

HIV AND CHILDBEARING

1. Uncertain Risks and Bitter Realities: The Reproductive Choices of HIV-infected Women

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IN DECEMBER 1985, THE CENTERS FOR DISEASE Control (CDC) officially recommended that women who are infected with the Human Immunodeficiency Virus (HIV) or who have the Acquired Immunodeficiency Syndrome (AIDS) should “be advised to consider delaying pregnancy until more is known about perinatal transmission of the virus” (Centers for Disease Control 1985, 725). More recently, Dr. James Curran, head of the CDC AIDS program, commented: “Someone who understands the disease and *is logical* [emphasis added] will not want to be pregnant and will consider the test results when making family planning decisions” (*CDC AIDS Weekly* 1988, 2). Many state department of health materials go beyond the CDC’s advice and reconmend unequivocally that HIV-infected women should not become pregnant (Bayer 1990). Nonetheless, many women who are HIV positive or who have AIDS are having babies. They are doing so even when they know they are infected, even when they have been counseled about the risks of perinatal transmission, even when they already have a child with HIV infection or AIDS, and even when that child has died (Holman et al. 1989; Selwyn et al. 1989). (In this article we will use the term “perinatal transmission,” rather than the more global, but largely synonymous term “vertical transmission.”)

Expressing a widespread sentiment, a philosopher at a recent meeting asked, more in puzzlement than hostility: "What kind of moral universe do these women live in, anyway?" Most public-health officials, physicians, policy makers, and the general public consider the stark reality of the birth of HIV-infected babies inexplicable, unjustifiable, or immoral.

This article is an attempt to refute that view by describing the framework of values, norms, and practices encompassing women's sexual and reproductive lives—a moral universe—and the economic, cultural, and social reality from which it is derived. We intend to challenge the premise, underlying public-health and physician-dominated programs, that vigorously encouraging HIV antibody testing and counseling while vigorously discouraging pregnancy will prevent the births of many or most HIV-positive children. We strongly support the availability of testing and counseling, offered with informed consent and linked to specific, appropriate treatments and services. However, if the objective of such programs is preventing pregnancies or births, rather than providing women with clear information about their options and the services to carry them out, we are concerned that voluntary programs will inevitably give way to widespread and systematic coercive measures.

Our misgivings about coercion stem from history as well as current attitudes. In "The Coming of Custodial Democracy," political commentator Charles Murray predicts that as AIDS becomes increasingly identified with inner-city populations, "Understanding and patience are going to dwindle across the political spectrum, to be replaced by animosity and/or indifference" (Murray 1988, 23). Although one might argue with Murray's benign characterization of public attitudes to date, it is certainly clear that indifference already exists, and animosity is often barely disguised. Furthermore, of all the groups that might be targets for that animosity, women who give birth to HIV-infected babies will surely be high on the list.

Although recognizing the gravity and consequences of continued perinatal transmission, and in no way wishing to encourage it, we will argue that HIV infection, as one of a range of conditions that can be passed from mother to fetus, should not be particularly singled out for moral censure and coercive policies. Other, less stigmatized conditions are equally or even more likely to be transmitted, to result in suffering or death for the child, and to be costly to the family and society.

It is true that, unlike most other situations of perinatally transmitted

conditions, mothers with HIV have dismal long-term prognoses themselves. Those who have developed AIDS face almost certain death. However, many women with chronic diseases, and some who are dying, choose to become pregnant, even at considerable risk to themselves; they are more treasured by their families and admired by society for doing so. The recent film *Steel Magnolias* is one such celebration in the popular culture. HIV-infected women, in contrast, are considered irresponsible for having babies who may face early death and whose future care may be a burden to society. Surely class and ethnicity play a role in these different societal responses and judgments. It is interesting to speculate what the response would be if the majority of HIV-infected women were white wives of hemophiliac men, a group that is numerically smaller but equally at risk for giving birth to seropositive babies but about which there is practically no public concern.

Because reproductive decisions are crucial to biological and social life, HIV-infected women must remain free to make reproductive choices that are consistent with their cultural, religious, and personal values. When given supportive counseling and access to contraception and abortion services, some women will choose to forgo or to terminate pregnancy. We unequivocally support their right to choose contraception and abortion, and we believe that there is a concomitant professional and public obligation to provide those services. However, many women, perhaps the majority, will choose to continue their pregnancies. In their view, having babies may be not just a defensible moral choice; it may be the most reasonable and available choice, a natural outcome of all the forces in their lives, in which avenues for self-definition and expression other than mothering are largely absent. In the best of all worlds infected babies would not be born, HIV would not exist, and neither would poverty. In the reality of the 1990s, disease and deprivation frame the existence of many poor women.

Federal and state public-health officials who exhort HIV-positive women to forgo pregnancy are responding understandably to what is in their view primarily a problem of disease transmission to newborns; perinatal transmission is producing a new group of infected persons. The spread of disease to women is rarely described as a concern in and of itself; it is typically linked to the possibility of transmission to infants. In the first years of the epidemic, debates about breaching confidentiality to notify partners at risk focused on gay relationships; women were not perceived as at risk. Indeed, the original name for the

disease, GRID (Gay Related Immune Deficiency) identified the supposed target population. As it became clearer that women were contracting AIDS heterosexually, as well as through needle sharing, proposals for mandatory reporting of HIV infection and contact tracing focused on spouses or long-term sexual partners, presumably women who might be unaware of their exposure. However, with the emotional impact of pediatric AIDS, public concern for women has been overshadowed by apprehension about the fate of their potential children.

To support our conclusion that public policy about perinatal HIV transmission must take account of a moral universe and a social reality that encompass more than the single risk of perinatal HIV transmission, we will review the epidemiology of HIV among women and children, the lives of HIV-positive children and their mothers, and the social, cultural, and political contexts in which individual women either actively make reproductive choices or passively accept the consequences of their sexual behavior. We focus on six contexts: churches and pronatalist ideology, the cultural value of reproduction, reproductive rights and counseling, poor women's diminishing access to health care, making reproductive choices in uncertainty, and the tension between individual and community over moral responsibility in reproductive decisions. We conclude with some recommendations for alternative policies to prevent perinatal transmission.

The Epidemiology of Women and Children with AIDS

As the epidemic moves deeper into communities where drug use is endemic, it is disproportionately affecting poor African Americans and Latinos. (Except in direct quotations or when referring to CDC or New York City surveillance statistics, which use the terms "Black" and "Hispanic," we will use these terms to describe communities of color. For more explanation on why these terms are now preferred, see de la Vega 1990). The stigmatizing and inaccurate designation of "risk groups" has been thoroughly discredited; the term "risk behavior" now predominates. However, that term gives rise to still another confusion. There is nothing inherent in being African American, Latino, homosexual, heterosexual, or an intravenous drug user (IVDU) that puts a

person at risk for contracting HIV. Similarly, there is nothing inherently risky about sexual behavior per se. What links groups and risk is the prevalence of HIV in populations and communities. The chances of becoming infected by sexual or drug-using behavior increase with the likelihood that one's partners are HIV infected. Drug-using women are more likely to have an infected needle-sharing partner and thereby to contract HIV in New York City than in Chicago, where the HIV seroprevalence is lower. Non-drug-using heterosexual women are more likely to have an HIV-infected sexual partner in communities with high seroprevalence rates—that is, poor inner-city neighborhoods.

