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The Americans With Disabilities Act and the Reproductive Rights of HIV-Infected Women

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THE AMERICANS WITH DISABILITIES ACT AND THE REPRODUCTIVE RIGHTS OF HIV-INFECTED WOMEN

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I. Introduction

In passing the Americans with Disabilities Act of 1990 (ADA),[1] Congress acknowledged that discrimination in access to health care is a continuing problem for individuals with disabilities.[2] Thus, it is not surprising that gaining and retaining access to health care is a major concern of individuals infected with HIV. Many AIDS activists hailed the enactment of the ADA as a great step forward in remedying the problem of health care access.[3] Although HIV infection is not specifically mentioned as a covered disability in the text of the ADA, the legislative history of the Act indicates that Congress considered people infected with HIV among those protected groups covered by the statute.[4] Some writers

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1. Pub. L. No. 101-336, 104 Stat. 327 (codified at 42 U.S.C. §§ 12101-12213 (Supp. III 1991) (aiming to eliminate discrimination against individuals with disabilities).

2. 42 U.S.C. § 12101(a)(3) (Supp. III 1991).

3. Michael Specter, *On the Front Lines of Medical Politics: Lobbies Emerge As Powerful Advocates of Consumer Health*, WASH. POST, Jan. 30, 1990, at Health 15 (noting that the passage of the ADA was a great triumph for AIDS activists because it helps those with AIDS and HIV gain access to treatment).

4. H.R. REP. No. 485, 101st Cong., 2d Sess., pt. 2, at 51 (1990), *reprinted in* 1990 U.S.C.C.A.N. 303, 333.

> It is not possible to include in the legislation a list of all the specific conditions, diseases or infections that would constitute physical or mental impairments because of the difficulty of ensuring the comprehensiveness of such a list, particularly in light of the fact that new disorders may develop in the future. The term includes, however, such conditions, diseases and infections as: . . . infection with the Human Immunodeficiency Virus . . . .

Id. Case law also indicates that individuals with infectious or contagious diseases may be considered disabled under an earlier antidiscrimination statute, the Rehabilitation Act of 1973, Pub. L. No. 93-112, 87 Stat. 355 (codified as amended at 29 U.S.C. §§ 701-796i (1988 & Supp. III 1991)). *See, e.g.*, School Bd. of Nassau County, Fla. v. Arline, 480 U.S. 273, 289 (1987) ("We hold that a

even assert that Title III of the ADA creates a duty on private health care providers to treat individuals infected with HIV.[5] There is some question about whether the ADA does in fact modify the common law to create a duty on the part of private health care providers to treat individuals infected with HIV in the absence of some prior contractual arrangements between the parties.[6] The Act, however, aims to eliminate the denial of services to disabled individuals on the basis of their handicaps.[7] As one commentator noted, "the ADA goes a long way toward . . . ensuring that providers do not unreasonably turn away or refer patients with disabilities."[8]

Under Title III of the ADA,[9] private persons or entities that operate public accommodations cannot discriminate against disabled individuals.[10]

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person suffering from the contagious disease of tuberculosis can be a handicapped person within the meaning of § 504 of the Rehabilitation Act of 1973 . . . ."). Although not specifically mentioned in the original Act or the *Arline* decision, it is now well established that persons infected with HIV may be considered disabled under the Rehabilitation Act. *See, e.g.*, Doe v. Centinela Hosp., No. CV 87-2514, 1988 U.S. Dist. LEXIS 8401, at *32 (C.D. Cal. July 7, 1988) (holding that a person with HIV can make out a claim of being "treated as an individual with a handicap" under the Rehabilitation Act); *Doe v. Jamaica Hospital, Kings County, Supreme Court*, 205 N.Y. L.J. 27 (1991) (describing a case where an HIV-infected woman filed a claim against a physician and a hospital under section 504 of the Rehabilitation Act for discrimination based on her HIV status).

5. *See, e.g.*, Jill Cohen, *Access to Medical Care for HIV-Infected Individuals Under the Americans with Disabilities Act: A Duty to Treat*, 18 AM. J.L. & MED. 233, 239-42 (1992) (relying on congressional intent as indicated in the legislative history). *But see* Lawrence O. Gostin, *The Americans With Disabilities Act And The U.S. Health System*, 11 HEALTH AFF. 248, 251 (1992) (noting that, under the ADA, physicians may evade their duty of care under the guise of clinical judgment).

6. *See* Gostin, *supra* note 5, at 250 (stating that, although the ADA does not completely answer the question of whether physicians owe a duty to treat, it attempts to clarify the duty to treat).

7. *See* 42 U.S.C. § 12101 (Supp. III 1991) (finding that discrimination against disabled persons persists in health services and stating that the purpose of the Act is to eliminate discrimination against individuals with disabilities).

8. Gostin, *supra* note 5, at 250.

9. 42 U.S.C. §§ 12181-12189 (Supp. III 1991) (containing provisions related to public accommodations operated by private entities).

10. *See* 42 U.S.C. § 12181(7) (Supp. III 1991) (defining when private entities are considered public accommodations); 42 U.S.C. § 12182(a) (Supp. III 1991) (stating the general prohibition of discrimination on the basis of disability by places of public accommodation). In this Article, I focus on private health care providers. Public health care providers are covered under Title II of the ADA. 42 U.S.C. §§ 12131-12165 (Supp. III 1991). The Rehabilitation Act of 1973 is more limited than the ADA. Rehabilitation Act of 1973, Pub. L. No. 93-112, 87 Stat. 355 (codified as amended at 29 U.S.C. §§ 701-796i (1988 & Supp. III 1991)). It prohibits discrimination against individuals with disabilities by federal entities and recipients of federal funds. Rehabilitation Act § 504, 87 Stat. at 394 (codified as amended at 29 U.S.C. § 794 (1988 & Supp. III 1991)). Section 504 applies to the recipients of federal funds and covers all health care providers who accept Medicare and Medicaid patients, but the section does not expressly include all private medical offices. *See* 29 U.S.C. § 794(b)(3)(A)(ii) (1988 & Supp. III 1991) (specifying that private organizations that provide health care are subject to the Rehabilitation Act if they receive federal financial assistance); 45 C.F.R. § 84.3 app. A at 376 (1992) (noting that health care providers who receive Medicaid as

As defined in the Act, public accommodations include hospitals and professional offices of health care providers.[11] Professional offices of private sector health care providers may be considered places of public accommodation under the ADA, even if the offices are located in private homes.[12] The ADA also prohibits discrimination on the basis of disability in the full and equal enjoyment of goods, services, facilities, privileges, advantages, and accommodations of any place of public accommodation.[13] In addition, the ADA prohibits a public accommodation from providing different or separate benefits to persons with disabilities unless a separate benefit is necessary to ensure access or service that is as effective as those granted to individuals without a disability.[14]

To date, the bulk of early lawsuits filed under the ADA on behalf of individuals infected with HIV involved situations where the plaintiffs were refused treatment.[15] Gender has not been a significant factor in these

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payment are "recipients" under the Rehabilitation Act and are subject to its provisions). Prior to the ADA, some courts ruled that private medical and dental offices, clinics, hospitals, and dispensaries are places of public accommodation, but these decisions were based on state or local laws, not federal law. *See, e.g.*, Hurwitz v. N.Y.C. Comm'n on Human Rights, 535 N.Y.S.2d 1007 (Sup. Ct. 1988) (upholding the jurisdiction of the New York City Commission on Human Rights to declare that private dental offices are places of "public accommodation" within the meaning of Human Rights Law); Plaintiff's Complaint for Damages and Injunctive Relief at 7-8, Walsh v. Cicmanec, 1989 AIDS Litig. Rep. (Andrews Pub.) 2400 (Cal. App. Dep't Super. Ct. Jan. 1, 1989) (categorizing a chiropractic office as a place of public accommodation for purposes of claiming California Civil Code violation through allegations that the chiropractor refused service to the patient because he suffered from AIDS); *cf.* John O'Brien, *AIDS Bias Claim Upheld Against Doctor*, 203 N.Y. L.J. 2 (1990) (describing the ruling in *Elstein v. State Div. of Human Rights*, which held that the Human Rights Division did have jurisdiction to decide a claim of bias against an AIDS patient by a private doctor).

11. *See* 42 U.S.C. § 12181(7)(F) (Supp. III 1991) (listing "professional office of a health care provider, hospital or other service establishment" among those private entities considered "public accommodations"); 28 C.F.R. § 36.104 (1992) (defining places of public accommodation identically to 42 U.S.C. § 12181(7)(F)). In this Article, the term "health care provider" includes individual health care workers and the institutions (e.g., hospitals and nursing homes) and organizations (e.g., Health Maintenance Organizations and Preferred Provider Organizations) with which they are affiliated.

12. 42 U.S.C. § 12181(7)(F) (Supp. III 1991); 28 C.F.R. § 36.104 (1992); Nondiscrimination on the Basis of Disability by Public Accommodations and in Commercial Facilities, 56 Fed. Reg. 35,544 (1991) (codified at 28 C.F.R. pt. 36) (prohibiting discrimination on the basis of a disability by private entities in places of public accommodation and requiring new places of public accommodation to be made readily usable by persons with disabilities). The only exceptions are facilities that are owned or operated by religious entities, private clubs, or establishments exempted under Title II of the Civil Rights Act of 1964. 42 U.S.C. § 12187 (Supp. III 1991); 28 C.F.R. § 36.102(e) (1992).

13. 42 U.S.C. § 12182(a) (Supp. III 1991); 28 C.F.R. § 36.201(a) (1992). Section 36.201 also prohibits unequal services or the exclusion of persons with disabilities on the basis of disability for reasons other than those specifically set forth in the statute. 28 C.F.R. § 36.201 (1992).

14. 42 U.S.C. § 12182(b)(1)(A)(iii) (Supp. III 1991).

15. *See, e.g.*, ADA Health Care: Fuentes v. Reich, 1992 AIDS Litig. Rep. (Andrews Pub.)

cases.[16] However, women infected with HIV have special medical problems that distinguish them from men, stemming primarily from the fact that the virus can be transmitted perinatally from mother to child.[17] It is important to address these problems because of the growing number of women with AIDS. AIDS became the sixth leading cause of death among all women between the ages of twenty-five and forty-four in 1989.[18] Currently, women account for ten percent of all reported cases of AIDS in the United States, and the number of women with AIDS is increasing.[19] To date, approximately eighty-five percent of the AIDS cases reported in women occurred in women of childbearing age.[20] These percentages do not reflect the number of women who are infected with HIV but do not have AIDS.[21]

Another important factor to consider in discussing the unique concerns surrounding women with HIV/AIDS is the demographics of HIV-infected women. The vast majority of women believed to be infected with HIV come from poor urban communities of color.[22] More specifically,

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7917 (C.D. Cal. Apr. 10, 1992) (commenting on a case in which a health care center allegedly refused to see a patient because he was HIV-positive); Americans with Disabilities Act: Charon v. Hull, 1993 AIDS Litig. Rep. (Andrews Pub.) 9303 (N.D. Ohio Jan. 12, 1993) (describing a suit in which the plaintiff claimed that a hospital refused him emergency room care after finding out that he was HIV-positive); ADA Health Care: Toney v. U.S. Healthcare, 1992 AIDS Litig. Rep. (Andrews Pub.) 7919 (E.D. Pa. Apr. 10, 1992) (describing a case in which it was alleged that a primary care physician refused to continue to treat a patient after the patient tested positive for HIV); Americans with Disabilities: Totten v. Castle Dental Center, 1993 AIDS Litig. Rep. (Andrews Pub.) 9852 (Tex. Dist. Ct. Apr. 27, 1993) (summarizing a suit against a dental center that refused to provide further dental work to a patient after learning he was HIV-positive).

16. *See supra* note 15 and accompanying text. These cases involved only men.

17. *See* A.E. Ades et al. (European Collaborative Study), *Children Born to Women with HIV-1 Infection: Natural History and Risk of Transmission*, 337 LANCET 253, 258 (1991) (reporting a 12.9% perinatal transmission rate from mother to child).

18. Centers for Disease Control and Prevention, *Mortality Patterns—United States, 1989*, 41 MORBIDITY & MORTALITY WKLY. REP. 121, 124 (1989).

19. David Michaels & Carol Levine, *Estimates of the Number of Motherless Youth Orphaned by AIDS in the United States*, 268 JAMA 3456, 3456 (1992) (noting that from 1981 to March 1992 women accounted for 10% of the 218,301 cases of AIDS reported to the Centers for Disease Control and Prevention, and noting that, upon closer examination of these figures, women comprised 9% of the first 100,000 reported AIDS cases and 12% of the second 100,000 cases).

20. *See* Division for HIV/AIDS, Center for Infectious Diseases, Centers for Disease Control and Prevention, *AIDS in Women—United States*, 265 JAMA 23, 23 (1991) [hereinafter Division for HIV/AIDS] (defining childbearing age as between the ages of 15 and 44).

21. Estimates indicate that approximately 80,000 women in the United States may be infected with HIV. Marta Gwinn et al., *Prevalence of HIV Infection in Childbearing Women in the United States: Surveillance Using Newborn Blood Samples*, 265 JAMA 1704, 1706 (1991).

22. *See* Carol Levine & Nancy Neveloff Dubler, *Uncertain Risks and Bitter Realities: The Reproductive Choices of HIV-Infected Women*, 68 MILBANK Q. 321, 324-27 (1990) (noting the disproportionate impact that AIDS has on minorities and the poor); Michaels & Levine, *supra* note 19, at 3459 (identifying the following cities with large numbers of reported AIDS cases among women of childbearing age: New York (5,357), Newark (1,271), Miami (924), San Juan (674), Los

approximately seventy percent of women with AIDS in the United States are African-American or Hispanic.[23] Roughly one-half of these women have histories of intravenous drug use, and another quarter were infected as a result of heterosexual contact with infected drug users.[24]

The demographics of women with AIDS and women infected with HIV in the United States, along with the sources of their infection, may account for the lack of public sympathy for them.[25] As a class, women with HIV and AIDS are seen as irresponsible women whose voluntary conduct is responsible for their condition and as inappropriate parents because of their drug use or association with drug users. Their association with drug use, coupled with the historical antagonism toward childbearing by poor women, especially women of color and women with disabilities,[26] only reinforces public sentiment in favor of limiting the reproductive freedom of these women.[27] As a result of these considerations and because most infected women are of childbearing age, the public health and medical communities have focused much attention on

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Angeles (354), and Washington, D.C. (254)). HIV/AIDS-related causes are the leading cause of death among African-American women between the ages of 15 and 44 in the states of New York and New Jersey. Susan Y. Chu et al., *Impact of the Human Immunodeficiency Virus Epidemic on Mortality in Women of Reproductive Age, United States*, 264 JAMA 225, 226 (1990). For example, "the 1988 death rate for HIV/AIDS in black women 15 to 44 years of age was nine times the rate for white women the same age." *Id.* at 227. Thus, it is not surprising that the number of children whose mothers have died from AIDS are concentrated in cities like New York City, Newark, Miami, San Juan, Los Angeles, and the District of Columbia. Michaels & Levine, *supra* note 19, at 3459; *see also* U.S. DEPARTMENT OF COMMERCE, ECONOMICS & STATISTICS ADMINISTRATION, BUREAU OF THE CENSUS, 1990 CP-1-1B, 1990 CENSUS POPULATION—GENERAL POPULATION CHARACTERISTICS—METROPOLITAN AREAS § 1 (1990) (revealing that the percentage of minorities in some of the major U.S. cities ranges from 11.7% in Miami Beach to 70.4% in Washington, D.C.).

