AIDS and the Future of Reproductive Freedom

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LIBERAL INDIVIDUALISM HAS REPRESENTED A powerful liberating ideological challenge to both the legal moralism that sought to enforce conventional values by state power and the intrusive and restrictive claims of social orthodoxy. The defense of privacy, so central in that confrontation, has defined realms of social life to be protected from coercion and pressure. No reading of the transformations of the past three decades could fail to recognize the achievements of the liberal challenge (Karst 1980). Certainly, the profound, even if fragile, alteration of the moral and legal standards surrounding sexuality and procreation attest to the stunning victory of those who sought to free individuals from intrusive social and public policies. Now that abortion rights, first secured by the 1973 Supreme Court decision in Roe v. Wade, have become so vulnerable to the political currents crystalized by the Court in its 1989 Webster ruling, the achievements of the liberal ascendancy during this era seem all the more striking.

AIDS has represented a challenge to the central impulse of liberal individualism, forcing into the social realm matters that had come to be viewed as of no legitimate public concern; it has revealed the limits of the ideology that had provided the wellspring of cultural and political reform. Pediatric AIDS has contributed yet one more element to the broad encounter with the liberal commitment to the sanctity of re-
productive choice, encumbered neither by governmental restrictions nor social pressures. How will the threat of a maternally transmitted lethal infection affect the tolerance for an ethos that has proclaimed the utter privacy of each woman’s reproductive decision? Will the grim reality of pediatric AIDS generate pressures for social interventions that would shape, direct, constrain, limit, or control those decisions in ways that might contradict the pronatalist demands of the movement that seeks to restrict severely or eliminate the right to abortion? Much will depend upon how many babies are born infected with HIV and die. Much more will depend on the social perceptions provoked by those numbers.

As of March 1989 about 1,500 cases of AIDS in children below the age of 13 had been reported to the Centers for Disease Control (1989). In approximately 1,200 cases, just over 400 in the last year alone, HIV infection had been vertically transmitted—from mother to fetus; the remaining cases have been linked to blood transfusions or the use of clotting factor in hemophiliacs. With the securing of the safety of the blood supply it is a certainty that virtually all new cases of HIV infection in infants will be the consequence of maternal infection.

Without satisfactory national seroprevalence studies of women of childbearing age and of adolescent girls, some of whom will become pregnant, there is no very good way of estimating the number of infected babies that may be born, nor of projecting the number of pediatric cases of AIDS. The frequency with which infected women transmit infection to their fetuses also remains uncertain, the most commonly suggested range being between 25 and 50 percent. Finally, much will depend upon the extent to which infected women continue to become pregnant and carry their pregnancies to term. Here too, the data are only preliminary. A Brooklyn hospital found no difference between the reproductive decisions of infected and uninfected women (Sunderland et al. 1988). A study conducted at a Bronx methadone maintenance program corroborated those findings. More than 20 percent of both infected and uninfected women had become pregnant during the course of a two-year period. More than 25 percent of those same women became pregnant a second time (Selwyn et al. 1989).

Even more so than is the case with HIV infection in adults, the burden of pediatric AIDS has been geographically concentrated, mimicking the epidemiology of drug addiction. New York, New Jersey, Florida, Texas, California, and Puerto Rico will continue to be the cen-
ters of vertical HIV transmission. And even in those regions the prevalence of pediatric HIV disease will be concentrated in particular communities. In New York City, where 1.25 percent of women of childbearing age are infected, hospitals serving neighborhoods with high levels of intravenous drug use have reported rates of infection as high as 4 percent (Novick et al. 1989). At one Newark, New Jersey, hospital the rate was 5 percent (Tom Denney, personal communication).

In sum, although the precise dimensions of the potential problem of pediatric AIDS remain uncertain, it is clear that the number of cases will continue to rise over the next years. The cost in both social and medical resources that will be required to care for such children and the toll in human suffering will not be negligible. An editorial in the Journal of the American Medical Association could thus declare: “The contribution of the [progeny of HIV-infected women] to infant mortality in the nation’s inner cities will soon dwarf that of other congenital infections such as cytomegalovirus, herpes and syphilis” (Landesman, Willoughby, and Minkoff 1989, 1326).

Just as the threat of transfusion-associated cases of AIDS aroused the deepest of social fears, the specter of maternally transmitted HIV infection has touched the deepest emotions. During the past eight years we have become all too familiar with the capacity of American society—and of other societies as well—to distinguish between the “innocent” victims of the epidemic and those who, however unwittingly, have been implicated in their own unfortunate state. Unable to protect themselves from the decisions of their mothers, HIV-infected babies provide the paradigmatic case of past and future undeserved suffering. But even for those who have rejected as morally irrelevant, and socially divisive, the question of how individuals have become infected and the distinctions between individuals who had become infected before the first cases of AIDS were recognized and those whose behaviors exposed them to risk after much was known about the possibilities of self protection, the plight of children born to disease and early death continues to be especially poignant, warranting a special urgency.