For these reasons, whereas blacks and Hispanics constitute only about 20 percent of the population of the United States, they account for 42 percent of the 136,204 AIDS cases reported to the CDC from 1981 through April 1990 (Centers for Disease Control 1990). In this period, 12,607 cases of AIDS among women aged 13 or older were reported. An analysis of the data from 1981 to December 31, 1988, covering the first 6,983 cases of AIDS among women, showed that they represented 8 percent of all cases, but 10 percent of cases reported in 1988. The cumulative incidence of AIDS was 13.6 times higher among black women and 10.2 times higher among Hispanic women than among white women. Just over half (51.6 percent) of the women with AIDS were black; 27.9 percent white; 19.5 percent Hispanic; 0.6 percent Asian/Pacific Islander; and 0.2 percent American Indian/Alaskan Native. Intravenous drug use was the most common risk factor (52 percent); 18 percent had a sex partner with a history of drug use; 7 percent had a sex partner otherwise at increased risk for or known to be infected with HIV (bisexual men or hemophiliacs); 11 percent had histories of blood transfusion; and 4 percent were born in countries with predominantly heterosexual transmission. A final 8 percent had undetermined means of exposure (Centers for Disease Control 1989a). Since these data were analyzed, the numbers have doubled, but the percentages remain relatively constant, except that the category of heterosexual transmission continues to increase (Centers for Disease Control 1989b).

Women are dying of AIDS in growing numbers. According to the CDC, although other causes of death among women aged 15 to 44 years have remained relatively stable during the last decade, the death rate due to HIV infection quadrupled between 1985 and 1988. By 1987, in New York and New Jersey, HIV/AIDS among black women

in this age group moved ahead of malignant neoplasms and heart disease to become the leading cause of death. If current nationwide mortality trends continue, AIDS can be expected to become one of the five leading causes of death among women by 1991. Moreover, deaths attributable to HIV/AIDS are widely believed to be underreported (Chu, Buehler, and Berkelman 1990).

In the Bronx, the prevalence of HIV infection in women giving birth is 1 in 43 (Novick et al. 1989). Nationwide, from 1981 to April 1990, 2,315 cases of pediatric AIDS (0 to 13 years of age) have been reported to the CDC. According to the 1981-1988 data review, most (82 percent) were under the age of five at diagnosis, and 40 percent were under one year. Mirroring the racial composition of women with AIDS, 52.5 percent of the children were black; 23.9 percent white; 22.9 percent Hispanic; 0.5 percent were Asian/Pacific Islander; and 0.2 percent American Indian/Alaskan Native. Over three-quarters (78 percent) are presumed to have acquired HIV infection perinatally from their mothers, 13 percent from blood transfusion, and 6 percent from blood products used to treat hemophilia. (The percentages of pediatric AIDS cases in the last two categories can be expected to decline in the future as a result of blood screening.)

African-American and Latino pediatric AIDS patients are more likely to have mothers with histories of IV drug use or of sex with IVDUs than are white children. They are also much more likely to be poor. AIDS care is increasingly financed by Medicaid (an increase in New York state from 36 percent in 1983 to 49 percent in 1986 and still climbing), and women's health care is heavily concentrated in the Medicaid population (P. Arno and J. Green 1990. Personal communication). In addition, the areas of the city with the highest rates of infection (outside of Greenwich Village, the center of the gay male population) are the South Bronx (Hunts Point/Mott Haven) and East Harlem, among the poorest neighborhoods in the city (New York City Department of Health 1989). The New York City Department of Health compared the postal ZIP codes of residence as reported on the AIDS surveillance form for heterosexual cases with risk of intravenous drug use diagnosed through 1987 with the 1980 U.S. Census Bureau's poverty indices. Not surprisingly, there was a strong positive correlation between the proportion of individuals below the poverty level and the number of AIDS cases (Stoneburner et al. 1990).

The phenomenon of perinatal transmission is too recent to have pro-

duced a clear picture of the natural history in infants and children. A prospective study of 117 infants in France concluded that approximately one-third of the infants born to seropositive mothers will have evidence of HIV infection or AIDS by the age of 18 months (Blanche et al. 1989). According to Dr. Stephen C. Joseph, former health commissioner for New York City, the current rate of transmission in the city is 29 percent (Joseph 1989a). All babies born to HIV-infected mothers carry maternal antibodies; in approximately two-thirds of the infants, these antibodies will disappear by the age of 15 months. The babies are then presumed to be uninfected (Pizzo 1989), although some born to drug-using mothers may have developmental difficulties (not uncommon in this population). Of the remaining third, who are truly infected, some are born dying, others will sicken within the first few months of life and die quickly, and still others will have evidence of disease intermittently over years. Nevertheless, some may remain healthy for years; some children aged five or six are only now developing symptoms of HIV illness (Auger et al. 1988).

However, accepted rates of perinatal transmission of HIV virus may be misleading. A recent article reported that in studies describing the effects of cocaine use in pregnancy, the "likelihood of a negative study being selected for presentation was negligible" (Koren et al. 1989, 1441). So too, professional journals may not as readily publish studies that demonstrate a less efficient transmission of HIV, selecting instead studies that show higher rates of transmission.

The Lives of HIV-infected Children

Although there is as yet no cure and no long-term treatment, some HIV-infected children may benefit from therapies currently being tested (Pizzo 1989). At present, the situation for most is more comparable with a long-term chronic disease like cystic fibrosis, rather than a degenerative and inevitably fatal illness like Tay-Sachs, from which most children die before the age of three. Given the current state of knowledge, there is no way to predict whether an HIV-infected woman will infect her fetus (the chances are in fact that she will not), no reliable way to determine in utero or at birth whether a baby is infected (unless it is born with symptoms), and no way to foretell the likely course of the disease over time. This array of uncertainties is weighed

very differently by public-health officials and physicians and by women at risk.

Physical suffering and developmental and neurological impairments are only a part of the painful and uncertain existence many of these infants and toddlers may face. Their psychosocial situation may be precarious at best, a condition they share with many poor babies. Some states, including New York, consider habitual drug use by a parent as *prima facie* evidence of child neglect. In New York City, if a baby tests positive on a toxicology screen (ordered when the mother is suspected of drug use), a mandatory report to the Office of Special Services for Children (SSC) is triggered (Chavkin 1989). Because the investigation may be prolonged, the mother may be discharged without the baby, thus further jeopardizing the formation of a mother-infant bond. Some of these infants are returned to their mothers; others are ultimately adopted; the majority are placed within the overwhelmed foster-care system, or with family members, many of whom are ill prepared to cope with their needs.

Can these infected children be said to “benefit” from their lives? The answer depends on their health status and living situation. Visit a neonatal intensive-care unit where cadaveric infants born with AIDS are breathing laboriously, and one is inclined to say no. Visit a family with an asymptomatic mother and child or a pediatric transitional residence where cheerful, responsive, asymptomatic or only mildly ill HIV-infected babies are lovingly cared for, and one is inclined to say yes. These responses are no different from those that occur with other serious illnesses with an erratic and unpredictable course.

A child-centered analysis based only on the worst outcomes leads many to the conclusion that all HIV-infected babies are doomed and therefore should not be born, and that public policies should be developed to prevent or discourage HIV-infected women from giving birth. A typical view is that expressed by Mary Steichen Calderone, co-founder of the Sex Information and Education Council of the United States (SIECUS), who wrote, in arguing that “innocent” and “grotesque” fetuses born to drug-abusing mothers have a right *not* to be born: “And there is also the fetus infected by an AIDS-carrying mother. Until a cure is found for this wildfire disease, why should the same right not to be born be withheld from this fetus?” (Calderone 1989).

