although the direct-threat-to-self argument does not hold up well to scrutiny, it does not automatically mean that healthcare providers should have no right or responsibility to think critically about the potential harm to women inherent in some choices about pursuing pregnancy. Increasingly, fertility providers are being urged to take greater care in helping to create pregnancies that pose untoward risks to pregnant woman and their fetuses or to future children.<sup>186</sup> Certainly, the miracle-working physician who blithely helps women become pregnant with literal litters of children,<sup>187</sup> or pats himself on the back for helping a

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183. See Lyerly & Anderson, *supra* note 180, at 849 (describing the problematic nature of policies limiting the reproductive choices of HIV-infected women).

184. See CenterSite.net, *supra* note 165 ("Paralyzed pregnant women face the same normal array of pregnancy complications as do other women. However, the likelihood that these complications will occur is higher in paralyzed women than in other women.")

185. See U.S. Nat'l Library of Med. and NIH, *Medline Plus Health Topics*, <http://www.nlm.nih.gov/medlineplus/highriskpregnancy.html> (last visited Mar. 9, 2009) (noting various conditions that create a high-risk pregnancy situation, including being pregnant with more than one baby, previous problem pregnancies, or being over 35).

186. See, e.g., Elizabeth Cohen & Doug Gross, *Georgia 'Octomom Bill' Would Limit Embryo Implants*, CNN, Mar. 3, 2009, <http://www.cnn.com/2009/US/03/03/georgia.octomom.bill/index.html> (describing efforts currently being undertaken to limit multiple births due to in vitro fertilization).

187. See, e.g., Maggie Michael, *Egyptian Woman Gives Birth To Septuplets*, THE HUFFINGTON POST, Aug. 16, 2008, [http://www.huffingtonpost.com/2008/08/16/egyptian-woman-gives-birt\\_n\\_119327.html](http://www.huffingtonpost.com/2008/08/16/egyptian-woman-gives-birt_n_119327.html) (reporting that in August 2008, Ghazala Khamis, a twenty-seven-year-old Egyptian woman who already had three children, gave birth to

seventy-year-old woman bear twins,<sup>188</sup> has crossed an ethical line and made medically questionable decisions that society and the profession should not support or imitate.<sup>189</sup> This is particularly so because many fertility specialists transfer care for patients to an obstetrician once a pregnancy is well established, generally after the first trimester.<sup>190</sup> As such, the pregnant patient's health is primarily the concern not of the fertility specialist, but of the physician who will provide the care leading to the birth of the child. The fertility specialist, because he is responsible only for creating a pregnancy, logically has less of a claim to the protection provided to those helping a pregnant woman maintain her own health and that of her fetus over the course of a pregnancy. There are valid reasons for providers to be cautious and thoughtful about how and to whom they provide services. The basis of their caution, however, should be solid medicine and science, rather than amorphous and misguided judgments about risk.

The direct threat provisions also refer to threats to others,<sup>191</sup> and it is in this capacity that physicians might have a stronger argument for refusing to provide care to significantly disabled women. For HIV-positive people, the risks inherent in procreating

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septuplets as a result of taking fertility drugs). In February 2009, Nadya Suleman, a single mother of 6, gave birth to octuplets after undergoing IVF. See, e.g., Caplan, *supra* note 45 (describing Suleman's situation). These cases, and others like them, have been at the center of international debates about the ethics of fertility practice. *Id.*

188. See *Another 70-year-old in India has IVF Baby*, MSNBC, Dec. 8, 2008, <http://www.msnbc.msn.com/id/28112285> (reporting the birth of a girl to a woman who had been trying for 50 years to become pregnant).

189. See, e.g., Eike-Henner Kluge, *Reproductive Technology and Postmenopausal Motherhood*, 151 CANADIAN MED. ASS'N J. 353, 353–55 (1994) (making the ethical case for excluding post-menopausal women from access to assisted reproductive technology); Darshak Sanghavi, *Pregnant Pause, Who Should Pay for In Vitro Fertilization?*, SLATE, Feb. 13, 2009, <http://www.slate.com/id/2211151/> (proposing mandated infertility coverage as financially more sound than the current U.S. system).

190. K. B. Copperman et al., *Patients' Return to Referring Physicians for Obstetrical Care is Related to the Duration of Their Infertility*, 82 FERTILITY & STERILITY (SUPP. 2) S101 (2004) ("A patient referred by an obstetrician/gynecologist is routinely encouraged by the reproductive endocrinologist to return to the referring physician for prenatal care and delivery.")

191. See 42 U.S.C.A. § 12182(b)(3).

Nothing in this subchapter shall require an entity to permit an individual to participate in or benefit from the goods, services, facilities, privileges, advantages and accommodations of such entity where such individual poses a direct threat to the health or safety of others. The term 'direct threat' means a significant risk to the health or safety of others that cannot be eliminated by a modification of policies, practices, or procedures or by the provision of auxiliary aids or services.

*Id.*

are fairly simple to delineate and, with the proper access to treatment, can be significantly reduced. The first "other" to whom an HIV-positive person presents a direct threat is the sexual partner with whom that person would have unprotected sexual intercourse in order to create a pregnancy. HIV-positive people have several options to avoid the risk of sexual transmission of HIV while trying to achieve pregnancy. For an HIV-positive man, without the use of fertility treatment, having unprotected sex with an HIV-negative partner puts both the partner and the fetus at risk.<sup>192</sup> Fertility treatment can avoid such risk in several ways. First, prior to artificial insemination, sperm can be washed to substantially reduce the risk of HIV transmission.<sup>193</sup> That sperm can also be used to create embryos outside of the body through intracytoplasmic sperm injection (ICSI)<sup>194</sup> and IVF, which eliminates the risk of HIV transmission between sexual partners.<sup>195</sup> An HIV-positive woman and her HIV-negative male partner could also choose artificial insemination to eliminate the risk of transmitting the virus between partners during unprotected sexual intercourse.<sup>196</sup>

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192. See D. Hollander, *Risk of HIV Transmission is Raised by High Viral Load, Presence of Genital Ulcers*, 27 INT'L FAM. PLAN. PERSP. 156 (2001) (noting that one study found that "[o]n average, each time a monogamous, heterosexual couple in which one partner is HIV-positive has intercourse, the probability that the virus will be transmitted to the uninfected partner is 0.11%" and that the risk of transmission increases with the viral load of the infected partner); see generally CDC, *How is HIV Passed from One Person to Another?*, <http://cdc.gov/hiv/resources/qa/qa16.htm> (last visited Feb. 23, 2009) (stating that heterosexual sexual activity is a primary mode of HIV transmission).