23. Working Group on HIV Testing of Pregnant Women and Newborns, *HIV Infection, Pregnant Women, and Newborns: A Policy Proposal for Information and Testing*, 264 JAMA 2416, 2416 (1990) (citing CENTERS FOR DISEASE CONTROL AND PREVENTION, HIV/AIDS SURVEILLANCE REPORT, Aug. 1990, at 10); *see* Division for HIV/AIDS, *supra* note 20, at 23 ("Although black and Hispanic women constitute 19% of all U.S. women, they represent 72% of all U.S. women diagnosed with AIDS.").

24. Michaels & Levine, *supra* note 19, at 3456.

25. *See, e.g.*, Kim Painter, *Guilt, Innocence and AIDS*, USA TODAY, Dec. 18, 1991, at 1D (noting how the public makes distinctions between the "innocent victims" of AIDS with whom it sympathizes, such as hemophiliacs, blood recipients, and babies, and those who engaged in "wrong behavior" and became infected, such as drug users or individuals who had unprotected sex).

26. *See infra* Part II.A.-B.

27. *See, e.g.*, John D. Arras, *AIDS and Reproductive Decisions: Having Children in Fear and Trembling*, 68 MILBANK Q. 353, 370-71 (1990) (arguing that it is "seriously irresponsible and wrong" for a woman infected with HIV to bear a child when she is homeless, drug-addicted, without family support, and in poor health); Judith Grad, *Ethics and AIDS*, *in* HIV POSITIVE: PERSPECTIVES ON COUNSELING 37, 39 (Margot Tallmer et al. eds., 1991) ("Some people believe, as I do, that it is morally wrong to risk bearing a child who has so high a likelihood of living a short life that will end in excruciating pain.").

minimizing the risk of maternal-fetal transmission of the virus.[28]

In 1985, the increased incidence of perinatally transmitted HIV and AIDS cases caused the Centers for Disease Control and Prevention (CDC) to recommend that women infected with HIV delay or forego bearing children—a recommendation seconded by the American College of Obstetrics and Gynecology (ACOG) in 1987.[29] Many health care providers adopted these recommendations and currently counsel HIV-positive women not to have children.[30] Some commentators note that this

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28. *See infra* note 29 and accompanying text (discussing the various responses of the medical community to the issue of reproductive choices for HIV-infected women). *See generally* Nancy E. Kass, *Reproductive Decision Making in the Context of HIV: The Case for Nondirective Counseling, in* AIDS, WOMEN, AND THE NEXT GENERATION 308 (Ruth R. Faden et al. eds., 1991) (discussing counseling of HIV-positive women about their reproductive options and criticizing physicians who voice their unsolicited professional opinions regarding the wisdom of certain choices when they are giving information).

29. Centers for Disease Control and Prevention, *Recommendations for Assisting in the Prevention of Perinatal Transmission of Human T-Lymphotropic Virus Type III/Lymphadenopathy-Associated Virus and Acquired Immunodeficiency Syndrome*, 34 MORBIDITY & MORTALITY WKLY. REP. 721, 725 (1985) [hereinafter CDC, *Recommendations*]; *see Human Immune Deficiency Virus Infections*, ACOG TECHNICAL BULL. (Am. C. of Obstetricians & Gynecologists), Dec. 1988, at 5 (recommending that obstetricians and gynecologists should discourage HIV-positive women from becoming pregnant). The most recent statement by ACOG regarding the care of pregnant women infected with HIV was issued in June of 1992. This statement, however, did not address the issue of the HIV-infected woman who is not pregnant but who is seeking counseling about future pregnancies. *Human Immunodeficiency Virus Infections*, ACOG TECHNICAL BULL. (Am. C. of Obstetricians & Gynecologists), June 1992, at 3-4. A joint publication of the American Academy of Pediatrics and ACOG contains a statement on HIV infection which states:

> The identification of an HIV-infected pregnant woman as early in pregnancy as possible is important to ensure appropriate counseling and medical care, including pregnancy termination if this is her choice; to plan medical care for the infant; and to provide counseling about family planning, future pregnancies, and the risk of sexual transmission of HIV to others.

AMERICAN ACADEMY OF PEDIATRICS AND AMERICAN COLLEGE OF OBSTETRICIANS AND GYNECOLOGISTS, GUIDELINES FOR PERINATAL CARE 126 (Roger Freeman & Ronald Poland eds., 3d ed. 1992). This book also does not address the issue of the HIV-infected woman who is not pregnant and seeks counseling about future pregnancies.

In contrast to the CDC and ACOG positions, the introduction to the American Public Health Association's policy statement #8814 addressing HIV infection reads: "the Association has consistently affirmed the right of women to make their own reproductive choices and acknowled[ges] that any attempt to force or pressure a woman to undergo a sterilization procedure against her will is contrary to Association policy . . . ." American Public Health Association, *Counseling and Testing for Perinatal Transmission of AIDS*, 79 AM. J. PUB. HEALTH 359, 359 (1989).

30. "State, and some local, health departments have in a variety of ways adopted the substance of the CDC's recommendations on vertical HIV transmission as their own. . . . [T]he goal of preventing the birth of infected babies has been explicitly embraced by public health officials." Ronald Bayer, *AIDS and the Future of Reproductive Freedom*, 68 MILBANK Q. 179, 191 (Supp. 2 1990). The CDC had recommended: "Women with virologic or serologic evidence of [HIV] should be counselled regarding their own risk of AIDS and the risk of perinatal and sexual transmission. . . . Infected women should be advised *to consider delaying pregnancy until more is known about perinatal transmission of the virus*." CDC, *Recommendations*, *supra* note 29, at 725 (emphasis

type of counseling represents a departure from the traditional nondirective reproductive counseling paradigm developed in the context of counseling women about genetic risk.[31] Some of these commentators also speculate that the race and socioeconomic status of the women disproportionately affected by HIV influenced this shift in the counseling paradigm.[32]

These criticisms make it important to determine whether there is sufficient medical evidence to support counseling women with HIV to forego childbearing. The reality is, however, that current medical knowledge does not mandate the CDC directive. For instance, the limited medical knowledge currently available about pregnancy in HIV-infected women does not reveal a proven direct correlation between pregnancy and accelerated progression of the disease in women.[33] Moreover, the rate of maternal-fetal transmission of HIV in the United States is no more than thirty-six percent and is possibly as low as thirteen percent.[34]

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added). Ronald Bayer argues that, despite the fact that the CDC did not strongly encourage women not to become pregnant, there can be no doubt about "how the CDC believed women ought to act in the face of HIV infection." Bayer, *supra*, at 191. As a result of this, "[i]n many cases, health departments have ignored the subtle equivocation in the CDC's phrasing and have declared: 'We follow the recommendations of the CDC and urge women not to become pregnant.'" *Id.* at 192.

31. *See, e.g.*, Taunya L. Banks, *Women and AIDS: Racism, Sexism and Classism*, 17 N.Y.U. REV. L. & SOC. CHANGE 351, 373-76 (1989-90) (noting that a nondirective counselor only counsels the family about genetic risks and has no right to advise against having a child even when the risk of transmitting a serious genetic defect or HIV is great); Levine & Dubler, *supra* note 22, at 345-46 (noting that prospective parents of children with other inheritable diseases are not counseled in the same way as prospective parents with HIV). *See generally* Bayer, *supra* note 30, at 179-204 (discussing counseling choices and procreative rights).

32. *See, e.g.*, Banks, *supra* note 31, at 361-65 (noting a long history of racist medical policy in the United States); Bayer, *supra* note 30, at 182 ("That the women who are most at risk for bearing infected children are poor, black and Hispanic, and most often intravenous drug users or their sexual partners, heightens the sense of disquiet about the prospect of a repressive turn in public policy.") (citation omitted); *see also* Levine & Dubler, *supra* note 22, at 337-39 (discussing how middle-class America has aimed to control the reproductive decision making of poor women of color and mentally disabled women). To date, the vast majority of women infected with HIV are African-American or Hispanic. *See supra* notes 22-23 and accompanying text.

33. Some studies conclude that for an asymptomatic woman with HIV, pregnancy poses no additional risk. *See* Marie-Louise Newell et al., *HIV-1 Infection in Pregnancy: Implications for Women and Children*, 4 AIDS S111, S112 (Supp. 1 1990) (noting that more recent studies do not indicate differences in the progression of HIV between pregnant and nonpregnant HIV-positive women); Peter A. Selwyn et al., *Prospective Study of Human Immunodeficiency Virus Infection and Pregnancy Outcomes in Intravenous Drug Users*, 261 JAMA 1289, 1293 (1989) (reporting that for seropositive women, the rates of antenatal medical and obstetric complications were no different than for seronegative women and noting that none of the seropositive women developed AIDS either during their pregnancies or after a thirteen month postpartum follow-up). Although the "knowledge concerning the impact of pregnancy on the course of HIV disease is . . . meag[er] and conflicting," there is also evidence that pregnancy may accelerate the course of HIV disease. Susanne Lindgren et al., *HIV and Child-Bearing: Clinical Outcome and Aspects of Mother-to-Infant Transmission*, 5 AIDS 1111, 1111 (1991).

34. Michaels & Levine, *supra* note 19, at 3459; *see also* Ades et al., *supra* note 17, at 258 (finding a 12.9% transmission rate in a June 1990 European study of 372 children who were 18

There is also inadequate information about how the virus is transmitted from mother to fetus, and "there is no safe and effective technique for the fetal diagnosis of HIV infection."[35] In contrast to the CDC, one group of researchers has concluded that health care providers should counsel "women with clinical or immunological evidence of HIV illness . . . that transmission to the infant may occur."[36] This recommendation varies significantly from CDC's recommendation that HIV-infected women delay or forego pregnancy.

In this Article, I argue that, under the ADA, directive reproductive counseling of HIV-positive women not to bear children constitutes separate, different, unequal, and less effective medical treatment and services based on their physical disability. Specifically, any reproductive counseling policy for HIV-positive women based solely on their seropositive status constitutes separate, different, unequal, and less effective counseling than that received by able-bodied women making reproductive choices. I also argue that any blanket policy of refusing to provide reproductive-related services, including abortion and infertility services, constitutes separate, different, unequal, and less effective medical treatment based on a protected physical disability in violation of the ADA.

In Part II of this Article, I argue that the failure of HIV-infected women to receive equal and effective medical treatment and services from health care providers in reproductive matters is a continuing problem for most women with disabilities and that the problem is exacerbated by the fact that women disabled by HIV infection tend to be poor and women of color. I explore the history of governmental and medical interference with the reproductive decisions of low income, minority, and disabled women. I then discuss how the constitutional protection of the right of these women to procreate is ambiguous and insufficient.

In Part III of this Article, I argue that health care providers' decisions on reproductive matters must be scrutinized more closely because they

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months or older); Laura Boylan & Zena A. Stein, *The Epidemiology of HIV Infection in Children and Their Mothers—Vertical Transmission*, 13 EPIDEMIOLOGIC REVS. 143, 155-68 (1991) (discussing various studies that have been conducted to determine the vertical transmission rate of HIV from mother to child); Jody W. Zylke, *Another Consequence of Uncontrolled Spread of HIV Among Adults: Vertical Transmission*, 265 JAMA 1798, 1798 (1991) (reporting that studies revealed that transmission rates vary from 10% to 50%, but the most likely rate ranges from 25% to 35%).

35. Marsha F. Goldsmith, *Specific HIV-Related Problems of Women Gain More Attention at a Price—Affecting More Women*, 268 JAMA 1814, 1814-15 (1992). For example, at least one study found that "race, age, gravidity, history of sexually transmitted diseases and/or the use of injected drugs or crack cocaine, anemia and detectable p24 antigen were not directly associated with transmission. Neither was the CD4 count." *Id.* at 1815. Another study suggested that the mother's strain of HIV may determine whether a child is born with HIV. *Id.*

36. *See id.* (discussing a study of 129 HIV-infected women conducted by Dr. Pauline Thomas and her colleagues in the New York City Perinatal HIV Transmission Collaborative Study Group).

often reflect nonmedical, moral judgments about parental fitness that are influenced by the disability and by the race and socioeconomic status of the patient. I also assert that health care providers may have difficulty avoiding making decisions on nonmedical bases because they have conflicting professional obligations growing out of the two-patient obstetric model that views both the pregnant woman and the fetus as patients.[37] As a result, the desires of women infected with HIV may be subordinated to the health care provider's biased judgment about the quality of life of any potential offspring.

In Part IV of this Article, I argue that, under the ADA, nonmedical considerations distort health care providers' assessment of available medical information and undercut the right of HIV-positive women to make voluntary, fully informed choices about whether or not to bear children and to obtain the medical assistance they need to realize their choices. These so-called "medical" decisions violate at least the spirit of the ADA because they impermissibly interfere with the reproductive freedom of women with a protected disability. In each instance where the health care provider's decision to counsel a woman not to become pregnant or to exclude her from infertility services is influenced by the woman's physical disability, the decision is suspect.

In Part V, I conclude that most courts handling ADA claims will be unduly deferential to these so-called objective medical opinions on reproductive matters and will narrowly interpret the statute's provisions. Therefore, it may be difficult to successfully pursue HIV-related reproductive claims unless Congress amends the ADA to clearly indicate that discrimination in reproductive matters against women with protected disabilities violates the Act. Otherwise, many disabled women, especially women infected with HIV, will continue to receive different and unequal reproductive-related treatment and services.

In setting out these arguments, I do not raise any questions about basic

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37. *See infra* notes 110-117 and accompanying text. Increasingly, advances in perinatal technology result in cases where maternal and fetal needs come into conflict over the treatment of the fetus *in utero*. *See* Veronika E.B. Kolder et al., *Court-Ordered Obstetrical Interventions*, 316 NEW ENG. J. MED. 1192, 1194 (1987) (describing cases in which court orders have been sought to override maternal refusal for fetal therapy or surgery in the interests of the "second patient," the fetus). When maternal and fetal needs are in conflict, some physicians view the fetus as a separate patient and believe that high-tech fetal interventions are appropriate even over the objections of the pregnant woman. *See* Lisa C. Ikemoto, *The Code of Perfect Pregnancy: At the Intersection of the Ideology of Motherhood, the Practice of Defaulting to Science, and the Interventionist Mindset of Law*, 53 OHIO ST. L.J. 1205, 1236-40 (1992) (discussing physicians' attempts to override pregnant mothers' objections to new experimental fetal therapies when the physicians disagree with the mothers' choices). Feminists argue that this view of the maternal-fetal relationship undercuts women's autonomy during pregnancy. *Id.* at 1294-95 (suggesting that, once one rejects the assumption that fetal interests should trump those of the pregnant mother, one is left with a strong presumption that the mother's autonomy interests are too important to override).

access to health care. Rather, I am assuming that the health care provider has voluntarily undertaken the care of a woman who is infected with HIV and that the provider is trained and experienced in obstetrics and gynecology. The primary questions I address are the extent to which the ADA prohibits health care providers from controlling, through directive counseling or by refusing to provide abortion or infertility services, the procreational choices of women with disabilities and specifically women with HIV.