Many HIV-infected babies are no worse off than babies born with other severe and life-threatening birth conditions, yet there are no

comparable claims that all such babies should have been aborted. Indeed, as a society we point proudly to expensive and technically elaborate neonatal intensive-care units constructed to support the imperiled lives of premature infants. The vast majority of these newborns are also poor, and adequate prenatal care would have prevented most of these premature births and their attendant disabilities. Moreover, in the extended discussions among bioethicists, physicians, and lawyers that followed the Baby Doe and similar cases, a consensus has emerged that babies with serious disabilities should be treated except in cases where they are born dying and where treatment would not only provide no benefit, but would also increase pain and suffering. John Arras, a philosopher, has argued for an “ethic of ambiguity” in decision making about imperiled newborns:

[W]hy should the sentiments of normal adults be used as the touchstone of meaningful life for imperiled newborns? Although most normal adults are no doubt well-meaning and genuinely concerned not to abuse their standard of judgment, they are undoubtedly biased in favor of normalcy. . . . Adopting the child’s viewpoint would be difficult in practice, but it would conform more closely to the spirit of the best-interest standard. The issue, after all, is the welfare of the child, not the hopes and fears of adults that might be projected onto the child (Arras 1984, 30).

The Lives of HIV-infected Women

In the case of HIV infection, it is not only the lives of infected babies that are at stake, but also the lives of their mothers, the majority of whom are poor women of color. In the sanitized and dissociated language of the epidemiological statistics, HIV-infected women are primarily described by their race or ethnicity or by their risk behavior. These impersonal categorizations, however, do not adequately capture their life experiences. In the descriptions that follow, we will, of necessity, generalize, fully acknowledging that individuals differ and that some women in the same circumstances have surmounted serious deprivations and hardships. Nevertheless, what follows is, we believe, a reasonably accurate social portrait—underscoring the sets of cultural assumptions and beliefs that influence, implicitly if not explicitly, individual decision making.

Poverty tends to flow across generations (Farley 1988). Women in very poor families have grown up largely isolated from the economic goods of majoritarian society. Public education is grossly inadequate. In some New York City inner-city neighborhoods the dropout rate in high school is estimated at from 60 to 80 percent, over twice as high as the official citywide statistics (Asencio 1990; Berger 1990). Even those who graduate from high school may not have the basic skills for employment. Education offers less payoff for poor people than for the middle class (Bowles and Gintis 1976). Put another way, the teenagers and young women who are particularly at risk for HIV infection do not have access to economic or educational institutions that reward postponed childbearing.

In some urban poor communities, moreover, sexual activity begins as young as age 11 or 12 for girls and a few years older for boys. The role of sex in these children's lives is neither an erotic expression nor a response to romantic love, but rather a happening—a part of the “warm body syndrome” or the search for comfort. For many urban poor there is neither privacy nor time for loving sexual encounters and many of those which lead to pregnancy (and perhaps to HIV transmission) occur in hallways with both partners fully dressed. Sex in a drug culture tends to produce either money to buy drugs or the drugs themselves (Stone et al. 1989). Many of these young people live in unsupervised and anomic settings. Because truancy from school is the norm rather than the exception, socializing and sex, rather than education, established the basic structure of the day (New York State AIDS Advisory Council 1990). The expansion of the drug culture and the unprecedented economic power it has brought to the young people who become enmeshed in it have further removed the possibility of planning for alternative futures.

As a result of these conditions, the rate of unintended pregnancy is considerably higher among poor teens of all races than among the teenage population as a whole. There is a low level of knowledge about and use of contraceptives (Mays and Cochran 1988). Attempts to educate young women about the possible negative effects of teenage pregnancy have been largely unsuccessful. The only exceptions have been programs that provide consistent, well-supported services and messages throughout the community (Stout and Rivara 1989). Eighty percent of teenage mothers did not consciously want to get pregnant but did so anyway because of a lack of knowledge about contraception, or a desire

to be liked by a particular boy. When they do get pregnant, poor teenagers are less likely to get an abortion (National Research Council 1988). They do not abort because having a baby carries the possibility of love and purpose. Yet there is no clamor for intensive and meaningful education and skill building about contraceptives. Indeed, much government attention remains focused on preventing agencies from counseling about contraception and certainly about abortion.

HIV-infected women are mainly young, in their twenties and early thirties, although the number of adolescents is increasing. Over half are IVUDs. Poverty and location place women in the path of HIV, as neighborhoods fall subject to the marketing strategies of drug distribution. A growing number of women use cocaine, or crack, the drug's smokable, highly addictive, readily available form. Crack use often results in hypersexuality, and the women may be forced to sell sex for drugs or money. The link between crack and HIV as well as increasing rates of sexually transmitted diseases (STDs) is only now being recognized (Weissman, Sowder, and Young 1990).

Some women who are infected with HIV are homeless adolescents who have acquired the disease through street trade—selling sex to support a drug habit. Some are adolescents whose only risk factor was occasional unprotected heterosexual intercourse and whose infection was discovered during the routine physical following an application to the armed services or the Job Corps (Hein 1989). And some are women who did not know that their spouses or long-time partners were HIV-infected.

Approximately 200 women with symptomatic HIV infection have been or are cared for by the AIDS team at Montefiore Medical Center, where one of the authors (N.N.D.) directs the Division of Legal and Ethical Issues in Health Care. Over 90 percent of these women have dependent minor children who are cared for by female relatives during periodic acute hospitalizations and after death. In interviews and support groups, HIV-infected women describe a world in which they are often dependent on men for self-esteem and in which long-term, mutually monogamous marital or sexual relationships are highly prized but not often available.

These conditions, in short, offer fertile ground for the spread of HIV infection. In such settings, women's risks—of abuse, violence, loss of housing, illness, discrimination—are daily fare. To them, AIDS is just another, and less immediate, risk.

The Cultural, Political, and Social Contexts of Reproduction

Churches and Pronatalist Ideology

Cultures, groups, or societies who feel themselves particularly threatened, such as populations in time of war or persecuted religious minorities, see reproduction as an affirmation of life and a hope for survival. A similar phenomenon may be at work in the African-American community, where 23 percent of all males are incarcerated or under the supervision of the corrections system (Maurer 1990) and 1 in 12 men in their twenties are in prison or jail (Morris 1988), where the health status of men is poorer than in many parts of Africa, and where whole families are dying of AIDS.

The pronatalist message is conveyed by both religious and secular institutions. In a secular society, the role of religion in influencing individual attitudes and behavior is difficult to evaluate. It is even harder to assess the impact of religious beliefs on the attitudes and behaviors of those who are members of a community but not formally affiliated with a particular religious organization. Yet it seems clear that churches are a powerful mobilizing force in African-American and Latino communities and that their teachings and activities, as well as their reluctance to address certain issues, reflect and influence their constituents' cultural and ideological concerns. The churches are not only bastions of religious belief, but also the center of many social welfare programs, providing day care, food, shelter, and referrals to other services.

One reason it is difficult to generalize about the power of African-American churches, as well as the Protestant and Pentecostal churches serving one-third of the Latino population in New York City, is that they are decentralized and largely autonomous. Moreover, in both Latino and African American communities, the churches' basic constituencies—the middle class and stable working class—are struggling to leave urban centers where drug use is endemic. Nevertheless, like the Catholic churches that serve an additional third of the Latino population (Fernandez 1989), most of the African-American churches are “doctrinally fundamentalist and socially conservative” (Dalton 1989, 211). In 1984, Ronald Reagan carried a majority of Hispanic Catholics “because of his conservatism and his opposition to abortion” (Stevens-Arroyo 1988). It seems clear that opposition to abortion is widespread

among African-American ministers and among civil-rights organizations mainly advocating for the rights of minority groups. As Donna Brazile, a black political consultant, said in explaining the lack of African-American participation in a pro-choice march on Washington in April 1989, "If the minister says, 'This is genocide, this is sterilization,' you're not going to get the choir girls out of the loft" (Dionne 1989).

