Women and the Health Care System

The Casey Decision
Pregnancy Police
Reproductive Technology and Perfect Choice
Drug Treatment and Women
From its inception in 1968, the Health Policy Advisory Center—Health/PAC—has been a unique progressive voice on domestic and international health issues. Through the Health/PAC Bulletin and the books Prognosis Negative and The American Health Empire, as well as outreach to a national network of grassroots groups, Health/PAC continues to challenge a “medical-industrial complex” that has yet to provide decent, affordable care.

IN THIS ISSUE

Health is What Unites Us
Blythe Avery urges us to use the power of health issues to educate and organize ..... 5

Planned Parenthood v. Casey: Eroding Access to Reproductive Services
Marianne Lado considers the implications of the Casey decision 6

In Pursuit of Perfect Choice: Feminism and Reproductive Technology
Loretta Ross argues that instead of condemning reproductive technology, women should take control of it to expand their choices 8

When Pregnancy is a Crime
Jacqueline Berrien surveys the proliferating prosecutions of women for using drugs during pregnancy ........................................................... 12

Women and Children Last: Barriers to Drug Treatment for Women
LaRay Brown traces the bureaucratic maze women must negotiate to obtain drug treatment in New York City and describes a model treatment program 15

The Rural AIDS Front
Jena Heath reports on how rural clinics help those far from the urban epicenters of the AIDS epidemic .......................................................... 20

Integrating Paradigms: Teaching Traditional and Western Medicine with Guatemalan Refugees
Jamie Tessler recounts her work with rural health promoters in Guatemalan refugee camps ................................................................. 22

Media Scan
Ilene Winkler reviews Toxic Work, the story of women made sick by their jobs ..... 28

Occupational and Environmental Health
David Kotelchuck considers the possibilities for OSHA reform ........................................ 30

Peer Review ................................................................. 31

Vital Signs
Environment and breast cancer; women’s health legislation; needle exchange 32

Health Policy Advisory Center
47 West 14th Street, 3rd Floor, New York, New York 10011 (212) 627-1847
Health/PAC Bulletin
Volume 22, Number 2 Summer 1992


Executive Director Nancy McKenzie
Editor Ellen Bilofsky
Managing Editor Sharon Lerner
Researcher Martin Cozza

Women and the Health Care System

Women have a unique relationship to the health system. As patients, they require not only the general health care needed by any adult, man or woman, but also the specialized services related to their reproductive system. As workers in the health system, they make up 70 percent of the entire health labor force. As mothers, they are in most cases directly responsible for the day-to-day care of their children, including health care.

Health/PAC Bulletin, April 1972

In the 20 years since Health/PAC published this editorial, also entitled “Women and the Health Care System,” much has changed, and much remains the same. Women are still uniquely bound to the health care system. Whether or not they have or plan to have children, women are tied to the system by their reproductive functions; and, women’s reproductive cycles are being subjected to increasing medical intervention—warranted or not—as in the aggressive medical treatment of menopause and infertility. In addition, because of their roles as caretakers, women use the system of health care not only for their own health needs but also for those they are responsible for. At these points, then, women’s rights have been and continue to be vulnerable, as the articles in this issue show, because it is so much harder for women to walk away from health care, regardless of how poorly it meets these needs or how often it jeopardizes their rights and their dignity.

What has changed since 1972 is the growing impoverishment of women. “The feminization of poverty” became a slogan in the early 1980s, reflecting the fact that women and children represented two-thirds of the poor in the United States. Indeed, as Diana Pearce pointed out in her original 1978 essay, “The Feminization of Poverty: Women, Work, and Welfare,” being a woman is highly correlated with poverty and its collateral effects. Today, women and their children constitute 80 percent of poor people in this country, and over half of all poor families are headed by women. And as the ranks of the poor grow, many women to the ranks for whom the right to abortion has already been essentially denied, as Marianne Lado describes here in her analysis of the decision. The lack of facilities performing abortions and the cost of the procedure already vitiate this choice for many women, even where legal restrictions do not. One clinic in Louisiana, where a near-total ban on abortion is on legal hold, reports that so many women there think abortion is already illegal that they are coming in with complications resulting from self-induced abortions.

Coming as we put this issue on Women and the Health Care System to bed, the decision exemplifies what the articles in this issue describe: the punitive attitude toward women of the legal and health care systems, particularly poor women and women of color, who attempt to assert control over their lives and their bodies. It should also be noted that in upholding Roe, the Court reaffirmed “the state’s power to restrict abortion after fetal viability” and the state’s... (Continued on p. 35)
people of color continue to be hit hardest. Middle- and low-income Americans have suffered a real loss of income through increasing unemployment and lowering of real wages. According to the Center on Budget and Policy Priorities, for example, 18 percent of all full-time workers did not earn enough to raise their family’s income above poverty level in 1991, compared to 12 percent in 1979—a 50 percent increase in the number of full-time working people who are unable to escape poverty. Again, these changes have been especially devastating for families headed by women and particularly in African-American and Latino communities, where the median income is only one-half that of whites in the United States.

This feminization of poverty, needless to say, makes women’s access to health care more and more difficult at the same time that it increases the need—by creating conditions that prevent people from taking adequate care of themselves and increase illness. Then, as government programs have been dismantled (see “Shredding the Safety Net,” Summer 1991 issue), women also have substantially less access to institutional support, particularly health care, for themselves and for their children. Between 1980 and 1990, poor women have suffered reductions in federal funding that amount to:

- a 14% cut in maternal health benefits,
- a 40% cut in community clinics,
- a 35% cut in health benefits to children and the elderly,
- a 67% decrease in employment assistance,
- a 74% decrease in housing assistance,
- a 66% cut in Title X funds for contraceptive services (the only source of contraception for 83 percent of the clients of Title X clinics), and the cuts continue today. Moreover, there has been tremendous retrenchment in basic care for women and their children due to the overall lack of primary care services across the nation.

Thus, women and their children, already highly dependent on the health care system and forced by increasing poverty to rely on government support, have been affected most by the cuts in services. This, then, is the backdrop against which the mounting attacks on women’s reproductive rights, detailed in this issue, must be viewed. At the same time that government is curtailing

---

The Medicalization of the L.A. Uprising

In the aftermath of the Los Angeles uprising and at the request of the state of California, the Centers for Disease Control quietly sent in their experts in epidemiology, injury control, and statistics to investigate. Bob Howard, a spokesperson for the CDC admitted that this was the first time the agency had been involved in “urban unrest” (although since the CDC has just announced the formation of a National Center for Injury Prevention and Control, it will presumably be more involved in the future), but explained that the CDC “will analyze any sort of problem situation that has a significant impact on public health.” Given the definition of disease as “any condition or problem that has a significant impact on an organism,” he said, the situation in Los Angeles “could certainly be characterized as a disease or a factor.”

Without seeing the final report—the analysis of the data has just begun, and Howard could not comment on the details of the investigation because it is up to the state of California to make it public—the CDC is probably doing the right thing, albeit for the wrong reasons. They will be looking at “all the areas that might lead to the problem,” Mr. Howard said, including “housing, economics, and social problems that exist out there.” But why do we need a team of public health experts to tell us what we already know (and what the Kerner Commission already reported nearly 25 years ago)?

Why characterize the riots as a disease rather than an uprising or rebellion? The idea is that no one has to take responsibility for a disease. After watching Washington withhold the resources for the fight against AIDS, we know better. The decision not to attack the root causes of public health emergencies, the factors that encourage the spread of a disease, is a very political one, as Rodrick Wallace and Deborah Wallace showed in great detail in the Summer 1991 issue (“Contagious Urban Decay and the Collapse of Public Health”).

Poverty, racism, indifference, and capitalism can certainly be viewed as viruses, but if so, they are man(sic)-made. We must watch closely to see how the medical metaphor gets played out in the analysis of the L.A. uprising and other “urban unrest,” making sure that our demand is not just some “medicine” to make the patient feel a little better, but eradication of the causes of the “disease.”

—Ellen Bilofsky

Koreatown, Los Angeles, the morning after. Ravaged by disease?
the availability of contraceptive services, abortion, prenatal care, and drug treatment for women, for example, it is prosecuting pregnant drug users!

The nature of these attacks on women have also changed in the last 20 years. In 1972 women were in the process of redefining their rights and discarding traditional constraints, and the women’s health movement was delineating a more active role for women in taking control of their own care. As a result of these movements, women were only one year away from winning the right to abortion, originally conceived as simply one aspect of reproductive health care.

Today we are in the midst of backlash against feminism and on the verge of losing that right. Attacks on women, their reproductive rights, and their right to treatment have never been greater, as Marianne Lado, Jacqueline Berrien, and LaRay Brown show in this issue in their discussions of the threat to abortion, the elevation (Continued on p. 35)

---

**Health is What Unites Us**

*BYLYE AVERY*

The National Black Women’s Health Project came together in 1983, when we realized health promotion was not working for black women in the way that it was traditionally done. It’s not that health information is not good, and it’s not that people don’t have the information. It’s that there is no integration of the information, and most of it does not have an analysis that includes our perspective as black women. We came to understand that the approaches to health promotion that work have to have a specific perspective, and that perspective needs to come from the affected population.

Health educators who want to know about infant mortality should talk to women whose babies died. For those who want to know about teenage pregnancy, the experts to consult are those women and men who had babies as teenagers, not those of us who avoided it. We’re the experts on how you get through the teenage years without getting pregnant. That’s what we can talk about. But instead we get anointed as the experts, and we work on our own agenda, and it misses.

Health is not just about information. Health is about feelings. You can’t tell women all about breast cancer and not deal with their feelings about what has happened to them. We are afraid to deal with feelings because we’re supposed to be the health care professionals; we’re supposed to give the information, devoid of the feelings. But the information doesn’t make sense to people, because they’re thinking about their feelings. So the information is going in and laying there on top, and there is no integration.

And we can’t talk about health unless we’re going to be able to first deal with the physical danger and the violence that people experience in their lives. Any one of us could be killed just walking outside because somebody who doesn’t even know us is upset with somebody else. So we have to deal with violence. Sometimes I think those of us in health need to throw down everything and not deal with their feelings about what has happened to them. We are afraid to deal with violence. Sometimes I think those of us in health need to throw down everything and not deal with their feelings about what has happened to them. We are afraid to deal with violence. Sometimes I think those of us in health need to throw down everything and not deal with their feelings about what has happened to them.

We have to know how difficult it is before we talk about non-compliance. What a stupid word! There is a reason why people are not doing things, and it’s our job to get to that reason. It’s our job to develop our own agenda, and it misses.

We need to get creative, but in order to do that, we have to free our own minds to give ourselves permission and give permission to each other to be creative, to be out there, to unite.

But first of all we need to feel good about who we are. We have to know what we are about, because if we don’t, there is very little chance that we can help anybody else. When you’re telling people what to do, think about whether you can do it yourself. I’ll never forget the AIDS counselor who was trying to tell women they had to get their partners to wear condoms every time. The night she got ready to tell a man she was with that he had to put on a condom, her hands started sweating, sweat rolled down her legs, she opened her mouth, and nothing came out. Then she realized how difficult it is to do.

We have to know how difficult it is before we talk about non-compliance. What a stupid word! There is a reason why people are not doing things, and it’s our job to get to that reason. It’s our job to develop ourselves so that we use our relationship and our personal power to help with the empowerment of the individual. Empowered individuals build healthy, empowered communities.

But we don’t need missionaries working for us. We need the white sisters and brothers to work with poor white people so that they can learn how to work with their own diversity. All white people are not alike. And one thing the National Black Women’s Health Project has taught me is that there is no monolithic black woman. Some of us come with straight hair, some of us come with no hair, some of us come with dreadlocks, and we have to learn how to be together with each other. But most white people don’t know how to work with diversity, so that when they come to work with black people, they come with guilt, as missionaries, and we are not left empowered. So be in it for you.

We’ve got some serious problems in this country; we’ve got very confused priorities. I don’t know how national health care reform is going to happen without a revolution, because there are some powerful forces that don’t want anything to change. But things have to change, and we have a strong position. Health is what unites all of us. It is the thing that we all have in common, so it is a powerful tool to organize around. It is the most important thing.
Planned Parenthood v. Casey

Eroding Access to Reproductive Services

MARIANNE ENGELMAN LADO

Marianne Lado’s analysis of Planned Parenthood v. Casey, essentially completed before the decision was handed down on June 29, proved prophetic. In it she explains how, while appearing to uphold the standards established in Roe v. Wade, the Supreme Court has taken a giant step backwards, eroding the already threatened reproductive rights of women, especially poor women and women of color, still further.

On June 29, 1992, the United States Supreme Court announced its decision in Planned Parenthood v. Casey. By a narrow majority of five to four, the Court declined the Bush administration’s invitation to withdraw constitutional protection of a woman’s right to decide whether to terminate her pregnancy, protection that was guaranteed in Roe v. Wade. Although a majority of the Court refused to overturn Roe expressly, neither the substance of the Court’s ruling nor the narrow majority by which Roe was affirmed bode well for the future of the right to abortion generally, or the prospects for access to reproductive health services, particularly for the poor. Indeed, the Court’s approval of the many restrictions at issue in Casey, with the exception of a spousal notification requirement that the Court rejected, is a dramatic departure from Roe and its progeny.

In its historic 1973 ruling in Roe v. Wade, the U.S. Supreme Court recognized that the right to privacy “is broad enough to encompass a woman’s decision whether or not to terminate her pregnancy.” In Roe and subsequent cases, the Court established the limits of state authority to regulate the performance of abortions and announced strict standards of review by which state restrictions of abortion services were to be adjudged. Over the past decade, however, the Supreme Court has increasingly turned its back on the central holding of Roe v. Wade. Today, the future of the right to abortion remains in grave peril.