II. History of Discrimination

A. Low-Income Women and Women of Color

Historically, women in the United States have had little control over their ability to procreate.[38] Effective contraception was unavailable until the twentieth century.[39] Some states even criminalized contraceptive use and counseling until the early 1970s.[40] However, with the introduction of the birth control pill in the late 1960s and the recognition in 1973 of a right to privacy encompassing the decision to have an abortion,[41] women in this country began to have real control in reproductive matters. Nevertheless, certain groups of women traditionally have had less control over reproductive decision making than others. For example, there is a well-documented history of sterilization abuse directed against women of color in the United States.[42] Federal and state governments were active participants in this abuse. In fact, the last widely reported case of government-supported involuntary sterilization occurred in the early 1970s

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38. *See* Ikemoto, *supra* note 37, at 1222-25 (1992) (discussing historical and legislative restrictions on a woman's decision to reproduce).

39. *See* JAMES REED, FROM PRIVATE VICE TO PUBLIC VIRTUE: THE BIRTH CONTROL MOVEMENT AND AMERICAN SOCIETY SINCE 1830 5-6 (1978) (noting that effective contraceptive regimens were not available during the nineteenth century).

40. For example, the U.S. Supreme Court struck down a state law that prohibited the distribution of contraceptives to married couples. Griswold v. Conn., 381 U.S. 479 (1965). The Court subsequently struck down a similar provision that applied only to single persons. Eisenstadt v. Baird, 405 U.S. 438 (1972).

41. Roe v. Wade, 410 U.S. 113 (1973).

42. *See* BETSY HARTMANN, REPRODUCTIVE RIGHTS AND WRONGS 240 (1987) (noting that poor women and women of color are often given hysterectomies that are unnecessary, even though a hysterectomy is a much more dangerous form of sterilization than is a tubal ligation). It also should be noted that "[t]he United States has played a major role in the introduction of sterilization into Third World family planning." *Id.* at 230. "The U.S. Agency for International Development (AID) funds the Program for International Education in Gynecology and Obstetrics, which brings foreign medical personnel to the United States to learn sterilization techniques, and the greater part of the Association for Voluntary Sterilization's (AVS) international program budget of about $10 million." *Id.* The initial concern of AVS was population control, and the organization was formerly linked with the eugenics movement. *Id.*

and involved two African-American sisters, Minnie Lee and Mary Alice Relf, fourteen and twelve years old, who were sterilized using Federal funds designed to help eliminate poverty.[43] Much has been written about the Relf sisters, other women of color subjected to involuntary sterilizations, and the federal regulations promulgated after their involuntary sterilizations were exposed.[44]

Government-sanctioned sterilization abuse of women of color continues today despite federal regulations requiring informed consent and a waiting period.[45] Even if these restrictions were effective in preventing overt abuse of sterilization,[46] the fact remains that "[c]lassism and racism lead physicians and other health care providers to urge sterilization on patients they believe incapable of using other methods effectively."[47]

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43. Relf v. Weinberger, 372 F. Supp. 1196 (D.D.C. 1974). The court in this case acknowledged that the Relf sisters' experience was not unusual and that there was "uncontroverted evidence in the record that . . . an indefinite number of poor people have been improperly coerced into accepting a sterilization operation under the threat that various federally supported welfare benefits would be withdrawn unless they submitted to irreversible sterilization." *Id.* at 1199.

44. *See* DANIEL J. KEVLES, IN THE NAME OF EUGENICS: GENETICS AND THE USES OF HUMAN HEREDITY 275-76 (1985) (highlighting the Relf sisters' case and describing how the subsequent requirement of informed consent was ignored as it concerned minority women); Andrea Asaro, *The Judicial Portrayal of the Physician in Abortion and Sterilization Decisions: The Use and Abuse of Medical Discretion*, 6 HARV. WOMEN'S L.J. 51, 93-101 (1983) (discussing the abuse of medical discretion in the sterilization of women); Adele Clarke, *Subtle Forms of Sterilization Abuse: A Reproductive Rights Analysis*, *in* TEST-TUBE WOMEN: WHAT FUTURE FOR MOTHERHOOD 188, 191-202 (Rita Arditti et al. eds., 1984) (discussing both blatant and more subtle types of sterilization abuse and their effects on poor women and women of color); Laurie Nsiah-Jefferson, *Reproductive Laws, Women of Color, and Low-Income Women*, *in* REPRODUCTIVE LAWS FOR THE 1990S 23, 45-49 (Sherrill Cohen & Nadine Taub eds., 1989) (noting that, although regulations to prevent unwarranted sterilizations were adopted in the 1970s, there has been no evaluation of the effectiveness of these regulations or the extent to which they have been followed); Dick Grosboll, Note, *Sterilization Abuse: Current State of the Law and Remedies for Abuse*, 10 GOLDEN GATE U. WOMEN'S L.F. 1147, 1153-56 (1980) (identifying cases in which poor women and women of color have utilized the legal system after being coerced into sterilization).

45. 42 C.F.R. §§ 441.250-441.259 (1992); 42 C.F.R. §§ 50.201-50.210 (1992). Federal regulations require that an individual give informed consent in writing before sterilization. 42 C.F.R. § 50.203(c). The individual must be fully informed of all possible risks, benefits, and alternatives, and also must be afforded the opportunity to have all her questions regarding the sterilization answered. 42 C.F.R. § 50.204. Federal regulations also mandate a waiting period of 30 to 180 days before the sterilization procedure is performed. 42 C.F.R. § 50.203(d); *see* Clarke, *supra* note 44, at 192-202 (describing some of the more common types of subtle sterilization abuse that currently occur).

46. The informed consent and waiting period restrictions are not very effective because there are no criminal or civil sanctions imposed when they are violated. The only adverse consequence of violating these regulations is loss of reimbursement for the sterilization. *See* 42 C.F.R. § 441.256(a) (1992) (requiring documentation of informed consent before receiving reimbursement from Medicaid); 42 C.F.R. § 50.209 (1992) (requiring the use of a specific informed consent form as a condition of funding).

47. Nsiah-Jefferson, *supra* note 44, at 47 (explaining that, for various reasons, poor women and women of color are more likely to be coerced into sterilization procedures).

This type of thinking may explain why government-financed sterilization is readily available while abortion is not:[48] sterilization has a permanence that abortion does not.[49] Some might even argue that sterilization of poor and minority women is more cost-efficient than abortion because it is done once, whereas abortion may be used repeatedly.

There is also a disturbing trend among medical authorities toward seeking court-ordered obstetrical intervention to force women, most of whom are women of color with low incomes, to have cesarean sections and intrauterine transfusions.[50] In addition, state courts have occasionally ordered pregnant women who abused illicit drugs or alcohol, or who were charged with child abuse or neglect, to use contraceptives.[51] The states

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48. *See id.* (noting that states that provide sterilization services through Medicaid programs are reimbursed for 90% of the costs, but that many states do not provide abortion services through Medicaid programs, and those that do will not be reimbursed by the federal government following the enactment of the Hyde Amendment); *see also* Barbara Brotman, *The Abortion Maze: Crazy Quilt of Laws Among States Likely to Get Even Worse*, CHI. TRIB., Jan. 14, 1990, at Perspective 1 (noting that thirty-seven states have passed laws forbidding the use of Medicaid funds for abortion in almost all circumstances since 1977). The unavailability of less costly and more temporary means of contraception may explain why African-American women currently have a higher abortion rate than white women. *See* Gina Kolata, *Studies Find Abortion is Common in All Race and Economic Groups*, N.Y. TIMES, Oct. 6, 1988, at B18 (noting that young, poor, African-American, unmarried women are most likely to have abortions). It seems that governmental policy in the United States increasingly tends to encourage some groups of women to permanently forego pregnancy. *See* Susan Sangree, *Control of Childbearing by HIV-Positive Women: Some Responses to Emerging Legal Policies*, 41 BUFF. L. REV. 309, 323-26 (1993) (discussing post-eugenics, government-sanctioned reproductive coercion). Another example of state governments' desire to restrict the reproductive choices of some women is the willingness of state governments to pay for the surgical implantation of Norplant into poor women, who are predominantly women of color. *See id.* at 333 n.89 (discussing proposed state legislation and policies).

49. In contrast, some women may see abortion as a better alternative than permanent sterilization because abortion does not permanently foreclose a woman's ability to become pregnant, whereas sterilization does. Thus, the choice of abortion over government-financed sterilization suggests that many African-American women are not ready to permanently forego their procreational choice.

50. *See* Kolder et al., *supra* note 37, at 1195 (analyzing the results of a study that found that pregnant women who were poor or who were women of color were more likely to be subjected to a court-ordered procedure in cases where they refused medical aid to the fetus). The study found that 81% of the women subjected to court-ordered obstetrical interventions were women of color, 44% were unmarried, and none were private patients. *Id.* at 1195. Other studies have made similar findings. *See* Nsiah-Jefferson, *supra* note 44, at 63 n.80 (reporting that women of color had the highest rates of cesarean sections). For a discussion and critique of this policy, *see generally* Janet Gallagher, *Fetus As Patient*, *in* REPRODUCTIVE LAWS FOR THE 1990S, *supra* note 44, at 185, 204-08 (pointing out that the burden of proof for court-ordered cesarean sections is much lower than is required for other court-ordered medical treatments).

51. For example, Darlene Johnson, a 27 year-old pregnant African-American woman was convicted of child abuse for beating two of her four children with an electrical cord after she found them engaging in potentially harmful activities. Johnson v. Cal., No. 29390 (Cal. App. Dep't Super. Ct. plea entered Dec. 3, 1990). The state judge gave her the option of spending one year in prison and three years on probation or four months in prison and three years on probation if she agreed to use the contraceptive Norplant for three years. Matthew Rees, *Shot in the Arm: The Use*

are divided over the constitutionality of such measures.[52] At least one commentator suggests that courts increasingly are adopting a "code of perfect pregnancy" that represents an ideology of motherhood, which implicitly excludes certain women, and in doing so tend to "default" to medical science in matters involving reproductive decision making by women.[53] This ideology of motherhood excludes poor women and women of color.[54] The practice of exclusion is often subtle. The biased decision making of health care providers regarding the sterilization of poor women and women of color is one example. These so-called medically based decisions, which are reinforced by the courts, are a particularly pernicious form of this practice.

B. Women With Disabilities

Americans assume that disabled women of reproductive age will not become mothers.[55] Although a few women are disabled in ways that limit their reproductive choices, the choices of most disabled women are restricted for nonmedical reasons. These "women encounter substantial

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and Abuse of Norplant, NEW REPUBLIC, Dec. 9, 1991, at 16. In 1991, the state of Kansas introduced legislation that would require the implantation of Norplant in fertile women convicted of felony possession and distribution of certain illegal drugs. *See id.* (describing legislative efforts in Kansas and other states). For criticism of this practice by the courts, *see generally* Dorothy E. Roberts, *Punishing Drug Addicts Who Have Babies: Women of Color, Equality, and the Right of Privacy*, 104 HARV. L. REV. 1419 (1991) (arguing against the prosecution of drug-addicted mothers and advocating governmental policies that recognize a woman's autonomy in reproductive decisions).

52. *See* Sangree, *supra* note 48, at 311-12 n.6 (discussing several cases involving court-ordered contraception which were invalidated because the court order was not reasonably related to the goal of rehabilitation).

53. *See* Ikemoto, *supra* note 37, at 1216-21, 1287-95 (describing the historical view that certain types of women, such as prostitutes, were unfit for motherhood and discussing the extent to which medical technology now allows the fetus to be treated as a separate patient by the doctor).

54. *See id.* at 1231-33 (noting that poor women of color are much more likely to be sterilized because many regard "excessive childbearing" by these women as undesirable and arguing that the "ideal for motherhood" is constructed along race and class lines).

55. Adrienne Asch, *Reproductive Technology and Disability*, *in* REPRODUCTIVE LAWS FOR THE 1990S, *supra* note 44, at 69, 79; *see also* Donna Hyler, *To Choose a Child*, *in* WITH THE POWER OF EACH BREATH 280, 281-82 (Susan E. Browne et al. eds., 1985) (recounting the negative reactions to the pregnancy of a woman with arthritis); JoAnn Le Maistre, *Parenting*, *in* WITH THE POWER OF EACH BREATH 284, 285 (Susan E. Browne et al. eds., 1985) ("Parenthood is the hardest job anyone will ever have. Yet, the physically limited parent may be the only parent . . . toward whom the community directs its anxiety about the difficulty of the job."); Susan Shaul et al., *Like Other Women: Perspectives of Mothers with Physical Disabilities*, *in* WOMEN AND DISABILITY: THE DOUBLE HANDICAP 133, 133-42 (Mary Jo Deegan & Nancy A. Brooks eds., 1985) (discussing societal resistance to viewing women with disabilities as potential parents). *See generally* CHILDREN OF HANDICAPPED PARENTS (S. Kenneth Thurman ed., 1985) (describing the presumption against disabled parents' fitness to rear children).

legal, medical, and familial resistance to their choice of motherhood."[56] Recent studies suggest that approximately two-thirds of all Americans view a woman's physical disability as an acceptable reason for her to have an abortion.[57] This value-laden judgment about the propriety of women with disabilities bearing children also applies to able-bodied women who may give birth to children with disabilities. In fact, "implicit in many reproductive technologies, and explicit in some, is the goal of preventing future disability."[58] There is subtle and even overt pressure on users of prenatal diagnosis to abort after detection of a disability.[59]

For example, several years ago Bree Walker Lampley, a successful and attractive television anchor in Kansas City, was the subject of a heated radio talk show program during which the show's host and callers discussed whether the then pregnant Ms. Lampley should have become pregnant since she has a rare genetic anomaly that she could have passed on to her child. Ms. Lampley has ectrodactylism, a condition that causes the hands and toes to be partially fused and to appear webbed. There was a fifty percent chance that Ms. Lampley's child would inherit the anomaly, and the host asked her listeners whether they thought it was fair to pass along a genetically disfiguring disease to one's child. Callers expressed extreme hostility towards Ms. Lampley and stated that they would prefer not being alive to having a disease like ectrodactylism. One caller who had partial color blindness remarked that it would have been "'hell' if he had passed on his disability" to his child.[60] This reaction demonstrates the public view that a disability of either the mother or her potential offspring forecloses the possibility of procreation. The reaction is even stronger for women of color, given the history of antagonism toward their bearing even able-bodied children.

C. Federal Constitutional Protection

The U.S. Constitution provides little protection for the reproductive decisions of poor women, women of color, and women with disabilities. The U.S. Supreme Court has addressed the right to procreate in only two cases. In the first case, *Buck v. Bell*, the Court upheld the constitutionality

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56. Asch, *supra* note 55, at 79.

57. *See* Mary Ann Lamanna, *Social Science and Ethical Issues: The Policy Implications of Poll Data on Abortion, in* ABORTION: UNDERSTANDING DIFFERENCES 1, 5 (Sidney Callahan & Daniel Callahan eds., 1984) (reporting the results of a survey that found that 64% of the respondents did not view abortion as morally wrong in situations where the mother was physically handicapped).