193. See James D. M. Nicopoulos et al., *The Effect of Human Immunodeficiency Virus on Sperm Parameters and the Outcome of Intrauterine Insemination Following Sperm Washing*, 19 HUM. REPROD. 2289, 2289 (2004) (describing the technique of sperm washing in which sperm is rid of "seminal plasma and non-sperm cells before insemination into the woman at the time of ovulation"); see also Sauer, *supra* note 78, at 33 (noting that studies indicate that sperm washing is a successful technique for avoiding HIV transmission in sero-discordant couples, and stating that "[t]he implementation of sperm-preparation techniques, popularly referred to as 'sperm washing,' appears to reduce the probability of horizontal transmission and has been recommended for nearly ten years as a means for HIV-1 serodiscordant couples to have a child" (citation omitted)).

194. See ASRM, *Patient Fact Sheet: Intracytoplasmic Sperm Injection (ICSI)*, available at <http://www.asrm.org/Patients/FactSheets/ICSI-Fact.pdf>.

195. See Sauer, *supra* note 78, at 34.

196. See, e.g., ASRM Ethics Comm., *supra* note 138 ("If a woman is HIV positive and her male partner is HIV negative, transmission of infection to the male partner can be avoided by using homologous insemination with the partner's sperm."); Lyerly & Anderson, *supra* note 180 ("When the woman is HIV infected and the male partner HIV uninfected, the use of artificial insemination should be encouraged. Home artificial insemination techniques can be easily taught and provide protection for the HIV-uninfected partner, who should continue to use condoms with each act of intercourse.").

For purposes of this Article, the more critical direct threat question focuses on the risk to the future fetus or future child, and this risk is the focus of the Sections that follow.

#### A. *Hypothetical People and Hypothetical Risks*

A fascinating aspect of the relationship between the ADA and disability discrimination in the context of fertility treatment is how the unique nature of fertility treatment creates conceptual difficulties that do not exist in the context of any other type of medical care. Fertility treatment is the only type of medical care in which the end goal is the creation of another person. This is distinct even from obstetrical care, in which a pregnancy already exists and the healthcare provider takes on the relationship with the understanding that she has obligations to both the pregnant woman and the fetus that she carries.<sup>197</sup> Obstetricians often speak of having two patients rather than one, and many people are comfortable with this formulation, even if they disagree on how the physician and the law should balance the interests of the pregnant woman and the fetus.<sup>198</sup>

A fertility doctor's claim that she has two patients, the pregnant woman and any future child, is significantly more tenuous, though this claim would form the bulk of a direct-threat-to-others defense in the context of an ADA claim. The argument would require a court to determine the status of a fetus as a person and the role of fertility providers in acting as protectors of future children.<sup>199</sup>

#### B. *The Question of Risk*

As is true when assessing a potential risk to the patient, the evaluation of a direct-threat-to-others claim is a four-part test.<sup>200</sup> First, is the harm posed by the patient in question serious in nature or severity?<sup>201</sup> Second, is the risk temporary and fleeting,

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197. See, e.g., ACOG Comm. on Ethics, *Maternal Decision Making, Ethics, and the Law*, 106 OBSTETRICS & GYNECOLOGY 1127, 1127 (2005) (discussing the tension between a pregnant woman's right to make medical decisions and fetal harm).

198. *Id.*

199. See, e.g., *Roe v. Wade*, 410 U.S. 113, 158 (1973) (holding that the unborn are not persons under the Constitution); *Davis v. Davis*, 842 S.W.2d 588, 596 (Tenn. 1992) (holding that the pre-embryos in dispute in the case were not persons under Tennessee law, though they were entitled to special consideration different from property).

200. 28 C.F.R. § 36.208(c) (2004).

201. *Id.*

or could it endure for a significant period of time?<sup>202</sup> Third, how great is the likelihood that the threatened harm will occur?<sup>203</sup> Where the harm is a substantial one, this factor is less important to the end calculus.<sup>204</sup> Fourth, and finally, is the harm imminent; in other words, how suddenly might it occur?<sup>205</sup>

The risks to a fetus carried by a disabled woman can be defined as direct and indirect risks. Direct risks are those that would result in transmitting the parent's disability to the child, or the risk of an adverse pregnancy outcome that is directly linked to the pregnant woman's disability, such as complications leading to fetal death or a child's disability. Both vertical transmission of HIV and transmitting genes that create disability fall into the direct risk category. Indirect risks are those that could affect the child post-birth as a result of how the parental disability affects the ability to parent. For instance, a child may be neglected as a result of a parent being too sick to care for her. These two types of risk, even to the extent that each could have deleterious consequences for the future child, should be evaluated separately as bases for denying fertility care to disabled women.

### C. Direct Risk

For the fetus carried by an HIV-positive woman, there is a direct risk of vertical (mother-to-child) transmission of HIV during gestation, birth, or during a period of breastfeeding.<sup>206</sup> Where treatment is accessible, physicians strongly urge women to engage in a course of antiretroviral therapy during pregnancy, labor, and post-birth in order for the baby to be at a substantially lower risk of such transmission.<sup>207</sup> Without intervention, the risk of vertical transmission hovers around 25%.<sup>208</sup> With various medical

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202. *Id.*

203. *Id.*

204. *Id.*

205. *Id.*

206. NIH, *HIV Infection in Infants and Children*,

<http://www3.niaid.nih.gov/topics/HIVAIDS/Understanding/Population+Specific+Information/children.htm#> (last visited Feb. 13, 2009) [hereinafter NIH, *HIV in Children*] ("Almost all HIV-infected children acquire the virus from their mothers before or during birth or through breastfeeding.")

207. PUBLIC HEALTH SERVICE TASK FORCE, RECOMMENDATIONS FOR USES OF ANTIRETROVIRAL DRUGS IN PREGNANT HIV-INFECTED WOMEN FOR MATERNAL HEALTH AND INTERVENTIONS TO REDUCE PERINATAL HIV TRANSMISSION IN THE UNITED STATES 3 (2008), available at

<http://aidsinfo.nih.gov/contentfiles/PerinatalGL.pdf> (explaining that there are also treatment protocols that can reduce the risk of transmission of HIV from mother to child).

208. NIH, *HIV in Children*, *supra* note 206 ("In the United States,

interventions, such as antiretroviral therapy and elective cesarean sections, the risk of vertical transmission falls to less than 2%.<sup>209</sup> In settings where formula is readily available, public health authorities also urge HIV-positive women not to breastfeed their children.<sup>210</sup>

Thus, a physician faced with such patients could argue that any direct risk of transmitting disease or substantial disability, slight or great, justifies a refusal to provide care because creating such a pregnancy unfairly places the future child in harm's way. The physician could not make general statements about risk, but would need to satisfy the appropriate test for evaluating direct threats in the context of providing medical care.<sup>211</sup>

First, it cannot be denied that the harm involved in vertical transmission of HIV is serious in both nature and severity as it involves a child forced to live with, and potentially die from, a chronic and life-threatening illness.<sup>212</sup> The child would be at risk for serious opportunistic infections as well as significant side effects from treatment.<sup>213</sup> Thus, vertical transmission of HIV

approximately 25 percent of pregnant HIV-infected women not receiving AZT therapy have passed on the virus to their babies.”).