At first blush, Planned Parenthood of Southeastern Pennsylvania v. Casey appeared to raise a narrow set of issues about the validity of particular provisions of the Pennsylvania Abortion Control Act, provisions that require physicians to give specified information to women who are deciding whether to have an abortion and that mandate a 24-hour waiting period, parental consent, and spousal notification before the performance of an abortion. In fact, however, as lawyers for the American Civil Liberties Union Reproductive Freedom Project reminded the Court, in earlier cases, for example City of Akron v. Akron Center for Reproductive Health, the Court had already declared similar restrictions unconstitutional. The Supreme Court’s reconsideration of the validity of such provisions reflected the continued interest shown by some of the justices in the Webster decision in eroding judicial protection of the right to abortion and in retreating from Roe v. Wade altogether. With Casey, the Court was once again faced squarely with the question, does a woman have the right to decide whether to terminate her pregnancy?

Illusory Rights

While the impact of a decision to overturn Roe would have been far-reaching, for many the right to abortion is already illusory. Poor women lack access to quality health care services that more affluent American take for granted. Low-income communities have few health care providers, and poor women are already forced to wait long hours in overcrowded clinics and emergency rooms and to travel at great expense for needed services. Financial barriers, particularly inadequate insurance coverage and limited personal funds, are the most important obstacles to obtaining care among women receiving insufficient health care. Indeed, simply paying for the abortion procedure itself entails serious hardship for indigent women who, in order to exercise their right to abortion, must often let bills go unpaid or buy fewer necessities, such as food and clothing. Today poor women, and a disproportionately high number of women of color, are often unable to share in the freedom of personal choice in matters of reproduction guaranteed by Roe.
Nevertheless, the significance of the Court’s decision should not be underestimated. Four members of the Court voted to abandon Roe altogether, a decision that would have removed all federal protection of a woman’s right to abortion and consigned the future of the availability of reproductive services to the vagaries of the political process in each of the 50 states and U.S. territories. Moreover, since provisions similar to those at issue in Casey had previously been ruled unconstitutional, the decision to uphold Pennsylvania’s restrictions signals retreat. The Court adopted a standard developed by Justice O’Connor in Akron Center that will permit states to regulate abortions unless the restrictions “unduly burden” the right to seek an abortion. Although Justice O’Connor argued forcefully that the Court should not explicitly overrule Roe, the undue burden standard rejects the greater protection Roe afforded a woman’s right to choose at early stages of pregnancy and replaces strict standards of judicial review with a vaguer balancing of the woman’s and the state’s interests. Indeed, according to this standard, the Court would view as substantial the state’s interest in the protection of potential life from the moment of conception, and might allow most restrictions short of an absolute bar on abortion. The undue burden test requires that courts determine which restrictions place a substantial obstacle in the path of a woman seeking to terminate her pregnancy.

With judicial protection of the right to abortion eroded in this manner and states allowed to impose increasingly stringent and burdensome requirements, the door is continuing to close on access to reproductive services. The impact will be particularly devastating for poor women and women of color, who often lack the economic resources to overcome barriers of cost, availability, and delay that are imposed or generated by state regulations. Significantly, only 13 states permit the use of state funds for medically necessary abortions. In 1969, fully 75 percent of all the women who died of illegal abortions were women of color, and from 1972 to 1974, the rate of mortality from illegal abortions for women of color was 12 times greater than that of white women. Even after legalization, high numbers of poor women of color were still precluded from obtaining safe and legal abortions. As a result, more than two-thirds of the deaths associated with early abortions in 1975 were of women of color.

For many poor women, the obstacles caused by the restrictions such as those in the Pennsylvania law will be not only burdensome, but insurmountable. The act requires women to delay treatment, to undertake multiple efforts to obtain care, and to overcome other psychological and procedural obstacles, for example, to obtain parental consent. Unless and until the Court truly reaffirms Roe v. Wade and its high level of judicial protection against intrusion on the right to abortion, and once again finds such restrictions unconstitutional, this nation can expect to experience the devastating effects of greater governmental interference with the availability of reproductive services for poor women and to see the reemergence of appalling disparity in mortality rates along racial and economic lines.

In Pursuit of Perfect Choice
Feminism and Reproductive Technology

LORETTA ROSS

It is up to science to meet the demands of humanity...that life shall be given "frankly, gaily" or not at all....Which shall it be?

Stella Browne, 1922

These words spoken 70 years ago not only described the demand for birth control in the first wave of the reproductive technology movement started by Margaret Sanger, but also speak to today's social and scientific dilemmas that still make it difficult for women to give life "frankly, gaily" or not at all. Paradoxically, the scientific technology to advance women's reproductive freedom is moving forward, while the social construct in which this freedom is exercised is moving backwards. Our technology allows greater control over our reproduction, but our society places increasing restrictions on our ability to use this technology.

As a woman of color who has been in the reproductive health movement for over 20 years, I have joyfully witnessed the strong emergence of women of color reproductive rights activists in the last two decades, but particularly since the alarm bell went off in the wake of the 1989 Webster decision. Thousands of women of color are now active in the reproductive freedom movement, which is undergoing its greatest democratization in history. The problem, however, is that we who are women of color, we who are poor, we who are differently abled are just now entering the reproductive health rights debate in significant numbers. In a sense we are 20 years behind. We are fighting to defend abortion rights and reduce infant mortality, battles that should have been over years ago. At the same time, many forms of reproductive technology have left us at the starting gate, creating a sort of time warp. While we are debating whether we are pro-choice, anti-choice, whether we will work with white women or not, reproductive technologies are being legislated, regulated, and implemented, often with disastrous consequences for our bodies. Our social discourse has not caught up with our scientific abilities.

Reproductive rights is ultimately about choice for women, about women's rights to make their own decisions, to take their own risks in order to get what they want, in order to make their lives a little bit better, no matter how wide or limited those choices are. Like it or not, women will use whatever technology is available to us as we make our reproductive decisions.

Perfect Choice

Our role in the feminist and scientific communities is to extend the boundaries of what is available to women, to make the choices as safe as is technologically possible, and to support a woman's right to make the decisions she must make for her life. That is very difficult for many of us so-called experts to accept, because we're trained in this society to think we have the information, the right, and the expertise to make choices for women and suppress their ability to make the choices for themselves. Our task, instead, as feminist health advocates, is to pursue the idea of "perfect choice" for women, a concept in stark contrast to the decidedly imperfect social and scientific choices we have today.

Perfect choice is the right to have the knowledge and means to make the choices that make sense to us.

What some might view as an impossibility, perfect choice is the right to have the knowledge and means to make the choices that make sense to us. Perfect choice involves access not only to abortion, but to prenatal care, quality sex education, contraceptives, maternal, infant, and child health services, housing, and reform of the health care delivery system.

For example, we expect science to provide us with contraceptive choices. At the same time, we demand that the pursuit of pharmaceutical profits will not again cause us to be human guinea pigs in experimental innovations in reproductive options, as has happened before. We do not unrealistically expect a perfect contraceptive that defies human error, unforeseen circumstances, or medical risks. However, reproductive technologies must be socially perfect: we demand to be in control of our own

Loretta Ross is program director of the Center for Democratic Renewal in Atlanta, GA, a national anti-Ku Klux Klan organization. This is a revised version of a presentation given at the Health/PAC forum on Women and Health at the American Public Health Association Annual meeting, Atlanta, November 11, 1991.
bodies using the best technology available, without limits because of income, race, physical abilities, or sexual preference. We, not doctors, courts, or pharmaceutical companies, should decide if and when we have children.

When perfect choices do not exist, women adapt themselves to whatever is available. Women often beg for sterilization when that is the only way, other than abstinence, to control their fertility. As feminists, we know that if abortion is recriminalized, then women will again resort to self-induced abortions, some using life-threatening methods limited only by their imagination and physiology. Desperate women will use desperate means, including infanticide and suicide.

When Science and Feminism Collide

We have the technology to meet women's needs, and we are developing more every day. What we lack is the social agreement that this technology should be available and accessible to all women. Even more problematic, even feminists and scientists who agree that reproductive freedom is a desired social value, disagree sharply on how this should be achieved. Reproductive technology has the capacity to both assist and abuse women at the same time, and this is where the feminist movement and the scientific communities collide.

Feminists are accused of politicizing the research process, as if it is not already political in and of itself.

The reproductive technology movement was the vehicle through which the feminist movement saw some of its earliest empowerment. The invention of the birth control pill freed up women's choices, freed up the debate about women being locked into child bearing by their biology, and gave women choices about their lives.

Now we have a collision between the scientific revolution and the feminist revolution in reproductive technology. What scientists advocate as possible and desirable may be refused by feminists as being unsafe and therefore undesirable, like the injectible contraceptive Depo-Provera. How we manage this collision will largely determine the reproductive choices women have well into the 21st century.

Many feminists understand that reproductive technology is not produced in a political vacuum. In fact, it is very political, despite the alleged objectivity of the scientific community. What technology is produced, for whom it's produced, who has access to it, whom it is forced upon, are all political questions. What feminists demand is an open, acknowledged politicization of the research process that incorporates the politics of the women's movement—the production of technology that is woman centered and woman controlled. Yet when we demand this shift in the approach to reproductive technology, feminists are accused of politicizing the research process, as if the process is not already political in and of itself.

The role of the scientific community in politicizing the reproductive research process can be characterized by the trend toward more sophisticated, high-tech options for both controlling and increasing fertility, in contrast with the feminist health movement's trend toward safer and, in some ways, more conservative approaches that are woman centered and woman controlled. For example, many feminists want more research into barrier methods of birth control, such as condoms, sponges, and diaphragms, while the scientific community prefers investments into more invasive hormonal devices, such as injectibles and subdermals, which are doctor controlled and
A doctor prepares a woman's arm for the insertion of six tubes of Norplant.

doctor dependent. This tension between the two movements is balanced upon our politics, our legal system, our ethical values, and our scientific, educational, and religious institutions, all of which politicize the process of developing reproductive options.

Anti-Abuse, Not Anti-Technology

As feminist health advocates, we understand and are wary of the negative effects of abusive medical technology. As a society, we would not even be talking about the rights of patients if it weren’t for the feminist women’s health movement. This was an idea that gained popular acceptance because the feminist health movement brought to light problems like the defective Dalkon Shield IUD and forced sterilizations. We educated ourselves and other women about our right to question physicians about what they were doing to our bodies. “What drug is this you’re giving me? What will it do? What are the side effects?” became common questions in every doctor’s office as people in our society became more informed health consumers.

Because of our vigilance in guarding against medical abuses, feminists are wrongly portrayed as being “anti-technology.” A more accurate description would be to say that we are against bad technology that harms women, and we are against the abuse of good technology. For example, the contraceptive implant Norplant is the first new birth control offered to American women in 25 years and, as such, is a welcome development, because our contraceptive choices are too few. However, within a year of its introduction, an African-American woman in California was forced by a judge—obviously forgetting that he was a judge, not a doctor—to accept temporary sterilization with Norplant as a condition of her parole. What also scares me about Norplant, a birth control technology that I otherwise support, is that the physician has the power to determine whether or not it will be removed. This power is subject to some of the most abusive and racist assumptions promoted by our society. This technology is not woman controlled or woman centered. It is practitioner controlled and practitioner centered and demonstrates how a relatively safe technological development can be abused.

Most of the reproductive technologies on the horizon have not been adequately addressed by the feminist health movement, although we have valiantly tried to keep up. Our caution and advocacy has kept some unsafe injectable technologies out of mass markets, although some Native American women report that Depo Provera is being used quite recklessly on reservations without any warning of the potential health risks.

Because of the highly charged controversy surrounding RU-486, many of its advocates are intolerant of women who offer a critique of the abortion-inducing pills. Objections are raised, however, not because we oppose abortion. Rather, we are, again, concerned about a technology that is practitioner dependent and has not been sufficiently studied to determine its impact on diverse populations, such as women who are over 150 pounds in weight. Similarly, women who already have inadequate health care face sharply increased risks if reliance is placed on a technology that requires multiple, and frequently expensive, visits to a doctor. We as feminists must be able to face up to these concerns and discuss them in concert with the scientific community that produces these technologies.

Women are forced by economics and deprivation to become breeders for an owning class of people.

This will require evaluating reproductive technologies from a different perspective. Both the feminist and the scientific communities agree that women deserve and need more reproductive options. The essential difference hinges on the question of safety and who decides what is an acceptable risk. It is clear that the more invasive hormonal devices and methods of birth control and infertility reduction will always carry certain risks. For some women these risks will be worth taking because they are offset by significant benefits. But women themselves, not their doctors or research scientists, must weigh the risks and benefits. One cannot prejudge what is good and what is bad for an individual woman. All one can do is give her the options and hope that she selects the option that is right for her. One must also support her decision to use the option you would not have chosen because, in fact, it is her choice, it is her body, it is her right.

10 Health/PAC Bulletin Summer 1992
A significant part of the controversy over reproductive technology revolves around high-tech solutions for infertility, such as in vitro fertilization and surrogate motherhood. Scientific solutions fail to address the social problems of who has access to this technology. Whose problem does it solve? Why do infertile people feel they must have children this way?