58. Asch, *supra* note 55, at 81.

59. *Id.*

60. Jay Mathews, *The Debate Over Her Baby: Bree Walker Lampley Has a Deformity. Some People Think She Shouldn't Have Kids*, WASH. POST, Oct. 20, 1991, at F1.

of a Virginia sterilization statute designed to prevent reproduction by institutionalized "mentally defective people," ruling that the state statute did not violate the substantive due process requirements of the Fourteenth Amendment.[61] In the second case, *Skinner v. Oklahoma*, the Supreme Court relied on equal protection analysis to distinguish, rather than overrule, *Buck* in striking down an Oklahoma statute authorizing the sterilization of habitual criminals.[62] The Court indicated that procreational decision making is fundamental and noted that courts should scrutinize state-initiated compulsory sterilization classifications strictly.[63] Although the Court did recognize the importance of procreational decision making, it did not hold that the right to procreate is *per se* a fundamental constitutional right worthy of absolute protection.[64] The Court did not elaborate on this point, but one can read *Skinner* to suggest that states can authorize involuntary sterilization of habitual criminals provided they can justify any discrepancies in treatment between different classes of criminals. Since *Skinner* does not prohibit all state-authorized involuntary sterilizations, it is conceivable that HIV-infected women may be targeted for involuntary sterilization in certain circumstances.

The most recent discussions by the Supreme Court concerning the right to procreate occurred in the abortion cases, beginning with *Roe v. Wade*[65] and ending with *Planned Parenthood of Southeastern*

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61. Buck v. Bell, 274 U.S. 200 (1927).

62. The Court argued that, while *Buck* relied on the fact that all within the same class would be treated equally, *Skinner* involved a situation where "the law lays an unequal hand on those who have committed intrinsically the same quality of offense . . . [and thus] has made as invidious a discrimination as if it had selected a particular race or nationality for oppressive treatment." Skinner v. Okla., 316 U.S. 535, 540-41 (1942).

63. *Id.* at 541 ("We are dealing here with legislation which involves one of the basic civil rights of man. Marriage and procreation are fundamental to the very existence and survival of the race.").

64. *Id.* Ultimately, the Court abandoned the fundamental rights analysis it used in *Skinner* in a string of contraceptive cases involving state intrusions on procreative choices. In *Griswold v. Connecticut*, the Court struck down a state law criminalizing contraceptive use and counseling, relying on a "zone of privacy," derived from various amendments to the Constitution, which encompasses the marital relationship. 381 U.S. 479, 484-85 (1965). In *Eisenstadt v. Baird*, the Court extended this protection from state interference in procreational matters to single persons when it struck down a statute that criminalized the distribution of contraceptives to single people but allowed distribution to married persons. 405 U.S. 438 (1972). In *Eisenstadt*, however, the Court refused to base its holding on a fundamental rights theory and relied instead on an even more ambiguous privacy guarantee, which it held applied to individuals as well as to married couples as a matter of equal protection. *Id.* at 453 (declining to state the scope of the privacy guarantee but noting that "whatever the rights of the individual to access to contraceptives may be, the rights must be the same for the unmarried and the married alike").

65. 410 U.S. 113 (1973). In *Roe*, the Court held that the state's interest in protecting the health of the mother or the life of the fetus cannot prohibit a woman's access to abortion during the first trimester of pregnancy. *Id.* at 164. Although the Court extended the right to privacy to encompass a woman's decision to terminate a pregnancy in many circumstances, it nonetheless cited *Buck* to support the claim that the right of privacy does not allow an individual "an unlimited right to do with

Pennsylvania v. Casey.[66] In *Casey*, the Court reexamined the source of the right to an abortion. A plurality of the Court reaffirmed the essential holding of *Roe* that a woman has a right to have an abortion before viability without "undue interference from the State."[67] The plurality acknowledged that the liberty guarantee of the Fourteenth Amendment Due Process Clause encompasses areas of personal liberty, including decisions relating to procreation.[68] The state has only a limited right to interfere in these areas and can justify interference only where there is an "important and legitimate interest in protecting the potentiality of human life."[69] The plurality in *Casey* also suggested, however, that the right to procreate carries with it an obligation to be responsible in making procreational decisions and asserted that it is this aspect of the right which the Court attempted to protect in *Roe*.[70] Thus, the right to procreate as

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one's body as one pleases . . . ." *Id.* at 154. Nevertheless, the Court indicated that state regulations limiting this right to bodily autonomy must be based on compelling interests and, while compelling, must nonetheless be narrowly drawn. *Id.* at 155.

66. 112 S. Ct. 2791 (1992).

67. *Id.* at 2804.

68. *See id.* at 2807 (citing a number of cases, including Carey v. Population Servs. Int'l, 431 U.S. 678, 685 (1977) and Eisenstadt v. Baird, 405 U.S. 438, 453 (1972)).

69. *Id.* at 2817 (quoting Roe v. Wade, 410 U.S. 113, 162 (1973)).

70. The Court makes this point eloquently in *Casey*: "[These Supreme Court decisions] support the reasoning in *Roe* relating to the woman's liberty because they involve personal decisions concerning not only the meaning of procreation but also *human responsibility and respect for it*." 112 S. Ct. at 2807 (emphasis added) (discussing *Griswold v. Connecticut*, *Eisenstadt v. Baird*, and *Carey v. Population Servs. Int'l*). Although some people believe that each pregnancy is so wonderful that it should be continued regardless of any difficulties posed in caring for a child, the Court noted that others argue that "the inability to provide for the nurture and care of the infant is a cruelty to the child and an anguish to the parent." *Id.* at 2808.

Although *Casey* may have clarified certain issues surrounding the extent to which the government may restrict women's access to abortion, it does not squarely address whether the government may direct or coerce women not to bear children. In *Casey*, however, the plurality justifies retaining the *Roe* rationale as necessary to protect both a woman's right to an abortion and her "interest in deciding whether to bear and beget a child . . . ." *Id.* at 2811. The plurality also suggests that, even if the Court overrules *Roe*, the cases relying on *Roe* that involve governmental restrictions on the right to bear children would remain sound because the facts of *Roe* confine its scope. *See id.* (discussing why errors in *Roe* would not seriously affect other types of cases involving reproductive issues). In other words, *Roe* involves a woman's choice concerning "post-conception potential life," whereas forced abortion or sterilization cases involve situations where the government is sanctioning the destruction of potential life. *Id.* Even some of the dissenting justices in *Casey* seem to agree with this distinction. For example, Chief Justice Rehnquist distinguishes marriage, procreation, and contraception from abortion because the latter "'involves the purposeful termination of [a] potential life.'" *Id.* at 2859 (Rehnquist, C.J., dissenting) (quoting Harris v. McRae, 448 U.S. 297, 325 (1980)). Justice Scalia, also a dissenter in *Casey*, indicates that there is a liberty interest in childbirth protected by the Constitution. *Id.* at 2874 n.1 (Scalia, J., dissenting).

The plurality cites two lower court cases where governmental agencies tried to prohibit minor women from bearing children to support the proposition that *Roe* has been relied upon to prevent the state from forcing women to terminate pregnancies or to undergo sterilization. *Id.* at 2811. In

protected by *Roe* arguably only extends to individuals who exercise it "responsibly"—the problem, of course, is with who is defining "responsibly" and how it is defined.

Other Supreme Court decisions focus on regulation of contraceptives designed to prevent pregnancy rather than terminate it,[71] but most of these cases are linked to other so-called fundamental rights such as the right to marry[72] or rear children.[73] Even in *Skinner*, the involuntary sterilization case, the Court characterized the right to procreate as an important component of the marital relationship.[74] As a result, the parameters of any constitutional right to procreate are not entirely clear.[75]

III. Implications for HIV-Infected Women

In light of the continued acceptance of controls on the reproductive choices of low-income women, women of color, and women with disabilities, and in light of the ambiguous scope of the constitutional right to procreate, it is not surprising that some government agencies and medical associations recommend that health care providers direct women infected with HIV not to bear children or to consider abortion if they are already pregnant. It also is not surprising that many other people in this

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Arnold v. Board of Education of Escambia County, Alabama, a federal appellate court used the *Roe* rationale to conclude that a state government would violate the Constitution if it coerced a minor woman to have an abortion. 880 F.2d 305, 311 (11th Cir. 1989). In *Avery v. County of Burke*, a federal appellate court also relied on *Roe* in holding that a county agency would violate the Constitution if it induced a minor woman to undergo an unwanted sterilization by misrepresenting that she had the sickle cell trait. 660 F.2d 111, 115 (4th Cir. 1981). The dicta in *Casey* suggest that some members of the current U.S. Supreme Court would closely scrutinize governmental efforts aimed at influencing women to obtain unwanted abortions or sterilizations, at least where minor women are involved. Planned Parenthood v. Casey, 112 S. Ct. at 2811.

71. *See* Griswold v. Conn., 381 U.S. at 485 (overturning a law that banned the use of contraceptives because such a ban would have its "maximum destructive impact" on the relationship of the husband and wife, "a relationship lying within the zone of privacy created by several fundamental constitutional guarantees"); Carey v. Population Servs. Int'l, 431 U.S. at 708 (Powell, J., concurring) (agreeing that a New York statute that prohibited the sale of contraceptives to minors was unconstitutional because it interfered with the well-established interest of parents to rear their children).

72. Loving v. Virginia, 388 U.S. 1 (1967) (holding that marriage is a fundamental right protected by the Due Process Clause).

73. *See* Stanley v. Illinois, 405 U.S. 645 (1972) (holding that the Due Process Clause requires that a court hold a hearing before the state takes custody to determine the father's fitness to rear children in a case where the parents were never married).

74. 316 U.S. at 541; *see supra* note 63 and accompanying text.

75. *See generally* John A. Robertson, *Procreative Liberty and the Control of Conception, Pregnancy and Childbirth*, 69 VA. L. REV. 405, 415-20 (1983) (analyzing doctrinal and ethical arguments for a right to procreate); Elizabeth S. Scott, *Sterilization of Mentally Retarded Persons: Reproductive Rights and Family Privacy*, 1986 DUKE L.J. 806, 826-40 (providing an overview of the right to procreate, with a special focus on its application to mentally retarded persons).

country seem to believe that no woman infected with HIV should bear children.[76] This attitude constitutes an impermissible wholesale categorization of certain women (women with HIV) as presumptively unfit to bear children—an approach also applied generally to persons with disabilities.

In this section, I discuss three measures that health care providers and others may use to discourage women with HIV from bearing children: involuntary sterilization, directive counseling not to procreate, and medical interventions during pregnancy. These are just some of the measures that can be used to prevent women with HIV from bearing children. Other measures that are cloaked in the rhetoric of clinical judgment may be more subtle.[77]

A. Involuntary Sterilization

Historically, state and private health care providers have used involuntary sterilization to prevent poor women, women of color, and women with disabilities from bearing children.[78] Therefore, it is not farfetched to speculate that some people may push for the involuntary sterilization of some HIV-infected women.[79] Involuntary sterilization persists today, in spite of the limitations imposed by the Supreme Court's decision in *Skinner*.[80] Many state statutes authorize the involuntary

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76. For a discussion of this point, *see* Bayer, *supra* note 30, at 194-200 (naming lawyers, philosophers, and eugenicists as among the proponents of discouraging or prohibiting reproduction in HIV-positive women).

77. *See infra* Part IV.

78. *See supra* Part II.

79. Calls for involuntary or coerced sterilization appear periodically in contemporary society. For example, in the 1950s and 1960s some states "proposed laws which required sterilization of unwed welfare mothers with more than two or three children because they were not 'fit to parent.'" Sangree, *supra* note 48, at 323. Similar measures also were proposed in the early 1970s but were rejected. *Id.* During the 1970s, sickle cell trait was used to justify the sterilizations of African-American women. *Id.* at 324. Mexican-American women often gave "consent" to sterilization while in labor as a condition to receiving prenatal treatment or having a baby delivered. *Id.* at 325. Even more recently, proposed uses for Norplant, a chemical contraceptive that temporarily "sterilizes" women for up to five years, mirror the proposals of the 1950s, 1960s, and 1970s. *See, e.g., Poverty and Norplant: Can Contraception Reduce the Underclass?*, PHILADELPHIA INQUIRER, Dec. 12, 1990, at A18 (arguing that Norplant should be free to any woman on welfare and that financial incentives should be given to encourage women to use it so that the "cycle of inner city poverty" could be broken).

Already some commentators suggest that coerced abortions and compulsory sterilization may be necessary as the number of HIV-infected women increases. *See, e.g.*, Robert Edelman & Harry W. Haverkos, *Reply to Letter to the Editor*, 261 JAMA 993, 993 (1989) (noting that, although the writers opposed restricting the procreational autonomy of women infected with HIV, they predicted that "as the pandemic widens and deepens in our society, increasingly powerful voices will be heard calling for such state-imposed restrictions").

80. *See supra* notes 62-64 and accompanying text.

sterilization of mentally impaired individuals and are invoked disproportionately against women.[81] Although the Supreme Court has not ruled directly on these statutes, the Court continues to cite *Buck v. Bell* with approval when discussing reproductive issues.[82] Thus, there is no general indication that any challenge to these statutes would be successful.

In the absence of specific enabling legislation, the lower courts are divided over the validity of involuntary sterilization. Some courts permit court-ordered sterilization, relying on some form of the *parens patriae* doctrine for authority.[83] Other courts acknowledge that a fundamental right is involved, but they ignore the analytical implications and permit involuntary sterilization nonetheless.[84] Most courts, however, deny

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81. Approximately fourteen states have statutes authorizing involuntary sterilization of persons with mental impairments who are deemed incapable of consent. Roberta Cepko, *Involuntary Sterilization of Mentally Disabled Women*, 8 BERKELEY WOMEN'S L.J. 122, 145-56 (1993); George P. Smith, *Limitations on Reproductive Autonomy for the Mentally Handicapped*, 4 J. CONTEMP. HEALTH L. & POL'Y 71, 77 n.35 (1988).

82. *See* Roe v. Wade, 410 U.S. 113, 154 (1973) (explaining that the Supreme Court has never recognized an unlimited right to privacy, as demonstrated by *Buck v. Bell*, and, thus, abortion rights must be considered against state interests in regulation). Lower courts also cite *Buck v. Bell* to justify the sterilization of mentally impaired individuals. *See, e.g., In re* Moore, 221 S.E.2d 307, 309 (N.C. 1976) (asserting that *Buck* allows for the sterilization of the "feebleminded" inmates in state institutions).