209. *Id.* As the NIH explains:

In 1994, a landmark study conducted by the PACTG [Pediatric AIDS Clinical Trials Group] demonstrated that AZT, given to HIV-infected women who had very little or no prior antiretroviral therapy and CD4+ T-cell counts above 200/mm<sup>3</sup>, reduced the risk of MTCT [mother to child transmission] by two-thirds, from 25 percent to 8 percent. In the study, AZT therapy was initiated in the second or third trimester and continued during labor, and infants were treated for 6 weeks following birth. AZT produced no serious side effects in mothers or infants. Long-term follow up of the infants and mothers is ongoing. A few years later, another PACTG study found that the risk of transmitting HIV from an HIV-positive mother to her newborn infant could be reduced to 1.5 percent in those women who received antiretroviral treatment and appropriate medical and obstetrical care during pregnancy.

*Id.*

210. *Id.* (“In countries where safe alternatives to breastfeeding are readily available and economically feasible, this alternative should be encouraged.”).

211. *Id.* (defining “direct threat” and the criteria to assess whether an individual poses a direct threat).

212. See Working Group on Antiretroviral Therapy and Med. Mgmt. of HIV-Infected Children, *Guidelines for the Use of Antiretroviral Agents in Pediatric HIV Infection*, available at <http://aidsinfo.nih.gov/ContentFiles/PediatricGuidelines.pdf> (describing the diagnosis and treatment of HIV infection in children); see generally Nat'l Inst. of Allergy and Infectious Diseases, *HIV Infection in Infants and Children*, available at <http://www.niaid.nih.gov/factsheets/hivchildren.htm> (noting the dangers of HIV infection in children and infants).

213. See Working Group on Guidelines for the Prevention and Treatment of Opportunistic Infections Among HIV-Exposed and HIV-Infected Children, *Guidelines for Prevention and Treatment of Opportunistic Infections among HIV-Exposed and HIV-Infected Children*, available at



satisfies the first prong of the ADA's direct threat test.

The temporal question of risk is more difficult to quantify, but it seems that vertical transmission would satisfy this prong of the test as well. The risk of transmission can be described as existing within the period of pregnancy and childbirth, with an additional risk of transmission during breastfeeding.<sup>214</sup> Therefore, the risk itself exists within a relatively fixed time period, and it is not fleeting. Importantly, however, the potential for transmission within that fixed time period can be substantially reduced by the treatment choices of the pregnant woman.<sup>215</sup> This leads to the next inquiry, which is the likelihood that the threatened harm will come to fruition. Even an HIV-positive woman with an optimal pre-pregnancy health status (meaning a low viral load, no opportunistic infections, and access to state-of-the-art medications) risks transmitting HIV during pregnancy, childbirth, or post-birth through breastfeeding.<sup>216</sup> Without treatment during pregnancy and childbirth, the risk of transmission hovers around 25%.<sup>217</sup> These risks, other than those posed by breastfeeding, cannot be completely eliminated, but they can be reduced to an extraordinarily modest level.<sup>218</sup> When treated based on CDC guidelines, an HIV-positive pregnant woman has an approximately 1–2% risk of transmitting her infection to a child.<sup>219</sup> However, the harm, if it comes to fruition, is substantial and weakens the importance of this factor to the overall analysis of direct threat.

Finally, the imminence of harm presents a difficult question. If the harm to the child is the transmission of HIV, then it is hard to argue that the harm is imminent simply by virtue of a woman with HIV being pregnant, given that the exact mechanism of transmission is not entirely clear, and that transmission could happen along a continuum from pregnancy, through childbirth, to post-birth.<sup>220</sup> Thus, while the harm is real, it is not clear that it is imminent in the way that that word is generally understood.

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[http://www.aidsinfo.nih.gov/currentfiles/Pediatric\\_OI.pdf](http://www.aidsinfo.nih.gov/currentfiles/Pediatric_OI.pdf).

214. See CDC, *Achievements in Public Health: Reduction in Perinatal Transmission of HIV Infection—United States, 1985-2005*, MMWR WEEKLY, June 6, 2006, <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5521a3.htm> (stating that “[t]ransmission can occur during pregnancy, labor, delivery, or breast feeding”).

215. *Id.*

216. *Id.*

217. *Id.*

218. *Id.*

219. *Id.*

220. *Id.*

To justify a direct risk claim, a physician could certainly marshal evidence that a direct risk exists, that it is significant, and that it could happen within a relatively compressed time frame. However, the physician would also have to contend with the reality that medical treatment can substantially reduce, although not wholly eliminate, risks to the pregnant woman and to her future child.<sup>221</sup> Part of the argument against allowing such discrimination is that in any pregnancy, there is some risk of adverse outcomes for the fetus. Every year in the United States about 3% of babies will be born with some birth anomaly.<sup>222</sup> Given that risk exists in any pregnancy, it is a weak argument that a 1% risk of HIV transmission is of such weight that it should justify refusing care to an HIV-positive woman.

In other realms, specifically criminal law, arguments about minimal or infinitesimal risk have not protected HIV-positive people from adverse legal outcomes. HIV-positive people have been successfully prosecuted for behavior such as spitting or throwing other bodily fluids that present either no risk or an extraordinarily slight risk of HIV transmission.<sup>223</sup> Arguably, however, the standard utilized by criminal courts should have no relevance in the discrimination context. First, criminal cases may involve conduct in which a person actually hoped to transmit HIV to another person, despite the fact that he or she was practically incapable of doing so.<sup>224</sup> This type of intent or reckless disregard would not be present in the case of a woman seeking pregnancy.<sup>225</sup>

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221. *Id.*

222. See CDC, *Birth Defects: Frequently-Asked Questions*, <http://www.cdc.gov/ncbddd/bd/faq1.htm> (last visited Mar. 8, 2009).

223. See, e.g., *Commonwealth v. Brown*, 605 A.2d 429, 431–32 (Pa. Super. Ct. 1992) (upholding criminal assault and reckless endangerment convictions for an HIV-positive inmate who flung fecal matter on a corrections officer). The CDC does not require that universal precautions be taken with feces or saliva, unless the saliva is or could be contaminated with blood. See CDC, *supra* note 138.

