CORPORATE GREED & FEDERAL RED TAPE ARE KILLING MY PATIENTS & MY FRIENDS
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.

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Lessons From the Empires

Health/PAC long ago coined the phrase “medical empires” to describe the large academic centers that serve as models for much of medical practice in the United States. From time to time, the Bulletin has reported on the struggles for equity and access waged by the communities that rely on these empires for their care. In this issue, Regina Neal describes how, under cover of today’s hospital deficit crisis and increasingly competitive environment, two New York City empires are asserting their autonomy to pick and choose the services they will provide to their surrounding communities. Columbia-Presbyterian Medical Center has drafted plans to drastically reduce its ambulatory care services, and St. Luke’s-Roosevelt Hospital Center refuses to reconsider plans to consolidate and relocate obstetrical and neonatal inpatient services. The continued conflicts suggest that the approaches taken in the past to guarantee access to health care services for poor and under-served communities—state regulation of the medical centers’ capital projects and the fine tuning of Medicaid and Medicare reimbursement rates—are not sufficient.

New York State’s Department of Health has spent years trying to force tertiary care pegs into primary care holes, using a tough certificate-of-need program as the hammer. The state (at the insistence of local advocates) held hostage the empires’ plans for capital expansion to force them to agree to meet community needs. At the same time, the state has maintained tight control of the reimbursement purse strings to hold down inflation in health care costs. Some critics argue, as does Neal, that “you get what you pay for,” and until the Department of Health greases the tertiary care peg with more reimbursement for hospital-based primary care, things can only get worse. Yet the refusal of New York State Health Commissioner David Axelrod to just throw money at the problem may not be as misguided as his critics maintain. After three decades in which hospital inflation consistently outpaced the Consumer Price Index, why should we believe that tinkering with reimbursement will have any lasting effect on future bottom lines?

We have to ask, just how much reimbursement is a hospital primary care visit worth? Without simultaneously reducing the inflated valuation of high-technology and intensive services, can we ever afford a high enough level of reimbursement for primary care to encourage hospitals to alter their practice priorities? Perhaps New York State’s reimbursement policies are not wrongheaded, but have not gone far enough. Proposed changes in Medicare reimbursement will create a relative-value scale for different procedures that attempts to improve the fee scale for primary care specialties while devaluing surgical and technologically invasive procedures. Experience with these proposed changes may show whether revaluation of reimbursement can help to produce major changes in entrenched medical practice.

In New York City, annually increasing operating deficits and a highly competitive DRG system of reimbursement have conspired to drive hospitals’ fragile finances to new levels of instability. But does that suffice to explain why these two empires have only now chosen to cut back on services they have been providing for decades? In the case of Columbia-Presbyterian’s ambulatory clinics, they have always claimed to be operating at a deficit.

The mission of academic medical centers, as Neal points out, has never been to provide primary care or other basic services for their communities. Neither Columbia-Presbyterian nor St. Luke’s-Roosevelt has a department of family medicine. Nevertheless, the empires have historically found it necessary to provide such services. Without poor sick people, the hospitals would not be able to carry out their academic mission of teaching medical students and training residents. In past years, the needs of the teaching mission overcame the difficulty of delivering ambulatory services in an environment driven by the requirements of inpatient care.

What has changed—and changed dramatically over the last two decades—is the demographics and epidemiology of clinic populations. These changes are the result of a number of concurrent developments: deepening urban poverty; the social epidemics of AIDS, substance abuse, and homelessness; and the decade-long campaign to dis-
THE EMPIRES STRIKE BACK

In the fall of 1985 in an issue titled "Fighting Back Against the Empires" (Vol. 16, No. 5), Health/PAC reported on the plans of four of New York City's academic medical center "empires" for major expansion. The focus of our coverage was the efforts of two of the communities served by these institutions to ensure that the plans were responsive to their needs. At the time, we were cautiously optimistic that these events were signs that "although the empires still dominate New York City's health care system, they no longer rule unchallenged." In the past six months, the plans of two of these institutions, Columbia-Presbyterian Medical Center and St. Luke's-Roosevelt Hospital Center, warrant another look at the success of the efforts to hold the major medical centers responsible for the welfare of the communities in which they are located.

Broken Promises
Columbia-Presbyterian Medical Center
REGINA NEAL

Columbia-Presbyterian Medical Center is a huge complex overlooking the Hudson River in northern Manhattan. Its influence spreads into the surrounding communities beyond the immediate Washington Heights neighborhood. During the summer of 1989, the clinical staff of Presbyterian Hospital, the teaching hospital for the center's medical school, was informed of a three-phase plan to reduce ambulatory care services in the outpatient department, Vanderbilt Clinic. The first phase of the plan, which was already being implemented, involved referring all patients without health insurance who live outside the medical center's immediate area to other hospitals. Selected specialty clinics would then be "consolidated"—that is, closed. With this tactic, Columbia-Presbyterian would shift an estimated 39,000 mainly primary care visits from these uninsured patients—many of whom have a long history of using this clinic—to other providers and cut an additional 14,000 specialty visits, while still being able to claim that it was providing primary care for its own community.

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The chronic underfunding of ambulatory care has made it impossible for the medical centers to be responsive to their communities.

The third phase of the plan, while not spelled out in detail in the Columbia-Presbyterian document, can be assumed to be the elimination of all outpatient services at Vanderbilt Clinic—a reduction of some 360,000 visits annually.

These events are the most recent development in a long struggle between the New York State Department of Health and Columbia-Presbyterian—a struggle heightened by the existence of a well-organized and articulate community in the area around the medical center. They are also the direct consequence of a health care policy in New York State that pays lip service to the importance of primary care and relies largely on the academic medical centers to provide it. The lever used to gain the cooperation of these centers has been stipulations attached to the approval of their major capital projects. However, the state has been unwilling to confront the ensuing conflict between the medical centers' established mission of teaching and research and the imposed obligation to serve the needs of local communities. Moreover, during the nearly decade-long tenure of Health Commissioner Dr. David Axelrod, the chronic underfunding of ambulatory care by the state through Medicaid funding has made it impossible for the medical centers—or any other provider, for that matter—to be responsive to and responsible for their communities.

In 1983, faced with $5 billion worth of hospital construction plans and with more hospital beds than were needed, New York State imposed a moratorium on approving requests for expansion and renovation of hospital facilities. State regulators announced that in return for approving construction, they would require the major institutions to serve the needy, and Governor Mario Cuomo and Dr. Axelrod announced that expansion and renovation plans addressing the needs of the poor would be given the most favorable reviews.
Patients waiting at a hospital clinic. Columbia-Presbyterian Medical Center plans a phased reduction in clinic services to the community.

At the time, Columbia-Presbyterian had submitted a certificate of need (CON) for a $500 million project to renovate the hospital at the medical center’s main site at 168th Street in Manhattan and to build a “community hospital” of 300 beds at the northern tip of Manhattan. The medical center’s original intention was only to rebuild the hospital at the main site; however, the New York State Department of Health pressured the hospital to fill in the gap for health services that had been created in the Washington Heights and Inwood neighborhoods of northern Manhattan by the closing of five community hospitals in the area over the previous ten years.

The medical center initially resisted, but in the end it agreed and submitted a plan for both rebuilding the main hospital site and constructing a new community hospital. The new “community” hospital met the letter of Axelrod’s demand, but hardly the spirit. It was to have a small emergency room and no outpatient clinics and would be located in an area remote from the greatest need. Clearly, it was oriented more toward the affluent Riverdale community across the river. The CON also included plans to establish an ambulatory care network that would create primary care resources at a variety of locations in the Washington Heights and Inwood communities. The state, convinced that Columbia-Presbyterian’s response was adequate and that it indicated the willingness to take responsibility for the needs of the community, praised the plan, as did New York City’s Health Systems Agency (HSA). Four months after the moratorium on expansion and renovations was lifted in December 1983, Columbia-Presbyterian’s plans were approved.

The Community Fights Back

However, the moratorium gave the Washington Heights and Inwood community a chance to review the proposed project plans as described in the CON. The review left the residents far less optimistic about the adequacy of the proposed system to provide for the needs of the community. Determined to have their views represented, a group of community residents formed the North Manhattan Health Action Group (NMHAG) in September 1983. The group set as its initial goal an assessment of the health needs and health resources in the community and evaluation of the adequacy of the plans proposed by Columbia-Presbyterian.

The review was considered essential by the community of approximately 180,000 residents, whose health needs are great. The area depicted in NMHAG’s report is made up of a large number of relatively young families, many of them recent immigrants from the Dominican Republic. As described by a variety of economic indicators, the community is poorer than Manhattan and New York City as a whole, and its health status is much worse. Of particular note is the high proportion of pregnant women—a large number of whom are teenagers—who receive late or no prenatal care, a clear indicator of the lack of primary care resources and financial access to health care in the area.

NMHAG found serious problems with Columbia-Presbyterian’s proposal. The primary care resources to be developed were inadequate, and community physicians, including those who would work at the ambulatory care sites, would not be able to admit patients to either hospital site. At the time of the NMHAG survey, only four of 175 physicians in the area had admitting privileges at Presbyterian Hospital. Despite the community’s reservations, the New York City HSA and the New York State Department of Health approved the CON.

New York State pays lip service to the importance of primary care while relying on the academic medical centers to provide it.
Closings of seven hospitals in Harlem and northern Manhattan in the 1970's and 1980's were met with protests from an outraged community, like this one at Sydenham Hospital in Harlem in 1980.

Determined to have their concerns heard and reflected in changes to the plan, NMHAG mounted a year-long, highly organized "bottom-up" campaign that mobilized the community. Their efforts resulted in an unprecedented arrangement in which Axelrod required Columbia-Presbyterian to work with NMHAG to "resolve the issues and to produce a model for primary health care in the community." NMHAG and representatives of Columbia-Presbyterian signed an agreement in October 1985. The agreement specified the size, general location, and scope of services that were to be provided at each of five ambulatory care network sites that were to be established in 1986. It also reflected an agreement on the scope of the physician shortage in the area and on ways to alleviate it. The primary care physicians in the ambulatory care network would "have the ability to admit and follow their patients in the Hospital," and Columbia-Presbyterian also agreed to a steering committee for the ambulatory care network that would have community participants as full members. The future seemed to hold promise.

Broken Promises
Fulfillment of the promise was slow in coming. Not until October 1987, a year after all of the sites in the ambulatory care network were to have been operating, was the first site, a geriatric center in the Fort Washington Houses complex, opened. A second site opened in 1988, and the third in January 1989. But none of these sites were located in the areas of greatest need within the community.

There is disagreement on what caused the extensive delays in establishing the promised sites in the network. The community charges foot dragging on the part of Columbia-Presbyterian—a sign of the familiar reluctance of the medical center to be responsive to the needs of the community. The medical center claims otherwise. During this same period, however, Columbia-Presbyterian hardly slacked off on its other priorities. It was able to establish three medical office complexes for doctors on staff at the center in Riverdale, on the Upper East Side, and in Chinatown. And by late 1989, Columbia-Presbyterian had also managed to rebuild the main hospital site (now called the Milstein Pavilion) and build the new hospital, known as the Allen Pavilion.

The community has not gotten what it was promised when it signed the agreement with Columbia-Presbyterian.

In the age of high-technology medicine, primary care is the stepchild.

Clearly, the community has not gotten what it had hoped for and what it was promised when it signed the agreement with Columbia-Presbyterian in the fall of 1985. Only three of the original five ambulatory care network sites have been opened, and the remaining two are those to be located in the areas of greatest need. The three clinics that are operating are at full capacity, and there are long waits for first visits for new patients, attesting to the need for these services. The ambulatory care network steering committee, of which NMHAG is a member, is currently evaluating the need to expand evening and Saturday hours at the clinics. There are no signs of any serious attempt on the part of Columbia-Presbyterian, in its role as a teaching hospital, to address the shortage of physicians in the community, however, nor has there been more than a marginal improvement in the ability of community physicians to admit and follow patients at the Columbia-Presbyterian hospitals.

During the summer of 1989, it became clear that the community's access to health care from the medical center was only going to get worse and not better. A year earlier, Columbia-Presbyterian had begun to make public a serious financial deficit that it attributed to its outpatient services. Chiefly responsible were the increasing volume of ambulatory services provided to uninsured patients both within and outside the Columbia-Presbyterian community and the inadequacy of the reimbursement for ambulatory services under Medicaid. This strategy ironically laid the groundwork for Columbia-Presbyterian to propose radical cutbacks in ambulatory care services, which began with the closing of its outpatient pharmacy in March 1989, even as it promised to expand primary care to the community.