In the surrogacy situation, we are seeing Brave New World meet The Handmaid’s Tale, as women are forced by economics and deprivation to become breeders for an owning class of people. When Anna Johnson, an African-American woman in California became a surrogate mother for a white couple for $10,000, I, along with many of my feminist colleagues, was saddened by the social situation that allows such a distortion of motherhood to exist. When the woman had the baby and then decided to fight for legal custody of the child she birthed, I felt even sadder, because even without knowing her or knowing any of the facts in the case, I knew that no court in America would give a white baby to a black mother. We in the feminist and scientific communities have to anticipate that these dreadful situations will occur again and again. We may decry women who choose to become surrogates because of economic deprivation, but we have to support them as they do so, creating great conflicts with our feminist values. At the same time, we must urge the scientific community to invest in research to prevent infertility, rather than in risky and questionable solutions after the fact.

We have to also support the privileged women who are so desperate that they would use what I consider to be such an obscene method of getting a child. There is an underlying desperation that is not addressed by our society that forces someone to make that choice.

Other reproductive technologies requiring our immediate attention that have been underway for nearly a decade are genetic screening, intrauterine intervention, and genetic manipulation. These technologies are subject to much debate within the feminist health community, but our concerns have centered mostly on issues of accessibility rather than ethical issues raised by such technology. With the exception of a prophetic project organized by Rutgers Law School five years ago to examine reproductive technologies, the primary concern has been, quite naturally, preservation of the legal right to abortion and its technology. My fear is that once again the technology and the research will have passed us by while we are forced to defend the minimal gains of the 1970s.

Complicating the situation is the current economic crisis in the United States, which affects the decisions made by developers of reproductive technology. The economy stratifies who has access to this technology and its degree of safety for different classes of women. Also of tremendous concern is the reemergence of neo-Malthusians who again predict that a population time bomb will strain the earth’s environmental resources. These population control advocates argue that eliminating poor people will eradicate poverty and save the environment. They want doctor-controlled birth control so that women have little individual control over their reproduction. Feminists counter that it is not the number of people on the planet that is the problem, even in the developing countries. The problem is that a minority of people, mostly in the developed nations, are consuming a disproportionate amount of the world’s resources, leading to environmental degradation.

**Vision**

We must evaluate reproductive technologies from a different perspective as we conclude this decade and century. Women deserve safer technologies and more options. Pharmaceutical companies desire and maybe even deserve bigger markets and less liability, if they are doing appropriate research and development. Scientists want and deserve more research opportunities and more understanding by health advocates of research techniques and risks. We have to build an atmosphere of cooperation among all of these groups. That is how we can make sure that women have the choices they need and the information about safety and risks they require to make fully informed decisions.

It is necessary to hold out for ourselves a vision of what we want to create for women so that we end up where we want to be. For this, we must wrestle with concepts like “perfect choice” and counter those who say we ask for the impossible. I, for one, refuse to accept the assumption that technological advances and women’s rights are incompatible. It worked, for a time, with the birth control pill, and we must make it work again. I am encouraged by advances made by researchers who developed Norplant. Not only did they develop an effective contraceptive that expands women’s choice, but they consciously involved many women from the feminist health movement in the process. This was certainly a step in the right direction. We can only hope that it will not be the last, because life should be given “frankly and gaily” or not at all.
When Pregnancy is a Crime

JACQUELINE BERRIEN

It has been said that if you must hire a lawyer in order to obtain treatment from a doctor, then you’re in trouble. The corollary is that if you go to see a doctor and instead you meet the police, you’re in trouble. Both of these statements describe the experience of many women in the health care system faced with increasing efforts to exact punishment in response to their conduct during pregnancy. Confronted by cutbacks in abortion services, limited access to general health care, including prenatal care, and a woefully short supply of drug and alcohol treatment slots, drug- and alcohol-dependent women face the cruelest dilemmas in their efforts to obtain the most basic health care.

Drug-addicted pregnant women in particular are increasingly confronted by police and prosecutors when they seek health care. The situation these women face includes discriminatory denial of drug and alcohol treatment services on account of pregnancy; a dearth of treatment facilities available to the uninsured and underinsured; the inaccessibility of treatment, particularly for women who are responsible for the care of other children; limited scientific knowledge about the comparative risks and benefits of attempting chemically assisted forms of treatment during pregnancy; and the fact that many treatment modalities were developed with largely male addicted populations, and, as a result, very little is known about what really does—and does not—work for women. Finally, to the extent that we know what works for women, we’re not offering very much of it. For example, very few treatment programs exist that have attempted to deal effectively with women’s roles as providers for the care of children and other family members (see “Women and Children Last,” by LaRay Brown, p. 15). Until we address that problem, as well as expand treatment facilities generally to meet the need, we are facing an especially cruel situation when prosecutors pursue a policy of punishing women for being addicted and pregnant.

Prosecutions Proliferate

The phenomenon of punishing women on account of addiction, drug use, or alcohol use during pregnancy first emerged with any significance in the mid-1980s. That’s not to say that it never happened before. There were isolated attempts to prosecute women for some sort of drug-related activity during pregnancy, but the emergence of crack cocaine spawned a flurry of punitive responses around the country. We’ve now reached the point where prosecutions of drug-addicted or alcohol-dependent pregnant women have been initiated in over half the states. A few states have led the list—Florida and South Carolina are the most notable examples—but prosecutions are not a regional phenomena, and this is not a southern problem or a rural problem. It is everywhere, literally.

When the first of these cases appeared, many observers thought it would be a temporary or fleeting situation, that more humane responses would soon prevail, and people would ultimately realize that you don’t solve anything by locking women up. We were wrong, and the punitive efforts have proliferated across the country, emerging in rural areas and urban areas, recreated from prosecutor to prosecutor. In fact, we have been informed about several conventions of district attorneys featuring panels on how to bring cases of this kind. We’re finding that there are more, not fewer, cases being brought against drug-addicted or alcohol-dependent pregnant women and that they’re not abating.

The American Civil Liberties Union (ACLU) has been fighting this trend state by state, case by case. While we have been able to win battles, the war looms large. The successes that we’ve had have hinged primarily on one point: existing criminal laws were never meant to address this kind of behavior. When women are prosecuted on account of drug or alcohol use during pregnancy, the prosecutions have usually been brought under one of two theories. One has been that the women should be prosecuted for violating some sort of narcotics trafficking statute—the same laws that are used to address street pushers. An example of that was State of Florida v. Johnson, in which the prosecution argued that the woman’s drug use had violated a statute outlawing criminal delivery of narcotics, because the drug was delivered from her to the fetus in the seconds before the umbilical cord was clipped.

The other theory, as played out in State of Ohio v. Andrews, has been to proceed with charges based upon some sort of child abuse or child endangerment statute that prohibits endangering the life or threatening the safety of a child—thus defining the fetus as a child. With prosecutions based on either of these theories we’ve generally been able to get charges dismissed or to win, at least on appeal, because the laws were really not created or
intended to address the behavior of a pregnant woman toward the fetus.

But we’re now about to reach a second generation of cases on this issue, because legislators increasingly are revising the statutes to make it clear that they do intend to address behavior affecting the fetus in utero, that they do intend for the laws to address maternal conduct during pregnancy. We haven’t reached the point yet where we’ve had to challenge the constitutionality of one of these laws, but given the state of the law around abortion rights and reproductive rights generally and the impending threat that Roe v. Wade will be overturned by the Supreme Court, we’re not looking forward to it.

The attack on Roe dovetails with the trend of criminal prosecution of pregnant women. Put simply, if pregnancy is a criminal act for an addicted woman, and if abortion becomes criminal, what option will exist for a pregnant, drug-addicted woman? She can be arrested either way. As the prosecutions proceed, and as legislators go back to the drawing board to make their laws clearly apply to behavior during pregnancy, we must carefully monitor new developments and be mindful of novel approaches to penalize the conduct of women during pregnancy.

Civil Proceedings

There is another set of legal proceedings that may be less visible, but are far more common than the criminal prosecutions that typically draw the headlines. These are the civil proceedings resulting in termination of parental rights and, a related phenomenon in the criminal justice system, making plea bargains contingent upon women either giving up their children, at least for a period of court-ordered treatment, or in effect “consenting” to civil commitment to receive drug treatment. In at least one well-publicized California case, Darlene Johnson was told toward the end of her drug treatment that she would only be released if she would agree to have the contraceptive device Norplant implanted. In another case, United States v. Vaughn, a pregnant woman pleading guilty to second-degree theft was subjected to an extraordinarily lengthy jail term because the judge believed that, given her history of drug use, she should remain in jail for “a long enough term...to be sure she would not be released until her pregnancy was concluded.”

We thought people would realize that you don’t solve anything by locking women up. We were wrong.

As people who come into contact daily with the health system and with women in need of health services, we must be especially alert to these less visible threats to women’s liberty. Like criminal prosecutions of pregnant women, civil proceedings are often premised upon the idea that pregnant women who use drugs or alcohol deserve to be punished and are incompetent to direct their own reproductive lives. The results of family court proceedings and other confidential systems for responding to pregnant drug and alcohol users will rarely end up in a published legal opinion or national headline, but nevertheless may have the same effects of jeopardizing a woman’s liberty and health, by forcing her to choose between entering a health care system where her drug or alcohol use may be reported to law enforcement officials and forgoing treatment altogether to avoid those consequences.

Arguing for Alternatives

The threats to women’s freedom to make choices about their health have never been greater, and the need for involvement has never been more urgent. There is no greater moment for the voices of the health care community to be heard loudly, clearly, and in unison about the dangers of governmental intervention in these most
private matters and about the need for preserving the health care relationship inviolate from government interference.

**If pregnancy is a criminal act for an addicted woman, and if abortion becomes criminal, what option will exist for pregnant, drug-addicted women?**

We must not only join the front line attack, however, but also be very visible and very vocal in arguing for alternatives to the sorts of repressive and punitive public health policies that some states have adopted. South Carolina, for example, has a policy in which women reporting to a publicly funded clinic for prenatal care are required to sign a consent form agreeing, among other things, to allow urine testing for drugs and to allow reporting of those test results to the district attorney in the event that they fail to comply with any aspect of the treatment program, including missing prenatal care appointments.

Responsible public policy shaped and influenced by informed and caring health care providers can be offered as alternatives to such measures. For example, in the face of high infant mortality, Mississippi decided to funnel money into a more extensive prenatal care program. As might be expected, it produced tangible results: a decreased infant mortality rate, improved maternal health, improved neonatal health, and improved birth outcomes. These kinds of programs need to be held up as examples for legislators and policymakers, who seem unable to understand—or perhaps choose to ignore—other more humane, responsible, and sensible alternatives to the punitive measures that have been adopted.

New York City provides another model of more humane health policy decision making. At one point, New York City removed the children of women testing positive for drug use. However, over a period of two years, the city eventually abandoned its policy of automatically removing children and began to divert its resources to efforts to keep the family intact through the provision of counseling, drug treatment, and other services needed by family members when there is addiction in the family. There is still much to be done to make this policy a reality and provide sufficient treatment and other services to meet the needs of families, but because of the efforts of a number of concerned policymakers, health care providers, and social workers, the principal goal has become keeping the family together.

There is a great deal we must do to ward off the attacks on reproductive rights and women's liberties. Legal workers and health care workers must work together in creating humane alternatives to some of the punitive measures that have been adopted in our states or neighboring states. We must work together in resisting the threats to the rights of women who are simply seeking health care.

---

**Health/PAC Seminar Series Probes Pregnancy Police**

Health/PAC capped its successful seminar series at the New School for Social Research on June 24 with an all too timely discussion of the assault on women's rights. The three presentations highlighted attempts not only to blame but to prosecute the victim—attempts to control women by criminalization of their behavior while pregnant or ill. Dr. Wendy Chavkin of Beth Israel Medical Center and Columbia University School of Public Health and well-known researcher in the area of pregnancy and drug treatment, reviewed the recent history of prosecutions of pregnant drug users in the context of anti-abortion imagery that redefines the pregnant woman as adversary of the fetus.

A new and in some ways parallel trend described by Elizabeth Cooper, attorney with the American Civil Liberties Union AIDS Project, is the prosecution of HIV-positive individuals for transmitting the virus through consensual sex. In one particularly disturbing example, a woman, allegedly a sex worker, was prosecuted using the HIV test results of her newborn infant as proof that the mother was HIV-positive and had had unprotected sex.

Tynia Richard, attorney with the Planned Parenthood Federation of America, spoke about a number of actions showing the trend toward government invasion of women's private lives. She supplied a last-minute update on the *Planned Parenthood v. Casey* Supreme Court case and dissected the latest Bush administration interpretation of the so-called gag rule, in which doctors—but not nurses—in clinics receiving federal Title X funds are permitted to counsel women about abortions but cannot refer them to facilities that provide them. Ms. Richard also spoke about the challenge to coalition building as more women of color become involved in the reproductive rights movement, suggesting that "building an integrated movement requires a sharing of information, as well as control, acceptance of compromise, and acceptance of difference."

Previous seminars in the series dealt with "medical empires" today; the advent of Medicaid Managed Care in New York City; the national health care debate in the presidential election campaign; privatization of municipal hospitals; and the role of the economy in the new public health epidemics.

In addition to the second round of seminars next fall, a special series will focus on women and health. If you're not already on the mailing list, to receive notification of the meetings contact Regina Neal at (718) 633-6272.
Drug abuse often compounds the immense difficulties that the poor face in finding jobs, housing, child care, education, and health care. For many, drug abuse effectively precludes the constructive resolution of all other problems. Drug abuse has strained many already overburdened community institutions to the breaking point and destroyed the economic and social strengths of many neighborhoods. The effects of increasing drug and alcohol abuse among women is particularly devastating because of their pivotal position in both family and community structure in poor neighborhoods. Between 1970 and 1984, the number of Black and Hispanic families headed by women more than doubled. Among the poorest third of Black families, over 70 percent were headed by women in 1990.