224. See, e.g., *State v. Smith*, 621 A.2d 493, 517–18 (N.J. Super. Ct. Law Div. 1993) (upholding attempted murder, aggravated assault, and terroristic threats convictions for an HIV-positive inmate who threatened to kill a corrections officer by spitting and biting).

225. People living with HIV, just like those who do not have the disease, desire to create families with children. Data indicates that “[a]lmost one-third of HIV-infected men and women receiving medical care in the US desire children in the future. Furthermore, 20% of serodiscordant couples would practice unsafe sex in order to conceive.” A GUIDE TO THE CLINICAL CARE OF WOMEN WITH HIV 241 (Jean R. Anderson ed., 2005), available at <http://hab.hrsa.gov/publications/womencare05/WG05chap7.htm#WG05chap7a> (citations omitted). Given this desire, there is nothing surprising about people with HIV seeking pregnancy and there is no reason to think that an HIV-positive woman would actively seek to infect a child with HIV. In fact, the substantial drop

Second, not only would there not be any malicious behavior on the part of the woman seeking pregnancy, it may actually be the case that she is participating in fertility treatment precisely to avoid the transmission of HIV. Thus, while there might be public health concerns about HIV transmission from mother to child or between people who are sexually involved, references to criminal conduct are completely misplaced when discussing people who are seeking to build families.

A concern about vertical transmission would be stronger when a prospective fertility patient indicates that she will not take the recommended drugs during pregnancy, or makes clear an intention to breastfeed in spite of strong recommendations against it. These cases would likely be exceedingly rare, but would include women who have legitimate concerns about the undetermined long-term consequences of participating in an HIV drug regimen during pregnancy.<sup>226</sup> This unease could be reinforced by the fact that the vast majority of children will not contract HIV from their mothers, even if the pregnant woman takes no medication during her pregnancy.<sup>227</sup>

Even so, it is unclear that these scenarios would create a risk significant enough to protect the physician from a claim of unlawful discrimination. It would be useful to compare the physician's practice in the context of other known risks to a potential fetus. A physician who does not discriminate against people with the potential to pass on other deadly illnesses such as Tay-Sachs—which is inheritable, cannot be cured, and inevitably leads to an early death—has no plausible argument to justify not treating an HIV-positive woman, who poses an equal or even lesser risk of transmitting an illness that, while life-threatening,

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in the number of children infected with HIV by their mothers can be attributed in part to the widespread use of antiretrovirals by pregnant women to reduce the risk of HIV transmission to their newborns. CDC, *Mother-to-Child (Perinatal) HIV Transmission and Prevention*, Oct. 2007, <http://cdc.gov/hiv/topics/perinatal/resources/factsheets/perinatal.htm>.

226. PERINATAL HIV GUIDELINES WORKING GROUP, PUBLIC HEALTH SERVICE TASK FORCE RECOMMENDATIONS FOR USE OF ANTIRETROVIRAL DRUGS IN PREGNANT HIV-INFECTED WOMEN FOR MATERNAL HEALTH AND INTERVENTIONS TO REDUCE PERINATAL HIV TRANSMISSION IN THE UNITED STATES 59–60 (U.S. Dept. of Health & Human Servs. 2008) (2007), available at <http://aidsinfo.nih.gov/contentfiles/PerinatalGL.pdf> (concluding that the data is insufficient to determine the long-term risk for neoplasia or organ system toxicities in children that have been exposed to antiretroviral drugs in utero).

227. CDC, *Pregnancy and Childbirth*, <http://cdc.gov/hiv/topics/perinatal/index.htm> (last visited Mar. 9, 2009) (stating that the risk of vertical transmission without antiretroviral treatment or breastfeeding is 25%).

can be treated.<sup>228</sup> Even if a child does contract HIV from her mother, her potential for extended life is greater than that of a child born with Tay-Sachs.<sup>229</sup>

Thus, the risk of HIV transmission to a child is difficult to quantify and, even when quantifiable, does not necessarily justify refusing care in all cases.<sup>230</sup> In such a case, a physician certainly would be justified in gathering more information from the patient and perhaps referring her to other sources, including specialists in HIV and pregnancy, in order to help her understand her own disease and the risk of transmission to a child. Only where a woman continued to assert no interest in taking steps to reduce the risk of transmission would a physician be justified in refusing care, and then only if such care would be denied to any person who posed a similar threshold of risk to a child.<sup>231</sup>

228. Tay-Sachs is a fatal disorder, the incidence of which is particularly high among people of Eastern European and Ashkenazi Jewish descent. Office of Comm'n. & Pub. Liaison, Nat'l Inst. of Neurological Disorders & Stroke, NINDS Tay-Sachs Disease Information Page, <http://www.ninds.nih.gov/disorders/taysachs/taysachs.htm> (last visited Mar. 9, 2009). Children afflicted with Tay-Sachs generally die by the age of 4, even when offered the best possible treatment. *Id.* Both parents must carry the Tay-Sachs gene in order to produce a child with Tay-Sachs. *Id.* When both parents carry the gene, the risk of creating a child who will have Tay-Sachs is 20%. *Id.*

229. The National Institute of Allergy and Infectious Diseases reports that:

Researchers have observed two general patterns of illness in HIV-infected children. About 20 percent of children develop serious disease in the first year of life; most of these children die by age 4. The remaining 80 percent of infected children have a slower rate of disease progression, many not developing the most serious symptoms of AIDS until school entry or even adolescence. A report from a large European registry of HIV-infected children indicated that half of the children with perinatally acquired HIV disease were alive at age nine. Another study of 42 perinatally HIV-infected children, who survived beyond 9 years of age, found about one-quarter of the children to be asymptomatic with relatively intact immune systems.

Nat'l Inst. of Allergy & Infectious Diseases, HIV Infection in Infants and Children, <http://www.niaid.nih.gov/factsheets/hivchildren.htm> (last visited Mar. 9, 2009).

230. While far from the outcome of choice, the child welfare system exists specifically to deal with questions of risks to born children, but has been known to seek control over the choices of pregnant women in the interest of protecting a fetus. *See, e.g.,* *Jefferson v. Griffin Spalding County Hosp. Auth.*, 274 S.E.2d 457 (Ga. 1981) (ordering a cesarean section against the wishes of a competent pregnant woman); *Raleigh Fitkin-Paul Morgan Mem'l Hosp. v. Anderson*, 201 A.2d 537 (N.J. 1964) (allowing court-ordered blood transfusions for a pregnant Jehovah's Witness). As such, the fertility provider is not the last line of defense when it comes to the interests of a fetus or child.

231. When a potential fertility patient living with HIV possesses "lifestyle risks . . . which may compromise parental competence and/or jeopardize the welfare of the child, such as non-compliance to HIV treatment," physicians may ethically refuse to work with the patient. F. Shenfield et al., *Taskforce 8: Ethics of Medically Assisted Fertility Treatment for HIV Positive Men and Women*, 19 HUM. REPROD.