The latest actions by Columbia-Presbyterian and the results for the community suggest another example of how...
costly and difficult it is to badger large academic medical centers to do what they do not want to do: take responsibility for meeting community needs. And it would also seem to justify the community's widely held perception that narrow self-interest and deception are the primary forces that move the medical empires. Yet, while Columbia-Presbyterian's actions are extremely distressing, considered in the context of the current fiscal realities of providing ambulatory care in New York State, they are less than surprising. For ten years, the state Department of Health, headed by Dr. Axelrod, has produced an endless supply of talk on the priority that primary care must be given by all providers in New York State. For the same ten years, however, reimbursement of ambulatory care clinic services under Medicaid has been frozen at $60 per visit; private physician's rates have been frozen since the mid-1970's and now average $11 per visit. These rates are now driving even the so-called Medicaid mills out of business. Add to this the mounting numbers of uninsured individuals who have increasing needs for health care services, and the result is the crisis we face today.

In the age of high-technology medicine, primary care is the stepchild. New York State's current primary care policy has failed utterly. This failure stems not only from the lack of adequate mechanisms to finance services. It is also a result of ignoring the fact that academic medical centers' established missions of teaching and research are not naturally compatible with a mission of primary care service to the community. So, while the concept of forced responsibility has driven the state's policy, judging by the outcome, virtually no energy has been put into developing other community-based alternatives for the provision of primary care—let alone into financing such alternatives. The result has been the continuing shrinkage of primary care services in the communities with large and growing needs for these services and with the fewest alternatives, and a further erosion of trust on the part of these communities for the institutions that have promised to meet their needs.

Given this context, Columbia-Presbyterian's actions can be seen as a direct response to disincentives to providing primary care that have been established by New York State. One has to wonder how many other providers are also dumping ambulatory care patients and shrinking services in response to the same disincentives. The only thing that may make Columbia-Presbyterian different is that it went public. □

Harlem Hospital, an already overcrowded and underfunded city hospital, will by forced to absorb the overflow from the service cuts at Columbia-Presbyterian and St. Luke's-Roosevelt.

Ignoring the Community's Needs

St. Luke's-Roosevelt Hospital Center

REGINA NEAL

In the past 20 years, the New York City communities of Harlem and northern Manhattan have witnessed the closing of seven community hospitals: Jewish Memorial, St. Elizabeth's, Cabrini, Delafield, Wadsworth, Logan, and Sydenham. During this same period, these areas have also suffered a rapid decline in the number of physicians in private practice. More recently, Presbyterian Hospital began a phased reduction of ambulatory care (see "Broken Promises,” p. 4), and in March 1989 both Presbyterian Hospital and Mt. Sinai Hospital (which lies on the border of East Harlem) abandoned outpatient pharmacies that together provided 758,000 visits in 1987.¹

Already hurt by these reductions, the communities of Central and West Harlem now face yet another retrench-
Community groups demonstrate against the proposal to move obstetrical and prenatal care out of St. Luke's Hospital, March 4, 1989.

In the face of the overwhelming evidence of need for obstetric and neonatal inpatient services, HSA recommended relocating them.

Roosevelt modernization plan. Clearly, the medical center wants to cast its lot with the growing gentrify located in the area of its downtown site. By contrast, St. Luke's Hospital, on the southern border of Harlem, is in a community with a much larger, younger, and poorer population. Household size in the St. Luke's hospital area is larger by 66 percent, and the median income, at $14,149 in 1985, was 52 percent lower than that in the Roosevelt Hospital area. The two communities differ in their racial and ethnic composition as well, with the St. Luke's area 59 percent black and the Roosevelt area 71 percent white.2

The consolidation of these inpatient services to the Roosevelt Hospital site is part of a $467 million modernization plan first proposed in 1986.3 The New York State Department of Health approved the plan in December 1986, with the recommendation of the New York City Health Systems Agency (HSA), the local planning agency charged with making presumably disinterested recommendations to the state on community health needs and allocation of resources. Although protests organized by a coalition of community organizations against the dislocation of services failed to halt the plan, they did lead the Department of Health to attach a number of conditions to its approval of the medical center's certificate of need (CON). Among them, the state required that demand for obstetric, neonatal, and pediatric services be monitored over time and that decisions about the need for and location of these services be reevaluated before any consolidation took place.

The New York State Department of Health clearly held out the promise that if the needs for these services changed, the decision would be modified. Yet, Raymond Sweeney, director of the Office of Health Systems Management (the branch of the state health department that covers hospitals), acted to foreclose the possibility that
the decision could be altered by creating bureaucratic obstacles to any change. “If a determination is made that additional services are needed at the St. Luke’s site,” he wrote in a letter to the president of St. Luke’s-Roosevelt in March 1987, “it is recognized that a proposal would constitute a separate certificate of need application, subject to affordability and financial feasibility reviews.” In other words, to make any alterations in the plan would mean having to fulfill the CON requirements for an entirely new project, substantially delaying the plans and creating financing problems. This could bring the entire modernization project to a halt and ultimately cause it to fail.

Sweeney’s letter goes on to suggest expanded outpatient and emergency services “as an alternative to inpatient care at the St. Luke’s Division” and urges “accelerated and ongoing education efforts [to show that] the new configuration of the services is in fact, not detrimental or negative, relative to the respective communities.” While the alternatives Sweeney proposes are undoubtedly crucial, his suggestion is essentially a diversionary tactic—an attempt to divert attention away from the threatened services and focus on another needed—but currently nonexistent—set of services.

The Community’s Needs

In the ensuing three years, the northern Manhattan and Harlem communities have experienced the same scourge of illness and poverty that has engulfed other New York City neighborhoods: increasing infant mortality rates; growing numbers of women who receive late or no prenatal care; and rising numbers of newly reported cases of tuberculosis, syphilis, measles, and AIDS. Although these problems can be found throughout the city, poor communities have among the highest rates for all these health indicators as well as a small and rapidly shrinking pool of resources to deal with them.

In response to the continuing concern expressed by the community coalition, the state Department of Health provided funds to the Health Action Resource Center to organize the West Side/West Harlem Community Planning Coalition for an independent study of maternal and child health needs in the community. The resulting “Report and Recommendations on Maternal and Child Health Needs” compellingly documents the pressing health needs of the community and the probable effects of withdrawing obstetric and neonatal services. It recommends that these services be maintained at both the St. Luke’s and the Roosevelt sites and also that prenatal care for substance-using women and ambulatory care for women and children with HIV illness be enhanced. The West Side/West Harlem Community Planning Coalition presented the report to Dr. David Axelrod, New York State Commissioner of Health, in April 1989, along with a demand that the decision to move services out of the Harlem community be reconsidered.

Rather than squarely confronting the problem, Axelrod instead turned it back to the HSA, charging it to conduct yet another study and make yet another set of recommendations. The new HSA study, “Assessment of Maternal and Child Health Needs in Upper Manhattan,” reads like a brief for maintaining obstetric and neonatal services at St. Luke’s for the mostly poor residents of Central and West Harlem.

Of greatest significance are the findings that 77 percent of obstetric patients and 89 percent of neonatal patients who were residents of Central and West Harlem were either on Medicaid or uninsured. The overwhelming majority of this group of obstetric patients—94 percent—deliver in a hospital within the area, suggesting, again, that travel to an out-of-area hospital, such as the Roosevelt site, is unrealistic. Indeed, the report notes that women who are uninsured or on Medicaid are far less likely than insured patients to deliver at out-of-area hospitals. The report goes on to note that low-income women “usually present at the obstetric facility closest to their residence and will not generally migrate from Upper Manhattan to Roosevelt Hospital.” Moreover, although HSA did not note this, the proposed arrangement of services is likely to lead to discontinuity of care. Poor women are more likely to need emergency deliveries. Under these circumstances, even if they are receiving outpatient prenatal care at St. Luke’s Hospital or another site sponsored by St. Luke’s-Roosevelt, they are liable to end up at Harlem or Presbyterian Hospital, where they and their history are unknown, thus complicating an already complex delivery.

Yet, in the face of the overwhelming evidence of the need for obstetric and especially neonatal inpatient services in Central and West Harlem that it had documented, and in spite of continued opposition from the community and local politicians, HSA in its final report recommended the relocation of services to the Roosevelt Hospital site. The rationalization? To do otherwise “may require the hospital to amend and resubmit its CON...leading to further delays in proceeding with the project...[and] would result in either significantly increasing project costs or decreasing project scope...”

In evaluating the options, HSA ignored the fact (although stated in the report) that consolidation of services at St. Luke’s instead of Roosevelt would offer many advantages for the neediest residents of Upper Manhattan, including minimal disruption of utilization patterns and hospitalization closer to home for mothers and their infants.

The report also neglected the effect of the plan on other facilities. Instead, it off-handedly announced that “after consolidation, it is anticipated that many Medicaid/self-pay patients currently utilizing St. Luke’s will migrate to other Upper Manhattan facilities [and] Presbyterian/Allen Pavilion, [and] Harlem [Hospital]...may be required to
reallocate some of their bed capacity for Medical/Self Pay [sic] patients residing in these zip codes to insure access to inpatients [sic] services." HSA thus sidestepped any consideration of increased costs to other facilities, provoking the New York City Health and Hospitals Corporation, the agency responsible for the city's public hospitals, to respond: "We simply do not have the resources to increase capacity further at the [Harlem Hospital] facility."7

There is no reason to expect that the end result will be other than a loss of inpatient services without the promised ambulatory services.

HSA constructed a strained rationalization for its conclusions: "These data re-affirm that access to, and the availability of, inpatient obstetrical services is not a concern."8 Resulting shortages of neonatal services could be addressed by expansions at Harlem and Presbyterian Hospitals, the report reiterated, assisted by creation of a perinatal regional transport system that would use ambulances to move sick babies from these communities to Roosevelt. Again, the ability and willingness of these hospitals to pick up the additional work load—not to mention the cost—were left unexplored.

HSA further rationalized that ambulatory care would be more effective than inpatient services in improving maternal and infant health in upper Manhattan. Furthermore, HSA decided, "the critical factor that will determine the actual impact of consolidation...is improved community education, outreach and prenatal care services."9

Trading in Services

This confidence in such "long-run" solutions is astonishing, given the inadequacy of the current prenatal and other primary care options in New York City. The community is being asked to trade in existing services for the promise of more and better services of another, more transient kind. They are apparently asking too much to have both inpatient and outpatient services. Yet, there is no reason to expect that the end result will be anything other than a loss of the inpatient services without development of the promised ambulatory services.

The planned abandonment by St. Luke's-Roosevelt has galvanized the community. It has continued to resist the proposal through the same coalition of community organizations that opposed the initial decision in 1986 to allow these services to be moved and whose pressure resulted in the study by the West Side/West Harlem Community Planning Coalition and the HSA report that followed it. In November 1989, the coalition organized a public meeting attended by over 100 community residents to respond to the first draft of HSA's report. Essentially all the speakers at the meeting who were not connected to St. Luke's-Roosevelt considered both the plan to move services out of St. Luke's and the assessment conducted by HSA inadequate. Testimony was provided by a wide range of local political leaders, all of whom vowed to support the community in its struggle to keep the services at St. Luke's.

On March 4, 1990, 300 people marched and rallied to oppose, once again, the decision to remove these services from the community that so sorely needs them. The issue has received mounting press coverage and political support. The position of the community on this issue could hardly be more clear.

Despite the evidence and community sentiment, HSA refuses to consider the most reasonable option—consolidating services at the St. Luke's site—supposedly because it might require the development of a new CON. As this is written, the decision rests with Commissioner Axelrod, who could exert some leadership to resolve this issue. The formalities of CON review are part of the regulatory process that his department controls, and he has the ability to alter this portion of the plan. Instead, Axelrod has said that he will respond to the HSA report and recommendations, as well as the community opposition, in April, adding, "It doesn't necessarily mean that I will have a decision by then."10

In the meantime, the St. Luke's-Roosevelt modernization plan, which the community supports as necessary to ensure that St. Luke's Hospital will exist for them in the future, moves forward. Further delays simply mean that a decision to alter the original plans to fit current and projected needs becomes less likely as more of the project is completed. And the community is left out in the cold.