83. *See, e.g., In re* P.S., 452 N.E.2d 969, 976 (Ind. 1983) (rejecting the idea that the courts cannot decide to involuntarily sterilize incompetents without express legislative authority); *In re* Matejski, 419 N.W.2d 576, 578-80 (Iowa 1988) (noting that the district court has, within its equity powers, the ability to decide to involuntarily sterilize an incompetent person); *In re* Moe, 432 N.E.2d 712, 718-19 (Mass. 1982) (explaining that it is within the court's powers to act in the best interests of an incompetent person, since such persons deserve a forum in which to exercise their constitutional rights); *In re* Hayes, 608 P.2d 635, 638 (Wash. 1980) (determining that the courts have inherent power to decide to order the sterilization of mentally incompetent people, just as it has such authority to protect the interests of infants). Under the *parens patriae* doctrine, courts have the "inherent power to protect those within the state who cannot protect themselves because of a legal disability." *In re* Terwilliger, 450 A.2d 1376, 1381 (Pa. Super. Ct. 1982). In other words, the state stands in the shoes of the parent on behalf of those individuals with some legal disability that prevents them from acting in their own behalf. *See In re* C.D.M., 627 P.2d 607, 612 (Alaska 1981) (asserting the plenary jurisdiction to authorize sterilization and invoking *parens patriae* in support of the court's obligation to protect "incompetents"); Wentzel v. Montgomery Gen. Hosp., Inc., 447 A.2d 1244, 1253 (Md. 1982) (noting that courts of equity must have plenary jurisdiction over disabled persons in order to afford the necessary relief to protect the interests of such individuals); *In re* Grady, 426 A.2d 467, 481 (N.J. 1981) (relying exclusively on the *parens patriae* doctrine); *In re* Sallmaier, 378 N.Y.S.2d 989, 991 (Sup. Ct. 1976) (noting that the common law allows the courts to act as *parens patriae* with respect to incompetents); *see also* Cepko, *supra* note 81, at 158 (describing how various jurisdictions use the *parens patriae* doctrine to order sterilizations of incompetents).

84. *See, e.g.*, Ruby v. Massey, 542 F. Supp. 361, 369 (D. Conn. 1973) (analogizing sterilization to abortion and acknowledging that sterilization affects a woman's ability to procreate, but then abandoning the fundamental rights analysis by holding that a mentally incompetent minor woman's "rights" would be violated if the court-ordered sterilization was denied); *see also* Cepko, *supra* note 81, at 159 (explaining that both federal and state courts tend to interpret statutes in ways

petitions for involuntary sterilization of mentally disabled individuals in the absence of some statutory authorization.[85]

Most of the modern involuntary sterilization cases involve women who lack the legal capacity to consent to sterilization.[86] In these cases, the judgment of someone else is substituted for that of the woman, and that person controls the sterilization decision. Arguably, these cases are distinguishable from most cases involving women infected with HIV. There may be a few HIV-infected women who suffer some preexisting disability affecting their legal capacity, or who, as a result of HIV, are so neurologically impaired as to lack legal capacity. These cases would be most analogous to the current involuntary sterilization cases but would be relatively rare.

Although involuntary sterilization laws have their roots in the eugenics movement of the 1920s,[87] several other reasons are given to justify the involuntary sterilization of disabled women today. For example, in several cases, petitioners for involuntary sterilization of developmentally disabled women argued that mentally impaired individuals are incapable of adequate parenting and, therefore, that their offspring will become a financial burden on the state.[88] A number of courts reject the financial-burden

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that expand their power to authorize involuntary sterilization).

85. Most of these cases, however, were decided before *Stump v. Sparkman*, in which the Supreme Court held that a judge who authorized the sterilization of a "somewhat retarded" minor in a state without an enabling statute was immune from suit. 435 U.S. 349 (1978). Although the Court never addressed the specific issue of whether a judge legally could authorize involuntary sterilization in the absence of any state law, post-*Stump* decisions often cite the case for that principle. *See, e.g., In re* C.D.M., 627 P.2d at 611 (stating that a state superior court has the jurisdiction to make sterilization decisions because no state statute or case law specifically prevents it); *In re* Terwilliger, 450 A.2d at 1379-80 (noting that an orphans' court has jurisdiction to rule on the sterilization of a mentally disabled woman because *Stump* held that courts have jurisdiction to rule unless case law or statutes prohibit it).

86. *See infra* note 88 and accompanying text. In these cases, the court grants a petition by a parent or guardian to sterilize a person who has not consented to the procedure, usually after a hearing. *See id.* These cases should be distinguished from cases of coerced sterilization.

87. *See generally* PHILIP R. REILLY, THE SURGICAL SOLUTION: A HISTORY OF INVOLUNTARY STERILIZATION IN THE UNITED STATES (1991) (discussing the origin of the eugenics movement in the United States and the involuntary sterilization laws that were produced largely as a result of the movement). Reilly describes two waves of sterilization laws. State legislatures enacted a number of sterilization laws between 1909 and 1913. *Id.* at 71. These laws were directed primarily at prisoners, feeble-minded persons, and the insane. *Id.* at 41. The courts struck down many of these laws as cruel and unusual punishment or as violative of the Due Process Clause or the Equal Protection Clause. *Id.* at 50-55. The second wave of the eugenics sterilization laws began after 1922, fueled largely by concerns about the large increase in immigration and the move of African Americans to the North. *Id.* at 71-72.

88. *See, e.g.*, Guardianship of Kemp, 118 Cal. Rptr. 64, 65 (Ct. App. 1974) (reversing a lower court order that granted the involuntary sterilization petition of the parents of a developmentally disabled adult woman, claiming financial burden to both them and the general public); Wentzel v. Montgomery Gen. Hosp., Inc., 447 A.2d 1244, 1247-48, 1254 (Md. 1982) (refusing to order a

justification, reasoning that the issue in each case is the best interest of the woman and not the welfare of society,[89] but a few courts accept this justification.[90] In fact, two states by statute expressly authorize involuntary sterilization based on the ground of benefit to society.[91]

The benefit-to-society line of argument is actually a manifestation of long-standing societal hostility towards disfavored groups:

> This "societal concern" over preventing the birth of children to poor incompetent women indicates that the sentiment expressed by Justice Holmes in *Buck* that society benefits from sterilizing those who "sap the strength of the State" retains popularity. Indeed, the culture remains preoccupied with coercing poor women, incompetent or not, from reproducing . . . . In the sterilization context, "inability to care for children" refers to more than the resources necessary to actually care for children. . . . The implication is that "inability to care for children" are code words that justify societal control of mentally disabled women's reproduction.[92]

This same concern applies to another class of women with disabilities, women infected with HIV, and the financial-burden justification is implicit in arguments advanced today to justify discouraging HIV-infected women from bearing children.[93] Since existing case law at both the federal and state levels does not clearly support or refute the financial-burden rationale, it is important that federal antidiscrimination laws aimed at protecting

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sterilization procedure for a retarded 13-year-old girl and rejecting *inter alia* the guardian's argument that the girl's child will place a financial burden on the state); *In re* Simpson, 180 N.E.2d 206, 208 (Ohio P. Ct. 1962) (ordering the sterilization of a developmentally disabled woman, who had one child already for whom she could not provide adequate care, and justifying the ruling on the ground that further pregnancies would create additional burdens on the county and state welfare departments); Frazier v. Levi, 440 S.W.2d 393, 394-95 (Tex. Civ. App. 1969) (rejecting a mother's petition requesting the sterilization of her mentally incompetent daughter in which the mother asserted that she could not afford to care for any more of her daughter's children).

89. Wentzel v. Gen. Hosp., 447 A.2d at 1254 (allowing court-ordered sterilization of incompetent minors when it is in the best interest of the child as determined through specified procedures); *In re* Grady, 426 A.2d 467, 481 n.8 (N.J. 1981) (authorizing the sterilization of incompetent persons when it is found to be in their best interest).

90. *See, e.g.*, North Carolina Ass'n for Retarded Children v. North Carolina, 420 F. Supp. 451, 457-58 (M.D.N.C. 1976) (upholding a statute allowing sterilization of mentally defective persons when it is determined to be in the best interests of the general public); *In re* Simpson, 180 N.E.2d at 208 (accepting the argument that additional children would impose a burden on the welfare department in authorizing a developmentally disabled woman's sterilization).

91. *See* MISS. CODE ANN. § 41-45-1 (1993) (allowing sterilization if the procedure is in the best interest of the state and the patient); N.C. GEN. STAT. §§ 35-36 to 35-50 (1992) (permitting the sterilization of a mentally retarded individual if it is in the best interest of the individual or if the interests of society would be furthered by the sterilization).

92. Cepko, *supra* note 81, at 161-62.

93. *See, e.g., Doe v. Jamaica Hospital*, *supra* note 4, at 27 (involving an HIV-infected woman who was told by a health care provider that abortion was the best alternative because a baby with AIDS "would suffer and become a burden on society").

individuals with disabilities clarify this issue.

A second argument asserted to justify the involuntary sterilization of mentally impaired individuals is the need to prevent the birth of children with physical and/or mental defects. Admittedly, there is a real possibility that some children of women with HIV will be born infected with the virus.[94] Those people who express concern about the quality of life of a disabled infant argue that living with a disability is too great a burden to impose on a person.[95] This value-laden conclusion, however, denigrates the personal worth of people with disabilities and runs counter to the objectives of the ADA.[96] Moreover, similar arguments have been made unsuccessfully in tort actions for wrongful life.[97] Although a policy to limit the birth of children with disabilities would seem to be an impermissible basis for restricting procreational autonomy, the ADA does not squarely address this issue.

Other than the societal antagonism toward individuals with disabilities, the quality-of-life argument in support of discouraging the birth of infants with disabilities may be a disguised variant of the financial-burden argument. Individuals are likely to assume that taxpayers will share some or all of the costs of the care of disabled children. Therefore, some may argue that preventing the birth of children with disabilities is "good" for society because their absence from society reduces the "financial costs" to taxpayers.

Some philosophers and lawyers argue that there is a moral limit on the exercise of reproductive freedom, namely situations where others may be injured.[98] Taken together with the financial-burden and quality-of-life arguments, this argument is used by these commentators to justify intervention by government and health care providers in the reproductive

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94. *See supra* notes 34-35 and accompanying text.

95. *See supra* note 60 and accompanying text.

96. Some of the objectives of the ADA are: (1) to increase the dignity and independence of individuals with disabilities; (2) to provide them the opportunity to be fully participating members of society; and (3) to eliminate major obstacles that are not inherent in each individual's disability but that arise from external and unnecessary barriers. NATIONAL COUNCIL ON THE HANDICAPPED, ON THE THRESHOLD OF INDEPENDENCE, A REPORT TO THE PRESIDENT AND THE CONGRESS OF THE UNITED STATES XIV-XV (1988).

97. In wrongful life actions, the child sues the health care provider claiming that the provider's negligence caused the child's life and that life itself is the impairment for which the child seeks compensation. Generally, the courts deny recovery for policy reasons, citing their "inability" to measure the value of never having been born as the justification for denying relief. These courts feel uncomfortable with arguments that value not being born over life as a disabled person. *See* W. PAGE KEETON ET AL., PROSSER AND KEETON ON THE LAW OF TORTS § 55, at 370-73 (5th ed. 1984) (discussing the tort of "wrongful life" and judges' reluctance to allow recovery on this type of claim).

98. *See* Bayer, *supra* note 30, at 194 ("The 'harm principle'. . . provides a moral limit on the exercise of freedom when others may be injured . . . .").

decisions of women infected with HIV.[99] Undoubtedly, a few people might advocate extreme intervention in the form of compulsory temporary or permanent sterilization of noncompliant HIV-infected women and this attitude is consistent with the historical attitudes toward women and childbearing.[100] Such a proposal, whatever the proffered justifications, is clearly, as I noted earlier, inconsistent with the spirit of the ADA.[101]

B. Discouraging Pregnancy

Although a few health care decision makers might advocate involuntary sterilization of HIV-infected women, most health care decision makers would oppose such proposals. They would nonetheless favor less coercive means of discouraging these women from bearing children. Currently, reproductive-related counseling of HIV-infected women is not regulated, and many health care professionals are quietly advocating directive counseling for women who are identified as HIV-positive and fertile.[102] Directive counseling occurs when the patient does not receive an unbiased assessment of her medical situation and thus cannot make an informed personal decision free of persuasive, or even coercive, influences.

Because of the potential for the patient to transmit HIV to her child perinatally, the question of whether an HIV-infected woman should become pregnant or should continue her pregnancy after she learns of her HIV-positive status is value-laden. The health care provider may have strong opinions on the undesirability of an HIV-positive woman having a child. The situation is ripe for health care providers to abuse their power through directive counseling.

As a result, patients may be led into accepting treatments or undergoing procedures which strip them of their bodily autonomy.[103] Health care providers may innocently or negligently misrepresent the rate

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99. *See, e.g.*, Arras, *supra* note 27, at 373 (discussing some of the more radical coercive interventions into the reproductive choices of HIV-positive women, such as forced sterilization, abortion, and the threat of cutting off health benefits if the woman chooses to have the child).

100. *See generally* Ikemoto, *supra* note 37, at 1257-58 (noting that the nineteenth century view of women as childbearers led to the belief that "extraordinary" restrictions could be placed on their lives).

101. *See supra* note 96 and accompanying text.

102. *See supra* note 30 and accompanying text.

103. For example, the health care provider is concerned about both the pregnant woman and her potential child. The provider may believe that there are some treatments or medical procedures designed to benefit the potential child that the pregnant woman resists. As a result, the woman may be coerced to undergo the treatment or medical procedure and thus be labeled a bad or uncaring mother for resisting medical advice. Increased incidents of court-ordered medical interventions involving pregnant women suggest that some courts consider these women to be obligated to do all that is necessary, short of giving up their lives, to enhance the health and survival of their potential children. *See infra* Part III.C.

of vertical transmission of HIV. Providers may not clearly distinguish between advice relating to childbearing that is based on current medical information and advice that represents the provider's personal opinion about what is best for the patient's or potential child's well-being. This so-called medically based advice can have a powerful and perhaps coercive effect on some women's reproductive decision making.

Where the state or federal government is the health care provider, the Constitution may offer HIV-infected women some protection against directive counseling. First, directive counseling to abort may violate a woman's right to privacy.[104] Second, it is also arguable that the counseling of a woman to have an abortion by a government agent violates the government's duty to protect the fetus. Even in *Roe v. Wade*, the Court recognized that at some point the government has an interest in protecting the fetus, and this interest justifies restricting the privacy interest of a pregnant woman.[105] This interest is in conflict, however, with the previously mentioned financial-burden and quality-of-life arguments advanced in support of involuntary sterilization of disabled women.[106] A government may advance these arguments to support discouraging HIV-infected women from becoming pregnant. The courts have not addressed this conflict, and it remains unclear whether or under what circumstances a government agent can counsel, compel, or coerce a woman to terminate a pregnancy.

Even if these issues were clear, the courts generally have construed the Fourteenth Amendment to cover only state actors and most likely it cannot be used to protect women harmed by private-sector health care providers. Given the lack of protection some women face, the scope of federal statutory protection like the ADA becomes particularly important. Thus, women infected with HIV are a good paradigm to use when discussing the need for specific legislation under the ADA to protect the reproductive choices of all women with disabilities.

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104. Granted, the Supreme Court's decision in *Planned Parenthood of Southeastern Pennsylvania v. Casey* raises questions about the exact standard to be applied in these cases. 112 S. Ct. 2791 (1992); *see supra* notes 66-70 and accompanying text. *Casey*, however, involved an individual's choice about not bearing a child postconception. *Id.* Thus, arguably, once a woman has exercised her right to procreate, any governmental action which interferes with procreation is more personal and invasive. *See supra* note 70.

105. 410 U.S. at 150. The Court noted: "In assessing the State's interest, recognition may be given to the . . . claim that as long as at least *potential* life is involved, the State may assert interests beyond the protection of the pregnant woman alone." *Id.*

106. *See supra* notes 88-97 and accompanying text.