As for a woman living with quadriplegia, the direct risk evaluation will generally be easier. Any woman who became quadriplegic as a result of a spinal cord injury certainly would not be capable of transmitting that injury to a child. The condition can also be caused by a disease of the spinal canal, including polio or spina bifida,<sup>232</sup> but the transmissibility issues here are more difficult to quantify. While polio is very contagious, it is exceedingly rare in this country, and because of immunization, seldom leads to paralysis.<sup>233</sup> There is no known cause of spina bifida, so it would be impossible to blame the pregnant woman if she bears a child with this birth defect.<sup>234</sup> It is the case, then, that even though quadriplegia can be understood as harm to an individual living with the condition,<sup>235</sup> the person does not generally pose a threat to others in any appreciable way, in terms of being able to transfer her quadriplegia or its underlying cause to another. Thus, a woman with quadriplegia cannot be said to pose a direct risk to offspring.

#### D. Indirect Risk

Risk can also be understood as a claim that an individual's disability makes her more prone to substandard parenting. In this case, the risk to the child is that she will be born to a parent who

2454, 2456 (2004); *see also*, Zutlevics, *supra* note 98, at 1959 (noting that even if a child is born HIV-positive, "it is possible [for the child] to live a life of quality for many years in a way that is precluded by Tay-Sachs").

232. Patricia Tatman, *Youth and Spinal Cord Injuries*, INCLUSIVE 4-H (2005), available at <https://uwadmnweb.uwyo.edu/wyo4h/Inclusive/spinal%20cord.pdf> (defining spinal cord injury and describing the various types).

233. CDC, *Polio Disease—Questions and Answers*, <http://www.cdc.gov/vaccines/vpd-vac/polio/dis-faqs.htm> (last visited Mar. 29, 2009) (describing polio symptoms and presenting its incidence in the U.S.).

234. Doctors believe that spina bifida results from a combination of environmental and genetic factors, including low levels of folic acid. Mayo Found. for Med. Edu. & Research, Spina Bifida, <http://www.mayoclinic.com/health/spina-bifida/DS00417/DSECTION=causes> (last visited Feb. 20, 2009). However, the precise causal mechanism of this disabling condition remains a mystery. *Id.*

235. A medical model of disability focuses on disability as a "biological problem or limitation" and uses language that reinforces "negativity" about the lives of disabled people. Marsha Saxton, *Why Members of the Community Oppose Prenatal Diagnosis and Selective Abortion*, in *PRENATAL TESTING & DISABILITY RIGHTS* 147, 149 (Erik Parens & Adrienne Asch eds., 2000). In contrast to the medical model, the disability paradigm fostered by people living with disabilities:

regards disability as a socially constructed phenomenon and is based on a view of disabled people as a minority group, much like women or persons of color targeted with social discrimination and denied full access to the mainstream life of the community. According to this perspective, once the oppression is revealed, the assumptions of the medical view (the more impaired, the less quality of life) are exposed as false.

*Id.* at 150.

is incapable of providing her with conditions of care that are in the child's best interest.<sup>236</sup> An HIV-positive parent is at risk for early death and perhaps an extended period of deterioration that her child will be forced to witness.<sup>237</sup> However, with the availability of HAART, among other factors, people with HIV are living longer and healthier lives.<sup>238</sup> A parent may also find it hard to nurture a relationship with a child when dealing with her own illness.<sup>239</sup> The future child might be subject to disruption, distress, and other unwanted and potentially destructive experiences and emotions. The quadriplegic mom poses a risk to her child by virtue of her physical limitations, necessitating significant assistance with the physical demands of caretaking for a child.<sup>240</sup> A physician might be reluctant to help a woman achieve pregnancy who will never be able to rock her child in her arms, change his diaper, or teach him how to ride a bike. Further, there is a risk that the child will bear an unfair burden of caretaking for his mother. These hypothetical children may also endure social ostracism, teasing, and judgment based on their mothers' disabilities. Overall, this indirect risk assessment examines how a parent's disability could make her a less desirable parent, either because of her own limitations, or the limitations of a society that provides so poorly for the needs of

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236. See generally CDC, *Living with HIV/AIDS*, <http://www.cdc.gov/hiv/resources/brochures/livingwithhiv.htm> (last visited Mar. 29, 2009) (explaining the diseases that HIV-positive people are prone to developing).

237. People living with HIV may experience a latency period for ten or more years before they begin to experience significant symptoms associated with their infection. Mayo Found. for Med. Educ. & Research, *HIV/AIDS: Symptoms*, <http://www.mayoclinic.com/health/hiv-aids/DS00005/DSECTION=symptoms> (last visited Mar. 9, 2009). As the disease progresses, people living with HIV and then AIDS may have any of the following symptoms: swollen lymph nodes, diarrhea, weight loss, fever, cough and shortness of breath, pneumocystis carinii pneumonia (PCP), soaking night sweats, persistent white spots or unusual lesions on the tongue or in the mouth, headaches, blurred and distorted vision, and persistent, unexplained fatigue. *Id.* People living with AIDS may also develop specific cancers such as Kaposi's sarcoma, cervical cancer, and lymphoma. *Id.*

238. John Henkel, *Attacking AIDS with a 'Cocktail' Therapy*, FDA CONSUMER, July-Aug. 1999, at 12, available at [http://www.fda.gov/CDAC/features/1999/499\\_aids.html](http://www.fda.gov/CDAC/features/1999/499_aids.html) (reporting that HAART helped "the domestic AIDS death rate drop by 47 percent in 1997").

239. See, e.g., Mark A. Schuster et al., *Hugs and Kisses: HIV-Infected Parents' Fears About Contagion and the Effects on Parent-Child Interaction in a Nationally Representative Sample*, 159 ARCHIVES PEDIATRICS & ADOLESCENT MED. 173, 179 (2005) (describing the fears of some HIV-positive parents about transmitting HIV to their children through casual contact or contracting an opportunistic infection from interacting with their own children).

240. For instance, a parent who was incapable of using her arms due to a disabling condition would need assistance conducting the basic caretaking functions for a baby, such as changing diapers, preparing and holding a bottle, or placing the child in a crib.

disabled people.