5. Ibid., pp. 45, 108.
6. Ibid., p. 42.
9. Ibid., pp. 87, 91.
W omen—The Missing Persons in the AIDS Epidemic

Part II

CAROLA MARTE AND KATHRYN ANASTOS

In the Winter 1989 issue, Anastos and Marte wrote about the neglect of women in defining and treating AIDS. Women in the AIDS epidemic, they wrote, are considered mainly as vectors of transmission to men or children, not as people who are themselves HIV-infected and victims of transmission. They are predominantly women of color who, by the dictates of poverty and racism, live in communities at high risk for HIV infection. They are subjected to demeaning attitudes, poor health care services, and tragically late diagnosis in many cases. In this article the authors examine the issues of reproductive rights and HIV testing in women hospitalized for childbirth. Wendy Chavkin continues the discussion on p. 19, focusing on the efforts of AIDS prevention programs to target women solely because of their reproductive function and on the lack of services available for women who are tested.

W e are now at the point where women infected with human immunodeficiency virus (HIV) are threatened with denial of the right to choose when and if to bear children. The tremendous concern, whether or not from altruistic motives, about the increasing number of babies being born infected may well provide a convenient weapon in the growing attack on reproductive rights. Undeniably, the illness and death of an infant or child with AIDS raises painful and complicated questions. Should the birth of HIV-infected babies be prevented by contraception and abortion? Can the interest of the state in limiting human suffering—the child’s and/or the family’s—and in limiting the cost of caring for children afflicted with AIDS ever override a woman’s right to choose when to bear a child? If so, under what circumstances? When is it legitimate for a court to identify or treat illness in a child without obtaining the consent of the parents? How do we as a society make these difficult decisions?

Perinatal HIV Testing

Recently there have been increasing demands for mandatory HIV testing of women of childbearing age. The stated goals are to reduce the number of HIV-infected children born and to identify infected infants so that they can receive medication and care that may extend their lives. It is important to understand the background and implications of this position.

In December 1985, the Centers for Disease Control published guidelines for “assisting in the prevention of perinatal transmission” of HIV. These recommendations stated that “infected women should be advised to consider delaying pregnancy until more is known about perinatal transmission of the virus.” Many state and city health departments followed suit and established recommendations that pregnancy in HIV-infected women be “delayed” or “postponed.” It should be clear, given the small likelihood that a cure for HIV will be available in the next several years, that advising a woman with HIV-infection to postpone pregnancy is in fact advising her to prevent conception or, if pregnant, to elect abortion—in other words, to give up the possibility of having a child.

New York State, in 1987, mandated that counseling and voluntary testing for HIV be offered to all pregnant women. In 1989 the New York State Department of Health considered instituting a form of mandatory testing. It proposed “unblinding” the ongoing epidemiologic study of HIV infection rates in all newborns—that is, revealing the identities of babies who tested positive in what had been designed as an anonymous survey of all New York State births. The mothers would then be offered the option of learning their newborn baby’s test result. According to a Department of Health press release, the purpose would be...
for women to learn their own HIV status (as will be explained, an HIV-positive baby implies an HIV-positive mother) and to seek medical care for themselves and "medical monitoring" for their infants. In response to objections from health care providers and women's advocacy groups, however, that plan was withdrawn in favor of an expanded program of counseling and voluntary testing for pregnant women and women giving birth.

Removing the anonymity from the test results of the babies presented both ethical and scientific difficulties. The validity of altering a research protocol midway through the study or of trying to use epidemiological data—designed to provide information about the prevalence of HIV statewide—in place of individual testing will not be argued here, other than to state that this violates basic tenets for sound research design. Of concern to us are the areas where the scientific difficulties have confounded the ethical problems.

In the first place, the baby's test result is being used as an indirect—or proxy—test for the mother's status. Testing a newborn for antibodies against HIV can give accurate information only about the mother, not the infant. This is because all newborn babies receive antibodies against many infections, including HIV, from their mothers while in the womb. They retain these maternal antibodies for several months after birth. Thus, although the babies of HIV-infected women test "positive," most have not acquired the virus itself and therefore are not truly infected.

If "unblinding" the newborn study can only determine whether the mother is infected, and only the mother can benefit from immediate treatment (because the baby's true status will not be known for some time), then clearly the mother herself should be tested, and in a setting where consent is meaningful and adequate counseling is provided. Under the best of circumstances, making a decision about testing oneself or one's child is complicated and can be confusing. It is even more difficult in a time of such extreme emotional and physical changes as childbirth. A woman who has just given birth should benefit from the same standard of care deemed optimal for all persons at risk and should not be singled out for a universal testing policy or an altered and less rigorous consent procedure.

A second major criticism of the initial New York plan was that adequate medical and social services were not available for women and children who tested positive. If the rationale for coercing women into learning their babies' test results was that both women and infants would benefit from early treatment, then it should have been obligatory on the part of the state to fund programs that could provide these services. In general, the willingness of public health agencies to provide more generous funding for seroprevalence studies than for direct medical and social services to the individuals identified by these studies casts doubt on the sincerity of their expressed rationale of helping those suffering from HIV infection.

Also in 1989, the New Jersey Department of Health proposed instituting "routine" prenatal HIV-testing with the "right of refusal." The mother was to be told that, as part of routine prenatal blood tests, a specimen of her blood would be sent for HIV testing. Informed consent would not be required, nor would counseling about HIV-testing and AIDS be mandated, as it is in New York. It is highly unlikely that a woman in this situation would refuse testing because without adequate counseling she would not understand the implications of the test and its results. This proposal was not passed by the New Jersey legislature.

Mandatory testing of pregnant women is being proposed because of the "failure" of programs adhering to the principle of voluntary informed consent. That is, "success" is defined as testing large numbers of women, and a program is considered to have "failed" when women decline to be tested. Thus, New Jersey's public health authorities, confronted with the fact that large numbers of women at risk were not getting tested, proposed a policy in which "routinized" testing would be a proxy for mandatory testing—placing on patients the burden of becoming informed in order to refuse. Like the proposed New York policy, the New Jersey policy would have particularly affected inner-city women because of their disproportionate representation among infected women.

In a society with formidable barriers to health care for its less advantaged populations, a contradiction arises when the public health agencies themselves have an interest in obtaining access to those same populations—for example, to determine seroprevalence rates. The barriers work in both directions. However, three "captive" populations that are registered in our society and therefore are available for testing are immigrants, prisoners, and women giving birth (since virtually all babies are born in hospitals and registered). Because inner-city women are heavily represented in these captive populations, they are especially vulnerable to curtailment of the right to informed consent.

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**Advising a woman with HIV infection to "postpone" pregnancy is in fact advising her to give up the possibility of having a child.**
In our experience, most women request testing if they receive sufficient information in an atmosphere of trust during counseling about HIV disease. Trust includes trust in confidentiality and trust that they and their children will have access to the services they will need. When women are informed that, if infected, drug therapy is beneficial and available for them and that more intensive medical follow-up is recommended for their children, most do choose testing for themselves and their children in order to obtain medical care and so that they themselves may remain alive to care for their children.

It is unfortunately true that many inner-city women and women of color, among others, are not reached by the calls for testing and often are not aware of its availability or its significance. This does not represent a moral failure on the part of the women; it represents a failure of our health care system—a denial of access—to those who are uninsured or underinsured and to those who live in inner-city areas.

Treatment Decisions for Children

Prescribing toxic, experimental medications such as AZT for HIV-positive babies who are symptom-free will not become feasible until there is a reliable method to distinguish passive antibody transfer from active infection at the time of birth. When testing for true HIV infection in newborn babies becomes available, the question will arise of whether the state has the right to preempt health care decisions concerning children in cases where parental consent is withheld. Whether decisions about treatment for children should be left to parents, as their right, under all circumstances is problematic. Alternatively, should states have the right to mandate treatment without parental consent?

The federal approval for providing AZT to HIV-infected children, announced recently, will put further pressure on authorities in New York and other states to institute more coercive testing and treatment policies. Unfortunately, public health authorities as well as politicians often formulate or legislate policies without full review of the underlying constitutional and ethical questions. This is especially so in the turbulent climate surrounding an epidemic that is life-threatening and carries the onus of sexual transmission and illicit drug use.

The original New York State proposal for “unblinding” the newborn seroprevalence study demonstrates how it is possible to blur the lines between what are, in fact, separate and distinct issues lying at the heart of discussions about AIDS in children and infants. What is at stake is not simply medical decision-making but maternal and infant rights. Several very different issues are intertwined.

One is the attempt to guarantee prevention of the birth of infants with HIV infection. Eliminating congenital HIV infection can be achieved only if HIV-infected women never have children. This is not protection of the child; it is, in fact, state intervention to prevent the existence of infected children at the expense of the parental right to bear children and at the expense of children who would be born uninfected.

A second is the question of who has the right, parent or state, to make which decisions about an infected infant’s treatment, which at this time is limited to interventions with experimental drugs, as far as the HIV infection itself is concerned. Is HIV infection a case where the state can legitimately abrogate the parents’ legal status as guardian of their children and thereby the parental right to consent to or refuse testing or a specific treatment for the child?

A particularly complex issue raised by the existence of AIDS in infants, one for which no analogy exists in current medical practice, is the conflict between a newborn or child’s right to treatment and the mother’s right to confidentiality and informed consent with respect to her own condition. There is no other illness or condition in which diagnosing an illness in the child simultaneously diagnoses the mother, in which the mother may reasonably have been unaware of her own illness, and in which exposing her diagnosis may expose her to discriminatory and possibly catastrophic experiences at work and in her community.

Thus, when therapy for HIV infection in newborns becomes available, one might well argue that HIV-infected children should be identified so that they can receive appropriate monitoring and the best available treatment. It will be essential to take into consideration, however, that identifying an infected child simultaneously identifies the mother as infected and therefore should require full protection of her right to privacy. This is a question that is likely to reach the courts.
Reproductive Choice and Directive Counseling

In considering the question of reproductive choices, of particular importance for a woman of childbearing age is whether or not her state requires informed consent for HIV testing. The right to voluntary informed consent, grounded in the courts’ protection of personal autonomy, has become axiomatic in medical practice in the United States and is often protected by legislation. Voluntary informed consent refers to the right of any patient to be fully informed about the risks and benefits of a medical intervention. It includes her right to disagree with her physician and refuse medical intervention—for example, medications, diagnostic tests such as spinal taps, and surgical procedures such as sterilization or abortion. Which procedures require informed consent often depends on local practice. Since blood tests usually do not require informed consent, specific legislation has granted this protection for HIV testing in some states—in New York, for instance, but not in New Jersey.

Voluntary informed consent implies unbiased counseling in which objective information is provided on the pros and cons and the relative risks involved in different medical choices. However, providers as well as patients have biases that influence their outlook. For instance, when considering the risks of childbirth for an HIV-infected woman, different factors come into play for a woman who already has a large family, including one sick child, than for a woman who has no children or has had a beloved child who has died.

The biases of individual providers will color how they view particular patients and how they weigh the risks or benefits of a given alternative. Their own values about what is important about child rearing, their prejudices about the lives of women of color in inner cities, and their impressions about a patient’s quality of life will be especially significant in discussing emotionally charged decisions such as the birth of a potentially infected child.

Directive counseling takes place when a physician or other health care provider goes beyond offering the necessary information for informed consent and attempts to instruct or persuade a patient to make a particular choice; for instance, “You should have an abortion so you won’t bear an infected child.” Some physicians and health care providers believe it is their right or their obligation to provide directive counseling on reproductive choices to women known to be HIV-infected. This seems to be true of many providers who do not otherwise engage in directive counseling with women who are not infected or not thought to be at risk for HIV-infection. In our own experience, many providers believe that abortion is the only rational choice for an HIV-infected woman who is pregnant. A number of patients have reported being told, when pregnant, that an abortion would and should be arranged (see sidebar).

The ethical problems entailed by directive counseling and the importance of maintaining respect for the patient’s attitudes and preferences have been much discussed in recent years. In general, the principle of non-directive counseling has become officially, if not universally, accepted by the medical establishment. It is always advocated for genetic counseling, which provides the closest analogy for HIV disease and reproductive choices. When amniocentesis identifies a fetus with a genetic defect, the mother is not instructed that she should abort. Rather, the parents are presented with the known medical facts and allowed to decide on a course of action. Why is this not also the standard for counseling HIV-infected women? Does HIV-infection justify urging choices on women that suit the agenda and beliefs of the counselor? Does the willingness to pursue directive counseling derive from prejudices about poor women and their right to bear children?

A policy designed to prevent the birth of HIV-infected children runs the risk of tacitly condoning directive counseling. It is important for public officials as well as individual providers to acknowledge openly that this issue exists and to explain why their ethical position on directive counseling in the

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Eliminating congenital HIV infection can be achieved only if HIV-infected women never have children.