Clearly, women’s drug and alcohol use devastates the women themselves, many already rendered physically and mentally vulnerable by the circumstances of poverty and lack of access to health care. The effects on their children are also tragic, both because they affect the health of the child-to-be at the prenatal level and because women, as the traditional caregivers, affect their children.

Yet, at the same time that women’s needs for mental health and drug treatment services are growing (see sidebar), existing public health systems are suffering cutbacks and dismantling. Moreover, the services that exist, particularly drug and alcohol treatment, are not designed to serve women and their children effectively.

Although much attention has been focused on the rise of crack cocaine use, alcoholism and alcohol use continue to be significant problems for women and their children. The combination of both alcohol and drug use or the use of many types of drugs at once poses particular problems for treatment providers. Moreover, chemical dependency is often accompanied by other significant mental health problems, further exacerbating women’s difficulties in obtaining the services they need to achieve relief and recovery.

In New York City, as elsewhere, the need for drug treatment far exceeds the resources available. The full
Women, Children, and Drug Use

- An estimated 500,000 children in New York State have parents who are drug users. Half the clients of residential drug treatment programs and two-thirds of methadone program clients have children.

- There were an estimated 10,000 drug-addicted mothers in New York City in 1991, a more than threefold increase since 1988.

- More than 90 percent of women who use drugs fail to get drug treatment before giving birth.

- There was an increase of 3,746 percent in substance abuse by pregnant women in New York City between 1980 and 1988, with increased use of cocaine a contributing factor.

- An estimated 1 in 60 newborns are infected with HIV in some areas of New York City, primarily as a result of maternal drug use.

- The number of women in prison New York State increased 59 percent from 1988 to 1989, largely as a result of drug abuse.

- The major cause of deaths among women ages 15 to 44 in New York City are drug abuse, AIDS, and homicide.

- Fetal alcohol syndrome occurs in approximately 1 in 400 live births in New York State. Another 2,000 children are born with alcohol-related birth defects each year. Fetal alcohol syndrome now leads Down’s syndrome and spina bifida as the country’s major cause of birth defects with associated mental retardation. Of the three, only fetal alcohol syndrome is totally preventable.

Obstacles to Treatment

Chemically dependent women who are trying to get help from public mental health programs, such as those provided by New York City’s Health and Hospitals Corporation, face basic and specific barriers to recovery due to the fragmentation and lack of coordination of services among provider agencies. In New York City, women must negotiate at least four different bureaucracies, since agencies for addictions treatment are separate from departments of child and family welfare, housing, and other entitlement services. Women face additional obstacles in dealing with the Department of Employment.

When a woman in New York City enters a residential treatment program, she often has no alternative but to place her children in foster care through the Child Welfare Administration (CWA) if she has no family to keep them. If she is in a day treatment program, she needs homemaker services, which are provided through CWA, but she often has no one to coordinate the provision of these services with her treatment or medical needs.

The Department of Welfare tries to coordinate housing and services for homeless women and their families through entitlement programs such as Aid to Families with Dependent Children (AFDC) and the Women, Infants and Children nutrition program (WIC). But here, as at every point in the bureaucratic maze, there is no coordination and no assistance provided in obtaining drug treatment services.

Even without the confusion and institutional barriers that women using public programs face, the treatment services offered by the City of New York suffer from a grave lack of readily available slots of every kind. Although there have been increases in funding within the last two years for the development of programs for women, particularly pregnant addicts, access to treatment remains difficult. There are virtually no treatment programs able to accommodate them as women with families, on either an inpatient or outpatient basis, and no comprehensive residential services for women that can include their partners, and their children. In New York City there are less than a handful of residential rehabilitation services for women and children—The United Bronx Parents’ La Casita and Odyssey House’s MABON may be the only existing examples.

Women’s attempts to obtain treatment can involve a choice between their own well-being and that of their children.
disregard for their family life and the often mandated placement of their children in foster care, their attempts to obtain treatment can involve a choice between their own well being and that of their children.

Women struggling to regain their children after losing them during drug treatment are viewed as "incompetent" and written off.

Once women participate in drug treatment and their children are placed in foster care, the women find little institutional support for their attempts at recovery. The child welfare system has no comprehensive plan or organizational structure for the stages of mental health recovery or recovery from drug dependency. For example, there are no protocols to deal with relapses into substance abuse, which are common. Because the rules are inflexible, a relapse causes the continued disruption of families as the family members and welfare and foster care agencies try to contend with the changing circumstances.

In addition, families are assigned to different workers within the Child Welfare Administration at different stages of intervention, further contributing to fragmented casework planning. The system also fails to provide intensive therapeutic services to women who are trying to regain custody of their children. Foster care workers generally do not have time to do the intensive therapy work that is needed, and social workers, working with preventive services and boarder babies, focus primarily on providing treatment for women who have not yet lost their children. Women struggling to regain their children after losing them during drug treatment are mostly viewed as "incompetent" by the system and written off.

Mothers seeking treatment avoid the foster care system as much as possible. They rely on family and friends to take care of their children, if they are not mandated by law to use foster care. But placement of children with relatives can promote intergenerational, financial, and emotional conflicts that can undermine the mother’s authority and exacerbate the stress of her recovery, and thus serve as a disincentive to continue treatment. While extended family placements are often helpful and sometimes essential, they are also made difficult because support benefits are greater for children in foster care than on welfare.

Women who are homeless have an additional layer of bureaucratic difficulty. Residential treatment programs are not coordinated with permanent housing options for those who are homeless, and after treatment these women are thrown back into situations that invite relapse or may prevent treatment in the first place. Women with their children in the shelter system must confront pervasive drug use there. Yet, if they choose to enter treatment, placing their children in foster care, they face a Catch-22 situation. Once they leave the shelter system for any reason, even to enter drug or mental health treatment, they forfeit their place on the long waiting lists for housing and must start all over again, which may mean months or a year more wait to obtain an apartment. And, once they leave residential treatment, having placed their children in foster care, they cannot get them back again, because they have no permanent housing. Moreover, because the women do not have current custody of their children, the housing agency gives them lower priority for permanent housing. This is true for women who are mandated to place their children, as well as for those who do so voluntarily. This Catch-22 situation would frustrate and demoralize the strongest of people. Those who are poor, without community or family support, and in need of treatment can easily lose the ability to persevere.

Much of this difficulty could be avoided if there were adequate numbers of publicly subsidized child care arrangements and slots in most drug treatment or preventive service agencies. Specialized care for medically fragile newborns is especially needed. Ideally, these child care services would be designed as a comprehensive parenting program within each drug treatment setting.

Besides the insuperable obstacles to treatment, to continued custody of their children, and to permanent housing, women who have drug and mental health treatment needs also face considerable difficulties in getting benefits from entitlement programs, such as welfare and WIC. These programs are often unavailable to women and their newborns during the medically critical first months after birth due to perpetual delays in the opening of new cases, often caused by the slow acquisition of vital documents.

For women in day treatment, homemaker services, like child care, are essential. Such services are not easy to obtain and are often withdrawn after six months, at a time when most women are in very early and fragile stages of sobriety. (Drug users often need a full 18 months of rehabilitation in order to avoid relapse.)

As a final obstacle and indignity, federal welfare policy discourages—if not prohibits outright—women in recovery from applying to long-term educational and vocational programs following treatment by threatening to close a recipient’s case, reduce their benefits allocations, or withdraw support services altogether if they apply for additional help from such programs. This avenue closed, women are forced to accept coercive work incentive programs that offer few long-term opportunities for economic independence and low wages that maintain the women in poverty.

Comprehensive Services

Women who depend on the public mental health system for help with substance abuse need a complete range of treatment, health, and social support services. A woman must not be forced to choose between separation from her children and treatment. Services must be developed that focus on women, their children, and their partners, treating all these individuals simultaneously.

Program models must be assessed by their impact on two key areas: family cohesion and the long-term economic stability of program participants. Recovery is a process of empowerment, based on long-term development and self-awareness, with the goal of individual autonomy. Self-sufficiency is critical to long-term sobriety.
Community-based centers or consortia of providers designed to provide a complete package of necessary support services for women in a central location must be funded and implemented. These centers or consortia should combine drug and alcohol treatment for women, as well as other mental health services, with support services ranging from housing, to job training and skills, primary health care, and child care services. At the same time, the program must work with the women’s children, providing necessary educational, developmental, health, and preventive services. Such a comprehensive treatment program would offer a continuum of treatment, with the following specific components:

**Intensive Residential Treatment.** Many women in the early stages of withdrawal from addiction need to begin treatment in intensive treatment programs especially designed to meet their needs. The program should consist of highly structured drug and alcohol abuse treatment services that concentrate on overcoming the addiction. Daily activities should center on group and individual therapy. Support and direction from peers is a key component of successful residential treatment programs, with women assuming greater responsibility as they progress through the program. Thus, a specific focus on women who are pregnant or have children is essential in encouraging their recovery.

Children who have a parent who abuses drugs and alcohol often have not had the attention and care that is necessary for healthy development. Because women in treatment need to focus on overcoming their own addiction, much of the initial care of the children will need to be provided by care givers in the residential program. Services that should be available for children include individual assessment, child care, specialized nurseries, recreation, and age-appropriate prevention and treatment (when appropriate) to deter substance abuse later in life.

Poor health usually accompanies substance abuse. Pregnant women who are drug and alcohol users present particularly difficult medical problems at a time when even healthy women can have trouble getting adequate obstetrical care. Medical services are a necessary component of the program for both women and children. Needed services range from well child care to emergency services. Health services should be provided on site where possible, and the program must establish connections to services provided in the community when more intensive medical services are required.

**Supportive Living Facilities.** A supervised residence for women and their children should be available as an alternative level of care for women who graduate from intensive residential treatment so that they may continue their progress toward independence or for women who do not need intensive treatment services but are not ready to leave a supported community. This component in the continuum of treatment should begin to focus on the family’s life after treatment to promote adjustment to a drug-free life-style.

Recovery is a process of empowerment, based on long-term development and self-awareness, with the goal of individual autonomy.

In this stage of treatment, women would choose to receive drug counseling and begin to develop skills that will enable them to maintain a self-sufficient family. For example, women might participate in appropriate educational and vocational programs so that they could apply for and maintain steady employment. As they progress, women would assume increasing responsibility for the care of their children.
With the continued support and guidance of program staff, women would then develop a discharge plan for themselves and their family to provide for a smooth and successful transition to the next stage of treatment and beyond to independent living within the community. The discharge plan should integrate the concept of case management to ensure that the women and their families are connected with support services outside the treatment program. Services available to residents of the supportive living facilities would include:

- In-house drug treatment services, including individual and group counseling and HIV prevention and education services.
- Day care, recreation, family counseling, and support services for the children.
- Case management, to begin to link women to services in the community.
- Health care for both women and children, similar to that provided in the intensive residential treatment component.
- Vocational and employment services and education.
- Life skills training, including stress management, household management, money management, and the development of parenting skills.
- Discharge planning.
- Mutual self-help and peer support.

Although most of these services should be provided on site, some could be made available near the residential facility. They must be guaranteed, however, and coordinated through individual case management on behalf of each woman and her children.

**Independent Apartments.** Another level of care may be needed in some communities to continue the process of helping the reunited family unit make the transition to total independence.

At the independent apartment stage of the treatment continuum, services would be designed to make independent living possible and successful. Women would live in an apartment and assume primary responsibility for caring for their children and maintaining the household. Apartments should be clustered to allow peer support. Treatment staff would no longer be on site 24 hours a day, but many support services would remain available.

Program staff should make frequent visits, and case management staff would ensure continued connection to social, vocational, and educational services and outpatient drug and alcohol abuse treatment. Homemaker services and child care are provided so that women could go to school, work, or community programs. Children would continue to receive counseling and participate in age-appropriate educational and recreational programs.

Before the women graduate to truly independent living, staff would work with each woman and her children to develop a comprehensive discharge plan to ensure that arrangements were made for permanent housing and community services, including enhanced outpatient services.

**Permanent Housing.** As part of the discharge-planning process, the program’s case managers, working with state and local housing and social service agencies, would assist families in obtaining permanent housing. Once in permanent housing, the families would continue to receive enhanced outpatient and case management services determined by the family’s needs.

**Enhanced Outpatient Slots.** As part of the effort to provide continued care and treatment in the community, the program must provide outpatient services that meet the particular needs of women who are pregnant or have children. Enhanced outpatient services should include child care, specialized nurseries for children, and case management to ensure women’s access to health, social support, educational, and vocational services.

These enhanced outpatient services should also be available to women in the community who need support and treatment but do not require residential intervention. Reaching women before they require residential treatment is cost-effective and allows the family to maintain ties to the community and support networks.

**Outreach Services.** Community outreach services should be available to identify and reach women and children in need of the services because of emergencies or relapse.

The development of a comprehensive treatment continuum for chemically dependent women in family support communities will eliminate existing barriers to treatment, reduce the number of children placed in foster care, and provide a cost-effective means of keeping families together. By adding new components to treatment and coordinating other support services needed by these families, the public mental health and drug treatment systems will be more effective in assisting this high-risk population.

The goal of the public system should be to make treatment available to all those who need it and, through active outreach efforts, to increase the number of substance abusers who seek help. Limited resources necessitate hard choices about who is to receive treatment and how that treatment is to be provided, but women deserve priority and comprehensive attention.