As a threshold matter, it is unlikely that indirect risks to future children were on the minds of the members of Congress who passed the ADA.<sup>241</sup> A basic understanding of a direct threat, which was likely Congress's focus, appears to contemplate relationships and risks between and among actual individuals, such as a doctor and patient or an employer and employees, as opposed to risks capable of coming to fruition only in the context of a pregnancy, birth, and period of parenting.<sup>242</sup>

Even if parenting quality is defined by the statute as a risk, it seems clear that if physicians have any right to judge the future parenting capabilities of a person living with a disability, they should, at most, seek to evaluate whether the potential parent can meet some minimum threshold of acceptability. Within the context of child welfare and the parental choices or abilities subject to State interference, the appropriate standard for evaluating parental fitness is not whether a parent is the best available caregiver, but is whether she can provide an adequate—not an outstanding, or even a very good—level of parental care.<sup>243</sup> While it would be wonderful to ask every parent to be the best caretaker possible, that standard simply cannot be reconciled with an individual's fundamental right to the care and custody of her children.<sup>244</sup> Thus, it seems appropriate that if fertility providers have the power to deny potential parents, their standards for doing so should be no more stringent than the standards for removing an existing child from the care of its parents.

There are several rationales that physicians might use to protect their interest in refusing care to disabled patients who

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241. Indeed, the Senate thought of the public accommodations section of the ADA as remedying the problem of isolation. That is, the bill was designed to provide physical access to public spaces for people with disabilities, to promote "full participation" in society. See S. REP. NO. 101-116, at 10-12 (1989).

242. 28 C.F.R. § 36.208 (2008) (specifying that nothing in the ADA "require[s] a public accommodation to permit an individual to participate in or benefit from the goods, services, facilities, privileges, advantages, and accommodations of that public accommodation when that individual poses a direct threat to the health and safety of others").

243. See *Troxel v. Granville*, 530 U.S. 57, 68-69 (2000). According to the court: [S]o long as a parent adequately cares for his or her children (*i.e.*, is fit), there will normally be no reason for the State to inject itself into the private realm of the family to further question the ability of that parent to make the best decisions concerning the rearing of that parent's children. *Id.* (citation omitted).

244. See *id.*; *Meyer v. Nebraska*, 262 U.S. 390, 399 (1923) (stating that the Fourteenth Amendment guarantees "[w]ithout doubt . . . not merely freedom from bodily restraint but also the right . . . [to] establish a home and bring up children").

present indirect risks of future “bad” parenting or parenting that somehow fails to meet a minimum threshold of acceptability. While States are not primarily in the business of evaluating parental fitness, the fact that state laws mandate that physicians and other healthcare providers report suspected abuse or neglect of children suggests both a societal interest in protecting children and a belief that physicians are in a unique position to see and judge potential risks to children.<sup>245</sup> While this might be so, the physician’s role need not translate into a broader power to judge prospective parents’ future parenting skills with a crystal ball approach. Further, when a physician reports abuse or neglect of an existing child, the state child welfare system has an obligation to investigate the claim in a manner that protects the rights and interests of both parents and children.<sup>246</sup> When fertility providers imagine a future of abuse or neglect before a woman even has the chance to become pregnant, there are no such checks on the use of the system.<sup>247</sup> Like physicians, teachers are also under a statutory mandate to report suspected abuse or neglect, but no one could seriously claim that it would be fair or constitutional to allow teachers to screen potential parents to avoid the risk of future abuse or neglect of a child.<sup>248</sup> Thus, while society does assume that some professionals, including teachers and physicians, have a duty to children above that of many other professions, the power to effectuate that duty is rightly limited.

Furthermore, if providers are making judgments about

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245. According to the federal government, 48 states and the District of Columbia require various groups of professionals, including physicians, teachers, social workers, and child care providers, to report suspected abuse or neglect of child. CHILD WELFARE INFO. GATEWAY, MANDATORY REPORTERS OF CHILD ABUSE AND NEGLECT: SUMMARY OF STATE LAWS 1-2 (2008), [http://www.childwelfare.gov/systemwide/laws\\_policies/statutes/mandaall.pdf](http://www.childwelfare.gov/systemwide/laws_policies/statutes/mandaall.pdf).

246. For instance, many states have laws mandating case plans to both protect the best interests of a child placed in state custody and to seek return of that child to the custody of her parent. See, e.g., N.J. Stat. Ann. § 30:4C-55 (1999) (requiring the state child welfare agency to prepare the case plan in consultation with the child’s parents or legal guardian and, when appropriate, the child). Most States will not allow parental rights to be terminated unless the State provides clear and convincing evidence of parental unfitness and establishes that the termination will be in the best interests of the child. CHILD WELFARE INFO. GATEWAY, GROUNDS FOR INVOLUNTARY TERMINATION OF PARENTAL RIGHTS: SUMMARY OF STATE LAWS 2 (2007), [http://www.childwelfare.gov/systemwide/laws\\_policies/statutes/groundterminall.pdf](http://www.childwelfare.gov/systemwide/laws_policies/statutes/groundterminall.pdf).

247. Unless the refusal to provide care is made on some discriminatory basis identified by existing civil rights laws, providers would be free to engage in discrimination against purportedly unfit future parents. See ASRM, *supra* note 4.

248. See CHILD WELFARE INFO. GATEWAY, *supra* note 50 (explaining the requirements of clear and convincing evidence and of consideration of what is in the best interest of the child in order to terminate parental rights).



parenting skills and the threat to a child's interest posed by an inadequate parent, those determinations must involve some measure of rigor. The assessments must be individualized—not based on suppositions or stereotypes—and they must call on the expertise of a range of professionals, including medical providers and experts in family or child therapy.<sup>249</sup> If providers want to use disability as a marker for bad parenting, they should be forced to supply concrete evidence of an actual assessment of the individual patient. No such refusals should be allowed to rest on blanket rejections made without any attempt to ascertain the parenting skills of the potential patient through interviews with skilled providers, home studies, or other mechanisms.<sup>250</sup> Such work would undoubtedly increase the cost of fertility services,<sup>251</sup> but it would also force healthcare providers to reflect on the seriousness of their refusals to treat individuals, the consequences of such refusals for disabled women, and the difficulty of predicting future conduct.

Fertility providers might also claim a version of a right to conscientiously object to providing certain types of services to some clients. There is no doubt that healthcare providers can make some decisions, even those based solely on conscience, about what care to provide and to whom.<sup>252</sup> For instance, it would not be appropriate to force a plastic surgeon to provide unnecessary plastic surgery to a sixteen-year-old simply because his parents were willing to pay for it. Many States have determined that healthcare providers should be exempted from performing personally objectionable procedures, such as abortion.<sup>253</sup> The same idea applies when discussing fertility care of this nature. As

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249. This type of individualized inquiry is precisely what is contemplated by the ADA. See DOJ, *Questions and Answers*, *supra* note 135.

250. These mechanisms are similar to what is already done in the context of adoption. CHILD WELFARE INFO. GATEWAY, THE ADOPTION HOMESTUDY PROCESS (2004), [http://www.childwelfare.gov/pubs/f\\_homstu.cfm](http://www.childwelfare.gov/pubs/f_homstu.cfm) (describing the many elements involved in screening adoptive parents).