ACTUP and WHAM (Women’s Health Action Movement) protest underenrollment of women in NYU’s clinical drug trials.
domain of reproductive choices should be different for HIV-infected women than for uninfected women, if indeed that is the case.

Leaders in public health have made clear their belief about how HIV-infected women ought to be led to choices. “There is no reason that the number of pediatric AIDS cases shouldn’t decline,” said Dr. James Curran, director of AIDS activities at the Centers for Disease Control. “Someone who understands the disease and is logical will not want to be pregnant and will consider the test results when making family planning decisions.”

This statement assumes that preventing HIV infection in children of HIV-positive women takes absolute priority over all other considerations for individual families or parents, even though there is a greater chance of a child being healthy than infected. The argument that a woman who chooses to conceive or continue a pregnancy in the face of possible HIV infection must be either ignorant or unreasonable, or both, reveals the speaker’s point of view. It does not acknowledge the leap from bias to moral imperative, and it demonstrates a lack of sensitivity to the profound cultural and social differences between the world of male professionals and the individual worlds of women, especially women of color in the inner cities.

In our previous article we discussed the fact that many HIV-infected women do not choose abortion even after counseling about the risks of bearing an HIV-infected child. (That risk is currently thought to be approximately 35 percent—possibly lower for women in an early stage of infection and higher for women with AIDS and advanced disease.) We noted the influence of many cultural factors in the choice of an HIV-positive woman to become pregnant or, if pregnant, to choose to carry the pregnancy to term. For many women, having children may be the only means of attaining a sense of identity and status. In addition, for poor women, a two out of three chance of bearing a healthy child may seem better odds than those they routinely face in other areas of their lives. Overall, HIV-infected women seem to make choices about pregnancy for the same reasons that uninfected women do.

Implications of Coercive Counseling and Testing
The guarantee of full reproductive rights to women who are infected with the human immunodeficiency virus—who may transmit the virus to a fetus during the course of a pregnancy and delivery—is admittedly a difficult topic. However, it is important to recognize the full implications of policies and legal measures designed to prevent the birth of children to HIV-infected women. As Ronald Bayer points out, the logical endpoint of such measures would be “mandatory and repeated testing of all women of reproductive age, criminalized childbirth, coerced abortion or compulsory sterilization.”

Consideration of the right of HIV-infected women to bear children must take place in the current climate of attack on reproductive choice by the Catholic church and by the highly visible and organized anti-abortion lobby. Combined with the resurgence of overt acts of racism, this may well permit a social and political climate in which coercion would become tolerable, especially when those most affected are poor women of color.

Reproductive rights for women are a relatively recent and hard-won accomplishment. It was in the 1965 Griswold v. Connecticut and the 1973 Roe v. Wade decisions that the U.S. Supreme Court established a woman’s right under law to make her own choices about family planning and pregnancy on the basis of the individual’s constitutional rights of privacy and personal autonomy. The interpretation in these decisions continues to undergo modification and limitation, with the possibility that further restrictions on abortion will be allowed by the Supreme Court in the near future.

**Does HIV infection justify urging choices on women that suit the agenda and beliefs of the counselor?**

In the face of the Court’s initial protection of reproductive rights, the federal government has attempted to restrict access to services for women who are dependent on publicly funded health care. Under current regulations of the Department of Health and Human Services, first promulgated during the Reagan administration, any clinic...
or family planning service providing abortions or even offering information about abortion would lose federal funding for all its programs, not just those directly related to pregnancy. The Supreme Court is expected to review this directive.

Coercive policies aimed at discouraging HIV-infected women from bearing children take on special significance when access to abortion is officially restricted. Poor women, who have limited access to health care because they can afford only publicly financed services, are placed in a bind. They are directed to prevent or terminate any pregnancies because of the possibility of bearing an HIV-infected child, but they are simultaneously denied the means to do so, whether by restrictive legislation or by funding limitations on abortion. Given this conflict between outlawing abortion and the official goal of preventing the birth of newborns who might carry HIV infection, we can anticipate increased pressure for coercive testing and sterilizations among women who are at risk or found infected. And risk may be defined as simply living in a community where HIV infection is prevalent.

If limitations on abortions and abortion funding for poor women continue to increase, sterilization abuses will follow, although, as in earlier years, they will be hidden from public view in the hospitals and clinics that serve the poor. Involuntary sterilizations are again being reported in New York City's hospitals. Are these related to the spread of HIV disease to women of childbearing age? Will we relive the experiences of earlier decades—before their exposure in the 1970's—when poorer women were vulnerable to the pressure for institutionally prescribed sterilization? By the early 1970's, for example, 35 percent of women of childbearing age in Puerto Rico had undergone tubal ligation or hysterectomy, often without being informed that such a procedure was planned. We believe that a repetition of this history is possible.

The Coercion of Carol Doe

When Jamaica Hospital encouraged Carol Doe (not her real name) to undergo a test for the HIV virus as part of her prenatal care, she had little reason to fear the results. The 38-year-old Haitian woman, a Medicaid patient, had heard the hospital had excellent high-risk pregnancy care, which she needed because of her age, a weight problem, and two prior operations. Doe agreed to the HIV test, feeling that there was no harm in knowing the results, and because she did not know whether she had received transfusions during her surgery. The test came back positive.

This was only the beginning of Doe's nightmare. Her subsequent treatment led the Center for Constitutional Rights (CCR) to file suit on Doe's behalf for discrimination, based on the handicap of HIV status, against Jamaica Hospital and New York City's Health and Hospitals Corporation (as the operator of Kings County Hospital, where Doe was also treated). Not only was she accorded inferior treatment because of her newly discovered disability, they claim, but she was coerced into aborting her pregnancy against her will.

At the same time that she found out the results of the test, Doe was advised that she should tell no one else of her HIV status, that her chances of having a baby with AIDS were extremely high, and that she should abort the fetus. In fact, an HIV-positive woman has a better than 50 percent chance of bearing a child who will not have the virus. She was also told that she should go home and write her will because she was going to die. (The woman was asymptomatic for AIDS.)

Doe chose to continue her pregnancy. When she came in for her routine checkup, she was instead taken to another building for a meeting with several high-ranking medical personnel. According to Doe, they told her that having a child with AIDS is worse than having a child with spina bifida (Doe's older daughter has that disability), that such a child would be a burden to society, and that she would be wrong not to give up the baby to abortion.

Doe insisted that she wanted to have the baby and pleaded with hospital officials to continue her course of care. They refused her this option, stating that the hospital was not "equipped" to treat her. There is no justification for this. While HIV-positive women may require closer monitoring for infection during pregnancy, this is not beyond the capability of a major hospital. And, according to physicians consulted by CCR, hospital staff must treat all patients with the precautions accorded to HIV-positive patients, since there is no way of knowing an individual's status without a test.

A frightened Doe was referred to Kings County Hospital, a public facility, for a second-trimester abortion. The abortion was performed without pro-
Women in Double Jeopardy

The emotional and legal focus on the potentially infected child unfairly neglects the predicament of the mother. The quality and length of her life, as an infected individual, is rarely mentioned in discussions about the birth of HIV-infected children. Rather, it is her responsibility not to produce an infected offspring that becomes the legal and judicial priority. Every infected woman, whether or not she is a mother, deserves the best available care and treatment. Surely it is in our own interest as a society to put our maximum efforts and resources into care for those who are mothers and who will leave so many healthy children orphaned if they die prematurely. Why is increased funding sought for testing but not for treatment?

It is difficult to offer a benign interpretation of expensive strategies for prenatal and perinatal HIV-testing and the simultaneous neglect of prevention and treatment services for those tested. Although the opportunity to seek prevention is rare. The quality and length of her life, as an infected individual, is rarely mentioned in discussions about the mother. The ethical and legal focus on the potentially infected child unfairly neglects the predicament of the mother. The quality and length of her life, as an infected individual, is rarely mentioned in discussions about the birth of HIV-infected children. Rather, it is her responsibility not to produce an infected offspring that becomes the legal and judicial priority. Every infected woman, whether or not she is a mother, deserves the best available care and treatment. Surely it is in our own interest as a society to put our maximum efforts and resources into care for those who are mothers and who will leave so many healthy children orphaned if they die prematurely. Why is increased funding sought for testing but not for treatment?

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lead to efforts to identify HIV-infected women in order to restrict their reproductive choices. The battles over reproductive choices are being played out on the state and local fronts. This has been the case for the struggle over abortion rights, and is now true also for the issue of mandatory HIV testing of pregnant women—and its proxy, “routinized testing.” Careful consideration must be given to a woman’s right to choose for herself whether and when to bear children, despite the risks associated with HIV infection.

The two-class system of medicine in the United States has wreaked havoc in the lives of poor women and women of color. The neglect and unjust treatment of women in the HIV epidemic represents a microcosm of long-standing problems in the delivery of adequate women’s health services. Many serious social and ethical issues have surfaced in the HIV epidemic in new form. As the least empowered members of our society, these women are taking the initial brunt of questionable and potentially dangerous official policies. Of particular concern are the abrogation of reproductive rights and the movement toward routine testing of women of childbearing age as a selected risk group. Many crucial decisions are now being made at the state and local levels, and it is important that as many people as possible become informed about the issues concerning HIV infection and reproductive rights.

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Lessons, continued from p. 3

mantle most federal social welfare programs, with the resulting transfer of responsibility, mostly by default, to state and local governments. Such changes may help explain why the two empires have picked this time to assert their independence.

Columbia-Presbyterian finds itself increasingly surrounded by drugs and violence—the 34th precinct in which it is located has the highest homicide rate in the city. This is probably making the administrators of this renowned center of medical research and expertise uneasy about its continued ability to compete for staff, faculty, students, and patients. The other empires, crudely put, have better real estate. Columbia-Presbyterian, stuck in the mortar of its own buildings, is likely to believe it must try to control the percentage of beds and waiting-room chairs occupied by troubled populations to avoid being branded with a public hospital image. Because New York State’s progressive laws forbid hospitals to close emergency rooms or to refuse to treat emergency cases, cutting ambulatory clinic visits is the only way to control the social “mix” of admissions.

St. Luke’s-Roosevelt is likely to have similar “marketing” concerns about the social composition of its patients, which may explain its insistence on consolidating obstetrical and neonatal inpatient services at its midtown campus. Located in the midst of major gentrification, St. Luke’s-Roosevelt, unlike Columbia-Presbyterian, has improving real estate. But for it to capitalize on its geographic good fortune and assure its continued fiscal viability, St. Luke’s-Roosevelt must increase the number of well-insured patients using all its services. The middle-class families St. Luke’s-Roosevelt needs to attract are not apt to choose to have their babies—or future health care—in a hospital they perceive to be populated by the troubled poor and situated at the edge of a neighborhood that symbolizes urban decay. For the medical empires, unfortunately, the competitive realities outweigh the legitimate public health concerns expressed by the low-income community with which St. Luke’s-Roosevelt has a long-standing relationship.

What lessons, if any, are to be learned from these events? First, although the empires all share a fragile fiscal reality, what each must do to survive and compete varies. The variability in response may be influenced as much by location as by any other factor. Second, while never anxious to serve great numbers of the poor and troubled, the empires did so historically because their academic mission required it and the economics of hospitals permitted it. That is no longer the case. Today, when the empires find poor and troubled sick people too great a burden, they are acting to limit their access. The current competitive environment rewards those most skilled at attracting the well insured, even if that means abandoning the most needy and vulnerable. Finally, we are again reminded that in the long run, the solution is to come up with the right peg: that is, to develop alternatives to the empires—programs dedicated to providing primary care in our communities.

—Arthur Levin
Public health programs aimed at preventing further spread of the AIDS epidemic have been tailored to specific populations, such as gay men and intravenous drug users, in recognition of the fact that different groups have varied and specific needs, issues, and world views that would affect their response to such efforts. One large and heterogeneous subgroup that has been aggressively targeted by public health officials consists of fertile women—women considered in relation to their reproductive capacities.

While there are various reasons to construe fertile women as a specific group in relation to AIDS, the one most often cited is the prevention of "vertical" transmission of the disease to a fetus in utero; and the intervention commonly proposed is to identify infected women through an antibody test either prior to or during pregnancy. The presumption is that women identified as seropositive who are not already pregnant can then avoid conception, either through contraception or sterilization. The purpose of detecting a woman's serostatus during pregnancy has been less clearly articulated, because health officials have been reluctant to confront the controversial issue of abortion. Explicitly stated, however, the rationales for identifying HIV-positive women during pregnancy include the need to provide the best medical care during the pregnancy; the opportunity for infected women to avoid subsequent pregnancies; the possibility of beginning therapeutic interventions with future children as early as possible, either by enrolling pregnant seropositive women in clinical trials on behalf of their fetuses or by enrolling their newborns immediately after birth; and, of course, the option of terminating a pregnancy.