Like infants suffering the consequences of fetal alcohol syndrome and drug withdrawal, babies with AIDS—the “littlest victims”—provoke the demand for preventive intervention. Here, the reformist zeal that so frequently has attended efforts to save children from their parents’ misdeeds may merge with the eugenic tradition of challenging the absolute right of parents to bear children at high risk for congenital
disorders, since only a decision not to bear children can prevent the birth of infected infants to infected mothers. It is the specter of such reformist zeal and the legacy of eugenics that haunt the discussion of how to achieve the otherwise unassailable goal of preventing the birth of babies who will die of AIDS.

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 (Centers for Disease Control 1989). How would infected women be identified? What efforts would be made to discourage them from becoming pregnant? How directive and how aggressive would the counseling of such a woman be? What would be the response to those who did become pregnant? Given the increasingly restrictive social regime surrounding abortion, what measures beyond counseling might be employed to prevent the birth of infected infants? The disquiet provoked by concerns about the course of AIDS-related policy has been amplified by the broader challenge to the reproductive freedom of women. Might efforts to limit the toll of pediatric AIDS not only draw upon the movement to restrict the hard-won victories of the 1960s and 1970s but further erode reproductive rights as well? Might such efforts not only draw upon a tradition of subtle eugenic practices but foster the revival of an explicit eugenic ideology?

The most apocalyptic visions of what measures might be taken to control the spread of AIDS involve the wholesale abrogation of the privacy and reproductive freedom of all HIV-infected women, as well as those considered at high risk for infection. Writing in the *Journal of the American Medical Association*, Robert Edelman of the National Institute of Allergy and Infectious Diseases and Harry Haverkos of the National Institute on Drug Abuse argued that the existence of heterosexual transmission of HIV infection in the United States would compel society to confront the question of the “suitability of infected individuals for marriage and natural parenthood” (Edelman and Haverkos 1989). The logic of seeking to enforce standards of “suitability” for procreation would of necessity lead to mandatory and repeated testing of all women of reproductive age, criminalized childbirth, coerced abortion, or compulsory sterilization. Although opposed to such repressive interventions, Edelman and Haverkos nevertheless warn that the demand for effective prophylaxis might well create a climate within which coercion would become tolerable: “We can predict that as the
pandemic widens and deepens in our society, increasingly powerful voices will be heard calling for such state imposed restrictions."

The possibility of such massive coercion—despite the array of ethical, legal, constitutional, political, and logistical objections that would be provoked—has also been noted by Norman Fost, chair of the bioethics committee of the American Academy of Pediatrics. Locating the problem of HIV infection in both historical and contemporary sociopolitical contexts, he has sounded an alarm. More than 100,000 retarded women were sterilized in the period between 1920 and 1973 on the assumption that they could transmit their condition to their children. Both the prospect of the social burden of having to support an ever-increasing population of "incompetents" and the specter that they would in turn bear retarded children provided the eugenic basis for such interventions. "If the country could get behind that it surely could get behind sterilizing women to prevent a much more serious problem." The vulnerability of women's reproductive freedom, given the current political climate, he asserted, increased the likelihood of a repressive turn in public policy. "There is," Fost stated, "a very powerful legal trend for intrusion on women for social reasons" (Abraham 1988).

Whether such drastic measures on so wide a scale will be provoked by the AIDS epidemic in the next years cannot be predicted. In the first years of the epidemic, gay men were able to articulate forcefully the importance of preserving the values of privacy in the face of a lethal viral challenge, and public health officials in alliance with liberal political leaders came to recognize that reliance on repressive measures could well subvert the prospects of prevention. The result was a voluntarist political culture that shaped the main currents of AIDS policy (Bayer 1989). Much will depend on the extent to which that culture will survive the epidemic's next years in which hundreds of thousands of already infected persons will become profoundly and fatally ill. But in the absence of a dramatic erosion of the basic premises of voluntarism it is unlikely that harsh and repressive reproductive policies will emerge. More likely, there will be aggressive campaigns to dissuade infected women from bearing children. Ironically, the prospects for avoiding coercive policies may, at least in part, depend on the success of such persuasive interventions.

But even such measures will require a confrontation with the broadly shared perspective that has evolved over the past two decades on mat-
ters of reproductive choice. Because of the chronic nature of HIV infection, recommendations to women about their childbearing decisions will entail efforts to shape their entire reproductive lives. In that way, and because of the uncertainty of maternal transmission, the quandaries raised by HIV infection are much more like those posed by the risks of transmitting genetic disorders than by acute conditions. It was precisely with regard to the questions of public policy and clinical practice in the face of the risks of genetic disorders that the importance of preserving the right of women to make reproductive decisions had taken hold, unencumbered by political, professional, or social pressures. Shaped by the professional ethos of genetic counseling, medical ethics, and feminist thought, the ideology of nondirective counseling achieved hegemony, reflecting a singular commitment to liberal individualism. AIDS will surely challenge that ideology.