Ministers in some African-American churches have begun to address AIDS more directly and prominently, preaching messages of compassion and charity toward those who are ill (Goldman 1989). Prevention messages, however, are often phrased in moralistic terms, condemning homosexual behavior, sex outside marriage, and drug use. Such messages sometimes conflict with already well-established behaviors in the inner city. Moreover, because the majority of churchgoers are women, men are isolated from even this type of prevention message (Goldman 1990). Participants in church services and activities often see HIV as less significant, or as a less easily acknowledged problem, than unemployment, crime, drugs, homelessness, poor health care, and other urgent issues affecting community survival.

Beyond the urgency of other concerns, many African Americans view any attempts to interfere with or discourage reproduction as part of a plan for genocide. Harlan L. Dalton, an associate professor of law at Yale Law School and a member of the National Commission on AIDS, describes this deeply felt belief:

Two assumptions underlie the strong claim of genocide. The first is that the hostility of white America toward black America is so powerful, or the disregard so profound, that no depredation is unthinkable. This view is rooted in racial strife and feeds on the storehouse of sins visited upon blacks by whites. The second assumption is that under the right circumstances, the government is not above compromising the lives of innocent citizens (Dalton 1989, 221).

Although it is quite clear that many private citizens have seen AIDS as one way to rid society of drug users and other "undesirables" whom they consider a drain on society, these attitudes have not been translated into any explicit or even implicit government policy. Nonetheless, one should not underestimate the symbolic and emotional power of this perceived threat to minorities, nor the prevalence of punitive attitudes among the public.

This suspicion of white motives may also account for the variable use

of genetic screening by different communities. Dr. Stuart H. Orkin, a geneticist at the Harvard Medical School, has commented on the contrast between community practices. A prenatal test to diagnose beta-thalassemia, a disease of Greek and Scandinavian populations, has almost eradicated the condition; in the 20 years a prenatal test for sickle-cell anemia has been available, it has been requested from his staff only three times (Lauerman 1990). This discrepancy may reflect community values regarding prenatal screening or the genetic screening center's lack of outreach to the communities affected by sickle-cell anemia. Even if programs have a beneficent intent, efforts to stem the spread of HIV through the control of reproduction may be seen as attempts to destroy the African-American and Latino communities. There is a widespread perception in the African-American community that public-health information about HIV infection is in fact inaccurate or developed particularly to discourage sexual activity and reproduction.

The Cultural Value of Reproduction

Babies and pregnancy have a special symbolism for many poor women of color. Janet Mitchell, a perinatologist at Harlem Hospital, says, "Latino and black cultures place great value on a woman's fertility. Having a child elevates the status of the woman in her community." Moreover, she says, "Pregnancy may be the only time when drug-using women feel good about themselves. Numerous studies have shown that pregnancy is a strong motive for these women to go 'straight'" (Mitchell 1988, 51). Another author writing about reproductive issues stated:

Childlessness is a very serious concern in communities of color. As a result of cultural norms and restricted opportunities for women to have a professional career, motherhood and family life are generally valued very highly. Therefore, losing the option of procreating and parenting can be devastating to a poor woman or a woman of color (Nsiah-Jefferson 1989, 51).

A baby is the chance to have something concrete to love, or as important, to be loved by. It is proof of fertility and the visible sign of having been loved or at least touched by another. One HIV-infected woman at the Women's Center at Montefiore poignantly explained why she wanted to have a baby:

I really wanted something of mine, you know, mine, mine. I don't have nothing in this world . . . nothing that I really care about (A. Pivnick 1990. Personal communication).

For some who are HIV positive and who can face their own mortality, it is a chance, a better-than-even chance, to leave someone behind for a mother or husband to care for in the future . . . the link to immortality that genealogy presents. In Latino cultures, Ernesto de la Vega of the Panos Institute comments:

[P]art of [Latinas'] culturally-determined mission in life is to assure the life of the male and to provide him with existential continuity—that is, to provide him with a male baby that will inherit and pass on the family name. In addition, because a woman's life is traditionally defined by the presence of her male partner, she may wish to have, in the form of a child, a reminder of him so that she can feel she has a graspable part of him if he should die prematurely of AIDS (de la Vega 1990).

Sallie Perryman, an African-American woman whose husband, a former drug user, died of AIDS, and whose two brothers-in-law and one sister-in-law also died of the disease, says:

I . . . listened as I heard it . . . proposed that women of childbearing age postpone pregnancy or that HIV positive women consider [terminating] their pregnancies, knowing that the infant mortality rate for Black people in the United States is two times that of the white race and cognizant also of the fact that for every single infected child averted, to limit the transmission of AIDS, two healthy children would be eliminated. I ponder what the reality of such a proposal will be . . . applied to me and my family, where an entire generation of men have ceased to exist. . . . (Perryman 1990)

Although Perryman admits that “much of my community is still in denial,” a “collective unconscious” of the Jungian sort may be at work here. One need not accept the concept of an active governmental policy of genocide to appreciate the power of the loss of a generation of men through societal neglect and the community's desire to replace them through the birth of a new generation.

Other women have faced similar reproductive decisions; the Jewish woman of Middle-European descent faced with the possibility of a Tay-

Sachs child provides a good comparison. In that instance, society never considered condemning women or limiting or circumscribing their reproductive rights. It was assumed that affected women and men would make "responsible choices," defined as forgoing childbearing (perhaps in favor of adoption) if a possibility existed of producing a Tay-Sachs child, or aborting an affected fetus. In the history of this screening, however, there were few reports of screening abuses and violations of patient rights. In contrast,

a survey of counseling programs for sickle cell anemia recently found that almost half of the clients studied are screened without their informed consent, and that many facilities were deficient in providing education and post-screening counseling (Nsiah-Jefferson 1989, 34).

In the case of Tay-Sachs, moreover, the identification of danger and the creation of standards as guides for behavior were set by the Jewish community itself, by and for its members. Genetic screening was regularly promoted by religious leaders. The ethos and ethics emerged from, and were not imposed on, the afflicted community. The information was culturally, ethnically, and religiously compatible with the community it was designed to serve. In this respect, then, there was no real difference between the values of the Jewish community and the surrounding culture. Even in this most favorable of circumstances, stigmatization of those identified as "carriers" did occur, and some critics have pointed to elements of coercion in the programs (Goodman and Goodman 1982). More generally, Barbara Katz Rothman points out that the existence of prenatal diagnosis has, in the guise of expanding "choice," increased pressures on women to have small families of "perfect" children (Rothman 1986).

Another important reason why HIV-positive women may become pregnant or choose to continue a pregnancy is to replace a child lost through disease, denial of custody, or simply the complexities of life in poverty. In her study of the reproductive decisions of seropositive women who had already borne a child, Anitra Pivnick, an anthropologist at Montefiore, found that women who chose to terminate pregnancies had a significantly greater chance of having lived with a previous child for at least 85 percent of the child's life, of having been the direct recipient of welfare funds for at least one child, and of maintaining legal custody of at least one child (Pivnick 1990). She believes

that reproductive decisions are influenced by women's "histories of separation from and profound yearnings for lost children—children lost because of inadequately treated maternal drug use, lack of recognition of drug use as a chronic disease, difficulties in conceiving or carrying a child, a not always discriminating foster care system, the spiriting away of children by women's mothers, children's fathers, and other family members, thereby eliminating the possibility of communication between mothers and children. . . ."

