AIDS
Where Have All the Women Gone?
page 6
Since its inception in 1968, the Health Policy Advisory Center—known as Health/PAC—has served as a unique progressive voice for changing consciousness on domestic and international health priorities. Through the Health/PAC Bulletin and the books Prognosis Negative and The American Health Empire, and in its outreach to a national network of grassroots activist groups, Health/PAC continues to challenge a “medical-industrial complex” which has yet to provide decent, affordable care.

**IN THIS ISSUE**

**Women—The Missing Persons in the AIDS Epidemic**
Kathryn Anastos and Carola Marte show how and why women have been ignored in defining and treating AIDS .................................... 6

**In Their Own Voices**
Women with AIDS tell their stories .......................................................... 14

**Report from the Frontlines: Unsung Heroines of the AIDS Epidemic**
Richard Younge recounts a story of hope from his work in an inner-city community health center ................................................. 16

**The Commodification of Women's Health: The New Women's Health Centers**
Bonnie Kay analyzes the growth of a new health care phenomenon: women as health care market ............................................. 19

**After Webster... if Abortion Becomes Illegal**
Ellen Bilofsky examines the revival of interest in women's self-help abortions .. 24

**Floods of Blood: South Africa's Mines**
Craig Charney reports on the deaths of black miners and union efforts for reform ................................................................. 27

**AIDS Watch**
Nick Freudenberg discusses the rights of prisoners to AIDS education ........ 30

**Vital Signs**
A boycott of GE, a bill for the disabled, a bitter union battle at Planned Parenthood .............................................................. 32

**Watching Washington**
Barbara Berney reviews the latest switch in the battle for national health insurance ............................................................... 34

---

**Health Policy Advisory Center**
17 Murray Street New York, New York 10007 212/267-8890
Health/PAC Bulletin
Volume 19, Number 4 Winter 1989

**Board of Editors**

**Acting Editor**
Ellen Bilofsky

**Assistant Editor**
Caren Teitelbaum

© 1989 Health/PAC. The Health/PAC Bulletin (ISSN 0017-9051) is published quarterly in the spring, summer, fall, and winter. Second Class postage paid at New York, N.Y. Postmaster: Send address changes to Health/PAC Bulletin, 17 Murray St., New York, N.Y. 10007. The Health/PAC Bulletin is distributed to bookstores by Ubiquity Distributors, 607 Degraw St., Brooklyn, NY 11217. Articles in the Bulletin are indexed in the Health Planning and Administration data base of the National Library of Medicine and on the Alternative Press Index. Microforms of the Bulletin are available from University Microfilms International, 300 Zeeb Road, Dept. T.R., Ann Arbor, MI 48106. MANUSCRIPTS, COMMENTS, LETTERS TO THE EDITOR, AND SUBSCRIPTION ORDERS should be addressed to Health/PAC, 17 Murray St., New York, New York, 10007. Subscriptions are by $35 membership for individuals. Institutional subscriptions are $45.
The Changing Face of the AIDS Epidemic

The AIDS epidemic is not faceless. It moves through populations, communities, and neighborhoods of vastly differing vulnerabilities to illness. For individuals, the unrelenting, degrading progress of immunological disease toward almost certain death suggests a commonality of symptoms—albeit, a commonality that changes as new people are affected and more is learned about the disease.

What has become clear in this epidemic, however, is that social, community, and familial environments exert a powerful influence on how each person with AIDS experiences the disease. This hard-won but far from universal understanding is in large part an achievement of the political activism that has grown out of the experience of AIDS.

A health care system that does not understand and acknowledge the powerful social influences of racism, homophobia, and sexism cannot provide adequate and human care for people with AIDS. As long as the crises of the epidemic are defined by the public health, medical care, and research establishments and as long as treatment is in the hands of the pharmaceutical industry, the response to AIDS will remain an international disgrace. The significance of who defines health issues and solutions is a lesson learned by feminists many years ago (as Bonnie Kay makes clear in her article on “The Commodification of Women’s Health Care,”) and which gay activists have had to learn in the last decade. As the incidence of AIDS and HIV seropositivity skyrockets among poor communities of color, these communities likewise struggle to confront the social and political realities of a health care system that not only impedes a caring and appropriate response but does so through institutions that are increasingly racially segregated.

Women, like gay men a few years ago and communities of color today, suffer from the medical establishment’s blindness with respect to the epidemic. Just as gay men were misdiagnosed or belatedly diagnosed because of the assumption that their way of life contributed to their disease, women have been almost entirely eclipsed in the furor over the epidemic. It is not a question of some individual women who have not received attention or treatment. It is that women as a group have been neglected with regard to their medical needs, the myriad social and emotional needs that accompany their multiple roles in society, and the protection of their legal and constitutional rights.

Rarely has a disease been more monolithically defined than in the case of AIDS and AIDS-related complex (ARC). It is the Centers for Disease Control in Atlanta, the epicenter of U.S. public health, that determines the criteria by which opportunistic infections combine to justify an official diagnosis of AIDS or ARC. Because the epidemic first emerged among predominantly white homosexual and bisexual males, it is defined by their clinical history. Although the definition of AIDS and ARC has been broadened over time, it does not yet accurately reflect the clinical reality of women who are HIV-positive. The medical establishment has been slow to suspect or acknowledge the phenomenon of non-diagnosis or underdiagnosis of women with AIDS. The medical literature is almost devoid of information on women with AIDS, leaving practitioners who treat women at risk to fend for themselves. In their article, “Women—The Missing Persons in the AIDS Epidemic,” Kathryn Anastos and Carola Marte describe the problems that result from the bias at the heart of the clinical definition of the spectrum of HIV illnesses.

Equally important as the effect of gender on diagnosis is its effect on the interpretation of epidemiology. Discussions of women and AIDS more often than not focus on women as mothers and as sexual partners rather than as individuals facing the possibility of a devastating, ultimately fatal illness. To the extent it is dealt with at all, women’s risk of contracting HIV disease is treated largely out of public health concern for their partners or their children. And there is even less recognition of the
physical and psychological wear and tear of women's roles as caregivers both at home and at work—as wives, mothers, grandmothers, partners, and sometimes paid caretakers of people who are desperately sick and who otherwise would be abandoned. Richard Younge describes, through his experience as a physician, how women take on the burden of the epidemic as part of the many responsibilities of their everyday lives.

Women's role as mothers, of course, enormously complicates whatever legal rights they have as individual patients. This is particularly true in the current political climate, which gives preference to children over mothers. The preeminence accorded women's status as mothers makes their constitutional right to reproductive choice and their ethical rights to medical confidentiality and informed consent conditional rights—rights conditioned upon the status of a potential child. This ambiguity in legal and ethical obligation is increased further for low-income women who, because of their dependence upon the state for health care, must deal with health experts who see themselves as both ethically bound to protect their patients' autonomy and as agents of social policy aimed at population control.

There are, of course, many other issues concerning women and AIDS, which we will be treating in subsequent issues, and we invite readers to write with their comments or experiences. For example, a further complicating factor for low-income women is a prevailing attitude that they are somehow less responsible about personal and public health concerns and that, through this supposed self-neglect, they endanger their unborn children. Within the structure of our two-class health care system, these attitudes are acted out with official, if tacit, sanction. Low-income women—those generally affected by the epidemic—depend on public agencies for contraceptive care, prenatal care, and medical care. Because these agencies are vastly overutilized, access to medical care for these women and for their children is severely limited. These limitations alter the time frame for reproductive decisions—as in New York, where women routinely wait three months for a prenatal appointment—and makes the state a de facto decision maker.

These differences in the treatment of low-income women are perpetuated in the power and value differences they face when they do eventually deal with a health expert. Such differences are manifest in the balancing of a woman's right to refuse to be tested for HIV against a health official's assumption that her right to make this choice herself is conditional on the potential HIV status of her fetus. The issue of consent to testing dovetails here with the issue of a woman's right to confi-
Sex, race, and class differences stratify the medical promise that drugs and other treatments hold for women and their children. Women are routinely excluded from experimental protocols and thus do not have access to the few chemical methods of possibly staving off the infections that so far make HIV infection a terminal disease. A number of factors have precluded women’s access to clinical trials for these drugs. The first, again, is the possibility of pregnancy and that the drug may damage an existing or newly conceived fetus. When women are included, the research regimen may be such that women who have children cannot routinely appear at a clinic or afford child care when they do come.

Treatments that are not experimental may be out of reach because of the limited scope of treatment facilities. Pregnant women who are addicted to drugs, for instance, are routinely excluded from drug treatment centers in New York. The rationale is that these centers have no facilities for birthing and could not handle complications that would require neonatal care. (The American Civil Liberties Union is in the process of challenging this policy.) And, because low-income women rely on public agencies, their access even to drugs that have become routine is limited because the agencies may refuse to pay for the drugs or because the drugs are in short supply.

Finally, pregnant women are encouraged to be tested for the HIV virus with the offer of experimental drugs for the newborn, should the baby be HIV-positive. The true extent to which infants may be helped by these early interventions is heatedly debated. Some maintain that AZT, for instance, may be very dangerous to a newborn’s immune system. Others argue the need for wide dissemination of AZT as the most promising intervention. However the debate concludes, unless health experts take seriously their obligation to educate women about the possible benefits and consequences of treatments for their newborns, these arguments will inevitably fall on uninformed ears. Informed consent is never more meaningful than in experimental regimens targeted to groups of people likely to serve as research subjects for medicine’s advancement.

The AIDS policy of the medical establishment is increasingly informed by the differences in communities’ needs. This is as much a part of the battle for humane AIDS policy as are the struggles for treatment and access to medical care. And it is a battle that puts health policy at the mercy of history and community. In this and future issues of the Bulletin, we plan to stay abreast of the changing face of the epidemic as it affects women as well as others.

As these issues become more complex—issues of prenatal testing for HIV, of “unblinding” the anonymous testing of women in public hospitals to identify newborns at risk, of early pharmaceutical intervention—health analysts must proceed with caution, accept uncertainty in their policy, and learn from the lives of those affected with the HIV virus. Medical theory is monolithic as long as people do not have the power to tell how disease affects them. We believe that the increasing recognition of the complexity of these issues signals the growing empowerment of the people that the HIV virus affects.

—Nancy McKenzie

A Job Well Done

For the past three years the Health/PAC Bulletin has been guided by the firm, artistic hand of its executive editor, Joe Gordon. As of January 1990, Joe is no longer writing, editing, and designing the Bulletin and otherwise keeping Health/PAC’s often arrhythmic organizational heart beating. Having brought to life for our readers reports of frontline health care struggles in the United States and abroad, Joe has now jumped into the trenches and is working with HIV-positive children and their families at New York’s Albert Einstein Medical Center. Ellen Bilofsky, who has been working with Health/PAC for the past two years on a part-time basis, will be serving as acting editor until a permanent replacement can be found.