Genetic Counseling and Reproductive Choice

It was against the legacy of eugenics that the very term genetic counseling was coined in the post-World War II years. Unlike the eugenics movement—which had been driven by class, nativist, and racist concerns for the protection of the genetic stock (Ludmerer 1972; Kevles 1985)—the new practice was to be a "type of social work entirely for the benefit of the whole family without direct concern for its effect upon the state or politics" (Reed 1974, 336). Since neither the well-being of the community nor that of future generations was pertinent to the counselor's work, the professional task was to assist individuals confronted with the prospect of bearing children with genetic disorders to select "the course of action which seems appropriate to them in view of their risks and their family goals and to act in accordance with that decision" (Fraser 1974). In the years before the technology of prenatal diagnoses became available and in the era before Roe v. Wade had recognized the right of a woman to terminate her pregnancy, the purview of genetic counseling was of necessity largely restricted to preconceptual decisions. It was the scientific advance represented by amniocentesis and political change represented by the Supreme Court's 1973 abortion decision that made possible the extension of the scope of genetic counseling to the full range of reproductive decisions.
Remarkably, the commitment to nondirective counseling, so discordant with the traditions of clinical medicine, attained hegemonic status not only in the United States but also abroad. The Expert Committee on Human Genetics of the World Health Organization (1968) and the National Academy of Sciences (1975) both warned against eugenic goals and underscored the importance of a counseling process that permitted individuals to make choices free of pressure. Surveys of counselor attitudes both in the United States (Sorenson, Swazey, and Scotch 1981, 44) and abroad (Wertz and Fletscher 1988) demonstrated how profoundly the ideology of nondirective counseling had shaped professional attitudes. In one widely cited survey of American counselors, only 13 percent of those studied believed it appropriate to “advise patients about what to do.” Just 20 percent considered it appropriate to help shape patients’ decisions by informing them about what they themselves might do in similar situations (Sorenson, Swazey, and Scotch 1981, 44).

Despite the fact that evaluations of genetic counseling frequently revealed a commitment to reducing the fertility of those at risk for bearing children with genetic disorders (Bird 1985; Reed 1980), the recognition of the inevitable intrusion, however subtle, of personal values as counselors seek to guide their clients (Katz Rothman 1986; Rapp 1988), and the resurgent interest in eugenic goals in the face of enhanced diagnostic capabilities (Nelkin and Tancredi 1989; Perry 1981), the ethos of nondirective counseling has retained its dominance both as a professional ideology and as a guiding principle for public agencies.

Bioethics, Autonomy, and Reproductive Freedom

Paralleling the concerns of genetic counselors about professional coercion were those of the intellectuals who forged the discipline of bioethics. Emerging out of the turbulence of the 1960s and marked by the imprint of liberal individualism, the new field sought to provide a moral foundation for the enhanced power of patients. Against medical paternalism the antidote was autonomy. It is not surprising that the rapid developments in genetics—part of the “biological revolution”—drew the interest of bioethics, since such advances opened the prospect of medicalized social control. Just three years after its founding, the
Hastings Center (Institute of Society, Ethics, and the Life Sciences) produced ethical guidelines on genetic counseling that were antagonistic to both legal coercion and professional practices that might subvert the capacity of individuals to choose for themselves the appropriate reproductive course. Published in the *New England Journal of Medicine* and endorsed by virtually every figure identified with the creation of contemporary bioethics, these recommendations represented a seminal element in the emerging public consensus on genetic counseling (Institute of Society, Ethics, and the Life Sciences 1972).

The centrality of individual choice as a moral norm for genetic counseling, though consonant with the main currents of bioethics, has not gone unchallenged. From the beginning there were those who believed that the obligation to prevent harm required reproductive restraint on the part of individuals at high risk for bearing children who would suffer. At a minimum, such restraint would have made the use of contraceptive methods morally imperative (Callahan 1979). At its most extreme this perspective not only rejected the nondirective approach to counseling but urged legal restraints on those who might bear “defective” children (Shaw 1984). Drawing on the thoroughgoing utilitarianism that often set him at odds with the dominant trends in bioethics, Joseph Fletcher (1980, 132) argued:

> There are more Typhoid Marys carrying genetic diseases than infectious disease. If infectious diseases are sometimes grave enough to justify both ethical and legal restrictions on carriers why not some genetic diseases too? . . . We ought in conscience to have a humane minimum standard of reproduction, not blindly accept the outcome of every conception.

How marginal such views remained was underscored by the 1982 report on genetic screening by the President’s Commission on Ethical Problems in Medicine and Biomedical and Behavioral Research (1982). Like the work of the Hastings Center conducted a decade earlier, the commission report was marked by liberal individualism’s anticoercive, antipaternalistic orientation. Genetic screening and counseling, the report asserted, could serve to enhance human options but could, like other advances in medicine, deprive individuals of the capacity for self-determination. Autonomy could be threatened not only by governmental restrictions but by professional dominance. Both, in turn,
would subvert the possibility of truly free choice. "Someone who feels compelled to undergo screening or to make a particular reproductive choice at the urging of health care professionals or others as a result of implicit social pressures is deprived of the choice-enhancing benefits of the new advances."

Feminism and Procreative Rights

The contemporary feminist movement has contributed an explicitly political dimension to the professional and philosophical foundations of nondirective counseling. Central to feminism has been the assertion that women be permitted to determine their own reproductive lives, the demand for access to birth control and abortion services, the insistence that women be free of threats to the right to bear children, and, increasingly, that they be free to control the method, circumstances, and timing of the exercise of that right (Katz Rothman 1986; Ruzek 1978). "The notion of choice has served as an ideological cornerstone of the political program of the movement for reproductive rights and women's health" (Wikler 1986, 1049). Despite its divergent ideological roots and despite its concern with the collective experience and needs of women, the mainstream of American feminism has thus been profoundly influenced by the central tenets of liberal individualism.