The decision to reproduce or limit reproduction, to "bear or beget" a child, to permit or attempt to limit conception, or to abort after conception is a complex decision that only exists in the personal, cultural, social, economic, and religious context of any individual woman. A society that permits poverty, drugs, and economic dislocation, spends proportionately less for education of the poor while overlooking truancy and dropouts, and perpetuates neighborhoods with inferior health care and social services bears at least some moral responsibility for the consequences of these unleashed societal forces.

Reproductive Rights and Reproductive Counseling

Individual women's choices about reproduction are influenced not only by contemporary attitudes in their communities, but also by their communities' past history, in this case, a shameful history of abuse. Even if they have had no direct experience with attempts to control reproduction, women have grown up in social conditions in which such attempts have often been described and decried.

Middle-class, professional concern about poor women of color or mentally disabled women having babies repeats a familiar pattern, but the overlay of HIV is relatively new. At different times and in various ways, American society has attempted to control women's reproductive decisions. Although some attempts were frankly coercive, such as the forced sterilization of Puerto Rican women in the 1950s (Bey 1990), even the "voluntary" ones quickly evolved into efforts to restrict women's reproductive rights. Indeed, sterilization rates as high as 65 percent were reported for Latina women in two communities of the northeast United States.

Whether the underlying "defect" was poverty or sickle-cell trait, coercion never lay far behind counseling. The reasons are many: fear of

the fecund and awesome fertility of women, unwillingness to provide public support for "welfare mothers," a social class structure in America that, it can be argued, values and respects certain kinds of lives over others. It is interesting to note that *Buck v. Bell*, the Supreme Court decision that permitted the sterilization of a supposedly mentally retarded woman (later proved not to be), has never been overruled.¹ One can speculate whether this is a conscious policy or an oversight; nonetheless, Mr. Justice Holmes's statement that "three generations of idiots are enough" even now permits contemplating the forced sterilization of mentally retarded women. This question has been raised already in the case of drug-abusing mothers, many of whom are the same ones at risk for HIV. For example, Dr. Jan Bays, director of the Child Abuse Programs at Emmanuel Hospital in Portland, Oregon, says: "We must up the ante to criminalize or impose reproductive controls on people who are out of control. . . . the nice thing about jail is that moms get good prenatal care, good nutrition, and they're clean. . . . But we can't force people into treatment, even if they're in jail. . . . So people are talking about sterilization. . . ." (Bays 1989). Dr. Bays is perhaps unaware of the grim realities of prison life today. Many obstetricians who responded to a random telephone survey conducted by *Ob Gyn News* favored forced sterilizations, even though the American College of Obstetricians and Gynecologists has strongly opposed court-compelled procedures (Newman 1987).

Sterilizations have never been offered or imposed equally across the population. There were specific social-policy decisions to sterilize criminals, mentally retarded women, American Indians, and in some states poor African-American or Puerto Rican women (*New England Law Review* 1976). The federally financed sickle-cell initiative of the 1960s, which was couched in the form of education, was perceived by many of the target group to be an attempt to limit reproduction of African-American women who carried the sickle-cell trait. Some people assert that Planned Parenthood, which now stands strongly behind the rights of poor women to make reproductive decisions, began as an organization with an interest in limiting reproduction among these women, certainly for their benefit, but also for the sake of society.

Nsiah-Jefferson notes:

¹ *Buck v. Bell*, 274 U.S. 200 (1927).

Blatant sterilization abuse was exposed in the 1970's. Public assistance officials tricked illiterate black welfare recipients into consenting to the sterilization of their teenage daughters. Native American women under 21 years of age were subjected to radical hysterectomies, and informed consent procedures were ignored. Doctors agreed to deliver the babies of black Medicaid patients on the condition that the women be sterilized. Doctors have also conditioned the performance of abortions on "consent" to sterilization (Nsiah-Jefferson 1989, 46).

However, women whose reproductive rights were threatened have won significant rights. The case of *Relf v. Weinberger* established that young women could not be sterilized over their objection.² Regulations that began in New York City and then were extended to federally supported programs established that sterilization of a woman could not take place without adequately informing her, discussing with her the risk of and alternatives to sterilization, and, most important, protecting her by a mandatory waiting period of 30 days between the decision for sterilization and the intervention. By law, the delivery room could no longer be the setting in which physicians urged women to be sterilized, received permission, and promptly carried out the plan (Petchesky 1979). In practice, however, HIV-positive pregnant women not infrequently report such coercion (Franke 1989).

Poor Women's Diminishing Access to Health Care

While interference with reproductive choice is a "fact of life for most poor women and women of color" (Nsiah-Jefferson 1990), paradoxically these women often experience difficulties in obtaining health care, related or not to reproductive services. Access to health care in the inner city varies from limited to nonexistent. There are few developed patterns of integrated health-care use and preventive care. Prenatal care for drug users is grossly inadequate, and most drug-treatment programs do not enroll pregnant women and are not set up to permit a woman with child-care responsibilities to comply with the rules (Chavkin 1989). The system is complex and indistinct, and is entered only in emergency or as a last resort.

² *Relf v. Weinberger*, 368 F. Supp. 1383 (1974).

A survey of nine poor communities in New York City revealed that one-third of the women who gave birth in 1986 received inadequate prenatal care (that is, no care at all or care that started in the third trimester). In the Mott Haven community in the Bronx, over 50 percent of mothers who gave birth had inadequate care. The unmet need for obstetrician-gynecologists in poor areas of New York is 62 percent greater than the unmet need for all primary care providers—an additional 500 physicians (Brellocks and Carter 1990). These grim statistics, combined with the seroprevalence data on women giving birth, foreshadow a rising curve of perinatal transmission. Even before AIDS, infant mortality was higher among poor inner-city populations than among middle-class whites. Expressed in number of deaths per year to infants under one year old per thousand live births, the mortality rate in 1983 was 9.7 for whites but 19.2 for blacks (National Center for Health Statistics 1986).

Sterilization and other attempts to limit reproduction are only one side of the restrictions on reproductive freedom. Abortion rights, given constitutional sanction under *Roe v. Wade* in 1973, have been increasingly threatened.³ Many women who cannot pay for an abortion themselves also cannot obtain one with public funds. In 1981 Congress restricted Medicaid payments for abortion to cases in which the woman's life is endangered by her continued pregnancy. Many states, urged on by Right to Life organizations, have limited further funding. Five states provide some limited further services and only 12 provide for general funding of poor women's abortions. For poor women in Michigan and Nevada, abortion for the reason of a possibly HIV-infected child is not an option. Federal funds may neither be used for abortion nor for any counseling or education that mentions abortion as an alternative. The Supreme Court decision in *Webster v. Reproductive Health Services* presents the clearest signal that *Roe v. Wade* may be overturned.⁴

The avenues for helping poor women reach reasoned judgments on reproduction and abortion are ever diminishing. The decision to abort is always a complicated and difficult one; when financial, emotional, personal, religious, and cultural barriers stand between the woman and the act, the path may seem insurmountable. Previously, many young women confronted with unplanned pregnancies had refused abortions

³ *Roe v. Wade*, 410 U.S. 113 (1973).