When we interviewed Joe for the job of editing the Bulletin, we challenged him to make it more accessible for health care advocates and workers. Issue by issue, Joe worked toward his vision of a Bulletin featuring strong, readable stories dramatically emphasized and humanized by graphic imagery. The quantum leap was accomplished despite Health/PAC’s growing budget deficit. Joe became a master at finding important health stories and authors who could write them, as well as the best quality production at a price we could afford. Looking at recent issues of the Bulletin, we can say without hesitation and with a great deal of pride that it has never looked better nor been so accessible.

Our appreciation to Joe for a job well done. We hope that he, along with his wife, Ann, and daughter, Jennie, will continue to be a major part of the extended Health/PAC family in the years to come.

—Arthur Levin
Women—The Missing Persons in the AIDS Epidemic

KATHRYN ANASTOS AND CAROLA MARTE

Our current understanding of the public health problem posed by the acquired immunodeficiency syndrome (AIDS) in women is seriously distorted by the underrepresentation of women in official data and the misrepresentation of their disease. Through November 1989, 10,369 women in the United States were reported to have the acquired immunodeficiency syndrome—9 percent of the total number of AIDS cases. In urban areas on the East and West coasts, the numbers are higher; for example, 13 percent of all people who have been diagnosed with AIDS in New York City are women. The percentage is higher still in the most recently diagnosed cases—18 percent of New York City cases since January 1988 are in women.

It is unlikely, however, that these numbers accurately reflect the number of women who in fact have serious manifestations of HIV (human immunodeficiency virus) infection, for several reasons. The diagnosis of AIDS depends not only upon demonstrated infection with HIV, but also upon the clinical manifestations of the disease—that is, the ways in which those infected become sick. Because those affected first were almost exclusively men, the case definition of AIDS is centered in how the disease has manifested in men, and gynecologic conditions are not included as manifestations of HIV infection. If women's disease manifests with the same infections as it does in men, it may be recognized and reported as AIDS; if the infections, still HIV related, are different, the women are not considered to have AIDS.

For example, HIV-infected women with severe infections of their fallopian tubes (pelvic inflammatory disease or PID) are not categorized as having AIDS. This is in spite of the fact that many doctors have found that these infections are worse in HIV-infected women: treatment is more difficult and less likely to be successful. This resistance to cure by ordinary therapy is the sign of a failing immune system.

Similarly, vaginal yeast infections in HIV-infected women are more severe and less likely to be cured by ordinary therapy. A woman may suffer from vaginal yeast infections even before she has thrush, a yeast infection of the mouth that affects both women and men and that is officially used as one of the criteria for a pre-AIDS condition (AIDS-related complex or ARC). Does it make sense that the same infection in another orifice—an orifice not present in men—is not categorized as an AIDS-related condition?

Moreover, and most seriously, a number of published reports indicate dramatically higher rates of abnormal Pap smears and cervical cancer in HIV-infected women compared to uninfected women. Cervical cancer in immune-suppressed women is known to be more severe and life-threatening than in women with healthy immune systems. It may advance with dangerous rapidity and often requires special treatment. Given the many years between the time a person becomes infected with HIV and the time he or she becomes ill with full-blown AIDS—now thought to average nine years—many HIV-infected women may die from cervical cancer, a potentially treatable disease, before they die from AIDS as officially defined. Clearly, the case definitions of AIDS and ARC should be revised to include those women whose severe infections and
malignancies are obvious manifestations of immune system failure induced by HIV infection.

Another major problem is that similar symptoms in both women and men are interpreted, investigated, and treated differently, because women are not expected to have AIDS. Underdiagnosis is thus a significant bias in epidemiologic data on women with AIDS. For example, one study showed that women with pneumocystis carinii pneumonia (PCP), the most common opportunistic infection in AIDS patients and a major cause of AIDS deaths, were more likely to be treated for minor respiratory ailments and not for PCP. The result was life-threatening respiratory failure and a higher death rate than in men who had the same symptoms and whose PCP was recognized and treated. The potential magnitude of this problem may be seen in recent statistics showing unexplained and dramatic increases in deaths of women from a variety of respiratory and infectious diseases. For example, in New York City and Washington, D.C., there were, respectively, a 154 percent and a 225 percent increase in deaths in young women (aged 15 to 45 years) from 1981 to 1986. Idaho, in contrast, has experienced no such increase in mortality rates in women. Chris Norwood of the National Women's Health Network, who compiled these statistics, has suggested that because these increased numbers of deaths in women are found in geographic areas with heavy concentrations of AIDS cases, they may in fact be uncounted HIV-related deaths.

A better understanding of the true scope of the AIDS epidemic in women requires us to reconsider all these factors. The case definition of AIDS must be changed to include gynecologic conditions. Some estimate must be made of the proportion of the observed increase in respiratory and infection-related deaths that is caused by HIV-induced immunosuppression. In addition, health care providers need to develop an increased clinical awareness of AIDS in women in order to achieve more accurate diagnoses of full-blown AIDS, even by the current case definition.

The problem of the “missing women” in the AIDS epidemic goes well beyond the epidemiology. Women have been forgotten in every aspect of AIDS medicine. Fundamental questions about the progression of this disease in women have not been asked or answered. Is cervical cancer more common in HIV-infected women? How does HIV infection affect pregnancy and childbirth? Do the different hormones in women and men affect the course of HIV infection? Do women fall prey to different opportunistic infections than men do? Do women respond differently to treatment regimens established for male patients? Do women suffer different side effects and toxicities from AIDS medications? Do women survive a shorter time after the diagnosis of AIDS has been made? Are the causes of death in women different than in men? In particular, gynecologic disease has until recently been entirely ignored in discussions of HIV-related conditions, and current guidelines for medical management do not include recommendations for gynecologic care. We have little information to indicate how often Pap smears should be done, and common symptomatic conditions such as vaginal yeast infections are not routinely discussed with patients or treated prophylactically.
lactically, as are comparable oral or anal conditions.

The neglect of women with HIV disease extends to other important areas. Very few women have been included in drug trials. The original studies of AZT in 282 patients included only 13 women, and many drug trials have specifically excluded women. The potential importance of gender differences in response to HIV infection is rarely addressed in current medical publications, and this lack allows only the most rudimentary understanding of AIDS in women. Physicians find little information available to help them understand HIV-related gynecologic conditions in women.

Similar symptoms in both women and men are interpreted and treated differently, because women are not expected to have AIDS.

Women at Risk
In the United States, AIDS declared itself first in gay men and subsequently among intravenous drug users, who are predominantly men. This history has led to our false perception of AIDS as a disease of men. This fallacy is quickly dispelled by the observation that in large areas of the world, for example, African and Caribbean nations where the dominant mode of transmission is heterosexual contact, women and men are infected with equal frequency. In addition, the increasing importance of heterosexual transmission in the United States has already produced a faster rate of increase in the numbers of women who have become sick through heterosexual transmission compared to any other group. For gay men in particular, massive educational efforts have been effective in decreasing the rate of new infections.

One factor in this epidemiologic shift is the crack epidemic and its associated hypersexuality and exchange of sex for drugs. Young women and adolescent girls have multiple sexual partners in a day in exchange for a dollar or a hit, and their "clients" are frequently older men with a history of intravenous drug use. As Willard Cates of the Centers for Disease Control observed, the crack houses are for heterosexual transmission to women what the bath houses were for transmission among gay men.

Of the 3,668 cases of AIDS reported in American women in the single year ending November 30, 1989, 51 percent are attributed to transmission by intravenous drug use; 32 percent are attributed to heterosexual trans-
mission; 9 percent to transfusion; and 9 percent to “undetermined means of acquiring infection” (compared to 2 percent in this category for men). The higher rate of “undetermined” risk in women is assumed to reflect heterosexual transmission in which the woman is not aware of her partner’s risk-taking behaviors. The category of women at double risk—those who are both intravenous drug users and partners of infected men or men at risk—is not calculated separately for women as it routinely is for men, even though these women are at substantially increased risk for infection. This matters because it subjects them to the victim-blaming attitude held by many: their source of infection is seen to justify their second-class treatment and care.

It is not clear how many of the estimated one million HIV-infected individuals in the United States are women. Among women who are HIV infected, many are unaware that they are at risk. In a CDC study of HIV-infected blood donors, 44 percent of 34 infected women studied could not identify a risk factor associated with their source of infection, and an equal number were known to have become infected through heterosexual contact. Other studies also indicate an increasing number of infected women who do not know how they acquired the infection. For example, 15 of 26 HIV-positive mothers in a South Bronx hospital and 5 of 12 mothers in a Brooklyn hospital had no history of intravenous drug use or other identifiable risk behavior.

In fact, for many women, their address alone places them at risk. Although area of residence is not officially viewed as a risk factor, data on seroprevalence make clear that, in fact, it constitutes a risk because it is so strongly associated with acknowledged risk factors. Epidemiologic data collected by the Centers for Disease Control (CDC) documents that seroprevalence rates in inner-city hospitals are high even when people with known risks are not counted. Recent CDC data show that as many as 8 percent of women and 18 percent of men visiting emergency rooms in some inner-city hospitals are HIV infected. Similarly, available information about women giving birth suggests that in some inner-city areas as many as 4 to 9 percent of deliveries are to women who are HIV infected. Breakdown of New York City data by zip code area also reveals that the most socially and economically devastated inner-city areas are those with the most HIV disease, whereas contiguous affluent areas may have much less HIV disease. For example, in 1988 the Upper East Side of Manhattan below 96th Street reported an AIDS case mortality rate of 27 per 100,000 people, compared to 48 per 100,000 for East Harlem on the east side of Manhattan above 96th Street.

A woman who lives in an inner-city area and follows a conventional life-style of marriage and raising a family, who does not use drugs and is monogamous, nonetheless runs a high risk of becoming infected because her partner has a high probability of being infected, usually because of drug use. In many cases, these women are not

Prostitutes are frequently seen as the guilty parties in the infection of women whose husbands are their clients.

Its history has led to our false perception of AIDS as a disease of men.

Delia caring for two of her five children at her mother’s home. All of her children have tested negative for HIV.

Winter 1989

Health/PAC Bulletin
aware that their partner is at risk. This means again that poor black and Latina women are at unduly high risk for infection, whatever their life-style, because poverty and lack of resources and opportunity keep them in areas of high HIV seroprevalence.

Women as 'Vectors'
Deeplly ingrained societal sexism as well as racism and classism have skewed the public perception of AIDS and HIV infection in women in the United States. Since the first case of a woman with AIDS was reported in the United States in 1981 in the Bronx, women have remained a forgotten group in the AIDS epidemic. They are regarded by the public and studied by the medical profession as vectors of transmission to their children and male sexual partners rather than as people with AIDS who are themselves frequently victims of transmission from the men in their lives. Until recently, one could gain epidemiologic information concerning women and AIDS mainly from perinatal studies and, to a lesser extent, from studies of prostitutes. Women have been defined primarily in terms of childbearing activities, despite the facts that pregnancy lasts a relatively short period of time and most of the serious AIDS-related illnesses in women occur outside of pregnancy.