Pregnant substance abusers desperately need prenatal care and are often motivated to accept treatment to improve the health of their babies. Mothers at risk of losing custody of their children are similarly motivated. Women should have the opportunity to be treated, to reach their full potential, to keep their families intact, and to protect their children from addiction, HIV infection, and developmental impairments. The destruction of the health and lives of babies and children by their mothers’ drug use represents an unacceptable cost in terms of medical care, foster care, special education, and long-term social problems.
The Rural AIDS Front

JENA HEATH

Betty C. boarded a bus and headed 60 miles west to Birmingham many times in the year before Alabama’s first rural AIDS clinic opened. “I missed a lot of appointments,” the mother of three said, “because I couldn’t get there.” During that year, Betty developed pneumocystis pneumonia. With children at home, no reliable car, and no way of affording one on her $3.95-an-hour laundromat wage, Betty C. was simply unable to obtain the consistent care that could have helped prevent the pneumonia.

Some of her problems were solved in December 1990, when the nation’s fourth rural AIDS clinic, AIDS through Support and Knowledge (ASK), opened in northeast Alabama. Three years after she had tested positive for HIV, Betty C. became the clinic’s first patient, finally receiving regular care from a doctor familiar with AIDS.

According to the Centers for Disease Control, this state of 4 million farmers, loggers, manual laborers, textile workers, and military dependents had 374 cases of AIDS in 1991, a 58 percent increase over 1990. These numbers will not startle urban health care workers who have battled hundreds of thousands of AIDS cases for 11 years now, but state health officials here are alarmed. The disease is growing faster in Alabama than in any other state with 50 or more AIDS cases.

In Calhoun County, home to ASK, and the 10 counties surrounding it, the increase was even higher—62 percent. In the first six weeks of 1991, 14 new cases were reported in this tiny region, nearly as many as in all of 1990. Heterosexual transmission was the attributed cause in 11 percent of Alabama’s AIDS cases last year, compared to 5 percent nationally.

Despite the numbers, there is little national awareness of the particular problems facing patients and health care professionals confronting the disease in rural settings and therefore little funding targeted toward them. “People with HIV here are extremely handicapped because of the lack of facilities,” says Dr. Paul White, Jr., who runs the Rural HIV Clinic in Albany, Georgia. “There’s a desperate need to develop a rural HIV model for the simple reason that all the resources have gone to large metropolitan areas.”

White’s clinic, which he proposes as such a rural model, provides outpatient services to people referred by private physicians and health departments in the area. In a joint management approach already in use in rural areas for other diseases, patients remain in the care of their own doctors, but receive management and treatment for their AIDS-related complications at the clinic.

Both White and Dr. Barbara Hanna, the primary care physician for all 100 patients at ASK, say treating AIDS in rural areas is complicated by several factors, not least among them the distances patients have to travel. “We have indigent patients with no transportation,” White says. “We are trying to deliver care over thinly populated areas where just getting to treatment can be an obstacle. Urban areas have local transportation. We serve a 6,000-square-mile area.”

Hanna says educating Alabamians about the disease is complicated by extreme homophobia. Despite the now well-reported dangers to heterosexuals, many people here in the Bible Belt persist in seeing AIDS as the sinful result of a sinful lifestyle. Many gays in small towns must still maintain almost entirely closeted lives. Others simply leave.

Rural Face of AIDS

The face of AIDS is different in rural settings than in cities such as New Orleans, where Hanna worked previously. “The numbers of women are increasing, but they’ve always been higher in women in Alabama,” she

Debra Wade, ASK executive director, at the clinic in Hobson, Alabama.

Jena Heath is a reporter for the Anniston Star, a 33,000-circulation daily in Anniston, Alabama.
Homophobia and fundamentalism complicate the problem of AIDS education in Alabama.

says, "It's been more of a heterosexual problem here than in the country as a whole, and I think that may have to do with the fact that we don't seem to have large metropolitan areas that attract gays. At the same time, we have a very uneducated, lower socioeconomic population where illiteracy, unstable homes, and drug use are common."

Indeed, the crack epidemic has not left rural America untouched. White blames the drug for much of the heterosexual transmission he sees in his 14-county health district in southwest Georgia.

There are other similarities between AIDS in rural and urban America. Hanna's patients in Alabama come down with the same opportunistic infections as the people she saw in New Orleans did. "The disease is the same," she says. It kind of spooks you sometimes because it is so patterned. It is the reactions to it and the knowledge that are different." However, Hanna has not as yet seen the dramatic outbreak of drug-resistant tuberculosis that her urban colleagues are fighting. ASK has had only two TB cases, and they were treatable. Georgia has reported only four cases of drug-resistant TB, White says.

Also, as in the cities, funding to keep fighting the epidemic is hard to come by—indeed, even harder than it is in the cities. Like White's Georgia clinic, ASK survives primarily on Ryan White grant dollars from the U.S. Department of Health and Human Services. The clinic received $278,000 in Ryan White money last year and has managed to scrape together $53,000 in matching funds. ASK also got a $10,000 donation from the rock group the Grateful Dead. The clinic treats mostly indigent patients. Sixty percent have no medical insurance at all. Thirty percent are on Medicaid, and the rest have some form of private insurance.

Local support has been less evident. The Alabama Department of Public Health has donated money and laboratory resources, but funding from the cities that surround the clinic has been non-existent. "There's city money in New York and San Francisco and Birmingham," Hanna says. "But there's none here. Anniston" (population 27,000) "is the 'big city' here."

Local Hostility

Located first in Oxford, Alabama, a predominantly white town of 9,000 people, ASK recently moved to nearby Hobson City, which is almost entirely black. Hanna and clinic director Deborah Wade say the move was necessary because they needed a bigger building to treat an ever-increasing number of people.

The town of Oxford was less than hospitable to the clinic. During a 1990 presentation Hanna gave to Oxford police and rescue workers about AIDS transmission, Oxford Mayor Leon Smith made his feelings clear. "Be sure that we will monitor" the clinic, he told Hanna before a packed audience at City Hall. "I'm not going to promise you that we'll be friendly." Residents were initially up in arms about the clinic, fearing their water would be contaminated and their children infected by discarded needles.

Though the hostility has softened, feelings about the clinic remain mixed. The state medical association reflected the sentiments of most of its members last year when it lobbied successfully to pass a law permitting HIV testing of hospital patients without their consent. The law passed with virtually no opposition. Yet, according to Dr. Greg Jones, a family practitioner in Anniston, many local physicians actually welcome the clinic, if only because it can provide care for those they themselves are afraid to treat because of their own homophobia or AIDS-phobia.

In such a climate, Hanna, Wade, and White say AIDS education remains their first priority, while expanding medical services is another. White opened another clinic in April in Thomasville, Georgia, the southern part of his health district. And Hanna and Wade plan to visit rural health departments and sexually transmitted disease clinics twice yearly to treat HIV patients who cannot get to Hobson City. They will also spread the word about AIDS, especially to those most at risk.
Integrating Paradigms
Teaching Traditional and Western Medicine
with Guatemalan Refugees
JAMIE TESSLER

Southern Mexico, January 1992

The aroma of eucalyptus bundles and boughs of bitter orange leaves stuffed inside my daypack reaches my nose after every pothole. I hope the training manuals, flipchart paper, and other supplies strapped to my bicycle basket will survive the mud that splashes up with every bump. Only 3 kilometers to the neighboring Guatemalan refugee camp, where an introductory course for rural health promoters is about to begin.

Today’s class on medicinal plant applications will include 17 Guatemalan refugees, most of whom have never worked with botanical medicines before. The class will systematize safe and useful remedies from locally available plants, and design a diagnostic framework that will both address the seriousness of an illness from a scientific perspective and embrace the belief system of the patient—no simple task.

We will also talk about the historical precedents that bring us to this point in time—what happened to the Mayan traditional medicine and how scientific medicine was imported—and we will examine the diseases that are born from poverty, marginalization, and dislocation.

Subhuman health conditions, landlessness, human rights violations, pervasive racism, and the accumulated indignation of colonization have led to the development of a diversified popular movement in Guatemala and a 30-year armed revolutionary struggle. Hundreds of thousands of Guatemalans reside in internal or external exile from this bloody civil war.

Life for most people inside Guatemala is a gloomy picture of suffering and misery. The infant mortality rate of 80 per 1,000 live births ranks just behind those of Haiti and Bolivia for the Central American and Caribbean region. Seventy-five percent of the population lacks access to potable water, and 82 percent of children under 5 demonstrate clinical signs of malnutrition.1 The most unequal land distribution in all of the Americas can be found in Guatemala. The top 10 percent of landowners hold 80 percent of the farmland. Eighty percent of all farmers do not have enough land to feed their families.2 Sixty-five percent of the population of Guatemala is indigenous, speaking 22 distinct Mayan languages.

The vast majority of the 46,000 recognized refugees3 located in the southern Mexico camps are Mayan Indians (who prefer to be known as indigenous people), who were driven over the border from the adjacent Ixcan jungle region during the brutal counterinsurgency campaign conducted by the Guatemalan army between 1978 and 1984.

The Guatemalan army followed the refugees onto Mexican soil, murdering several refugees accused of subversive activity. In response, the Mexican government forcibly relocated 18,000 refugees to the remote states of Campeche and Quintana Roo. The vital and successful cooperatives established in the Ixcan region in the 1960s by formerly landless highland peasants were viewed by the Guatemalan army as a support belt for the burgeoning revolutionary movement. An estimated 440 villages were razed in the army’s “scorched earth campaign,” leaving 50,000 to 75,000 dead, 35,000 disappeared, and 100,000 children orphaned (having lost at least one parent).4 The

Jamie Tessler is a health educator and activist who is joining the Health/PAC staff as coordinator of the Content of Drug Treatment grant project from the Robert Wood Johnson Foundation. From 1985 to 1988 she developed popular education materials for indigenous health promoters in Mexico and Guatemala.

With the lowest immunization rate in all of Latin America, Guatemala has demonstrated its marginal commitment to public health. A 1981 government study revealed that 70 percent of the deaths of children under age 5 were due to preventable diseases. Government sources from 1985 reported that 46 percent of the population were without any access to some form of health care. Nor is medical neutrality respected; 500 health promoters were murdered or disappeared during the counterinsurgency campaign of the early 1980s.

Rural Health Promoters

The high index of malnutrition and infectious disease in both the rural areas and refugee camps can only be reduced by a comprehensive community organizing effort. The movement to train and support rural health promoters in Central America had its inception in Guatemala in the early 1960s when residents of highland Indian communities in the Huehuetenango region asked the local Catholic mission dioceses for help with their health problems. In the absence of effective or comprehensive services from the government and without recognition from the Guatemalan Health Ministry, whose feeble attempts have failed to make a dent in the country’s health problems, the movement built on the centuries-old tradition of indigenous health practitioners who provided community-based services to impoverished rural peasants. Bulking on this tradition, nuns trained as physicians (“sister-docs”) responded to the indigenous people’s call for training, and developed and fine tuned course curricula. These dedicated church workers developed record-keeping systems and supervised hundreds of newly trained health “promoters.” Later on, the regional Catholic Church asked U.S. missions to send 10 percent of their personnel to Latin America to work with the poor. A highland community hospital also trained community-based health personnel. Then, after the 1976 earthquake, a flood of international nongovernmental and religious organizations arrived as part of the relief efforts and stayed on, and many of these became involved in training rural health promoters. It should be clear, however, that in several communities the indigenous peasants are in charge of their own programs and seek out both the funding and the technical assistance.

Rural health promoters are elected from their communities to be trained as primary health care educators. Promoters must be able to read and write, or be willing to learn, as a prerequisite for training. The training programs demystify the intimidating language of scientific medicine and present basic concepts in an understandable form. The training incorporates popular education methodologies and materials that reflect the cultural background and literacy level of the promoter. Rural health promoters, who serve without pay, provide both preventive and curative functions as well as community-based education.

Opposing Paradigms

From the beginning, rural health promoters were trained exclusively in the scientific medical model. A “political-economic” critique of scientific medicine was nurtured: Scientific medicine in itself was inherently good; the only problem was providing access to and distribution of services and medicines to the poor who needed them. Given the devastating health indices and endemic health problems, the introduction of the tools of scientific medicine certainly made some notable improvements. Yet the limits and dangers of this medical model revealed themselves over time.
Guatemalans did not approach the world of scientific medicine with a blank slate. A rich legacy of traditional healing practices has survived 500 years of Spanish invasion, colonization, repression, and racism. A highly developed crew of pre-Columbian health practitioners, including surgeons, herbalists, dental experts, poisonous bite specialists, and bone-setters served the Mayan nobility at the time of the Spanish invasion. Midwives, herbalists, and a myriad of spiritual and other healers served the common classes. Although much of this knowledge was lost when the Mayan ruling classes were decimated by the Spanish, it continues to be a principal source of health care for thousands of rural indigenous people.

Thus, indigenous medicine is not a “pure” and unadulterated construct. With colonization, these practices underwent a continuous process of transformation. Most practitioners of scientific medicine discounted the validity of traditional medicine modalities as “folklore.” Inherently preventive aspects of certain traditional medicine practices went unrecognized by the Western practitioners and became a lost resource. But only traditional practitioners respond satisfactorily to the “folk” illnesses, such as susto (fright). These illnesses form an integral part of the Guatemalan experience, reflecting deeply rooted belief systems, but Western practitioners ignored the deep cultural, religious, and mental health functions of these non-Western ailments. When the diagnosis and prescribed treatment fell outside of the culturally determined categories, patients often would not follow treatment protocols. The conflict between traditional and scientific medicine confounds the therapeutic relationship on every level.