⁴ *Webster v. Reproductive Health Services*, 109 S.Ct. 3040 (1989).

for a number of reasons: desire to have a baby, lack of information about possible avenues for help, concerns about payment, cultural attitudes favoring pregnancy and reproduction and rejecting abortion, the desire to possess totally an object or person whose loyalty will be unquestioned (but whose demands are not necessarily anticipated). Some women whose addiction to drugs overwhelms all other considerations may not be able to mobilize their energies to secure a timely abortion. There may even be women who neither care nor worry about the consequences for self and for child. They will disregard warnings and exhortations; nothing less than physical restraint or forcible sterilization—both options we categorically reject—will suffice. Creating a humane public policy and appropriate drug treatment for such desperately needy women is an immense challenge.

Women who do decide to terminate a pregnancy are increasingly unable to find services to carry out that plan. Access to abortion is even further limited for HIV-infected women whose serostatus is known or disclosed. A recent survey conducted by the AIDS Division of the New York City Commission on Human Rights found a systemic barrier to abortions for women who reveal that they are HIV-positive. In that study, 20 of the 30 clinics and private doctors called would not keep the appointment after the caller identified her serostatus. Twelve of the 30 providers indicated that they could not perform the procedure because of inadequate infection-control procedure, and not a single provider located in Brooklyn would make an appointment (Franke 1989).

Anticipating the Supreme Court decision in *Webster*, Dr. Stephen C. Joseph, former New York City Health Commissioner, wrote in May 1989 that limitations on abortions in other states would bring an influx of women to New York where abortions for residents and nonresidents alike are paid for by public funds. The increased burden on the health and welfare systems, as well as rising antiabortion sentiment, might lead the New York state legislature to restrict abortions. In that event, Dr. Joseph suggests, "HIV-infected women could be specifically exempted from a law restricting abortion" (Joseph 1989b). This view can only be explained by a theory that birth of an HIV-infected baby is "worse" than the birth of a baby with other illnesses. Part of this outlook may relate to the prognosis, but part also stems from the perception of an increased burden on public assistance by mothers who are poor women of color with a chronic, ultimately lethal disease. Perhaps the birth of these babies also seems an affront to the authority of gov-

ernments because public-health officials have declared that the birth of these infected babies should be prevented.

HIV-infected women—the same class of women who have traditionally been encouraged or coerced to limit reproduction, on grounds either of benefit to themselves and their families or of benefit to society—are now being encouraged to limit reproduction to prevent transmission of disease to their children and on grounds of costs to society. However, at the same time their options for making this choice independently are being restricted. Women placed in this no-win situation, not surprisingly, cannot win.

Making Choices in Uncertainty

Against this formidable background of political, cultural, and social forces, individual women make reproductive decisions in highly particularistic ways. In situations of uncertainty, such as the risk of contracting or transmitting HIV, probabilistic reasoning is essential. Yet probabilistic reasoning—the weighing of risks and benefits, the ability to conceive of abstract harm, and the skill of distinguishing between likely and unlikely future consequences—is difficult for almost everyone.

Risks that are immediate, catastrophic, and against which clear action can be taken are treated differently from risks that are long term, less serious, and offer few or unacceptable preventive actions, regardless of the statistical level of risk. Let the Food and Drug Administration discover a few poisoned grapes, and people will immediately stop eating grapes, no matter how remote the risk. How much more difficult it is to convince people to change ingrained and far riskier behaviors such as smoking, overeating, or sedentary life styles. If older, “wiser” patients at risk for cardiovascular disease have trouble adopting risk-reduction behaviors, it is not surprising that young women find it difficult to embrace information arguing for behavior change that is difficult to implement and that removes an element of satisfaction from their lives.

Uncertainty is a central concern for all seriously ill persons, and may be even greater for persons with HIV/AIDS because the disease is new and medical knowledge is advancing rapidly. Because so much attention has been focused on men with the disease, women may be particularly distrustful of medical information and predictions about their

own future and that of their potential children. Moreover, as Rose Weitz, a medical sociologist, points out: "Nongay PWAs [People With AIDS] (especially women) . . . are far less likely to have networks of fellow sufferers to whom they can turn for advice and information. . . . Others either are unwilling to accept help from groups dominated by gay men . . . or are unable to obtain help because their problems are too different from those of gay men" (Weitz 1989, 278).

One factor that seems to make a difference in all health-related risk assessments is the certainty of the outcome. That is, not all smokers will die of lung cancer or heart disease; some people will take that risk rather than give up the pleasure of smoking. One study of decision making in genetic disease found that certainty of outcome was a more compelling factor than severity of a birth defect in attitudes about abortion (Faden et al. 1987). A reliable prenatal diagnostic test for true HIV infection would undoubtedly affect many women's decisions.

The most crucial element in poor women's response to AIDS is their perception of its danger relative to the hierarchy of other risks and benefits present in their lives and the lack of resources to make alternative choices. In the case of perinatal HIV transmission, with its inherent uncertainty, many women are willing to take the risk because the alternatives—including rejection by a man, disclosure of their HIV status to family—may seem worse. Public-health officials, judging from their public posture, seem only to appreciate one risk—that of perinatal transmission.

Additionally, in decision making, women—regardless of class or education—may have a different value structure from men. In the world of HIV-infected women, other women are the most powerful continuing source of support. It is a world in which women make decisions with other women about babies who will be largely raised by women. Carol Gilligan's well-known but controversial work on moral development suggests, in a comparison of male and female responses to Lawrence Kohlberg's scheme of moral dilemmas, that, whereas women "try to change the rules in order to preserve relationships, men, in abiding by these rules, depict relationships as easily replaced" (Gilligan 1982, 44). To the extent that Gilligan's theory is relevant, it supports a characterization of the decision-making process as one that emphasizes relationships (that of mother to infant, woman to man), deemphasizes the "logical" rules imposed by powerful social institutions, mostly run by men, and reinforces feelings of powerlessness regarding choice.

In a community of high prevalence of HIV, a non-drug-using woman who wants to prevent perinatal transmission has three choices: insist on a negative HIV test from her male partner and trust that he will neither share needles or have sex with any other partners; abstain from sexual relationships; or insist on the use of condoms. The first is unrealistic; the second a price we cannot expect to exact involuntarily from any individual; and the third, which provides some protection from HIV infection, may alienate the sexual partner or result in physical abuse. As Albert Bandura points out, "Unlike protection against pregnancy, where women can exercise independent control, use of condoms requires them to exercise control over the behavior of men" (Bandura 1987).

In order to make a decision on the use of condoms therefore, a woman must first perceive herself as "at risk" for transmission of the virus, and then as able to take some protective action. This requires abstract notions of percentage risk or probable risk, the ability to conceive of a life plan with a future, and the foresight to conceptualize and integrate possible future negative consequences. It also may require the willingness to insist, in the face of opposition from a male sexual partner, on the use of a barrier contraceptive. This insistence on use of a condom implicitly involves creating a personal hierarchy of benefit and risk: is the risk of a loss of a sexual partner or abuse by that partner greater or less than the risk of acquiring AIDS?

A woman may approach the decision differently depending on her knowledge of her sexual partner, the power relationships in the alliance, previous reactions to the suggestion for condoms, and her willingness to risk rebuff, rejection, or even abuse. It is difficult to isolate knowledge of risk and action from male sexual attitudes and practices. Male partners may be uncooperative, hostile, or duplicitous. For example, a recent study found that men commonly lie about their sexual past and drug use, making it pointless for women who are dating them to ask about their past (Goleman 1988).