Both in clinical practice and public discussion, pregnant women with HIV infection are perceived as incubators of sick babies who are destined to become a burden to society, not as individuals with a life-threatening illness, nor as mothers in struggle and in pain. Mothering, which for most women is an intense and perhaps the strongest emotional bond of their lives, is seen as an irresponsible and selfish act if the woman is HIV infected and especially if she is also poor and of color. Many doctors and other health care providers feel that it is not only their right but their responsibility to counsel and persuade an HIV-infected woman to abort her pregnancy, even in the face of clear statements by the woman that she does not want to choose an abortion.

Such providers are poorly educated about, or choose to ignore, the reasons that their HIV-infected patients may wish to carry a pregnancy to term. A woman's choice is made in the context of cultural attitudes in which bearing children may be seen as the most valuable contribution a woman can make to her family and community. Families often exert pressure to plan pregnancies or to continue pregnancies already conceived. For many women, children may be the only means of attaining a sense of identity and status. In addition, poor women may perceive as favorable the risk described to them of transmitting HIV infection to their offspring. A 20 to 40 percent chance of bearing an infected child is a 60 to 80 percent chance of bearing a healthy child. This is a risk they may be willing to take; these odds seem better than those they routinely face in other aspects of their lives.

Several studies have suggested that HIV-infected women make decisions about pregnancy for the same reasons that uninfected women do. For instance, a study of decisions about pregnancy and abortion made by women on methadone maintenance found that a woman's HIV status was not the best predictor of her decision to terminate a pregnancy. These choices were more readily predicted by factors directly related to the pregnancy, such as the woman's feelings about it and
whether it was planned. HIV-infected women in this study who chose to continue their pregnancies cited family pressure, religious beliefs, and the desire to have a

Mothering is seen as an irresponsible and selfish act if the woman is HIV-infected, especially if she is also poor and of color.

child as important factors in making their decision—in other words, the same factors considered by women who are not infected.

Male Prerogative, Female Risk

Discussions of heterosexual HIV transmission in the United States are also frequently permeated with sexist assumptions. For example, there are a number of studies on HIV infection in prostitutes, presumably because this affects heterosexual transmission to men. In contrast, there has been no discussion in the professional literature of how women's lack of empowerment affects heterosexual transmission to women. Prostitutes are frequently seen as the guilty parties in the infection of women whose husbands or steady partners are the clients and the major support of the sex industry. This shifts the responsibility away from the man who engages in risk-taking sexual encounters. How many men inform their steady partners that they are exposing them to the risk of HIV transmission? The underlying inequity between women and men, at the level of individual relationships

Many health care providers feel that it is not only their right but their responsibility to persuade an HIV-infected woman to abort her pregnancy.

as well as in the culture at large, contributes to much of the transmission of HIV infection, particularly to women who do not perceive that they are at risk. The prevailing ethic that it is a man's prerogative to have multiple sexual encounters without condemnation has been uncritically integrated into official attitudes and research.

Sexist and classist attitudes allow the sweeping condemnation of prostitutes as transmitters of HIV infection. Studies have clarified that intravenous drug use by prostitutes, and not the prostitution itself, places women at high risk of HIV infection. The prevalence of HIV infection is low in prostitutes who don't use intravenous drugs. For example, the CDC compiled statistics from several previous studies demonstrating a seroprevalence of 3.5 to 45.3 percent in drug-using street prostitutes, whereas none of the call girls who did not use drugs were HIV infected.

Lack of empowerment is a problem for all women, and especially poorer women, in protecting themselves against HIV infection. Education is only the first step in successful prevention, and even when a woman does recognize the risk of contracting HIV infection from her sexual partner, she may not be able to protect herself adequately. A heterosexual woman is usually not an equal partner in the bedroom, and her requests that her partner use a condom may be met with refusal or even physical abuse. Many providers involved in counseling women

The shantytown on the Lower East Side where Delia lived. Several of the residents have since died.
about safe sex have had experience with patients who have been beaten because they asserted the need to use condoms. Both the woman and her health care provider must weigh the immediate risk of battering against the long-term risk of HIV infection and AIDS. Similarly, women in the sex industry often omit the use of condoms because of clients’ threats or offers of higher payment to do so. It is reportedly a widespread practice among prostitutes to be more careful about condom use with their clients than with their steady partners, although the steady partners are often intravenous drug users and may represent a far greater risk to the prostitution than her clients.²⁴

Sexism and the lack of empowerment it causes are having a serious impact on the AIDS epidemic. Women are unable to protect themselves adequately from infection because they are frequently unaware that they are at risk; and even when they are aware, they are unable to assert their need for protection. When women are infected with HIV, they frequently do not receive appropriate medical care because of underdiagnosis, a flawed case definition, and insufficient information about manifestations of HIV disease in women. Sexism feeds on itself with the false perception of women as victims rather than vectors of HIV transmission. When classism and racism join with sexism, as they do for inner-city women, the impact of AIDS is devastating. 

18. Hand, J. L., et al., “Newborn Screening for HIV Seropositivity in the South Bronx,” Fifth International Conference on AIDS, 

Delia, after finding out that her boyfriend had died of AIDS. The names on the wall are of those living in the shantytown. ("Dee" is Delia.)


23. Centers for Disease Control, Survey Summaries, "Distribution of AIDS Cases by Racial/Ethnic Group and Exposure Category."


Delia died December 30, 1989. She was 36 years old.
In Their Own Voices

Amidst the clinical discussions of the AIDS epidemic, it is sometimes hard to remember that people who have AIDS or who are HIV-positive are people who are ill, not merely cases and statistics. Each one of the 115,000 cases of AIDS so far diagnosed in the United States represents a person with a story. The people we get to hear tend to be those who have found a way to go on with their lives after discovering they have HIV disease. Among the resources that have made this possible are groups like Body Positive, which provides services and education for HIV-positive people. The following excerpts from its magazine, also called Body Positive, allow women affected by AIDS to speak in their own voices.

'I'm a Human Being with AIDS'
KATHY O'CONNELL

I feel like I need to move at a hundred miles an hour, not at a slow pace. Who knows how much time I have, so I want everything yesterday. I don't know what's going to happen to me tomorrow, so I want to be a winner today.

I'm living my life as normally as possible. A lot of times I don't think about this, except when I get sick and fear comes in. But I face things. I can't run away from them. I'm a fighter. I'm a survivor. Fear is "fuck everything and run"—or "face everything and recover." I'm choosing to recover from this, and I'm recovering from another disease, and that's addiction.

I'm not in bad health. I'm not in good health. I'm fatigued a lot of the time. Sometimes I want to stay in bed, but I get up and deal with life. And I feel that every moment counts. I'm not going to give up and let it overtake me. I feel like a positive attitude helps a lot.

There are so many beautiful people on earth, and just because we have AIDS does not mean we're not people, that we're not feeling, or not emotional. We shouldn't be hidden in the closet whatever our sexuality is....I've had experiences with men and women, straight men, gay men. I want all the love and affection I can get....

I know three or four other women who are positive. My one girlfriend who's positive has a boyfriend who's also positive and they just got engaged and I think it's wonderful. I know quite a few women and we all go through the same fears. As soon as we meet somebody, it's like, "What am I going to do? Should I tell this guy?"

In the beginning, I told people I was positive just because I wanted to get rejected so I wouldn't have to deal with any of these feelings. So they rejected me and I didn't have to deal with anybody. With the new man in my life, I did it differently. We got to know each other first. I'm not going to retreat from sexuality anymore. I won't be abstinent because I'm positive....

I'm a giver; I've always been a giver, but now I need to take for myself—take care of Kathy, so Kathy can take care of her son. I have a thirteen year old son to take care of and support; that scares me because I found out my ex-husband is positive too. I wonder where I'm going to go from here and it scares me.

The way I was brought up was to always give to somebody else—take care of your husband, take care of your son, then take care of yourself. But if I don't take care of myself, I can't take care of anybody else.

I stopped going to my group because people were always whining and complaining about how sick they are. It was depressing. I didn't want to go and absorb all that negativity because I'd go home and think, "yeah, I feel that too" or "oh, I've got that too." I stopped going to that group because I need to hear people dealing with it, not crying about it and talking about how awful it is. Let's do something to make it better is what I say. Instead of dying each day, I'm living each day....

"Instead of dying each day, I'm living each day."

It's been a crazy time. Mayor Koch came to my job at Multitasking Services because they were funding something to do with employment for people with AIDS. He was doing an interview and he said people who have AIDS are only gay or drug users, which puts us into categories that are not totally true. When people hear that it's people who are gay or use drugs, they immediately shut down because they can't identify with that. So I got really angry. If important people like Mayor Koch categorize people with AIDS, then people are just going to dismiss the issue. So when he was leaving, I shook his hand and said, "Hi Mayor Koch, I'm a human being with AIDS!"

—From Body Positive, September 1989
‘I’m Able to Give Them Hope’
ALICE TERSON

Alice Terson, a 37-year-old Hispanic gay single mother who is HIV positive, was interviewed by Body Positive when she became that organization’s new outreach coordinator. In these excerpts, Terson talks about her experiences as a former drug addict who went through a drug recovery program and a support group for people with AIDS, as well as her work with Body Positive trying to reach people with AIDS in their communities with information and services.

I had been incarcerated, at different intervals, for approximately five years. I felt like I belonged nowhere, with no one, and the only thing I knew about feelings was how to numb them with any chemical I could find. Having just been released from Rikers Island, I was afraid to return to the streets because I had lost the energy and the fight I needed to function on a street level. I had no sense of direction, but I knew that I could no longer make it on my own. I didn’t know how to live, I had mistaken existing as living, and I was killing myself one day at a time....

When I was drugging, I was alone. I had burnt all my bridges—family, friends, etc. So I slowly and very painfully started to repair the damage I had created. In the midst of all this, with the help of my support group, I was able to tell my son, mother, and sister of my being positive. I now know that they are there for me and I will never have to feel the kind of loneliness I had existed with in the past....

In my job at Body Positive I see it happening. People get on the phone and there’s all this distress, and all this tension, and first they say, “Well I tested positive. I got my results last week.” And they sound like there’s no hope: I got these results and I’m going to die.

I know that feeling. I know what I felt like when they told me. I already knew I was positive, because I knew how I had lived, but when they told me I was positive, I was ready to take my tent and park in front of somebody’s hospital. At any given moment, I was going to die.

So when somebody gets on the phone and talks like that, I just feel it and I’m able to give them hope....Based on what they tell me, and the tone of voice that they use, toward the end of the conversation I tell them that I’m positive, and it just changes the whole mood of that person....Their hunger for information comes to the surface, and it really wasn’t there before; it was just a lot of fear, just a lot of uncertainty and stuff....

Machismo does exist. The way that you’re raised is: A man gets married, and it’s OK for him to have a woman over here and a woman over there. That’s acceptable. He’s a man, he doesn’t lose anything.

This is how I was raised. A woman is the one who can’t go out there bed hopping. But it’s OK for a man to do it. And then you have heavy denial: “My man doesn’t do it!”...

Her husband is real macho. He’s actually bisexual, but nobody knows it—only he does, and those that he chooses to know. I’ve seen the man sitting in front of me on the train, with his wife and his child. I see that the man is bisexual, but his wife doesn’t see it. I see him eyeing the guy sitting next to me, his wife doesn’t see it.