The strong fire leaves the large rocks piping hot. Water from a clay pot thrown onto the rocks transforms the chuj (traditional Mayan steambath, also known as tuj or temascal) into a beach of mist, warmth, and comfort. “The chuj keeps you healthy,” Don Antonio* told me. “My grandfather built one, and his grandfather built one.” Maria adds more water to the rocks, and steam blanks out my consciousness. She hands me a bough of soft branches to gently beat my body, bringing the blood to the surface. Afterwards I am wrapped in blankets, given a hot drink to sip, and hurried off to bed.

Traditional Mayan chuj (steambath) recreated in refugee camp.

A quintessential survival tool Guatemalans use to preserve tradition is to obscure the traditional belief or practice inside the cloak of the opposing paradigm. Other beliefs were concealed through hard times, gently camouflaged in coded references, acting like chameleons so as not to attract attention, only to reappear in new forms later on. Dignified and tenacious acts of cultural survival can be found among traditional medicine practices in the refugee camps. It is more than a simple miracle, for example, that the chuj can be found in a few homes in the Mexican refugee camps. The chuj is a permanent piece of architecture designed for bathing, healing, and, at times, birthing and postnatal care. Originating in the cold highland climates, the chuj stayed with the highland Mam Indians as they moved to the steamy hot Ixcan jungle, again on the Chiapas border after fleeing army violence, and now hundreds of miles away in another disparate climate.

During the colonization process, religious workers tried to prevent families from entering the chuj together, claiming that it was immoral for men and women to be naked together, even if they were related. Spaniards at that time were convinced that bathing was dangerous, and tried to stop the use of the chuj strictly from a disease-prevention standpoint. The obvious benefit for certain muscle and joint ailments, respiratory illnesses, cleansing, and general relaxation is taken for granted 500 years later.

All names have been changed to protect the anonymity of those involved.

*
benefit the people. For example, the nopal, or prickly pear cactus, is a statuesque plant adorning the patios of many of the refugees' homes. For centuries, Mexicans have gathered the tender leaves, cleaned off the sharp spines with a machete, and prepared a tasty cooked salad. Guatemalans are less accustomed to eating the nopal, a symbolic plant for the Aztec nation. Yet nopal's unique high-fiber content slows down the action of glucose so effectively that it can dramatically reduce insulin levels. And so, diabetics in the camps (and throughout the world) depend for their survival on refrigerated insulin supplies, which are subject to frequent interruptions of electricity, failing refrigerators, or inadequate supplies, while an effective remedy grows nearby, free for the taking. Meanwhile, Japan imported 20,000 tons of nopal in 1987 strictly for medical purposes.\(^6\)

**Limits of Scientific Medicine**

Scientific medicine has taken on a dual role of both magic and danger for Guatemalans. The concept of scientific medicine as both technically and culturally superior has permeated deep into the recesses of the culture through sophisticated radio propaganda, advertising, and other media. The promises of fast cures from pills and injections raise hope for relief from chronic illnesses gendered by abject poverty and malnutrition. People want quick and easy solutions. Yet they have also seen disastrous results and have been mistreated by practitioners of the Western paradigm.

*May 1988, a village in the Ixcan jungle, a 3-1/2-hour hike in the mud from the nearest dirt road*

At the local tiendita (small grocery store), chocolate-flavored, single-dose packets of tetracycline are featured on long cardboard strips, like candy. These packets, damp with the relentless humidity of the Ixcan jungle, are prescribed to small children with persistent diarrhea. Expired tetracycline is extremely dangerous, and all tetracycline is contraindicated for children under 6 years old. If the diarrhea is caused by viral or parasitic factors, the child will only get worse from her disease and the side effects of dangerous medicines. No surprise that in some communities, women are reluctant to name children before they reach age 4, since so many will die. The loss of a nameless child is slightly diminished.

The experiences of the campesinos who utilize government health care services are consistently negative and counter the attraction of miracle pills and injections. Patients are given a prescription after an extremely brief, impersonal examination without being told what they suffer from, what caused their illness, or how to take the medicine correctly. The prescription may cost a week’s or month’s salary. Without adequate information or funds, patients frequently misuse medications and deplete family savings. Prevention is absent from the clinical interaction, so illnesses derived from poor sanitation and malnutrition recur. Iatrogenic illnesses abound. The institutionalized abuse of antibiotics throughout the developing world has had devastating results physically, economically, and medically as populations become resistant to the more common antibiotics. Fancier and more costly drugs are required when serious infections develop later on.

**Dignified and tenacious acts of cultural survival can be found among traditional medicine practices in the refugee camps.**

In the refugee camps, some of the Mexican physicians lack formal training in infection control. Hospitals are used only as a last resort and present an unmanageable expense to the family. Public hospitals are poorly staffed and are deficient or totally lacking in all basic supplies. People believe that hospitals are the place to go when it is time to die, and most prefer to die in their homes if possible.

Ironically, then, through their failures, Western medical interventions have played a role in stimulating the preservation of traditional medicine and practices. This dynamic is not unique to Guatemala. The failure of Western medicine to address the burning primary health care issues of the developing world is rooted in the assumptions of scientific medicine. Although the germ theory was a progressive step forward in the understanding of epidemic illness, the role of specific agents was excessively exaggerated. The social and economic roots of infectious diseases are obscured when all of the
responsibility is placed on nasty microorganisms that must be killed with just the right drugs. “Invisible and amoral microbes” are blamed, and the failure of governments to offer minimal public health services, comprehensive vaccination campaigns, and preventive health services is ignored.

**January 1992**

The training program opens up with a history of Mayan medicine, covering the damage caused by the Spanish invasion and its impact on health. The refugee health promoters and I examine how the refugees’ ancestors must have viewed practices such as bloodletting when they believed that each person is born with a finite amount of blood. The health promoters are asked to analyze the impact of colonial reorganization of communities, such as corralling dispersed communities into towns and the health impact of forced labor. The socioeconomic impact of the epidemics is compared with the current situation found in poor communities inside Guatemala and in the refugee camps. The relationship between war and disease becomes alive.

The 16th century Mayans were decimated by relentless outbreaks of catastrophic epidemic diseases brought by the Spanish invaders, such as smallpox, typhus, plague, and measles, for which they had no antibodies or treatments. Indigenous people today confront health problems caused or exacerbated by urban and environmental pollution, unsafe use of pesticides, and accidents associated with modern machinery unknown in previous decades. For many Mayan descendants, beliefs about the etiology of disease have remained the same since pre-colonial times. What has changed are the illnesses themselves. Serious infectious diseases resulting from the poverty and repression of civil war require new categories of medicines until the underlying causal factors are removed.

The Mexican herbal alternative, chaparro amargoso, is exceedingly bitter and strong tasting but does not cause the secondary affects Metronidazol is famous for. Not only are the synergistic effects of consuming both substances unknown and potentially dangerous, but it would also be extremely unpalatable and difficult for the ill individual to consume both remedies.

Dona Tomasa is the most articulate and outspoken of the 25 midwives in the class. She shares stories and recipes from her lifetime of experience attending births and the subsequent childhood illnesses of her patients. When asked how she learned her herbal repertoire, she declared that “most of it just came to me.” Unbeknownst to Dona Tomasa, comprehensive studies have been performed on all of her remedies, demonstrating their therapeutic value for the mentioned ailments. The only exception is the liquid base of her expectorant cough syrup recipe, which requires nothing short of Coca Cola, boiled together with the eucalyptus, chamomile, and vervain for 20 minutes.

Scientific medicine has not replaced the traditional forms of medicine, but serves as an additional system employed concurrently. At worst, however, the effectiveness of each approach is destroyed by incorrect usage. As trainers, our challenge is to teach concrete diagnostic categories and then provide clear-cut treatment protocols based on non-Western modalities (mostly medicinal plants). To make sure that the treatment is working, signs and symptoms must be carefully monitored and the diagnosis continuously reevaluated. A back-up plan must be in place to respond to worsening symptoms or life-threatening complications.

As community educators, rural health promoters are encouraged to build on traditional beliefs by supplementing the practices with a sound grasp of infection control. In the case of pneumonia, for example, which is a big killer, antibiotics are the appropriate course of action from all standpoints. Complementary herbal treatments include eucalyptus inhalations, homemade expectorant cough syrups, and astringent agents for throat inflammation and pain. Viral bronchitis is less likely to develop into pneumonia if the patient receives preventive care based on botanical remedies, rest, and adequate nutrition.

In the case of intestinal parasites such as amebiasis, the recommended pharmaceutical product, Metronidazol, is extremely toxic. Marked gastrointestinal distress, nausea, and headache often accompany the regimen. The Mexican herbal alternative, chaparro amargoso, is exceedingly bitter and strong tasting but does not cause the secondary affects Metronidazol is famous for. Not only are the synergistic effects of consuming both substances unknown and potentially dangerous, but it would also be extremely unpalatable and difficult for the ill individual to consume both remedies.

I am preparing a series of hands-on activities for the midwives training program. The participants have from 0 to 27 years of experience attending births, and several are particularly versed in the use of herbal medicines. The Spanish nurse who administers their program warns me before I start: “They have silly beliefs. They think that you have to tie the umbilical cord around the thigh until the placenta comes out or else it will be sucked up inside the body. I keep telling them that it isn’t true. These women don’t even know what menstruation is.”
When opposing paradigms meet, both racism and educational biases spurt to the surface. The health repercussions are serious: When a provider has destroyed the people's confidence in her, they may be hesitant to return to her when a more life-threatening illness hits.

The concept of scientific medicine as both technically and culturally superior has permeated deep into the recesses of Guatemalan culture.

In our work with health promoters, we ask, “Does this belief system actually cause harm? Is it neutral? Could there be some indirect benefit that we haven’t analyzed yet?” Sometimes opposing paradigms are complementary. For example, infection control practices regarding cutting and care of the umbilical cord, boiling instruments, and the use of herbal antiseptics validate what the indigenous people already know.

The available remnants of indigenous medicine alone cannot resolve the deteriorated conditions created by colonization. Western medicine cannot address the cultural and spiritual needs of a community; nor can scientific medicine deal with the mental health needs that are addressed by traditional practices and rituals. Moreover, some psychological difficulties engendered by institutionalized terror, the conditions of war, and the alienation of displacement among the refugees go beyond the ability of either medical paradigm to alleviate.

Portable Survival Skills

The counterinsurgency war has had a distinct effect on the survival of traditional medical systems. Refugees are displaced from their sacred land, often separated from extended family structures, and live in multi-ethnic communities for the first time in history. A campesina who was born in the highlands of Huehuetenango may have spent her life in five entirely disparate geographical and botanical zones. The elders are often left behind when refugees have to leave the highlands, or they may meet untimely deaths from malnutrition or political violence, disrupting essential links in the trail of oral history and essential knowledge.

Living in continual transit has taught Guatemalans to acquire portable survival skills and adapt to a multitude of challenging circumstances. Thus, the traditional, non-Western modalities that are most likely to be incorporated include those that are as portable and as easy to take as the prepackaged Western medicines. The call to reclaim traditional medicine modalities is fundamentally a request for more appropriate health technology. Modalities that may not be indigenous to the Mayans, yet fill these needs, will be quickly appreciated and adopted. So far, several health promoters have learned basic acupuncture methods and shiatsu massage techniques. Naturally, the herbs that are most commonly found in both Mexico and Guatemala are the highest priority to teach.

The safest, most effective, economical, and culturally appropriate therapies must be implemented from the grassroots, regardless of their origin. A collaborative partnership between rural health promoters, community leaders, enlightened practitioners of scientific medicine, and practitioners of traditional medicine is the only hope for developing successful programs that can improve the quality of life for poor Guatemalans.

As this article goes to press, 1,000 families prepare to return to Guatemala in January 1993. Refugees have demanded the right to a voluntary, collective, and organized return as well as permission to be accompanied by international organizations. Several delegations are planned for fall and winter 1992-93. For more information about the imminent return and how you can support, participate, or accompany refugees in this historic process, contact Witness for Peace, 2201 P Street, NW, Room 109, Washington, DC 20037, (202) 797-1160, or Peace Brigades International, Box 1233, Harvard Square Station, Cambridge, MA 02238, (617) 491-4226.

3. By the United Nations High Commission on Refugees. Both popular and official estimates place the number of Guatemalans in Mexico at close to 200,000. Many have been absorbed into Mexican communities, and a large number reside in Mexico City.
5. Many Mayan Indians prefer the term “invasion” to the conventional term “conquest,” claiming that their presence and perseverance today contradicts the notion that they have been conquered.
In 1984, Amy Cordero, an unemployed 37-year-old former GTE worker in Albuquerque, New Mexico, suffering from ovarian cancer, approached a lawyer named Josephine Rohr in an effort to prevent her house from being seized for payment of her outstanding hospital bills. During their initial conversation, Cordero happened to mention that many of her former co-workers at the giant electronics manufacturer’s Lenkurt division had also suffered hysterectomies and cancer. From this conversation was born a three-year legal fight by over 200 GTE workers and former workers—mostly Chicanas—to win compensation for the disabling, often fatal illnesses they suffered from on-the-job exposure to toxic chemicals.

Although Toxic Work began as the doctoral thesis project of Steve Fox, who worked on the lawsuits against GTE, it reads more like a mystery story—horrifying, moving, and vividly written. And, like a modern mystery, it doesn’t really have a happy ending. The struggle finally resulted in a not particularly generous out-of-court settlement with GTE. Additional product liability lawsuits were settled with DuPont and Shell; the suits against Dow Chemical had not yet been settled when the book was published. Amy Cordero and several co-workers did not live to see the end of the case.