Drug and methadone-maintenance counselors at Montefiore report that some women will not return for further discussion once contraception has been urged (Montefiore Staff 1990. Private discussion.) Some have been beaten by husbands and lovers for suggesting condoms. Others are so addicted to drugs that any interference with the business of selling sex and buying drugs will not be tolerated. One counselor explained that there are women on drugs who are so impoverished by

their crushing needs that "they live only in the present" . . . there is no concept of the future and thus no future notion of future harm to themselves or to others.

Moral Responsibility: The Individual and the Community

We have argued that focused public-health policies designed to prevent HIV-infected women from having children are likely to fail because they are too narrowly cast. American society stands on a tenuous ethical base if its only vigorous program for poor women is aimed at prevention of childbearing.

Government and society, through the agency of public-health officials, physicians, and courts, have no moral right to intervene in this singular aspect of women's lives. They do, however, have a moral obligation to respond to larger social, educational, health care, and economic agendas that will empower women to protect themselves effectively against HIV infection in the first place and offer them options for self-esteem and achievement that are not based on reproduction.

This is a difficult conclusion to defend. It demands acknowledgment of the role of poverty in women's lives in the inner city and respect for their autonomous choices. It also requires an acknowledgment that some unknown number of infected children whose existence might have been prevented by coercion will be born, suffer, and die. Their suffering, shared by their grieving mothers and caregivers, is an undeniable cost.

There are at least two possible responses to our arguments. One is that we are guilty of the philosophical sin of "ethical relativism." That is, by emphasizing the social context of poor women's decision making, we accept the validity of different, class-based moral judgments rather than a single standard. Our explanation of why HIV-infected women continue to get pregnant and have babies may be interesting, even true, but morally irrelevant. If it is morally unjustifiable to bear an HIV-infected baby with clear knowledge of the risks, it is morally unjustifiable for all women of all classes to do so. In a variation of this critique, we might be accused of depriving women of their independent moral agency by placing so much emphasis on the context of their lives. Whatever happened to free will, one might ask.

An indirect answer to these objections would turn the critique on its head. If we are guilty of ethical relativism in stressing social context, then those who place the risk of HIV infection above all other potential risks to the fetus are guilty of the same aberration. If there is to be one standard, it should be applied equally to cystic fibrosis, Down syndrome, spina bifida, and HIV disease, and to those defects of prematurity that adequate prenatal care would prevent. If the HIV standard were to be applied, none of the births of babies with these conditions—*except* HIV detectable with certainty prenatally—would be morally justifiable. Few make this argument.

Beyond the indirect response, this criticism requires a direct answer; we do not agree that there is an absolute standard by which the birth of an HIV-infected baby is morally unacceptable. There is no intent to create harm; in fact, the intent is just the opposite—to bring good into the world. There is no certainty that harm will in fact be done; the majority of babies born to HIV-infected mothers will not be infected. HIV-infected women have the same moral obligation as men to refrain from behaviors that put their sexual or needle-sharing partners at risk. Although there are alternatives to unsafe sex and sharing needles, there is no safe alternative for an HIV-positive woman who wants to give birth to a baby.

Although the birth of HIV-infected babies has clearly undesirable consequences from the point of view of mothers, public-health officials, medical professionals, and society, it is, in our view, the tragic but inevitable price we must pay for previous and current neglect of their mothers.

A comprehensive approach to the problems inherent in women's lives, with special sensitivity to issues of childbearing and disease prevention, is essential to prevent further perinatal HIV transmission. Counseling women to refrain from pregnancy without providing alternatives for self-fulfillment and without providing education and skills about sexuality and reproduction may prevent some pregnancies but may equally well drive women away from systems that will be perceived as harsh and condemning.

As an alternative to current approaches, we urge several concurrent policies. First, meaningful education about sexuality and reproduction should begin in elementary school. This may not only prevent the spread of HIV infection and STDs to these women and their subsequent children, but might also help them avoid sexual abuse as chil-

dren. Second, access to medical services should be increased for all poor people so that children develop a rapport with health-care professionals and a meaningful language for discussing health and reproductive issues. Third, there should be increased access to prenatal care to reduce the number of impaired, non-HIV-infected babies. Fourth, pregnant women who choose abortion to prevent the birth of a possibly HIV-infected child should have timely access to services. Fifth, improved housing and support services will allow mothers to maintain relationships with children and reduce separations and loss of custody.

Even if there were any realistic hope that programs to redress prior injustices will be created and supported, they will take time. And when it comes to the birth of HIV-infected babies, there is no time. For the short term, education programs to prevent HIV infection in young women must be given high priority. These programs must be developed and implemented by credible, community-based providers who understand and share the primary values of their audiences, but who can transcend barriers to make the reality of risk real and prevention possible. The programs should involve young men as well as young women, and they must be tied to practical health and social services.

For those who are already HIV infected, counseling and testing programs must provide the best information available about risks of reproduction and about options available for contraception and termination of pregnancies. Job opportunities and educational programs of real substance would do more to encourage prevention than exhortations about the dangers of reproduction. Emphasizing the moral responsibility of HIV-positive women not to bear an HIV-positive child is the wrong focus with the wrong lens. If fairness and justice are to be served, the lens must be wide enough to encompass the moral responsibility of male sexual partners and society.

References

- Arras, J. 1984. Toward an Ethic of Ambiguity. *Hastings Center Report* 14(2): 25-33.
- Asencio, M. 1990. Presentation at New York State AIDS Advisory Council Committee on AIDS and Adolescents, New York City, May 29.
- Auger, I., P. Thomas, V. DeGruttola, et al. 1988. Incubation Periods for Paediatric AIDS Patients. *Nature* 336(8):575-77.

- Bandura, A. 1987. Perceived Self-efficacy in the Exercise of Control over AIDS Infection. Paper presented at the National Institutes of Mental Health and Drug Abuse Research Conference on Women and AIDS: Promoting Health Behaviors, Bethesda, Md, September.
- Bayer, R. 1990. AIDS and the Future of Reproductive Freedom. *Milbank Quarterly* 68 (Suppl. 2):179-204.
- Bays, J. 1989. Punishing Pregnant Addicts: Debate, Dismay, No Solution. *New York Times*. September 10:E5.
- Berger, J. 1990. High School: Sometimes 7 Years to Diploma. *New York Times*. June 22:B1, B2.
- Bey, M.O. 1990. The Migration of Women: Colonial Control and Women's Liberation (Unpublished.)
- Blanche, S., C. Rouzioux, M.-L.G. Moscato, et al. 1989. A Prospective Study of Infants Born to Women Seropositive for Human Immunodeficiency Virus Type 1. *New England Journal of Medicine* 320(25):1643-48.
- Bowles, S., and H. Gintis. 1976. *Schooling in Capitalist America*. New York: Harper & Row.
- Brellocks, C., and A.B. Carter. 1990. *Building Primary Health Care Services in New York City's Low-income Communities*. New York: Community Service Society of New York.
- Calderone, M.S. 1989. Fetuses' Right Not to Be Born. *New York Times*. September 16:A27.
- CDC AIDS Weekly. 1988. October 3:2.
- Centers for Disease Control. 1990. *HIV/AIDS Surveillance*. June.
- . 1989a. Update: Acquired Immunodeficiency Syndrome—United States, 1981-1988. *Morbidity and Mortality Weekly Report* 38(14):232-33.
- . 1989b. Update: Heterosexual Transmission of Acquired Immunodeficiency Syndrome and Human Immunodeficiency Virus Infection—United States. *Morbidity and Mortality Weekly Report* 38(July 28):423-34.
- . 1985. Recommendations for Assisting in the Prevention of Perinatal Transmission of Human T-lymphotropic Virus Type III/Lymphadenopathy-associated Virus and Acquired Immunodeficiency Syndrome. *Morbidity and Mortality Weekly Report* 34(December):721-32.
- Chavkin, W. 1989. Testimony presented to the U.S. Congress, House Select Committee on Children, Youth and Families, April 27. Washington.
- Chu, S.Y., J.W. Buehler, and R.L. Berkelman. 1990. Impact of the Human Immunodeficiency Virus Epidemic on Mortality in Women of Reproductive Age, United States. *Journal of the American Medical Association* 264(2):225-29.