“I know what I felt when they told me I was positive. At any given moment, I was going to die.”

That’s what I have to confront out there in the community—the woman who says, “Well my husband, he only gets high sometimes.” Only sometimes? And the husband, I know, will go to a shooting gallery sometimes when he gets high, because he doesn’t want to carry his own works.

“But my husband gets high just sometimes, and there’s no way in the world my man could be infected, because my man only gets high sometimes!” Yeah, he looks like a nice guy....

He looks like a nice guy and he’s got all these tracks up and down his arms. “But he was very active when he was growing up, and those are all scratches on his arms.” I swear to God. This is the shit that I have to confront out in the community. And it may not only be the Hispanic and black communities, I’m sure that it exists all over the place. But I believe it’s a little higher in the Hispanic community, I really do....

I don’t like that I have HIV. I don’t like that at all. I like that I’ve been able to turn it around. I like that it’s my tool to pull somebody out of a rut, and that this is life threatening but I don’t really feel threatened by it....And the fact that I can live...well it took me a long time to get hope.

So, being that I have to have this and it’s not going away by itself, I guess I make the best of it, and I use it productively. A lot of people don’t know that I’m positive, and when I tell them, it’s like, “Really. Well then, I want to be like that.”

—from Body Positive, November 1989
Report from the Frontlines

Unsung Heroines of the AIDS Epidemic

RICHARD YOUNGE

I work as a family physician in a community health center in the Bronx. This is the type of setting I described in my application for medical school when they asked, “Where will you work in ten years?” My health center is one block north of the boundary of what many people call the “South Bronx.” But disease does not respect boundaries. My patients contend with the same diseases and epidemics as do all of the communities of the South Bronx: colds and flu, teenage pregnancy and high infant mortality rates, high blood pressure, diabetes, drug use, family disruption, poverty, homelessness...and now AIDS.

In my office, the AIDS statistics all have people’s faces.

The practice of medicine has rewards and frustrations for those of us who do primary care in underserved communities. The health care system and the medical establishment do little to suggest that anyone thinks what I do is useful or important.

I work with my patients to obtain services from a health care system that will do almost anything for an acutely sick person who is lucky enough to be in a hospital, but does amazingly little to prevent disease or to help people cope with their illnesses when they go home from the hospital.

The tremendous resources of the health care system are barely apparent until one of my patients gets sick enough to be hospitalized. Suddenly, the patient has easy access to tests, procedures, specialists, and therapy that, had they been available earlier, might have helped keep the patient well. I feel as if I have failed, because my goal is to keep my patients out of the hospital. My failure turns out to be the key to the treasures of the high-tech, acute-illness, hospital-oriented health care system. Then, if the patient gets better, he or she often loses access to all the medical resources that were available during the hospital stay. The patient returns to the environment that contributed to the illness. I return to struggling to give my patients good medical care in an under-resourced community primary care setting—until they get sick enough again.

For me, the rewards of doing primary care come from working with an individual or a family over time. I spend only a small part of my time diagnosing and treating curable diseases. Sometimes I can cure an acute problem like an ear infection. More often, I help my patients and their families to cope with chronic illness. I attempt to control symptoms, I watch for signs that the illness is progressing, I try to comfort and to give hope.

These frustrations are present with all the chronic problems that I treat—diabetes, high blood pressure, asthma, and arthritis, to name a few. AIDS illustrates the frustrations of doing primary care as well as any disease, perhaps better.

AIDS: A Family Problem

In the Bronx there are so many people infected with human immunodeficiency virus (HIV) that family physicians do not refer people with this problem to a specialty clinic. In fact, the AIDS clinic at the hospital is so busy that they send patients to my health center for care.

For example, 1 in 41 newborns in the Bronx are HIV-positive, according to the New York City Department of Health, compared to 1 in 80 for New York City as a whole and 1 in 625 for New York State. Each of these infants may eventually develop AIDS—or they may not; the estimate of the risk varies from 20 to 50 percent. The Bronx has one-third of the pediatric AIDS cases in the city, even though it accounts for only 19.4 percent of the births. In the Bronx, 65 percent of those diagnosed with AIDS are IV drug users, compared to only 20 percent nationwide. In the South Bronx, this figure is 86 percent. In my office, those statistics all have people’s faces.
AIDS is a primary care problem. As a family physician, I cannot view HIV infection as a syndrome affecting just one patient. AIDS is not simply an infectious disease affecting the immune system. It is a family problem, because HIV infection and the AIDS that usually follows can have a terrifying impact on a family. For asymptomatic people with HIV infection and their families, there is the often agonizing wait for what may inevitably become full-blown AIDS. Family members of people with AIDS have to cope with the demands of caring for a person with a chronic, progressively debilitating condition, and, until a cure is found, family members will have to come to terms with the probable early death of a loved one.

A common stereotype is that IV drug users are completely isolated from their families. AIDS has shattered that image for me. IV drug users have families who are very involved. Sometimes I meet them when they come to the hospital to see one of my patients. More often, a family I have known for a while will begin to show signs of stress. When I begin to ask why, too often I learn about someone with a drug problem or AIDS.

As one of my patients comes closer to death, I may meet a dozen members of the family with various conflicts, needs, issues, and reactions. Do we keep doing invasive and painful tests? What if the patient needs a respirator? What if he gets better? Who will take care of him? While he is in the hospital, who will pick up his public assistance check so his wife and children will not be evicted? Why didn't we do more—or less? Parents will ask me what they could have done differently. Brothers and sisters wish they had been closer. Lovers wonder if they will become ill themselves. Everyone wants to know how a 30-year-old ends up racked with fever, blind, demented, and dying.

I have to come to terms with the demands of caring for people with HIV infection, with their families, and with the death of people my age. These deaths affect me in a profoundly different way than the deaths of the elderly patients whom I treated when I was a resident a decade ago. Even though in the past few years, medical practices have improved the life expectancy of my HIV-infected patients, I still feel quite helpless and sometimes almost hopeless before my patients at risk for AIDS.

The problems of doing primary care in poor communities existed before I started to practice medicine and before AIDS. I thought that I went into this type of medicine with my eyes open. I knew that this type of work was undervalued. In spite of understanding why my type of practice is demanding and difficult, particularly in the face of the AIDS epidemic, I sometimes feel quite overwhelmed. This is the story of one family that helped me renew my hope.

**One Family's Story**

A year and a half ago, Mrs. M came to visit me. Mrs. M is a 50-year-old woman who looks younger than her age. She had breast cancer about seven years ago, has made a complete recovery, and is now, on the whole, very healthy. Mrs. M has been my patient for a few years, and in addition to being her physician, I have become a confidant. I also take care of her daughter, who now works for the New York City welfare agency and has a peptic ulcer to show for her efforts on behalf of that bureaucracy. I have followed the daughter through two pregnancies and one miscarriage. The miscarriage may have been related to cocaine use.

At her previous visit, Mrs. M had complained about a sense of emptiness since her children had grown and left home. As is often the case, my doctor's bag of tricks did not have a cure for emptiness, but I felt relieved that she did not have a more serious problem.

On this visit, Mrs. M came in with a small infant. He was just 4 months old, but he looked much smaller. My first impression was that the baby was asleep, because he was not moving very much. I then realized that he was awake, but not very alert or responsive. Mrs. M had come to ask me to be the doctor for this new patient, her foster child. Many of my patients care for foster children, so this did not strike me as an unusual request. She explained that Anthony had been with her since about a month after he was born. He had been premature, weighing 4 pounds, and he had spent the first four weeks of his life in the hospital.

Anthony's mother was hospitalized, too, since shortly after his delivery, Mrs. M said. At the first visit Mrs. M told me that Anthony's mother used IV drugs, but she did not know if the mother had AIDS. She spoke as if she knew very little about Anthony's mother.

Mrs. M did not seem very concerned about the possibility that Anthony might have been exposed to HIV or what that might mean for the future. Looking at Anthony at that first visit, I was worried. He seemed too small, too slow to react to his environment, not quite right.

---

The problems of doing primary care in poor communities existed before AIDS.

I do not really remember how or why I started to think that Anthony might be Mrs. M's grandchild. She always made it sound as if she had little information about his mother. Mrs. M's daughter was the one who finally let me in on this family secret: that in fact, Anthony's mother was her sister. No one had ever spoken about this other daughter before. This was my first exposure to grandmothers, aunts, or other family members stepping in to care for children whose parents have AIDS.
It turned out that Anthony's mother did have AIDS. She died about eight months ago. Mrs. M and I have spoken many times about Anthony's chances of being HIV-positive too—about 40 percent. In these conversations, I feel as if I am weighted down with the gravity of the problem. Mrs. M listens carefully. She asks questions that indicate to me that she understands what we are talking about. She consistently brings us back to a more upbeat place by the end of our visits with some affectionate story of Anthony's latest mischief or accomplishment. She reminds me that in spite of all that could go wrong, things look good so far, and that Anthony has helped to fill up some of the emptiness she had been feeling before.

We have been talking about testing him. Since I believe that patients should know about their options, I have described the pros and cons of testing, but I have left the decision up to Mrs. M. There is increasing evidence that early intervention improves survival in HIV-infected adults, but fewer studies have been done to document the efficacy of AZT or pentamidine in children. After initially agreeing to HIV testing, Mrs. M has now decided to think about it some more. She feels that there is too much risk that others in the family might reject Anthony if he is HIV-positive.

I am convinced that Mrs. M loves this child as she loved her own children and is his mother now. Mrs. M has said that eventually she wants to adopt Anthony. She will be there for him no matter what his HIV status may be.

Prognosis Unknown

Anthony is about 1 1/2 years old now. Until his last few visits, his weight had been much less than that of most children his age. Lately I have been getting reports about what a big eater he has turned out to be. The last time I saw him, his weight was about average for an 18-month-old. He had gone from a tiny wisp of a baby to an active, energetic toddler.

When I first saw Anthony, he had a bad diaper rash. His skin was beefy red, and he cried when his diaper was changed, almost screaming, as if he were in pain. He had thrush, too, and I was sure that this was the first opportunistic infection. These problems cleared up as they would in a healthy child.

Anthony's growth rate has picked up, too. Now when he comes in with his cousin, who is also 1 1/2 years, they seem more of an even match. Mrs. M takes care of Anthony and his two cousins while her daughter works.

I don't know how she keeps up with them. The disarray of my office after a visit attests to Anthony's new-found energy and motor skills. I still do not know his prognosis, and I discuss this at every visit with Mrs. M. In spite of the uncertainty, Mrs. M's commitment to Anthony remains solid. She has hope for his future and is determined to give him all the nurturing he needs today.

I still worry that, having attained certain developmental milestones like walking, talking, and using the toilet, children with HIV infection can then lose all their progress. They can slip backwards as neurological disease advances. This could happen to Anthony—the active, cheerful toddler with the engaging smile who was so pleased with his mastery of pushing chairs around my office and getting into places he isn't supposed to go.