The feminist perspective of genetic screening and counseling must be seen within this context. On the one hand, the information provided by such services has been viewed as extending the opportunity of women to make informed choices about whether to conceive and carry pregnancies to term. On the other hand, genetic diagnosis has been feared because of the dangerous prospect of the emergence of standards of "appropriate" reproductive decisions (Katz Rothman 1986, 23). "It is not acceptable that the understandable desire of many women to have as healthy a baby as possible would become a duty aimed at the welfare of the gene pool" (Stanworth 1987, 31). Barbara Katz Rothman's (1986) widely read Tentative Pregnancy represents an impassioned analysis of prenatal diagnosis which warns that the new reproductive technologies might ironically constrain choice by expanding the possibility for choice. Are we, she asks, losing the right not to choose?
Because of the historically rooted experience of women who have been the subjects of restrictive reproductive policy and professional practices, feminist discussion of genetic counseling has often centered on the important, but difficult to detail, disjunction between the reality and the official ethos of nondirective clinical behavior (Rose 1987). Alert to the empirical research that has demonstrated the subtly directive content of counseling that guides choices despite the claim to neutrality, feminists have been sharply critical of the "unbalanced" and distorting information which limits the options available to women. Thus, they have argued, for example, that the emphasis within counseling upon the burdens of bearing a child with some congenital defect denies prospective parents the opportunity to make reproductive choices in the light of the possibility that such a child could be a source of fulfillment (Hubbard 1988).

Given this perspective, it is not surprising that feminists have viewed substantive and public discussions of how women should exercise their reproductive options as threatening an erosion of always precarious reproductive freedoms. But despite such anxiety, current feminist literature has been compelled to address these matters. Radical theoreticians like Rosalind Petchesky (1984, 6), in search of a feminist/socialist ethic, have attempted to transcend the limits of individualism in order to confront "moral questions about when, under what conditions and for what purposes reproductive decisions should be made." Those allied to the disability rights movement, like Adrienne Asch (1989), have been troubled by the assumption that efforts to preclude the birth of less than perfect children are beyond moral scrutiny. And those alert to the potentially antifeminist implications of some reproductive choices that women, influenced by the broader culture, might make—aborting female fetuses because of a preference for male children (Hoskins and Holmes 1984) or agreeing to enter into maternal surrogacy agreements—have even begun to entertain the question of whether the absolutist defense of choice is still tenable (Wikler 1986). But with some few exceptions feminist writers still embrace, if only for strategic reasons, unrestricted reproductive decision making. Asch (1989, 82) has written, "I may deplore what some women do, but I am not yet prepared to take away their rights of self-determination." It is this commitment to self-determination that has defined the enduring feminist perspective on nondirective reproductive counseling.

It is against this rich, professionally and politically rooted, ideology
of privacy in reproductive decision making that the response to the threat of vertical HIV transmission must be viewed. Officials involved with AIDS prevention activities were often very distant from the concerns of those who had forged this ideological perspective. At times they seemed utterly uncomprehending of the sensitivities surrounding reproductive choice, especially those rooted in the fears of poor black and Hispanic women whose awareness of past policies of coercive sterilization would inevitably produce resistance to any form of directive fertility control. Indicative of this situation was the response of James Chin, former director of the infectious diseases program for the California Department of Health Services, and his colleague Donald Francis to the assertion that their recommendation that HIV-infected women not become pregnant—included as part of a broad strategy of prevention—was “directive” (Chin and Francis 1987). For them the charge was unwarranted, since they never questioned the ultimate right of infected women to choose whether or not to become pregnant. That, they believed, was at the heart of the “nondirective” posture which they, too, endorsed (Francis and Chin 1987). Given the extent to which public health officials, and especially those with primary responsibility for the protection of maternal and child health, had either explicitly or implicitly absorbed the ideology of nondirective counseling, the reaction to the prospects of the birth of HIV-infected infants was all the more striking.

AIDS and Counseling for Prevention

When the Centers for Disease Control (CDC) first addressed the problem of vertical transmission of HIV infection in December 1985, it spoke directly about the importance of identifying women at risk. The broad spectrum of clinical settings through which such women passed were to offer voluntary testing and counseling. The purpose was clear: the prevention of the birth of infected babies. “Infected women should be advised to consider delaying pregnancy until more is known about perinatal transmission of the virus” (Centers for Disease Control 1985, 725). The case for testing pregnant women, put forth with equal vigor by the CDC, was less clear, since for political reasons the option of abortion could not even be mentioned (Grimes 1987). Such silence was especially ironic since only counseling informed pregnant women about
the option of abortion and making the termination of pregnancy a possibility for those who chose such a course could serve the preventive goals of the CDC. Made at a time when relatively little was known about the actual risks of transmission for infected women to their fetuses, the recommendation that women be urged to consider forgoing pregnancy represented a determination to apply standard public health norms to the reproductive realm. In the face of uncertainty, prevention required the adoption of a posture of caution. What made this stance unusual was the reticence that convention had dictated in matters affecting the substance of reproductive choice.