The stated goal of all these interventions, it should be clear, is to prevent or ameliorate illness in future children. Although women constitute 9.6 percent of AIDS cases in the United States, and congenitally infected children comprise less than 2 percent, women have been targeted by AIDS prevention programs primarily because of their relationship to the fetus.

Other reasons posited by medical and public health professionals for selecting women of reproductive age as a target group for AIDS prevention purposes do involve benefits for the women themselves. These include the fact that women most often go for care at reproductive health care settings and thus can be reached most easily there; the hypothesis that women may be especially motivated to reduce risk-taking behavior when carrying a wanted pregnancy; the clinical import for women of possible exacerbation of HIV disease resulting from interaction between the immunologic changes of normal pregnancy and HIV infection; and the opportunity to empower women by offering them information about their health status and the chance to exercise their right to make reproductive decisions. However, to cite early therapeutic intervention with a woman herself as a rationale for routinely ascertaining
women’s serostatus is somewhat specious, since fertile women have traditionally been excluded from clinical trials, as well as accepted treatment, because of the possibility of inadvertently exposing an embryo to the medications. In fact, the Centers for Disease Control, which has consistently urged HIV testing of fertile women, specifically advises against offering pregnant women pentamidine prophylaxis against pneumocystis carinii pneumonia (PCP), the most common opportunistic infection among people with AIDS. (There is no equivalent guideline for use of AZT, and practice with pregnant women varies.)

Obstacles to Intervention

Most of the AIDS intervention programs that focus on fertile women have concentrated on promoting HIV testing and counseling in clinic settings where women go for reproductive health care. For example, the New York State Department of Health has mandated that all health facilities that offer family planning and prenatal care and receive state funds offer on-site testing. It did not similarly mandate that state-funded drug treatment programs do so, despite the much higher risk status of patients in drug treatment.

While the AIDS epidemic has stressed the health care system beyond the crisis point, perinatal care was already in crisis before factoring in AIDS.

Yet, there are significant obstacles to broadly implementing these interventions. The first pragmatic stumbling block to testing and counseling is one that currently afflicts all aspects of the health care system—a shortage of funds and personnel. Given present budgetary constraints, clinics in New York State have found it difficult to comply with the mandate for on-site testing and counseling. Second, women may refuse testing or may provide incorrect information about their risk status because they fear the consequences of having health officials record potentially stigmatizing information. The fears of these women will not be assuaged when they realize that there have already been proposals to abrogate the confidentiality of HIV test results in a unique fashion for women in reproductive care settings. New York State Health Commissioner David Axelrod has proposed “unblinding” the results of HIV blood tests currently done on all newborns for surveillance purposes, which would identify the HIV status of all new mothers in New York State without their prior consent.

Moreover, for poor women who have learned that they are HIV-positive, financial barriers to both abortion and prenatal care or the lack of availability of these services further constrain them from translating knowledge into reproductive choice. Eighty-two percent of counties in the United States have no abortion provider, and Medicaid plans cover abortion in only 12 states. It is currently estimated that 17 percent of women of reproductive age lack any form of health insurance and therefore have virtually no access to prenatal, family planning, gynecologic, or abortion services. And, while expanding HIV testing into the family planning setting, some states have simultaneously proposed reducing funding for family planning, sexually transmitted disease, and outpatient gynecologic services.

Women have been targeted by AIDS prevention programs primarily because of their relationship to the fetus.

Major structural inadequacies in the health care system also weaken the ability of AIDS prevention programs to reach women through reproductive health care services and to offer services once a woman’s positive serostatus is known. New York City, for example, has too few maternity and neonatal beds and far too few perinatal care providers for the growing numbers of high-risk patients needing care. A number of factors have combined to produce the increasing demand for maternal and infant services in
New York City, including mounting rates of poverty, drug abuse, and homelessness and the resulting increase in morbidity and mortality; rising rates of AIDS, sexually transmitted diseases, tuberculosis, and hepatitis; increases in births, birth rates, and birth-related illness and deaths; and changing patterns of practice that result in more labor-intensive and technologically advanced intensive care. This increased need has coincided with cutbacks in services and funds, reductions in the number of beds, and shortages of staff. Indeed, while the AIDS epidemic has seriously stressed the health care system beyond the crisis point, perinatal care was already in crisis before factoring in AIDS.

**Contraceptive Quandary**

Government’s failure to provide adequate resources for research in contraception has led to the development of few options in this area. Thus, promoting contraception as a means of preventing vertical transmission of AIDS is of limited efficacy. With restricted availability of the IUD and fears about the birth control pill (both founded and unfounded), women perceive fewer possibilities for contraception.

Almost no research has addressed approaches for combining AIDS prevention and family planning services. The epidemics of AIDS and sexually transmitted disease could provide the impetus for research into contraceptive methodology that merges fertility control with disease prevention and is acceptable to both user and partner. Barrier methods, which appear most likely to accomplish the first two goals, apparently fail with the third. Condoms are unpopular in the United States, reputedly particularly among males. And with machismo and female subservience still alive and well, too many women find it difficult to insist on their use.

The messages have been mixed as to whether condom use is intended to achieve disease prevention, fertility control, or both. This reflects ambivalence on the part of both the family planning groups and those working around AIDS. On the one hand, family planning organizations have given their allegiance to methods, such as the IUD and the pill, that can be used by women at a moment dissociated from the sexual encounter. Presuming that the sexual double standard cannot be challenged, these providers have thus been hesitant to aggressively promote the use of condoms.14 AIDS advocacy groups and health care providers, on the other hand, have been reluctant to incorporate the notion of fertility control into their efforts to encourage condom use for disease prevention. This attitude stems from the initial focus on gay men for whom contraception was not an issue, a lack of consciousness about the issue of birth control, and reluctance to become embroiled in one more controversy related to sexuality. Thus, the New York City Health Department’s condom campaign explicitly addressed sexual comfort for men, but did not mention the condom’s role in preventing pregnancy.15

Finally, and critically, implicitly promoting contraception or abortion to prevent vertical transmission of HIV infection may conflict not only with religious beliefs, but with the profound, positive significance reproduction has for many women. Childbearing is a major source of female worth and self-esteem in many cultures and may represent...
one of the few creative options open to women deprived of economic and educational opportunities.

**Insights from Genetic Screening**

The experience garnered in genetic counseling programs can offer considerable insight into how public health and medical programs interact with reproductive decision making, as AIDS counseling programs for women inevitably do. The screening programs for Tay-Sachs disease and sickle cell anemia were both wide-scale prenatal diagnostic efforts but met with opposite reactions in the two communities they were aimed at.

The Tay-Sachs program was initiated in Baltimore after extensive coordination with Jewish religious and community-based organizations there. This preparation of religious and secular leaders and public educational outreach resulted in community sponsorship and identification with this voluntary program and a high rate of acceptance. The subgroup of orthodox Jews who would not contemplate abortion refused the screening.

In contrast, the sickle cell screening program was perceived by black communities as imposed by the white medical and governmental establishments and consequently suspect of having a secret eugenic motivation. Those identified as carriers through screening of adults and mandatory screening of children were often stigmatized and discriminated against in employment, confirming these suspicions.

Against the background of this history, as well as the widespread lack of access to basic perinatal services, it is understandable that poor minority and other marginalized women feel suspicious when offered only one fragment of perinatal technology, such as an HIV test.

**Unless prenatal, abortion, family planning, and other needed services are available, discussions about AIDS and reproductive choice become empty rhetorical debate.**

The genetic counseling experience is instructive on another dimension as well: the diverse ways in which people incorporate prenatal diagnoses into their decisions about reproductive matters. The literature of genetic screening documents that people at high risk of conceiving children with serious genetic defects, who receive counseling about their problem at the time an already affected child is diagnosed, continue to have children, sometimes after having declared that they will not.

Partly in recognition that responses to information about the potential health of a future child are complex and variable, the genetic counseling profession adopted as a central tenet the nondirective stance, in which the counselor presents information and various options but supposedly does not attempt to influence the client’s choice. Such a nondirective stance is unusual for health care providers. However, it was accepted as the standard of behavior for counseling in reproductive decision making also as a reaction to the historical association of genetics with the eugenics movement and revelations of coercive sterilization of the retarded, the “promiscuous,” and poor minority women who were considered “unfit to breed.”

But public health policymakers have questioned this accepted ethic when it comes to maternal HIV infection. Consistent with the findings from counseling for genetic disease, the limited evidence to date indicates that pregnant women who are informed that they are seropositive are not necessarily choosing to abort. Yet health workers and policymakers have not been maintaining the same hands-off attitude toward reproductive choice in HIV-positive women that the prevailing ethic of nondirective counseling usually requires. Since most of the women affected to date have been members of disenfranchised minority groups who have previously been subjected to abuse in this arena, such as coercive sterilization, it is critical for policymakers to proceed with self-awareness and clarity. Otherwise, women at high risk may distrust and avoid the medical establishment that is ostensibly trying to reach out to them. Moreover, unless prenatal, abortion, family planning, and other needed services are available, discussions about AIDS and reproductive choice become empty rhetorical debate.

The tension between concern for women qua women and for women as fetal vessels or vectors of transmission of disease to others permeates all of the current efforts to target women for AIDS prevention work. This tension influences the framing of the questions, the design of the interventions, and the parameters considered in evaluating the outcomes. It surfaces most clearly around issues of reproduction in connection with pregnancy but not with gynecologic conditions; and the unique treatment of pregnant and postpartum women with regard to informed consent and confidentiality for HIV testing. Efforts to insert AIDS prevention activities into the context of pregnancy and heterosexual sex inevitably raise issues...
of women's subservience and empowerment.

Because reproduction has been centrally linked to the limitation of opportunities for women, attempts to change behavior in this arena can only succeed if designed with history and culture in mind. Efforts to protect women and infants have to be linked with concrete services so as to genuinely expand reproductive choice. □

5. Ibid.; and Grimes, op. cit.

ACTUP and WHAM protest underenrollment of women in NYU's AIDS clinical drug trials.
Labor Confronts the Health Care Crisis

LAURA McCLURE

The subject of health care is getting hotter and hotter for unions, as employers everywhere try to force rising costs onto workers. Health insurance premiums have been rising at an average rate of 15 percent per year since 1980, and over two-thirds of larger employers now require workers to foot part of the bill. But the average worker, whose real wages have dropped 8 percent since 1980, is in no position to absorb rising copayments and deductibles.

Some of the most bitter labor disputes in years are being fought over the issue of health care. Medical coverage was an issue in 78 percent of the strikes in 1989, compared to only 18 percent in 1986, according to a recent survey by the Service Employees International Union. NYNEX telephone workers spent months on the picket-line, in part to resist shifting of health care costs by the profitable telephone company (see Vital Signs, Fall 1989). The Communications Workers of America estimated that under the company's proposal, workers would have been paying $2,533 a year each for health insurance by 1992. The strikers defeated NYNEX on the cost-shifting issue for current workers, though not for retirees. Health care was also a factor in the recently settled strike at Pittston Coal Company. The miners walked out after Pittston unilaterally suspended health benefits to retired miners, widows, and disabled workers. Although the mine workers retained these benefits, the settlement included some

unique and dubious incentives for workers to minimize their personal spending on health care.

Striking telephone workers march in New York City's financial district to protest shifting of medical care costs to workers.

Some of the most bitter labor disputes in years are being fought over the issue of health care.

You might expect organized labor to be putting a lot of pressure on Congress for action on health care reform. But while the AFL-CIO and many of its member unions are calling for some kind of "national health care," few have embraced any real alternative to our current system. Indeed, given the general acknowledgement that our system is collapsing, it's surprising how little public discussion there is of our options. While lawmakers have been talking more about health care reform recently, there's still no serious, widespread consideration of real national health insurance or a national health service. Federal legislators are wincing at the thought of making any health care reforms at all, afraid that they'll suffer a repeat of last year's embarrassing reversal of their Medicare reform package. Alternative systems, such as those found in Canada, Britain, and elsewhere aren't given much of a hearing, either in unions or in Congress. One exception has been the efforts of the Oil, Chemical and
Atomic Workers union (OCAW) to educate its members about alternatives to our health care system. The union has endorsed a Canadian-style health plan for the United States.