I cannot help being more hopeful myself, in spite of my knowledge of the bleaker possibilities. My hopeful feeling comes to a large extent from watching Mrs. M interact with Anthony and his cousins. I think that her caring and nurturing has had a lot to do with how Anthony has grown over the past few months. And, of course, I hear from Mrs. M's daughter about how her mother spoils them all. So far, Anthony is well. He has had no worrisome infections, and his development has been fine. There is a lot to be hopeful and thankful for.

Almost all of my experiences with AIDS have been stories of pain. They have been stories of young men and women dying, individuals repulsed by the ugliness of AIDS, and families torn apart by the horrors they have witnessed. Sometimes I too have despaired, but I wanted to share a story of hope. The grandmothers and the aunts are some of the real heroines of the AIDS epidemic. They give unquestioning love to children orphaned by AIDS, some of whom will eventually become sick themselves. As a physician trained in the best tradition of Western medicine, I believe in science and I believe in miracles, too—not just the miracles of physicians healing their patients, but of patients healing their physicians.
The Commodification of Women’s Health

The New Women’s Health Centers

BONNIE J. KAY

The health care facility is often located in a home-like setting that has been renovated to include meeting rooms for workshops. The office is comfortably furnished, softly lit, and redecorated with green plants and women’s art. The accoutrements of service include unusually long appointments, access to one’s medical records and history forms, explanations of prescribed tests and drugs, reports of laboratory test results, even when normal, and prices quoted in advance.

Such amenities characterize the new women’s health centers that have appeared in growing numbers during the last five years. Could it be that mainstream medical care has finally responded to the demands of the women’s health movement for the demystification of medical care, respect for the patient, and control by women over the medical decisions affecting their health care?

A closer look reveals that the services many of these women’s health centers offer are directed only at a select segment of women: those who pay—or have health insurance that does. The target group is usually in their 20’s and 30’s, college educated, and employed. They are interested in maintaining a healthy life-style and peruse the popular press for articles on premenstrual syndrome (PMS), endometriosis, breast cancer, osteoporosis, and the like. Few have had contact with women’s groups that address the political issues related to women and health care. The services these women receive at women’s health centers frequently cost more than they would at a private doctor’s office—the extra time spent with a clinician is expensive.

The gentle atmospherics, “paddle fans, herb teas, and green plants,” that invite women “to relax and make themselves at home” are the marketing tools of the 1980’s. In contrast to 20 years ago when the women’s health movement articulated its critique of the medical care system, women are now consciously recognized by medical centers, nonprofit hospitals, and proprietary health care companies alike as a large and lucrative market.

Cultivating a Clientele

In many respects, these women’s health centers should be viewed as part of the larger development of ambulatory care centers by hospitals, promoted as a means to cultivate a clientele who will use the hospitals’ inpatient services in the future. Estimates of the number of ambulatory centers in the United States range as high as 4,000, including both hospital-owned and independent, for-profit centers. Primary and urgent care centers account for the bulk of these, but the greatest growth over the previous year has been among single-purpose centers, including diagnostic imaging centers, health clubs, and cancer care centers. Many of the services in these specialized settings are targeted at women: screening for breast cancer and osteoporosis, women-only alcohol treatment programs, mental health and stress-management workshops, PMS and gynecological care, and nutritional health care.

Bonnie J. Kay is a researcher specializing in women’s reproductive health care.
counseling and exercise. In fact, a 1984 survey by the
American Hospital Association of over 3,000 hospitals
with health-promotion programs found that 49.9 percent
provided programs especially designed for women, fre-
quently in the form of women's health centers.3

One recent issue of the local newspaper in Ann Arbor,
Michigan, featured advertisements from three area hos-
pitals with women's health programs.4 Two announced
public lectures on topics such as “Menopause: A Time of
Changes, Challenges and Growth” and “Women and
Estrogen: A Part of Your Life.” The third program offered
“Women's Night Out for the Health of It,” complete with
dinner at $19.50, featuring a former columnist for the
Detroit Free Press lecturing on “In Search of Intimacy.”

On the surface it appears that the health needs of
women have finally become a legitimate item on the
medical care system's agenda. “The Health Industry
Finally Asks: What Do Women Want?” trumpets Business
Week, adding as its response, “New services are
springing up for female patients fed up with conven-
tional care.”5

Many women's health centers are directed only at
a select segment of women: those who pay—or have
insurance that does.

Yet, while the services provided as part of these
women's health programs are no doubt useful to some of
the women who can afford them, these women's health
centers are also offering up a more subtle form of the
exploitation that the women's health movement initially
opposed, in which health care is defined as a commodity
to be marketed and sold for maximum profit to the
provider, rather than a need to be filled for the benefit of
the individual. Women are seen as easily manipulated by
superficial accommodations (the “paddle fans, herb teas,
and green plants”) with the ultimate aim of filling mater-
nity and surgical beds to maintain the financial viability
of the medical institution. A center's existence is assured
as long as it can document referrals to hospital services
and it doesn't alienate local physicians or invade their
turf.

As the medical system recognizes “women's health” as
a legitimate area for research and treatment, it “medical-
izes” women's normal life processes, such as birth, men-
struation, aging, and even eating. They are redefined as
pathological events, subject to the expertise of physicians
for diagnosis and treatment. The understanding of these
life events, which have strong political, economic, and
social aspects and influences, is limited to the medical
arena.

Whereas demystification of medical care was the cen-
tral tenet of the women's health movement, the new
women's health centers promote remystification. The
very language of social change has been coopted to fit
new attempts to maintain the status quo or to further
develop a class-based health care delivery system. The
most obvious example is the use of the phrase “women's
health center” itself, borrowed from the alternative
groups that formed the basis of the women's health
movement.

Phyllis Heiland

The Women's Health Movement

The women's health movement expanded the analysis of the U.S. health
system offered by the social change movements of the 1960's. The larger
movement focused on the neglect of pre-
ventive care; physician-induced, cultur-
ally induced, and socially induced
illness; and the economic inequalities of
society as reflected in the health care
system. The women's health movement
added to this an emphasis on the imbal-
ance of power in the medical system
along gender and class lines—among
health workers and between providers
and clients. This critique viewed rela-
tionships in health care as reflections of
relationships in the broader society. Its
analysis of the medical practice model,
for example, revealed a compliant, pas-
sive patient facing a dominant, usually male, authority figure in those areas of health care that are exclusively female: routine obstetrical and gynecological care.

Women's health groups were the visible part of this critique and formed a major force for promoting social change and raising the consciousness of women. Some groups chose to provide health services to women directly, while others organized to collect, evaluate, and disseminate information on providers of women’s health care. These groups emphasized a non-hierarchical structure, shared decision making, and a holistic approach to health. Groups that provided services sought to demonstrate, by example, an alternative to the existing hierarchical and class- and gender-based medical system. Good examples are the Feminist Women’s Health Centers in Los Angeles and Chico, California; Portland, Oregon; Concord, New Hampshire; and Atlanta, as well as the Emma Goldman Clinic in Iowa City. Groups that provided information focused on using economic pressure as a means to institute change from within by directing women to providers who shared the movement's values and reflected those values in the provision of services. The Chicago-based Health Evaluation and Referral Service (HERS) has existed since 1973 using this approach.

In contrast to the challenge the women's health movement presented, today's women's health centers are mere fronts for the medical care system, more palatable entry points into the realm of medical care. A central tenet of the women's health movement was the personal empowerment that resulted from taking control over choices affecting one's health, in the broadest sense of the word, and most important, being able to define what those choices were. For instance, if abortion services are not available for women, being able to choose between an illegal abortion and carrying an unwanted pregnancy to term is not a meaningful choice. Similarly, if a woman's options for childbirth are limited to choosing between a hospital with a high rate of cesarean sections and one with a slightly lower rate, when what she really wants is a home birth, she is not truly exercising control over her health care.

It is this aspect of choice that is glaringly absent from the recent-day women’s health centers and health programs. These centers may treat clients in a polite, respectful manner, and individual women may feel personally in control of the circumstances of their health care, but broadly speaking, control remains with those who define the underlying purposes of the new centers and their programs. And hospital administrators are quite forthright about these purposes: to enhance the hospital’s public image, to fill hospital beds, and to promote the financial status of their institutions in what they perceive as a competitive market.

The Health Sector as a Marketplace

During the late 1970's, as health economists and policy analysts searched for ways to explain and contain continually spiraling health care costs, the notion of the health sector as a medical marketplace became increasingly common. The Reagan Administration’s dramatic cuts in support for health and social services in 1981 and its clear preference for strengthening ties with the profit-oriented business sector provided the right climate for transforming health care services into commodities not unlike chewing gum and automobiles. The nonprofit medical sector responded by adopting management models from the business sector that emphasize efficiency and profitability rather than equity as criteria for deciding what mix of services to provide and to whom they should be provided.

Under these circumstances, the traditional distinction has been blurred between the need for health services, a concept based on health status compared against an accepted standard, and the demand for health care, that is, which services health consumers will pay for. The push to ensure economic viability in an environment of decreasing economic support from the public sector has meant that health providers have redefined necessary health care as services that consumers are willing to purchase at a price at least high enough to cover the costs of production. If that price is too high for some (i.e., the poor), it doesn't matter as long as the numbers willing to pay are sufficient to cover costs.

Thus, health needs are determined not by the health status of various groups in a community but by the pref-
Women as Health Care Markets

Women use a lot of health and medical care. They consume about 60 percent of all health services in the United States. Over 60 percent of all surgery is performed on women. Women schedule one-third more office visits to physicians than men and return for a repeat visit 6 percent more often. As mothers, women also direct the medical care of their families. As one “health promoter” puts it, “If the hospital treats mom, the rest of the family will follow closely behind.”

Capturing the “women’s market” is seen by many providers as critical to the continued economic viability of their organizations in these days of declining inpatient censuses. Articles in the health trade magazines talk about “market segmentation” (dividing patients into young, middle, and mature; or employed and not), and development of “product lines” (for example, breast diagnostic programs, PMS screenings, and osteoporosis examinations). A text on Marketing Women’s Health Care asks, among other questions, “Why is attractive decor as essential as technical competence in attracting women patients?” and “How can you turn a maternity stay into a long-term relationship?”

Another book, titled Reaching Women: The Way to Go in Marketing Healthcare Services, discusses “strategies used to win over women consumers and keep them coming.”

Hospitals are chastised for “missing out on the women’s market” by continuing to view women’s health as restricted to the maternal role and reproductive system. Instead, women’s health centers are touted as presenting a “bold new strategy” that will allow a hospital to “differentiate itself from the competition.” Sally Rynne, a popular consultant to many hospitals interested in developing programs aimed at attracting women, identifies a host of advantages for hospitals undertaking to develop women’s centers, including profitability, increased demand for inpatient services from referrals from the centers, a wider scope of clients beyond those seeking obstetrical services, and the ability to capture new sources of potential patients.

Redefining the Agenda

The medical sector has taken the concept of empowerment and redefined it to mean providing information about which choices to make; these “choices,” it turns out, have been reduced to services that can return a profit. Not only do women’s health centers narrowly cir-
cumscribe the agenda for those who can afford to pay, but they completely exclude those women who lack income or insurance to pay for those services.