251. The cost of a home study can range from \$300–\$3,000. *Id.*

252. See Rachel Benson Gold & Adam Sonfield, *Refusing to Participate in Health Care: A Continuing Debate*, 3 GUTTMACHER REP. ON PUB. POL'Y 8 (2000), available at <http://guttmacher.org/pubs/tgr/03/1/gr030108.pdf> (explaining the continued discussion over mandating contraception coverage).

253. For example:

Forty-five states allow health care providers—whether or not public funds are involved—to refuse to participate in the delivery of abortion services. . . . Moreover, while 39 states protect providers who refuse to participate in abortion from discrimination, only eight follow the federal law in also protecting those who do choose to participate.

*Id.* at 8.

in the abortion context, these providers do not refuse care because they perceive a lack of medical necessity in an objectionable procedure. Instead, the law allows them to turn their backs on providing a certain type of healthcare because it offends their dignity, morals, religion, or professional ethics.<sup>254</sup> However, where a provider's conscience conflicts with a societal and legal edict against discrimination, it is right for the provider's conscience to yield. The California Supreme Court has recently found such to be the case when fertility providers refused to provide services based on a potential patient's sexual orientation.<sup>255</sup> Despite the physicians' assertion that they harbored deep personal objections to helping lesbians become biological parents, the court decided that discrimination in this context was illegal, as it violated the state's prohibitions against discrimination based on sexual orientation.<sup>256</sup> Similarly, when a physician's reluctance to help a disabled woman become pregnant is based on bias, anti-discrimination statutes should provide redress for the person denied services.

A decision not to provide fertility services because of a medical risk to the patient or the future child is markedly different from a decision not to treat based on an evaluation of the future parenting potential of a candidate. When there is some quantifiable risk to a future child, such as transmission of HIV, a physician might be justified in having concerns about helping a woman achieve pregnancy. By contrast, where the concern is essentially about parenting ability, the prohibitions against discrimination should be available to disabled women, as fertility specialists do not have the training, skills, or other tools necessary to fairly assess what is in the best interest of an existing child—let alone a child who has not yet come into being.<sup>257</sup> Fertility clinics are not child welfare agencies, nor should they be. Physicians

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254. *See id.*

255. *Benitez v. North Coast Women's Care Medical Group*, 44 Cal. 4th 1145, 1161 (Cal. 2008) (stating that violations of California's prohibition against discrimination were not protected).

256. *See id.*

257. According to one scholar:

The best interests standard was developed to afford decisionmakers a tool with which to make fact-specific inquiries into whether the interest of a particular child would be served by particular parents. The standard is thus not particularly well suited to clinical decisionmaking about children who have yet to be conceived and about whom little is known.

Richard Storrow, *The Bioethics of Parenthood: In Pursuit of the Proper Standard for Gatekeeping in the Clinical Setting*, 84 FERTILITY & STERILITY (SUPP. 1) S19, S20 (2005).

possess tremendous power over women who need reproductive assistance to conceive a child, but the law should not allow that power to be limitless. There is little to no legitimacy in predicting parenting ability based on a person's status as a disabled person. Denying access to the tools of reproduction premised on nothing more than knowledge of an individual's disability reinforces the same stereotypes about disability that the ADA discourages.

### *E. The Fetal Patient*

Even when direct or indirect risks to a future child could be quantified, there remains the underlying quandary of whether making a best interests determination about a non-entity is an appropriate inquiry for a court in any instance. Where the actors involved in a dispute are all clearly people in the juridical sense, the question of direct threat can be evaluated with some measure of legitimacy.<sup>258</sup> When, as in the case of individuals seeking fertility services, the balancing of interests in the direct threat evaluation involves a person (the fertility patient) and a nonexistent entity with the potential to become a person, it is wise to contemplate whether an interest in a hypothetical person can ever trump the rights of an existing human being. In this case, the debate is not simply about hypothetical risk; it is also about a hypothetical person. Debates about abortion, criminalization of acts that harm a fetus, and control of pregnant women's choices all raise the question of how to view a fetus for purposes of legal regulation, but the question at the core of the dilemma raised in this Article is what is owed in the abstract when no entity—potential person or otherwise—exists.<sup>259</sup>

Courts and legislative bodies have found multiple occasions to act on behalf of a fetus. Such actions include prosecutions and successful civil suits against individuals who harm a fetus.<sup>260</sup> Actions have even been instituted against pregnant women who

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258. See DOJ, ADA Title III Technical Assistance Manual § III-3.8000 Direct Threat (1993), available at <http://www.ada.gov/taman3.html> (describing the analysis of a direct threat to others in the context of the ADA).

259. See, e.g., JEAN REITH SCHROEDEL, IS THE FETUS A PERSON? A COMPARISON OF POLICIES ACROSS THE FIFTY STATES (2000) (examining the major areas of law that could award the fetus the status of personhood).

260. See, e.g., *Commonwealth v. Cochran*, 142 S.W.3d 654, 661 (Ky. 2004) (overruling the "born alive" rule in Kentucky and allowing for criminal convictions for harm done to a viable fetus); *Grodin v. Grodin*, 301 N.W.2d 869, 871 (Mich. Ct. App. 1980) (allowing a civil suit to proceed against a mother who, during her pregnancy, took drugs that left her son with brown and discolored teeth); *Witner v. State*, 492 S.E.2d 777, 786 (S.C. 1997) (upholding the criminal child neglect conviction of a woman who used cocaine while pregnant).

have made choices perceived to threaten a fetus.<sup>261</sup> A range of state laws deals with this issue, with some clearly defining a fetus, and even an embryo, as a person who is to be accorded all of the rights owed to all persons.<sup>262</sup> Federal law has also created criminal sanctions for certain harmful acts committed against a fetus, including killing or attempting to kill an “unborn child.”<sup>263</sup> To the extent that a court was comfortable using family law paradigms to decide issues of discriminatory access to fertility treatment, it could also be argued that it is not in the best interests of a child, existing or contemplated, to be raised by a parent who either has a significant health issue, like HIV, or who is paralyzed and lacks the physical capacity to provide the daily care that a child needs.

Faced with the dilemma of evaluating a direct threat to others, courts may interpret existing law as protecting a fetus—thereby making such a direct threat evaluation appropriate, if at all, when a woman is in fact pregnant. But the most sensible point at which a fertility provider would choose to discriminate against a

261. See *Witner*, 492 S.E.2d 777; *Grodin*, 301 N.W.2d 869.

262. The National Conference of State Legislators (NCSL) notes that thirty-six states have fetal homicide laws that qualify a fetus as a person for purposes of homicide prosecutions. NCSL, FETAL HOMICIDE (2009), <http://www.ncsl.org/programs/health/fethon.htm> (“An in vitro fertilized human ovum exists as a juridical person until such time as the in vitro fertilized ovum is implanted in the womb; or at any other time when rights attach to an unborn child in accordance with law.”).