To some extent this break with accepted norms may be explained by the professional backgrounds of the CDC officials most responsible for formulating AIDS policy. It was venereal disease control, rather than the delicate question of how to face the matter of relative risk in the face of reproductive decisions, that informed their thinking. Indeed, they never seriously considered the relevance of the large and complex literature on nondirective genetic counseling to the problem of pediatric AIDS (James Allen, personal communication). But they did not long remain unaware of that alternative perspective. At least three of the consultants brought together by the CDC to consider its draft recommendations warned of the potential abuses that might follow from an explicit effort to discourage pregnancy.

Janet Mitchell, a black obstetrician, noted the history of coercive reproductive practices faced by minority women in public hospitals (Lori Andrews, personal communication). Advice, she feared, would ineluctably take on restrictive dimensions. Both Lori Andrews, a specialist on the legal aspects of reproduction on the staff of the American Bar Foundation, and Leroy Walters, a medical ethicist, urged the adoption of the genetic counseling model in the framing of public policy on perinatal HIV infection. To those pleas the response was one of incredulity. “Don’t you want to stop the spread of AIDS to infants?” they were asked by CDC officials.

The language adopted by the CDC was somewhat tentative in form. Women were advised to consider the delaying of pregnancy. (Virtually all discussion of vertical HIV transmission focuses on women; rarely are infected men a subject of discussion.) Suggesting a “delay” of pregnancy conveyed a less drastic impression of what was, in fact, being called for. Since the available scientific evidence made clear that HIV infection was lifelong it was not a postponement but a forgoing of
pregnancy that was required by the preventive orientation. Furthermore, by urging women to "consider" a fundamental curtailment of their reproductive lives it appeared that the CDC was not itself counseling women to make such a choice. Nevertheless, there can be no doubt about how the CDC believed women ought to act in the face of HIV infection. In virtually every statement by officials since the December 1985 recommendations were published in *Morbidity and Mortality Weekly Report*, the preventive goal has been put forth bluntly. Speaking about the logic of testing and counseling, James Curran, director of AIDS activities at the CDC, stated: "There is no reason that the number of [pediatric AIDS cases] shouldn't decline. . . . Someone who understands the disease and is logical will not want to be pregnant and will consider the test results when making family planning decisions" (*CDC AIDS Weekly* 1988). If anything, Curran's CDC colleague Martha Rogers was more direct in addressing the challenge of vertical HIV transmission. Women and their sexual partners would have to "suppress often strong desires to bear children" (Rogers 1987, 109).

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. (These data are based on a survey of state health departments; information on policy was conveyed in the form of personal communications and copies of state policy statements.) Across the nation, in locales with virtually no cases of pediatric AIDS as well as in those with relatively high levels of maternal transmission, in jurisdictions that have stressed the importance of protecting the privacy and social interests of the infected and those that have been less concerned with such matters, the goal of preventing the birth of infected babies has been explicitly embraced by public health officials. Like the CDC, state health departments have typically remained circumspect about the role of testing in pregnant women. In a few instances the possibility of abortion has been mentioned. In no case were women urged to terminate their pregnancies or even urged to consider such procedures.

Although virtually all states have spoken about postponing pregnancy, only a few have adopted the CDC's circumspect formulation that urged women to "consider" such a course. New Jersey, with its heavy burden of pediatric AIDS cases, has done so. Far more common has been the more straightforward recommendation that "women postpone or avoid pregnancy for the time being." Michigan, for example, has "strongly encouraged [infected women] to delay pregnancy." The
San Francisco Health Department, so exquisitely sensitive to the ethical problems posed by counseling and to the rights of infected men, was equally blunt. "Whenever possible, women infected with HIV should be confidentially identified and educated about the risks of perinatal transmission. Infected women should be advised to postpone pregnancy. . . . [Pregnant women] should be counseled to postpone subsequent pregnancies" (Rutherford et al. 1987, 105). In 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."

In at least two instances states have employed both the tentative formulation used by the CDC as well as more overtly directive language, suggesting thereby institutional tensions and ambivalence. Addressing the physicians of New York State in July 1985, the commissioner of health recommended that infected women postpone pregnancy. In January 1988 the state's "Guide to Physicians on Counseling and Testing Women of Childbearing Age" adopted the less-directive CDC formulation. In the same month, however, a health department brochure meant for distribution in family planning clinics stated: "Having a baby? Have a test for the AIDS virus first. . . . If you have the AIDS virus: Postpone pregnancy to protect your baby and you. . . ."

In Massachusetts even greater confusion reigned in 1988. The commissioner of health stated: "While the AIDS office urges all women to be aware and concerned about possible transmission and its consequences, there is no policy in place to direct women to make any one choice over the other" (Deborah Prothrow-Stith, personal communication). This nondirective posture, so consistent with the prevailing model of genetic counseling, was reflected in a health department pamphlet, "Women, Babies and AIDS," which never even suggested postponement of pregnancy as an option. Nevertheless, another state-produced brochure, "Family Planning Facts about AIDS," asserted: "Women with positive test results should not get pregnant until more is known about HIV infection and pregnancy."