Information has become a marketing tool for attracting clients to a particular provider. Women's health centers are primary outreach tools for hospitals. Public lectures on topics such as PMS, osteoporosis, and stress—are issues that have been used in the past by the women's health movement to raise the consciousness of women about the social and political aspects of their experiences—are now marketing magnets. And, of course, the context in which such information is presented is much narrower, generally focusing on medical aspects and biological explanations and ignoring social, economic, and political issues.

Women's health centers don't make money on educational services. They are "loss leaders," used to enhance the parent hospital's public image and develop a pool of paying customers who will be more inclined to use the more lucrative, technologically intensive inpatient services should the need arise. And the need will arise, based on the medical system's discovery and redefinition of a growing number of women's common life experiences as medical problems amenable to medical intervention. Along with birth and menstruation, eating, aging, and economic stress have become popular as medical issues.

In the short term, more work needs to be done to sensitize women to the more subtle forms of exploitation by the medical system. Locally, alternative women's health groups (they still exist and are more prevalent than many realize) can be effective in pressuring the new women's health centers to broaden their focus beyond paying clientele and open their medically focused educational activities to include discussion of alternatives to traditional medical approaches.

Health care is whatever people will pay for—a commodity for sale.

In the long term, however, the transformation of women's health services into salable commodities is simply a symptom of a larger ill that cuts across gender lines. Broadly speaking, health needs are defined by the preferences for health services of those who can pay for them. Those who cannot are pushed to the periphery of a health system that increasingly relies on economic class as the basis for allocating its resources. The continuing struggle for social change must develop support for the idea that health is a public good (to use the economists' phrase), and medical marketing plays an unhealthy role in its delivery. Making commodities of health services denies health care to all those who cannot pay for it and perpetuates a health policy that serves the few at the expense of everyone else.

---

13. Ibid., pp. 15, 17.
Birth Control Fails: How to Abort Ourselves Safely, by Suzann Gage. The book is a step-by-step guide to techniques of self-abortion, ranging from herbal methods to a suction abortion. The centerpiece is menstrual extraction, removal of the contents of a woman's uterus, including menstrual fluid—and an embryo if present—and designed to be carried out in the supportive atmosphere of a self-help group. Other topics include sterile technique, complications, and how to trick a doctor into performing an abortion by simulating a miscarriage (using calf’s liver and good acting techniques). The organization is also organizing a national “Self-Help Tour” to bring information to women in their communities.

The federation, founded in 1975, is an umbrella association of about 30 women's health clinics that were created during the height of the women's movement. Their goal was to provide direct health services as an alternative to existing care that was considered exploitive of women. The premise of the manual, distributed by women who have already experienced a time when all abortions were underground, is that a professional abortion may be illegal, unaffordable, or otherwise impossible to obtain. In fact, the manual was written in response to the need of imprisoned Chilean women in the early 1970’s who became pregnant after being raped by prison guards. The book was smuggled in to these women, who had nothing to lose.

"We see menstrual extraction as an insurance policy."
But what of the women who might be practicing self-abortion today? As articulated in their new video, No Going Back: A Pro-Choice Perspective, FFWHC believes that women will get abortions, whether they are legal or not.

"Our priority should be to insist that women have access to the best care."

and that with the availability of safe, legal abortions under attack, it is their job to make sure that illegal abortions are as safe as possible. "It's less than perfect health care," acknowledges Lynne Randall, director of the Atlanta Feminist Women's Health Center, but safe when done in the context for which it was designed. "It is logistically not possible to do it by yourself." Although it is difficult to think about while legal abortions are still available, "now, while we can still talk about abortion," Randall says, "we need to spread the information. Dissemination of information will be a lot harder" if abortion becomes illegal.

"We see menstrual extraction as an insurance policy," says Shireen Miles, associate director of the federation. "We don't believe it will make abortion accessible for every woman. But what is accessible are some terrifying alternatives—Lysol and coat hangers."

Loretta Ross, program director of the National Black Women's Health Project in Atlanta, concurs that while ideally abortion would be safe and legal, her group supports "the right of women to do self-abortion through menstrual extraction as a safer alternative to back-alley abortions" if abortion becomes illegal or severely restricted. She notes that the low cost of the procedure—the whole kit is less than $100—might make it accessible to third-world and poor women when other forms would not be. "It would be like a return to the past," she says, with underground networks developing again. "Experience around the world has shown that when you make abortion illegal, women don't stop getting abortions—they just stop getting safe ones. No matter what their socioeconomic group, women will try to control their child spacing."

Ironically, even though abortion is still legal, the government has recently stepped in to restrict the distribution of the FFWHC's menstrual extraction kits as an unlicensed device that poses a risk to public health. "The very idea that women are talking about taking abortion into our own hands is challenging to the government, and they're going to stop it," says Randall. "But we still have free speech rights and we can talk about it and we can implant the idea that women have the right and the ability and the skills to learn this if they need to."

A Question of Safety

Some feminists, however, are concerned about the risks of self-abortion techniques. "I have a lot of trouble with it on safety grounds and as a political strategy," says Dr. Wendy Chavkin of the Columbia University School of Public Health. "The women most likely to be affected by restrictions on abortion are the same women most likely to have medical problems. These women are not in the same bleak circumstances as the Chilean women in prison, and our priority should be to insist that they have access to the best care."

Cynthia Pearson, acting director of the National Women's Health Network in Washington, D.C., agrees that the goal is for women to have access to safe abortion and that the way to guarantee this is through the legislative arena. "But in some states women won't have access," she says. To encourage discussion of possible responses to the Webster decision among local pro-choice groups, the network has issued a booklet entitled Abortion Then and Now: Creative Responses to Restricted Access, which contains reprints of old and current articles describing methods women used to cope when abortion was illegal. In addition to underground referral networks, self-help abortions, and the experiences of women in other countries, the packet recalls the Jane collective, an almost mythical group of women who set up an underground abortion referral network in Chicago for four years, starting in 1969. Through observing their illegal abortionist, these women learned to perform the procedure themselves and then dispensed with their services. In addition to providing this service for the women they could reach, the Jane collective attempted to empower women by taking both medical care and social change into their own hands. The collective performed thousands of abortions, with a safety rate purportedly as good as that of legal abortions in New York State.
deal with incomplete abortions, perforation, and infection—all of which happen in clinic abortions as well. According to the federation, an estimated 20,000 to 30,000 menstrual extractions have been performed in groups around the country, with no reported deaths or perforations.

Chavkin is not convinced by these arguments. "Getting the group support may make a real difference in how somebody experiences abortion, and that's very positive," she comments. "But it's a separate question from whether the occasional medical crises like seizures or cardiac arrest can be competently treated by these people in this setting." Miles says the FFWHC's response to criticism from the medical community is "Are you going to be doing the illegal ones?"

RU-486

The organizations that support menstrual extraction are also actively involved in the attempt to bring into the country another type of abortion technology: RU-486, the so-called abortion pill (See Vital Signs, Winter 1988 issue). Feminists from FFWHC and NWHN, as well as from the National Organization for Women, who have visited France to investigate the drug, have been largely positive about its efficacy, ease, and safety. These groups have joined other major women's, health, science, and family planning organizations in creating a Reproductive Health Technologies Project to conduct a public education campaign pressing for RU-486 to be made available here. "We have reservations about possible side-effects of chemicals," says Randall of the FFWHC, but given the current alternatives, the group is very happy with it. It is considered quite safe when taken in conjunction with prostaglandin and—somewhat like menstrual extraction—when done in a supportive setting with adequate supervision.

It is well known that U.S. pharmaceutical companies are under considerable pressure from anti-abortion groups to refrain from marketing the drug, despite its other applications unrelated to abortion. And, according to Pearson, while the Federal Drug Administration is reportedly prepared to approve RU-486 should it become available here, the drug's French manufacturer, Roussel-Uclaf, is now negative about either importation or testing in the United States. Roussel-Uclaf is no longer making RU-486 available outside of France. Moreover, RU-486 has been specifically excluded from the recent FDA ruling, designed for AIDS medications, that small amounts of an unapproved drug can be brought into the country for personal use.

Rumors abound that RU-486 will soon be available underground, if not legally. Some predict that it will make current abortion technology obsolete. This attitude is worrisome to others, however, who are concerned both with the safety of the drug and its potential to distract women from the fight to keep abortion legal.

While actively involved in rallying public opinion in favor of RU-486, NWHN is cautious about its potential for misuse here. The population for the original clinical testing of the drug in France did not include poor women, rural women, or women of color, and, says Pearson, the drug's developers deserve credit for not using these women as guinea pigs. However, these groups have different health concerns from middle-class women and could react differently to RU-486. For example, it might exacerbate concerns from middle-class women and could react differently to RU-486. For example, it might exacerbate diabetes in Native American women or the fibroid problems of black women. Maltreated women might be more likely to hemorrhage.

Ross of the National Black Women's Health Project, while welcoming RU-486 as a "wonderful addition" to the array of abortion methods, is also concerned about its accessibility to poor and third-world women because of the importance of medical supervision and the need for recurrent medical visits. She points out, however, that the same women who would have problems with RU-486—for example, rural women or women on a reservation who are 50 miles from the nearest clinic—would also have these problems with current methods of abortion.

Is the threat to legal abortion pushing women into embracing questionable technologies such as self-abortion and RU-486? Do these technologies represent women taking control of their bodies or a danger to women? As with most technology, the benefit seems to depend to a considerable degree on who controls it and the context in which it is used.

How serious are the differences over issues of self-help technology in the pro-choice movement? "There will always be a tactical difference," says Pearson. "The fight is large enough that there's room for all sorts of strategies."
Fl oods of blood, floods. " The refrain from a song of black South African miners provides a chilling description of the toll claimed on life and limb by the mines there. It is hardly an exaggeration.

More than 700 men—the vast majority black—die on the job in South Africa's mines in an average year. Miners who survive face an almost one in two chance of permanent disability over a 20-year working lifetime.

The roots of this appalling situation lie both in South Africa's apartheid system, which institutionalizes racial discrimination, and in its authoritarian capitalism, similar to that of third-world "miracle" economies such as those of South Korea, Taiwan, or Brazil. Racial rule and the unchecked pursuit of profit have meant that black workers were treated as cheap labor units, easier to replace than protect.

The growth of black trade unions and the rising costs of accidents are exerting increasing pressure for change, but, despite some progress, the response from industry and the government remains inadequate. As a result, for lack of any alternative, the mine workers' battle for safe working conditions has become tied to the struggle against apartheid and for political and social democracy.

The Bloody Record

Mining has long held a central place in the South African economy. The discovery of gold and diamonds there a century ago launched the country's industrialization. Mineral exports still provide a large part of its foreign currency earnings.

Members of the South African Chamber of Mines, which represents the principal mine owners, employ 580,000 of South Africa's nine million workers. The larger mines are like underground cities. Tens of thousands of workers—most of them black—break and transport ore along dozens of miles of tunnels, many as deep as two miles below the surface.