Alternative Systems

Last November, Pete Meyers, who makes his living packaging Listerine in Lititz, Pennsylvania, traveled to Ontario with 47 other members of OCAW as part of that union’s campaign for a national health care system. When Meyers poked his head behind a door marked Accounting Department in a hospital in Hamilton, Ontario, he discovered that there were only two desks in the room. In his local hospital in Pennsylvania, Meyers says, there’s a whole floor for accounting. Later, a young woman undergoing kidney dialysis in the hospital told Meyers that, under Canada’s national health insurance system, she pays absolutely nothing for this expensive procedure. Meyers’ experiences point up some of the essential differences between the two systems.

Canada’s health care system used to be similar to ours. But in the late 1960’s and early 1970’s, after some successful experiments at the provincial level, Canada moved to replace its private health insurance companies with a national health insurance program covering all citizens. It is funded by both federal and provincial taxes and administered mostly by the provinces. While not the ideal system we might envision, the Canadian program provides universal general health care for 30 percent less per capita than we pay in the United States. (The United States spends more on health care than any country in the world.)

Health care is cheaper in Canada largely because the public is not paying for the profits of the United States’ 1,550 private health insurers, for advertising, or for all the bookkeeping costs incurred by both hospitals and the insurance companies. According to the Boston-based group Physicians for a National Health Program, in the United States we spend 23 cents of every health care dollar on bureaucracy, while Canadians spend only 13 cents. The average physician in the United States spent $25,000 just on billing last year.

Every Canadian is issued a plastic card that guarantees free health care at any hospital, clinic, or doctor’s office. Hospitals and clinics get lump sum payments from the government, provided they stay within specified cost restrictions. This type of financing saves money, since it’s much simpler to keep track of than a fee-for-service system. Because of government-imposed limits on spending, Canadian hospitals are less likely to invest in the expensive state-of-the-art equipment that U.S. hospitals find profitable, but the average citizen gets better care.

Although Canada has scrapped its for-profit insurance system, it has not eliminated insurance altogether—or the profit motive for health care providers. But in Britain and some other European countries, health care itself—not just insurance—is provided through the government. The British pay about half the amount we do, per capita, for their national health service.

Business and Labor’s Health Care Campaign

Meanwhile, more and more corporations, from Bethlehem Steel to Chrysler, have been coming out on their own for some kind of “national health care” solution. But what does business really want? The corporations are looking for relief from their rising health care costs, and that may win their support for some form of publicly funded health care programs. But the corporations are not likely to support any program that jeopardizes the for-profit health care delivery system or the private health insurance industry—and this is what makes the U.S. system so costly and inefficient. So the corporations would be asking the U.S. public, which already pays the world’s
Business support for health care reform has been embraced uncritically by much of organized labor.

in their communities and lobby their representatives for legislation that would “control costs, improve quality of care and expand access” to health care.

The comments of one AFL-CIO benefits specialist reflected the same curious predilection for putting business interests first. “We want to lift the companies and unions from the burden of health care inflation,” she explained. An AFL-CIO-backed health care plan, she said, “wouldn’t put all the burden on the employers, and small businesses would be lifted from the burden of facing health care costs through government subsidization.”

The AFL-CIO campaign does convincingly convey some of the failures of the United States system, which it describes as a “patchwork” that leaves growing millions of individuals uninsured. It charges that too many health care dollars go to overpaid specialists or to pay for “inappropriate procedures.” It documents the inequalities of the system and notes the rising infant mortality rate, especially among blacks.

Yet in its literature, the federation doesn’t propose a particular alternative to the present system or even put the issue up for debate. It just asks local unionists to mobilize

The pamphlet goes on to assure the reader that radical reform is not in the cards: “Opponents of a national health care program still call any attempt to contain costs ‘socialized medicine,’ but they are wrong. In countries that have socialized medicine, the government owns health care facilities and physicians are government employees. No one is proposing such a system for the United States.”

The campaign adopts a peculiarly apologetic attitude toward business. For instance, one pamphlet tries to counter the “myth that we have the best health care system in the world” by first noting how much employers have to pay for health care, thus “exacerbating foreign competition.”

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point of casting aside a Canadian-style plan. "The Canadian system is wonderful. But remember, Canada has a different culture, a different economy, different politics. We need to build on what we already have." Sheinkman noted that in West Germany, health insurance is "run through nonprofit, nongovernmental plans, many union-sponsored."

The various health care reform proposals that have been floated over the years were barely even mentioned at this conference, much less debated. However, OCAW Secretary-Treasurer Tony Mazzocchi did host a panel of speakers from England and Canada and briefly plugged the Canadian-style plan his union has endorsed. "You have to push for a specific program people can get behind," Mazzocchi argued later. "We should be out there in the lead. We ought to frame the parameters of the health care debate." Some of the unionists who spoke from the floor at the end of the conference also called on organized labor to publicly endorse a particular plan, but by then the top leaders had left the hall.

Staking Out the Proposals

Unions have supported a variety of health care plans at different times. In fact, many unions are listed as endorsers of several very different reform proposals. Until recently, health care reform was such an abstract question that unions didn't necessarily have to settle on one plan over another.

Now, however, union leaders are beginning to stake out distinct territory on the issue. Unfortunately, these vitally important decisions may be made without debate and deliberation among union members themselves, if the February conference is any indication. If's a safe bet that most union members have no idea where their union stands on particular health care proposals.

In the last few weeks, the leaders of several major unions—including SEIU, the Communications Workers of America, and the American Federation of Teachers—appear to have settled on a particular health plan—and it

Many people are cheered by the AFL-CIO's new call for "national health care"—even if that term remains undefined.

is one of the most modest plans on the table. These unions are joining corporations like NYNEX and 3M in supporting a proposal put forward by the National Leadership Commission on Health Care. The commission, which is chaired by Gerald Ford, Richard Nixon, and Jimmy Carter, includes the giant health insurance company Blue Cross/Blue Shield on its board.

This consortium proposes the creation of a public fund for uninsured workers, which they call the "universal access" or UNAC program. Money for the fund would come from a fee levied on all employers and on all individuals with incomes at least 150 percent above poverty level. Individuals without employer-paid health insurance would be covered by UNAC and would pay fees based on a sliding scale. There would be no cap on deductibles or copayments for insurance provided by employers. The plan seems basically designed to beef up the Medicaid program (which it would incorporate), while preserving the role of private, profit-making insurance companies. Medicaid currently covers only 37 percent of Americans under the poverty line.

The United Auto Workers (UAW) is putting its weight behind another health care reform plan, this one initiated by the Committee for National Health Insurance. This joint labor-business committee, founded in 1968, is chaired by former UAW President Doug Fraser. The committee is recommending that states administer contracts with private health insurance companies, acting as a kind of go-between for consumers, insurance companies, and health care providers. States would have the power to withhold funding to health care providers who don't stay within a pre-approved biennial budget.

"What this plan does is preserve the private insurance system—providing that the insurance company has a state-approved plan as to its efficiency and responsiveness to consumers and that it rates consumers on an across-the-board basis," explains Mel Glasser, a longtime UAW staffer who is executive director of the committee. "This is probably the most important thing about the plan, as far as the insurance industry goes, because it eliminates the whole business of discrimination." Glasser believes that under this program, health insurance companies would see their profits "sharply reduced," and that might set the stage for phasing out the private health insurance system.

Both of these union-backed plans have yet to take the form of legislation. The main health care reform bill actually in circulation is the Kennedy-Waxman bill. The legislation has many union backers, but it's not clear how solid that support really is. The Kennedy bill would require that all employers with more than 25 employees provide insurance for people who work more than 17.5 hours per week. The small-business exemption is actually quite sizable, however; according to the General Accounting Office, nearly half of all uninsured workers are employed by
firms that have fewer than 25 employees. The Kennedy plan would also boost Medicare and Medicaid coverage for workers who are not insured through their employer.

One of the most radical health care reform proposals has been floated by Congressman Ronald Dellums every year since 1977. This bill would establish a national health service along British lines. The health service would largely supplant the for-profit health care delivery system with a public one financed by a "progressive surtax on individuals and a payroll tax on corporations, as well as with the funds currently allocated for Medicare, Medicaid, and other health programs." However, organized labor has not, in general, been willing to back a measure so antithetical to the interests of the corporate health system.

OCAW and the United Electrical Workers (UE) stand virtually alone in their willingness to challenge the private health insurance companies. The reform plan backed by OCAW, which was formulated by Physicians for a National Health Program (PNHP) and is based on the Canadian system, would create a "single tax-funded comprehensive insurer in each state, federally mandated but locally controlled." As in Canada, every citizen would be entitled to free health care, with no deductibles or copayments. Hospitals and nursing homes would receive an annual lump sum from the government, based on a negotiated agreement. Doctors could elect either to be paid on a fee-for-service basis or to be salaried through an HMO or other institution.

PNHP suggests that the program could be first tested on the state level. In that state or states, and during the phasing-in period for the national system, "funding would mimic existing patterns to minimize economic disruption—but all payments would be funneled through the national health program. Thus, Medicare and Medicaid monies would go through the NHP; employers would pay an NHP tax equivalent to the average now spent for health benefits; and individuals would pay a tax equivalent to the current average out-of-pocket expenditure."

Labor's 'Realism'
The Canadian-style plan supported by OCAW has been dubbed "unrealistic" by most leaders of organized labor. "Realism"—meaning what can be achieved, rather than what would be best for workers—has, in general, guided the AFL-CIO's legislative strategy on health care and other issues. Typically, labor sets out on a legislative campaign with the goal of achieving modest reform through negotiation, not with the idea of forcing substantive change through massive mobilizing. So, many people are cheered by the AFL-CIO's new call for a locally based campaign for "national health care," even if that term remains undefined.

The United Electrical Workers union, which is not affiliated with the AFL-CIO, often finds itself almost alone in calling for far-reaching legislative reforms. UE Legislative Director Bob Kingsley says his union is "really pleased to see OCAW out in front" on national health care. Kingsley recently led a meeting of UE locals in Vermont called to organize a statewide public hearing on national health care. UE is pushing for a Canadian-style plan, although he says the fine points have yet to be worked out.

Kingsley feels organized labor's limited outlook on health care reform is part of a larger political problem. "One of the failings of the labor movement, especially in recent years, is its failure to define an agenda independent of the Democratic Party," he says. "If the starting point is working with the Democratic Party to determine what is politically achievable, I don't think we are going to end up with a national health plan that meets the needs of American workers. We have to set forth a vision, a common sense answer to the crisis in health care in this country, and then build support for it." OCAW's Mazzocchi, a vociferous proponent of a U.S. labor party, often makes the same point.

Even so, organized labor's new active interest in legislative action on health care represents a break with the past. The die was cast after World War II, when American unions won their first union contracts providing employer-paid health insurance. Ever since, most unions have been satisfied to protect their own members' access to health care through battles at the bargaining table. Some unions set up their own health and pension plans, which became a corrupting source of power and money for union leaders.

The average worker, who is unorganized or unemployed, has suffered because of organized labor's failure to forge the kind of broad social movement that could force substantive national reform for all workers. It's one reason why the United States and South Africa remain the only two industrialized countries without any kind of national health care plan.

3. Labor and Management: On a Collision Course Over Health Care.
Follow-Up:

Sharon Kowalski and the Rights of Nontraditional Families

ELLEN BILOFSKY

Although Karen Thompson has finally been reunited with her lover, Sharon Kowalski, after nearly five years of enforced separation, she is still angry, still fighting to ensure her partner’s proper care.

Thompson and Kowalski are lesbian lovers in Minnesota who were separated as a result of Kowalski’s disabling automobile accident. The two primary issues in their struggle are the disabled woman’s human rights—including adequate health care and a say in decisions affecting her—and Thompson’s right, as an unrelated loved one, to be involved in her care.

As reported in the Spring 1989 Bulletin, Thompson fought a lengthy and bitter legal battle (with grass-roots support from gay and disability rights groups around the country) and eventually won the right to visit her lover. To prevent Kowalski’s lesbian friends from seeing her, the injured woman’s parents—her court-appointed guardians—had placed her in a nursing facility far from the home she had shared with Thompson. The nursing home was

not equipped to provide rehabilitation for someone suffering Kowalski’s degree of brain damage. Thompson’s lawsuit also succeeded in enforcing Kowalski’s legal right to be evaluated to determine her potential for rehabilitation and her ability to participate in decisions about her own treatment and life arrangements.