Support for the systematic effort to discourage pregnancy in HIV-infected women came also from professionals involved in maternal and child health as well as from their professional associations. At the April 1987 Surgeon General's Workshop on Children with HIV Infection and Their Families, the task force charged with the responsibility for developing recommendations on reducing the risks of maternal/fetal trans-
mission explicitly urged that infected women be "advised to defer pregnancy," although it noted the "difficulties" that would be faced by many women who might consider such a course. Two months later the Committee on Obstetrics, Maternal and Fetal Medicine and Gynecologic Practice of the American College of Obstetrics and Gynecology (1987) published a report stating that infected women "should be strongly encouraged not to become pregnant and should be provided with appropriate family planning assistance." The college's Technical Bulletin, which serves as a professional standard of practice, adopted a similar stance in 1988, stressing that infected women should be discouraged from becoming pregnant. Not hobbled by the political constraints impinging upon recommendations of many public health officials, the Technical Bulletin could state that HIV-infected pregnant women should be informed about their reproductive options, including elective abortions.

How much such positions reflect the beliefs of practitioners, obstetricians, and nonmedical counselors, and how effective such statements have been in helping to shape their beliefs and practices, is not yet known. Some reports suggest that, at least insofar as physicians are concerned, a directive approach to both the question of the postponement and termination of pregnancy has begun to emerge. Dismay about the willingness of infected women to carry their pregnancies to term has been evident to some who continue to urge a traditional nondirective counseling posture. "People are not going to admit [publicly] they're doing directive counseling. But we all know it's being done" (Abraham 1988). In a survey of two pediatric residency programs in New York City, 65 percent of the respondents "agreed" or "strongly agreed" with the proposition that "women should not have babies who will be at risk for [AIDS]." That was true for only 25 percent when the risk was for Tay-Sachs disease, and 15 percent when the risk was for cystic fibrosis—both leading to painful and tragically shortened juvenile lives—and 9 percent when the risk was for Down's syndrome. It is not surprising, therefore, that 43 percent of the respondents would mandate the testing of pregnant women, and that the remaining 57 percent believed that women should be directly counseled to undergo testing. None of the respondents believed that nondirective counseling for antibody testing was appropriate (Betty Levin, personal communication).

Physicians had always been more directive in their approach to reproductive matters than had nonmedical counselors in a way that
reflected the conventional practice of medicine. But these data suggest much more. The study’s respondents had clearly indicated a greater willingness to adopt a directive posture with regard to AIDS than with other grave genetic disorders. It is possible that both the class and racial/ethnic background of those at risk for transmitting HIV infection played a critical role. That so many infected women were also intravenous drug users may also have been a significant factor. But whatever motivated the responses of those surveyed, it is clear that the disquiet provoked by pediatric AIDS had elicited a willingness to embrace, in a remarkable way, clinical practices that deviated from the conventions of nondirective counseling.

Among those working in the field of bioethics, there has been a notable reluctance to apply formulaic responses to the issue of maternal HIV transmission. Despite the nondirective posture conventionally adopted in matters involving severe genetic disorders including Tay-Sachs (Ellias and Annas 1987), a number of philosophers (e.g., John Arras, personal communication) and lawyers have asserted that they were troubled by efforts to denounce as unethical attempts to discourage pregnancy among infected women. The “harm principle,” which provides a moral limit on the exercise of freedom when others may be injured, has emerged as a countervailing force to conceptions of autonomy that had heretofore treated directive counseling as a threat to free choice.

Nothing more tellingly reveals the extent to which the threat of perinatal HIV infection had generated an urgent preventive posture than the response of the March of Dimes. Established in 1938 to combat polio, the organization had in 1958 redefined its mission to include the prevention of birth defects. Out of its own organizational and professional history, but especially as a consequence of its desire to distinguish sharply between a commitment to the preventions of birth defects and an endorsement of abortion, a strong ideological commitment to preserving the reproductive freedom of those served by recipients of its grants emerged. Indeed, it adopted a policy that explicitly forbade its grantees from directly counseling those at risk for bearing children with defects (March of Dimes Birth Defects Foundation 1973). In its public campaign to prevent the birth of babies with HIV infection—conducted in brochures as well as television spots—the March of Dimes urged women at risk to be tested before pregnancy so that they might make “informed decisions.” But despite the emphasis on permitting women to make their own choices, there could be little
mistake about how the March of Dimes believed those choices should be made. “A baby born with AIDS is born dying,” states the off-camera voice as the strings supporting a baby-like marionette are cut by a pair of scissors (March of Dimes Birth Defects Foundation 1988).