263. The operative portion of the law, now codified as Title 18, Section 1841 of the United States Code, reads as follows:

Sec. 1841. Protection of unborn children

(a) (1) Whoever engages in conduct that violates any of the provisions of law listed in subsection (b) and thereby causes the death of, or bodily injury (as defined in section 1365) to, a child, who is in utero at the time the conduct takes place, is guilty of a separate offense under this section.

(2) (A) Except as otherwise provided in this paragraph, the punishment for that separate offense is the same as the punishment provided under Federal law for that conduct had that injury or death occurred to the unborn child’s mother.

(B) An offense under this section does not require proof that—

(i) the person engaging in the conduct had knowledge or should have had knowledge that the victim of the underlying offense was pregnant; or

(ii) the defendant intended to cause the death of, or bodily injury to, the unborn child.

(C) If the person engaging in the conduct thereby intentionally kills or attempts to kill the unborn child, that person shall instead of being punished under subparagraph (A), be punished as provided under sections 1111, 1112, and 1113 of this title for intentionally killing or attempting to kill a human being.

(D) Notwithstanding any other provision of law, the death penalty shall not be imposed for an offense under this section.

18 U.S.C. § 1841 (2004).

disabled woman would be before she even becomes pregnant. If the provider's goal is to protect a potential child from perceived direct or indirect risks, the only logical point at which to do so is before a pregnancy exists. The provider cannot claim an interest after the woman is pregnant because he or she could exercise no control over whether the woman brought that pregnancy to term. To allow for discrimination due to a direct threat, a court would have to sanction discrimination based on what is possible, which is a relatively preposterous basis upon which to litigate (although it, too, is not without precedent). In the criminal context, courts have upheld probation conditions ordering individuals not to reproduce, partly in the interest of protecting future children from a deadbeat dad or abusive parents.<sup>264</sup>

The logical leaps necessary to support this idea are worrisome. In the context of abortion, it is clear that States have an interest in pregnancies from their onset.<sup>265</sup> No court, however, has yet articulated an interest in potential pregnancies that would allow sanctioning otherwise illegal discriminatory behavior. If a court protects a physician's interest in acting on behalf of hypothetical people, just how far might that interest stretch? If fertility providers serve two patients—the woman seeking pregnancy and the fetus they both hope to create—on what basis does the provider claim greater allegiance to one over the other? Even in the context of an existing pregnancy, courts have been unwilling to elevate the interests of a fetus above those of the pregnant woman.<sup>266</sup>

Here, in contrast to cases involving pregnant women seeking to avoid forced cesarean sections or blood transfusions, the potential patient is actually seeking to *force* a physician to touch her by providing fertility care, as opposed to asserting her right not to be touched.<sup>267</sup> This is an important distinction, though it is

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264. See, e.g., *State v. Kline*, 963 P.2d 697 (Or. Ct. App. 1998) (holding that the defendant's right to procreate was not abridged by an order not to procreate after a conviction for mistreatment of his child); *State v. Oakley*, 629 N.W.2d 200 (Wis. 2001) (upholding a probation condition that a defendant not procreate after his conviction for failing to pay child support).

265. See *Planned Parenthood of Se. Pa. v. Casey*, 505 U.S. 833 (1992) (reaffirming that States have a "legitimate interest" in potential life throughout pregnancy).

266. See *In re A.C.*, 573 A.2d 1235 (D.C. 1990) (reversing a trial court order that allowed for an unconsented cesarean section on a woman dying of cancer).

267. See, e.g., *Jefferson v. Griffin Spalding County Hosp. Auth.*, 274 S.E.2d 457 (Ga. 1981) (ordering a cesarean section against the wishes of a competent pregnant woman); *Raleigh Fitkin-Paul Morgan Mem'l Hosp. v. Anderson*, 201 A.2d 537 (N.J. 1964) (allowing court-ordered blood transfusions for a pregnant Jehovah's Witness).

not clear that a woman in this position is not as equally entitled to legal redress as a woman refusing forced treatment. Many discrimination cases are predicated on forced interactions and intermingling when defendants wished to avoid such contact.<sup>268</sup> When an employer must hire or retain a disabled employee or a store must install devices to accommodate the needs of disabled patrons, the law forces contact that the defendant (here the employer and store, respectively) sought to avoid. By using the ADA to force a provider to treat a certain disabled plaintiff, the law would be forcing an interaction not only to vindicate the rights of the disabled plaintiff but also, hopefully, to educate the defendant about the need to provide services based on science rather than stereotypes.

### Conclusion

The goal of this Article is not to claim that fertility providers should have no ability to determine the scope of their practice by excluding some individuals from their patient pool. However, both law and ethics suggest that there are limitations to that power. Under the ADA, a person who can establish that she meets the threshold disability criteria of the statute is entitled to an individualized evaluation of her fitness to participate in fertility treatment.<sup>269</sup> The crux of this evaluation should be a determination of whether she is medically fit for the rigors of treatment and pregnancy and whether her disability is such that it causes a direct risk to the fetus or others that cannot be eliminated by readily achievable reasonable accommodations. When this medical determination finds that a patient's health status is adequate, the law should be careful about extending the physician's power so far that the potential parent's disability can be used to determine that she lacks parenting skills, and thus can be fairly discriminated against in her quest for procreation.

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268. For instance, in employment discrimination cases, plaintiffs may seek to work for an employer who had fired, refused to hire, or taken some other adverse employment action against the employee. *See, e.g.*, Title VII of the Civil Rights Act of 1964, 42 U.S.C. §2000e-2 (West 2003 & Supp. 2008) (prohibiting discrimination in employment on the basis of race, sex, national origin, and religion, and allowing aggrieved plaintiffs to seek remedies including hiring, promotion, and reinstatement).

269. 28 C.F.R. app. B § 36 (1991) (noting that "[t]he determination that a person poses a direct threat to the health or safety of others may not be based on generalizations or stereotypes about the effects of a particular disability" and that the discrimination must be based on an individual assessment that considers the particular activity and the actual abilities and disabilities of the individual).

As the country debates the ethics of fertility treatment and worries about rogue fertility providers, it is critical to also raise voices in defense of those who face both natural and socially constructed barriers to parenting. Women with disabilities have far too frequently faced discrimination in their quests to become parents. As reproductive technology creates expanded opportunities for these women, it would be a disservice to them—and the children who they would raise with love and care—to deny them the opportunity of biological parenthood routinely given to so many others.