Underground, "the day-to-day accident toll is staggering," says sociologist Jean Leger, one of South Africa's leading experts on mine safety. Between 1975 and 1987, official figures show, more than 8,000 workers died in workplace accidents in gold, coal, and diamond mines. More than 190,000 were permanently disabled over the same period.

Such accidents happen far more often in South Africa's mines than in those of other industrialized countries. In 1983, the death rate in South Africa among underground coal miners was 2.46 per 1,000 workers—five times the fatality rate in American coal mines in the same year and 16 times that in British mines. These disparities cannot be explained by differences in conditions of operation. British coal mines are deeper and more difficult to work in than those in South Africa.

Nor did conditions improve over the years. A study by Leger and H. S. Eisner, a retired laboratory director from the British Health and Safety Commission, showed no overall decline in death rates in the gold mines between 1970 and 1985. In the coal mines they found a slight decrease in deaths, barely of statistical significance. Deaths from rockbursts, the most frequent type of accident, actually increased over the 1960's and 1970's,
according to research by Leger and M. Mothibeli, a black South African colleague.

In the 1980's, a series of grim, deadly disasters at South African mines received worldwide publicity. An explosion in the Hlobane coal mine in 1983 killed 86 workers. In 1985, 33 miners died in an accident in another. The most recent major accident occurred at a coal mine in 1987, leaving dozens more dead.

More than 700 men—the vast majority black—die on the job in South Africa's mines in an average year.

But the worst of the South African mining disasters was the Kinross gold mine fire of 1986. The walls of a tunnel lined with polyurethane foam ignited during a welding operation. The poisonous fumes released blew rapidly through the mine ventilation system, killing 177 miners.

Smaller accidents, ones that kill or injure only a few miners, occur far more frequently. Last year the Weekly Mail of Johannesburg reported that "accidents of one or two men being killed by a piece of falling rock have become so routine that newspapers do not always find the space to publish them."

'Pit Sense'

Black miners' long experience in the narrow, dark, hot, tunnels, where they drill charge holes and blast ore, usually allows them to recognize the signs that a rockfall is coming. Said one, "You hear rattling sounds, fine particles fall, and the whole place becomes dusty. When the roof supports also bend—that is a sign of a rockfall. Once that sound happens, once or twice, there is just a minute or less, then there's going to be a rockfall."

Although this sort of "pit sense" has been recognized among miners by managers in Britain and elsewhere, the racist paternalism of South Africa's mines means that it is often ignored there. Instead of using miners' accumulated knowledge, the mines' safety procedures are based on rote repetition of subdivided tasks. Underground, white supervisors, anxious for high-output bonuses, also frequently ignore black miners' warnings of danger, according to a survey Leger and Mothibeli conducted among 178 black mineworkers. According to one miner they interviewed, "Even when I tell [my white supervisor] of the signs [of an impending rockfall, he] does not come with me to inspect and give advice. When we complain, [he] forces us to work there. I was charged [with indiscipline] for refusing to go and work in a dangerous place."

The mines have been able to function with these conditions because black workers have been inexpensive and easily replaced. Under the apartheid system, black workers are unskilled migrant laborers, housed and fed cheaply in shabby barracks, while their families grow what little they can in overcrowded black reservations hundreds of miles away. Citing the miners in-kind benefits and their families' small plots as justification, the mines claim they need not pay a living wage. The $60-a-month minimum wage for underground workers in 1985 was barely half what a rural household needed for subsistence—and that was after a decade of steady increases.

As a result of this abundant supply of low-wage labor, South African mines have been slow to make use of ore-breaking machines that have reduced accidents else-
where. Instead, they rely on old-fashioned explosives to break rock.

The hazards faced by miners have been compounded by their lack of representation in the workplace and in the political system. As in other newly industrializing nations, South Africa’s cheap-labor “miracle” economy has rested on weak unions and autocratic government. The combination of repressive capitalism and white minority rule explains the traditional complacency of business and government toward the loss of black life in South African mines.

Forces for Change

In the past few years, forces for change have finally begun to make themselves felt in the mines. The most important has been the explosive growth of the National Union of Mineworkers (NUM), which now claims more than 250,000 members. To show it was serious about safety, the union called a one-day national strike after the Kinross fire. It has also fought alongside the anti-apartheid movement for the vote for the disenfranchised black majority. By winning wage increases for blacks, NUM also encouraged the mines to pay more attention to safety, according to Halton Cheadle, a South African labor lawyer.

Accidents happen far more often in South Africa’s mines than in those of other industrialized countries.

The growing organization and militancy of workers may have finally marked a turning point for mine safety. Although it is too early to see conclusive trends, Leger points to a sharp downturn in accidents since the 1983 Hlobane disaster as union pressure for reform has risen. It has also led to several important procedural advances. In 1987, the Chamber of Mines agreed to allow representation for workers in setting safety procedures and to recognize their right to information about workplace hazards. Some coal mines have established regular safety meetings of employee representatives. Legal color bars keeping blacks out of skilled work have also been ended.

Yet both mine workers’ representatives and management recognize that the long-run answer to the safety problem entails fundamental changes in the way the mines operate. They disagree profoundly, however, on what those changes should be. The Chamber of Mines’ answer is the gradual application and/or development of mechanized mining techniques, which are safer and need fewer workers. NUM’s view was summed up in a poster it issued after the Kinross disaster: “Safety or profits—nationalize the mines under workers’ control!”

Memorial service held in Johannesburg by union for 177 mine workers killed in the 1986 Kinross disaster.

AIDS Watch

Prisoners’ Rights

Nicholas Freudenberg

Is there a right to AIDS education? Does government have the responsibility to provide people with the knowledge and skills they need to protect themselves against HIV infection? Several cases brought by inmates of state prison systems and currently in the federal courts are raising these questions. Establishing the legal right of prisoners to know about AIDS could set an important political precedent for other populations.

In late 1987, the Alabama state legislature passed a law requiring mandatory HIV testing for all inmates and segregation of those who test positive, whether they are sick or not. The Alabama Department of Corrections established two segregation units, one for men, the other for women. In 1988, a group of inmates represented by the American Civil Liberties Union’s National Prison Project filed a class action suit in federal court (Harris v. Thigpen) charging that mandatory testing violated constitutional protections against search and seizure and rights to privacy and that identifying seropositive patients subjected them to discrimination. It also charged that inadequate medical care, including the failure to provide counseling for inmates before or after testing, constituted cruel and unusual punishment.

Finally, the inmates claimed that Alabama’s testing and segregation policy was an ineffective as well as unconstitutional means to achieve the desired goal—prevention of HIV transmission—and that comprehensive AIDS education would be both a more humane and a more effective strategy.

A similar class action lawsuit was filed in federal court by a group of inmates in facilities run by the Connecticut Department of Corrections (Doe v. Meachum). They charged, among other things, that since the Supreme Court found that “deliberate indifference to serious medical need” (Estelle v. Gamble, 1976) of prisoners violated the Constitution’s Eighth Amendment barring cruel and unusual punishment, failure to provide AIDS education to a population at very high risk of developing HIV infection violated their constitutional rights. They further argued that the Department of Correction’s failure to educate inmates and staff about how HIV infection is transmitted subjected some seropositive inmates to harassment from guards or physical attacks from other inmates.

Since Connecticut had not yet established a systemwide policy on AIDS education and counseling, despite more than 400 inmates identified as being infected with HIV and an estimated 25 percent seroprevalence, the plaintiffs charged that these failures to provide education and counseling constituted “deliberate indifference to the medical and mental health needs of prisoners.” A recent settlement of the case provided additional resources for AIDS education, representing an important victory for inmates.

While it may be several years before there is legal clarity on prisoners’ rights, the moral, political, and economic arguments for the right to AIDS education are strong. Several recent expert panels, including the Presidential Commission on the Human Immune Deficiency Virus Epidemic, the Institute of Medicine, and the National Research Council, have affirmed that education remains the principal strategy for containing the epidemic. Even dramatic new medical advances in treatment or vaccine development would not replace the need for AIDS education. Moreover, the benefits of effective education go beyond AIDS: the strategies for protecting oneself against HIV infection can also protect against other sexually transmitted diseases, unwanted pregnancy, hepatitis, and the negative consequences of substance abuse. Why, then, would anyone oppose making AIDS education universally accessible?

Even more shocking, many public health authorities have instead focused on individual responsibility for prevention, rather than attacking societal failures to provide, for example, school health and sex education, television advertising of condoms, drug treatment on demand, or comprehensive community-based AIDS education. Thus, numerous laws and policies have been passed requiring HIV testing for specified populations (e.g., immigrants seeking legal status, federal prisoners, prostitutes, sex offenders), reporting of people who...
are found to be infected, informing the sex partners of infected patients, and testing women for HIV infection to prevent perinatal transmission. While some of these programs may have a place in some settings, they share a common focus on targeting victims of AIDS.

As the AIDS epidemic nears the end of its first decade, the chorus of politicians and public health workers, buoyed by the mass media in calling for more responsible individual behavior, needs to be countered with renewed calls for institutional responsibility.

The lawsuits asserting that prisoners have the right to AIDS education suggest a strategy that goes beyond victim blaming to a more positive agenda: creating a social environment that supports prevention of the disease. Just as the labor and environmental movements have won important victories expanding their right to know about the hazardous materials they face and the actions they can take to protect themselves, so AIDS activists and educators can contribute to a redefinition of social rights and responsibilities for health.
Boycott Exposes GE's Dark Side

The same group that originated the successful consumer boycott of Nestle for its callous marketing of infant formula in the Third World has targeted General Electric for its manufacture of products other than those that "bring good things to life."

INFECT, which began its boycott of the consumer giant in 1986, is seeking to pressure GE to cease both its production of nuclear weapons components and its lobbying efforts with the federal government on their behalf. GE produces critical components for more nuclear weapons systems than any other manufacturer.

INFECT's broad-ranging public education campaign is focusing attention on a lengthy list of GE's environmental abuses. These include the 1949 "experiment" at the Hanford Nuclear Reservation plutonium plant on the Columbia River in Washington State, where GE secretly discharged a cloud of radioactive gas hundreds of times the size of the emission at Three Mile Island. The soil around the plant is contaminated; and suspicious illnesses, miscarriages, and clusters of cancer in the surrounding human and animal populations have been linked to it. The Federal Water Pollution Agency has called Columbia "the most radioactive river in the world."

GE's operations have left a trail of radioactive waste around the country. The water and soil around its Pinellas, Florida, plant, which manufactures the neutron generator—the "trigger" for every U.S. nuclear warhead—is contaminated with radioactive tritium. The plant is located within two miles of ten public schools. Just last August, GE's plant in Lynn, Massachusetts, was cited for 60 violations of state toxic waste regulations. And New York State is still struggling to decontaminate the Hudson River where GE plants dumped 500,000 pounds of PCB's between 1946 and 1975.

Through its street corner and direct mail campaign, INFECT has obtained 350,000 signatures from people pledging to boycott GE products. The group claims that 10 people are actually boycotting for every actual signer. Hospitals, supermarket chains, and universities have taken GE products off their shelves. INFECT estimates that GE has lost $56 million in sales, and that the corporation's advertising budget has increased 300 percent in an attempt to maintain its "warm, fuzzy image."