That Thompson prevailed over Kowalski’s parents was a tremendous victory both for the rights of loved ones who do not fall under the traditional category of “family” and for the rights of disabled people to be taken seriously as competent human beings. Since the Bulletin’s last report, the court has moved Kowalski to an extended care facility, where Thompson and other friends can visit her freely, and Kowalski has resumed her rehabilitation in preparation for less-structured care. The doctors who conducted Kowalski’s court-ordered evaluation explicitly recognized her desire to return home to live with Karen Thompson again and set that as the goal of her rehabilitation. The National Committee to Free Sharon Kowalski, considering its purpose achieved, has disbanded.

Unfortunately, the fight for Sharon Kowalski’s rights did not end there. Although Kowalski’s father, Donald, asked to be removed as guardian because he was not happy with the changes in her situation, St. Louis County District Court Judge Robert Campbell has indicated off the record that he will neither restore Kowalski to partial com-

Sharon Kowalski before her court-ordered transfer from the Hibbing, Minnesota, nursing home where she was confined for four years.
After four years of isolation, Kowalski no longer believes in the future.

The order was overturned on appeal as unconstitutional, but Thompson feels that it represents an attempt to contain the damage done to the court's and state's credibility by the negative publicity about Sharon Kowalski's neglect. And that neglect—a violation of her medical rights—has caused deterioration in Kowalski's physical and mental condition that can never be undone. For example, although she was able to bear weight on her legs soon after the accident, as a result of lack of exercise her legs no longer straighten and her feet are permanently bent back. Her motivation to learn new skills, such as using the speech synthesizer Thompson rents for her, is poor. After four years of isolation, says Thompson, "she doesn't believe in the future." Although Thompson can take Kowalski out of the institution on day passes, a staff member must accompany them because of the parents' fear of sexual abuse.

Despairing of getting an appropriate guardian for her lover, at the end of August 1989 Thompson filed for guardianship of Sharon Kowalski. "I will never again believe that my silence will protect me," she said. "That's what helped get us here" in the first place.

Legitimizing Nontraditional Families

Thompson hopes her case will make people aware of the need for legislation, like the proposed New York State "health proxy" bill, to prevent such tragedies from occurring again. This measure would allow an individual to designate someone—not necessarily a family member—to make decisions about medical treatment if he or she were to become incompetent. This is explicitly legal in only a few states, although in most other states it is possible to use so-called durable powers of attorney for the same purpose. The New York State bill, which is under consideration in the 1990 legislative session, also allows an individual to specify in advance treatment that the designated agent could authorize. Because such treatment could include terminating life-support measures, the bill has engendered considerable opposition from religious and right-to-life groups who oppose such practices, and its fate is uncertain.

At the same time, there is a growing recognition in society of the legitimacy of nontraditional families. In July 1989, the New York State Court of Appeals ruled that gay couples (and unmarried heterosexual couples) whose relationships met certain considerations, such as "exclusivity and longevity," could be considered family under New York City's rent-control regulations. Although the decision dealt with housing law, the case in fact stemmed from a health care crisis: the death of a man as a result of AIDS, after which his partner was threatened with eviction. The decision legitimizes gay relationships in certain specific situations, but it is not a recognition of gay marriage or its equivalent.

Although the court did not extend its ruling to cover any health-related benefits, New York City's then Mayor Ed Koch shortly thereafter issued an executive order granting bereavement leave to city employees who register
their "domestic partners." The decision was again related to the AIDS issue, which has made more visible the suffering of gay individuals whose partners have died. The ruling also affects unmarried heterosexual couples, however, as well as other people who might be caring for an unrelated friend.

It is no longer sufficient for the traditional family to set the parameters within which basic health care decisions are made.

Koch sidestepped the issue of considering these "domestic partners" as family for purposes of health care coverage because of the substantial costs involved, leaving that issue for collective bargaining. The city's current policy is also being challenged in another law suit filed by the Gay Teachers Association on behalf of three New York City teachers. Their attorneys, the Lambda Legal Defense Fund, charge that the city discriminates in denying health benefits to their partners because of their marital status and sexual orientation. The case is currently before the New York State Supreme Court in Manhattan.

Six cities currently recognize some form of domestic partnership, including Berkeley, Los Angeles, West Hollywood, and Santa Cruz, California; Madison, Wisconsin; and Takoma Park, Maryland; and others are considering establishing such a category. However, in a recent referendum in San Francisco, the one city considered most likely to legitimate gay and nontraditional families, voters recently rejected the domestic partnership ordinance unanimously approved by the city's Board of Supervisors. The law would have recognized unmarried partners who registered with the city clerk as legally equal to married couples. In addition, it would have granted bereavement leave and hospital visitation rights to city employees in such domestic partnerships.

Activists attribute the San Francisco defeat to complacency in the face of a well-organized opposition, and don't expect the setback to be permanent. And, as the Bulletin went to press, two New York legislators have introduced a bill in that state to create legal domestic partnerships and prohibit discrimination based on marital status.

In the age of AIDS and openly gay relationships, it is no longer sufficient for the traditional family to set the parameters within which basic health care decisions are made. Cases such as that of Karen Thompson and Sharon Kowalski and the increasingly apparent burdens of partners of people who suffer from or die of AIDS-related illness have made clear the need to protect the rights of people who are not in traditional relationships.

The new address for the Karen Thompson Legal Fund is 801 Washington Memorial Drive, St. Cloud, MN 56301.

Two women at a 1987 wedding ceremony in front of the Internal Revenue Service in Washington, D.C., where 2,000 gay men and lesbians were married.
After 20 years of activism, it is now possible to have an analysis of women’s health needs and to discuss with some fluency the range of social, economic, and political issues that intersect with women’s physical and mental well-being. The three anthologies for this review reflect the strength of the feminist movement as it has taken on the central struggle of women for control of their bodies. Each book reflects a different level of sophistication in the understanding of that struggle and each, not surprisingly, covers areas not adequately dealt with by the others.

Women’s Health

The anthology most limited in scope is Women’s Health: Readings on Social, Economic, Political Issues. Meant to be a reader offering an “anti-racist, multi-cultural perspective” on women’s health issues, it contains articles designed for a women’s studies course on Women and Their Bodies in Health and Disease at the University of Wisconsin. It serves as an introductory anthology—one intended to acquaint the uninitiated with some of the issues confronting women and their bodies and the women’s health movement.

The weakness of the book is tied to the audience it is designed to educate. Hence, most sections tend to be topical for middle-class college students and superficial with respect to heterosexuality, with respect to the class basis of reproductive technology, with respect to the struggles of poor women for adequate contraceptive, prenatal, and medical care, and, finally, with respect to the politics of disease. The section on Cancer and AIDS, for instance, has no treatment of HIV and women and the article entitled “Myths about AIDS” is narrowly focused on how one can’t get the disease by just being around a person with AIDS! The authors promise to continually update the anthology, but Women’s Health will remain parochial unless the authors attempt to address sexuality, economics, and class as structural limitations on women’s lives.

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Healing Technology

Most useful to an economic understanding of health issues for women is Healing Technology: Feminist Perspectives. While the feminist movement has been activist in orientation, research and analysis have now become central to an understanding of the health care industry’s influence upon women’s lives. And it is a welcome sign that such thinking bears important fruit not merely for women’s lives, but also for a political and economic understanding of the health care industry itself. No feature of social analysis reflects the power differentials among race, gender, and class as does an analysis of technology. Hence, with this book one gets a glimpse of the feminist issues contained in Women’s Health, but with the added analysis of the deep roots that determine them.

Healing Technology is thorough in its treatment of the social roles of technology, and this is its strength. The authors are correct, I think, to emphasize technology in the three ways in which it substantially affects women’s lives: as determinative of social and health norms, as a consumer item, and as environment, without collapsing these three roles into one another. And there is no attempt to articulate a position that women can dispense with technology or wholly own it. Technology in general and health technology in particular is treated as both formative of women’s health and an item in other formative influences. Technology is shown to be obvious, ubiquitous, as well as invisible in its influence.

Healing Technology is introduced by its editor, Kathryn Strother Ratcliff, who was largely instrumental in setting up the 1986 conference on Women, Health and Technology that formed the first discussion of these issues and that is the basis of the anthology. Ratcliff’s essay is remarkably helpful in situating technology at the heart of the health industry and at the heart of the environment of working women. This essay sets the level of expectation for the rest of the book, an expectation that is not always fulfilled.

The first two sections of the anthology deal with Reproductive Technologies: Economic and Social Implications and with Health Care Technolo-
gones: Political and Ethical Considerations. Three articles in particular contribute substantially to an understanding of the ways in which reproductive and health technology develop into social ideology and into an understanding of the populations at whom the particular social ideology of motherhood is primarily aimed.

In "From the Pill to Test-Tube Babies: New Options, New Pressures in Reproductive Behavior," Elizabeth Beck-Gernsheim provides an analysis of new and "old" reproductive technologies and their relationship to the historical phenomenon of 20th century "modernization." This section asks the important and cultural question of whether reproductive technology has had the general tendency to liberate women (and men) or to further or differently enslave them. This larger philosophical consideration lays the foundation for Beck-Gernsheim's attempt to put the specific technologies of birth control pills and the more recent technologies of fertility within the context of technology's influence upon individual choice in general, upon social and individual needs and their interpretation, upon social burden as it relates to resources or the lack of them and, finally, upon democracy itself as that form of government that reveres individual freedom above all other social goods. As the author concludes, because reproductive technology is now focused upon fertilization and enhanced control of the quality of the fetus, women, primarily, are caught "in the endless circles of the infertility career. As with the pill, reproductive technology becomes reproductive ideology."

It is important to point out the gendered nature of health technology, and to emphasize the over-determination of women's health needs and their futures through health technology by such things as bone marrow tests for osteoporosis and mammograms. It is equally necessary to point to the schizophrenic nature of such technologies—that while they are proffered as state-of-the-art diagnostic tests and indispensable to health or to womanhood, in a for-profit health care system technological advances are almost always unavailable to low-income women. Without an economic understanding, such analyses largely overlook the extent to which class and race differences form and are formed by the developing technologicalization of health care. The lesson here is that what is a consumer health item and, thus, health ideology for the consumer is virtually non-existent for the low-income consumer, both in health care terms and in social ideology. This explains why the United States can have an ideology of motherhood for middle-income women and simultaneously disapprove of births among low-income women, particularly women of color. Ratcliffe's essay "Health Technologies for Women: Whose Health? Whose Technology?" forms a kind of bridge article between these two class influences as they get played out in the economic agendas of our for-profit health care system.

Authors render a great service when they take the time to give the numerical outlines of the deficiencies in our health care system as they pertain to low-income populations. The gaps in health care in America are becoming fissures through which the impact of power differentials, whether they be those of technology or of health financing, magnify the low health status of women and put their health, their empowerment, and their rights in direct jeopardy. Those of us who know Nsiah-Jefferson's work expect to be enlightened by her continuing analysis of race and class upon the health of low-income, largely minority women. With Elaine Hall, Nsiah-Jefferson lays out the differential effects of reproductive technology upon women who mostly have little access to developing technology; who have little choice when they do have access to it; and whose fundamental rights to consent, choice, and information are systematically thwarted by the social attitudes of the health experts they, and not middle-income women, must rely upon as they negotiate their health through state programs. This article is an indispensable addition to feminist debate.

The final section of the book, Occupational and Environmental Technologies: Research and Resources for Change, is very valuable for uniting the themes and economic analysis at the heart of Healing Technology. This section extends feminist analysis to the workplace—that is, to working-class women, who have historically been essentially absent from that analysis. The introduction to this section by Myra Marx Ferree is far-reaching in its understanding of the gendered structures of the workplace and the environment. In "Sustaining Our Organizations: Feminist Health Activism in the Age of Technology," Gail O. Mellow makes a compelling case for a much wider agenda for feminist activism with respect to technology. As Mellow points out, the emerging challenge is to move beyond a focus merely upon reproductive technology. This requires a coordinated look at issues of profit making in health care, health insurance, the impact of catastrophic illness on families, the use of women as underpaid health care workers, and the hidden and not-so-hidden consequences of developing workplace technology for women's health and disempowerment. Mellow ends her essay echoing Fannie Lou Hamer, who said, "I am sick and tired of being sick and tired."

AIDS: The Women

Anyone who works in the HIV epidemic, or in any area of human service to the sick, knows the extent to which the knowledge of the situation of each individual is the basis for good therapy and health policy. This is a recognition that is born as much from health activism by women as from that organized around disability. It is knowledge that has been furthered recently by AIDS activism and by eight years of experience with HIV infection. Health activists all struggle not merely for resources and for funds to respond to their communities' needs, but for the proper understanding of illness, disability, and, now, HIV and its place in people's lives.