C. *Medical Interventions During Pregnancy*

"Access to care appears to be a continuing, many say increasing, problem for HIV-infected women."[107] This is not surprising since the women disproportionately affected by the epidemic traditionally have the least access to health care.[108] Even when access to health care is available, HIV-infected women are likely to be treated differently from other women because of their seropositive status.[109] Some difference in treatment may be medically warranted, but other differences in treatment or medical information may be based solely on the connection between a woman's seropositive status and her ability to become pregnant and possibly transmit HIV perinatally.

One leading principle of bioethics is that there should be "respect for persons." This principle means "that individuals should be treated as autonomous agents and that persons with diminished autonomy are entitled to protection."[110] This principle of respect for persons would seem to support the notion of nondirective counseling and general autonomy for women in reproductive matters. As applied to pregnant women, however, this principle has been interpreted to mean that the fetus also is entitled to protection because of its diminished capacity.[111]

A second leading principle of bioethics is that of "beneficence," which dictates "that persons are treated in an ethical manner not only by respecting their decisions and protecting them from harm, but also by making efforts to secure their best interests or well-being."[112] The physician often sees her obligation to pregnant women under this principle as the protection and promotion of the best interests of both the women and

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107. Goldsmith, *supra* note 35, at 1816. Goldsmith quotes Dr. Patricia Kloser from the New Jersey Medical School to the effect that "'My guess is that in Newark there are 10 HIV-infected women untreated in the community for every one that is in the clinic for care.'" *Id.*

108. *See* Margaret C. Heagarty & Elaine J. Abrams, *Caring for HIV-Infected Women and Children*, 326 NEW ENG. J. MED. 887, 887 (1992) (explaining that most women and children with HIV are poor, urban, minority-group members who have limited access to health care).

109. *See infra* notes 138-153 and accompanying text for a discussion of HIV-positive women's experiences in obtaining abortion services.

110. Alan R. Fleischman, *The Fetus Is a Patient*, *in* REPRODUCTIVE LAWS FOR THE 1990S, *supra* note 44, at 249, 250.

111. *Id.* There is some disagreement about whether the fetus possesses autonomy or merely the potential for autonomy. For example, under the bioethical principle of "beneficence," the "interests of the fetus do not stem from its moral status as an independent entity, but derive from its future standing as an infant and child, as well as a future member of the moral community." *Id.* at 250-51; *see also* Kolder et al., *supra* note 37, at 1194 (explaining how applications of wrongful death statutes and suits for compensation for injuries incurred before conception that later cause fetal injuries cut against the recognition of the fetus as an independent person since they require that the child be born alive). A more complete discussion of this point is beyond the scope of this Article.

112. Fleischman, *supra* note 110, at 250.

their fetuses. Where these interests conflict, the medical outcome (live or well woman versus live birth or well infant) should be determinative of in whose favor the balance is struck.[113] Applying this principle, if the outcome is the live birth of a baby and the medical procedure used poses minimal health risks for the mother, any objections of the mother should be discounted.

I agree with feminists who oppose bioethicists and others who place the mother and her fetus in conflicting positions;[114] however, given the trend in medicine toward treating the fetus as a patient, it is foreseeable that women infected with HIV who decide to become pregnant will be more likely than most other pregnant women to be subject to forced medical interventions on behalf of the fetus. Studies of court-ordered fetal interventions indicate that they are more likely when the pregnant woman is poor, a woman of color, or a patient in a public hospital.[115] As mentioned previously, the current demographics of women with HIV fit this profile.[116] Health care providers may question the judgment of any woman with HIV who consciously chooses to become pregnant after learning that she is infected. Once the woman becomes pregnant, the provider's attention is divided between the woman and her fetus. Thus, the impact of these two leading principles of bioethics on the current thinking about the propriety of HIV-infected women bearing children is extensive and weighs heavily against autonomy. Recognition that a fully informed, otherwise competent pregnant woman has a right to control medical decisions regarding the health of herself and her fetus is long overdue. Lack of autonomy in this area is especially problematic for disabled women, and the ADA is silent.

Given that seventy to eighty percent of the babies born to women infected with HIV will not have the virus,[117] and thus will have the potential to reach adulthood long after their mothers have died, a health care provider may conclude that it is more important to ensure the future health of this child, even at the expense of its mother. The provider will

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113. *Id.* (arguing that physicians must weigh the benefits and the risks for both the mother and the fetus and make therapeutic choices).

114. *See generally* Janet Gallagher, *Prenatal Invasions and Interventions: What's Wrong With Fetal Rights*, 10 HARV. WOMEN'S L.J. 9 (1987) (exploring the fundamental rights of a pregnant woman that protect her against governmental intrusion into her medical decisions); Dawn E. Johnsen, Note, *The Creation of Fetal Rights: Conflicts with Women's Constitutional Rights to Liberty, Privacy, and Equal Protection*, 95 YALE L.J. 599 (1986) (discussing the development of fetal rights doctrine which creates an adversarial relationship between a woman and her fetus).

115. *See* Kolder et al., *supra* note 37, at 1195 (noting from the results of a national survey that 81% of women forced to undergo court-ordered interventions were minorities, 44% were unmarried, and all were in public hospitals or receiving public assistance).

116. *See supra* notes 22-23 and accompanying text.

117. *See supra* note 34 and accompanying text.

be unsympathetic to a woman's refusal to act in the manner recommended as most beneficial for her child. She may continue to take illegal substances, use alcohol, eat improperly, or otherwise threaten the well-being of her fetus. Some providers will simply use all available forms of moral persuasion to influence their noncompliant patients, but others may resort to the courts in overriding the patients' autonomy and seeking legal action to guarantee compliance. Although health care providers who seek such court orders tend to do so out of an excess of enthusiasm or even arrogance, many courts are likely to side with them, especially given the socioeconomic and medical status of the noncompliant pregnant women with HIV.

IV. Rights Under the ADA

A. General Overview of Access to Medical Care Under the ADA

Elimination of discrimination in access to health care was a goal of the ADA,[118] and the House Committee on Education and Labor's report on the ADA explicitly referred to the continuous discrimination in medical treatment against individuals with disabilities.[119] The legislative history of the ADA, however, indicates that Congress did not intend to require health care providers to render treatment that is outside the providers' area of specialty.[120] The ADA also does not require a health care provider to render treatment in a situation where the disabling condition creates specialized complications for the patient's health that the provider lacks either the knowledge or the experience to address.[121] Under the ADA, a health care provider can only refer a disabled patient to another health care provider when she would refer other patients with the same condition.[122]

In this respect, the ADA modifies the common law regarding the duties of medical professionals. At common law, health care providers were under no legal obligation to treat any patient in need.[123] Even

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118. *See* 42 U.S.C. § 12101(a)(3) (Supp. III 1991) ("[D]iscrimination against individuals with disabilities persists in such critical areas as . . . health care . . . .").

119. *See* H.R. REP. No. 485, 101st Cong., 2d Sess., pt. 2, at 31 (1989), *reprinted in* 1990 U.S.C.C.A.N. 267, 312 (noting that discrimination against the disabled occurs in almost every aspect of their lives, including medical treatment).

120. *Id.* at 105-06, *reprinted in* 1990 U.S.C.C.A.N. at 389.

121. *Id.* at 106, *reprinted in* 1990 U.S.C.C.A.N. at 389.

122. *See* 42 U.S.C. § 12182(b)(1)(A)(iii) (Supp. III 1991) (noting that it is discriminatory to provide disabled individuals with public accommodations that are different or separate from those provided to other individuals "unless such action is necessary to provide the individual . . . with a[n] . . . accommodation . . . that is as effective as that provided to others").

123. Gostin, *supra* note 5, at 250.

where the required care fell within the health care provider's competence, physicians could base their decisions not to treat upon cost (i.e., in refusing poor patients),[124] prejudice (i.e., in discrimination on the basis of race or lifestyle),[125] liability concerns,[126] or subtle judgments about which patients deserve scarce health care resources.[127] Without question, the ADA prohibits medical decisions not to treat that are based solely on prejudice stemming from a person's disability. Nevertheless, since most commentators agree that the ADA does not guarantee access to health care, but simply prohibits denial of equal access based on a person's disability, a private health care provider still can refuse legally to treat based on a patient's inability to pay.[128] Provider decisions based on liability concerns or subtle judgments about patient access to scarce health care resources are less clearly violative of the ADA.[129] Undoubtedly, some of these issues will arise in the context of treating HIV-infected women of childbearing age.[130]

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124. *See id.* (noting that many physicians based their decision not to treat HIV-infected individuals on the costs associated with caring for uninsured or Medicaid patients).

125. *See id.* (describing how civil rights legislation made it illegal for physicians to discriminate on the basis of sex or race but noting that discrimination based on lifestyle (i.e. drug use) still occurred before the advent of the ADA).

126. For example, today some physicians refuse to deliver babies because they fear medical malpractice suits for children born with certain disabilities. *See* Jane Perkins & Kathleen Stoll, *Medical Malpractice: A "Crisis" for Poor Women*, 20 CLEARINGHOUSE REV. 1277, 1278 (1987) (noting that physicians, particularly obstetricians and gynecologists, are unwilling to treat poor and minority women due in part to the increased risk of malpractice liability caused by the health status of these women). It should be noted that the perception that poor patients sue more frequently for medical malpractice is a myth. *See* Molly McNutty, *Are Poor Patients More Likely to Sue for Malpractice?*, 262 JAMA 1391, 1391-92 (1989) (explaining that poor people who have been victims of medical malpractice rarely pursue their right to sue); Mary G. Mussman et al., *Medical Malpractice Claims Filed by Medicaid and Non-Medicaid Recipients in Maryland*, 265 JAMA 2992, 2994 (1991) (finding that, despite physicians' concerns about malpractice suits being filed by Medicaid patients, these patients were no more likely to sue than non-Medicaid patients).

127. Gostin, *supra* note 5, at 250.

128. There is some question about whether a public, as opposed to a private, health care provider can refuse to treat a disabled person based on cost. In August 1992, the Bush Administration refused to give Oregon an exception under the federal Medicaid program so that the state could institute an experimental health care rationing program designed to significantly increase access to health care for people in that state. The Administration reasoned that the Oregon plan, which excluded certain highly expensive categories from Medicaid coverage, would violate the ADA because the restriction would have a disproportionate impact on people with disabilities. Spencer Rich, *Oregon Medicaid Rationing Program Rejected as Biased against Disabled*, WASH. POST, Aug. 4, 1992, at A5.

129. For example, in my opinion, a physician could refuse, as a matter of policy, to treat certain conditions in individuals over 70 years of age because of liability concerns and concerns about the use of scarce health care resources by individuals with shortened life expectancies. Even though a disproportionate number of people over 70 have some disabling condition, unless the disabled person could prove that the primary basis for the physician's refusal to provide treatment was a protected disabling condition under the ADA, there would be no basis under the ADA for an unlawful discrimination claim.

130. For example, some physicians might be concerned about their legal liability for counseling

Although section 301(7) of the ADA broadly defines "public accommodation" to include the professional office of a health care provider, hospital, or other service establishment,[131] the substantive guarantee of access to public accommodations under the ADA is qualified. The Act does not require a public accommodation to permit an individual to participate in or benefit from the goods, services, facilities, privileges, advantages, and accommodations of the public accommodation if that individual poses a direct threat to the health or safety of others.[132] The ADA defines "direct threat" as "a significant risk to the health or safety of others that cannot be eliminated" by modifying policies, practices, or procedures or by providing auxiliary aids or services.[133]

The regulations promulgated under the Act set forth a test to determine whether an individual poses a direct threat to the health or safety of others. The test requires a three-prong individualized assessment based on reasonable judgment that looks at: (1) the current medical evidence or the best available objective evidence to determine the nature, duration, and severity of the risk; (2) the probability that the potential injury will actually occur; and (3) whether reasonable modifications of policies, practices, or procedures will mitigate the risk.[134] This is essentially the same approach adopted under the Rehabilitation Act.[135] Thus, under the ADA, no

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an HIV-infected woman to become pregnant because they fear a child born with HIV might file a civil action for wrongful life. As a general rule, however, most courts have refused to entertain these suits because they require courts to find that living with an impairment is worse than never having been born. KEETON et al., *supra* note 97, at 370-71. Physicians also fear that parents will bring a wrongful birth action to recover for injuries the parents incurred from the birth of an unwanted and impaired child. Generally, wrongful birth suits have been brought where there was a genetically transmissible disorder and the physician failed to recognize the risk, failed to test for the disorder, or failed to inform the parents of the risk of transmission. *Id.* at 370. For a more complete discussion of the question of health-care-provider tort liability and women with HIV, *see* Karen H. Rothenberg, Reproductive Choice and Reality: An Assessment of Tort Liability for Health Care Providers and Women with HIV/AIDS 21-23 (Sept. 30, 1992) (unpublished manuscript, on file with the author) (examining the current legal standards and potential for maternal and health-care-provider tort liability at various points of the decision-making process for HIV-positive women).

An example of a situation where a health care provider might claim limited resources as a basis for refusing to treat a woman infected with HIV is a request for infertility services. *See infra* Part IV.B.2.a.

131. Pub. L. No. 101-336, § 301, 104 Stat. 327, 354 (codified at 42 U.S.C. § 12181(7) (Supp. III 1991)).

132. 42 U.S.C. § 12182(b)(3) (Supp. III 1991); 28 C.F.R. § 36.208 (1992).

133. 42 U.S.C. § 12182(b)(3) (Supp. III 1991); 28 C.F.R. § 36.208 (1992); *see* 28 C.F.R. § 36.302 (1992) (specifying that public accommodations must make reasonable modifications in their policies, practices, and procedures, if necessary, in order to provide goods and services to individuals with disabilities); 28 C.F.R. § 36.303 (1992) (mandating that places of accommodation must provide the auxiliary aids and services necessary to prevent the exclusion or segregation of persons with disabilities).

134. 28 C.F.R. § 36.208 (1992).

135. *Cf.* Doe v. Centinela Hosp., No. CV 87-2514, 1988 U.S. Dist. LEXIS 8401, at *28 (C.D.

covered health care provider can refuse to accept a disabled person as a patient, unless it can be shown that either the treatment required is outside the provider's area of specialty or that the disabled person poses a direct threat to the health or safety of others, including the health care provider.

Nevertheless, this test does not help courts to distinguish clearly a lawful refusal to treat based on genuine clinical judgment from an unlawful refusal based on bias against an individual's disability:

> While the act certainly prohibits a refusal to treat based upon prejudice or irrational fear, some medical practices are far more subtle. Practitioners are defending their decisions to not treat or to refer patients with communicable conditions by arguing that this is an exercise of clinical judgment and does not constitute discrimination, and that to restrict the physician's right to decide whom to treat or when to refer is to dictate the practice of medicine.[136]

Since the ADA provides no real guidance on this issue, a question exists as to the extent to which courts will review medical decisions involving patients with disabilities.[137]

There is little relevant case law on determining when a decision not to provide medical services is based on a legitimate clinical judgment and when the decision constitutes unlawful discrimination. In the one analogous case under the Rehabilitation Act, *Doe v. Jamaica Hospital*, the state court never reached these substantive issues because it ruled that since the physician-hospital employee did not directly receive any federal funds, he was not personally liable under the statute.[138] Nevertheless, the plaintiff's allegations illustrate the problems inherent when courts are inclined, often out of necessity, to rely on medical judgments that may be biased or unscientific.