The group points out that GE also manufactures expensive medical systems, including X-ray equipment, magnetic resonance scanners, ultrasound equipment, and nuclear medical products. One boycott endorser, a religious order that runs the ASC Health System in southern Illinois, reconsidered an order for two CAT scanners—a $1 million loss for GE. Individual health care workers have prevailed upon their hospitals to do likewise. INFECT asks you to boycott GE and Hotpoint products and to let GE know why.

For more information, contact INFECT, 256 Hanover Street, 3rd Floor, Boston, MA 02113, (617) 742-4583.

—Ellen Bilofsky

Businesses Undermine Bill

The proposed Americans with Disabilities Act (ADA) is predictably facing tremendous opposition from the business community. If passed, this legislation will broaden the rights guaranteed by the 1973 Rehabilitation Act—which prohibits discrimination against the disabled by institutions receiving federal funds. Introduced two years ago by Senator Tom Harkin of Iowa, the ADA guarantees equal access to public transportation, public accommodations, telecommunications, and employment-related opportunities and facilities.

Under pressure from corporate interests, the bill has been watered down from the form in which it was first introduced. It originally contained such requirements as compelling businesses to make themselves accessible to disabled people unless doing so would result in bankruptcy. Now businesses have an out if making the requisite structural changes would cause them "undue hardship"—a phrase subject to wider interpretation.
Some of the most vocal opposition has arisen from major bus companies. These companies have already won such victories as extending the time period within which they must make changes after the bill’s passage. And Wayne Smith, executive director of the United Bus Owners of America, recently complained in a New York Times op ed piece that “so far, debate on the bill has been entirely framed by handicapped proponents, who insist that it is inappropriate to discuss costs in a ‘civil rights’ issue.”

Smith’s condescending characterization of the bill as a “‘civil rights’ issue” epitomizes what Disability Rag editor Mary Johnson describes as the perception that disabled people suffer discrimination of a different, somehow more legitimate kind. The public’s view of the disabled, she says, has lagged behind that of other groups traditionally victimized by prejudice. The recognition that disability rights are as much of a civil rights issue as the treatment of, for example, African-Americans and women is not yet a part of our national consciousness.

Despite the strength of the business community, most disability rights activists are optimistic that the act will pass the House this spring. Even conservative politicians apparently realize, at least to an extent, that disabled men and women have been treated unfairly. And activists seem to agree that whatever form it takes, the ADA’s passage will be, in Johnson’s words, a “cane or wheel in the door.”

Choice for Planned Parenthood Workers

The women and men who work at Planned Parenthood’s Margaret Sanger Clinic spend their day helping other women exercise their reproductive rights. They face bomb threats and Operation Rescue picket lines as an occupational hazard. But when these workers decided to help themselves, they faced a new set of obstacles.

These clinic workers, telephone operators, nurses, counselors, cashiers, and lab technicians—many of them single mothers and women of color earning less than $11,000 per year—felt Planned Parenthood had an obligation to live up to its ideology of empowerment for women when it came to its own workers. In the summer of 1987, they began to organize for better wages, a health plan that would cover dependents, healthier working conditions, and dignity and respect on the job.

In September 1988, despite an aggressive anti-union campaign orchestrated by a Park Avenue union-busting law firm, the Planned Parenthood workers voted 27 to 5 to join the Communication Workers of America. A bitter contract struggle followed, with management twisting the language of the pro-choice movement into anti-choice rhetoric. They argued that a union shop would take away workers’ “right to choose,” and that providing health care for dependents would discriminate against women who chose not to have children.

After a year without a settlement, the new union members decided to publicize their situation in an open letter to the pro-choice community, asking for postcards of support to Planned Parenthood’s president Diana Gurieva. The union was also able to bring political pressure to bear. The timing of the negotiations, shortly after the Supreme Court’s Webster decision, was fortuitous. Even as Planned Parenthood fought the union in New York, Faye Wattleton, president of its national organization, was in Washington asking the Council of Labor Union Women for labor’s support on pro-choice issues.

A contract agreement was signed on October 12, 1989. It provided for Planned Parenthood to pay part of the cost of dependents’ health care benefits, partial health coverage for part-timers, raises of 4 percent in each of two years, and an agency shop.

Planned Parenthood’s management does not like to comment on the bitterness of the dispute, preferring to view it as “resolved, and resolved well” and mainly a question of the non-profit organization’s limited resources. But workers see it as an issue of control of the work force. “The service sectors are the last frontier for unions,” comments one shop steward, “and they have a very big investment in keeping unions out.”

Planned Parenthood workers feel the difficult struggle paid off in more than the eventual contract. According to the shop steward, a surgical nurse and counselor who is also a mother of three, when they began working with the union a year and a half ago, the climate surrounding reproductive rights issues was very different. “We pioneered language that placed abortion rights in the context of union rights,” she says. “The union saw that personal choice cannot exist in a vacuum—for example, economic security is necessary to have a true choice about continuing a pregnancy.”

They persuaded CWA Vice-President Jan Pierce to set up a series of labor breakfasts explaining why unions should support the pro-choice position. CWA helped to organize 40 buses from the New York area to the April 9, 1989, March for Women’s Lives in Washington, D.C. Long-time observers of the labor scene feel the inclusion of the Planned Parenthood unit has had a consciousness-raising effect on the union. Planned Parenthood workers feel they’ve succeeded in getting representation for themselves and a “foot in the door” to labor support for the pro-choice movement.

—Ellen Bilofsky
Business Week reports that universal health insurance is "in" in 1990. The New Republic warns that no one should hold his or her breath waiting for it to come. "Curiouser and curiouser," as Alice said in Wonderland. In the 1970's when we debated national health insurance, the opposition was the hospitals, the doctors, the insurance companies, and big business. Now many of the players have switched sides, but is NHI any closer?

The hospitals, even the for-profits, want every patient coming through the door to have payment attached. Many physician organizations officially support universal coverage. The New England Journal of Medicine is publishing proposals for national health insurance (provided they support fee-for-service payment for physicians). Even the Health Insurance Association of America (HIAA) wants universal health insurance coverage. HIAA proposes that the private insurance companies will sell to people who can pay, and the government can pay those same insurance companies to cover the rest. A cynic might conclude that everyone has an angle.

Some big businesses are realizing that they don't want to deal with health care at the bargaining table and that they don't want to subsidize employers who don't cover their workers. Employers that thought they could contain costs by self-insuring and various management strategies have discovered they can't, and they don't want their management distracted by trying. They are discovering that using health benefits to stabilize the work force can backfire, because the workers with the highest medical bills are those least likely to leave, thus raising premium costs.

Executives at such corporate giants as Ford and Chrysler are looking at the Canadian system and licking their lips. Even the National Association of Manufacturers is thinking that Canada may have a good thing going. At least in Canada and Europe, health costs don’t show up on industry's bottom line to hinder competitiveness.

With support like this, surely the president and Congress will do something about health care financing and access. Not necessarily. They are certainly looking at the problem. Congress has a commission, the Pepper Commission, chaired by Jay Rockefeller from West Virginia, which promises to issue its recommendations by March 1. Bush has a commission, the Advisory Council on Social Security, which four years ago came up with catastrophic coverage for Medicare recipients. It is chaired by Deborah Steelman, who was Bush's domestic policy advisor during his election campaign. The Department of Health and Human Services has an internal department task force on the uninsured and long-term care. But looking and issuing reports is not action.

Congress hesitates to act because the money is not there. There is no money because Congress will not raise taxes, increase the deficit, or cut defense spending. The American public does not want to pay more taxes. And there is a lot of legitimate competition for existing tax dollars—clean air, cleaning up toxic waste dumps, long-term care, education, affordable housing—as well as lots of illegitimate competition—there are savings and loans institutions to be bailed out.

Last year, Congress was still reading the president’s lips: “No new taxes.” This year is an election year—a critical one, because the 1990 census will be used to redistrict state and federal legislative districts. So whoever controls the state legislatures and governor’s offices in 1990 will be in charge of gerrymandering the new legislative districts. The Republicans will not want Bush to push for tax increases. The Democrats will certainly not propose new taxes without support and even leadership from the president. So here's to 1991.

Moving into the 20th Century
The Pepper Commission might suggest mandated benefits, which hit small businesses and those with many low-wage or part-time employees particularly hard, and which businesses strongly oppose. They might suggest a "pay or play" scheme like the one passed in Massachusetts. That presents less of a
problem to employers of low-wage workers, but either plan will be an administrative nightmare for the employed uninsured. These workers tend to change jobs often. Constantly dropping them from one insurance roll and picking them up on another will cost plenty and could be disastrous. Moreover, if the plan requires a deductible every time a worker changes jobs, many low-income people may be required to pay lots of premiums without ever collecting anything.

Only a unitary-payer (read “government”), universal coverage system will protect this group. And really, such a system will best protect big business as well.

Perhaps we need a new strategy. Forget the thousands of postcards from individuals to members of the Pepper Commission, Congress, or the president. We need to convince the chief executive officers of the Fortune 500 that NHI, with a single payer and universal coverage, will save them money, grief, and labor trouble. Don your best business suit, check the donor list of your favorite organizations, and visit your neighborhood CEOs. Tell them they'll never again have to negotiate with a hospital or PPO. No more strikes over health benefits. Perhaps NHI can fold in the medical portion of workers' compensation and save money there too.

You say radical change is not the American way of health care reform. You say a single-payer system is not politically feasible. Someone must have said that about Social Security in 1934 and Medicare in 1964. In the United States, real systemic reform is rare, but not unheard of. Let's move the United States into the 20th century by the year 2000.

A Magazine for Health Rights

The policies of Ronald Reagan and George Bush have created the greatest health inequities this nation has ever known. We live in the shadow of epidemic hunger, homelessness, and drug addiction. The health care status quo can and must be changed, and the Health/PAC Bulletin is dedicated to making health care the inalienable right of all citizens, regardless of their income, illness, race, gender, sexual orientation, abilities, or disabilities.

The Bulletin is widely recognized as the only health care journal that routinely exposes the powerful corporate, political, and professional forces which are misallocating the precious resources of the nation's largest industry.

If you want to know what you can do to restore health rights to the top of the nation's agenda, then join the thousands of concerned readers who look to the Health/PAC Bulletin for ground-breaking reporting, criticism, and analysis.

YES, I want to receive the Health/PAC Bulletin.

☐ Individuals $35 ☐ Institutions $45
☐ 2 years $70 ☐ Student/low income $22.50

I want to help Health/PAC support the fight for health rights. Enclosed is my tax deductible contribution of ☐ $15 ☐ $25 ☐ $50
☐ $100 ☐ other

Name ____________________________

Address ____________________________

City ____________________________ State ______ Zip ____________

Charge: ☐ Visa ☐ Mastercard

Number ____________________________ Exp. date ____________

Signature ____________________________

Send your check to Health/PAC Bulletin, 17 Murray Street, New York, NY 10007