Wooing GTE

Author Steve Fox traces this tragic story from the first wooing of GTE, one of the country’s largest electronics manufacturers, by the Albuquerque town fathers. At a time when many other electronics manufacturers were abandoning Silicon Valley, GTE moved its Lenkurt division manufacturing operations out of California in the 1970s and 1980s. In GTE’s case, the move was at least partly motivated by a desire to escape unionization, as the International Brotherhood of Electrical Workers (IBEW) had organized the Silicon Valley plant.

The city of Albuquerque put up over $4 million to build the new plant, which manufactured and assembled components used in telephone switching equipment. A “pro-business” climate was promised. The city was more concerned with having the plant conform to local architectural standards than with safety conditions; exhaust vents were intentionally placed below the air intake system so they would not stick up higher than the Spanish-style roof shingles.

The Lenkurt workers were drawn from the ranks of the unemployed and underemployed. The plant work force was 95 percent women and over 75 percent people of color, mostly Chicanas. However, GTE was in for a surprise. In response to the company’s authoritarian style of management, the workers quickly responded to IBEW’s organizing efforts. Despite GTE’s attempts at intimidation, the National Labor Relations Board forced the company to recognize and bargain with the union, and a first contract was signed in 1975. Labor relations remained stormy, with major work stoppages and strikes in 1978 and 1979. By 1982, GTE had begun moving much of the assembly work to a new plant in Juarez, Mexico.

Chemicals ‘Can Cause Death’

From the beginning, the women complained about safety conditions. Toxic Work quotes extensively from the workers’ own descriptions of the filthy conditions, open vats of chemicals—some labeled “Can Cause Death”—and horrifying disregard of safety procedures. Some of the most severe illnesses, for example, came from working with an extremely quick-drying epoxy called Lencast that had been invented by GTE engineers; it was made by combining resin and hardener from two different manufacturers, in direct violation of the written warnings from both companies, and then heating the toxic mixture.

The workers describe how their miserable working conditions, stress, deteriorating health, and family pressures all combined. Women tell of constant illnesses ranging from flu to dizziness, of forgetting things and bizarre behavior at home, and of humiliations such as having to wear adult Pampers to work because they were unable to leave the production line to take care of the excessively heavy menstrual bleeding many experienced.

Grievances by the union and com-

Toxics A to Z is an excellent resource—a comprehensive encyclopedia of the dangers we face from toxic chemicals and pollution. Although nearly 500 pages long, the book is well organized and written for non-scientists.

Toxics A to Z is really two books in one. The first half contains chapters explaining how to evaluate hazards, how they affect the body and the environment, and major sources of pollution, such as air, water, and pesticides. There is a chapter on existing and proposed laws regulating toxics, and many useful suggestions on actions individuals and communities can take to limit exposure to pollution. The second half is a reference guide to over 100 individual toxic substances ranging from asbestos to PCBs to noise. Each is described in detail according to the categories of physical and chemical properties, exposure and distribution, health and environmental effects, protection and prevention, regulatory status, and technical information.

One criticism: because Toxics A to Z is written primarily for people concerned with pollution in the home and the environment, it often does not put enough emphasis on the workplace as a source of damage to health. Many of the entries on individual substances do include substantial information about workplace exposures. But in the first half of the book, for example, there is an entire chapter on radiation that does not even mention health workers. It's as if the authors can't quite conceptualize that the reader concerned about clean water at home might also be a dental technician worried about overexposure to x-rays at work.

In their discussion of the Occupational Safety and Health Administration and right-to-know laws, the authors say that the labor movement isn't strong enough by itself to control pollution. In the 1990s, no one could argue with that observation! But it is still essential to understand that "consumers" and "workers" are often the same people and that environmental groups need to be more sensitive to workers' concerns. —I.W.

Ilene Winkler is a telephone worker and union steward with Local 1101 of the Communications Workers of America.
Occupational and Environmental Health

Tragic Fires Spark OSHA Reform Efforts

David Kotelchuck

After 25 of their colleagues lost their lives in the deadly fire at the Hamlet, North Carolina, poultry plant, the surviving workers have now lost their jobs. The owner, Imperial Food Products Company, has announced that the plant is not being reopened but will be shut down permanently. This is the social equivalent of hit-and-run driving—drive the workers mercilessly, then, after a disaster, run away! Socially and morally, this company decision is a crime, but legally it may not be.

There is hope, however, that this incident will spark legislation that may prevent such tragedies in the future. Fury at the unnecessary deaths has lit a prairie fire across the country for reform of the Occupational Safety and Health Act (OSHA).

For 20 years, workers and occupational health activists have been frustrated with the cumbersome OSHA law and its biases, both the implicit and the explicit, in favor of employers. During the last ten years under the Reagan and Bush administrations, OSHA has largely become a dead four letters, and many workers have simply given up on it.

Then, a few years ago, many U.S. unions decided it was time to fight back, and their health and safety staffs began drafting an OSHA reform bill. This bill, the Comprehensive Occupational Safety and Health Reform Act (COSHRA) was introduced in both houses of Congress on August 1, 1991, with the endorsement of the national AFL-CIO.

The effort to pass such a major piece of legislation often takes several years, so unions and their allies began gearing up for a long legislative battle. Then, in early September, after the Hamlet, North Carolina, poultry plant fire, the American people got angry—angry at North Carolina state OSHA for doing such a poor job of protecting its workers and angry at federal OSHA for letting this disaster take place.

Suddenly, lots of expected opposition from Southern Democrats and Republicans has melted away. Republican Governor Martin of North Carolina, formerly a right-wing, anti-labor congressman, has announced that he now supports the reform bill. Anti-labor congresspeople are on the defensive, and the reform bill is on a fast legislative track. It is awaiting floor action in the House of Representatives, and supporters of the bill hope to have it passed there in the fall. The Senate vote is expected at a later time.

The House bill (H.R. 3160) was introduced by Rep. William Ford (Dem.) of Michigan and 18 other representatives, and the Senate bill (S. 1622) by Senators Edward Kennedy (Dem.) of Massachusetts and Howard Metzenbaum (Dem.) of Ohio. The two bills are nearly identical. A description of some of their basic provisions follows.

Workplace safety and health programs. At present, employers are required to comply with all OSHA standards and to provide a workplace “free from recognized hazards.” But they are not required to have an overall safety and health plan for the plant or company—that is, to have an affirmative, proactive program to protect workers’ health. If the plant is free of violations, then the employer is not required under OSHA to do anything more, even if improvements could be made relatively easily that would significantly protect workers’ health.

The OSHA reform bill requires just such a health and safety plan, which must be in writing, and it describes procedures for identifying and correcting hazards and investigating accidents. The plan must include training for workers about plant hazards, to be held on company time with no loss of pay. Refresher training must be provided annually.

The right to refuse to work. At present, workers are supposed to be pro-

A poultry worker who survived the fire testifies before the House Labor Committee. Will the tragedy lead to reform?
tected from discrimination if they complain about unsafe conditions. But they only have 30 days to file a complaint of discrimination, and such cases may then take many months to resolve. The OSHA reform bill gives workers six months to file a complaint and speeds up settlement of such cases. More important, the bill specifically gives workers the right to refuse unsafe work if the job threatens serious injury and if the employer has been notified but has not yet taken corrective action.

Fines and criminal penalties. The reform bill would allow OSHA to impose increased fines. For the first time, employers would also face stiff jail sentences of up to five years for willful violations of standards that result in death or serious injury (and up to ten years if this is a second conviction). To date, no employer has ever gone to jail for violation of the federal OSHA law, and under current law employers face sentences of at most one year in jail.

Health and safety committees. All workplaces with 11 or more employees would be required to have a health and safety committee, with equal numbers of worker and management representatives. Such committees would be strictly advisory—management would still be legally responsible under law for health and safety conditions in the plant. Unions like the United Electrical Workers, which have traditionally opposed joint labor-management committees, would still keep their union health and safety committees, and these committee members would bargain across the table with management, as they do about other issues and during negotiations. In unionized plants, union locals will select their representatives. In non-union plants, workers would vote for their committee representatives.

All workers covered. At present, state and local workers, including police and fire officers, are not protected by federal OSHA. Also, in industries regulated by their own often inadequate laws and federal agencies, workers such as transportation, nuclear, and longshore workers are exempt from coverage. Under the new bill, all public and private workers are covered by OSHA.

OSHA can relinquish its authority to other agencies only if it first determines that they provide adequate protection. This represents a major loophole in protection, of course, since, for example, at present federal OSHA can and has relinquished authority to inadequate state OSHA plans, such as that in North Carolina. However, this provision would give us a basis to organize politically for stronger protection as has been done most recently (and sadly) after the fact of 25 deaths in the case of North Carolina.

There are many provisions in this reform bill that can help protect workers’ health and safety. There can be no more fitting memorial to the dead workers in North Carolina and elsewhere over the years than the passage of a bill to protect the health and lives of fellow workers today and in the future.

David Kotchuck, a member of the Health/PAC board, is director of the graduate Environmental and Occupational Health Sciences Program at Hunter College of the City University of New York. This column is adapted from a recent article in UE News.

Peer Review

Not for Healthy People

Every evening during news-hour there is a barrage of ads for over-the-counter drugs claiming cures for things most human bodies do naturally such as sleep and go to the bathroom. This is the money side of medicine. It is annoying but at least obvious. More subtle and disturbing is the hidden, quiet side of money in medicine diluting pure research and putting human beings in danger. This is the case in the new study that places healthy women on the drug tamoxifen as a preventative for breast cancer.

Every news show from Boston local to the national network news carried a basically one-sided story about the new drug study, showing tamoxifen in a wholly positive light and condoning the concept of the study.

Tamoxifen is not a drug for healthy people. It has been successful in preventing recurrence in adjuvant breast cancer patients. Those patients studied had a serious illness for which tamoxifen was part of the treatment. Side effects experienced were a trade off for a chance of continuing life. However, to subject healthy women to any side effects seems contrary to medicine.

How can results be measured here? Someone needs to look at the whole story.

ELLEN TUCKER

Brattleboro, VT
Women, Breast Cancer, and the Environment

As the number of women killed by breast cancer in the United States surges another 2 percent each year, reaching almost 50,000 in 1992, due attention has not been given the role of the environment in the epidemic, even with the recent surge of press and medical concern about the disease. In fact, the causes of breast cancer are overwhelmingly environmental. The logic behind the environmental connection is easy to follow: The supposedly unexplained rise of breast cancer is actually due, at least in part, to women's increasing use of toxic products, work in hazardous environments, and lives amidst chemical refuse that has mounted since the industrial revolution.

This is not to say that factors other than the environment do not have a role in the development of breast cancer. Many such risk factors have been identified, among them being relatively young at the onset of menstruation or old upon having a full-term pregnancy or reaching menopause; having a first blood relative with the disease; being Jewish; and being of relatively high socioeconomic status. However, 70 to 80 percent of breast cancer patients do not have any of these risk factors.

There is overwhelming evidence linking the dramatic rise in numbers of women who develop breast cancer—from one in 20 women in 1960 to one in nine today, which comes out to over 180,000 women in the United States in 1992 alone—to dynamic environmental factors such as living and working conditions, exposure to radiation, place of residence, and pollutants that we eat, drink, and breathe. Cancer rates have been shown to alter radically in populations that migrate to new places. Also, as in Israel, breast cancer incidence has been shown to drop dramatically as a result of banning the use of three pesticides. And, of course, the links of certain types of cancer to specific carcinogens have been publicly acknowledged (lung cancer to smoking and cancers of the lung and colon to asbestos are prime examples). Based on such evidence, Dr. Louise Brinton, Chief of the Environmental Studies Section of the National Cancer Institute (NCI) estimates that 60 percent of breast cancers are environmentally caused, and even "conservative" scientists estimate that environmental factors are responsible for 80 percent of all cancers.

Yet many possible causal factors for breast cancer are barely explored, including the effects of widespread use of birth control pills and hormone replacement therapy; the presence of fat-soluble chemical residues from PCBs and pesticides such as DDT in breasts (there has been some discussion of the toxic effects of these chemical residues on infants); exposure to radiation (from nuclear weapons testing, emissions from nuclear power plants, and even mammography); and the pervasive presence of estrogen in cattle feed, with its residues in meat, to name just a few.

Little progress has been made on the prevention of breast cancer in general. At NCI, a division of the National Institute of Health, only $11 million of the $92.7 million allocated for breast cancer research in 1991 was for primary prevention—and NCI's "prevention" strategy includes the controversial Breast Cancer Prevention Trial, in which healthy women at risk for breast cancer will be given tamoxifen, a drug known to cause liver changes and increase women's risk for endometrial cancer. Research on prevention with a focus on environmental pollutants has not even begun. Dr. Brinton cites the difficulty of pinning down environmental factors outside of diet and working conditions, both of which are only now beginning to be explored. NCI is undertaking a Dietary Prevention of Breast Cancer Study as well as an evaluation of the role of exposure to radiation on the job in the development of breast cancer in female radiological technologists. Until the role of these and other factors that are easier to identify and rule out are studied, she says, more pervasive environmental factors will be hard to isolate and confront.

In the meantime, what of the New York State study conducted since 1989 that found breast cancer rates in parts of Long Island 16 percent above the national average? Congress has approved funding for a
follow up study to be conducted by either NCI or the Centers for Disease Control (CDC) to determine why the incidence is so high. Perhaps, as participants in a recent public hearing boldly suggested, it is related to environmental conditions such as landfill contamination and drinking water contamination! A representative of the CDC went so far as to call such assertions compelling—but, she went on to say, the federal government could not help “until further study.”