Despite the broad-based support for efforts to identify HIV-infected women so that they might be counseled and discouraged from becoming pregnant, the conventional nondirective posture has been given voice by feminist critics of the emerging consensus. For them the alacrity with which public health officials and clinicians had embraced the goal of dissuading HIV-infected women from becoming pregnant was in large measure a reflection of the willingness to override the preferences of poor black and Hispanic women who had always been vulnerable to the pressure of white professional men. A woman’s right to choose had to be preserved despite the risks associated with AIDS. Those who were not pregnant had a right to counseling that would permit them to make choices unencumbered by directive interventions. Those who were pregnant had a right to bear a child or to abort. Directive counseling would inevitably entail elements of subtle coercion and might ineluctably lead to more blatant forms of pressure. Only nondirective counseling—whatever its limits—would preclude the subversion of reproductive rights. This perspective was captured by the Supreme Court at a moment when the liberal majority that had crafted the ruling in Roe v. Wade still held sway. “Counseling about pregnancy outcome must not be conducted in such a way that its goal is less to inform than to influence which option the woman should choose.”1 The fears provoked by the tone and substance of public policy on vertical transmission of HIV infection extended beyond the issue of AIDS, however. Animating the deeply felt anxiety was the concern that the carefully wrought but always vulnerable ideology of reproductive freedom could be subject to a severe insult by the effort to control the spread of HIV infection. Those fears were intensified by the political vigor of the antiabortion movement, the receptivity of elected officials to its demands, and the very clear indications, even prior to Webster that the Supreme Court might be willing to reconsider or fundamentally circumscribe its 1973 abortion ruling.

If feminists and their political allies were troubled by the possibility

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of the erosion of women's rights, those whose perspective was shaped by concerns for the rights of women of color responded to the call for reproductive restraint with the memories of compulsory sterilization abuse all too fresh (Proctor 1988). The even more recent debacle associated with mandatory sickle-cell screening also framed their reaction. Among the most forceful critics of the public health posture on HIV infection and pregnancy was Janet Mitchell, a black obstetrician and perinatologist. Centering her challenge on the failure of those counseling deferral of pregnancy to appreciate the cultural and social contexts of reproductive choice and on their failure to understand the very different ways in which professional, often white, counselors and poor, often black and Hispanic, women understood the meaning of relative risk, she has underscored the importance of procreation to the women in whose defense she has written. For intravenous drug-using women the counsel of restraint was portrayed as especially "devastating," threatening to deprive them of what hope they had for a better life. "We forget that those women have a strong innate need to procreate. . . . We must be cautious in how we approach our need to do good, to do no harm." For Mitchell (1988, 51) the central issue forced by the public health assertion that HIV-infected women should avoid pregnancy "is the right of every woman to reproductive self-determination, regardless of her station in life." More stridently, the claim that the risk of bearing an HIV-infected baby should lead all infected women to forego pregnancy has been termed by some a strategy for racial depopulation, as genocidal (Helen Gasch, personal communication).

AIDS and the Future of Reproductive Choice

Despite the well-established convention of nondirective counseling in reproductive matters, as a matter of both professional ideology and practice, there is no question but that counselors have—at times more frequently than most would find comfortable to acknowledge—sought to press women at risk to follow a particular course. In recent years some clinicians and academic commentators have publicly argued the case for directive counseling for those at high risk for genetic disorders such as Huntington's chorea. But those who have broken ranks with the conventions of reproductive counseling have done so virtually al-
ways as individuals challenging those conventions. What makes the prevailing situation regarding perinatally acquired HIV infection so striking is that professional associations of medical practitioners and public health agencies at federal and state levels have adopted a directive posture. There has been, therefore, a dramatic reversal of the institutional context of the public discussion. What can account for this rupture with convention?

It is, of course, possible that those charting public policy on pediatric AIDS have thought about it differently because of the language of crisis that has surrounded virtually every dimension of the epidemic. Furthermore, concern about the potential social costs that would be incurred by the care of HIV-infected babies may have contributed to the sense of urgency. From a public health perspective it was not a very long step from the directive advice given to those who were infected about the necessity of changed sexual and needle-sharing behavior to directive advice about becoming pregnant, if not about the course to follow if already pregnant.

Contributing to the climate within which the determination to discourage pregnancy among HIV-infected women was made, and the response with which it was greeted by many of those who had so forcefully defended the ethos of unencumbered individual reproductive choice by women, was the broad-based challenge to the ideological hegemony of individualism in American society. It was no longer cultural conservatives alone who raised questions about the intellectual, social, moral, and political consequences of a liberalism so individualistic in its commitments. Within bioethics the almost singular devotion to "rights" and autonomy has come under repeated attack that extends arguments first made by foundational figures such as Daniel Callahan (1981), William May (1975), and Leon Kass (1985). Feminist thinkers, too, have been compelled to confront the limits of individualism as they face the question of maternal surrogacy and amniocentesis for gender selection. Finally, advances in genetic diagnosis have revitalized eugenic thinking, permitting a challenge to the orthodoxies of genetic counseling. Nothing more tellingly reveals the current receptivity to critiques of individualism than the warm response accorded to Habits of the Heart by Robert Bellah et al. (1985), a volume that so forcefully and imaginatively argued the case for a renewal of a communitarian perspective.