- Dalton, H.L. 1989. AIDS In Blackface. *Daedalus* 118(3):205-27.
- de la Vega, E. 1990. Considerations for Reaching the Latino Population with Sexuality and HIV/AIDS Information and Education. *Siecus Report* 18(3):1-8.
- Dionne, E.J. 1989. Advocates of Abortion Rights Seek to Win Blacks' Support. *New York Times*. April 16:1.
- Faden, R.R., A.J. Chwalow, K. Quaid, et al. 1987. Prenatal Screening and Pregnant Women's Attitudes toward the Abortion of Defective Fetuses. *American Journal of Public Health* 77(3):288-90.
- Farley, J. 1988. *Majority Relations*, 2nd ed. Englewood Cliffs, N.J.: Prentice-Hall.
- Fernandez, N.J. 1989. Hispanics and HIV Infection: Can the Churches Help? (Unpublished.)
- Franke, K.M. 1989. *HIV-related Discrimination in Abortion Clinics in New York City*. City of New York Commission on Human Rights, AIDS Discrimination Division, June.
- Gilligan, C. 1982. *In a Different Voice*. Cambridge: Harvard University Press.
- Goldman, A.L. 1990. Black Minister Recruits More Men for Church. *New York Times*. July 5:B2.
- . 1989. Blacks Pause to Consider AIDS Peril. *New York Times*. June 12:B1, B9.
- Goleman, D. 1988. The Lies Men Tell Put Women in Danger of AIDS. *New York Times*. August 14:29.
- Goodman, M., and L. Goodman. 1982. The Overselling of Genetic Anxiety. *Hastings Center Report* 12(5):20-27.
- Hein, K. 1989. Commentary of Adolescent Acquired Immunodeficiency Syndrome: The Next Wave of the Human Immunodeficiency Virus Epidemic? *Journal of Pediatrics* (January):144-49.
- Holman, S., M. Berthaud, and A. Sunderland, et al. 1989. Women Infected with Human Immunodeficiency Virus: Counseling and Testing during Pregnancy. *Seminars in Perinatology* 13(1):7-15.
- Joseph, S.C. 1989a. Kenneth D. Blackfan Lecture: Pediatric AIDS in New York City: A Perspective from the Epicenter. Boston, June 7.
- . 1989b. Abortions by the Busload? *New York Newsday*. May 5:86.
- Koren, G. 1989. Bias against the Null Hypothesis: The Reproductive Hazards of Cocaine. *Lancet* 2 (8677):1440-42.
- Lauerman, J. 1990. The Time Machine. *Harvard Magazine* (January/February):43-46.
- Maurer, M. 1990. *Young Black Men and the Criminal Justice System: A Growing National Problem*. Washington: The Sentencing Project.

- Mays, V.M., and S.D. Cochran. 1988. Issues in the Perception of AIDS Risk and Risk Reduction Activities by Black and Hispanic/Latina Women. *American Psychologist* (November):950.
- Mitchell, J.L. 1988. Women, AIDS, and Public Policy. *AIDS & Public Policy Journal* 3(2):50-52.
- Morris, N. 1988. Race and Crime: What Evidence Is There That Race Influences Results in the Criminal Justice System? *Judicature* 72(2): 111.
- Murray, C. 1988. The Coming of Custodial Democracy. *Commentary* 86(3):19-24.
- National Center for Health Statistics. 1986. *Monthly Vital Statistics Report, Annual Summary of Births, Marriages, Divorces and Deaths: United States* 34(13).
- National Research Council, Panel on Adolescent Pregnancy and Child-bearing. 1988. *Risking the Future*. Washington; National Academy Press.
- New England Law Review*. 1976. Coerced Sterilization Under Federally Funded Family Planning Programs. 11:589-614.
- New York City Department of Health, Health and Surveillance Unit. 1989. *AIDS Surveillance Update*, November 29.
- New York State AIDS Advisory Council, Committee on AIDS and Adolescents. 1990. Presentation, New York City, May 29.
- Newman, A. 1987. Patterns of AIDS Spread Elicit Proposals to Tighten Precautions—Involuntary Sterilizations? *Obstetrics & Gynecology News* 22(1):36-37.
- Novick, L.F., D. Berns, R. Stricof. 1989. HIV Seroprevalence in Newborns in New York State. *Journal of the American Medical Association* 261(12):1745-50.
- Nsiah-Jefferson, L. 1989. Reproductive Laws, Women of Color, and Low-Income Women. In *Reproductive Laws for the 1990's, A Briefing Handbook*, eds. S. Cohen and N. Taub. Clifton, N.J.: Humana Press.
- Perryman, S.M. 1990. AIDS: Perspective of a Black Women as an Epidemic Among the Myriads. Presentation at Sixth International Conference on AIDS, San Francisco, June 20.
- Petchesky, R.P. 1979. Ethics and Public Policy: The Federal Sterilization Regulations. *Hastings Center Report* 8(5):20-41.
- Pivnick, A. 1990. *Residence and Reproduction*. (Unpublished.)
- Pizzo, P.A. 1989. Emerging Concepts of the Treatment of HIV Infection in Children. *Journal of the American Medical Association* 262(14):1989-92.
- Rothman, B.K. 1986. *The Tentative Pregnancy: Prenatal Diagnosis and the Future of Motherhood*. New York: Viking-Penguin.

- Selwyn, P.A., R.J. Caster, E.E. Schoenbaum. 1989. Knowledge of HIV Antibody Status and Decisions to Continue or Terminate Pregnancy among Intravenous Drug Users. *Journal of the American Medical Association* 261(24):3567-71.
- Stevens-Arroyo, A.M. 1988. Latinos Divided by Their Faiths. *Newsday*. June 3:88.
- Stone, A.J., D. Morisky, R. Detels, and H. Braxton. 1989. Designing Interventions to Prevent HIV-1 Infection by Promoting Use of Condoms and Spermicide among Intravenous Drug Abusers and Their Sexual Partners. *AIDS: Education and Prevention* 1(3):171-83.
- Stoneburner, R.L., M.A. Chiasson, I.B. Weisfuse, and P.A. Thomas. 1990. The Epidemic of AIDS and HIV-1 Infection among Heterosexuals in New York City. *AIDS* 4(2):99-106.
- Stout, J.W., and F.P. Rivara. 1989. Schools and Sex Education: Does It Work? *Pediatrics* 83(3):375-79.
- Weissman, G., B. Sowder, and P. Young. 1990. The Relationship between Crack Cocaine Use and Other Risk Factors among Women in a National AIDS Prevention Program—U.S., Puerto Rico, and Mexico. Presentation at the Sixth International Conference on AIDS, San Francisco, June 23.
- Weitz, R. 1989. Uncertainty and the Lives of Persons with AIDS. *Journal of Health and Social Behavior* 30(3):270-81.

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