In *Jamaica Hospital*, the plaintiff, Carol Doe, learned that she was

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Cal. July 7, 1988) (explaining that to determine whether the exclusion of an HIV-infected person from a drug treatment program fell within the "direct threat" exception of the Rehabilitation Act required the court to examine several factors, including the nature, duration, and severity of the risk and the probability that there would be harm to others).

136. Gostin, *supra* note 5, at 251.

137. In *School Board of Nassau County, Florida v. Arline*, a Rehabilitation Act case, however, the U.S. Supreme Court said that "courts normally should defer to the reasonable medical judgments of public health officials." 480 U.S. 273, 288 (1987). Lawrence Gostin claims, though, that "increasingly courts are looking beyond the mantle of clinical judgment and are examining patterns of behavior that may be masking prejudice." Gostin, *supra* note 5, at 251.

138. *See Doe v. Jamaica Hospital*, *supra* note 4, at 27 (granting the physician's motion for summary judgment as to the cause of action in the complaint which alleged a violation of section 504 of the Rehabilitation Act of 1973). The court noted that the U.S. Supreme Court had limited the reach of section 504 to persons or entities who actually receive funds and not to persons, such as this physician, who indirectly benefit from the federal funds. *Id.* (citing U.S. Dep't of Transp. v. Paralyzed Veterans, 477 U.S. 597, 606-07 (1985)).

pregnant in 1988.[139] Because she was 38 years old, weighed over 300 pounds, and had previously given birth to a child with spina bifida, she chose to attend a high risk, prenatal clinic at Jamaica Hospital.[140] Doe alleged that, when she tested positive for HIV, both the social worker and a prenatal clinic specialist informed her that her chances of having a baby with AIDS were great and that she should have an abortion.[141] They referred Doe to the Chief of Obstetrics and Gynecology, who referred her to another hospital that the physician claimed was better qualified to treat a pregnant woman infected with HIV.[142] She subsequently had an abortion performed at the second hospital.[143]

In 1989, Carol Doe filed a civil action against both hospitals and the physician, alleging that they arbitrarily discriminated against her due to her physical disability—HIV.[144] She alleged this discrimination violated section 504 of the Rehabilitation Act of 1973. In her complaint, Carol Doe asserted that she had been denied treatment at Jamaica Hospital because of her seropositive status and that she had received separate, different, unequal, and ineffective counseling upon which to make her reproductive choices based on her seropositive status.[145] She also asserted that the hospital that performed the abortion had failed to counsel her about the reproductive choices available to her based on her seropositive status.[146]

This would seem to be an easy case under the ADA. Unless the health care provider could establish that the patient's seropositive status created specialized complications for her health for which the provider lacked either the knowledge or experience to address, or that her HIV status caused some direct threat to others, the ADA was apparently violated. Under the facts of the case, the health care provider would seem to have a difficult burden of proof under the ADA.

In 1990, the New York City Commission on Human Rights conducted an investigation of fifty health centers that offered abortions.[147] Twenty

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139. *Id.*

140. *Id.*

141. *Id.*

142. *Id.* The physician also claimed he counseled Doe on the physical and emotional effects of HIV infection and on her fears of having another child born with spina bifida. In contrast, the court relates that Doe claimed that the doctor told her that "having a baby with AIDS is worse than having a baby with spina bifida, that the baby would suffer and become a burden on society, [and] that she should have an abortion . . . ." *Id.*

143. *Id.*

144. *Id.* (citing § 504 of the Rehabilitation Act of 1973).

145. *Id.*

146. *Id.*

147. *See* Elisabeth Rosenthal, *Abortion Clinics Often Reject Patients With the AIDS Virus*, N.Y. TIMES, Oct. 23, 1990, at A1 (discussing the problems faced by HIV-positive women seeking abortions).

of these clinics refused to provide medical services once they were told that the patient had tested positive for HIV.[148] Most often these clinics cited "medical" factors, such as the lack of appropriate sterilization equipment and inexperience in treating HIV-infected patients, to justify their refusal to perform the abortions.[149] The Commission learned from medical experts that the abortion and sterilization procedures for women infected with HIV are no different from the procedures used for uninfected women.[150] The risk of transmission of the virus from patient to physician is "very small, but finite" provided physicians follow universal blood precaution procedures.[151] If the provider claimed, however, that she referred the patient to another facility because of some other risk factor, like drug use, that might complicate the situation.[152]

Thus, these abortion providers seem to be violating the ADA. They cannot show that the woman's HIV infection creates special problems that they lack the knowledge or expertise to address. Because of their ability

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148. *Id.* The centers included free-standing clinics and abortion clinics in hospitals. *Id.*

149. *Id.*

150. *Id.*

151. *Id.* at B5. Although the risk of HIV transmission from patient to health care provider exists, there are few reported cases of such work-related transmission. *See* Centers for Disease Control and Prevention, *Surveillance of Occupationally Acquired HIV Infection—United States, 1981-1992*, 268 JAMA 3294, 3294 (1992) (reporting that, as of September 1992, there were 32 documented and 69 possible occupationally acquired cases of HIV infection). The risk of infection varies according to the type of medical procedure involved. When the procedure called for is noninvasive, the risk of transmission of the virus is extremely low. When invasive procedures are warranted, and the health care provider is likely to be exposed to blood and other bodily fluids, the risk of transmission of HIV is greater. Nevertheless, the CDC concurs with the findings of the Commission that the risk of transmission may be significantly reduced by adopting the recommended safety precautions. *See* Centers for Disease Control and Prevention, *Recommendations for Preventing Transmission of Human Immunodeficiency Virus and Hepatitis B Virus to Patients During Exposure-Prone Invasive Procedures*, 40 MORBIDITY & MORTALITY WKLY. REP., RECOMMENDATIONS & REPS. 5-6 (1991) (outlining the precautions that health care providers and facilities should use to prevent transmission from providers to patients).

152. The ADA makes a theoretical distinction between the use of an illegal substance and the status of being addicted. Addiction is considered a disability, although in most instances the ADA excludes illegal drug users from coverage. 42 U.S.C. § 12210 (Supp. III 1991); *see* 28 C.F.R. § 36.104 (1992) (defining current illegal use of drugs as use that occurred recently enough to justify a reasonable belief that a person's drug use is current or that continuing use is a real and ongoing problem). The law provides a limited exception for health services, or services provided in connection with drug rehabilitation, if the individual is otherwise entitled to such services. 42 U.S.C. § 12210; *see* 28 C.F.R. § 36.209(b) (1992) (explaining when an individual is entitled to public health services, despite current drug use). Thus, if the provider could prove that drug-using pregnant women always were referred to other providers, the action would not violate federal antidiscrimination law. One can envision, however, a situation where a blanket policy to exclude drug-using pregnant women from certain medical services is merely a cover to avoid treating women infected with HIV, a disproportionate number of whom currently are identified as having drug-using histories. *See supra* note 24 and accompanying text. It might be difficult under the ADA to distinguish between a lawful denial of services because of current drug use and an intent to discriminate against a protected disabled group, some of whom are also drug users.

to substantially minimize the risk of transmission, they will have a difficult time showing that HIV-infected women present a direct threat to others. The ability to control the risk of transmission presents an especially strong argument that HIV infection alone is an insufficient basis for denying medical treatment to an otherwise qualified patient.[153]

B. Access to Reproductive Information and Services

1. Directive Counseling to Forego Childbearing

Undoubtedly, there will be some HIV-infected women without AIDS symptoms who will consciously want to become pregnant.[154] I am arguing that a health care professional who directly counsels all women with HIV not to become pregnant may violate the ADA under some circumstances. Some may contend that directive counseling is appropriate and does not violate the ADA since it will dissuade some HIV-positive women from bearing children but will not pose an impenetrable barrier to childbearing. While it is true that counseling cannot be equated with a direct prohibition, many women, irrespective of their race or education, do not seriously question health-related advice from medical providers, and this is particularly true of low-income women.[155] Therefore, so-called clinical advice can have a powerful and perhaps coercive effect on some women's reproductive decision making.

Unfortunately, many women first learn of their seropositive status during pregnancy or at the time their child is born.[156] Currently, the CDC recommends that all fertile women "at risk" for HIV infection be routinely tested.[157] Given the sharp increase in HIV infection among

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153. Lawrence Gostin, executive director of the American Society of Law and Medicine, agrees with this conclusion:

> Courts . . . are unlikely to accept occupational risks as a justification for discrimination: The risk is exceedingly low and can be kept low through the "reasonable accommodation" of strict adherence to infection control procedures. Health care professionals will probably be expected to accept some level of risk in carrying out their jobs in the same way that fire fighters or police officers cannot excuse themselves from particularly dangerous assignments.

Gostin, *supra* note 5, at 251.

154. Preliminary data suggest that there is no difference between the reproductive decisions of infected and uninfected women. *See* Bayer, *supra* note 30, at 180 (discussing the problem of AIDS transmission from mother to fetus).

155. Nsiah-Jefferson, *supra* note 44, at 39.

156. *See, e.g.*, Lindgren et al., *supra* note 33, at 1112 (reporting that three-fourths of the women in a study of maternal-fetal transmissions of HIV were diagnosed during pregnancy or within a few weeks after giving birth).

157. Lawrence L. Minkoff, *Care of Pregnant Women Infected with Human Immunodeficiency Virus*, 258 JAMA 2714, 2714 (1987). The Centers for Disease Control is currently revising this

women and the risk of perinatal transmission, it seems likely that the CDC's future recommendations will continue to advise the testing of women of childbearing age to prevent perinatal transmission of the virus. Undoubtedly, voluntary testing of fertile women should be encouraged to give women information about their health. When the goal also includes minimizing the risk of perinatal transmission of HIV, testing is most valuable if it occurs before pregnancy. At that point, an HIV-positive woman can make an informed choice about whether to become pregnant.

Any HIV testing of fertile women designed to minimize the risk of perinatal transmission of the virus raises the issue of what information should be provided to fertile HIV-positive women. Counseling is an essential component of any HIV-testing program, but, when counseling on reproductive matters, an approach that fully respects and facilitates patient autonomy in the decision-making process is most appropriate. Although a fairly recent development in both law and medicine, it generally is accepted today that the patient's values should govern medical decision making.[158] As some commentators point out, however, practice lags behind theory in the medical community.[159] "[P]hysicians routinely make judgments based on risk-benefit calculations, judgments that could plausibly be viewed as not purely medical and that therefore could be made by patients based on their personal benefit and risk preferences."[160]

Currently, HIV counseling is not regulated. As noted in the introduction to this Article, however, governmental and medical organizations recommend directing HIV-positive women not to become

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guideline. CDC, *Recommendations*, supra note 29, at 724.

158. In law, this principle is embodied in the tort doctrine of informed consent. *See, e.g.*, Canterbury v. Spence, 464 F.2d 772, 780-81 (D.C. Cir. 1972), *cert. denied*, 409 U.S. 1064 (1972) (citing the proposition that true consent can only be gained when a patient is knowledgeable about his or her options and the attendant risks); JAY KATZ, THE SILENT WORLD OF DOCTOR AND PATIENT (1984) (exploring the doctor-patient relationship and the decision-making process); David Orentlicher, *The Illusion of Patient Choice in End-of-Life Decisions*, 267 JAMA 2101 (1992) (describing the societal consensus that patient self-determination should guide decisions concerning life-sustaining treatment); Marjorie M. Shultz, *From Informed Consent to Patient Choice: A New Protected Interest*, 95 YALE L.J. 219 (1985) (arguing that patient autonomy should be a legally protected interest). To recover, however, the plaintiff must prove: that she was not fully informed of all material or relevant risks; that she suffered some physical injury as a result; and, that if adequately informed, a reasonable person would have decided differently. Thus, it may be misleading to characterize the legal requirements of informed consent as grounded in patient autonomy since recovery is based on the values of a "reasonable" person and not the individual patient's personal values. *See* KEETON et al., *supra* note 97, § 32, at 191 (describing the general rule that informed consent contains an objective component).

159. *See* Orentlicher, *supra* note 158, at 2102-03 (explaining that physicians' values still predominate in medical decisions due to resistance by physicians who refuse to recognize patient autonomy, especially when confronted with the possibility of medically undesirable treatment).

160. *Id.* at 2103.

pregnant or to bear children.[161] Directive counseling, whether it occurs in a public or a private nongovernmental setting, may create potential legal problems under the ADA if, in counseling an HIV-infected woman to forego motherhood, the provider bases her advice on nonmedical or medically questionable factors.

HIV-related reproductive counseling designed to minimize perinatal transmission of the virus is analogous to reproductive counseling for genetic diseases. HIV infection is similar to a genetic disorder that can be transmitted perinatally. Following this line of reasoning, HIV-related reproductive counseling is similar to many types of genetic reproductive counseling in that there is no medical cure for the infection and that the fetus cannot be treated prior to birth.[162] Therefore, it can be argued that HIV-related reproductive counseling should be treated in the same way as reproductive counseling for genetic diseases that are not treatable prior to birth.[163] Since directive genetic counseling is considered inappropriate,[164] directive reproductive counseling of HIV-infected women should be considered inappropriate. At a minimum, a counselor should have to justify the discrepancy in counseling techniques.

Many proponents of directive HIV counseling may explain the distinction between genetic counseling and HIV counseling by asserting that HIV infection differs from genetic disorders because it entails not only the chance of perinatal transmission but also the likelihood that the mother's life expectancy will decrease. Therefore, some will argue, the mother's decreased life expectancy is relevant enough to render the two situations distinguishable. Although this argument may apply to most, but not all genetic disorders, the decreased life expectancy of the mother generally is not seen as a reason to direct, as opposed to advise, women not to become pregnant.[165] Popular culture provides numerous instances where women

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161. *See supra* note 29 and accompanying text.

162. A child born with HIV antibodies may not be infected with HIV, and it may take up to sixteen months before an accurate diagnosis can be made. Carol Levine & Ronald Bayer, *The Ethics of Screening for Early Intervention in HIV Disease*, 79 AM. J. PUB. HEALTH 1661, 1662 (1989).

163. Traditionally, routine prenatal genetic testing has not been performed for medical conditions that cannot be treated prior to delivery and that can only be avoided by not becoming pregnant or by aborting the fetus. *See id.* at 1664-65 (discussing the lack of justification for mandatory HIV screening because no therapeutic benefit will result).

164. *See id.* at 1666 (noting that genetic screening and counseling should not be undertaken unless beneficial medical services can be provided); *see also* Levine & Dubler, *supra* note 22, at 346-48 (arguing that governmental involvement in the reproductive choices of women is wrong and that a comprehensive approach involving education, access to health and prenatal care, and improving services is what is really needed).

165. *See* Banks, *supra* note 31, at 374-75 (noting that there are several genetic disorders which are fatal, yet there are no mandates for abortion for these disorders, and arguing that HIV-infected women should be treated the same as women with genetic disorders in terms of counseling on reproductive options).

with terminal or life-threatening illnesses have borne children and are considered to be noble and self-sacrificing. For example, in the film *Steel Magnolias*, a diabetic woman elects, against the advice of both her physician and her mother, to become pregnant and subsequently dies while her child is still a baby.[166] The daughter's action is portrayed as noble and self-sacrificing because the child's birth ensures the continuation of the bloodline of both the woman and her husband. Traditionally, childbearing is viewed as a way to ensure one's immortality—a concern that may be even more pressing for someone who knows that her life expectancy is shortened. Since the impulse to procreate before dying is understood and glorified, societal concern about the decreased life expectancy of HIV-infected mothers may have more to do with societal concerns that, because of their socioeconomic and marital status, their offspring will become burdens on the community.