The willingness of public health officials to urge infected women not to become pregnant must also be understood in the light of an emerg-
ing trend of seeking to compel pregnant women to undergo medical treatments in order to protect the lives of their fetuses (Nelson and Milliken 1988). One study reported on 21 cases in which court orders were sought to override maternal refusals of such therapy. Permission was granted in all but three cases. When the directors of maternal/fetal medicine fellowship programs were questioned, just less than one-half believed that women who defied medical advice, thus endangering their fetuses, should be detained for medical supervision. Similar proportions believed that court orders should be sought for intrauterine transfusions. Less than one-quarter of the respondents consistently upheld the right of competent women to refuse medical advice. To the authors of the report, the implications of the trend for the full range of the rights of pregnant women were all too clear (Kolder, Gallagher, and Parsons 1987). For George Annas (1987, 1213) the instances of coercive treatment suggested an ominous turn: “The beginning of an alliance between physicians and the state to force pregnant women to follow medical advice for the sake of their fetuses.”

The possibility of such an alliance haunts the discussion of the potential impact of efforts to prevent the birth of infants with AIDS. Will the adoption of a directive posture on perinatal HIV transmission contribute to current attempts to circumscribe the reproductive rights of women? Will they foster a climate within which eugenic perspectives will be given added legitimacy? Although historically linked, the social forces seeking to restrict reproductive freedom and those advancing eugenic goals now have been uncoupled. Indeed, the social forces that may succeed in achieving the former may attain their goals at the expense of the latter.

The contemporary movement against the unrestricted reproductive freedom of women has, especially through the influence of the Roman Catholic Church, a pronatalist dimension. Opposed to abortion, it contains also an important constituency that is hostile to the compulsory sterilization of women. It is thus unlikely that the threat of maternal HIV transmission will result in a politically effective campaign for compulsory sterilization, or coerced abortion. As strategies of prevention, such efforts would not only confront the opposition of those who have struggled to protect the reproductive rights of women but of their bitter opponents in the antiabortion movement as well. Against such an alliance no “public health” drive to prohibit surgically the birth of babies with HIV infection is likely to achieve broad-based political sup-
It is, however, possible that some local efforts will be made to criminalize the birth of HIV-infected babies. Such moves might derive their intellectual justification from the proposals to punish women who bear children with severe genetic disorders (Shaw 1984), and might derive political support from aggressive prosecutors who have so recently sought to indict drug-addicted women who have given birth to addicted babies.

The prospects are greater for a contribution to the advancement of the eugenic perspective. Historically, the eugenics movement had sought to restrict procreation on the part of those who might bear “defective” children who would, in turn, contribute to racial degeneration by having children who would further pollute the genetic pool. But concern about the propagation of undesirable genetic material has not been the only concern. At times eugenicists have sought to prevent the birth of those with disorders, however unlikely the prospect that they in turn would bear children. The prospect of the birth of children who would pose a social burden, of those who, because of their handicaps, would never be able to attain economic independence was sufficient to provoke an interest in restrictive policies. The eugenic worldview has thus been extended to include “any effort to interfere with individuals’ procreative choices to attain a societal goal” (Perutz 1989, 35). It is within such a broadly conceptualized eugenic outlook that efforts to convince HIV-infected women to forgo pregnancy must be understood.

There are, of course, critical differences among procreative policies that would systematically seek to enforce a program of communal enhancement, those that would seek to discourage women or couples from choosing to bear children when the risks of severe disability are high, and those that would enhance the likelihood that women will bear healthy children with the fewest impediments to fulfilling lives. Rarely do those with eugenic commitments today propose the enactment of laws that would deprive at-risk individuals of the freedom to procreate. Rather, as in the case of HIV infection, they tend to stress the role of persuasion—sometimes quite aggressive—and public education even for the best in utero care of the fetus. Nevertheless, even a noncoercive eugenics could have profound and often troubling consequences. A eugenic ethos might not only affect the ways in which individuals would choose to exercise their reproductive options, but the social tolerance for those born less than perfect, including the way in
which those with congenital disorders might be treated by the health care system, the extent to which the cost of providing such care would be viewed as too socially burdensome, the prospect of treating impaired newborns, and perhaps including them as prime candidates for "rationing." Proponents of policies with eugenic implications cannot avoid a serious consideration of such issues, however benign their intentions.

Whether the eugenic dimensions of current policies designed to limit the birth of infants with AIDS will contribute to a climate of social intolerance for those with HIV infection, and whether such policies will contribute to a more general climate of intolerance for those with disabilities and genetic disorders, will in large measure depend on the balance of political, social, and intellectual forces far broader than those directly linked to the epidemic. AIDS is but a small part of the medical, political, and ideological context within which contemporary controversies over eugenics are being waged. Indeed, the very uniqueness of the HIV epidemic may serve to circumscribe the impact of policies adopted to prevent its spread.

But whatever the ultimate impact of effort to prevent the maternal transmission of HIV infection, the broadly shared preventive impulse provoked by pediatric AIDS has provided yet another instance of the inadequacy of the prevailing ideological underpinnings of the commitment to reproductive freedom. The limits of liberal individualism, which has sought to shield procreative decisions from restrictive social and moral judgments, have become increasingly apparent even to those who have drawn upon its force to press for social and political reform. The question that now presents itself is whether it will be possible, under contemporary political conditions, to frame an ideological perspective that will transcend those limits without calling forth the very conditions against which liberalism represented such a liberating challenge, that will be capable of informing the public culture within which women will make their decisions about reproduction.

References


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