This struggle makes books like AIDS: The Women important. Through various narratives of the epidemic, the reader is allowed entrance into the reality of HIV infection, a reality that illuminates the commonality of sickness as much as the abandonment that many of the HIV-affected women are condemned to and which they try, and often succeed in, overcoming. AIDS: The Women is about the entire spectrum of participants in the epidemic: patients, lovers, partners, children, AIDS professionals, AIDS educators. The stories, largely from the Americas and Western Europe, are
personal accounts by the individuals themselves or interviews by the editors. The 44 stories—many of which are translated from German, Norwegian, or Spanish—are short, touching, and exceptionally well written. The book also includes a glossary of terms, a resource directory, and a bibliography.

Section I, Families, Lovers and Friends, is largely about women with HIV-infected partners and their painful coming to terms with increasing debilitation and death in a loved one. But the editors have taken pains to include other ways in which women are responsive to their intimate situations. There are very moving stories of remembrance of loved ones, but also angry testimony about being infected; plaints about being burdened by siblings with the disease; stories of despair about the future of whole communities; narratives of extreme heroism; and even very dark humor.

AIDS: The Women reads like most folk stories do if collected only with a view to topic or issue. There is much variation in these stories. Some selections are wholly compelling in their simplicity. Others are obvious; some are very sophisticated and even glib. No reviewer could do justice to the wide range of experiences reflected here. The enormously high quality of the reading experience can only be due to the editorial acumen of the collectors and to a rare sensitivity to the story content of the contributors they interviewed.

What the stories have in common is their portrayal of how women confront the epidemic differently from men—as part of the multiple burdens and social habits and strengths of their everyday lives. This book is an excellent source for understanding those burdens and the particular heroism we associate with women simultaneously implicated in life on the fronts of working, partnering, mothering, nurturing. This is particularly true in the present anti-woman climate that not only favors children over women but views low-income pregnant women as somehow willfully endangering the health of their fetuses.

The section entitled The Professional Caregivers confronts the very complicated moral and social ambience of these HIV clients. Many stories tell how service providers find this environment impossibly resistant to tolerance and empathy for the HIV-infected woman. As one caretaker puts it:

It is considered a woman's fault if she becomes pregnant, if she gives birth to an infected or addicted or HIV-positive child. And if the child dies, if she gets sick, if her partner is infected? It is a vicious cycle, all the more for an addicted parent, an addicted mother, a woman.

What comes across powerfully in AIDS: The Women, and which is not often noted in the increasing literature on HIV, is the extent of the effect of the epidemic upon the professional caregiver. The stories in The Professional Caregivers, in particular, disclose what each doctor, social worker, case worker, or counselor must somehow find or invent for their clients in family support, community ties—almost all necessary services. Because there are practically no services for women with AIDS—practically no drug treatment programs (since pregnant women are expressly excluded); no child care; overutilized clinics; multiple gaps in social services, such that getting transportation money for clinic appointments may be impossible—those who work with these women operate largely in a vacuum, even as their location may be within very large social service or medical institutions.

In a rather extraordinary story by Kate Scannell entitled "Skills and Pills," we are privileged to glimpse into the life-change of a physician as she encounters an enormously afflicted and dying patient. The story is instructive in a broad way, for it highlights what AIDS workers know: the significance of HIV is the suffering it causes, and the significant therapy for HIV is almost always unconventional because it requires listening, understanding, and disentangling the extent of the needs for empowerment and dignity. Dr. Scannell, after describing her exquisite medical training and her expectations for technological and pharmaceutical mastery of contemporary disease, relates two days in the life of a new patient who appears in the emergency room. In one long paragraph, Dr. Scannell describes graphically what Raphael's level of HIV infection looks like and the extraordinary pain he is experiencing. "Tears literally squeezed out from the cracks between his eyelids. He asked me to help him." The rest of "Pills and Skills" is a litany of the awful procedures that Dr. Scannell puts Raphael through and the forgiveness she seeks.

After I left the hospital that night, feeling exhausted but confident I'd given "my all," another physician on duty was called to see my patient. Raphael asked the physician to help him. The physician stopped the intravenous fluid and potassium, cancelled the blood testing and the transfusion, and simply gave Raphael some morphine. I was told Raphael smiled and thanked the doctor for helping him, and then expired later that evening.

Kate Scannell's story is courageous, for it reflects the extent to which the AIDS epidemic makes us think newly about all that we do and encounter. It inspires one about individuals while disclosing how much our medical institutions miss the point about suffering. It is my favorite story in AIDS: The Women because it reflects such humanity and such awareness of the paradoxes we face as patients and providers in the epidemic.
Preventing the further spread of HIV infection in this country requires dramatic new initiatives in prevention and treatment of drug abuse. In 1989, 29 percent of people diagnosed with AIDS were infected through drug use, a 20 percent increase from the previous year. And more and more, experts fear that the next cohort of AIDS cases will occur among crack users whose sex and drug behavior put them at high risk of AIDS infection.

The same old approaches favored by politicians of both major parties have proven ineffective. As President Bush calls for increased federal spending for more police officers, jail cells, and judges, it has become clear that he is proposing not a war on drugs but a war on drug users. While proposing to lock up every drug user may make good politics, simple arithmetic shows the impossibility of this task. In New York City, for example, the New York State Division of Substance Abuse Services estimates there are 200,000 intravenous drug users and that 600,000 people have tried crack, a derivative of cocaine; perhaps half that number are regular crack users. Federal officials estimate there are half a million heroin users in the United States and about six million cocaine users. Locking up even a small fraction of drug users would bankrupt governments already in precarious financial health.

Democrats propose instead to spend more to add new treatment slots, a call that has been echoed in cities and states plagued by drugs. While treatment should be available to all addicts who want it, by itself this will not solve the problem. Most treatment programs are successful for only about a third of those who enter, and specialists have yet to develop treatments known to cure cocaine addiction. Most important, however, unless the addicts who have successfully completed treatment can go back to an environment that helps them stay off drugs, most become addicted again.

A Third Option

A third option, rarely supported by government, is to enlist grassroots organizations like soup kitchens, homeless, church groups, and block associations that already serve drug-plagued communities to play a stronger role in drug treatment and prevention.

Community organizations can help drug users in a number of ways. Currently, the addict can find drugs on any street corner, but information on treatment and referrals is much harder to obtain. The goal should be to make treatment easier to learn about and find than drugs. Community groups can play a much more active role in this than they do now. They can also help those who complete treatment to stay off drugs. In the South Bronx, for example, several programs offer free food to homeless people. Those who have drug problems are helped to find and enter treatment; afterwards they are offered temporary housing. Yet these programs can serve only a handful of those who need help. Most drug treatment specialists agree that family, peer, and community support for staying off drugs and having a job are critical for long-term abstinence. Community organizations can help in both these roles.

U.S. Secretary for Drug Policy William Bennett has correctly observed that school drug programs have had limited success in preventing substance abuse. But most of these programs have simply provided information on drugs or attempted to scare people off drugs, two strategies that health education researchers have demonstrated to be largely ineffective. Successful programs need to offer real alternatives to drug use, build peer support for abstinence, and develop social skills young people need to protect themselves against drugs.

Again, community organizations have much to offer young people. In the East New York section of Brooklyn, for example, the United Community Center has launched a Shield the Children campaign designed to protect children in this drug-ravaged neighborhood. The organizers are working to improve education, housing, and recreational programs so that young people have available activities not related to drugs and prospects for a future free of drugs or crime. Thousands of other community programs around the

Continued on p. 37
OMB Loses on Health and Safety Standard

After nine years of untrammeled growth in power and influence under Presidents Reagan and Bush, the Office of Management and Budget (OMB) has finally had its wings clipped. In a seven-to-two decision on February 20, the U.S. Supreme Court ruled that the OMB had overstepped its authority in blocking application of a key health and safety standard to the construction industry.

The Hazard Communication Standard, which requires that companies post warning labels on their products and provide health and safety information about them to workers on demand, has been at the center of political controversy since it was first proposed in 1980 by Eula Bingham, director of the Occupational Safety and Health Administration (OSHA), during the waning days of the Carter administration. The new Reagan administration quickly withdrew this important worker protection standard, reissuing it in weakened form and limiting it to manufacturing.

This arbitrary exclusion of workers outside manufacturing was challenged in 1983 in federal district court by a group of labor unions, including the United Auto Workers and United Steelworkers, as well as Public Citizen, a public interest group allied with Ralph Nader. The challenge won, and in 1987 OSHA revised the standard again to include virtually all workers under its jurisdiction.

But Reagan's functionaries would not let this victory for workers' protection lie. OMB came upon the scene and blocked application of the standard to the construction industry, based on the so-called Paperwork Reduction Act. Now, ten years after the Hazard Communication Standard was first promulgated, the Supreme Court has finally ruled that OMB had overstepped its authority in blocking this standard. While OMB has the power to regulate forms required by the government from private parties, it does not have the right, according to the Court, to regulate paperwork between private parties, such as information exchanged between employers and employees.

As part of the executive branch of government, OMB is accountable to neither Congress nor the public. It was thus a perfect vehicle for Reagan and his successor to attack the hard-won legislative gains of the occupational health and safety movement. While the Supreme Court has slammed the door on this intrusive agency this time, defenders of workers' health and safety will have to be on guard against similar sneak attacks in the future.

—David Kotechuck

Rationing the Irrational

Can rationing be made rational? That was the assignment given to a medical ethicist by public health officials in Alameda County, California, to deal with increasing strains on the budget, reports David Kirp in The Nation ("Rationing Life and Death," March 5, 1990).

Faced with shrinking state funds and growing use of public hospitals and clinics, public health providers in Alameda County (which includes Oakland and Berkeley) were forced to turn away poor people whose serious medical conditions would otherwise receive prompt attention. A man showed up in a public hospital emergency room with a blood pressure reading of 260/180 and difficulty breathing because a clinic was too busy to renew his prescription for medication. One uninsured woman was forced to wait for heart surgery until she was 65 and eligible for Medicare. By then, it was too late.

Triage incidents such as these convinced Dave Kears, director of the county public health agency, that the squeeze on funds for public health was already creating unplanned rationing of health services. He decided to make the implicit explicit by hiring medical ethicist John Golenski to compile a list of health services in order of importance. Golenski would work with discussion groups of consumers, health advocates, and health professionals to determine which services were most worthy of funding.

The 50 members of Golenski's discussion groups were ambivalent about their task. While recognizing the problems produced by a system of de facto rationing, they also were aware that their findings could be used to legitimize chronic underfunding. What's more, they were forced to
confront the real-life consequences of shifting dollars from one area of health care to another. Rational discussion deteriorated into fights over which of their various constituencies would win and which would lose.

In the end, the group took the only rational approach and declared that rationing a failing public health system was impossible and immoral. The project collapsed because it "started at the wrong end, with the foregone conclusion that rationing was best," according to Isaac Slaughter, director of the West Oakland Mental Health Clinic. The real task is to "deal with the front end of the problem," he said, "trying to make things less inadequate, not trying to ration inadequacy."

For health advocates working for more publicly accountable planning in their own communities, the lesson is a hard one. Despite the moral high ground taken by the rationing group, things haven't changed in Alameda County. The funding situation hasn't improved, difficult budget decisions still are being made administratively, and people still are going without needed care. In a country that spends more on health care than any other nation in the world, we still have gross inequities between the public and private health care sectors and a health care system that can't protect the public's health.—Cheryl Merzel

AIDS Watch, continued

country serve low-income young people and could help their constituents to find real alternatives to drugs.

A successful war on drugs requires creating the communities that can help addicts find treatment and stay off drugs and prevent others from beginning to use drugs. No drug czar in Washington can impose those values on a community, particularly on communities that are likely to distrust the motives of government. Instead, programs to fight drugs at the neighborhood level need to originate within the communities hardest hit by the drug epidemic. Community organizations, which have always struggled to improve living conditions in their area, know their constituents and have a credibility based on their record. Yet, ironically, these very programs that could help to counter the drug epidemic have been hardest hit by budget cuts at the city, state, and federal levels in the last ten years.

Community groups cannot take on this new task without additional resources. They need money to hire new staff, train existing workers, and set up housing, job training, and recreation programs. Funding such programs is not a substitute for developing new federal initiatives on employment, housing, and health care. But by beginning to give financial support to neighborhood groups, governments can help to sustain one of the most powerful antidotes to drug use: a strong and united community. Those who are serious about a war on drugs need to take some of the money intended for building new jails and spend it instead on a more effective, economical, and human strategy.□

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