2. *Access to Medically Assisted Reproduction*

Some women infected with HIV who want to become pregnant after learning of their seropositive status will have infertility problems and will need medically assisted reproductive services.[167] The CDC recommendations[168] imply that health care providers may advise HIV-infected women who want to become pregnant against seeking fertility services and that reproductive services clinics may refuse to take HIV-infected women as patients. A refusal by a health care provider to provide this type of medical service may pose an insurmountable barrier to childbearing. Under the ADA, it is not clear whether health care providers legally can refuse infertility services to all women infected with HIV without some scientific basis for the decision.

a. Generally

Reproductive technology has advanced tremendously over the past twenty years, providing women with fertility problems and the financial

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166. STEEL MAGNOLIAS (Tri-Star Pictures 1989); *see also* Levine & Dubler, *supra* note 22, at 323 (arguing that many women who have chronic, and even fatal diseases, choose to have children and that "they are treasured by their families and admired by society for doing so").

167. *See, e.g,* J.R. Smith et al., *Infertility Management in HIV Positive Couples: A Dilemma*, 302 BRIT. MED. J. 1447, 1450 (1991) (describing a case study of an HIV-positive couple who after learning of their seropositive status and receiving pregnancy counseling, opted to continue with infertility management). For example, African-American women are one and one-half times more likely to have infertility problems than white women. Nsiah-Jefferson, *supra* note 44, at 49 (citing a 1982 study by the National Center for Health Statistics). This is significant since most of the U.S. women with AIDS are African-American or Hispanic. *See supra* note 23 and accompanying text.

168. *See supra* note 29 and accompanying text.

means with a vast variety of treatment options.[169] Without addressing the medical resource questions posed by some of the more expensive, and less successful, medically assisted reproductive options, I am assuming for the purposes of this discussion that money is not a problem for the HIV-positive woman requesting medically assisted reproductive services. Of course, in reality, most of the women currently identified as infected with HIV lack the financial resources to seriously consider using infertility services.

Physicians who specialize in infertility problems have a tremendous amount of control over women who want to bear children but who need medical assistance. These physicians, often men, determine the availability of infertility services for all women who seek them. Many physicians, without much scientific evidence, counsel women with multiple sclerosis and other disabilities not to have children "because it has seemed 'obvious'" that disabled people will not make good parents.[170]

Most *in vitro* clinics are highly selective and often use factors like socioeconomic and marital status to screen potential patients.[171] Some commentators claim that reliance on these factors is the health care provider's way of deciding who are "deserving and appropriate parents."[172] Often the decision by health care providers to deny fertility treatment has little to do with medical considerations. Since questions already exist about the propriety of disabled women bearing children or the extent to which women with HIV deserve to become parents,[173] it is reasonable to conclude that fertility services will be denied HIV-infected women based on their seropositive status.

The general public tends to believe in the idealized notion of the altruistic physician who makes objective medical decisions. This mythological physician relies only on medical information and impartially assesses the patient's medical condition in determining whether medically assisted reproductive treatments are advisable. Anecdotal information, however, suggests that, when physicians decide not to perform reproductive services on some women, they fail to distinguish clearly between the objective, medical factors and the nonmedical, value-laden,

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169. *See* Melanie Howard, *Feeling's Mutual for Quint Moms*, WASH. TIMES, Nov. 3, 1991, at A11 (discussing major advances in fertility problem treatments).

170. Deborah Kaplan, *Disability Rights Perspectives On Reproductive Technologies And Public Policy*, *in* REPRODUCTIVE LAWS FOR THE 1990S, *supra* note 44, at 241, 241-42 (noting the lack of medical research on the effects of pregnancy in disabled women).

171. *See* GENA COREA, THE MOTHER MACHINE: REPRODUCTIVE TECHNOLOGIES FROM ARTIFICIAL INSEMINATION TO ARTIFICIAL WOMBS 145 (1985) (discussing the lack of access by poor and minority women to new reproductive technologies).

172. *Id.* (quoting a Norfolk, Virginia, fertility clinic physician).

173. *See supra* Part II.B.

and personal factors they use to make their decisions.[174] Physicians' attitudes toward women who want to become parents seem to be influenced by societal preconceptions about motherhood.

b. Infertility Services for HIV-Infected Women

Whether a health care provider can refuse to assist a woman with HIV who has fertility problems and wants to bear a child would constitute a difficult case under the ADA. Although it may not violate the Constitution's protection of the right to bear children,[175] denying fertility services may violate the ADA unless the health care provider can affirmatively demonstrate either that the HIV-infected woman does not meet legitimate eligibility criteria[176] or that the woman poses a direct threat to the health or safety of others.[177] Whether either of these factors exists in any given situation may not be an easy determination. Nonetheless, a blanket policy against providing infertility services to HIV-infected women would be suspect since, under the ADA, individual assessment is required in each case.[178] To justify any blanket exclusion, the provider of infertility services would have to demonstrate affirmatively that there were accepted scientific reasons why all financially able women with HIV do not meet eligibility requirements.

Under the public accommodation section of the ADA,[179] a problem arises in trying to distinguish between lawful and unlawful refusals to treat where the health care provider determines that the disabled person is not "qualified" for the requested services. The issue of refusing infertility services to HIV-infected women is an example. I personally know of a health care provider who regularly treats women with HIV and who provides other women with infertility services, but who has refused, on at least two occasions, to provide infertility services to HIV-infected women who requested them. When questioned, the provider initially responded

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174. *See* Gostin, *supra* note 5, at 251 (arguing that it is often difficult to distinguish between judgments made because of medical expertise and those made because of prejudice or irrational fear).

175. *See supra* notes 61-75 and accompanying text.

176. *See* 42 U.S.C. § 12182(b)(2)(A)(i) (Supp. III 1991) (noting that discrimination includes "the imposition . . . of eligibility criteria that screen out . . . an individual with a disability . . . , unless such criteria can be shown to be necessary for the provision of the goods [or] services . . . being offered"). Providers may also avoid a finding of discrimination if they show that a modification of policies, practices, or procedures would fundamentally alter the nature of the services. 42 U.S.C. § 12182(b)(2)(A)(ii) (Supp. III 1991).

177. 42 U.S.C. § 12182(b)(3) (Supp. III 1991); *see supra* notes 132-135 and accompanying text.

178. *See, e.g.*, Anderson v. Little League Baseball, Inc., 794 F. Supp. 342, 342 (D. Ariz. 1992) (questioning whether a blanket policy of prohibiting wheelchairs on the playing field is permissible because the ADA requires an individual assessment of the risks).

179. 42 U.S.C. § 12181-12189 (Supp. III 1991); *see supra* notes 9-14 and accompanying text.

that, in her medical judgment, women with HIV were inappropriate candidates for infertility services. When pressed further to clarify the basis for her conclusion, she admitted that, in her "professional" opinion, women with HIV should not have children because of the burden rearing children places on a person with a chronic and almost certainly fatal disease. Nevertheless, she could cite no purely scientific reason for a blanket exclusion of women based on their seropositive status.

The tendency of courts to defer to judgments by medical professionals without a more probing inquiry is commonplace. HIV is a complicated disease, and infertility technology is an ever-changing, complex field. Both facts raise legal, ethical, social, and economic issues that can only help influence those medical providers of infertility treatment. Given the strong feelings, both inside and outside the medical community, about the propriety of HIV-infected women bearing children, discrimination almost certainly will occur in this area absent some judicial or legislative action. As mentioned previously, the courts seem unlikely to provide strong protection of individual patient autonomy in the area of infertility treatment.

V. Recommendations

Although one can argue reasonably that the ADA, as currently written, should be construed to protect the reproductive rights of women with disabilities, there is no guarantee that the courts will interpret the statute that expansively. In recent years, the Supreme Court has been unwilling to interpret federal antidiscrimination statutes broadly. For example, Title IX of the Education Amendments of 1972 prohibits sex discrimination in any federally funded education "program or activity."[180] The Supreme Court in *Grove City College v. Bell* held that the phrase "program or activity" could not be read so broadly as to prohibit discrimination throughout a college if the only federal money reaching the institution came through the school's participation in a federal student financial-aid program.[181] Many thought that this interpretation was contrary to the intent of Congress, and in 1988 Congress confirmed this belief by enacting legislation overriding the Court's decision in *Grove City*.[182] However, during the intervening four years between *Grove City* and the corrective legislation, dozens of alleged instances of sex discrimination in federally

180. Education Amendments of 1972, Tit. IX, § 901(a), 20 U.S.C. § 1681(a) (1988).

181. 465 U.S. 555, 574-75 (1984).

182. *See* 20 U.S.C. § 1687(2)(A) (1988) (providing for a broad interpretation of "program or activity" that includes *all* operations of an institution and prohibits discrimination if any one of these receives federal financial assistance).

funded education programs were beyond the power of the federal government to prohibit.[183] In numerous other instances, the Court has interpreted other federal antidiscrimination statutes narrowly and arguably inconsistently with congressional intent.[184]

Nothing in the legislative history of the ADA clearly indicates an intent to protect reproductive freedom. However, even if the legislative history on this point were clear, judicial protection of reproductive autonomy would not be guaranteed. Some members of the current Supreme Court, notably Justice Antonin Scalia, openly disregard legislative intent, relying instead on the plain meaning of the statute whenever an interpretative question arises.[185] Therefore, a clear textual

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183. In the wake of the *Grove City* decision, the investigation and litigation of a number of sex discrimination complaints halted. S. REP. NO. 64, 100th Cong., 1st Sess. 11-16 (1988) (describing the cutbacks in administrative enforcement as well as the adoption by lower federal courts of a restrictive interpretation of "program and activity" in Title IX, Title VI, and the Age Discrimination Act cases as a result of the *Grove City* decision). Undoubtedly, many more otherwise valid claims were never filed.

184. *See, e.g.*, Presley v. Etowah County Comm'n, 112 S. Ct. 820 (1992). In *Presley*, the Supreme Court rejected the claim of African-American petitioners that the Voting Rights Act of 1965, as amended, covered post-election changes in the duties of local elected officials and that those changes were subject to the Act's preclearance requirement. *Id.* at 832. In his dissent, Justice Stevens objected to the majority's narrow construction of the statutory language, arguing that it was inconsistent with the legislative history of the original 1965 Act and the 1970 and 1982 extensions of the Act. *Id.* at 837 (Stevens, J., dissenting). Subsequently, Congress, in the 102d session, held hearings on legislation designed to overrule *Presley*. *See Voting Rights Act: Bilingual Election Materials, Expert Witness Fees, and* Presley*: Hearings Before the Subcomm. on Civil and Constitutional Rights of the House Comm. on the Judiciary*, 102d Cong., 2d Sess. (1992) (gathering testimony on whether to extend § 203 of the Voting Rights Act for an additional fifteen years and whether changes in the text of § 203 are necessary in light of the alleged need for broader language assistance programs and recent court cases such as *Presley*). In 1993, the House introduced another bill to amend the Voting Rights Act of 1965. H.R. 174, 103d Cong., 1st Sess. (1993). The bill, which would be known as the *Voting Rights Extension Act of 1993*, attempts to clarify some of the definitions of the 1965 Act. The bill clarifies that "the term 'procedure with respect to voting' includes any change of procedural rules, voting practices, or transfers of decision making authority that affect the powers of an elected official or position." *Id.* The Subcommittee on Civil and Constitutional Rights of the House Committee on the Judiciary held hearings on H.R. 174 on March 18, 1993.

In *Patterson v. McLean Credit Union*, the Court held that the phrase, "make and enforce contracts," contained in 42 U.S.C. § 1981, referred only to discrimination in the formation of contracts and not to contract performance. 109 S. Ct. 2363, 2376-77 (1989). Prior to this decision, every federal appellate court had held that § 1981 applied to discrimination in the performance of contracts. H.R. REP. NO. 40, 102d Cong., 1st Sess., pt. 1, at 90 (1991) (describing how *Patterson* undermined the previous consensus of the federal courts of appeals in interpreting the Civil Rights Act). After *Patterson*, the federal courts dismissed hundreds of section 1981 race discrimination claims. *Id.* at 91. Congress subsequently enacted the Civil Rights Act of 1991, which had the effect of overriding *Patterson*. 42 U.S.C. § 1981(b) (Supp. III 1991). For a more complete discussion of these points, *see* Muriel Morisey Spense, *The Sleeping Giant: Textualism as Power Struggle*, SO. CAL. L. REV. (forthcoming) (describing the debate over the use of legislative intent in interpreting ambiguous statutory provisions).

185. *See, e.g.*, Green v. Bock Laundry Mach. Co., 490 U.S. 504, 528 (1989) (Scalia, J.,

statement on reproductive autonomy is needed.

I propose that the ADA be amended to prohibit disability-based discrimination in reproductive matters. An antidiscrimination provision covering reproductive matters seems especially appropriate given the strong evidence that both public and medical sentiment tends to disapprove of individuals with disabilities, especially women, who affirmatively exercise their right to procreate. The proposed amendment would not preclude health care providers from fully informing individuals with disabilities about the medical consequences of pregnancy (for women); the demands of rearing children (for women and men); and, where applicable, the likelihood of transmission of any parental trait or disorder to potential offspring. The proposed amendment, however, would make it less likely that courts could uphold blanket policies limiting reproductive options and order involuntary sterilization or medical interventions for women with disabling conditions.

VI. Conclusion

There are compelling policy reasons for insuring that women infected with HIV have access to medical treatment and appropriate counseling that respects their autonomy in reproductive decision making. Policies developed to address reproductive choices of HIV-infected women should encourage independent and informed decision making by each woman and should be based on current medical knowledge. This approach is the one favored by the ADA. Absent strong congressional language, however, it is uncertain whether this objective will be realized for vast numbers of women infected with HIV. There are too many people in the medical community and society in general who favor coercive policies that would discourage reproduction based solely on a woman's antibody status. Given the Supreme Court's reluctance in recent cases to interpret broadly congressional antidiscrimination statutes, an amendment to the ADA is needed. This amendment should affirmatively state that discrimination in reproductive matters against individuals with disabilities is unlawful. Such

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concurring in the judgment) (contending that, in construing the meaning of specific words in a statute, deference should be given to the meaning that most closely approximates the ordinary usage of the word and not to a particular meaning understood by only a few); Edwards v. Aguillard, 482 U.S. 578, 610-11 (1987) (Scalia, J., dissenting) (supporting Louisiana's Balanced Treatment for Creation-Science & Evolution-Science Act as constitutional on its face and refusing to speculate on the possible unconstitutional motives behind the passage of the Act); William J. Popkin, *An 'Internal' Critique of Justice Scalia's Theory of Statutory Interpretation*, 76 MINN. L. REV. 1133 (1992) (critiquing Scalia's text- and rule-based approach to statutory interpretation); Note, *Justice Scalia's Use of Sources in Statutory and Constitutional Interpretation: How Congress Always Loses*, 1990 DUKE L.J. 160 (examining Scalia's textualist approach in interpreting statutes and his originalist approach in interpreting the Constitution).

an amendment is the only way to guarantee reproductive autonomy for individuals with disabilities.