**Veto Sets Back Women’s Health Research**

Buried in the controversy in Congress over ending the Bush administration’s ban on federal funding of fetal tissue research, the Women’s Health Equity Act (WHEA) is languishing. Actually a collection of 22 separate legislative proposals designed to promote research on women’s health issues, major items from WHEA were included in the bill reauthorizing spending for the National Institutes of Health (NIH), which President Bush vetoed because of the action on fetal tissue. The important question of whether life-saving medical research on treatment of conditions such as Parkinson’s disease and Alzheimer’s disease using aborted fetal tissue would encourage women to have more abortions (see “An Issue of Tissue,” Vital Signs, Summer 1989) overshadowed this potentially significant action for women’s health.

Women, of course, make up over 50 percent of the population, but only 13 percent of the budget of NIH, the major source of funding for health research in the country, is directed toward women’s health issues. This might not be noteworthy if studies of diseases in the general population applied equally to women. Even putting aside largely gender-specific conditions such as breast and cervical cancer, however, there are often significant differences in the ways men and women experience the same diseases or respond to specific treatments, as well as in the incidences of illness.

HIV infection is a current case in point in which symptoms differ among men and women, yet women have routinely been excluded from clinical trials of AIDS treatments as well as from the very definition of AIDS. Similarly, although heart disease is the number one killer of women, and, in fact, women who suffer a heart attack are more likely than men to die, none were included in two major studies of heart disease that enrolled over 37,000 men. There is a comparable lack of research on health conditions affecting black people and other minority groups.

Spurred by a 1985 Public Health Service study finding that women were not receiving equal health care, NIH initiated a policy to promote the inclusion of women, as well as minorities, in all clinical research. In 1990, however, the General Accounting Office found that the policy was not being consistently or fully implemented or monitored.

In response, Rep. Patricia Schroeder and Sen. Olympia Snowe, co-chairs of the Congressional Caucus for Women’s Issues, introduced the Women’s Health Equity Act. At the same time, then acting director of NIH, Dr. Bernadine Healy, created the Office of Research on Women’s Health (ORWH). The current legislation would have permanently authorized the office which, in its present form, exists at the discretion of the NIH director, and would have codified the policy on including women and minorities in research. The office would continue its present functions of overseeing and monitoring research on women’s and minority health at NIH, including identifying research needs, supplementing funding and coordinating research among the health institutes. In addition, OWHR would be charged with establishing data banks on women’s health and gender differences, creating a program for obstetrical and gynecological research at NIH, and working to increase the number of women scientists in high-level positions. In addition to addressing issues of equity in research, the legislation in the NIH bill would have authorized a total of $460 million for research on breast cancer, ovarian cancer, osteoporosis, and contraception and infertility.

In the two years of its existence, ORWH has already achieved a significant increase in funding for women’s health research, particularly breast and ovarian cancer, and has established centers for research on contraception and infertility. The office is also coordinating, along with the Office of Disease Prevention, the Women’s Health Initiative, a major NIH study of the prevention of chronic diseases—heart disease, cancer, and osteoporosis—affecting women over the age of 45. A special attempt will be made to include women from minority groups in the research.

As Cindy Pearson of the National Women’s Health Network points out, even if these provisions of WHEA are
enacted in a subsequent form, it "would only be a symbolic victory" if Congress does not allocate the funds to implement them. Moreover, she noted that in the political climate of Congress, the Caucus for Women's Issues sidestepped the most controversial issues affecting women's health, such as abortion or, indeed, national health care itself. It is somewhat ironic, therefore, that the important but less politically charged provisions of WHEA are being delayed by the abortion-related fetal tissue issue.

—Ellen Bilofsky

For a summary of the provisions, contact the Congressional Caucus for Women's Issues, 2471 Rayburn Building, Washington, DC 20515, (202) 225-6740.

A Change for Needle Exchange

The HIV-prevention strategy of needle exchange—in which injection drug users turn in their used needles and syringes in exchange for new ones (see "Casualties of War: Fighting the Health Consequences of Drug Policy," Fall 1990 issue)—is finally gaining legitimacy among public, private, and community-based agencies in New York. On May 13, the New York State Department of Health filed landmark emergency regulations that will allow not-for-profit organizations to legally operate needle exchange programs.

The new regulations in effect decriminalize the activity of needle exchange and become part of what is often referred to as New York State's needle possession law. This statute requires individuals to have a doctor's prescription in order to possess, use, or buy hypodermic equipment, but Acting State Health Commissioner Lorna McBarnette has the power to exempt certain persons or classes of people. Thus, although the needle possession law is still on the books, the new regulations will allow individuals who are enrolled in authorized needle exchange programs to possess needles and syringes without a doctor's prescription. Any not-for-profit organization can apply to the state health commissioner for authorization to become a needle exchange site.

On the same day that the regulations were filed, the American Foundation for AIDS Research (AmFAR) announced that it was awarding nearly $300,000 in grants to five needle exchange programs across the country, two of which—the Lower East Side Needle Exchange Program and the Bronx-Harlem Needle Exchange Program—are in New York City. These two programs have been operating illegally over the past 21/2 years, supported by funding from ACT UP and operated completely by volunteers. Other AmFAR grants will go to the Drug Policy Foundation, a Washington, DC, group, to implement a needle exchange program in Chicago; the Boulder (Colorado) County Health Department to evaluate needle exchange programs in more rural areas; and the San Francisco Department of Public Health for medical services and HIV testing and counseling to be attached to the underground needle exchange program operated by Project Point.

The New York City programs hoped to begin expanding their current efforts as early as July 1. The New York State AIDS Institute is contributing an additional $450,000 in state funds to the two programs. The commitment of the New York City Department of Health to the program's success represents a reversal of the long-held opposition to needle exchange of Mayor David Dinkins, who had closed an earlier city-run program.

AIDS activists have long cited New York State's needle possession law as a major factor contributing to HIV transmission among injection drug users in New York City. The prescription requirement prevents most drug injectors from easily obtaining injection equipment, forcing them to share the scarce equipment that is available on the black market. Only ten states have needle possession laws with prescription requirements. At the same time that New York filed its new regulation, Connecticut became the first state to repeal its needle possession statute.

Although the new regulations will increase the number of injection drug users who will be able to have legal access to needles and syringes, many AIDS activists feel the regulations fall far short of having a significant impact on total HIV transmission among drug injectors in New York State. Injection drug users in areas without authorized needle exchange programs will still be unable to obtain injection equipment legally and will still be subject to arrest and prosecution for illegal possession of equipment. In cities such as New York, which has an estimated 200,000 drug injectors, the number of individuals who need access to sterile needles and syringes on a regular basis will still far outnumber the ability or resources of agencies to provide it.

—Rod Sorge

The author has been one of the coordinators of the ACT UP needle exchange programs and will be program director of the
of the fetus over the needs and rights of the mother, and the
denial of drug treatment to pregnant women. The
"gag rule," which prohibits dissemination of information
about abortion to women using facilities receiving federal
Title X family planning funds, alone affects 3.7 million
women, one-third of whom are women of color.

The health care system, then, is where women’s pov-
erty and their vulnerability to attack intersect. It has
become the battleground where these attacks on women—
primarily poor, primarily women of color—are fought.
As Jacqueline Berrien and Loretta Ross show (see “When
Pregnancy is a Crime” and “In Pursuit of Perfect Choice”)
it both criminalizes and capitalizes on women’s economic
desperation: pregnant drug users are prosecuted, while
surrogate mothers are paid to be pregnant.

In the poverty and desperation of their lives, many
poor women find it virtually impossible to avoid un-
wanted pregnancy or to obtain abortion, to get screened
for early disease, and not to fall into such hopelessness
that substance abuse is the sequela. Women are twice as
likely as men to suffer from depression, and an unbeliev-
able number are battered as daughters, wives and part-
ners, and mothers (37 percent of women experience
significant physical or sexual abuse before age 21; one in
every three murdered women are killed by their husband
or partner). The health care system not only fails to ade-
quately address these problems, but is complicit in women’s
further victimization, as LaRay Brown’s description in
"Women and Children Last” of the obstacles pregnant
drug users face in getting treatment so poignantly illustrates.

The complicity of the health care system in women’s
victimization can be seen on many fronts. Although women
visit medical offices 25 percent more often than men and
are more likely to undergo surgery and hospitalization,
research on their health needs is sorely lacking. Although
heart disease is the greatest cause of death for women in
this country, the major studies of heart disease have been
done solely on men (see “Veto Sets Back Women’s Health
Research,” Vital Signs p. 33). The clinical manifestations of
AIDS in women, the fastest-growing population in the
AIDS epidemic, remain largely unacknowledged, and

women are still essentially excluded from clinical re-
search trials that are often the only sources of treatment
as well as knowledge about treatment.

Attempts to keep women from maintaining control
of their own reproductive health take the form of institu-
tional neglect as well as violent attacks. Women attempt-
ing to exercise their right to abortion meet highly
organized and violent protests. Yet, as noted, government
budget priorities ignore women’s reproductive needs.
The annual budget for contraceptive research is equal to
what the Defense Department spends in 15 minutes. The
only new form of contraception marketed in this country
in 25 years, Norplant, is an implanted device that is totally
under the control of a physician. The retrenchment in care
for women’s reproductive health under federal mandate,
the loss of physicians willing to perform abortion, the
"gag rule” on abortion referral, the prosecution of preg-
nant drug and alcohol users, and the abandonment of
HIV-positive women together show not only an emerging
medical neglect but also an ambivalent and hostile atmo-
sphere even for women who do have access to the health
care system.

In the articles in this issue of the Bulletin, most of which
are based on Health/PAC’s panel on Women and Health
at the American Public Health Association meeting in
Atlanta last November, we try to point to the some of
structures of the health care system that do as much to
victimize women as to help them. Each of the authors
details not only a lack of access to the health care system
but outrageous institutional strategies either designed
with disregard for women’s particular needs or to entrap
and punish them. As Mary Ellen Hombs of the National
Housing Law Project has pointed out, in times of social
change there is the possibility of altering institutions or of
altering individuals. In the reactionary eighties and nine-
ties, America has opted for altering individuals—primar-
ily women.

With more than 25 proposals for reform of the health
care system before Congress, there is virtually no discus-
sion of the discrimination against women and people of
color that structures the American health care delivery
system. We are unlikely to see any substantial health care
reform in this election year. And we should be ever mind-
ful that even "universal health care” as it has been formu-
lated so far, even in the most progressive proposals, does
not sufficiently address the need for changes in health
care delivery for women.

Giving women access to a system that they haven’t
defined and that ignores their needs is not enough. Women
need more than access to health care that is ambivalent
toward them. They need more than financial coverage
for treatment in a system that cannot acknowledge diseases
and clinical conditions unique to women. They need more
than health care that is hospital based when their lives
necessitate that they be at home or at work. Women need
a true set of alternatives to the American way of health
care. And women must design that agenda or be shut out
of health care by institutional structures that do not ade-
quately acknowledge them as patients, as citizens, as
human beings.

—Nancy McKenzie
—Ellen Bilofsky
—Sharon Lerner

The Decision that Pleased No One, continued from p. 3
interest “from the outset of the pregnancy in protecting
the health of the woman and the life of the fetus that
may become a child.” This sounds suspiciously like the
basis for the incarceration of pregnant women on
the grounds of harming their fetuses that Jacqueline
Berrien discusses in this issue. Roe itself was not a
guarantee of women’s freedom, but a means to keep
that freedom under control.

The focus now shifts to Congress, where the Free-
dom of Choice Act, which attempts to codify Roe v.
Wade, is being considered in both houses. The pro-
posed act has already been watered down by the inclu-
sion of a parental notification clause and other
qualifications in an attempt to secure its passage.

In trying to prove that it is above political pressure,
the Court has demonstrated that political pressure
matters. We must keep the heat on. —Ellen Bilofsky

Summer 1992
Health/PAC Bulletin 35
HEALTH/PAC BULLETIN
Covering the Crisis in Health Care...and Beyond

The Health/PAC Bulletin, the nation’s longest-publishing progressive health policy journal, has been in the forefront of health rights advocacy for nearly 25 years. Our demand is simple—decent, accessible health care for all—but our analysis of the health care crisis is thorough and in depth.

Published by the Health Policy Advisory Center, a non-profit, public-interest membership organization, the Bulletin looks beyond stop-gap measures to the heart of the health care crisis. Recent issues, for example, have examined the gaping holes in the health care safety net that threaten the very survival of large and growing segments of the population, especially the poor and people of color.

But, the Health/PAC Bulletin also goes beyond this analysis to explore progressive solutions to the health care crisis that could make “health care for all” more than just a slogan.

If you believe health care is everyone’s right...

You should be reading the Health/PAC Bulletin!

Please send me the Health/PAC Bulletin
☐ Individual $35  ☐ Institution $45  ☐ Student/Low Income $27.50
☐ I already subscribe. Please renew my subscription. ☐ 2 years $70
Enclosed is my additional tax deductible contribution to support Health/PAC’s fight for health rights. ☐ $25  ☐ $50  ☐ $75  ☐ $100  ☐ Other

Name: ___________________________  Charge: ☐ Visa ☐ MC
Address: ___________________________  Card No. _______________  Exp. Date: ___________
_______________________________  Signature: ________________________________

Health/PAC, 47 W. 14th St. 3d Floor, New York, N.Y. 10011

Note to Subscribers: If your mailing label says 922 your subscription expires with this issue.